

Durham E-Theses

How Decisions Are Made for Children and Young People with Life-Limiting Conditions: A Critical Ethnographic Study

OH, SEUNGHOON

How to cite:

OH, SEUNGHOON (2025) *How Decisions Are Made for Children and Young People with Life-Limiting Conditions: A Critical Ethnographic Study*, Durham theses, Durham University. Available at Durham E-Theses Online: <http://etheses.dur.ac.uk/14232/>

Use policy

The full-text may be used and/or reproduced, and given to third parties in any format or medium, without prior permission or charge, for personal research or study, educational, or not-for-profit purposes provided that:

- a full bibliographic reference is made to the original source
- a [link](#) is made to the metadata record in Durham E-Theses
- the full-text is not changed in any way

The full-text must not be sold in any format or medium without the formal permission of the copyright holders.

Please consult the [full Durham E-Theses policy](#) for further details.

***How Decisions Are Made for Children and Young
People with Life-Limiting Conditions: A Critical
Ethnographic Study***



Oh, Seunghoon

Department of Sociology and Social Policy

University of Durham

This dissertation is submitted for the degree of

Doctor of Philosophy

Declaration

I hereby declare that the work presented in this thesis has not been submitted for any other degree or professional qualification, and that it is the result of my own independent work.

Full Name Seunghoon Oh

Date

Abstract

This research aims to uncover the multi-dimensional decision-making processes of children and young people with life-limiting conditions in the Republic of Korea. The study uses observation, semi-structured interviews and document analysis, with a total of 120 interviews conducted. Ethical approval was obtained from the Ethics Committee of the School of Applied Social Science, Durham University, and the Institutional Review Boards in Korea (No. 4-2017-0868).

The study identified four emerging themes in the multi-dimensional decision-making processes. The first theme relates to the structural level of decision-making, highlighting oppressive decision-making processes with hidden social injustice and the hidden web of oppression, drawing on the work of Emmanuel Levinas and Pierre Bourdieu.

The second theme focuses on the family level of decision making, highlighting the undervaluing of the best interests of children and young people with life limiting conditions. The findings reveal oppression in space, time and modes of communication, drawing on the work of Levinas and Michael Polanyi.

The third theme focuses on the tacit dimensional level of decision-making processes, showing the reproduction of distorted beliefs in decision-making processes, ultimately leading to internalised oppression. This theme uses Polanyi's notion of tacit knowledge.

The fourth theme is about the extent of privilege in decision-making processes and how decisions are judged according to outcomes. The study illustrates how certain outcomes are praised or blamed, leading to forms of privilege or deprivation. The findings illustrate an understanding of social inequality using three interrelated Bourdieu concepts.

The findings suggest that ethical challenges such as oppression, distorted beliefs and social inequality need to be addressed in decision-making processes for children and young people with life limiting conditions.

This research has implications for enhancing social worker training to improve multidimensional decision-making for children and young people with life-limiting conditions, promoting holistic palliative care policies that prioritise virtue ethics, support interdisciplinary collaboration and require continuous policy evaluation.

Acknowledgements

First and foremost, I wish to express my deepest gratitude to my supervisors, Professor Roger Smith and Professor Robert Song, whose unwavering guidance, intellectual rigour, and patience have been instrumental in shaping this research. Their steadfast support during the most challenging and disheartening periods of my doctoral journey meant more to me than words can express. Even when I was on the verge of giving up, they never lost faith in me, offering encouragement with kindness and compassion. In particular, their insistence on ethical precision and attention to detail in my writing greatly enriched the depth and clarity of this thesis. I remain profoundly thankful for their continued belief in both my work and my potential, and for standing by me until the very end of this long and demanding journey. I am also sincerely grateful to Professor Lena Dominelli (University of Stirling), whose critical insights and thought-provoking questions during the early stages of my study challenged me to think more deeply about anti-oppressive practice and theory.

I am indebted to the Department of Sociology and Social Policy at Durham University for fostering a supportive and stimulating academic environment. I would also like to express my heartfelt thanks to Anne Park, whose administrative support proved invaluable throughout my doctoral journey. Although she was not formally recognised as a supervisor, her consistent support, thoughtful guidance, and quiet generosity made her feel very much like a third mentor throughout my doctoral journey.

I extend my sincere thanks to Dr Hanjeongwoo, whose generous support during my fieldwork made it possible for me to conduct rich and meaningful research. His guidance and encouragement throughout the data collection process significantly contributed to the depth and quality of this study. With the generous support of organisations such as the Children's Cancer Centre, SHARPS, the Special Commission on Social Disaster Investigation, the Asian Citizen's Centre for Environment and Health, My Welfare (NGO), and the Korean Association for Children with Leukaemia and Cancer, I was able to meet and interview many patients and families—without their help, this work would not have been possible.

I am profoundly grateful to my wife, Hyojeong Yoon, and to my beloved daughter, Yura Oh, for their unconditional love, patience, and unwavering support throughout this long and often difficult journey. Your presence has been my greatest source of strength and comfort. I offer my deepest thanks to my parents and parents-in-law, who instilled in me the values of perseverance and faith, and whose enduring support and heartfelt encouragement have meant more than words can express.

Contents

<i>HOW DECISIONS ARE MADE FOR CHILDREN AND YOUNG PEOPLE WITH LIFE-LIMITING CONDITIONS: A CRITICAL ETHNOGRAPHIC STUDY</i>	1
DECLARATION	I
ABSTRACT	II
ACKNOWLEDGEMENTS	III
CONTENTS	IV
LIST OF TABLE	XI
LIST OF FIGURES	XIII
ABBREVIATIONS	XVII
CHAPTER 1: INTRODUCTION	18
1.1 THE ARDUOUS JOURNEY OF DECISION-MAKING PROCESSES.....	18
1.2 WHY PAEDIATRIC PALLIATIVE CARE IN THE REPUBLIC OF KOREA?.....	20
1.2.1 <i>The Republic of Korea: The Continuing Issue of Paediatric Palliative Care in Health Inequality</i>	20
1.2.2 <i>Focuses on Medical Treatments but not Cool Room?</i>	23
1.2.3 <i>My Story: from a Reflective Pilot Journey to Acute Hospital-Based Palliative Medicine</i>	28
1.3 RESEARCH SIGNIFICANCE OF MULTI-DIMENSIONAL DECISION-MAKING PROCESSES.....	32
1.3.1 <i>Controversial Issues of Shared Decision-Making?</i>	32
1.3.2 <i>Shared Decision-Making in the Context of Multi-Dimensional Decision-Making Processes for Children and Young People with Life-Limiting Conditions?</i>	32
1.3.3 <i>Professional Decision Making in Palliative Care Social Work?</i>	33
1.4 RESEARCH AIMS AND QUESTIONS	34
1.5 OUTLINE OF THESIS STRUCTURE	36
1.6 CONCLUSION	39
CHAPTER 2: LITERATURE REVIEW	40
2.1 INTRODUCTION.....	40
2.2 AN INITIAL SCOPING REVIEW	40
2.2.1 <i>Identifying the Research Questions</i>	41
2.2.2 <i>Identifying Relevant Studies</i>	41
2.2.3 <i>Study Selection</i>	42
2.3 FINDING THE HIDDEN PAEDIATRIC DECISION-MAKING PROCESSES	47
2.3.1 <i>Medical Decision-Making for CYP with LLCs?</i>	47
2.3.2 <i>Ethical Challenges in Paediatric Palliative Care</i>	48

2.3.3	<i>The Role of Paediatric Palliative Care Social Work?</i>	49
2.3.4	<i>Navigating Hidden Hazardous Substances</i>	50
2.4	CONCLUSION	52
CHAPTER 3: HOW TO UNDERSTAND MULTI-DIMENSIONAL DECISION-MAKING PROCESSES?		54
3.1	INTRODUCTION	54
3.2	BARRIERS AND FACILITATORS, DISCRIMINATION AND/OR OPPRESSION IN DECISION-MAKING PROCESSES?	55
3.2.1	<i>Decision Processes: Supportive Care, Palliative Care and Hospice</i>	55
3.2.2	<i>Hidden Barriers and Facilitators?</i>	56
3.2.3	<i>Hidden Discrimination and/or Oppression?</i>	57
3.3	WHY LUCK IN THE DECISION-MAKING PROCESSES?	58
3.3.1	<i>Blind Luck</i>	58
3.3.2	<i>The Psychology of Luck</i>	59
3.3.3	<i>Epistemic Luck</i>	59
3.3.4	<i>Moral Luck</i>	60
3.4	EXPLORING MULTI-DIMENSIONAL DECISION-MAKING PROCESSES THROUGH THE LENS OF LEVINAS, POLANYI, AND BOURDIEU	61
3.4.1	<i>Examining the Structural Level of decision-making processes and/or External Influences of Blind Luck?</i> 62	
3.4.2	<i>The Family-Oriented Level of decision-making processes and/or-- Internal Factors of Blind Luck?</i>	64
3.4.3	<i>The Tacit Dimensional Level of decision-making processes: The Psychology of Luck and/or Internalised Oppression</i>	67
3.4.4	<i>The Privilege Level of decision-making processes: Moral and Epistemic luck and/or the Privileged or Underprivileged</i>	72
3.5	CONCLUSION	76
CHAPTER 4: CRITICAL ETHNOGRAPHY ON DECISION-MAKING PROCESSES		77
4.1	INTRODUCTION	77
4.2	CRITICAL ETHNOGRAPHY?	77
4.2.1	<i>Why Critical Ethnography?</i>	77
4.3	RESEARCH DESIGN AND RESEARCH PROCESS	80
4.3.1	<i>The Research Design</i>	81
4.3.2	<i>The Research Process</i>	82
4.3.3	<i>Sampling Strategy and Participant Selection</i>	83
4.4	RESEARCH METHODS AND DATA COLLECTION	83
4.4.1	<i>Semi-Structured Interviews</i>	85
4.4.2	<i>Participant Observation</i>	97
4.4.3	<i>Fieldnotes as the Face of the Others by Emmanuel Levinas</i>	103
4.4.4	<i>Collecting Documents and Analysing the Documents for Finding the Hidden Social Determinants of Health</i>	104

4.5	DATA ANALYSIS AND INTERPRETATION OF CRITICAL ETHNOGRAPHY	107
4.5.1	<i>Stage One – Compiling the Primary Record.....</i>	107
4.5.2	<i>Stage Two – Preliminary Reconstructive Analysis.....</i>	107
4.5.3	<i>Stage Three – Dialogical Data Generation</i>	108
4.5.4	<i>Stage Four – Describing System Relations</i>	109
4.5.5	<i>Stage Five – System Relations as Explained by Findings</i>	110
4.5.6	<i>The Issues on Translation of Language</i>	111
4.6	CONCLUSION	112
CHAPTER 5: ETHICS IN CRITICAL ETHNOGRAPHY – SERIES OF DILEMMAS		113
5.1	INTRODUCTION	113
5.2	ETHICAL EVOLUTION: HWANG WOO-SUK'S SCANDAL TO INSTITUTIONAL REVIEW BOARDS AND APPROVAL PROCESS.....	113
5.2.1	<i>Ethical Evolution in South Korean Research: From Hwang Woo-suk's Scandal to Institutional Review Boards</i>	113
5.2.2	<i>The Ethical Approval Process.....</i>	114
5.3	RESEARCH ETHICS: KEEPING PRINCIPLES OR BEYOND PRINCIPLES	116
5.4	CONFIDENTIALITY AND PARTICIPANTS' PROTECTION.....	118
5.5	POTENTIAL RISKS AND REFLECTION TO RESEARCHER.....	119
5.6	THE ISSUE OF PAYMENT: TO PAY OR NOT TO PAY?.....	120
5.7	CONCLUSION	123
CHAPTER 6: THE STRUCTURAL LEVEL OF DECISION-MAKING PROCESSES: BLIND LUCK, HIDDEN SOCIAL DETERMINANTS OF HEALTH, OR OPPRESSION?		124
6.1	INTRODUCTION	124
6.2	STAGE ONE: DECISION-MAKING PROCESSES IN A VICIOUS CIRCLE AS NEOLIBERALISM.....	125
6.2.1	<i>Impact on Neoliberal Policies on Paediatric Palliative Care and Doctor Shopping.....</i>	126
6.2.2	<i>Paediatric Palliative Care Education?</i>	132
6.2.3	<i>Work Overload without Responsibility: Ildangbaeg (一當百) and Tae-um?.....</i>	137
6.3	STAGE TWO: DECISION-MAKING PROCESSES IN HIDDEN SOCIAL DETERMINANTS OF HEALTH.....	140
6.3.1	<i>Humidifier Disinfectants</i>	141
6.3.2	<i>Radon-Emitting Mattresses.....</i>	148
6.3.3	<i>Working Areas: Semiconductor Industry.....</i>	155
6.3.4	<i>Asbestos-Contaminated Schools</i>	162
6.4	LUCK, SOCIAL DETERMINANTS OF HEALTH, OR OPPRESSION?	165
6.4.1	<i>Expectations from Paediatric Palliative Care Social Work?</i>	166
6.4.2	<i>The Limitations of the Role and Ethical Challenge?.....</i>	166
6.4.3	<i>Blind Luck in Decision-Making Processes?.....</i>	168
6.4.4	<i>Hidden Social Determinants of Health?</i>	170

6.4.5	<i>Oppression as Symbolic Violence?</i>	172
6.5	CONCLUSION: THE STRUCTURAL LEVEL OF DECISION-MAKING PROCESSES- OPPRESSION IN THE HIDDEN SOCIAL DETERMINANTS OF HEALTH OF DECISION-MAKING PROCESSES	173
CHAPTER 7: FAMILY-ORIENTED LEVEL OF DECISION-MAKING PROCESSES: BLIND LUCK, AND/OR ENSURING SHARED DECISION MAKING?		175
7.1	INTRODUCTION	175
7.2	STAGE ONE: INTO THE UNKNOWN JOURNEY	176
7.2.1	<i>The Two Kinds of Diagnosis</i>	177
7.2.2	<i>Diagnosis: Breaking or Keeping Bad News?</i>	179
7.2.3	<i>At the Time of Transfer?</i>	182
7.3	STAGE TWO: INTO THE UNKNOWN END-OF-LIFE	184
7.3.1	<i>Guideline of Advance Care Plans?</i>	185
7.3.2	<i>Focuses on the Cremation but not Bereavement Care?</i>	189
7.4	EXPECTATIONS AND ETHICAL CHALLENGES FROM PAEDIATRIC PALLIATIVE CARE SOCIAL WORK?	194
7.4.1	<i>Expectations from Paediatric Palliative Care Social Work?</i>	194
7.4.2	<i>Increasing the Number of Paediatric Patients with LLCs</i>	196
7.4.3	<i>Following Footprints of Medical Perspective</i>	197
7.4.4	<i>Forgetting the Face</i>	200
7.5	FOCUSING ON FAMILY-ORIENTED LEVEL OF DECISION-MAKING PROCESSES?.....	201
7.5.1	<i>“Three Minute” Consultation?</i>	201
7.5.2	<i>Enough Place for Neo-Confucian Family-Oriented Decision-Making Processes?</i>	204
7.5.3	<i>Different Perspectives of the Best Interests and the Voiceless of Children</i>	206
7.6	CONCLUSION: FAMILY-ORIENTED LEVEL OF DECISION-MAKING PROCESSES - FAILING TO ENSURE SHARED DECISION MAKING	208
CHAPTER 8: THE TACIT DIMENSIONAL LEVEL OF DECISION-MAKING PROCESSES: INTERNALISED OPPRESSION AND/OR THE PSYCHOLOGY OF LUCK?		210
8.1	INTRODUCTION	210
8.2	REPRODUCING DISTORTED BELIEFS IN DECIDING WITH FAMILY	211
8.2.1	<i>Taboo: Jaesu - Tough Luck in Hospital</i>	211
8.2.2	<i>Palliphobia</i>	214
8.2.3	<i>Toxic Faith and/or ‘Raising a Child Without Medicine (Anaki)’</i>	217
8.2.4	<i>To Avoid Child’s Funeral</i>	219
8.3	THE TACIT DIMENSION IN DECIDING WITH FAMILY: THE PSYCHOLOGY OF LUCK AND/OR INTERNALISED OPPRESSION?	221
8.3.1	<i>Expectations from Paediatric Palliative Care Social Work</i>	222
8.3.2	<i>The Psychology of Luck?</i>	223
8.3.3	<i>Internalised Oppression?</i>	225

8.4	CONCLUSION: THE TACIT DIMENSIONAL LEVEL OF DECISION-MAKING PROCESSES - INTERNALISED OPPRESSION.....	237
CHAPTER 9: THE PRIVILEGE LEVEL OF DECISION-MAKING PROCESSES: EPISTEMIC AND MORAL LUCK AND/OR SOCIAL INEQUALITY?.....		240
9.1	INTRODUCTION.....	240
9.2	STAGE ONE: THE PRIVILEGED OR UNDERPRIVILEGED.....	241
9.2.1	<i>Geographical Accessibility: Child and Family Care Plan?.....</i>	242
9.2.2	<i>In the “Hell-Joseon (Korea)” Financial Burden on Families.....</i>	249
9.2.3	<i>Tasks: Multi-Disciplinary Assessment of Needs?.....</i>	252
9.2.4	<i>Decision Processes with Unheard Voices or Not?.....</i>	260
9.3	STAGE TWO: PRAISING AND BLAMING THE RESULTS.....	262
9.3.1	<i>Doctor Shopping: Following Medical Miracle or Not?.....</i>	263
9.3.2	<i>Hit and Miss (福不福) in Education for Children and Young People.....</i>	269
9.3.3	<i>Self-cultivating (各自圖生) of Final Place.....</i>	272
9.3.4	<i>Virtual Reality in Bereavement Care?.....</i>	276
9.4	EXPECTATIONS FROM PAEDIATRIC PALLIATIVE CARE SOCIAL WORK AND UNDER OPPRESSION AS ETHICAL CHALLENGES?.....	279
9.4.1	<i>Expectations in the Privilege Level of Decision Process?.....</i>	279
9.4.2	<i>Depending on Donation and/or Ignored Social Inequality or Epistemic Luck?.....</i>	280
9.5	EPISTEMIC AND MORAL LUCK AND/OR SOCIAL INEQUALITY IN DECISION-MAKING PROCESSES?.....	282
9.5.1	<i>Epistemic and Moral Luck in Decision-Making Processes?.....</i>	282
9.5.2	<i>Decision Processes with Habitus, Capital, and Field?.....</i>	290
9.6	CONCLUSION: THE PRIVILEGE LEVEL OF DECISION-MAKING PROCESSES - SOCIAL INEQUALITY.....	303
CHAPTER 10: CONCLUSION.....		305
10.1	INTRODUCTION.....	305
10.2	THEORETICAL AND METHODOLOGICAL CONSIDERATIONS.....	306
10.3	KEY FINDINGS AS NOVEL CONTRIBUTION.....	309
10.3.1	<i>The Structural Level of Decision-Making Processes.....</i>	310
10.3.2	<i>The Family-Oriented Level of Decision-Making Processes.....</i>	313
10.3.3	<i>The Tacit Dimensional Level of Decision-Making Processes.....</i>	316
10.3.4	<i>The Privilege Level of Decision-Making Processes: Why Luck but Not Social Inequality?.....</i>	317
10.4	LIMITATION AND IMPLICATIONS.....	319
10.5	FUTURE WORK AND RESEARCH.....	322
10.5.1	<i>The Cultural Level of Decision-Making Processes.....</i>	322
10.5.2	<i>Virtue in Anti-Oppressive Practice.....</i>	323
10.5.3	<i>Anti-Oppressive Social Policy of Medical Cannabis.....</i>	324

10.6 CONCLUSION	325
REFERENCES	326
APPENDIX A: PUBLICATIONS ASSOCIATED WITH THIS RESEARCH	367
APPENDIX B: A PARTICIPANT INFORMATION SHEET	368
INFORMATION SHEET.....	368
INFORMED CONSENT FORM.....	373
APPENDIX C: INTERVIEW GUIDE FOR INTERVIEW.....	375
INTERVIEW GUIDE FOR INTERVIEW WITH PAEDIATRIC PALLIATIVE CARE SOCIAL WORKER.....	375
INTERVIEW GUIDE FOR INTERVIEW WITH PALLIATIVE CARE SOCIAL WORKER	380
INTERVIEW GUIDE FOR INTERVIEW WITH CHILDREN AND YOUNG PEOPLE’S PARENTS OR GUARDIANS / BEREAVED FAMILY MEMBERS	385
INTERVIEW GUIDE FOR INTERVIEW WITH PALLIATIVE CARE MEDICAL MEMBERS	390
INTERVIEW GUIDE FOR INTERVIEW WITH PAEDIATRIC PALLIATIVE CARE MEDICAL MEMBERS	395
USING ATLAS.TI TO GENERATE CODES FOR QUALITATIVE DATA ANALYSIS	400
SBR INVESTIGATOR/RESEARCHER - BASIC COURSE	403
1 HISTORY AND ETHICAL PRINCIPLES - SBR.....	404
2 DEFINING RESEARCH WITH HUMAN SUBJECTS – SBR.....	412
3 THE REGULATIONS AND THE SOCIAL AND BEHAVIORAL SCIENCES – SBR.....	415
4 ASSESSING RISK - SBR.....	421
5 INFORMED CONSENT.....	427
6 PRIVACY AND CONFIDENTIALITY	433
7 RESEARCH WITH CHILDREN - SBR	437
8 RESEARCH IN PUBLIC ELEMENTARY AND SECONDARY SCHOOLS - SBR	443
9. UNANTICIPATED PROBLEMS AND REPORTING REQUIREMENTS IN SOCIAL AND BEHAVIORAL RESEARCH	449
10 RESEARCH WITH PRISONERS - SBR.....	451
12 INTERNATIONAL RESEARCH - SBR	458
13 HOT TOPICS.....	463
14 STUDENTS IN RESEARCH	468
15 ARE YOU THINKING ABOUT BEING IN A RESEARCH STUDY?	490

16 CULTURAL COMPETENCE IN RESEARCH.....	496
--	------------

List of Table

Table 1-1 Demographic Characteristics of Children and Young People with Life-Limiting Conditions, 2015. Source from Cho Hee Kim et al., 2020	22
Table 1-2 Patient Care Performance Differences	26
Table 2-1 Specific Keywords	41
Table 2-2 Inclusion and Exclusion Criteria of Study Selection.....	42
Table 2-3 Scoping Review	47
Table 2-5 Environmental Exposure and Hazardous Substances-Related Diseases	52
Table 3-2 Luck and Different Levels of Decision-Making Processes	61
Table 3-3 The Relations between Rational and Irrational Beliefs in a Stressful Situation	68
Table 4-1 Semi-Structured Interviews from Cancer = 50.....	89
3) Table 4-2 Semi-Structured Interviews from Non-Cancer = 15.....	90
Table 4-3 Semi-Structured Interviews from Senior members of Paediatric Palliative Care Teams = 14	92
Table 4-4 Semi-structured Interviews from Local, National, and International Disciplinary Contexts =41	94
Table 4-4 Environmental Exposure and Hazardous Substances-Related Diseases.....	106
Table 6-1 Brief History of Hospice & Palliative Care Policy in the Republic of Korea	127
Table 6-3 Curriculum of the e-Learning Program for Training Social Workers in Hospice and Palliative Care	133
Table 6-4 Comparison of Educational Contents for Training Hospice and Palliative Care Social Workers	134
Table 6-4 Essential Manpower for Hospice and Palliative Unit.....	138
Table 6-6 Interviews with 12 of 15 Non-Cancer Patients Regularly Using Humidifier Disinfectants	142
Table 6-6 Screening-Level Risk Assessment for Humidifier Disinfectants Added to Humidifier Water	142
Table 6-7 Survivor and Death Toll due to Humidifier Disinfectants.....	143
Table 6-8 Diseases Identified as Associated with Exposure to Humidifier Disinfectants	144
Table 6-9 Children and Youth with Special Healthcare Needs (CSHCN)	145

Table 6-10 Names of Radon-Emitting Mattresses Source from Nuclear Safety and Security Commission (2018)	151
Table 6-11 Diseases that are Associated with Radon-Emitting Mattresses	154
Table 6-13 Impact of Semiconductor Industry Exposure on Cancer Case	156
Table 6-12 Reporting the Number of Workers' illnesses of the Victim's Family Members and/or Survivors	157
Table 6-13 Parents who have Children with LLCs and Used to Work in Electronics Production at Onyang,	161
Table 7-3 Total Scale of Paediatric Deaths from 2005 to 2014 According to Demographic Factors	191
Table 7-4 Korea Gallup Surveys on the Changing Location of Dying, the Changing Funeral Venues and Disposal Methods since the 1980s. Source from Park (2010: 26)	192
Table 7-5 Korea Gallup Surveys Rate of Cremation based on Age	193
Table 7-6 Total Scale of Paediatric Deaths from 2005 to 2014 According to Demographic Factors	197
Table 7-7 Comparison of Outpatient Consultation Time	203
Table 7-8 Different Perspectives for the Best Interests	207
Table 8-1 Toxic Faith and Anaki.....	219
Table 8-2 Jeong -full vs Jeong -less Persons	231
Table 9-1 Regional distribution of paediatric death attributed to CCCs from 2005 to 2014	243
Table 9-2 Different Accessibility of Hospital and Paediatric Palliative Centres	245
Table 9-3 Hospitalisation Costs and Financial Burden on Families.....	250
Table 9-4 Spoon Categorisation	251
Table 9-5 Seeking for Certainty and Medical Uncertainty	283
Table 9-6 Palliative Care Definitions	284
Table 9-7 Storytelling Source from 9 th January 2018 Fieldnotes	286
Table 10-1 Emmanuel Levinas, Michael Polanyi and Pierre Bourdieu.....	308
Table 10-2 Luck and Different Levels of decision-making processes.....	309
Table 10-3 Ethical Challenges and the Multi-Dimensional Level of decision-making processes....	310
Table 10-4 Environmental Exposure and Hazardous Substances-Related Diseases	312

List of Figures

Figure 1-1 Paediatric Palliative Care Centres in the Republic of Korea.....	20
Figure 1-2 The Cool Room, which is located in Gyeongsangbuk-do Pohang Medical Centre	24
Figure 1-3 Conceptual Framework-Hospital Profitability	25
Figure 1-4 Neonatal Intensive Care Units (NICU).....	27
Figure 1-5 “Lim Seong-joon, right, 13, who is suffering from chronic lung disease linked to a humidifier-disinfectant product, lies down on a mat next to his sister at their home”	30
Figure 1-6 A Flow Chart for the Case of Toxic Humidifier Disinfectants.	31
Figure 2-1 Search Terms	41
Figure 2-2 PRISMA-ScR flow diagram	43
Figure 3-1 Supportive Care, Palliative Care and Hospice Care.....	56
Figure 3-2 Death Ambivalence in the Lives of Children.....	69
Figure 3-3 Diagram of Tacit Knowing.	70
Figure 4-1 A Sampling Plane of Semi-Structured Interviews	86
Figure 4-2 Changed Sampling Plane of Semi-Structured Interviews N = 65 (Cancer 50 /Non-Cancer 15)	87
Figure 4-3 Structural Level of Decision-Making Processes: Decision-Making Processes in a Vicious Circle as Neoliberalism	96
Figure 4-4 Structural Level of Decision-Making Processes: Work Overload without Responsibility.....	97
Figure 4-5 The Role of Ethnographer: an Observer-Participant.....	98
Figure 4-6 Theoretical Roles for Observation	99
Figure 4-7 The Protest Camp with Victims, Activities and Me.....	100
Figure 4-8 Main Statements by SHARPS (Supporters, Health, And Rights of People in Semiconductor Industry)	101
Figure 4-9 8 th floor, Post Tower	102
Figure 4-10 Asbestos-related diseases and radon-emitting materials: decision-making processes on hidden social determinants of health (SDOH).....	102
Figure 5-1 Ethical Approval to Final Report.....	115
Figure 5-2 Korean Hand Calligraphy	121
Figure 5-3 Personalised Hand Fan 1.....	121
Figure 5-4 Personalised Hand Fan 2.....	122

Figure 6-1 Graphical abstract.	130
Figure 6-2 Taken from Fieldnote on 2 nd December, depicts my explanation of the differences between Supportive Care and Palliative Care.....	135
Figure 6-3 Jay Milstein’s Model (2005:564)	136
Figure 6-4 Reality and Improvement Directions of Nursing Labor in Korean Society (Fieldnote, 23/04/18)	137
Figure 6-5 Oxygen Demand of Age	144
Figure 6-6 Toxic.....	147
Figure 6-7 Medical Certificate of Death Immediate cause of death: Sepsis/ Causes: Acute Leukaemia Source from Ando Choi, who shared with me his daughter’s Medical Certificate of Death.....	149
Figure 6-8 Radon-Emitting Mattresses.....	150
Figure 6-9 “Number of weekly telephone calls for counseling at the Korea Institute of Radiological and Medical Sciences concerning the health effects of using radon bed mattresses. NSSC, Nuclear Safety and Security Commission.”	152
Figure 6-10 “Height of Mouth and Nose During Sleep, Excluding Subject Below 7 Years of Age.”	153
Figure 6-11 Stories from Clean Room (Joseph, 2017) and “the 11th anniversary of Hwang Yumi's death from leukaemia at work and the Samsung Workers’ Memorial Day.”	158
Figure 6-12 Another Promise “I will never give up you as I am father”	159
Figure 6-13 Workers Gave Birth to Children with Congenital Diseases.....	160
Figure 6-14 Asbestos-Contaminated Schools Pie Chart.....	164
Figure 6-15 Asbestos-Contaminated Schools Bar Chart	164
Figure 6-16 Rich chaebols are not punished for their sins, while poor workers get sick from working.	170
Figure 7-1 Starting Pathway: Diagnosis or Recognition of LLCs or LLCs:.....	177
Figure 7-2 Diagnosis or Recognition.....	180
Figure 7-7 End-of-life and Bereavement.....	185
Figure 7-8 End-of-life and Bereavement.....	189
Figure 7-9 Korea Gallup Surveys on the Nationwide Cremation Rates 1993–2017	193
Figure 7-10 Steps of Walking in an Acute Hospital from 6 am to 3 pm	198
Figure 7-11 The Waiting Space for Outpatients for Children and Their Parents	204
Figure 7-12 Waiting Room.....	205

Figure 7-13 “My precious treasure! I love you, My David!”	206
Figure 8-1 The Changed Number 4 as F in the Hospital	211
Figure 8-2 Deciding with CYP in Korea’s Children’s Hospice and Palliative Medicine from 1 st November 2017	215
Figure 8-3 Deciding with CYP in Korea’s Children’s Palliative Medicine.....	216
Figure 8-4 Distorted Beliefs and Luck	224
Figure 8-5 Oppression, Distorted Beliefs and Luck	227
Figure 8-6 Structural Topography of Cheong properties.....	230
Figure 8-7 In-Circle vs. Out-Circle	232
Figure 9-1 Living with LLCs or LLCs	242
Figure 9-2 Paediatric Palliative Care Centres in the Republic of Korea.....	244
Figure 9-3 Going to Canteen School Source: Canteen School Note	247
Figure 9-4 The Bucket List.....	248
Figure 9-5 Living with LLCs or LLCs	253
Figure 9-6 Trends in Paediatric Deaths from 2005 to 2014 in Korea by Age Categories. (A) Total, (b) Infant, (c) Child, and (d) Adolescent (crude number)	255
Figure 9-7 The Saddest Day of My Life.....	256
Figure 9-8 I Feel ... Too Much Burden.....	257
Figure 9-9 Girl with Stem Cell Trachea Repair.....	264
Figure 9-10 To Choose Between the Two?	266
Figure 9-11 Two Groups Got Down on Their Knees and Begged	271
Figure 9-12 Pediatric palliative care centers in the Republic of Korea.	273
Figure 9-13 Researcher's Child Explores Marine Life with Augmented Reality	276
Figure 9-14 I, Mother, Meet You Source from MBC: 2020.....	277
Figure 9-15 Negative ion, germanium products are sold on the internet. Souce from Juhee Yoo, 2021	288
Figure 9-16 Focusing on Becoming Survivors in decision-making processes	289
Figure 9-17 Starting Pathway: Diagnosis or Recognition of LLCs or LLCs:.....	292
Figure 9-18 Han Hye-kyung eats with the help of her mother, Kim Sinyeo, left. The 40-year-old has lived with a disability since 2005, following a surgery to remove a brain tumour. Han's family believes it was caused by her time working in a Samsung factory.....	293

Figure 9-19 Dong Hyun Yi, 2, whose lungs were destroyed by a humidifier steriliser in 2006, is pictured in hospital with a nose tube before surgery for a pneumothorax (top left) and smiling after the operation when he can breathe easier (top right). The photos above, from right to left, are used as the cover of *Stolen Breath* and as a symbol of humidifier damage. /Park Ki-yong (yellow jacket), who took part in a commemorative performance at Seoul City Hall on 31 August to mark the fifth anniversary of the humidifier disaster, sits on a large hanging painting of his son Dong-hyun (below) /Provided by Ahn Jong-joo (Ahn Jong-joo, 2016) 294

Figure 9-20 Before and After Changed Income Due to Doctor Shopping 299

Figure 9-21 Focusing on becoming survivors in decision-making processes..... 302

Figure 10-1 Barriers and Facilitators, Discrimination and Oppression 307

Figure 10-2 Barriers, Facilitators, Discrimination, Oppression, and Luck..... 308

Figure 10-3 Focusing on Becoming Survivors in decision-making processes 311

Figure 10-4 Diagnosis or Recognition..... 313

Figure 10-5 End-of-Life and Bereavement..... 314

Abbreviations

ACP: Advance Care Plans

CYP: Children and Young People

DNR: Do-Not-Resuscitate

IRB: Institutional Review Board

KUDP: The Korean Undiagnosed Diseases Program

LLCs: Life-Limiting Conditions

LTCs: Life-Threatening Conditions

NICU: The Neonatal Intensive Care Units

NSSC: The Nuclear Safety and Security Commission

PICU: The Paediatric Intensive Care Unit

SDOH: Social Determinates of Health

SHARPS: Supporters, Health, And Rights of People in Semiconductor Industry

Chapter 1: Introduction

In paediatric palliative care, surrogate decision making is complex and must take into account a number of factors to ensure that the best interests of the child and young person (CYP) are met. These include the impact of supportive care on bereavement, the complex relationships between adults, children and medical staff, and the balance between the child's autonomy and their best interests. These factors may influence decisions about medical treatments and interventions. Ongoing research and dialogue are needed to promote effective and equitable decision-making processes that prioritise the needs and preferences of CYP in paediatric palliative care. The focus on surrogate decision making for CYP with life-limiting conditions (LLCs)¹ is based on the belief that the additional layer of barriers arising from paternalism and interpretation of unexpected outcomes could be explored.

To achieve this goal, I set out to explore a place where CYP decision-making processes with LLCs were taking place, namely the Republic of Korea. Chapter 1 provides an overview of the research background and my history. First, this chapter presents the background of the research topic and the environment in which this research was conducted. Sections 1.1 to 1.2 outline the background of the Republic of Korea, including its context, demographic issues of paediatric palliative care in health inequality, and my history.

Secondly, section 1.3 provides the rationale and justification for the doctoral study undertaken and sections 1.4 to 1.5 state the aim and research questions of the study and present the overall structure of the thesis.

1.1 The Arduous Journey of Decision-Making Processes

Children and young people (CYP) with life-limiting conditions (LLCs) are often unable to participate in the decision-making process due to their condition and associated physical or cognitive limitations. This means that surrogate decision making is often required, where others, such as parents

According to Kissane, Kissane and Al (2017), there is disagreement about whether the term life-threatening (where cure is possible) or life-limiting (no reasonable hope of cure) is more appropriate when defining palliative care conditions. Most serious illnesses are characterised by prognostic uncertainty, and there is little consensus among experts about which conditions have 'no reasonable hope of cure'. In other words, life-threatening conditions (LTCs), where curative treatment is possible but may fail, and life-limiting conditions (LLCs), which cause progressive deterioration, where there is no reasonable hope of cure, and from which a child or adolescent will die. In this paper I use LLCs.

or healthcare professionals, have to make decisions on their behalf. Unfortunately, this approach can sometimes result in restrictions on the autonomy of CYP with LLCs. Despite efforts to involve CYP and respect their preferences, the need for surrogate decision-making can create challenges in ensuring that their voices are heard and their autonomy is respected. This can be particularly problematic when compared to the standard of decision-making for competent adults, where individuals typically have more control over the decision-making process.

Dominelli (2004: 98-109) questioned the lack of rights of children: why should children have fewer rights than adults? Concerning the law on adolescent consent, although under 16-year-olds are assumed to be incompetent (Cave, 2014: 2), adolescents, defined by WHO as 10 to 19 years old have a gap between the different young children. In the UK, the law assumes individuals under 16 lack decision-making capacity, but older adolescents may have a better understanding of their preferences and values. This can result in a gap in decision-making ability and understanding, with younger children needing more support. Age-specific factors are important when evaluating decision-making capacity in children with life-limiting conditions. In the UK, Cave (2013: 2) mentions “where under 16-year-olds’ refusals of treatment are contrary to their best interests, the law states that doctors may rely on parental consent.” Recently, developments of UK law (Cave, 2014) and medical ethics (Larcher, Craig, Bhogal, *et al.*, 2015) have helped us understand the process of decision-making concerning medical staff, CYP with LLCs and proxies.

If the patients are considered to be no longer able to communicate for themselves, thus requiring surrogate decision-making, the responsibility of a surrogate is inevitable. It is common to question whether a surrogate decision-maker can make decisions on behalf of an unconscious patient/incompetent person, who is cognitively impaired and unable to give informed consent: a surrogate is essential for anticipated issues in medical field. Anticipating the problems, advanced directives (AD) facilitate communication among patients, family members, and healthcare providers regarding the care of patients who can no longer communicate for themselves (Chan, Wong, Choi, *et al.* 2019: 72-77). Rather than being a single event, informed consent should be viewed as a flexible process that allows for changes over time, as medical outcomes may differ from initial expectations (Larcher, Craig, Bhogal, *et al.*, 2015; Gillam and Sullivan, 2011). The ethical and epistemic challenges (Cai, Robinson, Muehlschlegel, *et al.*, 2015; Wu, Zhuang, Chen, *et al.*, 2020; Byram, 2019; White, Jonsen and Lo, 2012) inherent in surrogate decision-making present serious obstacles to ensuring the safety and well-being of incompetent children and young people with life-limiting conditions, raising significant questions about the effectiveness of these measures in securing the best interests of this vulnerable population. Decisions about medical treatments are considered ideal when the anticipated

benefits outweigh the potential harms, and when these decisions are based on open and reliable communication between medical staff and patients. It is essential for such decisions to be thoroughly discussed and based on a clear understanding of the patient's condition and treatment options. Although medical staff and patients have hope that advanced medical technology will lead us to increased life expectancy, this remains an uncertainty.

1.2 Why Paediatric Palliative Care in the Republic of Korea?

1.2.1 The Republic of Korea: The Continuing Issue of Paediatric Palliative Care in Health Inequality

In the Republic of Korea, palliative and hospice care for children is only available in two acute hospitals that provide home hospice care, counselling and palliative care, and the gap between the capital and provincial cities based on health disparities is significant. According to the Korea Health Insurance Review and Assessment Service, the total number of children with cancer was 13,775 in 2014, and the total number of children with rare diseases was 97,358 in 2014.

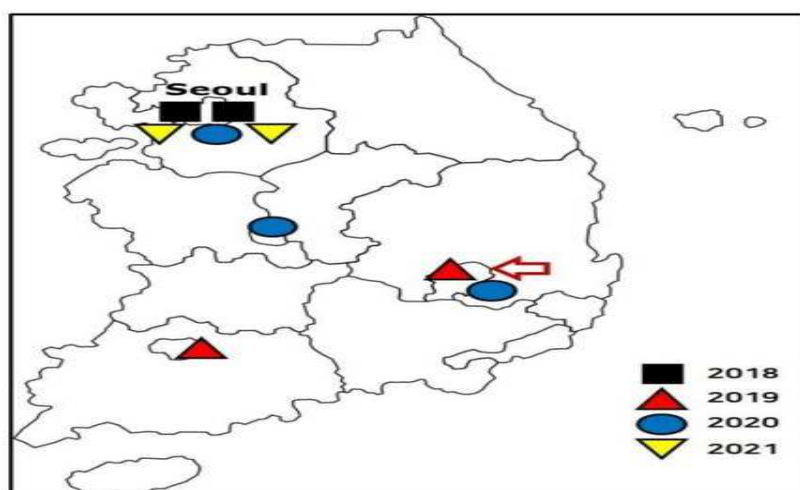


Figure 1-1 Paediatric Palliative Care Centres in the Republic of Korea.

Centres that opened in 2018 (■), 2019 (▲), 2020 (●), and 2021 (▼) are shown. The red arrow indicates the first local paediatric palliative care centre.

Source from Bae and Kim, 2022: 127

Although the number of paediatric patients with LLCs requiring hospice and palliative care increases by about 1,000 per year, in 2018 only two acute hospitals can provide palliative care, both in Seoul. There is also a shortage of paediatric palliative care team members. There will be a slight increase of seven from 2018 to 2021. Providing sufficient palliative care in acute hospitals, palliative care centres, local children's hospices and community care should be a high priority for the government, but this is not the case.

This research focuses on CYP with LLCs in the Republic of Korea at different stages of their disease trajectory. The choice of this demographic and geographical setting is influenced by the unique cultural and health care dynamics in South Korea that shape palliative care practices and decision-making processes. The study includes interviewees at different stages of their illness to fully understand the palliative care decisions faced at different stages of illness. By including both end-of-life decisions and considerations for withdrawal of active treatment, the study aims to capture a broad range of challenges and decisions faced by these individuals and their families. This approach ensures that the research covers a wide range of experiences, providing deeper insights into needs and responses at critical moments in care.

The inclusion of both end-of-life decisions and withdrawal of active treatment reflects the complex reality faced by many CYP with LLCs and their careers. Understanding these decisions across the spectrum of illness allows for a more nuanced exploration of the needs and ethical considerations that arise in paediatric palliative care, thereby informing better practice and policy. Using a person-centred and anti-oppressive approach, this study seeks to identify how these practices can be effectively integrated into current palliative care frameworks to enhance the empowerment and well-being of CYP with LLCs and their families.

Variables	Total, n (%)	Cancer, n (%)	Non-cancer, n (%)	p-value
Total	133,177	34,943 (26.2)	98,234 (73.8)	
Gender				<0.001
Male	71,764 (53.9)	17,121 (49.0)	54,643 (55.6)	
Female	61,413 (46.1)	17,822 (51.0)	43,591 (44.4)	
Age group (year)				<0.001
<1	9,084 (6.8)	363 (1.0)	8,721 (8.9)	
1–9	35,247 (26.5)	5,743 (16.4)	29,504 (30.0)	
10–19	49,120 (36.9)	13,987 (40.0)	35,133 (35.8)	
20–24	39,726 (29.8)	14,850 (42.5)	24,876 (25.3)	
Type of insurance qualification				<0.001
National Health Insurance	125,289 (94.1)	33,304 (95.3)	91,985 (93.6)	
Medical aid	7,888 (5.9)	1,639 (4.7)	6,249 (6.4)	
Level of income ^a				<0.001
High	46,137 (34.6)	12,750 (36.5)	33,387 (34.0)	
Medium	53,547 (40.2)	13,405 (38.4)	40,142 (40.9)	
Low	33,493 (25.1)	8,788 (25.1)	24,705 (25.1)	
Severity of disability ^b				<0.001
Severe	17,532 (13.2)	1,452 (4.2)	16,080 (16.4)	
Mild to moderate	3,618 (2.7)	1,140 (3.3)	2,478 (2.5)	
Without confirmed disability	112,027 (84.1)	32,351 (92.6)	79,676 (81.1)	
Diagnostic category ^c				
Malignancy		34,943 (26.2)		
Neurologic & neuromuscular			29,106 (21.9)	
Cardiovascular			20,483 (15.4)	
Renal & urologic			19,595 (14.7)	
Hematologic or immunologic			12,716 (9.5)	
Gastrointestinal			11,732 (8.8)	
Respiratory			8,976 (6.7)	
Other congenital or genetic defect			7,778 (5.8)	
Metabolic			7,505 (5.6)	
Premature & neonatal			5,946 (4.5)	
Miscellaneous			511 (0.4)	
Area of residence by administrative district				<0.001
Seoul, Gyeonggi, Incheon	80,996 (60.8)	22,415 (64.1)	58,581 (59.6)	
Gangwon	2,580 (1.9)	615 (1.8)	1,965 (2.0)	
Chungcheong	11,458 (8.6)	2,970 (8.5)	8,488 (8.6)	
Daegu, Gyeongbuk	9,377 (7.0)	1,815 (5.2)	7,562 (7.7)	
Busan, Ulsan Gyeongnam	17,288 (13.0)	4,331 (12.4)	12,957 (13.2)	
Jeolla	10,018 (7.5)	2,494 (7.1)	7,524 (7.7)	
Jeju	1,460 (1.1)	303 (0.9)	1,157 (1.2)	
Area of residence				0.058
Metropolitan	60,322 (45.3)	15,676 (44.9)	44,646 (45.4)	
Non-metropolitan	72,855 (54.7)	19,267 (55.1)	53,588 (54.6)	

Table 1-1 Demographic Characteristics of Children and Young People with Life-Limiting Conditions, 2015.
Source from Cho Hee Kim *et al.*, 2020

From: Healthcare utilization among children and young people with life-limiting conditions: Exploring palliative care needs using National Health Insurance claims data

- ^aLevel of income was categorized based on patients' NHIS premium as high level (upper 25% premium), intermediate level (middle 50%), and low level (lower 25%).
- ^bSeverity of disability was divided according to their disability grade into severe (grade 1–3) and mild (grade 4–6).
- ^cValues are not mutually exclusive.

In the 2020 study by Cho Hee Kim *et al.*, a population-level analysis of paediatric palliative care (PPC) in South Korea using the National Health Insurance Service database revealed a significant gap before 2015. Despite health advances, PPC was underdeveloped, affecting more than 1,000 children with life-limiting conditions each year. The research highlighted the need for PPC services that address the full spectrum of the disease trajectory, not just end-of-life care, leading to the establishment of a multidisciplinary PPC team and increased government support.

1.2.2 Focuses on Medical Treatments but not Cool Room?

Although there are 43 tertiary hospitals in the Republic of Korea, only two of them are located in Seoul and have multidisciplinary teams for CYP with LLCs in 2018. By the end of my fieldwork, the number had increased from 2 to 9 in 2021. I was disappointed that despite the increasing number of paediatric palliative care clinics in the Republic of Korea, there are no children's hospices.

Based on Figure 1-1 the map above, which shows two tertiary hospitals in 2018, where I observed processes at one of them and interviewed medical staff at both locations, there is no cool room for CYP with LLCs. Unsurprisingly, in the absence of national standards for paediatric palliative care, the two tertiary hospitals do not facilitate cool rooms, despite the availability of multidisciplinary teams for CYP with LLCs.

Helen Bennett (2020: 168-172) provides a guide to end-of-life care, which includes the care and support of the child and family after death. She looks at the practicalities of moving the child after death and setting up the cool room, a designated, quiet room where the CYP with LLCs can be kept for a few days after death or until the funeral, and where the family can spend time with their child.



Figure 1-2 The Cool Room^{2,3}, which is located in Gyeongsangbuk-do Pohang Medical Centre but CYP with LLCs cannot access the facilities.

From 2003 to 2004 the Ministry of Health & Welfare conducted a pilot project, in which I participated, for fostering program of Hospice and Palliative Care units. Finally, the Ministry of Health & Welfare announced palliative care places must facilitate cool rooms for patients and their family members. Regardless of age and gender, the cool room is to respect death with dignity. Before dying, the patient should be able to spend precious moments with their families to say goodbye. Near the end-of-life, as a pastor and a social worker, I supported the dying patient and their family member in the cool room. After the patient had passed away, a nurse and I washed the dead body and dressed it in their preferred clothes, which is not a shroud. While washing the dead body using medical alcohol and

² I translated 'end-of-life room' as 'cool room'. In Korea, a hospice or palliative care unit for adults should have an end-of-life room. Each hospice or palliative care unit has a unique name. Bennett (2014:40) states that once local policies and procedures have been agreed, details need to be widely communicated to all professionals and partner agencies such as acute hospitals. This will help to raise awareness of the local cold room facility and increase understanding of the options available to families.

³ According to recent research conducted by Tatterton, Honour, Billington, *et al.* (2022) in the United Kingdom, children's hospices offer designated "cool rooms" to give grief assistance. These rooms allow families to spend time with their deceased child and engage in farewell and memorial activities. Established in 1982 at Helen House, these facilities offer a serene environment for mourning and commemoration. They utilise advanced cooling technology to regulate the body's physiological changes following death. This integral component of hospice care focuses on addressing the emotional needs of families, as well as the practical components of care. It emphasises the comprehensive support provided during a time of deep grief and loss.

dress them in normal clothing, the bereaved family could express their emotion in the cool room with their family members, and close friends. Thus, the cool room for the patient and their family is essential. Acute hospitals in Korea do not have cool rooms. Lack of this facility deprives the parents of terminally ill children the choice of accepting aggressive treatments in PICU or to stop these treatments and take advantage of the facilities provided by the cool rooms. Apparently, most Korean hospitals are set up with and operated as non-profit corporations to improve public health and achieve public interest goals (Kim, Sohn, Moon, *et al.*, 2017). For these reasons, the cool rooms should be prepared and remain empty for the dying CYP with LLCs and their families.

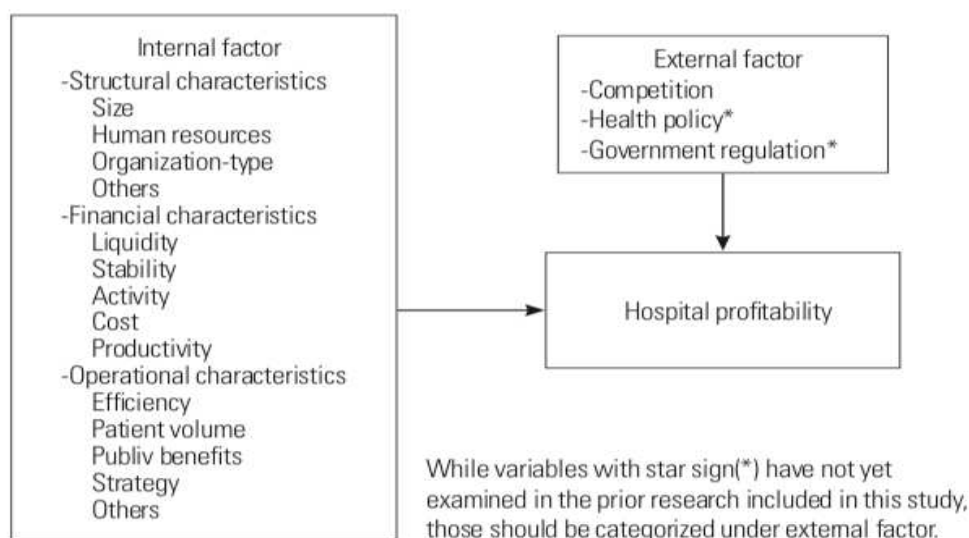


Figure 1-3 Conceptual Framework-Hospital Profitability

Source: Choi and Kim (2013: 400)

In fact, hospital profitability is under free competition and relies heavily on medical income from hospital operations, patient revenues, non-patient revenues and extraordinary income (Lee and Park, 2015). By changing the hospital industry, hospital profitability is inevitable even if running and managing cool rooms are related to public health and death with dignity. Choi and Kim (2013: 400) show hospital profitability, including internal factors and external factors. Based on Jee-Hyun Kim's conceptual framework-hospital profitability, Yang (2016) analyses the business performance of university hospitals for the past ten years.

Classification		2005	2006	2007	2005– 2007 Average	2012	2013	2014	2012– 2014 Average
Management performance	Patient revenues	1360	1626	1763	1,583	3665	3802	4023	3,830
	Patient expenses	1357	1586	1737	1,560	3607	3750	3921	3,759
	Operating profit	3	40	18	20	55	53	97	68
	Nonpatient revenues	51	79	89	73	224	226	248	232
	Reserve fund for essential business	74	92	67	77	20	22	251	97
	Normal profit	–11	23	2	4	59	41	49	49
	Net profit	1	–2	–14	–5	–40	–74	–48	–54
	Net profit 1	74	90	52	72	–19	–52	203	44
	Total assets	1118	1327	1470	1,305	3191	3627	3846	3554
	Total debt	726	857	940	841	1938	1957	2115	2003
	Total amount of capital	389	526	530	481	1252	1670	1728	1550

Table 1-2 Patient Care Performance Differences

Source from Yang, 2016: 18.

Management and financial data from 2005 to 2014 were collected from balance sheets, income statements and annual reports of 27 university hospitals. Yang (2016) reports that university hospitals have achieved good management performance over the past decade.

Using financial leverage, patient revenue, operating profit, non-patient revenue, total assets and total debt, the total had increased by more than twice. Running at least two cold rooms for children will not affect the hospital's substantial financial performance because it seems to be like running suite rooms in a boutique hotel. Although there is no data on the financial performance of the cool room, medical staff said that it does not affect the hospital's profitability. This is because the empty rooms cannot be linked to their profits, and wealthy patients can choose to pay for a suite room. Instead of

providing cool rooms, most hospitals in Korea have their own VIP (Very Important Person) rooms to provide high-quality medical services. For this reason, they are reluctant to prepare cold rooms.



Figure 1-4 Neonatal Intensive Care Units (NICU)

“Voices are growing that neonatal intensive care units (NICU) in Korea should be overhauled, in the wake of the deaths of four newborns at Ewha Womans University Medical Center’s NICU”

Source from Song (2018)

The VIP rooms, single rooms, neonatal intensive care unit or paediatric intensive care unit may be available when CYP with LLCs are in critical condition. Despite these options, the difficult decisions about transitioning from life-sustaining treatment to hospice care are never easy. Depending on the circumstances, medical treatment at the end of life ⁴ can lead to an increase in profits based on reported health expenditure (Yoon, 2022). After interviews, medical staff and some parents of patients said that the two tertiary hospitals would like to have various programmes for CYP with LLCs, but most resources are limited due to the focus on medical treatment. Therefore, I conclude that although parents and children are given a lot of information about the medical treatments available to them, many are not made aware of the cool room facility, which seems to be a hidden option when families prepare for the end of life.

⁴ Because medical treatments at the end-of-life cause family’s financial burden I will explore its details in Chapter 9 (9.5.2.2 Forms of Capital and the Gap of decision-making processes)

1.2.3 My Story: from a Reflective Pilot Journey to Acute Hospital-Based Palliative Medicine

In 2002, as an enthusiastic social worker, I started working at Sammuel Hospice for Adults to establish palliative social work. During my time there, I had to deal with my frustration and growing anger at the high expectations and demands of terminally ill patients and their families, with limited support from the palliative care team.

A young female orphan with LLCs was transferred from a hospital to a hospice during the 2002 FIFA World Cup in the Republic of Korea and Japan. While the majority of Koreans enjoyed watching the World Cup matches that summer, I tried to find the young girl's family members she wanted to meet before she died. It was not an easy task. While I was trying to locate them, with the help of the multidisciplinary team supporting me, she passed away peacefully. This left me not only with the task of organising the funeral, but also of communicating with the multidisciplinary team and experiencing the different communities in a hospice, working in a multidisciplinary team and having a privileged opportunity.

In 2005, the experience eventually became my personal challenge which led me to invent the hospice leadership programmes. This is because facing frustration and stress might be connected with complicated issues in palliative care, due to having to deal with complex issues in the giving of time and care and hindered by the lack of resources. For instance, taking poor palliative education and disconnecting social networking among palliative care centres cause complicated issues in palliative care. After successful hospice leadership programmes in 2005, I met some leaders, who were involved in the leadership programmes, such as a medical doctor, some social workers, a nurse, some pastors and professional volunteers. We discussed various questions such as what we should do next for the hospice movement and how we could provide more options for patients and their family members, regarding their capability to deal with the problems. From 2007 to until 2013, we set up and developed a number of hospices, a lifeline counselling centre and a bereavement scholarship charity. We set up and developed various hospices in the Republic of Korea and in other locations such as Ulaanbaatar in Mongolia and in Nepal, however the intervention or support of decision-making with the patient's family members and the palliative care team remains controversial.

By exploring practical decision-making in paediatric palliative care, I started the journey at Durham University to put a great deal of effort to enunciating further principles and resolutions. In 2016, from July to September, I piloted both acute hospitals in Seoul. Before starting, I had to check whether or not conducting fieldwork in an acute hospital was acceptable. Through the pilot study, I

refined the interview questions and made tests to decide whether to accept initial methods for identification of the components that are the norms and values that guide surrogate decision-making in the Republic of Korea.

After conducting the pilot study, I carefully thought about some reasons of disconnecting transitions among acute children's hospitals, children's palliative care centres, children's hospices, schools, and community care, but could not conclude the answers. In general, palliative care can be divided into non-cancer and cancer. Not surprisingly, there was no published data on the incidence and prevalence of life-limiting and life-threatening paediatric disease and current investigation for orphans with LLCs nor epidemiological and health services data before 2016.

Furthermore, finding samples from non-cancers, mainly rare diseases, is too difficult, although I estimated information on the numbers, diagnostic categories and age ranges of children with life-limiting or life-threatening conditions based on information available via the Korean Society for Hospice and Palliative Care.

Suddenly, I carefully read about the humidifier disinfectant disaster that occurred in the Republic of Korea in 2016 while pondering how to find samples from non-cancers. The disaster was caused by the inhalation of toxic humidifier disinfectants that were produced by Oxy, a local subsidiary of the British conglomerate Reckitt Benckiser. According to reports by the Korea Times, 235 people suffered lung damage and 51 people died. The victims and their relatives have since become plaintiffs in legal cases against the companies involved.

While considering how to find samples from non-cancer cases, I came across the news of the humidifier disinfectant disaster that occurred in the Republic of Korea in 2016. The disaster was caused by the inhalation of toxic humidifier disinfectants produced by Oxy, a local subsidiary of the British conglomerate Reckitt Benckiser. According to reports by the Korea Times, 235 people suffered lung damage and 51 people died. The victims and their relatives have become plaintiffs in legal cases against the companies involved.



Figure 1-5 “Lim Seong-joon, right, 13, who is suffering from chronic lung disease linked to a humidifier-disinfectant product, lies down on a mat next to his sister at their home”

Source from Lewis, 2016.

The humidifier disinfectant disaster in the Republic of Korea highlights the challenges facing the environmental health movement in the Republic of Korea, such as the influence of industry and the government’s focus on economic growth over environmental and health concerns. In Pandita (2019) “Building Environmental Health Movement in Asia: Lessons from Korea,” he describes how The Republic of Korea experienced rapid industrialization in the 1970s and 1980s, which led to environmental and health problems that were largely ignored by the government and industry. The Humidifier Disinfectant Disaster in the Republic of Korea was a public health crisis caused by the use of a humidifier disinfectant product that contained a toxic chemical called poly hexamethylene guanidine (PHMG). From 2001 to 2011, the product was widely used in humidifiers in the Republic of Korea, and it was found to be responsible for a range of respiratory illnesses and deaths, particularly in young children and pregnant women. According to Choi and Jeon (2019), the disaster resulted in over 1,000 cases of lung injury and 186 deaths. The victims experienced various symptoms, including

coughing, chest pain, shortness of breath, and difficulty breathing. The cause of the illness was not immediately clear, but after an investigation, the toxic chemical PHMG was identified as the culprit. The disaster resulted in a significant public outcry and led to changes in regulations and consumer awareness of product safety in the Republic of Korea. The incident serves as a cautionary tale about the importance of ensuring the safety of consumer products and the potential dangers of untested or inadequately regulated chemicals.

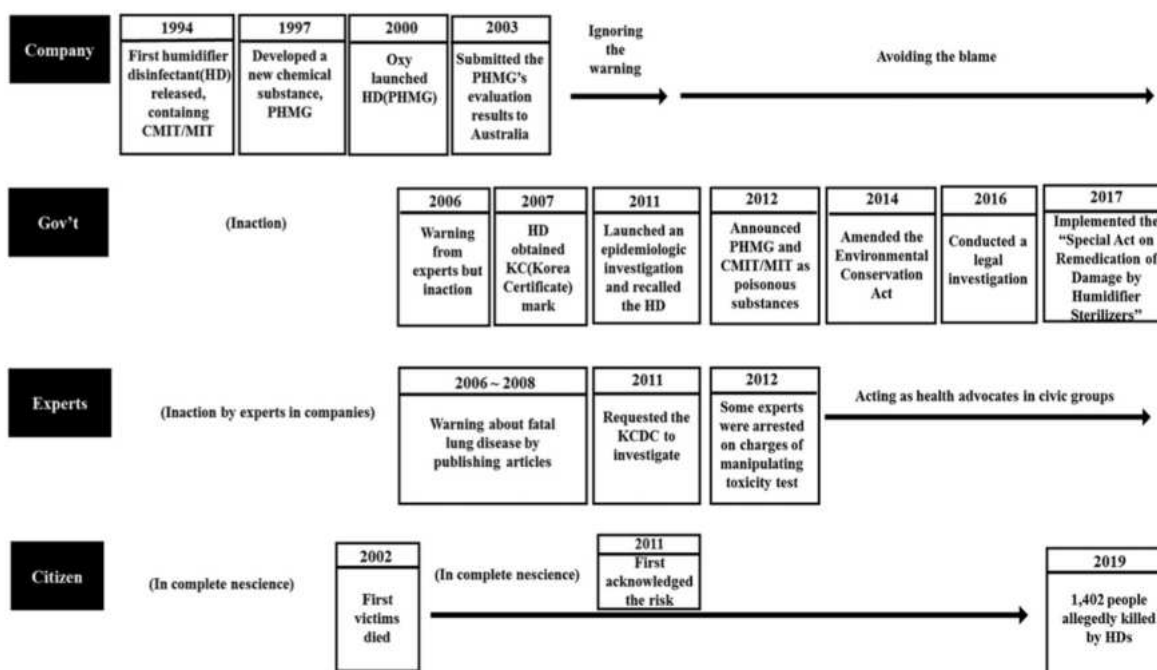


Figure 1-6 A Flow Chart for the Case of Toxic Humidifier Disinfectants.

Source from Choi and Jeon, 2019: 10

When I came across the story through the press and social media, I could not bear the anger inside me and had to seek social justice because the most vulnerable children were the victims and died. This is because there are serious epistemic and ethical questions about their effectiveness in ensuring the safety of research subjects. The reason for choosing the topic of surrogate decision making is my personal experience of working in various hospices as a palliative social worker in the Republic of Korea. This compelling desire is based on my individual interpretations and perspectives as I have struggled with a number of experiences, such as thinking about patients with LLCs, the increase in the number of orphans with LLCs, and the best interests of CYP being overlooked or overshadowed by the interests of adults.

In addition, I encountered numerous ethical issues, which heightened my desire to pursue a career in biomedical ethics, particularly in the fields of palliative care and social work. I have faced

numerous obstacles and hardships. I come from a broken home, a dysfunctional family, barely receiving any support from my parents.

1.3 Research Significance of Multi-Dimensional Decision-Making Processes

1.3.1 Controversial Issues of Shared Decision-Making?

Respect for shared decision-making raises a number of controversial issues involving medical, legal and ethical dimensions. It is often described as a 'slippery slope argument', particularly when factors such as age, cultural trust and paternalism are taken into account. The United Nations Convention on the Rights of the Child (UNCRC) (1989: 4) defines children as individuals from 0 to 18 years of age, although the upper age limit is debated. According to the International Federation of Social Workers' (IFSW) International Policy on Human Rights (1996: 8), "social workers are expected to provide the best possible assistance without unfair discrimination on the basis of gender, age, disability, colour, social class, race, religion, language, political beliefs, or sexual orientation." Despite the essential nature of shared decision making, there may be unstable standards in relation to children's rights. The IFSW (2002: 26) highlighted that the best interests of children are often overshadowed by the interests of adults. CYP with LLCs are entitled to fundamental rights, including full development in health care, social security, education and play.

The second is protection. When CYP are subject to medical malpractice or medical futility, the state has an obligation to intervene, protect, provide and promote palliative care and quality of life. The third is the participation of CYP in decision-making processes, especially at the end of life.

The participation of CYP is directly linked to children's rights. CYP should not only be considered in decision-making processes, but should also be given the opportunity to express their views on how to improve their quality of life. This requires a re-evaluation of the traditional bases for their exclusion, in particular assumptions about their cognitive capacities and rational decision-making.

1.3.2 Shared Decision-Making in the Context of Multi-Dimensional Decision-Making Processes for Children and Young People with Life-Limiting Conditions?

In general, parents or family members are eligible to become proxies and guardians on behalf of their children and to make decisions for them if they have become mentally incapacitated, incompetent or are under 18 years old. At that point, CYP lack the power to waive my rights proxy or family members. According to the *Encyclopaedia of Bioethics* (Post, 2004: 1310) “‘the surrogate decision-making’ process involves obtaining informed consent for treatment (or its refusal) from a surrogate named by the patient in an advance directive, or in the absence of such a directive, by the patient’s family members.” In patients’ preferences, a surrogate makes a decision by choosing one option that reflects the patient’s experience, beliefs, and values as informed by the physician’s recommendations. (Jonsen, Siegler and Winslade, 2010)

Regarding the circumstances of CYP with LLCs, it should require shared decision-making. According to the *Encyclopaedia of Bioethics* (Post, 2004: 388), shared decision-making defines, ideally, important healthcare choices which represent a consensus among parents, doctors, nurses, and CYP with LLCs, if they are mature enough and willing to participate (Goldman, Hain & Liben, 2021: 36-43). In the context of multi-disciplinary work, palliative social workers face difficulties such as enhancing the quality of life, ensuring the safety and best interests of incompetent patients, and avoiding futile treatments in multi-disciplinary work. In supporting the patient’s surrogate and informing them of the many variables, the role of a palliative care social worker will be reconsidered, considering the reality of surrogate decision-making.

Thus, the range of decisions for CYP with LLCs can be divided into three parts: medical treatments, non-medical treatments, and healthcare transition such as, hospital, hospice, home, school and community. The wide range of shared decision-making requires an understanding of complicated decision-making processes.

1.3.3 Professional Decision Making in Palliative Care Social Work?

The assessment in social work for a certain judgement requires the balancing of benefits and risks. There are some possible problems with ‘balancing potential benefits and possible harm’ (Taylor, 2013). As Beck and Shue (2003: S12) ask: “how does the risk-benefit ratio affect the consent process?” Calder, Mckinnon, and Sneddon, (2012) said that “risk is a dynamic concept and assessment of risk in child protection needs to be comprehensive if it methodically and analytically ponders both past and present in order to identify future risks to the child or young person. When conducting an assessment of risk, the focus is on the safety and well-being of the child.”

However, it is necessary to assess the risk-benefit ratio and ensure the qualification of an agency or inter-agency. Palliative social works play an essential role in the care of children and young people with life-limiting conditions, as they address the psychological and social needs of patients and their families (Goldman, Hain & Liben, 2021). However, there are two issues with the role of palliative social work in the Republic of Korea. Firstly, there can be some overlap between the roles of palliative care social workers and other members of the medical team in the hospital or clinical setting. Secondly, standardised assessment or guidelines have not yet been developed in the Republic of Korea (Demiris, Parker Oliver, Wittenberg-Lyles, *et al.*, 2012: 4; Carpenter, Patsios, Szilassy, *et al.*, 2011: 195-196; Hackett and Taylor, 2013).

From the perspective of the role of the palliative care social worker, it is important to acknowledge the potential overlap with other medical team members and to advocate for the development of standardised guidelines for their work in the Republic of Korea. This perspective is essential for understanding the unique challenges and opportunities associated with providing palliative care for children and young people with LLCs in the Republic of Korea.

1.4 Research Aims and Questions

The primary objective of this study is to elucidate the multi-dimensional decision-making processes for CYP with LLCs in the Republic of Korea. This research addresses a notable gap in the existing literature, which predominantly focuses on surrogate decision-making within the realm of bioethics but lacks a specific emphasis on medical social work and its role in the decision-making processes for CYP with LLCs. The intention is to contribute significantly to the enhancement of safeguarding measures for CYP in paediatric palliative care and to advocate for the promotion of their autonomy, as discussed in the seminal work of English, Sommerville, Brannan, *et al.* (2012:145-160). By bridging this knowledge gap, the study aims to identify and suggest improvements in the decision-making process, thereby ensuring more effective participation and support for CYP with LLCs in paediatric palliative settings. To enhance the clarity and brevity of the research questions, the new structure could prioritise the examination of decision-making processes for children and young people with LLCs at multifaceted decision-making processes as follows:

1. Structural level of decision-making processes: the objective is to examine the decision-making processes at the structural level, encompassing an exploration of decisions made within a vicious cycle and those influenced by hidden Social Determinants of Health (SDOH).

- **Research Questions:**

1. What are the key characteristics and stages of decision-making for CYP with LLCs at the structural level, taking into account hidden Social Determinants of Health?
2. How do social workers perceive their role and what are their expectations in the context of structural decision-making for CYP with LLCs?
3. What ethical challenges emerge in surrogate decision-making at the structural level?

2. Family-oriented level of decision-making processes: the objective is to examine the family-oriented decision-making processes, focusing on the rights of CYP with LLCs, standards of decision-making, informed family consent, and related ethical challenges.

- **Research Questions:**

1. How are decisions made for CYP with LLCs at the family-oriented level?
2. In what ways do social workers engage with families, and what roles do they play in these decision-making processes?
3. What are the ethical challenges in surrogate decision-making at the family-oriented level?

3. Tacit Dimensional level of decision-making processes: the objective is to explore decision-making at the tacit dimensional level, applying Michael Polanyi's concepts of tacit knowledge and personal knowing.

- **Research Questions:**

1. What processes characterise tacit-level decision-making for CYP with LLCs?
2. How do social workers identify and navigate the tacit dimensions in their decision-making roles?
3. What ethical challenges are encountered in surrogate decision-making at the tacit dimensional level?

4. Privilege level of decision-making processes: the objective is to delve into the privilege level of decision-making processes, examining how factors like socioeconomic status and access to resources influence decisions.

- **Research Questions:**

1. What are the decision-making processes for CYP with LLCs at the privilege level?
2. How do social workers perceive their role and what expectations do they have when dealing with privilege-related decision-making?
3. What ethical challenges arise in surrogate decision-making at the privilege level?

All three research questions are novel and have not been previously explored in the context of decision-making for CYP with LLCs. In addition, as this research specifically focuses on anti-oppressive practice (Dominelli, 2002; Mullaly, 2018; Nzira and Williams, 2009), it has some strengths. “A person-centred philosophy” (Dominelli, 1996:153; Dominelli, 2004: 3) in anti-oppressive practice embraces the concepts of participation, partnership, and empowerment, offering the potential for the service user’s voice to be heard and acted upon. This approach aims to investigate the possible correlation of decision-making under uncertainty in deciding with CYP and oppression. Since anti-oppressive practice and paediatric palliative care emphasise a holistic approach, this research aims to consider how paediatric palliative care social workers can influence change at three levels: micro, mezzo, and macro.

This research critically explores the multi-dimensional decision-making processes for CYP with LLCs. The main outcome of this research is to present the multi-dimensional decision-making processes, reveal the expectations and the role of paediatric palliative social workers and discover the ethical challenges in the ethos of surrogate decision-making.

1.5 Outline of Thesis Structure

In this thesis, I set out to explore the reality of decisions for CYP with LLCs living in Seoul, the Republic of Korea, suffering from LLCs. Understanding decision-making processes for CYP with LLCs is complex because the best interests of CYP have an extra layer of difficulty. By employing critical ethnographic research, I used a combination of observations and interviews and found that

surrogate decision-makers, paediatric palliative care service users and workers in multi-disciplinary staff honestly shared their experience of decision-making processes although it is sensitive and difficult to understand the complicated decision-making processes.

In **this introductory chapter**, the reader has been introduced to an overview of the research background and my story. A personal rationale will be provided for why this decision process for CYP with LLCs was undertaken. It presents the whole structure of the thesis.

Chapter 2 literature review provides the empirical rationale for the decision-making processes study, based upon a scoping review to understand the decision-making processes for CYP with LLCs, it follows the Arksey and O'Malley framework (2005) for scoping review of the literature: paediatric palliative decision-making processes, ethical challenges, and the role of paediatric palliative care social workers.

Chapter 3 How to understand multi-dimensional decision-making processes? Explores the lived experience of decision-making processes for CYP with LLCs underpinning the study in chapter 3. This chapter ponders some connections among barriers and facilitators, discrimination, luck, and oppression by outlining the multi-dimensional decision-making processes in greater detail. By drawing from the Other of Emmanuel Levinas (1906-1995), the tacit dimension of Michael Polanyi (1891-1976), and three concepts of habitus, capital, field, and symbolic violence from Pierre Bourdieu (1930-2002), I interpreted multi-dimensional decision-making processes at the structural level, the family-oriented level, the tacit dimensional level, and the privilege level of decision-making processes.

Chapter 4 A critical ethnography on decision-making processes shows the research strategy, including an explanation of the research questions and an overview of critical ethnography regarding surrogate decision-making. I then describe the research design and process, including a detailed description of the research process, based on social epidemiology, the sampling strategies, research methods and participation selection for rich data collection. I describe the theoretical approach utilised within the data analysis regarding critical ethnography in data analysis and interpretation.

Chapter 5 Ethics in critical ethnography: series of dilemmas reflects on the ethical challenges and methodological tensions that arose during my research process. As a critical ethnographer, I encountered several ethical tensions, particularly regarding the expectations and demands of multiple disciplinary workers, surrogate decision-makers, and CYP with LLCs. This chapter highlights the complexities of navigating these tensions while upholding ethical standards and conducting rigorous research.

Chapter 6 The structural level of decision-making processes: blind luck, hidden social determinants, or oppression The structure level of decision-making processes includes two stages: 1) those under a vicious circle and 2) those in hidden social determinants. Employing the Other of Emmanuel Levinas and the symbolic violence of Pierre Bourdieu, the structure level of decision-making processes can be understood to involve luck, social determinants of health (SDOH) and oppression.

Chapter 7 The family-oriented decision-making processes: blind luck and/or ensuring shared decision making? Explores the challenges and complexities associated with decision-making, particularly in the unknown journey of decision-making processes and the unknown end-of-life. The role of paediatric palliative care social workers is also examined, including their responsibilities and limitations. Despite their concern for the psychological and social well-being of patients and families, they may face ethical challenges in meeting expectations. To shed light on the limitations of shared decision-making, the chapter employs the Other of Emmanuel Levinas.

Chapter 8 The tacit dimensional level of decision-making processes: internalised oppression and/or the psychology of luck? The tacit dimensional level of decision-making processes focuses more on the transmission of distorted beliefs. Surrogate decision-makers take and maintain distorted beliefs such as taboo, linking denial and palliphobia, and avoiding a child's funeral. These hinder the best interests of CYP with LLCs. Even though paediatric palliative care social workers are expected to support and intervene in decision-making processes, there is none. Drawing on Michael Polanyi's view of tacit knowledge, I show how the psychology of luck and internalised oppression enables the relationship in the decision-making processes between oppression, distorted beliefs, and luck.

Chapter 9 The privilege level of decision-making processes: epistemic and moral luck and/or social inequality? Is divided into two stages, which reveal the experiences of individuals in privileged and underprivileged decision-making processes. The research highlights that while there are expectations for paediatric palliative care social workers to provide holistic care and improve the quality of life for patients and families, fundraising often takes priority over other responsibilities. To understand the decision-making processes in these contexts, I employ Bourdieu's interlinked concepts of capital, habitus, and field.

Chapter 10 Conclusion is the final chapter of this thesis. It summarises the findings, paying particular attention to decision-making processes such as the structural level, the family-oriented level,

the tacit dimensional level and the privileged level of decision-making processes. Each level of decision-making involves ethical challenges such as oppression, distorted beliefs and luck as social inequality. Limitations and implications are presented and recommendations for future research are proposed.

1.6 Conclusion

This chapter has provided an introduction to the research that follows, an overview of the research background and the researcher's history, and has presented the overall structure of the thesis. Particular attention has been paid to describing the meaningful contribution to some of the most pressing issues of our time.

In order to achieve this goal, I have set out to explore a site related to surrogate decision-making processes. By focusing specifically on the development of CYP with LLCs, I aim to begin to unravel the complexities of decision-making processes by adopting an inductive approach that takes practice as the starting point for theory development.

Chapter 2: Literature Review

2.1 Introduction

Following this introductory chapter, Chapter 2 presents a review of the literature on decision-making for CYP with LLCs. In order to understand the decision-making processes for CYP with LLCs, it follows the Arksey and O'Malley framework (2005) for scoping review of the literature in 2.2. Next, 2.3 reviews relevant literature relating to paediatric palliative decision-making processes, ethical challenges, and the role of paediatric palliative care social workers.

Next, in 2.4 the literature on service user involvement in decision-making will be surveyed, both to evidence *what should* be happening in medical decision-making for CYP with LLCs and to conduct potential, especially ethical challenges, and *why* this is not being operationalised from CYP and LLCs' perspective based on the role of paediatric palliative care.

2.2 An Initial Scoping Review

Regarding no previous literature reviews of any kind focusing on decision-making processes for CYP with LLCs, this scoping review of the literature following the Arksey and O'Malley framework (2005) was employed. This is because paediatric palliative care social workers in the Republic of Korea cannot account for decision-making processes for CYP with LLCs in terms of holistic approaches. By conducting a full systematic review of the literature, this section will examine the extent, range, and nature of prior research activity and identify gaps in the existing literature (Arksey and O'Malley, 2005).

2.2.1 Identifying the Research Questions

The scoping review addressed the question: What do we know about the decision-making processes for CYP with LLCs, the ethical challenges in the ethos of surrogate decision-making, and the role of paediatric palliative care social workers?

Paediatric palliative care OR decision making OR children OR and young people OR life-limiting conditions *AND paediatric palliative care social work OR the role of paediatric palliative care social work AND ethical challenges OR ethos OR surrogate decision making

Figure 2-1 Search Terms

Group 1	Paediatric Palliative Care
Group 2	Paediatric palliative care, decision making, children, and young people, life-limiting conditions
Group 3	Ethical challenges, Ethos, Surrogate decision making

Table 2-1 Specific Keywords

Specific keywords were identified, and a broad search strategy was developed, following Figure 2-1 and Table 2-2.

2.2.2 Identifying Relevant Studies

In this section, I address issues relating to using existing search strategy tools⁵, while exploring qualitative, quantitative, and mixed methods research studies based on paediatric decision making. In this retrospective review, articles and books published over the past four decades were scrutinised for their discussion of controversial concepts.

Focusing on retrieval research, the articles were selected with respect to search terms, conducted between the beginning of 1978 and 2022. Most of the articles could be retrieved from Web of Science,

⁵ According to Methley, Campbell, Chew-Graham, *et al.* (2014), PICO, PICOS, and SPIDER are useful frameworks for qualitative research. However, for this thesis, I have selected Arksey and O'Malley's framework (2005) because it is better suited for conducting scoping studies and allows for flexibility in clarifying concepts and revising research questions (Daudt, van Mossel and Scott, 2013).

Scopus, MEDLINE, Google Scholar and Embase followed by incremental searching of the bibliographies which are the most widely indexed databases showing the topic-research area. Finally, a total of 25 articles were identified.

2.2.3 Study Selection

I focused on a set of criteria which led to include or exclude identified studies from the searches, following Table 2-3 inclusion and exclusion criteria:

Inclusion Criteria	Exclusion Criteria
Sources written in English and Korean	Source published before 1978
Studies conducted at any location or place of paediatric palliative care	Sources written in languages other than English and Korean
Studies including peer-reviewed articles, empirical studies of any design – quantitative, qualitative, or mixed methods, focussed on children and young people with LLCs, any kind of paediatric palliative care, home care, outpatient and inpatient paediatric palliative care setting.	Studies focused on decision making for adults
Sources published between January 1978 and March 2022	non-peer reviewed articles such as editorials

Table 2-2 Inclusion and Exclusion Criteria of Study Selection

The study selection criteria were to maintain a clear focus on the decision-making processes for CYP with LLCs. Including any study design maximised the potential to collect diverse decision-making processes for CYP with LLCs in paediatric palliative care and the various perspectives allowed for the community, acute inpatient, outpatient, and home care.

CYP with LLCs are often not identified in terms of culture and social policy. This timeframe reflects changes in paediatric palliative care policy that have occurred over the past 45 years and enables the tracing of any evolution in practice over time.

The decision to restrict the search to papers in the English and Korean languages was a pragmatic one. The database searches were initially conducted in May 2016 and were repeated in September 2019. The results of that final search (September 2022) are reported.

The database searches produced a total of 29,300 results, with 252 duplicates. Following title and keyword screening, 245 relevant articles were identified. After screening the abstracts, the full articles were sought and reviewed. At this stage, 25 papers remained, excluding 10 studies which reported paediatric palliative care and showed surrogates' experiences but were not explicitly related to decision-making processes.

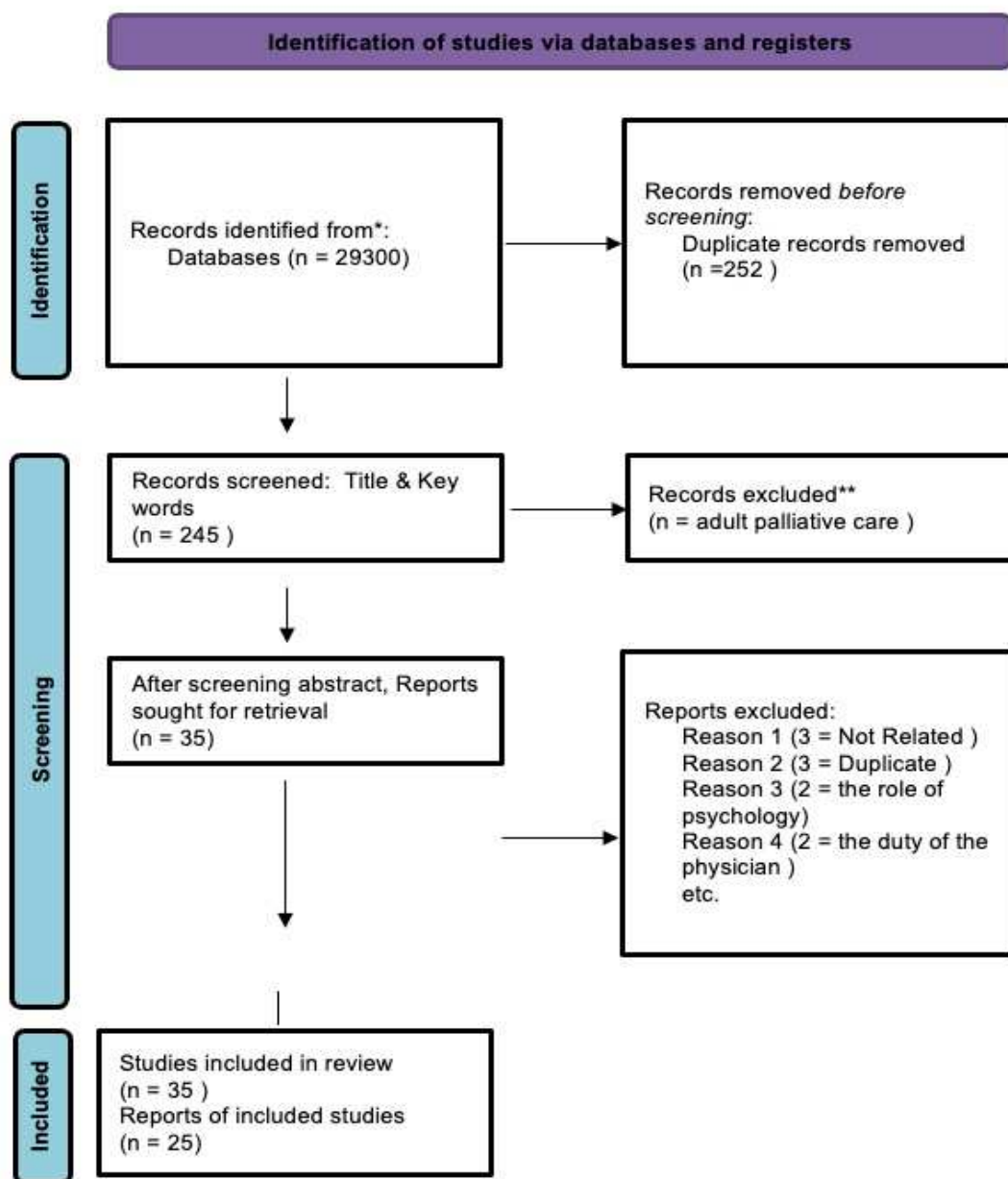


Figure 2-2 PRISMA-ScR flow diagram

After screening the titles and abstracts of 35 articles, 25 studies were found eligible for the scoping review. Out of the remaining ten studies, four were not relevant to decision-making processes

(one was a briefing on symptom and pain control and the others), four were duplicates, one focused on the role of psychology, and one focused on the duty of the physician rather than decision-making processes. Therefore, 25 studies were deemed eligible for inclusion in the scoping review.

For clarity, this process is summarised in a PRISMA-ScR flow chart in figure 2-4 (Tricco, Lillie, Zarin, *et al.*, 2018). In this literature review, the final 25 papers included in the scoping review were then charted based on a PRISMA-ScR flow diagram. Data was extracted relating to author, year of publication, title, geographical location, setting, methods and any comments on the paper, especially the focus of study.

N u m b e r	Author	D a t e	Title	Location	Setting	Design/ Methods	Comments
1	Badarau, Ruhe, Kühne, <i>et al.</i>	2016	Decision making in paediatric oncology: views of parents and physicians in two European countries	EU: Switzerland and Romania	participating parents and physicians in Switzerland and Romania, which were collected as part of a larger project investigating views and attitudes on child and adolescent capacity in healthcare in Switzerland.	Qualitative interview study	identified decision making as a heterogeneous process
2	Beaune, Leavens, Muskat, <i>et al.</i>	2014	Poverty and paediatric palliative care: what can we do?	Cannada	interdisciplinary healthcare providers that work in a paediatric palliative care setting at an urban children's hospital	Mixed methods	Screening and attention to the SDOH lie within the scope of practice of all healthcare providers.
3	Browning & Solomon	2005	The initiative for paediatric palliative care: an interdisciplinary educational approach for healthcare professionals	USA	the Initiative for Paediatric Palliative Care, a consortium of seven academic children's hospitals, Education Development Center, the National Association of Children's 4 Hospitals and Related Institutions, the New York Academy of Medicine, the Society of Paediatric Nursing, and the Association of Medical School Paediatric Department Chairs	Needs assessment research with clinicians and parents and reflects a commitment to culturally respectful, family-oriented care of children with life-threatening conditions.	An Innovative, comprehensive approach to paediatric palliative care education
4	Cadell, Johnston, Bosma, <i>et al.</i>	2010	An overview of contemporary social work practice in palliative care	Canada	the system of social work education at all levels	in the Canadian context and to illustrate them with case examples.	an overview of the palliative care social work practice competencies
5	Cadell, Kennedy & Hemsworth	2012	Informing social work practice through research with parent caregivers of a child with a life-limiting illness	Canada	For parents, caring for a child with a life-limiting illness, it is an evolving field of practice in social work.	mixed methods, two overarching themes were prominent in both the quantitative and qualitative data.	a critical role in informing best social work practices in field of practice
6	Carroll, Mollen, Aldridge, <i>et al.</i>	2012	Influences on decision making identified by parents of children receiving paediatric palliative care	USA	Children's Hospital of Philadelphia	a mixed-methods cohort study	Parents report grappling with several influences upon their decision-making processes that extend well beyond the standard discussions of medical information exchanges and the evaluation of risks and benefits.

7	Contro	2004	Hospital Staff and Family Perspectives Regarding Quality of Paediatric Palliative Care	USA	Staff members and family members	a mixed method	Staff members and family members stated their desire for more support.
8	Dalberg, Jacob-Files, Carney, <i>et al</i>	2013	Paediatric oncology providers perceptions of barriers and facilitators to early integration of paediatric palliative care	USA	the physician participants compared to nurse practitioner, nursing, and social work participants	four focus groups	to identify barriers and facilitators that might assist in understanding how care could be improved.
9	Dreesens, Veul, Westermann, <i>et al.</i>	2019	The clinical practice guideline palliative care for children and other strategies to enhance shared decision-making in paediatric palliative care; paediatricians' critical reflections.	the Netherlands	Paediatricians (15) were recruited through purposive sampling in three university-based paediatric centers	Semi-structured face-to-face interviews.	the recommendations needed to focus more on how to practice SDM, and offer more detailed recommendations, preferring a recommendation stating multiple options.
10	Feudtner	2007	Collaborative communication in paediatric palliative care: a foundation for problem-solving and decision-making	USA	communication between patients, families, and clinicians	have been filtered through his own experiences as a physician, family member, and patient	Collaborative communication builds the foundation upon which paediatric palliative care of the highest possible quality can be created
11	Feudtner, Carroll, Hexem, <i>et al.</i>	2010	Parental hopeful patterns of thinking, emotions, and paediatric palliative care decision making: a prospective cohort study	USA	Children's hospital and surrounding region.	Prospective cohort study.	emotional and cognitive processes have a combined effect on medical decision making.
12	Fineberg	2010	Social work perspectives on family communication and family conferences in palliative care	UK	family conferences	methods of literature review, focus groups with professionals and feedback from experts	excellent communication from healthcare providers has a tremendous impact on how families live through periods of illness and loss and how they view the experience for the rest of their lives as they grieve and adjust to their losses.
13	Gries, Curtis, Wall, <i>et al.</i>	2008	Family member satisfaction with end-of-life decision making in the ICU.	USA	In ICU patients dying in 10 medical centres	a cohort study Quantitative research	Increased family satisfaction with decision making is associated with withdrawing life support and the documentation of palliative care indicators including the following: physician recommendations to withdraw life support; expressions of patients' wishes; and discussions of families' spiritual needs.
14	Gwyther, Altilio, Blacker, <i>et al.</i>	2005	Social work competencies in palliative and end-of-life care	USA	Social workers from clinical, academic, and research settings	reviewed the literature and constructed this detailed description of the knowledge, skills, and values that are requisite for the unique, essential, and appropriate role of social work.	This document is intended to guide preparation and credentialing of professional social workers, to assist interdisciplinary colleagues in their collaboration with social workers, and to provide the background for the testing of quality indicators and "best

							practice” social work interventions.
1 5	Hinds, Menard, Jacobs	2 0 1 2	The child’s voice in paediatric palliative and end-of-life care	USA	three literature databases	a targeted literature review	The absence of the child’s voice in palliative and end-of-life care jeopardizes best care efforts.
1 6	Kaye, Rubenstein, Levine, <i>et al.</i>	2 0 1 5	Paediatric palliative care in the community	USA	Community based PPC (CBPPC) programs are increasingly integral to the coordination, continuity, and provision of quality care.	In this review, the authors examine the purpose, design, and infrastructure of CBPPC	strategies and resources for designing, implementing, and maintaining quality standards in CBPPC programs are reviewed.
1 7	Larcher, Craig, Bhogal, <i>et al.</i>	2 0 1 5	Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice	UK	the General Medical Council (GMC) document: ‘Treatment and care towards the end-of-life: good practice in decision making’.	taken into account developments in palliative care provision and the growing availability of ethical and other support in decision making, as well as issues that have arisen in response to the two previous documents.	decisions to withhold, withdraw or limit life-sustaining treatment in children with life-limiting or life-threatening illness
1 8	Liben, Papadatou & Wolfe	2 0 0 8	Paediatric palliative care: challenges and emerging ideas	the International Children’s Palliative Care Network (ICPCN)	Children’s Hospice International; The Association for the Care of Children with Life-Threatening Diseases and their Families; the National Hospice and Palliative Care Organization through its ChiPPS Project; and The Association of Children’s Hospices.	the literature review	to promote and facilitate communication and cooperation between all individuals and organisations throughout the world that are providing or supporting care to children with life-threatening conditions.
1 9	Parker Oliver, Washington, Demiris, <i>et al.</i>	2 0 1 2	Problem Solving Interventions: An Opportunity for Hospice Social Workers to Better Meet Caregiver Needs	USA	REFLECTIONs by five Associate Professors Problem Solving Interventions: An Opportunity for Hospice Social Workers to Better Meet Caregiver Needs	Reflective Qualitative	to describe one common social work intervention and discuss its applicability for hospice social workers. However, it should suggest the wide range of an ambiguous role
2 0	Popejoy, Almack, Manning, <i>et al.</i>	2 0 2 2	Communication strategies and persuasion as core components of shared decision-making for children with life-limiting conditions: A multiple case study	UK	Eleven cases recruited from three tertiary hospitals in England.	A longitudinal, qualitative, multiple-case study.	Professionals should be aware of the models of shared decision-making which include such communication strategies.
2 1	Postier, Catrine & Remke	2 0 1 8	Interdisciplinary paediatric palliative care team involvement in compassionate extubation at home: from shared decision-making to bereavement	USA	families choose to spend their child’s end-of-life at home	Two cases	PPC teams can pull together hospital and community resources to empower families to make decisions about when and where their child dies.
2 2	Rost, Wangmo, Niggli, <i>et al.</i>	2 0 1 7	Parents’ and physicians’ perceptions of children’s participation in decision-making in paediatric oncology: A quantitative study.	Swiss	Eight Swiss Paediatric Oncology Group centres	A Quantitative Study	should work towards creating awareness for systematic differences between parents and physicians with respect to the perception of the child, the disease, and shared decision-making.
2 3	Tomlinson, Bartels,	2 0	Challenges to participation in paediatric palliative care	Canada	By comprehensively reviewing the relevant literature	the literature review	must be aware of the ethical and logistical

	Hendershot, <i>et al.</i>	0 7	research: a review of the literature				challenges to maximize successful completion of the research and to obtain a representative sample.
2 4	Valdez- Martinez, Noyes & Bedolla	2 0 1 4	When to stop? Decision-making when children's cancer treatment is no longer curative: a mixed- method systematic review	Mexico, USA and UK	Clinical practice and medico- legal and ethical setting.	a mixed-method systematic review	Findings will hopefully stimulate further normative and descriptive lines of research in this complex, under- researched, field through a wider cultural lens that includes children's perspectives.
2 5	Wright, Aldridge, Wurr, <i>et al.</i>	2 0 0 9	Clinical dilemmas in children with life-limiting illnesses: decision making and the law	UK	to discusses several clinical scenarios	armchair research	discusses several clinical scenarios to better understand these decisions and the effects of changes in the law.

Table 2-3 Scoping Review

2.3 Finding the Hidden Paediatric Decision-Making Processes

2.3.1 Medical Decision-Making for CYP with LLCs?

The scoping review primarily focused on decision-making by doctors and did not specifically examine the decision-making processes of CYP with LLCs from multiple angles. Surrogate decision-makers and patients have a general awareness of medical decision-making, mainly medical treatments. Larcher, *et al.*, (2015) said from diagnosis to death and bereavement there are different choices to be made such as refusing treatment, being assessed concerning nutrition and hydration, taking palliative care, considering organ donation, and preparing the funeral service.

Although understanding the nature of children's and adults' rights should require elaborating the relationship and distinction between capacity and competency, Wright *et al.*, (2009) discusses several clinical scenarios in terms of legal frameworks. Competent decision-making should require rational abilities such as communicating with others, understanding information and making deliberate choices in decisions (Badarau, Ruhe, Kühne, *et al.*, 2016; Larcher, Craig, Bhogal, *et al.*, 2015; Popejoy, Almack, Manning, *et al.*, 2021; Postier, Catrine and Remke 2018; Rost, Wangmo, Niggli, *et al.*, 2017; Valdez-Martinez, Noyes and Bedolla 2014; Wright, Aldridge, Wurr, *et al.*, 2009). Decision-making

capacity is related to the ability to understand and judge the information which is provided along with one's needs and goals, reflecting one's values and best interests (Wright, Aldridge, Wurr, *et al.*, 2009).

Despite a long tradition of discussing children's capacity to make decisions in health care, our understanding of these issues in paediatric care is often limited by a lack of clarity. This complexity is compounded at different stages of physical and cognitive development, making it challenging to fully involve CYP with LLCs in decision-making, equitable care and discussions about their care and future.

2.3.2 Ethical Challenges in Paediatric Palliative Care

Second, this can illuminate ethical challenges which arise near the end-of-life. Given the space, time, and ways in which communication for consent can take place, for CYP with LLCs, shared decision-making is essential (Badarau, Ruhe, Kühne, *et al.*, 2016; Contro, 2004; Dreesens, Veul, Westermann, *et al.* 2019; Hinds, Menard and Jacobs, 2012; Kaye, Rubenstein, Levine, *et al.* 2015; Larcher, Craig, Bhogal, *et al.*, 2015; Liben, Papadatou and Wolfe, 2008; Popejoy, Almack, Manning, *et al.*, 2021; Postier, Catrine and Remke, 2018; Rost, Wangmo, Niggli, *et al.*, 2017; Tomlinson, Bartels, Hendershot, *et al.*, 2007). The chosen papers focus on treatment planning in shared decision-making. Popejoy, Almack, Manning, *et al.*, (2021) explore “the communication strategies used in shared decision-making for children with life-limiting conditions since the complicated ethical challenges required for children with life-limiting conditions, include artificial nutrition, commencement or discontinuation of medications, long-term ventilation and ceilings of care.” Despite the importance of shared decision-making, Hinds, Menard and Jacobs (2012) conclude that the absence of the child's voice in palliative and end-of-life care jeopardises the best care efforts and that seeking the ill child's voice in paediatric palliative care should now be standard of care.

To support shared decision-making, there are some complicated ethical challenges for CYP with LLCs (Dreesens, Veul, and Westermann, *et al.*, 2019; Kaye, Rubenstein, and Levine, *et al.*, 2015; Larcher, Craig, Bhogal, *et al.*, 2015; Popejoy, Almack, and Manning, *et al.*, 2021; Postier, Catrine and Remke, 2018). Firstly, Rost, Wangmo, and Niggli, *et al.*, (2017) point out different perceptions of the child, the disease, and shared decision-making and suggest that paediatric palliative care delivers interdisciplinary approaches. Similarly, Popejoy, Almack, Manning, *et al.*, (2021) highlight that professionals should be aware of the models of shared decision-making, including such communication strategies.

Shared decision-making is broad: when the setting is the hospital, it could be relatively simple, but it is a much broader concept when applying shared decision-making from community-based paediatric palliative care programmes to the hospital (Postier, Catrine and Remke, 2018). Kaye, Rubenstein, and Levine, *et al.*, (2015: 316) also emphasise that community-based paediatric palliative care programmes are increasingly integral to the coordination, continuity, and provision of quality care, although current paediatric palliative care models focus primarily on the hospital setting.

2.3.3 The Role of Paediatric Palliative Care Social Work?

The role of paediatric palliative care social work should support or intervene decision-making, when surrogate decision-makers struggle with pursuing the best interests for CYP with LLCs in the holistic decision-making processes. Cadell, Kennedy and Hemsworth (2012) describe the role of social workers in the delivery of palliative care as: advocacy, care delivery, community capacity building, decision-making, information sharing, self-reflective practice, assessment, care planning, evaluation, education and research, and working as part of an interdisciplinary team. Gwyther, Brennan and Harding, (2009: 89-90) emphasise that the role relates to enhancing quality of life, promoting justice and is multidimensional in involving clinicians, educators, researchers, advocates, community leaders, and policy analysts.

In terms of decision-making processes, medical staff face difficulties with the following: how to enhance the quality of life, ensure the safety and the best interest of incompetent patients and avoid futile treatments in interdisciplinary or multi-disciplinary work, although there are some principles and a framework for practice (Larcher, Craig, Bhogal, *et al.*, 2015: s6-s12). Paediatric palliative care social workers assess and support holistic decision-making processes: three difficult choices include following, rejecting, or withholding the given options. Fineberg, (2010: 213-214) points out that social workers assess and explore diverse aspects of family life when caring for families and planning communication with family members, including the patient, as family conferences are recognised as an important part of the work with families in the setting of palliative care.

In addition, Cadell, Kennedy and Hemsworth, (2012: 378) insist that the role of paediatric palliative care social work as a part of the interdisciplinary team is associated with informing the team of the social work practice that will be utilised within the field to direct interventions. Considering the right to self-determination of legal minors and its ethical aspects, Larcher, Craig, Bhogal, *et al.*, (2015)

take into account developments in palliative care provision and the growing availability of ethical and other support in decision-making.

The specific intervention in terms of the role of paediatric palliative care social work is related to some barriers and limited facilitators in some of the papers (Beaune, Leavens, and Muskat, *et al.*, 2014; Browning and Solomon, 2005; Carroll, Mollen, Aldridge, *et al.*, 2012; Dalberg, Jacob-Files, Carney, *et al.*, 2013; Feudtner, 2007; Gries, Curtis, Wall, *et al.*, 2008; Valdez-Martinez, Noyes and Bedolla, 2014). Gwyther, Brennan and Harding (2009: 89-90) argue that social workers are concerned with enhancing the quality of life, promoting justice and access to care for clients/patients, their biological or created families and/or other types of caregivers. Despite the importance of enhancing the quality of life and promoting justice, Parker Oliver, Washington, Demiris, *et al.*, (2012: 3) mention that the role of the social worker on the hospice interdisciplinary team and the role with patients are often confused and blurred with nurses and chaplains. Parker Oliver, Washington, Demiris, *et al.*, (2012: 4) insist that the ambiguous nature of the role of social work in hospice care is due in part to the lack of standardised assessment across the hospice setting.

Parker Oliver, Washington, Demiris, *et al.*, (2012: 4) suggest a problem-solving intervention in terms of the role, but it requires an understanding of decision-making processes such as collaborative communication (Feudtner, 2007; Gries, Curtis, Wall, *et al.*, 2008), cultural aspects (Carroll, Mollen, Aldridge, *et al.*, 2012; Valdez-Martinez, Noyes and Bedolla, 2014), emotional and cognitive processes (Feudtner, 2007), the SDOH (Beaune, Leavens, Muskat, *et al.*, 2014) and identifying barriers and facilitators (Dalberg, Jacob-Files, Carney, *et al.*, 2013).

2.3.4 Navigating Hidden Hazardous Substances

As documented in the fieldnotes, observations conducted in the hospital environment on Christmas Eve, 24 December 2017, revealed the presence of two distinct groups of patients. While one group, consisting of children and cleaning staff, left the hospital with their families or resumed their daily routines after outpatient visits, another group exhibited different patterns of behaviour. The second group, made up of families and patients who had recently become aware of the causes of their illnesses, exhibited markedly different behaviours. These observations led me to further reflection as a researcher. These family members' awareness of the mismanagement of hazardous substances in their homes, workplaces and schools not only influenced their immediate responses, but also highlighted the broader social determinants affecting their health. This realisation has shifted the focus

of my research towards examining the ways in which environmental and social factors shape the health outcomes of CYP with LLCs.

	Hazard Substances	Environmental Exposure/ Hazardous Substances-Related Diseases
Home	PHMG, PGH, CMIT, MIT from Humidifier disinfectants	<p>The Asian Citizen’s Centre for Environment and Health & the Korean Federation for Environmental Movement (KFEM)</p> <p>Humidifier disinfectant associated with lung injury (Ryu, Park, Lee, <i>et al.</i>, 2019), bronchiolitis and allergic rhinitis (Cho and Winzer, 2019)</p> <p>Social Disasters Commission (2022)</p> <p>Korea Centres for Disease Control and Prevention KCDC, (2011)</p> <p>Kim and Kwon (2012)</p> <p>Kim, Ahn, Yang, <i>et al.</i>, (2014; 2013)</p> <p>Leem and Kim (2020)</p> <p>Miller, Marty, Arcus, <i>et al.</i>, (2002)</p> <p>Lee, Kim and Kwon (2012)</p> <p>Bordini and Kliegman (2020)</p> <p>Toxic Joo, (2022) and Lee (2022a) highlight that “‘Toxi’ is a movie based on the ‘Humidifier Disinfectant Incident’ that plunged Korea into shock” The photo is from TF Cinema Review (Lee 2022a)</p>
	Radon-Emitting Mattresses	<p>the Asian Citizen’s Centre for Environment and Health & the Korean Federation for Environmental Movement (KFEM)</p> <p>Nuclear Safety and Security Commission (2018)</p> <p>Radon is a carcinogen: health hazards, such as lung cancer, respiratory diseases, (Seo, Ha, Kang, <i>et al.</i>, 2019)</p> <p>Cf There are problems of associations that have not been clearly established between radon and other diseases, such as leukaemia and thyroid cancer (Seo, Ha, Kang, <i>et al.</i> 2019),</p> <p>but one of my interviewees shared that due to radon bed mattress, his daughter died of leukaemia.</p> <p>Lee and Kim, 2022</p> <p>Kim, Jeong and Shin (2019)</p>
Work	Hazard Substances from Semi-conduct industry	<p>Supports for health and rights of people in semiconductor industry (SHAPS)</p> <p>Cancers and reproductive risks in the semiconductor industry (Ladou and Bailar, 2007; Smith, David Allan Sonnenfeld, Pellow, <i>et al.</i> 2006), Cases Series of Malignant Lymphohematopoietic Disorder (Lee, Kim, Park, <i>et al.</i>, 2011)</p> <p>Jo Jae-seok (2014).</p>

		<p>Im, (2014)</p> <p>(JTBC, 2021)</p> <p>Stories from Clean Room (Joseph, 2017)</p> <p>Another Promise (2014)</p>
School	Asbestos	<p>the Asian Citizen's Centre for Environment and Health & the Korean Federation for Environmental Movement (KFEM)</p> <p>Asbestos related diseases: mesothelioma, lung cancer, asbestosis, pleural plaques, pleural effusion, diffuse pleural thickening round atelectasis, mesothelioma and etc.</p> <p>(Kang, Kim, Kim, <i>et al.</i>, 2018; Kim, Kim, Kim, <i>et al.</i> 2016)</p> <p>NHS (2020)</p> <p>Miller, Marty, Arcus, <i>et al.</i>, 2002</p> <p>Shin, Son, Hong, <i>et al.</i>, (2008)</p> <p>(Kim, 2009).</p>

Table 2-4 Environmental Exposure and Hazardous Substances-Related Diseases

Showing Table 2-5, I analysed the documents provided by the interviewees and created a table showing environmental exposures and diseases related to hazardous substances that the reason for hidden SDOH (Kathryn Strother Ratcliff, 2017) continuously happens.

SDOH, according to the World Health Organization (2008), are “the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life.”

Besides, knowing the root causes is not only too difficult to understand, but also parents and CYP with LLCs cannot easily understand environmental exposure and/or hazardous substance-related diseases (DiGangi, 2019) regarding decision processes for CYP with LLCs.

2.4 Conclusion

This chapter presented an in-depth literature review of the most recent research on decision-making in paediatric palliative care since there are no studies on decision-making processes for CYP with LLCs. The scoping review has highlighted four core themes: medical decision-making for CYP with LLCs, ethical challenges in paediatric palliative care's decision-making, the role of paediatric palliative care social work and navigating hidden hazardous substances.

In Chapter 3, I shall go on to consider how we consider better analyse the processes of decision-making for CYP with LLCs' lives and experiences through the multi-dimensional decision-making processes, mainly based on the Other of Emmanuel Levinas (1906-1995), the tacit dimension of Michael Polanyi (1891-1976), and the concepts of symbolic violence, habitus, capital and field in Pierre Bourdieu (1930-2002).

Chapter 3: How to Understand Multi-Dimensional Decision-Making Processes?

3.1 Introduction

Chapter 3 of my thesis focuses on multi-dimensional decision-making processes in the context of children and young people with life-limiting conditions in Korea. Through my fieldwork, I found that decision-making processes are influenced by a range of factors, including barriers, facilitators, hidden discrimination, and hidden oppression. These dynamics are often intertwined and shape the experiences of children and young people with life-limiting conditions in Korea.

In section 3.2, I explore the various terms that are relevant to multi-dimensional decision-making, such as barriers, facilitators, hidden discrimination, and hidden oppression. These dynamics are often intertwined, with barriers and discrimination serving to limit access to facilitators and opportunities for children and young people with life-limiting conditions. It is important to note that the ultimate goal of decision-making in these cases is to enable the children and young people to live a normal life as survivors, rather than to succumb to their condition.

In section 3.3, I delve further into the role of luck in decision-making, including blind luck, the psychology of luck, epistemic luck, and moral luck. I analyse the interplay between luck and other factors at play in decision-making, such as cultural values and norms, to gain a deeper understanding of decision-making processes in the context of children and young people with life-limiting conditions in Korea.

By drawing on the concepts of the Other in Emmanuel Levinas (1906-1995), the tacit dimension of Michael Polanyi (1891-1976), and the interlinked concepts of habitus, capital, field, and symbolic violence of Pierre Bourdieu (1930-2002) in section 3.4, I demonstrate the importance of understanding the multi-dimensionality of decision-making processes. I explore how these concepts are relevant to understanding the different dimensions of decision-making, including the structural level, the family-oriented level, the tacit dimension and the privileged level of decision-making. Because luck is often perceived as an external force beyond our control, it is often intertwined with the other dimensions of decision-making. The relationship between luck and social inequality should be distinguished on the basis of the structural level, the family-oriented level, the tacit dimension and the privilege level of decision-making.

3.2 Barriers and Facilitators, Discrimination and/or Oppression in Decision-Making Processes?

The successful decision-making processes for CYP with LLCs can deal with various difficulties. Section 3.2 presents the range of terms: barriers, facilitators, hidden discrimination and hidden oppression.

3.2.1 Decision Processes: Supportive Care, Palliative Care and Hospice

The World Health Organization (2020) defines palliative care as an approach to improving the quality of life of patients (both adults and children) and their families facing a life-limiting illness. It addresses not only physical, but also psychosocial and spiritual problems, and aims to relieve suffering through early recognition, accurate assessment and appropriate management of pain and other problems. Palliative care uses a team-based approach to provide comprehensive support for patients and their carers, including practical help and bereavement counselling. It recognises palliative care as a basic human right to health and advocates person-centred and integrated health services tailored to individual needs and preferences.

Palliative care extends beyond traditional hospice services to include acute hospital care and supportive care and covers the entire illness trajectory from survivorship to bereavement. Decision-making in this context involves advance planning for end-of-life⁶, considering health care interventions, symptom management, supportive services and practical issues such as financial and legal arrangements. This proactive approach facilitates greater patient and family involvement in decision making, thereby improving the quality of care.

⁶ In the context of supportive care, palliative care and hospice care, advance care planning means considering end-of-life care needs and preparing for the eventualities of daily life. It includes discussions and decisions about health care interventions, symptom management and supportive services, as well as practical matters such as financial and legal arrangements. Advance care planning is an important aspect of patient-centred care that allows for greater patient and family involvement in the decision-making process and can improve the overall quality of care.

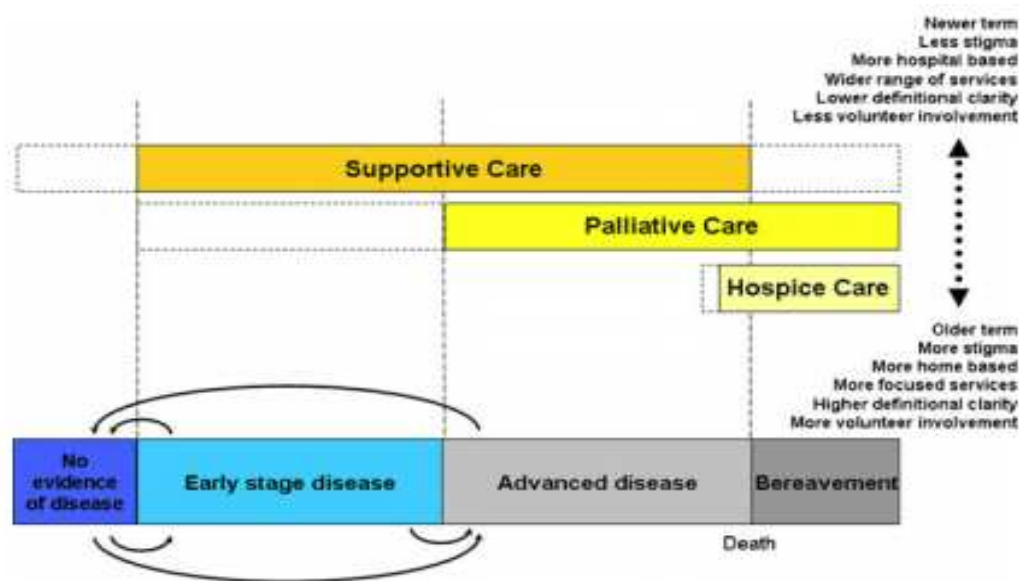


Figure 3-1 Supportive Care, Palliative Care and Hospice Care

Source from Hui, De La Cruz, Mori, *et al.*, 2012: 683.

In supportive care, palliative care and hospice care, the surrogate decision makers are confronted with three conceptual models: “barriers and facilitators” (Boland, Graham, Légaré, *et al.*, 2019), “discrimination” (Thompson, 2003; 2016) and “oppression” (Benuto, 2020; Dominelli, 2002; Smith, 2004; 2009; 2010 and 2017) when exploring multi-dimensional decision-making processes. Without understanding the complex decision-making processes of CYP in paediatric palliative care, it is not easy to identify barriers and/or a form of oppression in multi-dimensional decision-making processes. In supporting life-limited children and their families in “holistic and multi-disciplinary” approaches to paediatric palliative care (Brown, Warr and Shribman, 2007: 27)”, healthcare providers face moral dilemmas. In these situations, one of the following options must be chosen: ensuring safety, increasing the quality of life, avoiding futile treatments and pursuing the best interests of CYP with LLCs.

3.2.2 Hidden Barriers and Facilitators?

Within the given barriers, the theoretical models that are used to conceptualise decision support and shared decision-making can be feasible (Feenstra, Lawson and Harrison, *et al.*, 2015). Considering awareness of the lack of practical models to promote shared decision-making in paediatrics, Boland,

Graham, Légaré, *et al.*, (2019) conducted a systematic review, guided by the Ottawa Model of Research Use (Logan and Graham, 1998). They found that “the most frequent barriers were characteristics of the options (decision), poor quality information (innovation), parent/child emotional state (adopter), power relations (relationship), and insufficient time (environment). The most frequent facilitators were low stake decisions (decision), good quality information (innovation), agreement with shared decision-making (adopter), trust and respect (relationship), and shared decision-making tools/resources (environment) (Boland, Graham, Légaré, *et al.*, 2019, 1; 25).”

While the best interests of children and young people with LLCs are paramount, there can be significant barriers to shared decision making. To address these challenges, we explore the theoretical model of barriers and facilitators to shared decision making for paediatric patients in Table 3-1. In this section, we further discuss how these barriers and facilitators can be developed and implemented to improve decision-making processes, taking into account covert discrimination and/or oppression, the role of serendipity and the complexity of multidimensional decision-making.

3.2.3 Hidden Discrimination and/or Oppression?

In paediatric palliative care, barriers to decision-making often arise from social influences, environmental contexts and resource limitations, which can lead to 'discrimination' and 'oppression'. Thompson (2003: 82; 2016: 17) highlights that discrimination leads to oppression, which occurs at personal, cultural and structural levels: personal prejudice, cultural norms that disempower, and structural power inequalities, respectively.

Iris Marion Young (2022) and Mullaly (2018: 25) further describe oppression as multifaceted, encompassing exploitation, marginalisation, powerlessness, cultural imperialism and violence. It is pervasive and complex, often internalised by the oppressed, leading them to unconsciously perpetuate their inferior status, as explained as Adam (1978) explains.

In the context of paediatric palliative care, medical professionals and surrogate decision-makers may overlook how oppression influences decisions, often overlooking its structural roots in cultural, spiritual, linguistic, financial, ethnic and power dynamics. This can devalue patients in the decision-making process. There is therefore a critical need to incorporate anti-oppressive practices that focus on client-centred care and the elimination of inequalities, as advocated by Adams, Dominelli and

Payne (2009) and Dominelli (1996, 2002, 2004), who critique competency-based approaches in favour of addressing these broader societal issues.

3.3 Why Luck in the decision-making processes?

Interestingly, I found that CYP with LLCs and their parents only desire luck. They interpreted the results in terms of luck. Once outcomes are known, surrogate decision makers are often subject to blame or praise based on luck, which can lead to undeserved attribution. This highlights the need to critically evaluate the role of luck in decision-making processes. This is because people believe some results are associated with fortune and wish fulfilment. Theoretically, there are several aspects to understanding the concept of luck. Therefore, this section introduces blind, epistemic, moral and psychological luck. While luck is often perceived as an external force beyond our control, I found that in the specific cultural context of Korea, luck is often intertwined with the other dimensions of the decision-making process (Barrett, 2006; Friedland 1992, Orasanu, Martin, Davison, *et al.*, 1998; Wgenaar and Kerenm 1988; Wilkinson and Truog, 2013).

3.3.1 Blind Luck

Luck, particularly ‘blind luck’, plays an important role in decision making in paediatric palliative care, where outcomes are often influenced by unforeseen factors beyond control (Broncano-Berrocal, 2015; Church & Hartman, 2019; Cross, 1991; Matyas and Ottenbacher, 1993; Roumbanis, 2019). This concept, linked to moral and epistemic luck, is crucial when social workers support decision-makers, as it encompasses both internal and external uncontrollable elements that affect the outcomes of medical decisions.

Blind luck can lead to unexpected health outcomes - either positive or negative - such as a sudden improvement or deterioration in a patient's condition. This unpredictability can raise ethical dilemmas and safety concerns, particularly when decisions involve therapeutic or non-therapeutic medical research or innovative treatments (Henry N. Pollack, 2003). The unpredictability of blind luck requires careful planning, which may include advance care planning, funeral arrangements, and

decisions about organ and tissue donation (Kinley, Stone, Butt, et al., 2017; Lovell and Yates, 2014; Macmillan Cancer Support, 2017; Thomas, Lobo, and Detering, 2018).

Palliative care social workers need to navigate these complexities by supporting families and ensuring that decision-making processes take into account the potential for unexpected outcomes (Henry N. Pollack, 2003: 13). This includes addressing the ethical issues associated with the limits of control in medical decisions, particularly for CYP with LLCs, to mitigate conflict and support families in making informed decisions.

3.3.2 The Psychology of Luck

Church and Hartman (2019) explore how individuals perceive and attribute luck, highlighting the significant impact these attributions have on perceptions, well-being and decision-making. They examine several aspects, including the factors that lead people to attribute events to luck, the consistency of these attributions, the relationship between luck and risk assessment, and the role of emotions in assessing and responding to luck. They suggest that understanding these dynamics may lead to healthier responses to luck.

Further research by Day and Maltby (2003) and Pritchard and Smith (2004) explores how cognitive biases and personal factors such as ability or effort influence our perceptions of luck. Studies by Miller, Turnbull, & McFarland (1990) and Janoff-Bulman and Ronnie (1992) explore how experiences, particularly traumatic ones, affect individuals' perceptions of being lucky and unlucky, often leading those who have experienced negative events to see themselves as less lucky.

Taken together, these findings enhance our understanding of the psychological underpinnings of happiness and its profound influence on human behaviour and psychology.

3.3.3 Epistemic Luck

Epistemic luck refers to the influence of chance in the acquisition of knowledge and is particularly relevant to medical decision making where evidence may be incomplete or biased. Doherty (2005: 307) criticises evidence-based medicine (EBM) for its reliance on clinical research while neglecting the value of intuition and experience, which can lead to variation in intellectual virtue among

practitioners, resulting in epistemic luck. This lack of control over information can lead to unpredictable outcomes in decision making (Dickenson, 2003: 65).

In paediatric palliative care, where decision making involves complex factors, epistemic luck becomes critical. Social workers support families and healthcare providers in navigating these complexities, often in situations where EBM proves inadequate due to the nascent and uncertain nature of available medical knowledge. The unpredictable nature of such decisions requires a deep understanding of both the inherent limitations of knowledge and the potential for unexpected outcomes.

Recognising and addressing epistemic luck is crucial for paediatric palliative care social workers to ensure that decision-making is in the best interests of children facing life-limiting conditions. It is important to take a holistic approach that goes beyond reliance on EBM. Awareness of the limitations and potential gaps in the available evidence can reduce the risks arising from such uncertainties and support ethical and informed decision-making in this sensitive area.

3.3.4 Moral Luck

Moral luck is a concept that explores how agents are morally judged on the basis of factors beyond their control. Introduced by philosophers Bernard Williams and Thomas Nagel, it highlights the role of luck in the morality of actions, which is particularly relevant in healthcare decision-making for CYP with LLCs. Nagel (2012) categorises moral luck into four types: resultant (outcomes of actions), circumstantial (situational context), constitutive (characteristics of the agent) and causal (external factors influencing outcomes).

Dickenson (1991) suggests that moral luck is particularly important in decisions involving CYP with LLCs because of the high stakes and unpredictable outcomes, where health care providers may be praised or blamed for outcomes influenced by unpredictable factors. This complicates the assignment of moral responsibility, especially when surrogates make decisions that reflect the best interests of the patient, which may conflict with cultural or disciplinary perspectives.

Understanding moral luck is crucial in paediatric palliative care, underscoring the need to acknowledge the limits of human agency, respect patient wishes, and incorporate cultural sensitivity. A multidisciplinary and culturally aware approach can help to overcome these challenges and ensure that decisions are always made in the best interests of the children and young people involved.

3.4 Exploring Multi-Dimensional Decision-making Processes through the Lens of Levinas, Polanyi, and Bourdieu

Section 3.4 of my research delves into the complex nature of multi-dimensional decision-making processes in the context of CYP with LLCs. To investigate the connections among barriers, facilitators, discrimination, oppression, and luck in these decision-making processes, in this section, I draw from ideas of the Other of Emmanuel Levinas (1906-1995), the tacit dimension in Michael Polanyi (1891-1976), and of habitus, capital, field, and symbolic violence in Pierre Bourdieu (1930-2002).

This section illustrates that the different types of luck are linked to different levels of decision-making, as shown in the following table 3-2:

Blind Luck:	External Factors	The Structural Level of decision-making processes
	Internal Factors	The Family-Oriented Level of decision-making processes
The Psychology of Luck		The Tacit Dimensional Level of decision-making processes
Epistemic Luck		The Privilege Level of decision-making processes
Moral Luck		

Table 3-1 Luck and Different Levels of Decision-Making Processes

Blind luck, which refers to external and internal factors that are beyond our control and knowledge, is linked to both the external factors of the structural level and the internal factors of the family-oriented level of decision-making processes. This can create uncertainty and challenge decision-making processes for these children and their families, as factors that impact the outcome are not yet known or understood, even by medical professionals.

The psychology of luck, which is related to how individuals perceive and respond to luck, is connected with the tacit dimension level of decision-making. The ways in which decisions are made at this level often reflect cultural assumptions and biases, which can impact decision-making processes.

Finally, epistemic luck and moral luck are related to the degree of privilege in decision-making processes. The level of intellectual virtue varies widely, which means that decision-making can lead to unexpected outcomes due to a lack of control, and the examination of evidence from clinical research, which is emphasised in evidence-based medicine, can be unreliable. In addition, cultural values and norms, such as collectivism and respect for elders, may influence decision-making at the family level, which can be seen as a form of moral luck.

3.4.1 Examining the Structural Level of decision-making processes and/or External Influences of Blind Luck?

Analysing the structural level of decision-making processes through the lens of Emmanuel Levinas's Other and Pierre Bourdieu's symbolic violence, it becomes clear that within this level there are oppressive structures that manifest themselves in the form of the phenomenology of violence and symbolic violence. Blind luck, which encompasses external and internal factors beyond our control and knowledge, is linked to the external factors of the structural level. It reveals hidden social injustices and the covert web of oppression that exists within decision-making processes at this level. By understanding these dynamics, we can better navigate and address the challenges posed by blind luck and the structural level of decision-making, and ultimately work towards more just and equitable outcomes for all involved.

3.4.1.1 Telling the place of “I” and “the Other”

This thesis critiques the ethos of surrogate decision making for CYP with LLCs through the analysis of empirical data and multiple perspectives. It acknowledges the significant role of community, culture and tradition in shaping decision-making processes and emphasises the importance of reflecting on one's own experiences and the views of Others.

Drawing on the philosophical insights of Emmanuel Levinas, who critiqued Western philosophy's focus on individual subjectivity, this study explores how understanding and identity are fundamentally linked to our relationships with Others (Levinas, 1961: 54-56; 1974: 174). According

to Levinas's theories in *"Time and the Other"* (1995) and as further interpreted by Stan van Hooft (2006: 107), the essence of our being is inherently ethical, based on our concern for others.

The thesis emphasises for the need to incorporate multiple perspectives to enrich our understanding of surrogate decision making for CYP with LLCs. This multifaceted approach aims to promote a more comprehensive and ethically informed understanding of the complexities of decision making in this context.

3.4.1.2 The Structural Level: Responsibility or Violence in decision-making processes?

Parents making decisions for their children are devastated, whether they are deciding on futile treatments or palliative care. According to the Association of Palliative Care Social Workers (APCSW, 2016) and Jones (2004: 67; 2006), paediatric palliative care social workers seek to improve the care children and their families receive by providing information and emotional support for the decision-making process in a multi-disciplinary palliative care team, including advance care planning, psychosocial and spiritual support, pain and symptom management, care at the time of death, the financial burden on families of CYP with LLCs along with health care needs, funeral planning, respite and bereavement care. For this reason, paediatric palliative care social workers face difficulties such as how to improve quality of life, ensure the safety and best interests of incompetent patients, and avoid futile treatments in multidisciplinary work. When taking responsibility for CYP with LLCs, inter-agency communication in decision-making processes aims to protect them. They must take into account both the agency's responsibility and the safety and ethical concerns of the CYP with LLCs who must be protected.

However, because surrogate decision making can have unpredictable outcomes, an agency or interagency within the medical field can be held responsible for the decision and receive either praise or blame. Given the multi-disciplinary nature of the medical field, the question of which agents are likely to resist and attempt to bring about change is related to moral responsibility.

For the understanding of the concept of agency⁷ and of the Other we turn to Emmanuel Levinas (1985; 1991; 1994; 1995 and 1998). Levinas illuminated the ethical height of the other is to take

⁷ Bruce L. Miller defines agency as 'awareness of oneself as having desires and intentions and of acting on them. Agency does not imply that persons are never influenced by external forces or that persons never act impulsively. It is an account of how persons are able to act and not how they always act' (Post, S. G., 2004: 246-247). Alexander Rosenberg, (2005)

responsibility, emphasising the processual quality of essence. Levinas not only focused on the death, lives and the suffering of human beings but also enhanced them by complementing them with community cooperation for the responsibility of the other. Stan van Hooft (2006: 107) defines Emmanuel Levinas as a virtue ethicist because “virtue is not just that set of character traits that are required of us or applauded by Others but is our way of being ethical.” Since surrogate decision-making might respond not only to our beliefs but also to our situated experience within the community as family-oriented perspective, culture and tradition, the decision-making might assimilate others into our own perspective. Stan van Hooft (2006: 107) shows, “Levinas’s analysis explains how such motivations are part of the very structure of our being and that our most primordial mode of being is already ethical” so that we refuse to be assimilated as others. Instead, the theory can be applied and end up avoiding strong paternalism and shared decision-making processes.

In the context of decision-making processes, the concepts of the Other of Emmanuel Levinas and the symbolic violence of Pierre Bourdieu demonstrate the presence of oppressive structures, including the phenomenology of violence and symbolic violence. Symbolic violence, which refers to the ways in which social structures can oppress individuals or groups through their thoughts and actions, without the use of physical violence, is particularly relevant in this context. It highlights the ways in which dominant cultural norms and values can reinforce existing power structures to the detriment of those who are marginalised or oppressed. It is therefore crucial to consider the possibility of symbolic violence and other forms of oppression when examining the structural level of decision-making processes.

3.4.2 The Family-Oriented Level of decision-making processes and/or— Internal Factors of Blind Luck?

In order to analyse the family-oriented level of decision-making processes for CYP with LLCs, this study draws from the concepts of the Other of Emmanuel Levinas and the authority of Michael Polanyi. By exploring the unknown journey of decision-making from diagnosis to end-of-life or

says that “Marxian theories began to appear that identified the dominant racial or ethnic group or the dominant gender instead of the economic class as the agency of political and economic exploitation.” Mark Risjord, (2014:180-195) explains by employing the concept of Margaret Gilbert's agency, arguing that it implies the agents of joint actions as well as joint commitment, requiring processes for gathering information, reasoning, and decision-making at the group level.

survival, this study highlights the conflicts of best interests, the complications of paediatric decision-making, and the importance of understanding the holistic journey. Through this examination, it is possible to suggest assessments in terms of the family-oriented level of decision-making processes that can help better navigate and address the challenges posed by blind luck as an internal factor in decision-making. By examining these dynamics, it is possible to gain a deeper understanding of the complexities of family-oriented decision-making for children and young people with life-limiting conditions and to develop strategies to address these challenges.

3.4.2.1 Family-Oriented decision-making processes and/or the Neo-Confucian Point of View

The ethical framework proposed by Beauchamp and Childress (2019) has not been widely adopted in the Republic of Korea due to its focus on individual autonomy, which is inconsistent with Confucian culture's emphasis on family-oriented decision-making processes. In Confucianism, family sovereignty or family autonomy is considered more important than individual sovereignty or individual autonomy (Fan, 2015:6).

Yung (2015) argues that in the process of making a medical decision with the family, the patient can understand their condition, options, and best interests. However, understanding the patient's condition and knowing when it is the right time to make a decision under uncertainty can be challenging. Involving family members can be beneficial both in gathering information and sharing decision-making.

Interestingly, there are two opposing perspectives on the moral obligation to care for the elderly in Korean culture. Kysungsuk Choi (2014: 83-92) reports that most older people in Korea feel a moral obligation to their offspring and do not want life-sustaining treatment because they know it can be financially burdensome. On the other hand, Lee (2014: 137-148) highlights that the younger generation in Korea considers it their moral duty to care for their elderly parents because of the Confucian concept of filial duty (孝). This is because the virtuous relationship between father and son (孝) can be applied to the virtuous relationship between king and servant (忠).

Therefore, it is crucial to consider the cultural context of decision-making in the Republic of Korea, especially in the context of caring for older people and making decisions for CYP with LLCs. Decision-making should be seen as a collective process involving family members and cultural values,

and individual autonomy should not be prioritised over family autonomy. Healthcare professionals should consider the family's values, beliefs, and cultural practices when making decisions for their patients, especially in a diverse society.

3.4.2.2 When Conflicts Arise Regarding Best Interests: The Role of Epistemic Authority?

Irrespective of family-oriented or individualised decision-making processes, it is inevitable that family members will face conflicts of interest between family members and medical staff. In any case, surrogates should pursue the best interests of CYP with LLCs who have never expressed any views or preferences. However, the uncertainty of prognosis and authority in Neo-Confucian family-oriented decision-making processes pose some problems. Yung (2014: 112) points out that 'a more significant moral concern is that family involvement in the decision-making process of CYP with LLCs may conflict with their best interests, and may cause the patient to succumb to family interests under undue pressure. In addition, regardless of the authority of appropriate medical practitioners, family-oriented decision-making processes need to take into account 'the family dynamics of the decision-making process' (Hamilton and Catterall, 2007). Differences in attitudes to authority arising from religion, culture or superstition can lead to moral dilemmas between agencies.

Based on the Other from Emmanuel Levinas and Polanyi's point of view, that family involvement in the decision-making processes of CYP with LLCs can be explored. To begin with, Polanyi (1974) illuminated the positive authority of tradition. Also, Polanyi's authority (1974) might be useful in uncovering collective beliefs and authority in medical fields. Zagzebski (2012) examines the problem of disagreement between communities and between the self, the Others and the epistemic authority in communities. For understanding epistemic authority, two philosophers will be suitable for my research project, especially for authority and autonomy in belief.

Michael Polanyi's concept of authority (1958; 1966; 1969; 1964 and 1975) refers to a type of knowledge that cannot be fully articulated or expressed explicitly but can only be understood tacitly through experience and practice. According to Polanyi, this type of knowledge is crucial for personal and social growth and is often overlooked in the pursuit of purely objective or scientific knowledge. Polanyi argued that the authority of tacit knowledge is based on the trust we place in the individuals who possess it and the communities of practice that share and develop it. In this way, authority is not imposed from above, but emerges from below through a process of social validation and recognition.

Moreover, Levinas refuses to be assimilated to the Other and avoids strong paternalism in relation to family-oriented decision-making processes.

3.4.3 The Tacit Dimensional Level of decision-making processes: The Psychology of Luck and/or Internalised Oppression

Through my critical ethnography, I discovered that surrogate decision-making is influenced by various belief systems, including religion, attitudes, culture, superstition and stigma. It became clear that surrogate decision-makers often hold biased beliefs that are considered taboo, which can be linked to palliophobia – a fear of discussing and dealing with palliative care issues.

It is important to recognise that these belief systems may be deeply rooted and difficult to overcome. This is particularly true in cases where cultural and religious norms play an important role in decision-making processes. In such cases, it may be necessary to engage in culturally sensitive communication with surrogate decision-makers to better understand their beliefs and attitudes.

Furthermore, it is essential to address internalised oppression, which can occur when individuals from marginalised groups internalise the negative stereotypes and biases that are perpetuated by society. Such internalised oppression can lead to distorted beliefs about their own capabilities and worth, which can negatively impact their decision-making abilities. By recognising and addressing these issues, healthcare providers can help to mitigate the impact of biased beliefs on surrogate decision-making.

To understand the complexities of these beliefs, I employed Polanyi's view of tacit knowing, highlighting the functional, phenomenal, semantic, and ontological aspects. This allowed me to explore the relationship between irrational beliefs, internalised oppression, and distorted beliefs in the decision-making process.

3.4.3.1 Irrational Beliefs and Internalised Oppression

David, Lynn and Ellis (2010:18-19) define that “irrational beliefs refer to beliefs that are illogical, and/or lack empirical support, and/or are nonpragmatic; other terms, used interchangeably for these beliefs are maladaptive, unhealthy, and dysfunctional.”

	High Level of Rational Beliefs	Low Level of Rational Beliefs	No Rational Beliefs
High Level of Irrational Beliefs	I must pass the exam (high IB) I very much want to pass the exam and make my mom happy (high RB)	I must pass the exam (high IB) It would be nice if I passed the exam and made my mom happy but this is not so important (low RB)	I must pass the exam (high IB) I don't care about making my mom happy by passing the exam (lack of RB)
Low Level of Irrational Beliefs	It would be nice if I passed the exam but this is not so important (low IB) I very much want to pass the exam and make my mom happy (high RB)	It would be nice if I passed the exam but this is not so important (low IB) It would be nice if I passed the exam and made my mom happy but this is not so important (low RB)	It would be nice if I passed the exam but this is not so important (low IB) I don't care about making my mom happy by passing the exam (lack of RB)
No Irrational Beliefs	I don't care about passing the exam (lack of IB) I very much want to pass the exam and make my mom happy (high RB)	I don't care about passing the exam (lack of IB) It would be nice if I passed the exam and made my mom happy but this is not so important (low RB)	I don't care about passing the exam (lack of IB) It would be nice if I passed the exam and made my mom happy but this is not so important (low RB)

**Table 3-2 The Relations between Rational and Irrational Beliefs in a Stressful Situation
(e.g., taking an important exam)**

Source from David, Lynn and Ellis (2010: 16).

David, Lynn, and Ellis (2010) suggest that irrational beliefs refer to evaluative information processes that can lead to maladaptive and unhealthy behavioural and emotional outcomes. In the context of decision-making, a lack of knowledge combined with the taboo of death and cultural and religious prejudices can contribute to irrational beliefs. These beliefs can negatively influence decision-making processes, leading to maladaptive and unhealthy outcomes. Gorer (1955; 1965: 130) and Aries (1975) insisted that death is taboo because modern medicine focuses on prolonging life through professional intervention within medical institutions rather than dealing with the taboo. In addition, they see death and mourning as personal issues rather than social and cultural experiences due to increasing individualism. The relationship between happiness, irrational beliefs and internalised oppression can be understood as a dynamic one. Biased beliefs and superstitions can lead to irrational

decision-making and internalised oppression, which in turn can lead to unexpected results and outcomes, ultimately reinforcing the belief in luck or chance as a factor in decision-making.

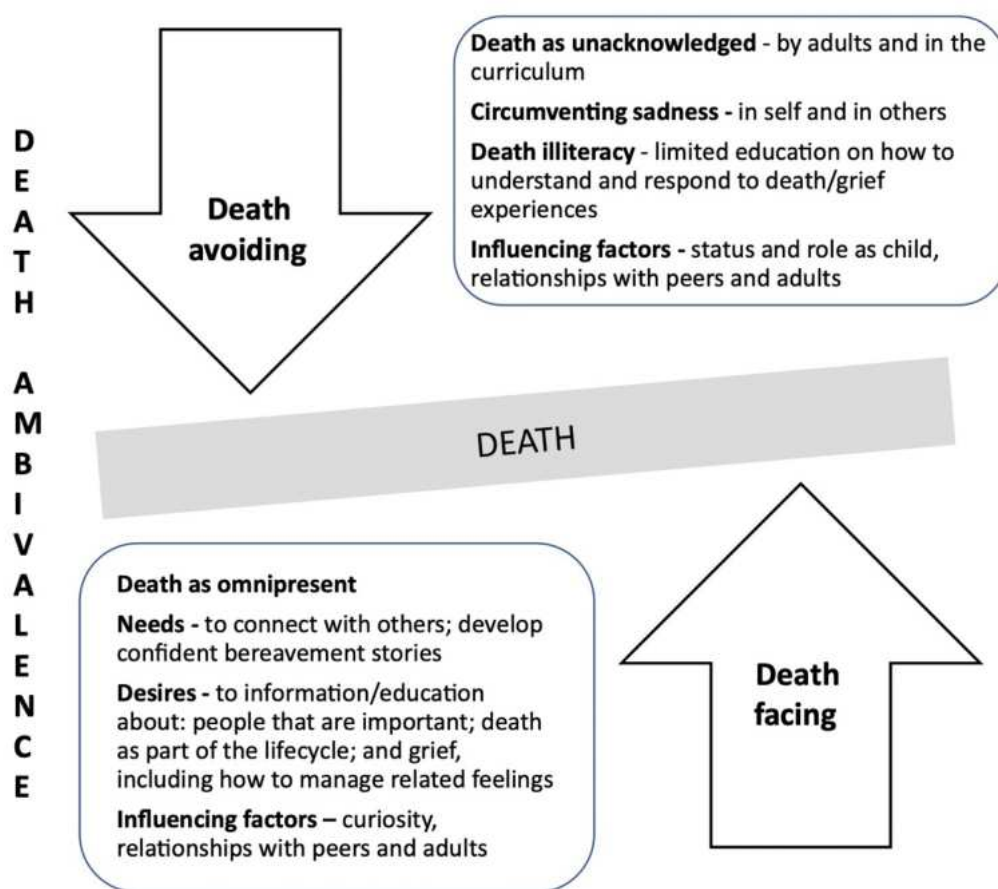


Figure 3-2 Death Ambivalence in the Lives of Children.

Source from Sally Paul, 2019: 567

Sally Paul (2019: 567) suggests that the concept of death ambivalence can be developed, a model of which is presented in Figure 3-2, as both facing death and avoiding death. She (2019: 568) mentions that if children avoid the presence of death in their lives and their death-related questions, they will not have the opportunity to develop resilience to a variety of loss experiences.

Moreover, Wong, Derthick, David, *et al.*, (2013:16-17); Rózsa, (2021) and Ng, Dodd, Gamble, *et al.*, (2012) insist that such beliefs contribute to the creation of dysfunctional self-schemas that may lead to psychological distress and disorders. Wong, Derthick, David, *et al.*, (2013:17) mention that a distorted view of one's self and of others may be related to internalised oppression, as it is a consequence of a set of self-defeating cognitions, attitudes and behaviours that have been developed as a result of consistently experiencing an oppressive environment.

3.4.3.2 Tacit Dimension of Michael Polanyi

Polanyi's emphasis on tacit dimensions (1962) highlights the importance of understanding the unconscious beliefs and values that influence decision-making processes. In his concept of fiduciary and tacit dimensions, Polanyi argues that belief contributes not only to emotion and willingness, but also to intellectual passion, which is crucial in decision-making processes. As a medical doctor, sociologist, and philosopher, Polanyi's ideas are deeply associated with three areas of knowledge theory: discovery, commitment, and calling. By examining the fiduciary and tacit dimensions (Oh, 2012), researchers can gain a deeper understanding of the role that beliefs and values play in decision-making processes, particularly in complex and emotionally charged situations such as those encountered in paediatric palliative care.

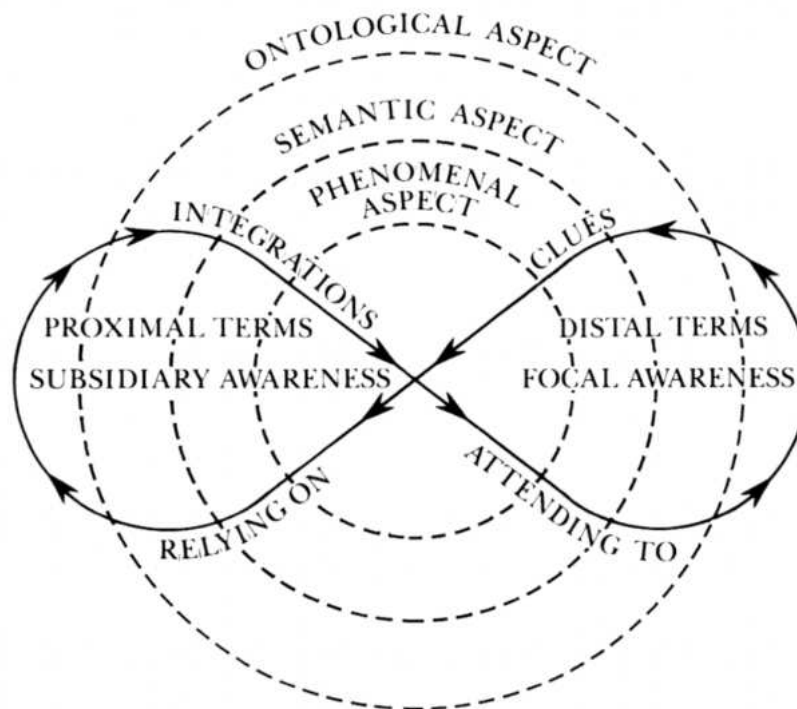


Figure 3-3 Diagram of Tacit Knowing.

Source from Gelwick, 2004: 77

Polanyi's concept of "tacit knowledge" emphasises the idea that knowledge is not just obtained through analysis and reason, but also through personal experience and values. This highlights the need for a comprehensive medical epistemology that goes beyond evidence-based medicine (Henry, S. G.,

2006: 187). Nagel's concept of "lack of control" suggests that the structural issues in a community can affect an individual's ability to make decisions based on their tacit knowledge (Polanyi, 1967). In other words, factors beyond an individual's control can impact their decision-making, making it important to consider both personal experience and structural factors when making decisions in medical contexts. Examining the doctor-patient relationship, the patient's prudent loved ones, and the "cultural authority of informed consent" (Corrigan, *ed.*, 2009: 199-212), it is apparent that there may be linguistic, medical, cultural, social, economic, and political power dynamics at play, which may be hidden behind the social production of power, leading to ongoing injustice. Therefore, a careful and thoughtful examination of these power dynamics is essential in order to understand the role of luck, irrational beliefs and internalised oppression in surrogate decision-making processes for CYP with LLCs and to develop an ethical and culturally sensitive decision-making framework.

Karl R. Popper (1972) and Michael Polanyi (1958) have different views on objective knowledge. Popper believes in certifying and removing personal commitment to achieve objectivity, while Polanyi explores the interplay between objectivity, probability and epistemic vice (*akrasia*). Polanyi's concept of personal knowledge (PK) offers a way to bridge the gap between objectivism and subjectivism, and between science and humanity. Oh (2007a) explains that (1) PK emphasises the fiduciary framework, which includes practical knowledge, passion and loyalty. (2) PK also values cooperation, preventing decomposition, sorting imitated knowledge, and acknowledging the authority of the teacher. (3) Tacit knowledge, including focal and subsidiary awareness, is essential to PK, as are the functional, phenomenal, semantic and ontological aspects of knowledge. Finally, (4) Polanyi's personal knowledge dwells in human knowledge, involving discovery, commitment, and calling. These concepts emphasise the importance of integrating management and objectivity, while prioritising responsibility and effort in the pursuit of professional knowledge.

Polanyi's concept of tacit knowledge is particularly useful for understanding beliefs and values in decision-making. By paying attention to the tacit dimension of Polanyi, especially in clinical medicine, a better understanding of the ontological, semantical, and phenomenal aspects of knowledge in medicine can lead to practical improvements in clinical care. Polanyi's perspective is also significant because it critiques objectivism and highlights the importance of subjective factors in decision-making.

In family-oriented decision-making processes, beliefs and authority can impede shared decision-making processes. Recognising the role of tacit knowledge in decision-making processes can help understand this issue and facilitate patient-centred care. Furthermore, the implications of tacit knowledge can help with planning under uncertainty and harmonising family-oriented decision-making processes with shared decision-making (Price and McNeilly, 2009).

3.4.4 The Privilege Level of decision-making processes: Moral and Epistemic luck and/or the Privileged or Underprivileged

In decision-making for children with life-limiting conditions, the level of privilege can influence the process. Pierre Bourdieu's concepts of habitus, capital, and field shed light on the inherent injustice and irrationality of decision-making. Recognising privilege or underprivilege is crucial in acknowledging social inequality and its impact on decision-making, as indicated by Bourdieu's interlinked concepts. In terms of the privilege level of decision-making processes for children with life-limiting conditions, the concepts of habitus, capital, and field of Pierre Bourdieu highlight the inherent injustice and irrationality in decision-making. Understanding the forms of privilege or underprivilege is crucial in recognising both those who suffer from social inequality and those who benefit from it, as indicated by the interlinked concepts of Bourdieu. Luck also plays a role in ethical responsibility and epistemological conditions, which can be analysed through the concepts of moral and epistemic luck. Therefore, it is essential to critically examine the power dynamics at play in decision-making processes for children with life-limiting conditions, particularly in terms of privilege and social inequality. This requires a nuanced understanding of the concepts of habitus, capital, and field of Bourdieu, and the role of luck in decision-making processes.

3.4.4.1 Epistemic and Moral Luck and/or the Privileged or Underprivileged

Beliefs about luck play an important role in how people perceive and attribute certain events. In the context of health inequalities, acknowledging privilege is crucial in shared decision-making processes. Evaluating curative treatments involves the interplay of epistemic and moral luck. Knowledge about decision-making is often linked to privilege, and epistemic luck includes both internal factors such as intuition and interpretation, and external factors such as storytelling, pseudoscience and misinterpretation of evidence. It is important to recognise the limitations of evidence-based medicine (EBM) and evidence-based decision-making processes (Elwyn, Frosch, Thomson, et al., 2012), as well as the potential influence of wishful thinking (Welsh, 1994) on decision making processes. Also, the quality of evidence depends on objectivity and probability, but the epistemic vice (akrasia) is associated with interpretations in the community regarding the issues

between EBM and decision-making processes. Although EBM is commonly emphasised, shared decision-making processes is undervalued and involves various conflicts. Goldenberg (2006: 2621) mentions that evidence-based medicine eschews unsystematic and intuitive methods of individual clinical practice in favour of a more scientifically rigorous approach for the advancement of medical knowledge.

Pritchard (2005: 136-140) points to three types of epistemic luck: capacity epistemic luck, evidential luck, and doxastic epistemic luck. 1) Capacity epistemic luck relates to an agent's intellectual virtue who is lucky to be capable of knowledge, even though intellectual virtues are a wide range of ability levels. In decision-making, unexpected results may occur due to differences in ability levels and the lack of control over luck. Philosophically, luck can lead to a lack of control in decision-making processes. 2) Evidential luck is accounted for in terms of the evidence and can be joined EBM. Doherty (2005: 307) says that "EBM de-emphasises intuition, unsystematic clinical experience and pathophysiologic rationale as sufficient grounds for clinical decision-making and stresses the examination of evidence from clinical research." Although EBM is normally emphasised, community-based decision-making is undervalued and involves various conflicts. Israel, Schulz, Parker, and Becker (2001: 177) insist "community-based research in public health is a collaborative approach to research that equitably involves, for example, community members, organisational representatives, and researchers in all aspects of the research process." 3) Doxastic epistemic luck is defined as believing that the proposition is lucky. Regarding "wish fulfilment" (Freud, 1911; Welsh, 1994) different beliefs from religion, attitude, culture and superstition causes either moral dilemmas or unexpected results among surrogates. Moreover, understanding evidential and doxastic epistemic luck is complicated, but people may be engaged in wish fulfilment while deciding for CYP with LLCs. Furthermore, the quality of the evidence is based on objectivity and probability, but the epistemic vice (*akrasia*) is linked with interpretations in community regarding the issues between EBM and decision-making. Haraway (1988) said that relying on "the facts", or "the evidence" to adjudicate between competing clinical practices or scientific beliefs assumes an inaccurate and deficient view of medical knowledge based on the numerous accounts of scientific knowledge as "situated knowledge" (Henry, 2006: 187). In terms of the patient centre approach, patients and their family members do not know what they know true, facts and beliefs. Because of this reason, knowing is associated with privilege.

Moreover, deciding for CYP with LLCs will illuminate the problem of moral responsibility arising from a particular form of moral luck, namely Nagel's notion of 'lack of control'. Although having nothing to do with 'moral blame' or 'moral praise', after deciding for CYP with LLCs, results may cause moral blame and moral praise.

In the context of decision-making for children with life-limiting conditions, curative treatments are often considered necessary, but there is a need to enhance holistic approaches that consider SDOH (Biermann, Mwoka, Ettman, *et al.*, 2021; Martins, Babajide, Maani, *et al.*, 2021; Yüncü and Fidan, 2019; World Health Organization, 2022), and healthcare transitions, such as hospital, hospice, home, school, and community. However, Payne (2010) suggests that poverty and poor awareness of palliative care are strongly related, leading to limited access to appropriate care. This highlights the issue of health inequality and the impact it has on marginalised and socio-economically deprived populations (Payne, 2010: 225).

Excluding considerations of SDOH and healthcare transitions from decision-making processes may result in moral luck, whereby individuals are praised or blamed for outcomes beyond their control. This is particularly important to consider in relation to the privilege level of decision-making processes, where epistemic and moral luck are intertwined with privilege and underprivilege. Therefore, it is crucial to recognise the need for comprehensive decision-making that addresses all relevant factors and prioritises the best interests of the child or young person with LLCs, particularly in the context of health inequality.

3.4.4.2 *Habitus, Capital, and Field of Pierre Bourdieu*

Decision processes can be understood in dynamic ways. Interestingly, the concepts of doxa and field in Bourdieu and of commitment and conviviality in Polanyi show similarities in explaining social structures and belief systems, even though both concepts are applied in different areas. However, both used the concept of power in social class, although Polanyi employed only Marxist analysis of class societies, and Bourdieu applied a broader view such as Marxist analysis along with Georg Wilhelm Friedrich Hegel and Émile Durkheim. From Pierre Bourdieu's work (1979 and 1991)'s three key constructs, namely habitus, capital, and fields (Houston, 2002; Tomlinson, 2004; Ugwudike, 2016), are utilized to investigate the mechanisms of the privilege level of decision-making processes in relation to the interplay of agency and structure in reproducing social inequalities.

Bourdieu's habitus (1977: 79; 93-94) might be useful in uncovering collective beliefs and the processes of agency in action. The privilege level of decision-making processes can be understood in Bourdieusian terms when the three concepts are brought together into an interlinked and dynamic schema. The privilege level of decision-making processes is structured within the habitus, which is both a 'structured and structuring structure' (Bourdieu, 1984: 171).

Bourdieu's concept of habitus refers to the way people develop certain ways of thinking, perceiving, judging, and valuing things within their own community, which distinguishes them from other communities. The habits that are developed within a community are both sustainable and transformable, and they reflect the social classes that exist within the community's social structure. In other words, the concept of habitus expresses the habits of individuals and social communities regarding the operations required to achieve a goal and the principle of organising and generating practices that lead to certain outcomes.

For instance, the habits of people in a specific social class may reflect certain values or ways of thinking that allow them to maintain their position in society. These habits are not always easy to recognize, but they have a profound impact on how people understand and interact with the world around them. By understanding the concept of habitus, we can gain insights into the ways that social structures operate and how they can influence the choices that people make. Therefore, habitus is an important concept to consider when analysing decision-making processes in different communities and social structures.

Drawing on a Bourdieusian approach, three forms of capital can be distinguished: economic, educational, and embodied cultural capital. These forms of capital are not just passive resources within a predetermined field but are understood as forms of power or capacity to act. Individuals with more capital possess specific communication styles and behavioural skills that are associated with their social class. For instance, the ability to share decision-making, provide truthful information, and obtain informed consent are all implicated in human action.

Moore (2008) argues that Bourdieu's understanding of capital is not limited to economic capital, but extends to social, cultural, and symbolic capital. Capital is not just an economic resource, but also encompasses social networks, cultural knowledge, and symbolic value. By taking into account the different forms of capital that exist in a particular social context, researchers can gain a more comprehensive understanding of the social structures and mechanisms that shape social phenomena.

Overall, understanding the forms of capital that exist in a particular social context can help researchers to better comprehend the communication styles and behaviours of individuals with different levels of capital, and how these differences may impact decision-making processes (Abel and Frohlich, 2012: 238). Bourdieu (1986 and 1993) explored various fields that involved the differentiation of social activities and agents, as well as where their social status is located. His concept of fields is useful for understanding medical fields, medical marketing, medical resources; and for exploring the dynamics of fields, arising out of the struggle of agencies, "oppression" (Dominelli,

2002), “power” (Smith, 2010), “bureaucratic medical system” (Payne, 2000; 2006) and “childhood in context” (Smith, 2009).

3.5 Conclusion

The chapter concluded by emphasising the need to consider the various dimensions of decision-making, including the structural level, the family-oriented level, the tacit dimension, and the privilege level, in order to understand the relationship between luck and social inequality in decision-making for CYP with LLCs. By gaining a deeper understanding of these complex decision-making processes, efforts can be made to address social inequality and improve decision-making processes for this vulnerable population.

The next chapter will provide an overview of the strategic approach adopted during the research process, including a description of the research framework and an explanation of the critical ethnography approach employed. This will provide a foundation for the subsequent chapters, which will delve into the empirical findings and analysis of the study. Overall, the goal of this research is to contribute to a more comprehensive understanding of multi-dimensional decision-making processes in paediatric palliative care settings, and to inform efforts to improve decision-making processes and support CYP with LLCs.

Chapter 4: Critical Ethnography on decision-making processes

4.1 Introduction

For this research study, I set out to examine the problem of decision-making processes for CYP with LLCs living in Seoul, the Republic of Korea. In this chapter, I will set out the strategic approach adopted during the research process, including an explanation of the research framework and an overview of critical ethnography. This will be followed by a description of the research design, including the research process, sampling strategies utilised and methods for data collection.

Owing to the nature of the research and understanding the complexity of decision-making processes, a wide variety of interviews and observations were used during the research process. Therefore, I also provide more detailed descriptions of the interviews utilised. I then move on to describe the theoretical approach to the data analysis, including the reflexive approach in narrative, case studies and reflective equilibrium in documentary analysis.

4.2 Critical Ethnography?

In this section, I will show that critical ethnography is more suitable than ethnography. Madison (2020) highlights that critical ethnography aims to expose power relationships when I emerge with in-depth and sustained involvement in a research setting: unequal power, ethical implications, and cultural differences.

4.2.1 Why Critical Ethnography?

Both critical and conventional ethnography, as outlined by Martyn Hammersley and Atkinson (2019), share methods such as observing cultural practices, engaging in communities, and questioning to understand cultural knowledge within a specific setting. The critical ethnographer delves deeper, examining the attitudes of medical staff towards decision-making and the impact of such decisions on patients, especially in CYP with LLCs. Critical ethnography challenges hidden power dynamics and

ideologies that conventional methods may overlook, proposing what could be rather than merely describing what is, as highlighted by Thomas (1993).

This approach is critical in addressing the complex decision-making processes involving children with LLCs, taking into account the diverse perspectives of children, their parents, and healthcare professionals. According to Creswell and Creswell (2018), a critical ethnographic study involves eight steps:

- 1) Highlight a literature gap,
- 2) Find a culture-sharing group to research,
- 3) Choose cultural topics for analysis,
- 4) Reveal power, hegemony, and advocacy for CYP with LLCs,
- 5) Conduct extensive research in the group's environment,
- 6) Analyse trends across multiple data sources to provide a cultural interpretation of the group,
- 7) Use a holistic culture picture to spread the culture-sharing group's patterns,
- 8) Convey them in writing or performance.

Through these steps, the thesis aims to explore and advocate for dynamic power and agency within the medical decision-making processes, seeking to reveal power inequities through critical ethnography.

4.2.1.1 Critical Ethnographer for Surrogate Decision-Making

By embracing ethical responsibility, critical ethnographers approach their research with a profound duty toward human rights, dignity, and compassion for the suffering. Observing unfair decision-making processes in palliative care, I empathised deeply with parents navigating these challenges, striving to address both the emotional burdens and systemic inequities they face.

I felt a heightened responsibility to patients, more than the palliative care staff and local community expected, prompting a deeper exploration of the motivations and philosophical underpinnings required for such challenges. In 2019, Dr Soyini Madison defined critical ethnography as synthesising diverse philosophical views and embracing intersectional complexity, a necessity in a field that lacks standard criteria.

Despite the developing process, I tried to set up a foundation of standpoints for the philosophy of radical criticism by employing the Other by Emmanuel Levinas, who focused on aspects of ontology and ethics, human rights (Bernasconi and Wood, 2002; Indaimo, 2015; Topolski, 2014; William Paul Simmons, 2011), justice (Elisabeth Louise Thomas, 2004; Fagan 2009; Tahmasebi-Birgani, 2014), feminism (Bell, 2001; Bernasconi and Wood, 2002; Bernasconi and Critchley, 2002; Chanter, 2001; Hand, 2014) and responsibility (Burggraeve, 1999; Chalier, 1993; Perpich 2008). After experiencing the Holocaust and World War II, Levinas insisted that moral theories avoid aspects of responsibility to the Other. He then focused on the experience of the self-other relationship. In *Being and Time*, Heidegger shows us a complicated discussion of the relation of Dasein (Being) that Levinas pointed out in the tragedy of Heidegger's philosophy. Unlike Heidegger, Levinas criticised the relation to 'being' as a question of ethics and being, which cannot operate apart from in the relation to the Other. This is because finding the meaning of the human being is entangled with the question of being and a fundamental ethical call, ending "egocentric" definition (*Ethics as First Philosophy*: 86).

Levinas explored how we can awaken our understanding of humanity and the finite nature of being, particularly through our encounters with the other (Oh, 2008). He argued for a fundamental return to responsibility for others, articulating this through four provocative claims about ethics (Hutchens, 2004):

1. Ethical issues need to be explored through relationships between individuals.
2. Personal responsibility to others precedes one's own freedom and choices.
3. The pursuit of the good of others is more important than the pursuit of one's own truth.
4. The ethics of responsibility should precede the ontology of freedom in philosophical discourse.

Levinas called for a re-evaluation of ontology and ethics, emphasising justice, human rights and responsibility. These rethinking influences critical ethnographers to approach their research with a deep commitment to human rights, dignity and empathy for suffering, and to consider both the immediate and wider effects of injustice and oppression in their studies.

4.2.1.2 Critical Ethnography to Find What Could be a Narrative

Storytelling and active listening are essential in the medical field to help doctors and surrogates of terminally ill patients understand each other's values. While narratives that diverge from patients' values raise concerns, they can also illuminate ethical dilemmas and complex healthcare decisions. Differences between medical evidence and narrative interpretation challenge consistency in medical practice.

The use of critical ethnography provides deeper insight into these ethical complexities by valuing surrogates' narratives, which reveal personal biases and commitments essential to understanding medical decision-making. This approach helps to identify and correct religious, cultural and superstitious biases that may influence decisions, even when surrogates are informed of the patient's wishes.

To address these issues, I have educated surrogates and physicians about informed consent and ethical practices, and analysed narratives to identify and mitigate biases that might compromise medical ethics. This method emphasises the need for critical thinking and thorough knowledge on the part of all involved.

4.3 Research Design and Research Process

In this section, I illustrate the design of the research and show an outline of the research process. Due to a tight academic schedule, I focused on the decision-making for CYP with LLCs in Korea rather than UK-Korea comparison study. I will give the three venues social epistemology-based timeframes. Merging three Seoul locales required compressed and intermittent selected research. I employ critical ethnography, participant observation, in-depth and semi-structured interviews, videos,

and document analysis. To understand choice processes, sampling and selection techniques and study participant descriptions are presented.

4.3.1 The Research Design

The aim of this research is to uncover the multi-dimensional decision-making processes for CYP with LLCs in the Republic of Korea. This is because the attempt to address the challenges surrounding the practical implications on people's experiences of decision-making processes about paediatric palliative care and ponder advance care planning. Parents making decisions on behalf of their children may face devastating choices, whether it is deciding to pursue treatments that are unlikely to cure the child's illness or to choose paediatric palliative care. In some cases, despite the intent of the treatment to cure, it may still be considered futile.⁸ If it ultimately does not succeed in improving the child's condition. I explored the supportive, palliative, hospice, and bereavement care options for the involvement of CYP with LLCs in decision-making processes at the three sites in Seoul, Korea, where he frequently encountered participants, including patients, their family members, medical staff, and various workers. I set a comparison between knowing and not knowing the root cause of CYP with LLCs since the causes of CYP with LLCs are diverse and a comparison between non-cancer and cancer is unrealistic to conduct research. After finishing the pilot study, I thought that referring the epidemiology of CYP with LLCs can be related to the knowledge about the conditions. The social epidemiology⁹ provides appropriate help to increase knowledge of the incidence of rare diseases in population groups living in different environments: having different habits, customs and working conditions.

⁸ The term 'futile treatments' refers to treatments that are unlikely to cure the child's illness, regardless of the intention behind pursuing treatment. Schneiderman (2011) explains that the concept of futility is complex and can be influenced by multiple factors, including clinical factors (e.g. the patient's medical condition, the treatment options available), ethical considerations (e.g. respect for patient autonomy, avoidance of harm), and societal norms (e.g. the availability of healthcare resources). He also notes that the definition of futility can vary depending on the perspective of the stakeholders involved, such as patients, families, physicians, and policymakers. Thus, he suggests that a collaborative approach that involves all stakeholders in the decision-making process is crucial to addressing issues of futility in healthcare.

⁹ Honjo (2004: 193) defines "social epidemiology is a branch of epidemiology that focuses particularly on the effects of social-structural factors on states of health." O'Campo and Dunn (2011: 1) insist "demonstrating the impact of growing social and health inequalities worldwide and have repeatedly demonstrated that health status is not distributed equally in society".

Understanding the impact of illness and life-limiting conditions on children and their families is crucial to improving paediatric palliative care. Social workers can better support these families by gaining insight into their experiences, helping to improve quality of life, ensure safety and avoid unnecessary treatments. Identifying environmental influences and challenges such as oppression is also crucial.

Ethnographic data is instrumental in testing and refining theoretical assumptions through the analysis of real-world cases and narratives. I have used critical ethnography to examine different decision-making processes in these settings, using narrative and case studies to deepen the analysis (Mason, 2002: 165). This research integrates evidence-based and holistic approaches to explore the complex social dynamics of participation and decision-making for children with life limiting conditions, developing an inductive model of understanding. Drawing on Duneier, Carter and Hakim Hasan's Sidewalk (2001) and Yin's theory-based cases (1999:1212), I have evaluated both inductive and deductive ethnographic methods and considered the limitations of approaches without a theoretical framework.

4.3.2 The Research Process

This researcher planned twice. The first was to volunteer in the designated locations after gaining permission from volunteer supervisors or representatives. Although it was challenging to balance observation and work, I was able to observe and research CYP with LLCs and their multi-dimensional decision-making processes. Since examining the best interests of CYP with LLCs involves multiple views, I focused on the interaction between medical professionals, CYP with LLCs, and their families. By actually observing them in the given places, I immersed myself in the same situations as the family members.

In understanding distinct cultures, multi-layered luck, and oppression in the Republic of Korea, I found concealed oppression and luck in decision making. I used critical ethnography to achieve these findings by being flexible with the research aims and specific research questions, which had already been decided. Due to several issues, I could still sensitively consider them.

I thoroughly examined the research process: what was decided, how, with whom, and when. CYP with LLCs and their families face oppression in decision-making, and palliative social workers

who support them may resist them. Palliative care social work overlaps with medical team members and lacks standardised assessments in the hospital or clinical setting.

4.3.3 Sampling Strategy and Participant Selection

To fully understand patients' lives, I extended the research beyond traditional end-of-life care settings to include supportive and palliative care settings, focusing on both cancer and non-cancer CYP with LLCs. This included a detailed study of patients' experiences at a cancer centre in Seoul that provides palliative care.

In response to social epidemiological evidence and a biocide disaster, I engaged with victims or survivors and selected three sites in Seoul, Republic of Korea, for comprehensive data collection. By immersing myself in the daily environment of paediatric palliative care social workers and adopting their perspectives, I was able to explore in depth different narratives and complex decision-making processes. Exploring various decision-makings for CYP with LLCs, I planned to focus on selection of research participants from two groups:

- 1) CYP's Parents/Family Members, Social Workers, and Paediatric Palliative care teams
- 2) School Social Workers, School Teachers, Social Workers from the Korean Organisation for Rare Diseases, Representatives of The Korean Association of Medical Social Workers (KORD), Managers from the Ministry of Health and Welfare (MOHW), Policymakers, Representatives of the International Association for Hospice & Palliative Care, and Representatives of the Association of Palliative Care Social Workers.

4.4 Research Methods and Data Collection

In this study, critical ethnography was used as the methodology to understand the multi-dimensional processes for CYP with LLCs in the Republic of Korea. I conducted 120 semi-structured interviews, took fieldnotes, participated in observations, and analysed documents to gather empirical data. Interviewees were chosen based on their age at the time of diagnosis, with all of them being diagnosed before the age of 19, although some may have been older at the time of the interview. I

formally contacted volunteer managers and representatives and was allowed to observe in the given places.

To conduct the research, the ethnographer used critical ethnography (Madison, 2020: 4; Thomas, 1993) as the methodology to investigate the processes surrounding CYP with LLCs. I gathered empirical data by conducting 120 semi-structured interviews, taking fieldnotes, participating in observations, and analysing documents. Interviewees were selected based on their age at the time of diagnosis, with all of them being diagnosed before the age of 19, although some may have been older at the time of the interview.¹⁰ The ethnographer contacted volunteer managers and representatives and was granted permission to observe in the designated locations.

To thoroughly understand the social dynamics in palliative care settings, I first described the physical environment, detailing interaction patterns, communication flows and decision-making styles such as paternalistic, shared and patient-centred, as well as conflict patterns. This analysis clarified roles and interactions between staff and interviewees.

Fieldnotes were crucial and included ideas, impressions and criticisms from the research team and interviewees. They addressed unexpected issues from observations, allowed for correction of errors and ensured alignment with research objectives, such as documenting interactions between staff and family members.

In addition, post-observation insights and follow-up questions with interviewees in settings such as children's hospices clarified ambiguities and provided new perspectives, facilitating self-reflection and theme identification.

As a critical ethnographer, it's essential to question and expose power dynamics, obligations, values and responsibilities, especially in relation to oppressive structures and social injustices within the settings studied.

¹⁰ I conducted interviews with three young adult cancer patients who were diagnosed during their teenage years, with the aim of gaining insight into their experiences of growing up with cancer and the ongoing challenges they continue to face in young adulthood.

4.4.1 Semi-Structured Interviews

To obtain the narratives of various key informants and interviewees, I conducted the face-to-face interview, exploring how paediatric palliative care teams and parents define the best interests and support the best interests of CYP based on critical ethnography.

Semi-structured interviews = 120

Cancer 50

Non-Cancer 15

Senior members of paediatric palliative care teams 14

Local, National, and International disciplinary contexts in decision-making 41

There are three interview methods: structured interview, semi-structured interview, and unstructured interview. In my approach to collecting qualitative data, I find that semi-structured interviews are particularly effective. These interviews are built around open-ended questions that allow for a rich, exploratory dialogue. Unlike fully structured interviews, this method allows me to adapt and delve into topics as they arise during the interview, reflecting the dynamic and diverse perspectives of the interviewees. While I usually follow a guide with some pre-determined questions, the flexibility of this approach is key to uncovering nuanced insights that structured methods might overlook. According to Patton (2002), the semi-structured interview can trigger interaction between the interviewer and interviewees and integrate individual perspectives and experiences. Bryman (2016: 201) said “using a semi-structured interview may ask some informants predetermined questions.” According to Patton (2002), the semi-structured interview can trigger interaction between the interviewer and interviewees and integrate individual perspectives and experiences. According to Bryman (2016: 201), semi-structured interviews can yield a broad range of instances, but they are less flexible than unstructured interviews. Since both an unstructured interview and a semi-structured interview have balanced advantages, my research employed the semi-structured interview technique since this researcher does not have enough qualitative research skills. Because the semi-structured interview allows the interviewing of various key informants several times in hospice and hospitals, it

was possible to conduct research with selected palliative care staff members of each children hospice organisation under study.

I chose to use semi-structured interviews rather than unstructured interviews due to their balance of structure and flexibility, which is more suited to my level of expertise. Bryman (2016) supports this method for its ability to elicit comprehensive information, allowing the researcher to capture in-depth and relevant data while accommodating interviewees' perspectives. Despite not having extensive qualitative research skills, I practiced different interview forms to understand participant engagement and content control (Morse, 2001; Corbin and Morse, 2003).

Prior to the interviews, I coordinated with qualified medical staff at the S Children's Cancer Centre to support interviewees who might be distressed by the research questions. Semi-structured interviews were conducted to explore parents' experiences of losing a child, survivorship stories, and decision-making processes for CYP with LLCs using a patient-centred approach (Michell, 2008). Following these sessions, I used snowball sampling through networks such as the Association for Parents of Children with Cancer and the Korean Organisation for Rare Diseases to reach both cancer and non-cancer patients. This method proved effective in accessing hard-to-reach communities (Patton, 2002). Recruitment and appointments were made by telephone, mobile apps such as Telegram and KakaoTalk, Facebook messengers, and at events such as palliative care seminars and conferences.

First, based on generic and disease-specific measures in assessing health status and quality of life (Patrick and Deyo, 1989: S217-S232; Coombes, Wiseman, Lucas, *et al.*, 2016: 935-949), I explored the experience of CYP with LLCs.



Figure 4-1 A Sampling Plane of Semi-Structured Interviews

Initially, my fieldwork focused on hospice and end-of-life care, but I later broadened the scope to include decision-making processes throughout supportive, palliative and bereavement care. External factors, particularly environmental ones, have had a significant impact on these decisions since epidemiologists and toxicologists identified them as causes of disease, as opposed to internal or genetic factors.

To address this complexity, I structured semi-structured interviews across different groups: cancer and non-cancer patients, those aware and unaware of the causes of their disease, survivors, CYP with LLCs, and bereaved families. In addition, we explored non-cancerous diseases such as moyamoya disease, which is prevalent in East Asian children, particularly in Korea and Japan (Seo, 2013; Lee and Kim, 2007), and Crohn's disease, which is rapidly increasing in Korean youth and shows a unique pattern compared to Western cases (Lee and Lee, 2014). Despite existing management guidelines for these diseases (Park, Yang, Ye, *et al.*, 2017 for Crohn's disease; Fujimura, Tominaga, Kuroda, *et al.*, 2022 for Moyamoya disease), there is a lack of specific guidelines to support decision making in these contexts. My research aims to deepen the understanding of decision-making processes for CYP with LLCs in these culturally and geographically specific settings.

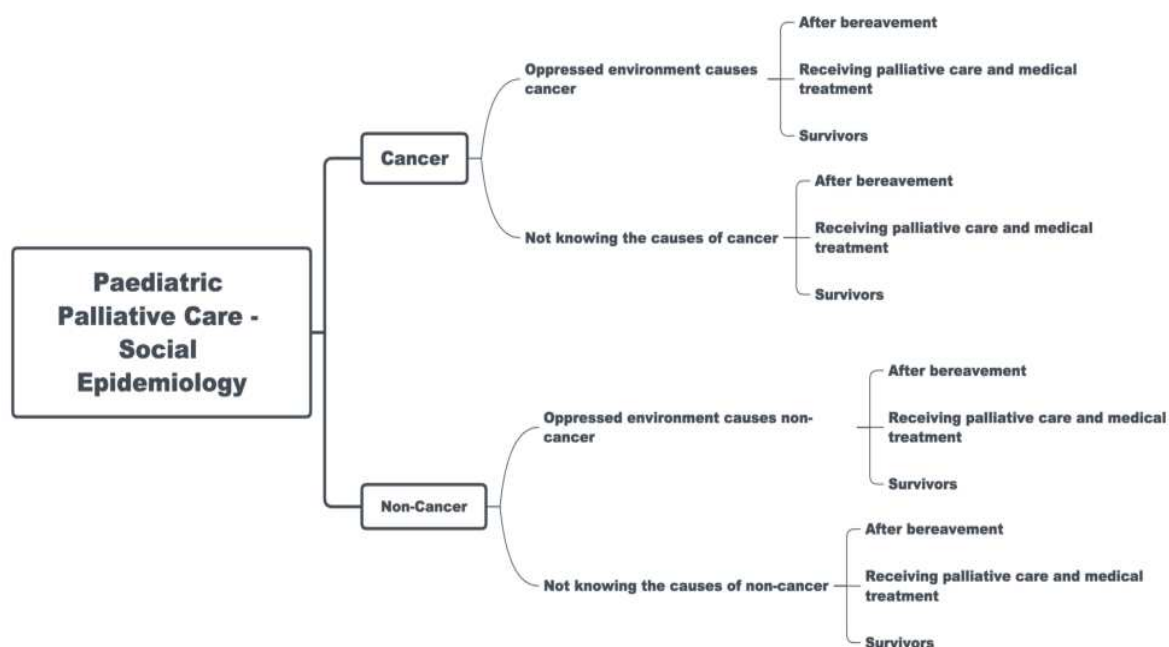


Figure 4-2 Changed Sampling Plane of Semi-Structured Interviews N = 65 (Cancer 50 /Non-Cancer 15)

Before starting my fieldwork, I did not consider the group of survivors, the ages of children and young people and social epidemiology.

- 1) Cancer 50: Semi-structured interviews with bereaved family who lost their CYP with LLCs and non-bereaved family who's CYP with LLCs.

	Date	Gender	Changed Name	Surrogate	Relation Interviewee	Age at Diagnosis	Age at Interview	Diseases Stages	Knowing Causes
1	20171116	Male	Minho Jeong	Minji Park	Mother	8	8	2	NO
2	20171123	Male	Taeyoung Kang	Mina Choi	Mother	7	7	2	NO
3	20171127	Male	Jihyun Han	Nari Shin	Mother	25month	26month	2	NO
4	20171130	Female	Seongmin Lee	Namsu Lee	Father	12	12	2	NO
5	20171130	Male	Jiwoo Kim	Doyoon Kim	Father	5	5	2	NO
6	20171219	Female	Hyunwoo Shin	Kyungmi Son	Mother	16	16	2	NO
7	20171221	Male	Haeun Lee	Ahyoung Kim	Aunt	16	16	2	NO
8	20180104	Female	Sooyoung Choi	Jihye Moon	Mother	3months	3months	2	NO
9	20180104	Male	Dachyun Jang	Rohan Jang	Father	5	5	2	NO
10	20180109	Male	Hyunsoo Kim		Patient	18	28	2	NO
11	20180111	Male	Joonhyuk Lee	Sunhee Park	Mother	6	6	2	NO
12	20180111	Female	Taehyun Choi	Yeonji Kim	Mother	18	18	2	NO
13	20180111	Male	Minjae Shin	Hyerim Song	Mother	3	3	2	NO
14	20180125	Female	Eunji Jung	Mihyun Kwon	Mother	4months	4months	2	NO
15	20180125	Male	Seojun Moon	Haeun Lim	Mother	8	8	2	NO
16	20180125	Male	Jihoon Kang	Chaewon Oh	Mother	2	2	2	NO
17	20171123	Female	Soohyun Lee	Chaeyoung Kim	Mother	17	17	3	NO
18	20171127	Male	Minsuk Kang	Areum Song	Mother	5	5	3	NO
19	20171219	Male	Junsu Park	Lina Choi	Mother	10	10	3	NO
20	20171219	Female	Yuna Choi	Ina Jang	Mother	12	12	3	NO
21	20171209	Male	Hyeonwoo Shin	Jiwoo Lee	Mother	9	9	3	NO
22	20180104	Female	Seoyeon Jung	Dasom Kim	Mother	10	10	3	NO
23	20180104	Female	Jiyeon Kwon	Ari Han	Mother	6	6	3	NO
24	20180108	Male	Byeongjun Yoo	Jihae Nam	Mother	3years 6months	3years 6months	3	NO
25	20180109	Female	Isol Moon	Chaewon Min	Mother	12	12	3	NO

26	20180111	Male	Woosung Lim	Bora Hwang	Mother	11	11	3	NO
27	20180129	Female	Miso Kim	Sunyoung Park	Mother	4months	4months	3	NO
28	20180129	Female	Ahrin Song	Minji Lee	P/Mother	18	25	3	NO
29	20171116	Male	Jaehyun Ma	Eunji Choi	Mother	16	16	4	NO
30	20171219	Male	Jackyung Go	Seulgi Baek	Mother	5	5	4	NO
31	20180409	Female	Dain Oh	Haeun Seo	Mother	11	13	Bereaved	NO
32	20180401	Female	Seondeok Kim	David Kim	Father	19	died at the age of 22	Bereaved	YES
33	20180228	Female	Deborah Oh	Hanna Park	Mother	19	40	Survivor	YES
34	20171121	Female	Sopia Taylors		Patient	18	22	Survivor	NO
35	20171127	Female	Danny Callahan Daun Kang	Baylee Collins Beomgyu Kang	Father	8	13	Survivor	NO
36	20171204	Male	Jamie Payne		Patient	13	19	Survivor	NO
37	20180201	Male	Joon Beom Moon	Minseok Moon	Father	3years 6months	9	Survivor	NO
38	20180201	Male	Luca Shaw Shinsun Park	Jiho Park	Father	5	10	Survivor	NO
39	20180205	Female	Minju Maeng	Hyebin Choi	Mother	5	10	Survivor	NO
40	20180207	Female	Lydia Brooks		Patient	17	21	Survivor	NO
41	20180207	Male	Dusuk Gong	Aran Kwon	Mother	9	15	Survivor	NO
42	20180207	Male	Bumsoo Seo	Jaeyoung Lim	Mother	16	21	Survivor	NO
43	20180207	Male	Minsu Baek	Sarang Oh	Mother	5	11	Survivor	NO
44	20180212	Female	Campbell Nixon Kyungbin Nam	Lina Byun	Mother	5	9	Survivor	NO
45	20180212	Female	Seohui Woo	Dahae Lee	Mother	12	18	Survivor	NO
46	20180222	Female	Jisoo Han	Hyun Ryu	Mother	12	17	Survivor	NO
47	20180222	Female	Minkyung Kook	Somyoung An	Mother	14	21	Survivor	NO
48	20180222	Female	Miyeon Min	Eunho Jo	Mother	9	15	Survivor	NO
49	20180515	Female	Jinhee Park	Sunha Kim	Mother	8	14	Survivor	NO
50	20200720	Female	Jenny Choi	Ando Choi	Father	15	died at the age of 22	Bereaved	Yes

Table 4-1 Semi-Structured Interviews from Cancer = 50

2) Non-Cancer 15: Semi-structured interviews with bereaved family who lost their CYP with LLCs and non-bereaved family who's CYP with LLCs.

	Date	Gender	Changed Name	Surrogate	Relation Interviewee	Age at Diagnoses	Age at Interview	Diseases Stages	Rare Disease	Knowing Causes
1	20180517	Female	Jihye Yu	Minho Yu	Father	8	18	2	chronic respiratory diseases	YES
2	20181207	Male	Minho Kim	Jahee Kim	Father	5	15	3	Moyamoya	NO
3	20180519	Male	Minji Choi		Patient	18	43	3	chronic respiratory diseases	YES
4	20180420	Male	Jaehyuk Min	Junseok Son	Father	5	17	3	chronic respiratory diseases	YES
5	20180420	Female	Byeolha Park	Dongha Lee	Mother	10	16	3	chronic respiratory diseases	YES
6	20180407	Female	Gayoung Kim	Eunji Choi	Mother	11	21	4	chronic respiratory diseases	YES
7	20180407	Female	Wonjun Choi	Minsu Choi	Father	50 days	died at the age of 50 days	Bereaved	chronic respiratory diseases	YES
8	20180519	Male	Viha Shin	Nari Shin	Sister	15	died at the age of 39	Bereaved	chronic respiratory diseases	YES
9	20180511	Male	Namsu Park	Hyunji Kim	Wife	19	died at the age of 40	Bereaved	chronic respiratory diseases	YES
10	20180515	Female	Eli Jang	Nari Jo	Daughter	15	died at the age of 18	Bereaved	Moyamoya	NO
11	20180514	Male	Seokjin Roh	Hyorin Seo	Wife	19	died at the age of 42	Bereaved	chronic respiratory diseases	YES
12	20180213	Male	Michael Lee		Patient	19	36	Survivor	Crohn	NO
13	20180226	Male	Seobin Ra	Seongil Ra	Father	5	15	Survivor	chronic respiratory diseases	YES
14	20180302	Male	Oseong Do	Carin Yoo	Mother	6	15	Survivor	chronic respiratory diseases	YES
15	20180517	Female	Elise Yu	Minho Yu	Father	7	20	Survivor	chronic respiratory diseases & Lupus	YES

3) Table 4-2 Semi-Structured Interviews from Non-Cancer = 15

- 4) Semi-structured interviews with senior members of paediatric palliative care teams (including physicians, registered nurses, art therapists, hospice chaplains and social workers) = 14

	Date	Gender	Changed Name	Agency	Paediatric Palliative Care Team
1	20180108	Male	Minho Song	S Hospital	Physicians
2	20180207	Female	Taeyeon Koo	S Hospital	Interpreter
3	20171206	Female	Jisun Park	S Hospital	Pharmacist
4	20171221	Female	Hyewon Jo	S Hospital	Pharmacist
5	20180518	Female	Minah Kim	S Hospital	Registered nurses-Counsellor
6	20180302	Female	Nara Jang	S Hospital	Registered nurses-coordinator
7	20180528	Female	Taeyun Shin	S Hospital	Registered nurses-coordinator
8	20180124	Female	Hana Kang	S Hospital	Registered nurses/Out-patients
9	20171206	Male	Vinseok Ryu	S Hospital	Social Work
10	20180517	Male	Samuel Pyo	S Hospital	Social Work
11	20180321	Male	Junsu Son	Seoul	Social Work
12	20180222	Female	Lina Baek	S Hospital	Hospital Children School's teacher
13	20180430	Female	Kyungmi Lee	Some Hospitals	Social Work/Art Therapists
14	20180419	Male	Robin Williams	Some Hospitals	Social Work/Drama Therapist

Table 4-3 Semi-Structured Interviews from Senior members of Paediatric Palliative Care Teams = 14

4) Semi-Structured Interviews Regarding Local, National, and International Disciplinary Contexts in Decision-Making =41

N o	Date	Multi- disciplinary contexts in decision- making	Gender	Changed Name	Agency
1	20180402	Local Level	Female	Min Lee	Member of Local New People's Party
2	20171215		Male	Minji Lee	Priest
3	20180206		Female	Jiwon Choi	Primary school teacher
4	20171212		Male	Junsu Kim	Primary school teacher
5	20180313		Female	Lucy Baek	Human rights activist
6	20171128		Female	Minseo Son	Executive Secretary / Han Bit Love for Children with Cancer (NGO)
7	20171108	National Level	Female	Atrium Seo	Environmental Network
8	20171119		Female	Eunji Ahn	Occupational and Environmental Medicine/ Supporters for the Health and Rights of People in the Semiconductor industry (SHARPS)
9	20171121		Male	Namsuk Roh	Lawyer/ Supporters for the Health and Rights of People in the Semiconductor industry (SHARPS)
10	20180405		Male	Chulsoo Kim	Activist / Supporters for the Health and Rights of People in the Semiconductor industry (SHARPS)
11	20180316		Female	Mina Kang	Certified Public Labour Attorney / Supporters for the Health And Rights of People in the Semiconductor industry (SHARPS)

1 2	20171117		Male	LeonardMoon	Representative The Korean Association of Social Worker
1 3	20171128		Female	Isabelle Shin	Representative The Korean Association of Medical Social Workers
1 4	20171215		Female	Nari Gwon	Chairman The Korean Association of Hospice and Palliative Care
1 5	20180108		Male	Eunsol Cho	Team Manager / My Welfare (NGO) for Changing Social Policy
1 6	20180110		Male	Beomseok Song	Medical Team Manager / My Welfare (NGO) for Changing Social Policy
1 7	20181223		Male	Joonmyun Ham	Co-Representative / My Welfare (NGO) for Changing Social Policy
1 8	20180117		Female	Miji Nam	Representative / The Korean Association of School Social Worker
1 9	20180207		Male	William Seo	Representative/ Social Workers for Changing the World (NGO)
2 0	20180213		Female	Minji Ahn	Executive Secretary/ Korean Association for Children with Leukaemia and Cancer
2 1	20180321		Male	Taeyul Sim	Priest / Walking Church
2 2	20180515		Male	Seokhyun Kwon	Pastor / Organisation of Legalising Medical Cannabis
2 3	20180411		Male	Gihwan Nam	Manager, Department of Health Policy, Ministry of Health and Welfare
2 4	20180516		Female	Seohyun Kim	Researcher, Health Insurance Review & Assessment Service
2 5	20180220		Female	Kyeonghee Hwang	Research Director Korea National Institute for Bioethics Policy
2 6	20180425		Female	Omar Gi	Special Assistant to the Politician, Liberty Korea Party
2 7	20180512		Male	Jiyeon Jo	Special Assistant to Politician,

					The Democratic Party of Korea.
2 8	20180513		Male	Minchul Ahn	Special Assistant to Politician, The Democratic Party of Korea.
2 9	20180423		Female	Hyeonsoo Hwang	Politician, The Democratic Party of Korea.
3 0	20180423		Female	Inna Yoo	Special Assistant to Politician, Justice Party.
3 1	20180527		Male	Gildong Roh	Vice-Chairman, Environmental Network Social Disasters Commission
3 3	20180516		Female	Jaehee Ryoo	Health Insurance Review & Assessment Service
3 4	20190130		Male	Jalim Lee	Social Policy and Bioethics
3 5	20190130		Male	Haerang Na	Social Policy and Bioethics
3 6	20180526		Male	Dooan Baek	Social Policy and Bioethics
3 7	20180520		Male	Gilsan Jang	Social Work and Social Determinants of Health
3 8	20190105		Male	Koretay Baek	Primary Health and Social Determinants of Health
3 9	20180426	International Level	Male	Owen Mitchell	Senior Science and Technical advisor IPEN a toxic-free future
4 0	20180412		Male	Henry Sterling	Bioethics Research Interdisciplinary Group Bioethicist
4 1	20180413		Male	Hiroki Takahashi	Bioethics Research Interdisciplinary Group: Bioethicist

Table 4-4 Semi-structured Interviews from Local, National, and International Disciplinary Contexts
=41

Secondly, I set up a sampling level of semi-structured interviews with social workers in paediatric palliative care: those with more than 60 months of experience, juniors with between 24 and 59 months of experience and novices with less than 23 months of experience.

However, as there was no junior social worker, I conducted semi-structured interviews with senior members of the paediatric palliative care team, including doctors, nurses, art therapists, hospice chaplains and social workers. There were 14 semi-structured interviews. This is because social workers have a dual membership: their professional identity and their work within a multi-professional paediatric palliative care team.

In line with critical ethnography principles (Madison, 2020), this study employed snowball sampling to explore the relational dynamics and decision-making processes among stakeholders in paediatric palliative care. This purposeful, issue-driven approach facilitated engagement with participants directly or indirectly involved in care, policy, and activism, and aligned with the study's aim to uncover systemic and ethical dimensions of decision-making. The sampling process unfolded in three phases. First, CYP with LLCs and their families were recruited through S Children cancer centres, and bereavement support groups. Second, healthcare professionals (e.g., doctors, nurses, social workers, therapists) involved in palliative care teams were included. Third, socio-political actors – including NGO workers, activists, and policymakers – were engaged to examine broader structural influences, accounting for the 41 semi-structured interviews exploring local, national, and international disciplinary contexts. Participants were accessed via communication platforms (e.g., Facebook Messenger, KakaoTalk, Telegram), professional networks, and events such as palliative care seminars and policy workshops. This iterative process ensured a theoretically and ethically guided recruitment strategy, enabling a nuanced understanding of the cultural and structural conditions in Korea. These interviews were triangulated with fieldnotes, observations, and document analysis to construct a cohesive dataset addressing the study's research objectives. Transparency was maintained throughout participant recruitment, with ethical considerations – such as informed consent and the management of emotional risks – upheld to ensure participant well-being.



Figure 4-3 Structural Level of Decision-Making Processes: Decision-Making Processes in a Vicious Circle as Neoliberalism

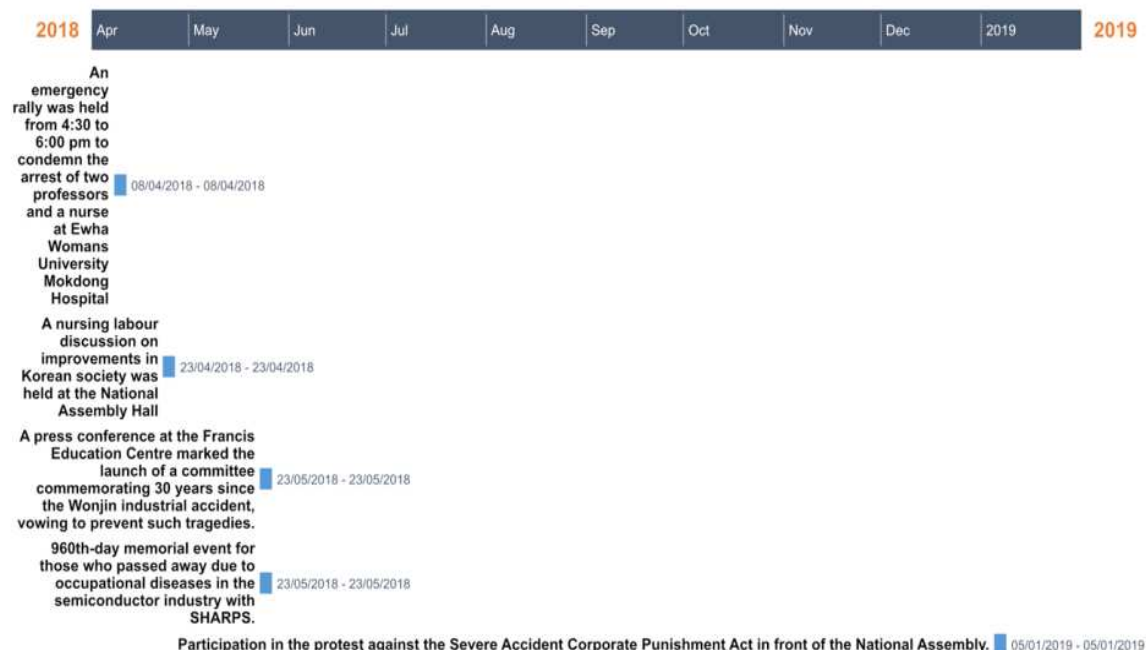


Figure 4-4 Structural Level of Decision-Making Processes: Work Overload without Responsibility

When a paediatric palliative care social worker considers the moral dilemmas in interdisciplinary work surrounded by local, national, and international disciplinary contexts, serious epistemic and ethical luck and multi-layered oppression can be identified in terms of their effectiveness in ensuring safety, increasing the quality of life, avoiding futile treatments, and pursuing the best interests of CYP with LLCs in relation to Figures 4-3 and 4-4.

4.4.2 Participant Observation

Madison (2020) notes that a staple of critical ethnography research data collection is observation. I immersed himself in the same situations as the paediatric palliative social workers in the three given places, where they live and interact with each other, and started to see and interpret things through my own eyes.

Participant Observation



Figure 4-5 The Role of Ethnographer: an Observer-Participant

Although I planned to take a part-time job or volunteer work in the given places, I focused on observation as a researcher since managing and balancing the role between working and observing was difficult. By opting for the overt role, interviewees were aware of my status as a researcher, which helped to avoid role conflict with social workers, given their intense workload and my background as a medical social worker. This awareness also facilitated the understanding of non-verbal cues which are crucial in building rapport and trust, which was particularly beneficial given my experience in hospice care where I was perceived as a trustworthy figure. Goodley (2000) highlights the contrast between the passive roles often assigned to people with learning disabilities and the active roles of self-advocates. As a researcher, maintaining an active role enabled me to eagerly collect rich data.

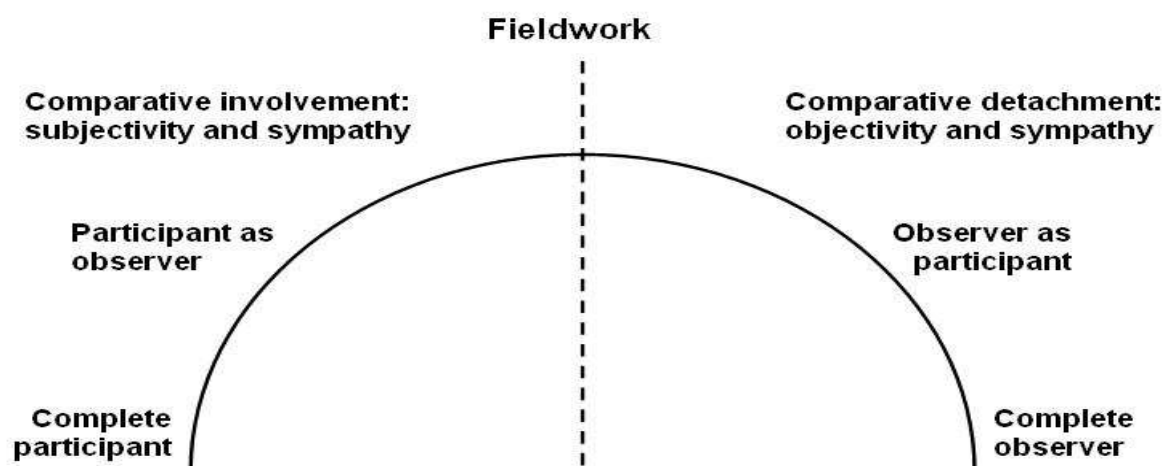


Figure 4-6 Theoretical Roles for Observation

Source from Atkinson & Hammersley, 2012:104

According to Atkinson and Hammersley, (2012: 104), there are some positions of the role: complete participant, participant as an observer, comparative involvement, comparative detachment, observer as a participant and complete observer. In terms of the role of the ethnographer as an observer-participant, I primarily act as an observer but may participate in group activities to a limited extent. This role involves minimal participation that is known to the group. For example, although I may be well informed about the role of the social worker, he did not participate directly but observed as a participant. However, attending conferences, meeting with members of parliament or attending funerals may be considered as participation if minimal involvement is required or if a specific role is required.

4.4.2.1 To Observe the Children's Cancer Centre in an Acute Hospital

My research site was the S Children's Cancer Centre in Seoul, South Korea, which specialises in palliative care. I observed the interactions between children, their families and medical staff, focusing on non-verbal communication in decision-making. By closely observing the children as they participated in various activities such as treatment, nutrition, education at the hospital school, leisure activities and even planning funeral services, I gained insights into different decision-making processes.

4.4.2.2 To Observe Meetings with Parents who Have/Had Young People Used to Work In Semiconductor Industries

When visiting regularly S Children's Cancer Centre, one of the parents gave me a name card after the interview. Based on the shared story of the father who lost his daughter, he believed that her work in the semi-conduct factories and exposure to unknown chemical substances may have been related to her diagnosis of leukaemia and eventual passing. I was unable to find conclusive evidence linking the workplace to the illness, but the father strongly believed in the connection. When taking part in the workshop by SHARPS, which means Supporters, Health and Rights of People in Semiconductor Industry and their working areas are such as Solidarity, Help, Action, Research and Public Relations, I could meet key informants and then regularly visit the protest camp which was located in front of the 8 exits at Gangnam Station.



Figure 4-7 The Protest Camp with Victims, Activities and Me

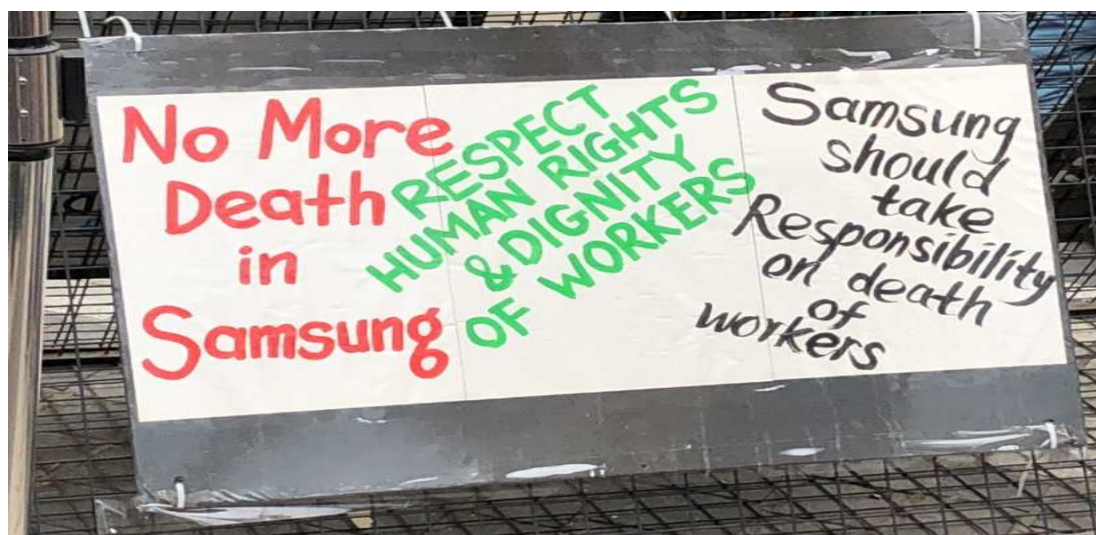


Figure 4-8 Main Statements by SHARPS (Supporters, Health, And Rights of People in Semiconductor Industry)

Most victims and survivors were forced into a desperate situation after making their own decision to work in semiconductor factories¹¹, receiving medical treatments, enjoying leisure and daily activities, and planning of funeral services. By participating in campaigns, I tried understanding the narratives from the various activities, volunteers and medical staff in the protest camp. I traced observing their different versions of the decision-making processes.

4.4.2.3 To Observe the Meetings with Parents Who Used Toxic Humidified Disinfectants

Yeyoung Choi (2017) highlighted that health harms from humidifier disinfectants should be seen as chemical harms, and for the first time drew significant attention to the biocidal chemicals in these products. These chemicals, designed to control harmful organisms, have been linked to serious respiratory problems and deaths. Choi's findings catalysed regulatory action on the use of biocides in consumer products. Jong Han Leem and Jong-Hyeon Lee (2017) noted that the problem was specific to the Republic of Korea, and was caused by household products. My own research faced challenges

¹¹ Smith, David Allan Sonnenfeld, Pellow, *et al.*, (2006) *Challenging The Chip* report about the social and environmental costs of electronics manufacturing, particularly the semiconductor industry, and explores grassroots efforts to promote sustainable and socially responsible technology production. They argue that the industry is driven by a race to the bottom in terms of labour standards and environmental regulations. They also offer case studies of grassroots movements and campaigns aimed at improving working conditions and promoting sustainability.

in engaging with victims and survivors, who were tired of repeated inquiries from researchers and were reluctant to participate further. Despite these hurdles, I was involved in a demonstration reflecting grief and received an important communication from a representative of the affected people during my involvement with the Special Commission on Social Disaster Investigation.



Figure 4-9 8th floor, Post Tower

When discussing their current situations of delayed compensation payments and taking responsibility for taking action against international companies and the government, I observed their discussions and expressions of embitterment.

Asian Citizen's Centre for Environment and Health



Figure 4-10 Asbestos-related diseases and radon-emitting materials: decision-making processes on hidden social determinants of health (SDOH).

I spent a minimum of 5 to 3 hours per day and a maximum of 15 hours per day conducting participant observation in three different locations. I also lived near the S Cancer Centre for nine months between November 2017 and February 2018. In addition, I spent six months between December 2017 and May 2018 conducting participant observation at two other locations: the Post Tower building and a protest camp.

4.4.3 Fieldnotes as the Face of the Others by Emmanuel Levinas

Ethnography serves as an important tool for understanding social phenomena, with fieldnotes playing a crucial role in capturing the complexity of the social environment within paediatric palliative care settings. Emerson, R.M., Fretz, R.I. and Shaw, L.L. (2001:353-355) emphasise the importance of fieldnotes in documenting interactions and communication patterns that illuminate the physical and social context.

In my study, fieldnotes provided a holistic view of the environment, capturing interactions, decision-making styles (paternalistic, shared, patient-centred) and conflicts, thus helping to identify roles and behaviours of interviewees and staff. These notes contained various elements such as ideas, impressions and criticisms, and although they may contain errors, clarifying them helps to focus the research on relevant issues. This method is particularly useful for documenting detailed interactions between palliative care professionals and families.

In addition, recording findings after observations in a children's cancer centre and asking questions of staff and interviewees helps to clarify any misunderstandings, with further comments providing new insights. This process not only enriches the data, but also encourages self-reflection and helps to identify emerging themes.

In this ethnographic study, I used critical ethnography and open-ended observation to document the complex social dynamics within paediatric cancer care. Guided by Bell, Caplan, and Karim's (2013: 487) framework, and influenced by Berg and Lune (2012) and Merriam (2016), I recorded detailed fieldnotes using both handwritten notes and digital tools such as the iPhone Memo app. These notes included event descriptions, observational insights and personal reflections, with a particular focus on patient-centred approaches and systemic issues such as medical bureaucracy.

Drawing on Levinas' concept of the 'Other', I critiqued egocentric decision-making patterns, noting how patient-centred care is often overshadowed by such tendencies in decision-making processes for CYP with LLCs. My notes also explored discrimination, inclusivity and service user involvement, highlighting the importance of respecting children's rights to improve patient-centred care.

The study highlighted the ethical challenges in decision-making, from supportive to bereavement care, with a dual focus on ethical thinking and practice. Ethical thinking involved scrutinising the decision-making process for ethical dilemmas, considering the immediate and long-term implications for the family (Mitchell, 2016). Ethical practice involved managing personal emotional responses during the research, which included debriefing sessions with peers and consultations with psychiatrists and counsellors to manage the emotional burden of engaging deeply with interviewees' experiences. This comprehensive approach ensured a balanced view of the systemic, ethical and personal dimensions that influence surrogate decision making in paediatric palliative care.

4.4.4 Collecting Documents and Analysing the Documents for Finding the Hidden Social Determinants of Health

In Chapter 2, the literature reviewed in this study focuses on the decision-making process in paediatric palliative care, ethical concerns, and the role of social workers in decision-making for CYP with LLCs and the study specifically analyses the collected documents on social determinants of health. I endeavoured to collect a diverse array of documents, assuming the role of a critical ethnographer. This included books, video clips, academic papers, workshops, symposia, press conferences, and conference proceedings. Through collaboration with interviewees, extensive data was obtained, with important documents exchanged via Messenger apps on Facebook, KakaoTalk, and Telegram. Interviewees willingly provided a variety of materials and recommended specific publications, enabling a comprehensive understanding of the social factors influencing health. Hidden social determinants of health were identified based on the environments where CYP live, categorised into key areas such as school, home, and work, following this table:

	Hazard Substances	Environmental Exposure/ Hazardous Substances-Related Diseases
Home	PHMG, PGH, CMIT, MIT from Humidifier disinfectants	<p>The Asian Citizen's Centre for Environment and Health & the Korean Federation for Environmental Movement (KFEM)</p> <p>Humidifier disinfectant associated with lung injury (Ryu, Park, Lee, et al., 2019), bronchiolitis and allergic rhinitis (Cho and Winzer, 2019)</p> <p>Social Disasters Commission (2022)</p> <p>Korea Centres for Disease Control and Prevention KCDC, (2011)</p> <p>Kim and Kwon (2012)</p> <p>Kim, Ahn, Yang, et al., (2014; 2013)</p> <p>Leem and Kim (2020)</p> <p>Miller, Marty, Arcus, et al., (2002)</p> <p>Lee, Kim and Kwon (2012)</p> <p>Bordini and Kliegman (2020)</p> <p>Toxic Joo, (2022) and Lee (2022a) highlight that “‘Toxi’ is a movie based on the ‘Humidifier Disinfectant Incident’ that plunged Korea into shock” The photo is from TF Cinema Review (Lee 2022a)</p>
	Radon-Emitting Mattresses	<p>the Asian Citizen's Centre for Environment and Health & the Korean Federation for Environmental Movement (KFEM)</p> <p>Nuclear Safety and Security Commission (2018)</p> <p>Radon is a carcinogen: health hazards, such as lung cancer, respiratory diseases, (Seo, Ha, Kang, et al., 2019)</p> <p>Cf There are problems of associations that have not been clearly established between radon and other diseases, such as leukaemia and thyroid cancer (Seo, Ha, Kang, et al. 2019),</p> <p>but one of my interviewees shared that due to radon bed mattress, his daughter died of leukaemia.</p> <p>Lee and Kim, 2022</p> <p>Kim, Jeong and Shin (2019)</p>
Work	Hazard Substances from Semi-conduct industry	<p>Supports for health and rights of people in semiconductor industry (SHARPS)</p> <p>Cancers and reproductive risks in the semiconductor industry (Ladou and Bailar, 2007; Smith, David Allan Sonnenfeld, Pellow, et al. 2006), Cases Series of Malignant Lymphohematopoietic Disorder (Lee, Kim, Park, et al., 2011)</p> <p>Jo Jae-seok (2014).</p> <p>Im, (2014)</p> <p>(JTBC, 2021)</p>

		Stories from Clean Room (Joseph, 2017)
		Another Promise (2014)
School	Asbestos	<p>the Asian Citizen's Centre for Environment and Health & the Korean Federation for Environmental Movement (KFEM)</p> <p>Asbestos related diseases: mesothelioma, lung cancer, asbestosis, pleural plaques, pleural effusion,</p> <p>diffuse pleural thickening round atelectasis, mesothelioma and etc.</p> <p>(Kang, Kim, Kim, et al., 2018; Kim, Kim, Kim, et al. 2016)</p> <p>NHS (2020)</p> <p>Miller, Marty, Arcus, et al., 2002</p> <p>Shin, Son, Hong, et al., (2008)</p> <p>(Kim, 2009).</p>

Table 4-5 Environmental Exposure and Hazardous Substances-Related Diseases

The research benefits from participant insights and social epidemiology findings, which are grouped into four areas. Using the principles of social epidemiology, I looked at two different groups to explore disease causation: people with cancer and people without cancer. The study included survivors, CYP with LLCs. Interviewees with knowledge of the underlying causes of the disease provided and recommended documents. Medical staff and a wide range of experts provided key documents in which they gathered evidence and key research papers or authors. A clear distinction needs to be made between data sources and their contribution to the research findings, and it appears that several of the interviews were in fact conversations with people to gain wider contextual knowledge rather than to contribute to the data set.

Therefore, by understanding the concepts of causality and correlation in the context of social determinants of health in Chapter 6, interviewees taught me to better identify factors from the given documents (Fieldnote 7th November 2017).

I am particularly grateful to the Supports for Health and Rights of People in the Semiconductor Industry (SHARPS) and the Asian Citizen's Centre for Environment and Health & the Korean Federation for Environmental Movement (KFEM) for their invaluable support. However, the views and arguments presented in this paper are mine alone and I take full responsibility for any errors or omissions.

4.5 Data Analysis and Interpretation of Critical Ethnography

In this section, I will explore how my perspective evolved over the course of the research and the analytical and interpretive procedures that I employed using Carspecken's (1996) five stages for critical qualitative research. I analysed the interview data thoroughly by employing narrative to better understand the lived experience of the interviewees and using the qualitative research programme ATLAS.ti to organise and code the data systematically (see appendix).

4.5.1 Stage One – Compiling the Primary Record

My study, using critical ethnography, aimed to narratively describe the cultural environment of paediatric palliative care, focusing on the decision-making processes of CYP with LLCs and their interactions within health care settings such as hospitals, hospices and community settings (Morse, Barrett, Mayan, et al., 2002). I spent 60-70 hours per week over nine months conducting fieldwork and semi-structured interviews (N=120), transcribing and anonymising data for comprehensive analysis, including passive observation in a children's cancer centre due to ethical restrictions on intervention.

Bauer (1987: 5-8) provided guidelines for narrative interviewing, emphasising the importance of non-intrusive questioning and consistency without cross-examination. My approach to interviewing was to create a comfortable environment for the interviewees and to facilitate additional insights that are critical to understanding the social dynamics within the palliative care setting. Following the interview, I meticulously documented conversations to capture fleeting data, following a 'memory protocol' to ensure that no important information was lost. Charon (2001a) notes that narrative interviewing can have a profound effect on understanding the roles and decision-making processes of medical staff and encourages personal reflection on their implications.

4.5.2 Stage Two – Preliminary Reconstructive Analysis

In my research, I followed Atkinson, Coffey, Delamont, *et al.*, (2014: 386-387) criteria for evaluating ethnographic data, focusing on four characteristics essential to narrative analysis: communicating experiences through narrative, representing experiences, highlighting undervalued features in different industries, and telling human interest stories. This method facilitated the identification of implicit structural elements from a patient-centred perspective and helped to reconstruct decision-making processes based on data discrepancies and theoretical frameworks.

In order to protect the personal data of the interviewees, I followed strict protocols at several stages: before and after the meetings, before the conference presentations, during the writing of the thesis and after publication. The data organised and coded using Atlas.ti, allowed for detailed categorisation and reconstructive analysis, articulating multi-dimensional decision-making processes. In addition, this analysis prompted a re-evaluation of my original research questions, shifting the focus to explore the role of social workers in paediatric palliative care and the complexities of surrogate decision making, including ethical challenges and systemic oppressions.

The refined research questions aimed to:

1. To explore decision-making processes for CYP with LLCs at structural, family, tacit and privileged levels;
2. To explore the expected roles of social workers within these decision-making processes;
3. To uncover challenges and oppressions within surrogate decision-making processes, considering their ethical challenges, luck, and oppression encountered within the processes of surrogate decision-making.

This comprehensive approach was designed to address and illuminate the intricacies of fairness and justice within decision-making processes, reflecting both immediate and wider implications for affected families.

4.5.3 Stage Three – Dialogical Data Generation

As a critical ethnographer, I explored the dynamics of surrogate decision making in paediatric palliative care, distinguishing between patient-centred and medical staff perspectives (Madison, 2019).

Using tools such as management meetings, patient education days and the distribution of information materials, I explored these two perspectives, referred to as emic and etic. My research was conducted at a single site in Seoul, which included a children's cancer centre at an acute hospital and two protest camps, where I engaged deeply with interviewees and documented their interactions for nine months.

To facilitate in-depth interviews, I established a rapport that allowed interviewees to openly discuss their experiences of surrogate decision making. These interviews were enriched with detailed fieldnotes and audio recordings to capture the subtle nuances of the conversations. I spent many hours on meticulous transcription to ensure accuracy and depth in data interpretation (Atkinson, Coffey, Delamont, et al., 2014: 391-392).

I applied Labov's narrative structure to analyse the data, identifying patterns that illuminated ethical decision-making processes within a multidisciplinary paediatric palliative care team. This analysis included assessing conflicts between health professionals and parents, using Banks and Gallagher's (2008: 64) guidelines to examine patient-centred approaches and surrogate decision making. I also explored the internal dynamics and power imbalances within the care teams, drawing on insights from Hill (1998) and Jünger *et al.*, (2007) to understand how these factors contribute to systemic oppression in care settings.

4.5.4 Stage Four – Describing System Relations

In the fourth stage of my research, I explored how environmental factors influence decision making in paediatric palliative care. Thomas (1993: 43) highlights the role of cultural symbols in creating power imbalances and ideological constraints that affect social participation and understanding. To explore these dynamics, I conducted in-depth interviews and direct observations at a cancer centre and local voluntary and faith-based organisations to capture the lived experiences of patients, parents, social workers and care teams.

Using Atlas.ti, I identified and developed themes and sub-themes through a detailed coding process, incorporating thick descriptions to articulate the relationships between different concepts and categories, including cultural values and my role as an ethnographer. This empirical and reconstructive analysis helped to delineate the systemic relationships between specific sites, providing a

comprehensive account of the context of surrogacy decision-making at local, national and international levels.

The research identified significant challenges in South Korea, particularly in managing conversations about curable and incurable conditions, addressing common fears, denial and bystander effects, while also addressing individual needs. The role of happiness, segmented into epistemic, moral and psychological dimensions, was explored to uncover biased beliefs and power imbalances. Systematic forms of covert oppression, such as avoidance of palliative care and reluctance to discuss the taboos of hospice care, were also documented. The analysis revealed multiple perspectives leading to interpretive gaps, which I then categorised and conceptualised using reconstructive analysis and dialogic data generation. This approach facilitated the articulation of cultural issues such as belief, oppression and happiness within the social system of paediatric palliative care.

4.5.5 Stage Five – System Relations as Explained by Findings

My research explored how distorted or biased beliefs influence decision making in paediatric palliative care, contrasting this with the reliance of medical staff on evidence-based medicine (EBM) to manage uncertainty and probability. I explored different social perspectives and identified gaps in interpretation by categorising and analysing themes such as beliefs, oppression and serendipity, with the aim of clarifying the multidimensional decision-making processes of CYP with LLCs.

The study also explored surrogate decision making within multidisciplinary teams and across different disciplinary contexts, both locally and internationally, drawing on a patient-centred approach (Mitchell, 2008) and the promotion of children's rights (Goldman, Hain and Liben, *eds.*, 2012; Bell, 2011). The dynamics within hospital palliative care teams were explored to understand internal relationships and decision-making processes (Hill, 1998; Jünger *et al.*, 2007).

In addition, gender relations were addressed, emphasising a non-hierarchical research relationship that empowered interviewees and allowed them to fully share their experiences (Olesen, 2005; Dominelli, 2004, 2005; Banks and Barnes, 2005). This feminist approach facilitated a deeper, holistic engagement with the interviewees' lives and enabled a comprehensive understanding of their perspectives.

Theoretical insights were drawn from the work of philosophers such as Emmanuel Levinas, Michael Polanyi and Pierre Bourdieu, as well as Beauchamp and Childress (2019), Buchanan (1989)

and Dworkin (1985) to frame the ethical and philosophical dimensions of surrogacy decision-making. The role of luck in decision-making processes was also explored, highlighting the discrepancy between personal beliefs and medical interpretations of outcomes. This comprehensive theoretical framework supported an in-depth review and discussion of multidisciplinary perspectives on decision-making in paediatric palliative care.

4.5.6 The Issues on Translation of Language

Throughout my research, I faced significant challenges related to language translation, especially when dealing with medical terminology and cultural nuances. Translating interviews, fieldnotes, video clips, documents and books from Korean to English was complicated by my limited understanding of the medical terminology used in palliative care team meetings and patient rounds. I often struggled to understand complex medical jargon and had to omit the translation of certain terms due to their specificity and my lack of medical background.

Geographical differences and dialects were also a challenge, especially as paediatric palliative care centres are concentrated in urban areas, but patients come from different regions. Although I could understand and speak all the dialects, translating them into English was almost impossible due to their deep cultural roots.

Emotional expressions such as swear words or slang used by younger generations were also difficult to translate. The lack of direct equivalents in English for many Korean slang and swear words meant that I could only translate a few accurately, such as ‘fuck’ and ‘bloody hell’. This linguistic barrier meant that I had to think carefully about how to adequately convey the emotional and cultural content of these expressions in my thesis.

Respecting social status through the use of titles, a practice rooted in Confucianism, was another cultural aspect I had to navigate. While titles are crucial in Korean to show respect, I often omitted them in translation to avoid cultural misrepresentation.

Furthermore, the translation of non-verbal cues, including body language and onomatopoeia, was limited by my skills and the intense demands of accurately rendering such nuances in another language. Consequently, some aspects of non-verbal communication were not thoroughly explored in my research due to these complexities.

4.6 Conclusion

In this chapter, I first discussed the research strategy, including an explanation of the research questions and an overview of critical ethnography in relation to multi-dimensional decision-making processes. I then described the research design and process, including a detailed description of the research process, based on social epidemiology, the sampling strategies, research methods and selection of interviewees for rich data collection. I described the theoretical approach used in the data analysis in relation to critical ethnography in data analysis and interpretation. I then reflect on some of the ethical dilemmas that arose during the research process and fieldwork.

Chapter 5: Ethics in Critical Ethnography – Series of Dilemmas

5.1 Introduction

Although I received two approvals and have no conflict of interest to declare, I had to consider ethical aspects such as egalitarian relationships and moral dilemmas. Regarding ethical aspects, the given methods ensure an egalitarian relationship between me and the interviewees or the interviewer and the interviewees. I thought there might be possible conflicts, especially moral dilemmas, between respect for autonomy and paternalism.

5.2 Ethical Evolution: Hwang Woo-suk's Scandal to Institutional Review Boards and Approval Process

Section 5.2 examines the development of research ethics in South Korea, particularly after the scandal involving stem cell researcher Hwang Woo-suk, which was characterised by serious ethical violations, including the illegal procurement of eggs and data manipulation. This incident led to significant changes in the research landscape, in particular strengthening the role and responsibility of Institutional Review Boards (IRBs) in overseeing ethical conduct. The section also reflects on my own experience of the ethical approval process, detailing my progression from obtaining approval from Durham University to completing IRB training. This culminated in obtaining dual approval from the Durham University and Severance Hospital IRB (No. 4-2017-0868), highlighting my commitment to maintaining rigorous ethical standards in scientific research.

5.2.1 Ethical Evolution in South Korean Research: From Hwang Woo-suk's Scandal to Institutional Review Boards

The section details the rise and fall of Woo Suk Hwang, a South Korean stem cell researcher whose misconduct was exposed by whistleblowers in 2005. Renowned for his work in human cloning, Hwang's reputation was tarnished after it was revealed that he had committed multiple ethical violations, including illegal egg collection and data falsification, in his research published in *Science*

in 2004 and 2005 (Jang Yong-jin, 2017; Buhm Soon Park, 2020; Lemonick, 2006; Han, 2006). These violations, such as paying for eggs, using eggs from his research team without proper consent, and manipulating research data, were in direct violation of the ethical guidelines set out in the Declaration of Helsinki.

The discovery of these unethical practices was largely due to the efforts of former researchers and TV show producers who questioned the authenticity of Hwang's work. This led to investigations by Seoul National University and subsequent revelations of extensive data fabrication, resulting in the retraction of his papers by Science and his dismissal from the university (Wade, 2005; Park and Kim, 2006; Kennedy, 2006; South, 2006; Choe, 2006).

The scandal highlighted the critical importance of research ethics and led to significant changes in the South Korean scientific community, particularly in the role and function of IRBs. These bodies have since taken on a more prominent role in overseeing research ethics, with increased training initiatives to ensure continued awareness and adherence to ethical standards among researchers.

5.2.2 The Ethical Approval Process

I obtained ethical approval from Durham University on 10 August 2017, after making certain adjustments to the ethics form that was filed on 5 June. As I awaited Durham's approval, I enrolled in a basic course on IRBs¹², which covered the following subjects:

- 1 History and Ethical Principles
- 2 Defining Research with Human Subjects
- 3 The Regulations and The Social and Behavioural Sciences
- 4 Assessing Risk
- 5 Informed Consent
- 6 Privacy and Confidentiality
- 7 Research with Children
- 8 Research in Public Elementary and Secondary Schools

¹² Chapter 11 is not included in the SBR Investigator/Researcher - Basic course.

9. Unanticipated Problems and Reporting Requirements in Social and Behavioural Research
- 10 Research with Prisoners
- 12 International Research
- 13 Hot Topics
- 14 Students in Research
- 15 Are You Thinking About Being in A Research Study?
- 16 Cultural Competence in Research

After successfully completing the basic IRB course, I submitted the ethics forms and obtained dual approval from Durham University and the S Hospital IRB, which thoroughly reviewed this study (No. 4-2017-0868). Following the fieldwork, I reported the project to the S Hospital IRB. The process of obtaining IRB approval took three months, which included completing an IRB module and submitting an ethics application under the guidance of a physician. I then lived near a palliative care centre in the Republic of Korea for nine months, spending the first three months securing IRB approval and the remaining six months conducting fieldwork.

Ethical Approval to Final Report



Figure 5-1 Ethical Approval to Final Report

After the fieldwork was completed, I continued to communicate with the interviewees via Facebook Messenger and Kakaotalk. I submitted the final report to the IRB between 10 February 2021 and 24 May 2021, after completing the rigorous data collection.

5.3 Research Ethics: Keeping Principles or Beyond Principles

Principles help me avoid mistakes. The economic and social Research council's 'Framework for Research ethics', 6 key principles of ethical research ([ESRC: 2015](#)):

1. Research participants should be engaged freely, without force or undue influence, and their rights, dignity, and autonomy should be respected and protected.
2. Research should be valuable and offset any risks or harm. Researchers should enhance research benefit and limit participant and researcher damage. Strong safeguards should reduce all risk and injury.
3. Research personnel and participants should be informed about the research's purpose, procedures, intended uses, involvement, risks, and rewards.
4. Respect participant and group requests for anonymity and confidentiality of personal data.
5. Research should be conceived, reviewed, and conducted to meet integrity requirements, quality, and transparency standards.
6. Research independence and conflicts of interest or partiality should be clearly stated.

My perspective may be narrow and I may not be able to understand the system holistically, although I also have the experience of working in hospices for about 12 years and teaching students for six years. Broad principles could be applied across sites and cultures when conducting fieldwork. These can be identified in a single site if the insider researcher can identify individual cultural perspectives. For ethical research, assessing potential ethical issues could prevent unexpected ethical

problems and enhance me if these principles, which provide guidance, are properly applied to fieldwork. For example, when considering a ‘small talk’ phase in the narrative interview, there could be serious ethical issues: ignoring informed consent, undermining participants' privacy and maintaining deception. Adhering to principles is therefore helpful to protect both myself and the subjects, and to ensure the safety of the interviewees.

However, adherence to principles cannot always be relied upon to ensure and improve ethical sensitivity and to deal with complicated moral dilemmas, such as conflicts between principles. Adherence to principles can at least prevent ethical problems, but it cannot improve ethical standards. In general, patients and their families rely heavily on doctors. Because of their credibility and authority, when doctors recommend medical research, patients and their family members participate in the research with informed consent.

Thanks to the help of one of the doctors, I met enough interviewees. Due to time constraints, the doctor could not give enough information to the patients and their family members. I explained their rights as patients and stressed that no pressure would be put on them if they refused to take part in the research, even if their doctor suggested it.

By employing the Other by Emmanuel Levinas (Lawton, 2000; Levinas, E., 1980; 1991; 2008a; 2008b; 2011 and 1999; Oh, S., 2005; 2008), I had to focus on patients' rights. By formally obtaining informed consent from interviewees, I could follow the given principles rather than the implicit dimensions of ethics. In other words, I can deceive others but not myself: ethical issues are not always obvious, and because of medical authority, issues can easily be hidden. I focused on their volatility in refusing to participate and showed respect for their autonomy. After receiving the detailed information, I gave them enough time to think carefully and decide whether they wanted to voluntarily participate in the interview. To avoid ethical problems, I guaranteed that the interviewee's priority was more secure than the interviewer's.

As a researcher, I avoided potential ethical issues of role conflict between counselling and research because the processes are different in palliative care, and both research staff and interviewees were fully informed of the purpose and methods of the study. Given the power hierarchies inherent in interviews, the interviewer can control the timing, pace and length of the interaction, sometimes without the interviewee's explicit consent. This practice can undermine the interviewee's autonomy, potentially create mistrust and disrupt the balance between interviewer and interviewee.

To avoid power hierarchies, I organised a reporting system for respondents and interviewees. I assessed how my actions could affect others when supervisors and staff were monitoring me, for example sending emails and reporting to the IRB. Moral issues complicated my status as a researcher. I had to be aware of the tacit dimension of interviewing as non-verbal language, timing, pace and length could inadvertently create a power relationship between interviewer and respondent. I advised respondents that they could leave without explanation. I considered that ethical uncertainties require ethnographers to be flexible when collecting data.

5.4 Confidentiality and Participants' Protection

After I stopped recording, I was able to expand on their story, perspective and interpretation of the event, but I would not formally disclose the information. Before starting my research, it was important to consider ethical issues in order to protect the participants (Dominelli, 2002; 2004b; Banks, 2003). Dinner and Crandall (1978) discussed the ethical principles, which can be divided into four main areas: prohibiting harm to the participant, preventing lack of informed consent, preserving the privacy of the participant, and promoting fidelity rather than deception.

Written consent forms and transcripts of face-to-face interviews as audio files in a safe were exclusively for me. To protect participants' identities, I stored data and recordings separately. The audio files were never shared and will be removed after the dissertation. The anonymity of participants and the confidentiality of their responses will be protected.

- 1) A code number that identifies each participant will be utilised in place of individual identifiers in the data, and the details will be known only to me, following that:

Original: "I was in the hospital for a week after injuring my left leg in a boda boda (motorbike taxi) accident. The nurse at the Mbarara Hospital chastised me when she found out my HIV status (Tsai, Kohrt, Matthews, *et al.*, 2016: 4)."

Anonymised: "I was in the hospital [after a transportation accident]. The nurse [] chastised me when she found out my HIV status." (Tsai, Kohrt, Matthews, *et al.*, 2016: 4)."

- 2) A participant's name and ID number file was saved in Dropbox separately.
- 3) I, who only has access to Dropbox after the study, deleted the final list of participant names.

4) Data identifiers are anonymised regardless of use, such as professional meetings, seminars, and PhD thesis publishing.

To address ethical concerns, the study examined participants' privacy standards. After interviewing them, I transcribed and checked for problems, then asked them if they wanted to change or delete stories via email or social network messenger.

To mitigate any discomfort caused by the interview questions, I carefully selected questions that would not cause participants undue distress. Participants were informed that they could stop or interrupt the interview at any time and were offered the option of having a patient or carer present. Participants were also informed of their right to refuse to be recorded at any time during the interview.

In order to address any emotional distress arising from the interview, I compiled a list of counselling providers. Participants were given my business card and information about nearby counselling services where they could seek further help if they needed it. This arrangement was included in the informed consent documents to ensure that respondents were aware of their options and could access help in a setting that was convenient for them, whether in the hospital or through an externally managed counselling service.

5.5 Potential Risks and Reflection to Researcher

Due to the significant psychological risks, I became upset after interviewing or re-listening to audio files and was reluctant to meet the next interviewees or was discouraged from observing the given sites. After each session, I debriefed with peer groups who had worked with me in the past or other professional colleagues, such as psychiatrists and counsellors, who were readily available. They are not related to my potential respondents.

With regard to the commercial contract for transcription, care must be taken to ensure the quality of the transcription, which is not easy. Due to a wide range of analytical approaches, I could be confused when dealing with the narrative properties of their data. (Mishler, 1986: 233–255; Elliot, 2005).

As a PhD researcher and critical ethnographer at Durham University, I am deeply committed to the ethical handling of sensitive data collected from CYP with LLCs. Recognising the emotional demands of this research, I ensured that support mechanisms such as qualified debriefing professionals

were available during the interviews to manage any potential emotional distress. Despite these precautions, I faced personal challenges, including depression and anxiety, due to the nature of the work from 2019 to 2022.

As well as understanding complex decision-making processes, the study has revealed the emotional impact on both the researcher and the participants, ranging from joy at positive outcomes to despair at negative ones. In addition, the study encourages reflection on the risks of whistleblowing, particularly in a cultural context such as Korea, where whistleblowers can face significant stigma and legal vulnerability.

This juxtaposition of personal experiences, ethical dilemmas and societal attitudes underscores the multiple challenges faced in conducting this research and highlights the need for ongoing ethical reflection and support in addressing the vulnerabilities associated with such sensitive issues.

5.6 The Issue of Payment: To Pay or Not to Pay?

As a self-funded researcher, I avoided offering cash or vouchers to interviewees to avoid any undue influence or coercion, as I felt it was crucial to maintain their autonomy. Instead, I only offered a cup of tea or coffee during the interviews to foster a good rapport. In South Korea, it is common for interviewees to receive around £70 or a voucher of equivalent value, especially if the interviews are funded by the government or an organisation. However, in my approach, one volunteer, a traditional calligrapher, made a unique contribution by creating a traditional fan with favourite words or phrases as a gift. This was given to the interviewees as a personal gesture after reviewing the summarised interviews with them, thus maintaining the voluntary nature of their participation.

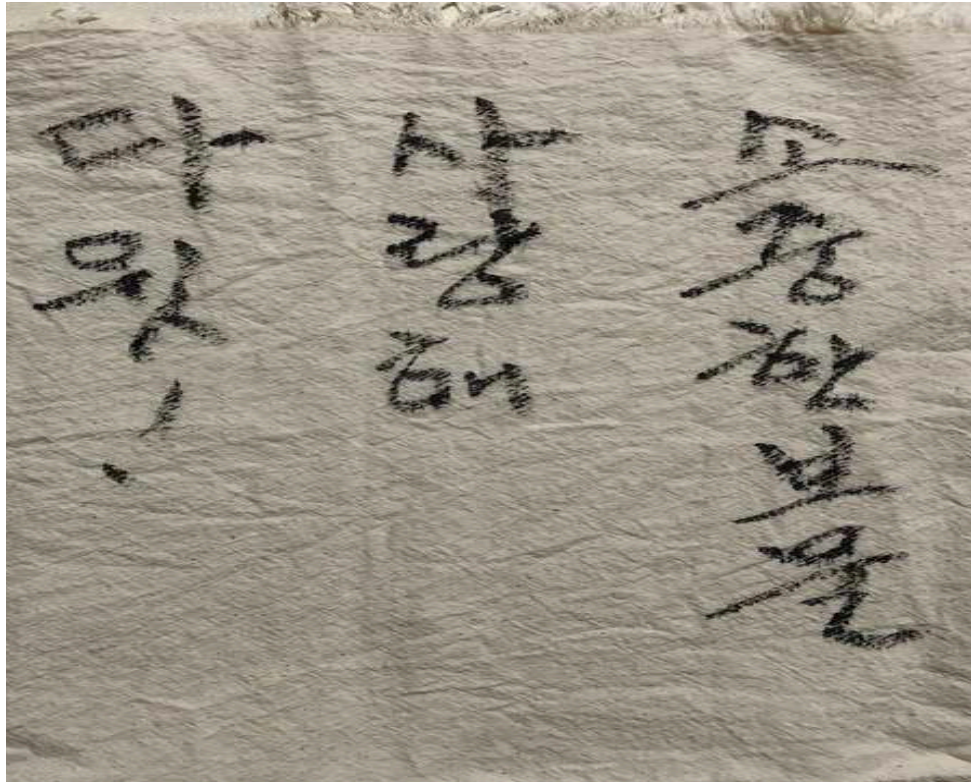


Figure 5-2 Korean Hand Calligraphy

My precious treasure! I love you My David! (Before sending it a traditional calligrapher showed me a sample.)



Figure 5-3 Personalised Hand Fan 1

Isaiah 41:10 (New Revised Standard Version) Do not fear, for I am with you, do not be afraid, for I am your God; I will strengthen you, I will help you, I will uphold you with my victorious right hand.



Figure 5-4 Personalised Hand Fan 2

Seunghoon Oh was created to receive the greatest love. Seunghoon Oh experiences this love in every part of her life. From the beginning, God has shown His love to bless Seunghoon Oh. As we greet and bless each other, there is a fruit of love. Because Seunghoon Oh is with us, we experience tremendous joy. Let us come before our God with gratitude in our hearts. Seunghoon Oh was created to receive the greatest love. (Seunghoon Oh is me)

Some parents asked me for some good maxims, as in Figure 5-2, or Bible verses about hope, as in Figure 5-3. Others just believed that I could bring something good for their child. In my experience, parents do not know how to express their feelings to their CYP with LLCs in Korea. In such cases, I gave gifts as shown in Figures 5-2, 3 and 4.

When the child and the parent received the surprise gift, it was an unforgettable experience. I arranged a modest gift for the interviewers, which encouraged the patient and their parents to tell the truth about the illness and to prepare for some of the worries. In addition, certain specialists were eager to help me with my research and introduced me to some gatekeepers, including the traditional calligrapher Go, Rokhee.

5.7 Conclusion

This chapter reflects on the ethical challenges I encountered during the research process. I had to navigate the ethical and methodological tensions during my research. As the critical ethnographer, this chapter illuminates ethical tensions, mainly the pressure of weaving from multiple disciplinary workers, surrogate decision-makers and CYP with LLCs.

I now move forward to discuss the research findings. These will be presented in the next four chapters, interweaving recent literature with empirical data to reflect the iterative approach to data analysis, focusing on decision-making processes. The next Chapter 6 will carefully explore the structural level of decision-making processes.

Chapter 6: The Structural Level of Decision-Making Processes: Blind Luck, Hidden Social Determinants of Health, or Oppression?

6.1 Introduction

In Chapter 6, I pondered the strategic approach adopted during the research process, including an explanation of the research framework and an overview of critical ethnography. This chapter critically explores that the structure level of decision-making processes includes two stages: decision-making processes under a vicious circle and decision-making processes in hidden SDOH, following that:

- 1) to find out the decision-making processes for CYP with LLCs: the structural level of decision-making processes.
- 2) to explore the expectations of social workers and the role in paediatric palliative regarding the decision-making processes for CYP with LLCs.
- 3) to discover the ethical challenges in the ethos of surrogate decision-making.

In Section 6.2, I will present stage one, which is decision-making processes under a vicious circle. In exploring the processes of paediatric palliative care, the study identified several issues, including paediatric palliative care under neoliberal policies, distorted care transitions and lack of training in paediatric palliative care. In addition, the study found that medical staff often struggle with work overload and may not feel fully responsible for the care of patients.

In addition, section 6.3 identifies stage two as decision-making processes in hidden SDOH, such as disinfectants for humidifiers, radon-emitting mattresses, the semiconductor industry and asbestos-contaminated schools. This is because decision-making processes should recognise that the health of CYP begins in their homes, schools, workplaces, neighbourhoods and communities.

In section 6.4 I will critically interpret luck, SDOH or oppression in decision-making processes. At the structural level of decision-making processes, the role of the paediatric palliative care social worker is not only unclear, but the expectation is higher and meeting the expectation is unrealistic in the hidden web of oppression.

I conducted a total of 120 face-to-face interviews consisting of 50 cancer, 15 non-cancer, 14 senior members of paediatric palliative care teams and 41 participants from local, national and international

decision-making contexts to explore how palliative care teams and parents support the best interests of CYP and the reasons for happiness or oppression in decision making processes. At the structural level of decision-making processes, I will interpret the findings using Emmanuel Levinas's Other and Pierre Bourdieu's symbolic violence.

6.2 Stage One: Decision-Making Processes in a Vicious Circle as Neoliberalism

From 2017 to 2019, South Korea's health insurance system will move from a large surplus to a large deficit, with coverage improving slightly from around 63% to 65.3%. These statistics raise a critical question: Were these policy changes really beneficial? While out-of-pocket expenses for patients have decreased, the impact on overall quality and accessibility of care, particularly in preventing overtreatment, remains complex and multifaceted (Kim, Hyunchul, 2023).

During my fieldwork, which involved quietly shadowing doctors, I was constantly confronted with the raw vulnerability of patients - most poignantly during an episode in which medical staff frantically performed CPR on a child enroute to the neonatal intensive care unit (NICU) while explaining the dire circumstances to the distraught family. This harrowing experience, witnessed from the sidelines, evoked an overwhelming emotional response. I found myself crying uncontrollably in a toilet, overwhelmed not only by a profound sense of compassion, but also by a deep-seated anger at the systemic injustices embedded in healthcare policy.

On reflection, I realised that these intense emotions were not just reactions to individual events, but responses to the ethical call of 'the Other' – Levinas's term for the face-to-face encounter that imposes a fundamental ethical obligation on us. These moments of witnessing suffering not only reveal the face of the Other, but also call into question our responsibility to respond, and highlight the inadequacies of a health care system shaped by neoliberal imperatives that often prioritise economic efficiency over genuine care. Although surrogate decision-makers might be unsure of the best interests of the CYP with LLCs, professional medical staff or experts could help them choose the best option when making a decision. What I also discovered was that decision-making processes were under a vicious circle of neoliberalism (Navarro, 2007). This section presents reproducing oppressive decision-making processes such as paediatric palliative care policy under healthcare privatization policy, distorted healthcare transition, lack of paediatric palliative care education, and work overload.

Fragmented care, unnecessary duplication of services, and a lack of paediatric palliative care education contribute to healthcare professionals struggling with work overload without clear responsibility. Taking responsibility for ‘the Other’, as posited by Levinas, should not be linked with distorted healthcare transitions. Instead, it ought to involve an integrative healthcare transition that prioritises the best interests of CYP with LLCs, ensuring that their care is continuous and coordinated.

In Section 6.2, I will present that the reason for decision-making continuously happening under oppressive conditions is because they live in a vicious circle allowing deregulation, hierarchical systems without responsibility and depending on donations.

6.2.1 Impact on Neoliberal Policies on Paediatric Palliative Care and Doctor Shopping

During my experience working in adult palliative care, I observed stark differences in the services available to CYP. Despite extensive experience, the lack of specialist paediatric palliative care guidelines often left me unable to adequately address the specific needs of younger patients. On 14 December 2017, my field notes capture a vivid example of the systemic pressures that contribute to ‘doctor shopping’. The notes describe an incident in which a professor, overwhelmed by his workload, performed CPR on a non-patient, a telling sign of the overstretch of medical staff. Such exhaustion among doctors often leaves families uncertain about the quality of care, forcing them to seek multiple medical opinions. This behaviour was echoed in my interviews with families of 65 patients with LLCs including 50 with cancer and 15 with non-cancer conditions, revealing a widespread pattern of ‘doctor shopping’¹³ driven by an accessible but overstretched health system. This behaviour reflects the broad accessibility of the Korean healthcare system, which recorded an average of 16.6 doctor visits per person in 2017, significantly higher than the OECD average of 6.8 (Kim, 20-23:2). This system facilitates easy access to a range of treatments without mandatory referrals, except in tertiary hospitals.

In contrast to my observations in adult care, paediatric palliative care in South Korea remains critically underdeveloped, despite the progress made in adult palliative care between 2002 and 2013.

¹³ Moumjid *et al.*, (2007) characterise doctor shopping as individuals consulting multiple health professionals or institutions for additional opinions on diagnosis or treatment, as opposed to seeking a second opinion from a non-primary care provider. Boscarino and Stelber (1982) describe hospital shopping as the selection of a hospital based on the quality of both the physician and the hospital facilities. In Japan, the term ‘self-referral’ refers to patients frequently changing doctors without an official referral (Guo *et al.*, 2002). In Korea, medical seeking behaviour is defined as visiting specialist departments at university hospitals to obtain referrals for specialist consultations not included in the health care system (Choi *et al.*, 2009).

The first hospice in Korea, the Little Company of Mary of Calvary Clinic, established in 1965 with a religious foundation, marks the beginning of hospice care in the region. However, the subsequent lack of progress in paediatric palliative care policy highlights a significant oversight in the provision of healthcare for children, an issue that has both professional and personal implications for those involved in the sector. Despite a strategic plan to conquer cancer for national cancer management, implementing the hospice and adult palliative care policy was started later, in 2002, by the government. I found that the paediatric policy may not fully address the unique needs and best interests of CYP with LLCs, following Table 6-1.

Year	Events
1965	- Little Company of Mary' of Calvary Clinic (1st hospice clinic in Korea)
1996	- 1st Ten-Year Plan to Overcome Cancer (1996~2005) by MoHW
2003/2004	- Pilot project for forstoring program of Hospice & Palliative Care unit by MoHW
2006	- 2nd Ten-Year Plan to Overcome Cancer (2006~2015) by MoHW
2008	- Designation of Hospice & Palliative unit by MoHW
2009/15	- Pilot project for case payment of PCU by National Health Insurance (NHI)
2011	- Revise 'Cancer Control Act' (based on Act of Hospice & Palliative Care unit)
2013	- Announce of "Plan for activation of Hospice & Palliative Care" by MoHW
2014	- Add on New item about Hospice & Palliative Care to Health care accreditation program of tertiary hospital, general hospital
2015	- Case payment of PCU by NHI
	- Revise 'Cancer Control Act' (based on Act of home & Consultation Hospice & Palliative Care
2016	- National Health Insurance Service cover hospice palliative care cost for terminal cancer patients
	- 3rd National Comprehensive Plan for Cancer Control (2016~2020) by MoHW
Act (2017.8)	- Hospice & Palliative Care and Self-determination life sustain treatment Act (2017.8)
	- Pilot Project of Home hospice payment by NHI
	- Pilot project of Convalescent hospice payment by NHI

MoHW: Ministry of Health & Welfare, PCU: Palliative Care Unit, NHI: National Health Insurance.

Table 6-1 Brief History of Hospice & Palliative Care Policy in the Republic of Korea

Source from Chang Gon Kim, 2017: 9

Interestingly, while there are well-known cancer centres, a policy for paediatric palliative care was only established in 2016. Following a study on the establishment of the hospice and palliative care system for children and adolescents (Ju, Moon, Lim, *et al.* 2018), a paediatric palliative care pilot project facility was operated by the Ministry of Health and Welfare and the National Hospice Centre of the National Cancer Centre.

Compared to adult palliative care policy, paediatric palliative care policy is relatively unknown and more focus is needed on the development of the Korean Healthcare Programme for Long-term Childhood Cancer Survivors (Oh, Lee, Kim, *et al.* 2013) and the Strategic Plan to Conquer Cancer.

In 2016, the Act on Decisions on Life-Sustaining Treatment for Patients in Hospice and Palliative Care or at the End of Life was enacted in South Korea (Kim, 2019: 4). While this law applies

to all patients in hospice and palliative care or at the end of life, including CYP with LLCs, there are no specific regulations or guidelines for CYP with LLCs to refuse futile life-sustaining treatment. Surrogate decision-makers of CYP with LLCs continue to play a crucial role in decision-making about life-sustaining treatment.

The first independent children's palliative care centre, Helen House, was established in the UK in 1982, followed by the USA, Australia and Japan. However, compared to other countries, Korea did not have an independent children's palliative care centre. Thanks to the Nexon Foundation, which donated 10 billion won to Seoul National University Hospital, Seoul National University Hospital will establish the country's first palliative care centre for CYP with LLCs in 2022. (Yoon, 2020; Kim, 2022) Throughout my work in adult palliative care, I became acutely aware of the profound disparities in service provision for CYP with LLCs. Despite my extensive involvement, I was often at a loss as to how best to address the needs of younger patients due to the glaring lack of dedicated paediatric palliative care policies. This experience not only highlighted the critical gaps in our healthcare system, but also profoundly influenced my professional ethos and highlighted the urgent need for systemic reform to establish a more inclusive and ethically informed approach to palliative care across all age groups. Despite the good news, I was left with a question:

If we think that a children's hospice should be different from an adult hospice, and should include people with rare diseases as well as cancer patients, then the place should have a number of important rooms. Palliative care for children should be different from palliative care for adults, even if it is provided. Hospice care started in South Korea in 1965. Fifty years later, there isn't a single children's hospital left in the country. There is only one team dedicated to children with cancer at a university hospital, but a trial is underway. Sadly, I feel that this lone beacon highlights a wider systemic void - a lack of spaces where children can experience the end of life with dignity and personalised care. This poignant reality struck me during my fieldwork as I grappled with the incongruity of adapting adult-centred models of palliative care for children. It became clear that children are not mere miniatures of adults; they have their own unique needs and deserve palliative care that is as distinct and life-affirming as their youthful spirits. There is no place for dying. I let out a sigh. The idea of palliative care for children and young people wasn't based on what adults would do. Children aren't copies of adults. (Fieldnote, 27 December 2017)

In recognising this, the government must acknowledge that paediatric palliative care is deeply intertwined with the public domain and deserves attention as a matter of public concern. Historically, the provision of hospice and palliative care in Korea has been characterised by collaboration between the private sector and religious organisations (Kim, 2017: 9). Therefore, it is of paramount importance to consider how these sectors can evolve to meet the specific palliative needs of CYP with LLCs.

The dual insurance system in South Korea, where people are often covered by both the National Health Insurance Scheme (NHIS) and private insurance due to gaps in NHIS coverage, has led to a unique health care dynamic. With greater coverage from private insurance for services not fully covered by the NHIS, individuals are incentivised to use healthcare services more freely, resulting in higher instances of doctor shopping. This behaviour is further reinforced by cultural attitudes that prioritise extensive medical consultation to ensure the best possible care. The interplay between the limitations of the NHIS and the complementary role of private insurance is an important factor in this trend. When CYP with LLCs are treated in tertiary hospitals, the initial focus is on a variety of medical interventions and symptom control.

From interviews with CYP with LLCs, I identified a pattern of healthcare decision-making that is predominantly linear, moving from supportive to bereavement care, which may not capture the full complexity of patients' needs. Decision-making processes in the best interests of CYP with LLCs should include a wide range of options, but I found that there is a limited healthcare transition focused on medical treatment. The structure of the Korean healthcare system, which does not emphasise the need for initial clinic visits before hospital consultations, further facilitates doctor shopping. Patients can access hospital services directly without prior screening or referral from lower-level health care facilities.

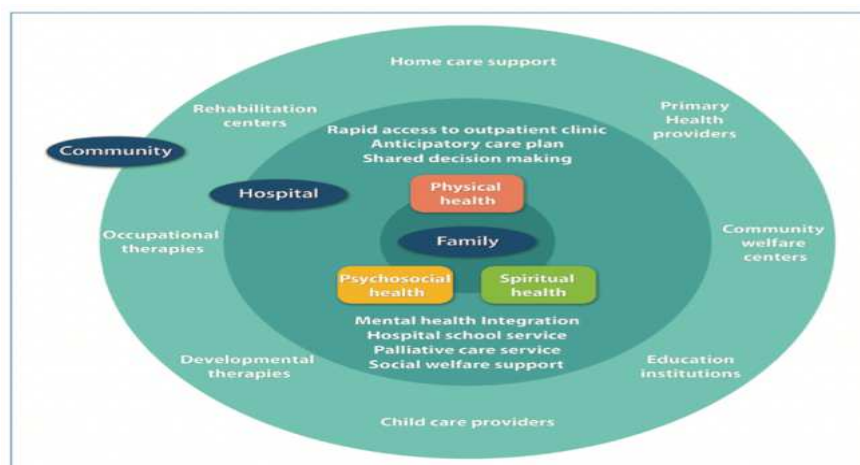


Figure 6-1 Graphical abstract.

The concept of integrative care for children with medical complexity

Source from Jung Lee, Min Sun Kim and Hee Young Shin, 2020: 30

According to Figure 6-1, Jung Lee, Min Sun Kim and Hee Young Shin, (2020: 30) reported that the current healthcare systems in Korea are not well organised for CYP with LLCs, resulting in fragmented, uncoordinated and emergency-driven care. Through an in-depth exploration of their lives and decision-making processes, I found that the majority prioritised curative treatments over an integrative model of care, which is often recommended to optimise the best interests of the patient. I uncovered two cases that have negative implications for the healthcare of CYP with LLCs.

Case Study Diagnosis and Treatment of Moyamoya Disease

Jaehee Kim, father of Minho Kim, shared his challenges following his son's diagnosis of moyamoya disease and subsequent surgery. The surgery left his son dependent, requiring monthly transfers to different hospitals due to surgical side effects, with only one paediatric rehabilitation centre available in Seoul (Interview, 07/12/18).

This case highlights the critical need for a comprehensive healthcare decision-making process that goes beyond immediate medical treatment to include palliative care and community support options to ensure a holistic approach to patient care. Despite the introduction of multidisciplinary paediatric palliative care teams in some tertiary hospitals in the Republic of Korea in 2015, supported

by the Ministry of Health and Welfare's Third National Cancer Control Plan (2016-2020), there remains a significant gap in community-based rehabilitation and support programmes for CYP with LLCs. Observations from several field notes in 2017 and 2018 point to a healthcare system that is overly focused on diagnosis and treatment, neglecting broader support needs such as educational support and community integration (fieldnotes: 15/12/2017, 19/12/2017, 20/12/2017, 26/02/2018, 18/05/2018).

Case Study: Educational Challenges in Healthcare

Jiwon Choi, a primary school teacher, described the lack of educational programs for children with cancer and other non-cancer conditions. Financial barriers prevent some students from receiving necessary surgeries, and efforts to fundraise within schools encounter resistance from staff and administration, underscoring the educational and social challenges facing CYP with LLCs (Interview, 26/02/18).

In the course of my research, I conducted interviews with 17 individuals representing a range of national disciplinary contexts. Each participant offered insights that shed light on systemic issues in health care. The following section provides a comprehensive account of the interviewees and the themes they shared.

***Leonard Moon**, representative of the Korean Association of Social Workers, underscored the necessity for enhanced palliative care policies (Interview, 17,11,2017).*

***Isabelle Shin**, representative of the Korean Association of Medical Social Workers, observed the absence of training in paediatric palliative care (Interview, 28,11,2017).*

***Nari Gwon**, Chairman of The Korean Association of Hospice and Palliative Care, presented an analysis of the advancements in adult hospice care in comparison to the neglect of paediatric services (Interview, 15,12,2017).*

***Miji Nam**, representative of the Korean Association of School Social Workers, drew attention to the discrepancy in the services provided to children (Interview, 17,11,2017).*

***William Seo**, representing Social Workers for Changing the World (an NGO), advocated for the implementation of novel care strategies (Interview, 7,2,2017).*

***Minji Ahn**, Executive Secretary of the Korean Association for Children with Leukaemia and Cancer, emphasised the necessity for the development of specialised guidelines (Interview, 13,2,2017).*

***Gihwan Nam**, Manager at the Department of Health Policy, Ministry of Health and Welfare, emphasised the inefficiencies resulting from the absence of a gatekeeping system (Interview, 17,11,2017).*

Seohyun Kim, a researcher at the Health Insurance Review & Assessment Service, offered a critique of the direct access to specialists that she identified as a contributing factor to hospital overload (Interview, 16,5,2018).

Kyeonghee Hwang, Research Director at the Korea National Institute for Bioethics Policy, discussed the ethical considerations pertinent to paediatric care (Interview, 20,2,2018).

Omar Gi, Special Assistant to the politician representing the Liberty Korea Party, discussed the policy-level changes that are required in order to improve the quality of paediatric care (Interview, 25,4,2017).

Jiyeon Jo, Special Assistant to the Politician of the Democratic Party of Korea, concentrated on the political dimensions of healthcare reform (Interview, 12,5,2018).

Minchul Ahn, Special Assistant to the Politician, The Democratic Party of Korea, reiterated the necessity for political backing in the context of healthcare reform (Interview, 13,5,2018).

Hyeonseo Hwang, a politician from the Democratic Party of Korea, underscored the necessity for legislative measures to facilitate the provision of paediatric palliative care (Interview, 23,4,2018).

Inna Yoo, Special Assistant to the Politician from the Justice Party, emphasised the importance of political advocacy in the context of healthcare (Interview, 23,4,2018).

Jalim Lee, an expert in social policy and bioethics, discussed the ethical implications of current care practices (Interview, 30,1,2019).

Haerang Na, also an expert in social policy and bioethics, talked about the bioethical needs in paediatric care (Interview, 30,1,2019).

Dooan Baek, another expert in social policy and bioethics, focused on the broader social implications of healthcare policies (Interview, 26,5,2018).

A key consensus that emerged from the individual interviews was that while considerable progress has been made in adult hospice care, paediatric hospice and palliative care remains significantly underdeveloped. These professionals were unanimous in their recognition of the urgent need for the establishment of robust guidelines to effectively guide practice in paediatric palliative care. This is exacerbated by the lack of a gatekeeping system, resulting in an influx of patients into tertiary hospitals and inefficient use of medical resources.

6.2.2 Paediatric Palliative Care Education?

Supporting decision making is essential and requires appropriate paediatric palliative care education for the training of hospice and palliative care social workers in Korea. This can be divided

into three types of educational areas: tertiary education, palliative care education by the Korean Association of Medical Social Workers, and palliative care education policy by the government. Firstly, tertiary education should provide paediatric palliative care education for social work students, but there is no paediatric palliative care education for social work students.

Secondly, palliative care education has been developed by the Korean Association of Medical Social Workers since 2007 in three levels of courses: basic, advanced and professional, but it stopped running the programmes in 2008. The final area is e-learning programmes, through which the government aims to train specialised social workers in hospice palliative care.

Main Category	Subject
Understanding palliative care	Understanding death Medical understanding of death Care of terminally ill patients: in reality and ideally Care of patients with end-stage model: status and prospects
Hospice and palliative care social work overview	Overview of hospice and palliative care Overview of the historical development of hospice and palliative care and social assistance
Understanding cancer	Understanding cancer Terminally-ill symptoms management 1 - mental and neurological symptoms Terminally-ill symptoms management 2 - digestive, respiratory, and circulatory symptoms Terminally-ill symptoms management 3 - emergency management and the last 48 hours
Hospice and palliative care social work training: assessment-intervention	Hospice and palliative care social work training course overview Field training in hospice and palliative care social work Understanding of comprehensive care assessment Understanding of psychosocial assessment Understanding of psychosocial assessment tools Understanding pain Pain assessment and pain management practices Approaches and understanding of spiritual care Hospice and palliative care social work intervention for patients and their families Hospice and palliative care social work intervention in groups Hospice and palliative care social work programs
Hospice and palliative care social work ethics	Understanding communication Communicating with terminally-ill patients Medical fees associated with hospice and palliative care Creating business plans and fund raising Volunteer management
Team work and evaluation of hospice and palliative care quality	Understanding bereavement care for the family Family bereavement care programs and operating practices Understanding of hospice and palliative care social work ethics Ethical issues in hospice and palliative care Strengthen ethical competence of hospice and palliative care social workers Approaches to developing communication between team members and team physicians Handling stress and burnout among team members Evaluation and improvement of hospice and palliative care quality On site training

Table 6-2 Curriculum of the e-Learning Program for Training Social Workers in Hospice and Palliative Care

Source from Hye-Young Shim and Yoon-Jung Chang (2015:12)

According to Table 6-3, the curriculum of the e-learning programme for training social workers in hospice and palliative care source, palliative care social workers learn basic modules but focus on palliative care for cancer. This is because the Korean government announced a plan to train more hospice and palliative care professionals in the second 10-year plan to conquer (Hye-Young Shim and Yoon-Jung Chang, 2015:9).

Subject	National Hospice and Palliative Care Organization (2001)	Wisconsin Hospice Care Planning (2001)	European Association for Palliative Care (1993)	Hospice & Palliative Care Handbook (1999)	Oxford Textbook of Palliative Medicine (3 rd ed.) (2004)	Korea Hospice Palliative Care Standards and Regulations (2003)	Advanced Course Development Social Worker (2011)	National Cancer Center Social Worker e-Learning (2014)
Understanding of death					○		○	○
Understanding of hospice and palliative care (History, philosophy, principles, etc.)				○	○	○	○	○
Individual and team approaches to hospice and palliative care role	○	○	○	○	○	○	○	○
Ethic and laws in hospice and palliative care	○		○		○		○	○
Pain control		○	○	○	○			○
Symptom control		○	○	○	○			○
Psychologic, social, and spiritual care	○	○	○		○		○	○
Dying patient care	○				○			○
Communication (counseling)	○	○	○		○		○	○
Family care/Bereavement family management	○	○	○	○	○		○	○
Hospice operation and management	○		○	○	○	○		○
Children's hospice				○	○			*
Non-cancerous terminal disease management					○			*
Complementary therapies		○			○		○	
Improve quality of hospice teams		○			○		○	○
Build partnerships and promote hospice schemes	○				○	○	○	○
Other (education, nutrition, finances, etc.)	○			○	○		○	○

*Updated core curriculum of e-learning programs for Hospice-Palliative Care Specialists.

Table 6-3 Comparison of Educational Contents for Training Hospice and Palliative Care Social Workers

Source from Hye-Young Shim and Yoon-Jung Chang (2015:12)

In Table 6-4, the comparison of educational content for hospice and palliative care social worker training, a social worker cannot learn paediatric palliative care. I also asked whether the e-learning programme was sufficient to change practice in paediatric palliative care. According to Supportive Care, Palliative Care and Hospice Care, CYP with LLCs struggled with developmental tasks.

In the course of my extensive one-on-one interviews with a wide range of stakeholders in the South Korean healthcare system, a significant consensus emerged among the interviewees. Despite the

diversity of their roles, they all identified a significant shortcoming in the system: the lack of adequate training in holistic approaches to care. The insights provided by these professionals, each in their own role, provide a comprehensive overview of the educational shortcomings affecting the field. Interviewees included:

Jiwon Choi and Junsu Kim, both primary school teachers, who underscored the educational needs within school settings (Interview, 6,2,2018).

Miji Nam, Representative of The Korean Association of School Social Workers, emphasized the urgent need for more comprehensive training for social workers in educational contexts (Interview, 17,11,2018).

Minseo Son, Executive Secretary at Han Bit Love for Children with Cancer (NGO), highlighted the gaps in support and training for staff within NGOs focused on children's health (Interview, 28,11,2017).

Eunsol Cho, Bernard Stevenson, and Jeremy Hamilton from My Welfare (NGO) for Changing Social Policy, who collectively pointed out the deficiencies in policy-driven healthcare training (Interview, 8,1,2018).

Minji Ahn, Executive Secretary of the Korean Association for Children with Leukaemia and Cancer, stressed the importance of specialized training for those working with paediatric cancer patients (Interview, 13,2,2018).

Each interview, conducted separately, served to reinforce the pervasive need for enhanced training programmes that adequately address the complexities of holistic care and ensure that all stakeholders are equipped to effectively manage and advocate for improved health outcomes.

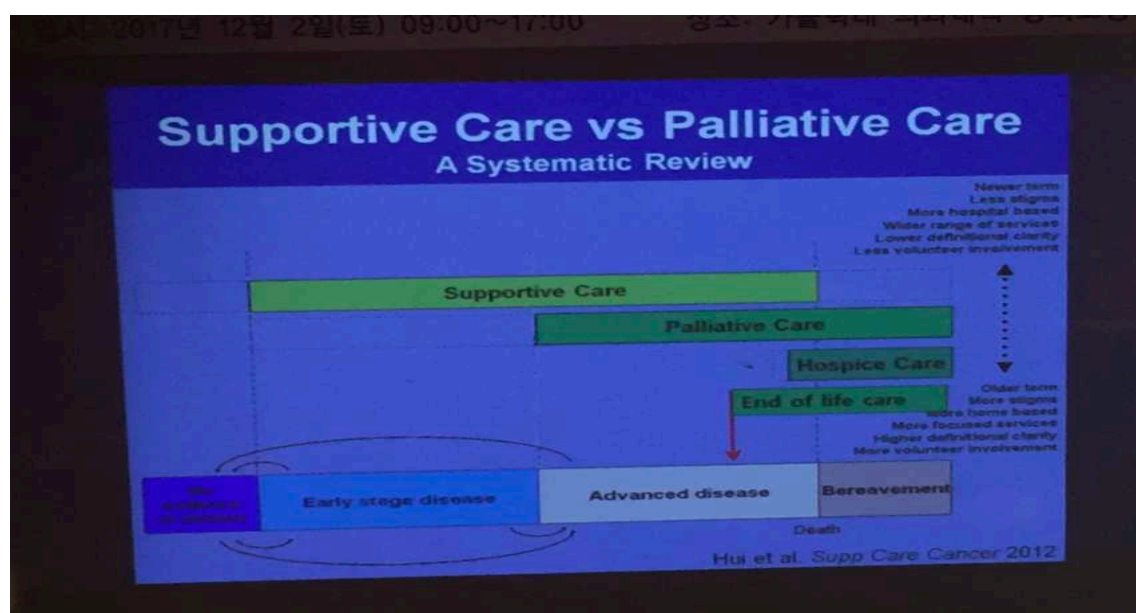


Figure 6-2 Taken from Fieldnote on 2nd December, depicts my explanation of the differences between Supportive Care and Palliative Care.

I found that decision-making processes involve a range of choices, which became clear when attending palliative care conferences in Korea and realising the transition from supportive to bereavement care (Fieldnote, 2 December 2017).

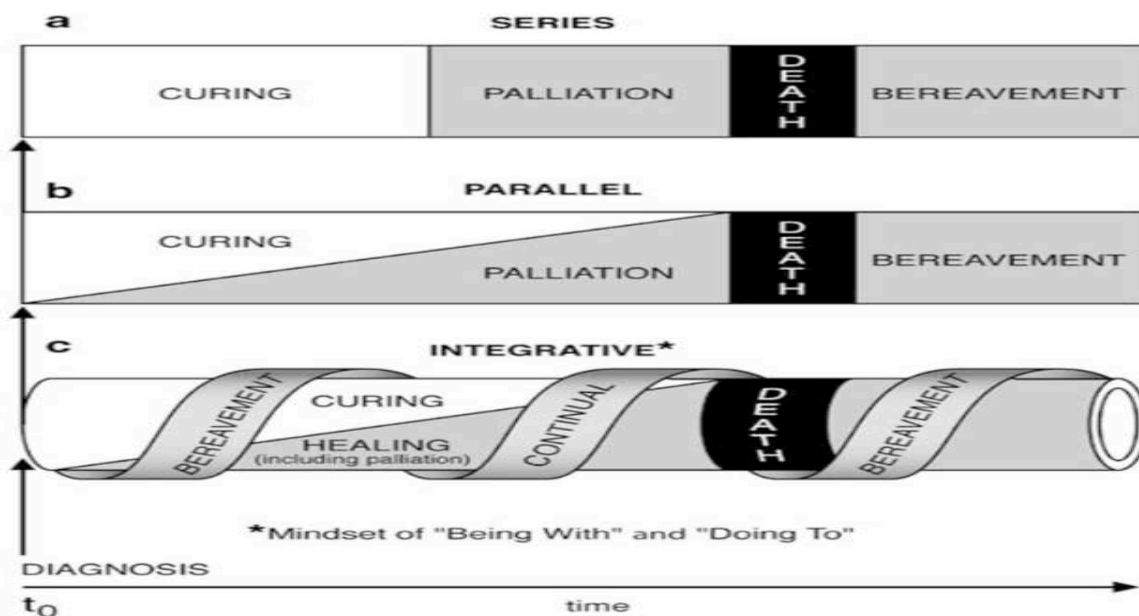


Figure 6-3 Jay Milstein's Model (2005:564)¹⁴

It is noteworthy that Jay Milstein's model of integrative care (2005:564) is rarely mentioned or used, highlighting a critical gap in the current educational framework for healthcare professionals. The analysis of health care decision-making in South Korea revealed a predominantly linear trajectory, moving from supportive to bereavement care. This approach contrasts sharply with more comprehensive models, such as Milstein's, which advocate an integrative paradigm that encompasses concurrent care strategies. Such models recognise the complexity of patients' needs throughout their illness and advocate the seamless integration of palliative care from the start of treatment, rather than as a last resort.

¹⁴ Jay Milstein presents that (2005:564) "Models of Care (a) Series model of care. In the traditional adult model of care for terminal conditions, care is represented in a sequential fashion against time: once curative measures have become futile, they are followed by palliative measures, death, and bereavement. (b) Parallel model of care. In the parallel model of care, curative measures that progressively decrease and palliative measures that progressively increase are introduced simultaneously. These measures are followed by death and bereavement. (c) Integrative model of care. In the universal integrative paradigm of care, healing and palliation, when indicated, are introduced in parallel with curative measures as soon as any diagnosis, especially a critical one, is made. Since a loss can be experienced even in the absence of death, bereavement is represented as a continual process from the outset. It usually undergoes an increase after death. In this paradigm, healing and bereavement are facilitated with a mindset of "being with" while curing is facilitated with the usual mindset of "doing to." Superimposing a vertical line anywhere along the time axis may indicate the balance between curing, healing and bereavement involved in integrative care for an individual."

professional norms and how they can sometimes be at odds with the practical realities and personal values of practitioners. This culture, ostensibly a tool for education, often degenerates into personal abuse, reflecting a deep-seated normalisation of overwork and sacrifice that is culturally valorised, further exacerbating the challenges within the healthcare system.

Due to their busy professional lives, they refused or postponed the interview, even though they supported this research on decision-making with children. During the 5 months I waited for the interview, three social workers left their jobs and two social workers moved elsewhere: *“The doctors are asking for an average of 48 hours per week, based on 26 weeks, with the option to work extra hours if they want. They also want 11 consecutive hours of rest per day, two days off every week or fortnight, with 20 minutes rest (or rest compensation) every six hours. That's not what we social workers are looking for. I don't think we can follow that. My workload has increased a lot recently and it's been really challenging to keep up with it all. From general paediatrics to paediatric cancer patients and rare diseases, I sometimes feel overwhelmed, but more often than not, I just sigh. I got to work early and should be finishing up around midnight. These days, people say that having a healthy work-life balance is the key to a better life! I'm struggling to achieve a healthy work-life balance. I get to work around 7am and always leave late at 9pm because that's what I'm used to.”* (Samuel Pyo, S Hospital Social Work, 17/05/2018)

In terms of Levinas' relation to the Other, medical social workers have already struggled with their work overload, following social workers: *I calculated how much time they spent in relation to the role of the palliative social worker in order to make a proper guideline for palliative social workers. They spent at least 55 hours from admission to bereavement.* (Vinseok Ryu, S Hospital Social Work, 06/12/2017)

Young Sook Lee, (2013: 67-68) explains the work overload: all hospitals should have at least one medical social worker based on the Cancer Control Act since 2016.

Classification	Number of people
Doctor/Oriental doctor	Number of doctor per daily 20 patients
Nurse	Number of nurse per daily 2 patients
Social worker	Over 1 person

Table 6-4 Essential Manpower for Hospice and Palliative Unit.

Source from Lee 2013: 68

In terms of production efficiency, it seems to produce new goods and services. In terms of economics, capacity utilisation and cost/revenue efficiency are important factors in increasing profits, with efficient medical staff. I thought the hospital looked like a mass production unit: making many copies of products, very quickly, using assembly line techniques to send partially completed products to workers who each work on a single step, rather than one worker completing a whole product from start to finish. Because the whole system is designed to increase the number of patients for medical treatment as well as to produce massive products, the medical staff were overworked. When a social worker was employed, he or she played multiple roles in a hospital and a hospice. Although there are temporary contract social workers and part-time social workers, the worker should have the multiple roles in different areas in the same place.

I followed the workflow and tried to understand different perspectives by walking around the field. The figure below shows my walking route. During my observation I found their roles and work overloaded and came to the same conclusion as a previous researcher. While analysing the data I collected, I had to seek treatment for depression, anxiety and insomnia. My psychological challenges echo those of many social workers and illustrate the profound personal impact of our professional environment. I had originally hoped to interview five social workers, but had to postpone the interviews five times. The reasons varied: some had resigned shortly after the interview was scheduled, while others were simply overwhelmed by their workload. This pattern suggests a worrying prevalence of burnout among social workers, a phenomenon well documented in the literature (Bruera, Higginson, von Gunter, *et al.*, 2021: 728).

Reflecting on these experiences and observations highlights the deep-seated systemic failures and cultural valorisation of self-sacrifice within the health care system. Medical social workers, who are in short supply in hospitals, often find themselves trapped in this oppressive culture, perpetuated by unrealistic expectations. Robin William, a fellow social worker, said that even those who want to enter the field are expected to volunteer indefinitely under these harsh conditions. Such demands not only threaten the well-being of staff, but also risk compromising the quality of patient care, leading to potential errors and diminished interactions with patients.

I conducted individual interviews with 14 senior members of paediatric palliative care teams, representing a range of disciplines and institutions. Each participant, from doctors to social workers, contributed their own perspectives and experiences within the sector. The interviewees and their roles are listed below:

Minho Song and Taeyeon Koo from S Hospital, in their respective roles as physician and interpreter, addressed the clinical and communication challenges inherent to paediatric care.

Jisun Park and Hyewon Jo, pharmacists at S Hospital, underscored the pivotal importance of medication education for CYP with LLCs management in palliative settings.

Minah Kim, Nara Jang, and Taeyeun Shin, registered nurses with specialisations ranging from counselling to coordination, expressed concerns regarding the lack of cohesion in care plans.

Hana Kang, focusing on outpatient services, highlighted the discrepancies between inpatient care and community follow-up.

Vinseok Ryu, Samuel Pyo, and Junsu Son, social workers, elaborated on their roles in connecting various aspects of healthcare.

The results of the interviews collectively revealed a critical insight: the healthcare system often operates on a model designed to maximise patient throughput, but which results in dehumanising working conditions. This approach treats individuals as mere components of a vast, impersonal system, with a focus on quantitative targets rather than the qualitative, holistic well-being of CYP with LLCs. The 14 interviewees reported significant challenges due to overwhelming workloads that hindered their ability to provide comprehensive and thoughtful care in a timely manner.

The pervasive ‘*Ildangbaeg*’ (一當百) mentality, which expects one person to do the work of a hundred, is an example of a form of symbolic violence. This expectation is closely linked to the culture of ‘*Tae-um*’, a term that literally means 'burning one's spirit to ashes'. Such a mindset normalises excessive workloads and undervalues individual health and well-being by promoting relentless self-sacrifice as an essential aspect of work. Within this framework, social workers and other health professionals are portrayed as lone heroes, creating an inherently unsustainable and fundamentally unfair expectation.

6.3 Stage Two: Decision-Making Processes in Hidden Social Determinants of Health

Section 6.3 describes the second stage of decision-making, focusing on hidden social determinants of health such as disinfectants for humidifiers, radon-emitting mattresses, the semiconductor industry and asbestos in schools. This analysis shows how these decision-making processes often overlook the health impacts on children and adolescents that begin in homes, schools, workplaces, neighbourhoods and communities. The mismanagement of hazardous substances is intricately linked to various diseases and complicates decision-making within these hidden social determinants. Despite this complexity, it is essential to understand these processes as they have a significant impact on the health and well-being of children and adolescents in different settings.

6.3.1 Humidifier Disinfectants

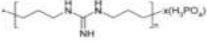
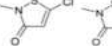
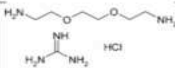
“I can't stand this injustice.” This is the anguished cry of victims of humidifier disinfectants, beating their chests and crying out their deep grievances. At the time, companies often promoted these disinfectants, falsely claiming that they could safely and healthily prevent limescale and bacteria. Deceived into believing they were using an environmentally friendly product, many victims are now suffering from illnesses they have never heard of and feel nothing but pain and injustice.

	Date	Gender	Changed Name	Surrogate	Relation Interviewee	Age at Diagnosis	Age at Interview	Diseases Stages	Rare Disease	Knowing Causes
1	20180517	Female	Jihye Yu	Minho Yu	Father	8	18	2	chronic respiratory diseases	YES
2	20180519	Male	Minji Choi		Patient	18	43	3	chronic respiratory diseases	YES
3	20180420	Male	Jaehyuk Min	Junseok Son	Father	5	17	3	chronic respiratory diseases	YES
4	20180420	Female	Byeolha Park	Dongha Lee	Mother	10	16	3	chronic respiratory diseases	YES
5	20180407	Female	Gayoung Kim	Eunji Choi	Mother	11	21	4	chronic respiratory diseases	YES
6	20180407	Female	Wonjun Choi	Minsu Choi	Father	50 days	died at the age of 50 days	Bereaved	chronic respiratory diseases	YES
7	20180519	Male	Viha Shin	Nari Shin	Sister	15	died at the age of 39	Bereaved	chronic respiratory diseases	YES
8	20180511	Male	Namsu Park	Hyunji Kim	Wife	19	died at the age of 40	Bereaved	chronic respiratory diseases	YES
9	20180514	Male	Seokjin Roh	Hyorin Seo	Wife	19	died at the age of 42	Bereaved	chronic respiratory diseases	YES
10	20180226	Male	Seobin Ra	Seongil Ra	Father	5	15	Survivor	chronic respiratory diseases	YES
11	20180302	Male	Oseong Do	Carin Yoo	Mother	6	15	Survivor	chronic respiratory diseases	YES

12	20180517	Female	Elise Yu	Minho Yu	Father	7	20	Survivor	chronic respiratory diseases & Lupus	YES
----	----------	--------	----------	----------	--------	---	----	----------	--------------------------------------	-----

Table 6-5 Interviews with 12 of 15 Non-Cancer Patients Regularly Using Humidifier Disinfectants

I met victims who had been using humidifier disinfectants since 1994, all of whom had never thought that they were the cause of their illnesses until one day they found out that the products they were using were toxic, and many of whom had to deal with guilt as well as frustration. I found that victims consistently expressed anger and guilt that they had bought the product without knowing it was toxic and used it regularly in their homes.¹⁵ Most people believed that humidifier disinfectants were good for their health and bought them in good faith, but these products caused serious illness or death. The Korea Centre for Disease Control reported in 16th, 4, 2021 that the total number of deaths was 1,653, with a further 5,766 people suffering from lung damage and a wide range of rare diseases directly related to the use of humidifier disinfectant.

Active ingredient	PHMG	CMIT/MIT	PGH
Chemical structure			
Subchronic inhalation NOEC ^a	-	0.34 µg L ⁻¹	-
Subacute inhalation NOEC ^b	0.024 µg L ⁻¹	-	0.024 µg L ⁻¹
Reference concentration ^c	0.00004 µg L ⁻¹	0.0017 µg L ⁻¹	0.00004 µg L ⁻¹
Content of active ingredient in product	0.125%	0.019%	0.5%
Emission rate	25 mg d ⁻¹	3.8 mg d ⁻¹	100 mg d ⁻¹
Steady-state concentration in a bedroom ^d	0.10 µg L ⁻¹	0.016 µg L ⁻¹	0.42 µg L ⁻¹
Risk quotient	2,500	9.41	10,500

^aAbbreviations: PHMG = polyhexamethyleneguanidine (CAS RN 89697-78-9), CMIT = 5-chloro-2-methylisothiazol-3(2H)-one (CAS RN 26172-55-4), MIT = 2-methylisothiazol-3(2H)-one (CAS RN 2682-20-4), PGH = oligo(2-(2-ethoxy)ethoxyethyl guanidinium chloride (CAS RN 374572-91-5). ^bValue taken from ref 5. ^cValue taken from polyhexamethylene biguanide hydrochloride³ (CAS RN 32289-58-0) because of structural analogy. ^dReference concentration calculated using an assessment factor of 600 for PHMG and PGH and 200 for CMIT/MIT. ^eSteady-state concentration calculated assuming an air change rate of 0.2 h⁻¹ and bedroom volume of 50 m³.

Table 6-6 Screening-Level Risk Assessment for Humidifier Disinfectants Added to Humidifier Water

Source from Lee, Kim and Kwon (2012: 2499)

¹⁵ I conducted fieldwork including the observation and interviews humidifier disinfectants' victims and survivors from November 2017 to May 2018, and based on this study, wrote a column titled "Sleeping Humidifier Disinfectants Act, Parliament Responds! Amend the Humidifier Disinfectants Victims Relief Act." Seunghoon Oh, postgraduate researcher at Durham University, UK, 26.04.2018. <https://www.pressian.com/pages/articles/194320>.

These toxicants include PHMG, PGH, CMIT, MIT from humidifier disinfectants have caused a biocidal disaster. Kim, Ahn, Yang, *et al.* (2014: 48) found that “since the beginning of 2006, epidemics of a fatal lung injury of unknown cause in children have been observed every spring in Korea. A recent study showed that this type of interstitial lung disease in children is associated with the use of disinfectant in humidifiers”. According to the Korea Centres for Disease Control and Prevention KCDC (2011: 817- 832), as of 31 August 2011, 28 adults, including 13 pregnant women, had been hospitalised for this unidentified lung disease, which is similar to acute interstitial pneumonia. This is why the doctor was completely devastated by the humidifier disinfectant disaster related to the case study. As of July 2020, the Korea Centres for Disease Control reported 6,817 suspected cases of humidifier disinfectant as a toxic chemical victim: the total number of deaths was 1,553, and 5,264 people suffered from lung injury, bronchiolitis, allergic rhinitis, and so on.

	Total	0-6	7-12	13-18	19-29	30-39	40-49	50-59	60-69	70-
Total	5,770	435	778	529	268	601	937	658	697	713
%	100	8	13	9	5	10	16	11	12	12
Survivor	4,434	171	767	529	248	511	875	528	444	361
Death Toll	1,336	273	19	11	37	92	90	154	280	380

Table 6-7 Survivor and Death Toll due to Humidifier Disinfectants

Source from Social Disasters Commission (2022)

The Social Disasters Commission (2022) reported that about sixty-seven million people were exposed to humidifier disinfectants in the 17 years between 1994 and 2011, but only 6,817 people, who were exposed to humidifier disinfectants, were reported to the government, which represents 1% at best.

Compared to adult groups, 8% of infants and 13% of children are more vulnerable than the 12% by 9%. of old people. While breathing, children are often exposed to dangerous chemicals when using humidifier disinfectants.

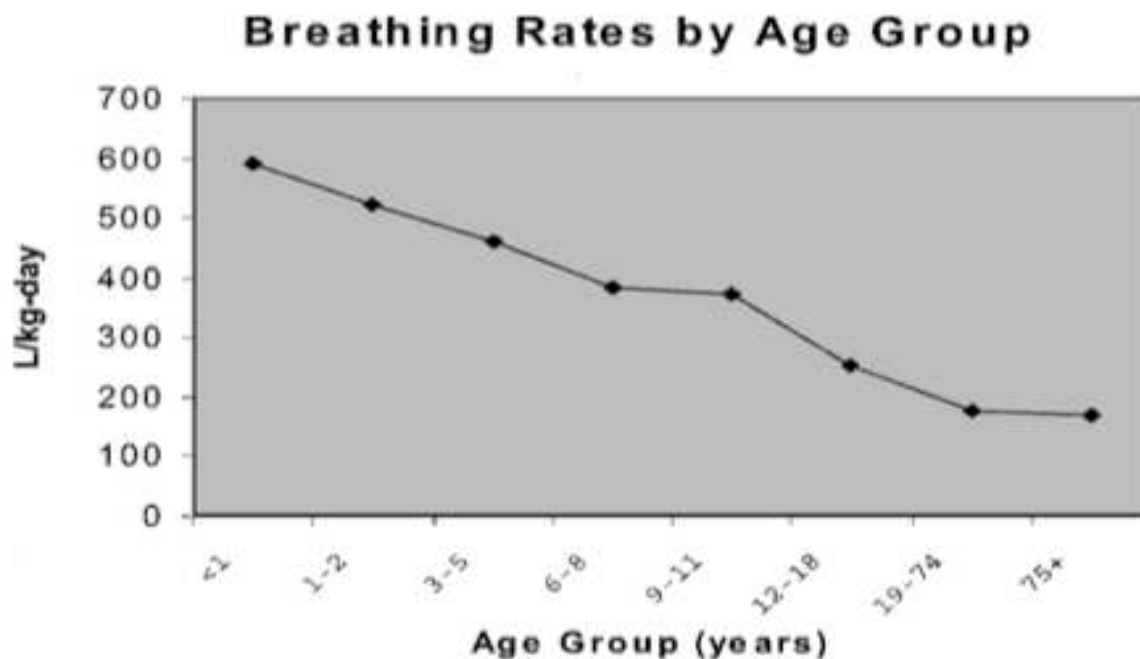


Figure 6-5 Oxygen Demand of Age

Source from Miller, Marty, Arcus, *et al.*, 2002: 405.

According to the Oxygen demand of age in years, children breathe more air per kilogram of body weight than adults. An infant has three times the minute ventilation of an adult, and a 6-year-old almost twice. Having trouble with breathing or a respiratory problem shows because children tend to be physically active. Catrine Tudor-Locke and Robert P Pangrazi *et al.*, (2004) reported that “the selected cut points for steps/day for 6–12-year-olds were 12,000 steps/day for girls and 15,000 steps/day for boys.”

Diseases	Allergic rhinitis	cutaneous condition	Asthma	Interstitial lung disease	Pneumonia	chronic obstructive pulmonary disease	Cardiovascular disease	Liver fibrosis
Estimating populations	340,000	170,000	140,000	10,000	80,000	20,000	7,000	4,000

Table 6-8 Diseases Identified as Associated with Exposure to Humidifier Disinfectants

Source from Social Disasters Commission (2020)

It is clear, therefore, that environmental toxicants found in both the home and indoors (Social Disasters Commission, 2019; 2020), will be delivered to children at higher internal doses than to adults (Kim, Kim, Lee, *et al.* 2015).

Furthermore, Kim, Ahn, Yang, *et al.*, (2013) shows that “children’s interstitial lung disease, also known as paediatric diffuse lung disease, is a diverse group of rare lung diseases that are associated with high morbidity and mortality.” Recently, Leem and Kim (2020) criticise the limited standards of diseases which is based on the victims and the survivors being eligible to receive compensation and medical support because investigations into the victims’ injuries revealed that fatal lung damage was initially reported: knowing an accurate association between humidifier disinfectants and lung injuries was limited evidence. Lee, Kim and Kwon (2012: 1) reported that “even though fatal lung damage was initially reported, investigations into the victims’ injuries revealed that the damage was not limited to the lungs, but that systemic damage was also confirmed.

There are many case reports which include neurologic disorders (ADHD, depression, posttraumatic stress disorder), muscular disorder (exercise intolerance, myalgia), energy metabolism disorder (chronic fatigue syndrome), and immunologic disorder (rheumatoid arthritis) in humidifier disinfectants’ victims.” The cases reported are not identically LLCs, but the reported cases adversely develop the CYP with LLCs. Considering these case reports, involving multi-system involvement in humidifier disinfectants’ victims, they should have required children and youth with special healthcare needs (CSHCN).

Heath Conditions in Children with Special Healthcare Needs (CSHCN)
<p>Attention-deficit/hyperactivity disorder Depression Anxiety problems Behavioural or conduct problems Autism, pervasive developmental disorder, autism spectrum disorder” Developmental delay Intellectual disability Communication disorder Asthma Diabetes Epilepsy or seizure disorder Migraines or frequent headaches Head injury, traumatic brain injury Heart problems, including congenital heart disease Blood problems, including anaemia or sickle cell disease Cystic fibrosis Cerebral palsy Muscular dystrophy Down syndrome Arthritis or joint problems Allergies</p>

Table 6-9 Children and Youth with Special Healthcare Needs (CSHCN)

Source from Bordini and Kliegman (2020: 1073)

Bordini and Kliegman (2020:1073) shows CSHCN¹⁶ have conditions that affect their daily activities and 9 out of 10 CSHCN have functional difficulties in the sensory, cognitive, movement, emotional, or behavioural domains according to Table 6-9.

Case

About ten years ago, I diagnosed one of the adolescent patients with cancer. The patient showed relatively good progress in cancer treatment after proper surgical therapies and external beam radiation therapy. I carried out numerous tests in an attempt to discover the reason for the cancer, however suddenly the patient suffered a relapse, the cancer had returned to their lungs. I had never experienced a case like this, the symptoms worsened, and a few weeks later, the child passed away. I couldn't do anything, totally felt helplessness, and even contemplated dozens of times to quit as a doctor. At that time, I did not know the cause of the child's disease, but recently her mother came to me and asked for the medical record to report the child had been exposed to humidifier disinfectant used in the home. (Minho Song, S Hospital Physicians, 08/01/2018)

Regarding the given case and disaster of humidifier disinfectants, the doctor could not assess what hazardous substances the patient was exposed to, although the medical decision-making for treatment was beneficial.

¹⁶ Kliegman, Robert M., (2019:1073) points that “CSHCN are defined by the U.S. Maternal and Child Health Bureau as those who have or are at increased risk for a chronic physical, developmental, behavioural, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”



Figure 6-6 Toxic¹⁷

Joo, (2022) and Lee (2022a) highlight that “‘Toxi’ is a movie based on the ‘Disaster of Humidifier Disinfectant’ that plunged Korea into shock” The photo is from TF Cinema Review (Lee 2022a)

In-depth interviews were conducted with 24 key stakeholders, each of whom plays a pivotal role in raising awareness, influencing social movements, and enhancing policies to prevent such crises in the future.

- **Min Lee**, a member of the Local New People's Party, employs her political platform to promote more rigorous health regulations for victims.
- **Minji Lee** and **Taeyul Sim**, priests who provide community support and advocate for moral responsibility in health crises.
- **Jiwon Choi** and **Junsu Kim**, primary school teachers, play an invaluable role in educating the younger generation about environmental health.
- **Lucy Baek**, a human rights activist, directs her attention to the rights of victims and campaigns for enhanced health standards.
- **Seokhyun Kwon** and **Gildong Roh**, in their respective pastoral roles, concentrate on legal and social advocacy for medical cannabis and environmental disaster recovery.
- **Gihwan Nam**, **Seohyun Kim** (who appears on two occasions with distinct roles), and **Kyeonghee Hwang** exert influence on health policy, research, and ethical standards at the national level.

¹⁷ On 18 May 2018, the individuals affected by the humidifier disinfectant disaster informed me of an impending film that portrays their first-hand experiences. It is recommended that the film be viewed and that its contents be incorporated into the research report. I was informed that all the interviewees had been interviewed and their narratives had been documented in a video format. However, the release of the film was postponed due to the global pandemic caused by the SARS-CoV-2 virus. I viewed the film while travelling back to the United Kingdom on 3 November 2022.

- **Omar Gi, Jiyeon Jo, Minchul Ahn, Hyeonseo Hwang, and Inna Yoo** serve as political aides and politicians, each contributing to legislative changes and public policy reforms.
- **Jalim Lee, Haerang Na, Dooan Baek, Gilsan Jang, Koretay Baek, Owen Mitchell, Henry Sterling, and Hiroki Takahashi**, possess expertise in social policy, health determinants, and bioethics, which is of importance for the formulation of well-informed and efficacious health policies.

The interviews collectively emphasise the need for comprehensive health and safety regulation and effective decision-making processes. Their insights illustrate the indispensable contributions of diverse professionals in responding to health crises and influencing policies that prioritise public safety and the well-being of vulnerable groups. This incident illustrates the critical importance of robust health and safety regulation and effective decision-making processes in relation to the telling the truth. This case highlights fundamental ethical challenges in surrogate decision making, in particular a significant lack of transparency that led to fatal outcomes, and highlights a widespread systemic inability to protect vulnerable groups. I also found a lack of systems to facilitate decision-making in the context of supportive, palliative and hospice care.

6.3.2 Radon-Emitting Mattresses

During fieldwork on May 10, 2018, I was informed by the Citizens' Centre for Environmental Health about a bed that was emitting radon gas, as reported by the Nuclear Safety and Security Commission (2018). The detection of radon and thoron in monazite, a naturally occurring mineral that releases negatively charged ions when utilised in mattresses and bedding, has generated significant apprehension among Koreans regarding Naturally Occurring Radioactive Materials (NORM). According to press sources, the mattresses of the beds were found to have radon levels of 620 Bq/m³. These mattresses were touted for their health benefits and were covered with anion powders. These levels greatly beyond the recommended standards for indoor usage. Bereaved parents, who lost their child to cancer, coped with grief and found new meaning in living after the death of child, contacted me via Facebook. Between May 2018 and 2020, one individual transmitted a video of his interview, his daughter's death certificate, and a lawsuit against the mattress firm to I using Facebook messaging.¹⁸

¹⁸ Despite **Ando Choi** providing all the necessary documentation, he expressed doubt about when and how this issue would be resolved, like the catastrophe created by the disinfectant used in the humidifier. Upon completing the documentation, I experienced a halt in their research owing to overwhelming emotions of despair and terror when assessing the extensive data, compounded by the challenges posed by the COVID-19 pandemic (20/07/2020 from Fieldnote).

Case

Almost three years ago, my daughter was diagnosed with cancer when she went to the Netherlands as an exchange student. Whilst there, she developed acute leukaemia very quickly and died in October 2017, only a year after being first diagnosed. My daughter was healthy and pretty. After losing my daughter, I have been struggling with depression, and my wife has been suffering more than me. We have used two-bed mattresses since 2009.’ In 202 I bought one more. Not only my daughter, but all my family were suffering from sickness. We realised why when I found out that these radon-emitting mattresses can cause this so sudden death. My wife also had a thyroid gland disease and whilst not having a specific illness, she still had a stroke and is undergoing treatment. (Ando Choi, Jenny Choi’s father, 20/07/2020)

People living in houses and frequenting indoor areas lack social awareness of the risk of radon-emitting mattresses.

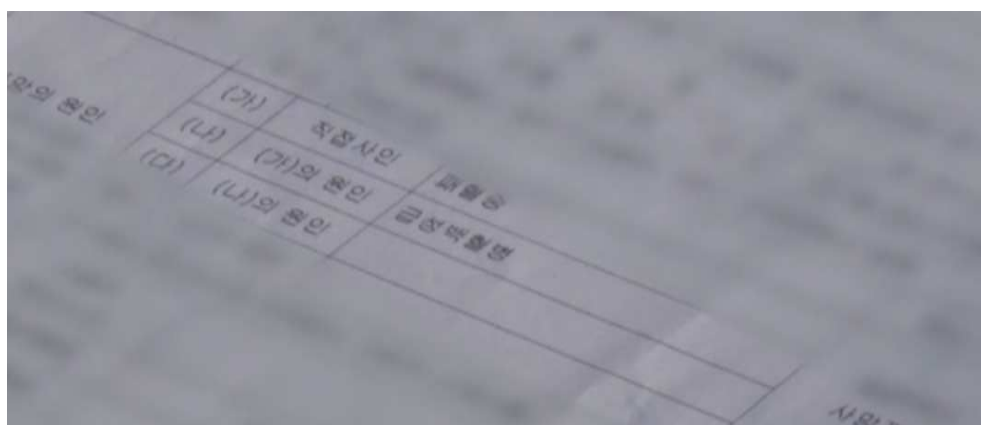


Figure 6-7 Medical Certificate of Death Immediate cause of death: Sepsis/ Causes: Acute Leukaemia
Source from Ando Choi, who shared with me his daughter’s Medical Certificate of Death

While preparing the end of my fieldwork, I read about radon-emitting mattresses, reported in major newspapers in Korea “a company’s bed mattresses emit a large amount of radon.” (Ahn, 2022; Seo, Kang, Lee, *et al.*, 2019; Yang & Kim 2021; Choi and Cho, 2020)



Figure 6-8 Radon-Emitting Mattresses

Source from Hwang, 2018

I found that about 90,000 radon-emitting mattresses were sold, but 70,000 were collected. Most of the users received compensation of about 300,000 won (about 200 pounds) for the collection action (Lee and Kim, 2022; Seo, Ha, Kang, *et al.*, 2019).

However, more than 5,000 people who refused the compensation began a class-action suit against Daejin Company for selling beds mattresses that emitted levels of a radioactive substance that exceed the safety standard (Kim, Kim and Lee, 2020).

No	Names of Products	mSv/Year	Sales Period	Output
1	Green Health 2	9.35"10"14		1,102
2	Neo Green Health	8.65"10"15		7,049
3	New Western Sleeper	7.6"10"18		14,231
4	Moselle	4.45"15"18		1,903
5	Neo Green Sleeper	2.18"10"15		991
6	Western Sleeper	1.94"10"18		36,416
7	Belarus	1.59"15"18		396

8	Power Green Sleeper Platinum	6.61"14"18	2,321
9	Green Sleeper	5.84"10"14	3,689
10	Premium Western (Sleeper)	5.65"10"12	2405
11	Power Twin Plus	3.37"10"15	2157
12	Rose Green Sleeper	2.84"10"14	1523
13	Premium Power Green Sleeper	2.7"10"15	6772
14	(Power Green Sleeper) Lime	2.62"14"18	2933
15	I Power Plus Sleeper	1.9"14"18	1294
16	I Power Green	2.73"14"18	537
17	Arete	3.67"15"18	551
18	Power Plus Pocket	7.48"10"13	599
19	Power Green Sleeper R	13.74"14	344
20	Green Health 1	4.06"10"11	264
21	Power Green Sleeper Hip North	1.37"14"15	270
Total			87,749

Table 6-10 Names of Radon-Emitting Mattresses Source from Nuclear Safety and Security Commission (2018)

Yang Yeon-ho and Choi Mira (2019) mention that the decision came after the Nuclear Safety and Security Commission (NSSC) ordered the company to recall 357 mattresses of six types contaminated with a radioactive material called radon, a carcinogen.

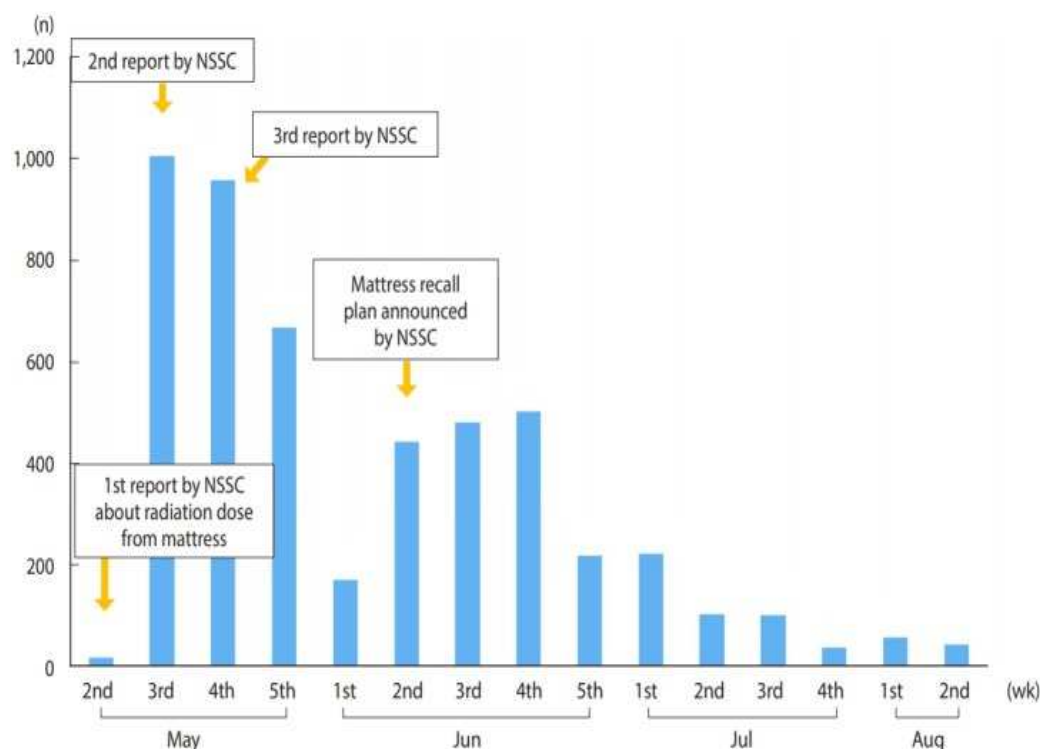
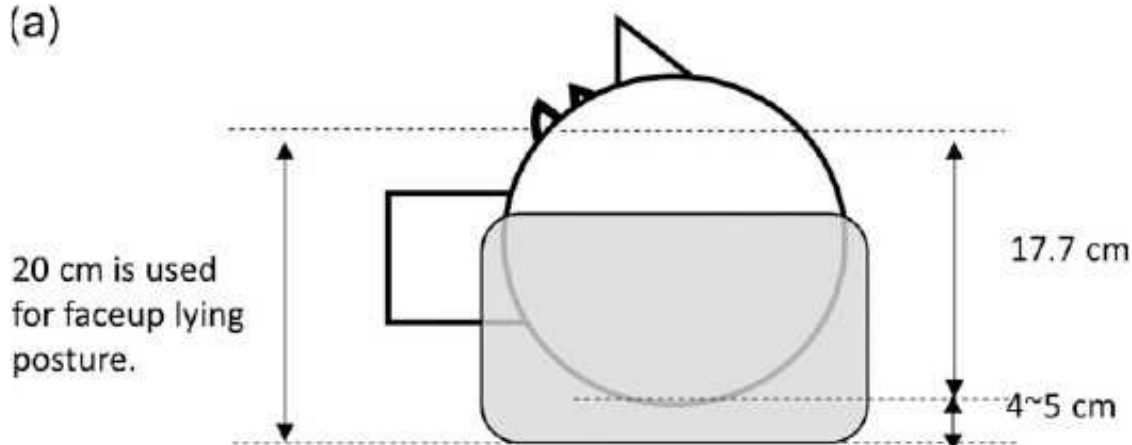


Figure 6-9 “Number of weekly telephone calls for counseling at the Korea Institute of Radiological and Medical Sciences concerning the health effects of using radon bed mattresses. NSSC, Nuclear Safety and Security Commission.”

Source from Seo, Ha, Kang, *et al.*, (2019: 2)

Seo, Ha, Kang, *et al.*, (2019: 1) mention that “radon is a naturally occurring radioactive material formed by the slow decay of uranium and thorium. Radon is a carcinogen and is the second leading cause of lung cancer.” The radon levels were up to 9.3 times above the tolerance standard.

(a)



(b)

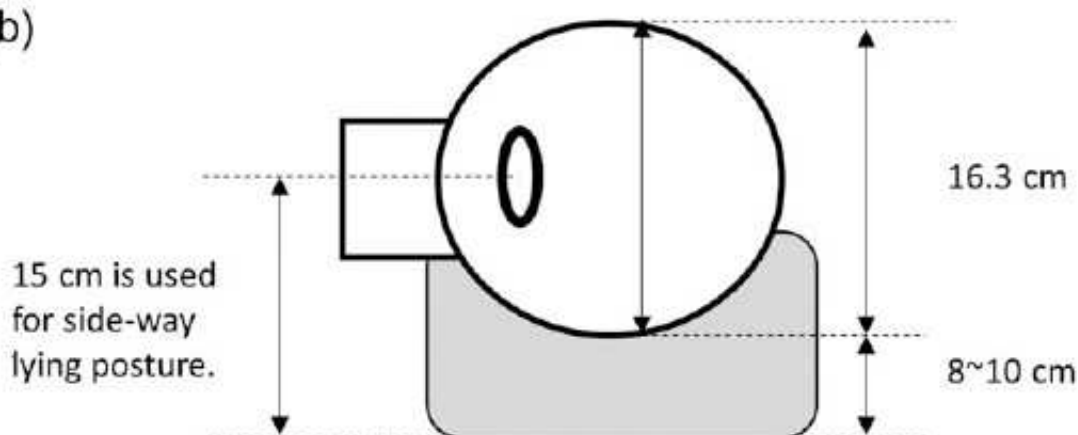


Figure 6-10 “Height of Mouth and Nose During Sleep, Excluding Subject Below 7 Years of Age.”

Source from Kim, Jeong and Shin (2019)

Kim, Jeong and Shin (2019) reveal that CYP with LLCs may be taken external exposure by radiation emitted by progeny radionuclides in uranium and thorium, and internal exposure through the breathing of radon progeny radionuclides produced in the decay chain. Thus, in this study, age specific dose conversion factors ($\text{mSv y}^{-1} \text{Bq}^{-1}$) by external exposure and dose conversion factors by internal exposure ($\text{mSv y}^{-1} \text{per Bq m}^{-3}$) were derived.

The Nuclear Safety and Security Commission (2020) reported that the Republic of Korea court has ordered the countr”s largest mattress manufacturer to compensate customers for health problems caused by toxic chemicals emitted from its products. The chemicals, including formaldehyde and benzene, were found to be 10 times higher than the legal limit. The case could pave the way for similar lawsuits in the country. The prosecutors investigating the case were unable to establish a direct causal relationship between the use of radon-emitting mattresses and lung cancer.

It said authorities would check how the companies are handling the matter. It added that efforts are underway to conduct radon testing on various consumer products to safeguard public health better.

		N	%
Total		180	100
Gender			
	Male	49	30
	Female	131	70
Age(until 2017 year)			
	~19	5	2.8
	~29	5	2.8
	~39	35	19.4
	~49	62	34.4
	~59	45	25.0
	~69	24	13.3
	70~	4	2.2
Duration of Exposure			
	~5 years	101	56.1
	5 years~	79	43.8
Type of cancer			
	Thyroid	74	41.1
	Breast	35	19.4
	Lung	25	13.8
	Leukemia	11	6.1
	Stomach	9	5.0
	Others	26	14.4

Table 6-11 Diseases that are Associated with Radon-Emitting Mattresses

Source from the Nuclear Safety and Security Commission, 2020

In terms of epidemiology, the Nuclear Safety and Security Commission (NSSC) shows the number of diseases that are associated with radon-emitting mattresses, is significant although the figures are different. Therefore, social awareness on the risk of radon exposure may relatively remain low despite the mismanagement of hazardous substances. Furthermore, the lack of decision-making processes to support CYP who need special care in addition to primary care, while ignoring SDOH and the management of hazardous substances, illustrates the critical importance of robust health and safety regulation and effective decision-making processes in relation to telling the truth. The incident illustrates serious ethical issues within surrogate decision making processes, particularly the failure to provide essential information, which had fatal consequences and highlighted the systemic neglect of vulnerable people. In addition, my findings indicate a complete lack of established systems to support decision making in supportive, palliative and hospice care.

6.3.3 Working Areas: Semiconductor Industry

Prior to commencing the fieldwork, I examined primary testimonies provided by Helen Clark, a representative from Semiconductor, and Jim Moore, a representative from IBM, both situated in the United Kingdom and the United States. Both were diagnosed with cancer following their careers in the semiconductor industry. These testimonies were included in the book '*Challenging the Chip*', which has been translated into Korean. After finishing fieldwork at the children's cancer unit in the morning, I attended a public hearing on Tuesday, November 28, 2017, till 10am. The discussion took place in the small, original conference room of the National Assembly and was attended by some victims and survivors from the semi-conductor sector. I began establishing a rapport in order to conduct an interview with one of the translators involved in the "*Challenging the Chip*" project. While she is not officially affiliated with the association known as Supporters for Health and Rights of People in the Semiconductor Industry (SHRPS), she assisted my recruiting interviewees. This setting allowed me to establish rapport with one of the translators of '*Challenging the Chip*.' Although she was not officially part of SHARPS, her assistance was instrumental in facilitating my recruitment of interviewees. The individuals from SHARPS, who played a pivotal role in providing support and advocating for the rights and well-being of semiconductor workers, included:

- **Eunji Ahn**, an expert in the field of occupational and environmental medicine, was responsible for the provision of medical assistance and counselling services to those affected by the incident.
- **Namsuk Roh**, a lawyer committed to the advancement of legal advocacy for the rights of these individuals.
- **Chulsoo Kim**, an activist who has made significant contributions to the promotion of awareness and the advancement of victims' rights.
- **Mina Kang**, a Certified Public Labour Attorney, is responsible for ensuring that labour rights are upheld and that workers receive the justice they deserve.
- **Taeyul Sim**, a member of the Walking Church, offers spiritual and community support to the workers.
- **Owen Mitchell**, a Senior Science and Technical Advisor at the UN, emphasises the pervasive nature of the challenges faced by semiconductor workers, noting that comparable issues are prevalent among industrial workers across the globe.

The collective endeavours of these individuals have not only shed light on the personal and systemic challenges encountered by individuals in this industry but have also propelled significant social movements aimed at reforming industry practices.

20180401	Female	Seondeok Kim	David Kim	Father	19	died at the age of 22	Bereaved	YES
20180228	Female	Deborah Oh	Hanna Park	Mother	19	40	Survivor	YES

Table 6-12 Impact of Semiconductor Industry Exposure on Cancer Case¹⁹

In my interactions with the group, I was introduced to key figures such as Seondeok Kim and Deborah Oh, who represent the deeply personal and poignant narratives of those directly affected. Seondeok Kim, who tragically died at the age of 22, and Deborah, who continues to live with the consequences of her exposure, are two such individuals. These accounts highlight the pressing necessity for a comprehensive grasp of the socio-economic factors that exert a disproportionate influence on young women, often of high intelligence, who find themselves assuming the role of primary breadwinners shortly after completing high school due to familial obligations.

In examining the decision-making processes of those in the semiconductor industry with long-term occupational exposures CYP with LLCs, it becomes evident that the interconnectedness of occupational hazards, societal expectations, and the broader socio-economic dimensions that influence the lives of these workers must be acknowledged. This necessitates a global perspective in addressing these challenges.

The interviews were primarily conducted at the protest site of the Supporters for Health and Rights of People in the Semiconductor Industry, which is situated next to Samsung's headquarters in Gangnam Station.

Case

My daughter was one of the top-performing students in the second year of high school. Her schoolteachers and the principal would often recommend her to student's careers working at the semiconductor factory of Samsung. When my daughter was about to graduate high school, she had to choose between going to college or getting a job at S semiconductor. She decided to follow a career working at the semiconductor factory, however, whilst working there she

¹⁹ Although I used a name generator, I carefully selected pseudonyms based on the unique characteristics of each participant, choosing names inspired by historical figures. I informed the interviewees of these choices and they expressed satisfaction with the names chosen. For some people, I chose names that reflected their stories and meanings. 1) Seondeok Kim: This name reflects her dignity and resilience in the semiconductor industry. 2) David Kim: Named after the biblical David who fought Goliath, this name symbolises a father's fight for justice against a corporate giant like Samsung. 3) Deborah Oh: Reflecting the biblical judge known for her wisdom and courage, this name honours her commitment to human rights activism. 4) Hannah Park: Named after her biblical counterpart known for her sacrifice and resilience, Hannah's name highlights her empathy and shared struggles with her child.

was diagnosed with a brain tumour. After many tests the medical staff advised she would require surgery, I asked what side effects there might be to surgery. They did not say she would end up disabled, however, they said... there was a 90% chance of her entering a vegetative state. (The lady broke down in tears when describing the situation) I sent her into surgery, it was in the morning at 9:13 am. I went to see her 10 pm that night at the ICU. They had tied up her arms and legs. The nurse told me that “she’s so strong, she was thrashing around enough to break the ICU bed, so we restrained. her” But you know what, I was so grateful to hear this. Because a vegetable cannot thrash around. (Hanna Park, Deborah Oh’s Mother, 28/02/2018)

Considering the case, working in the semi-conduct industry is a large, diverse, and dynamic industry, continually changing new developments in technology. However, in terms of occupational safety and health, Jeong-Ok Kong, (2012: 32) insists that there is not enough information known about the chemicals used in the electronics industry although worker” health hazards caused by chemicals in this industry have been taken seriously. According to Supporters for Health and Rights of People in Semiconductor Industry (2023), the number of workers’ illnesses is 497 and the deaths toll hits 199 from the electronic industry in the Republic of Korea by identifying and reporting the victim’s family members and/or survivors.

Company		Items	Report	Death
Samsung	Samsung electronics	Semi conductor	335	88
		LDC	90	22
		Sub Total	425	110
		Mobile phones, TV, Home Appliances	77	31
		Samsung electronics Total	502	141
	Samsung electro-mechanics	PCB, Electronic Components	25	17
	Samsung SDI	Cathode rays (Braun's tube) for Television, PDP, Electronic Components	60	16
	Techwon, SDS, etc	IT Modules, Panel PC, etc	9	6
Affiliates of Samsung Group(Electronics industry) Total			596	180
Non-Samsung	SK Hynix, ATK, Fairchild, Seoul, LG electronics, etc		90	16
Equipment Companies, Plumbing subcontractor			10	3
Total			696	199

Table 6-13 Reporting the Number of Workers’ illnesses of the Victim’s Family Members and/or Survivors

Source from Supporters for Health and Rights of People in Semiconductor Industry (2018)

In fieldwork, I met some survivors and victims' family members and conducted interviews about their decision-making processes which are largely based on their memories and experiences of individual workers of semiconductor factories. Most workers are young females, who come from quite remote areas, who through this type of work become bread earners in the family and giving up on higher education. There are two groups. One has been seriously injured or killed while working in electronics production. The other group, pregnant women in electronics production and being exposed to various chemicals, their children either in their neonatal state, or upon birth, were often diagnosed with rare diseases or which developed at a later stage.

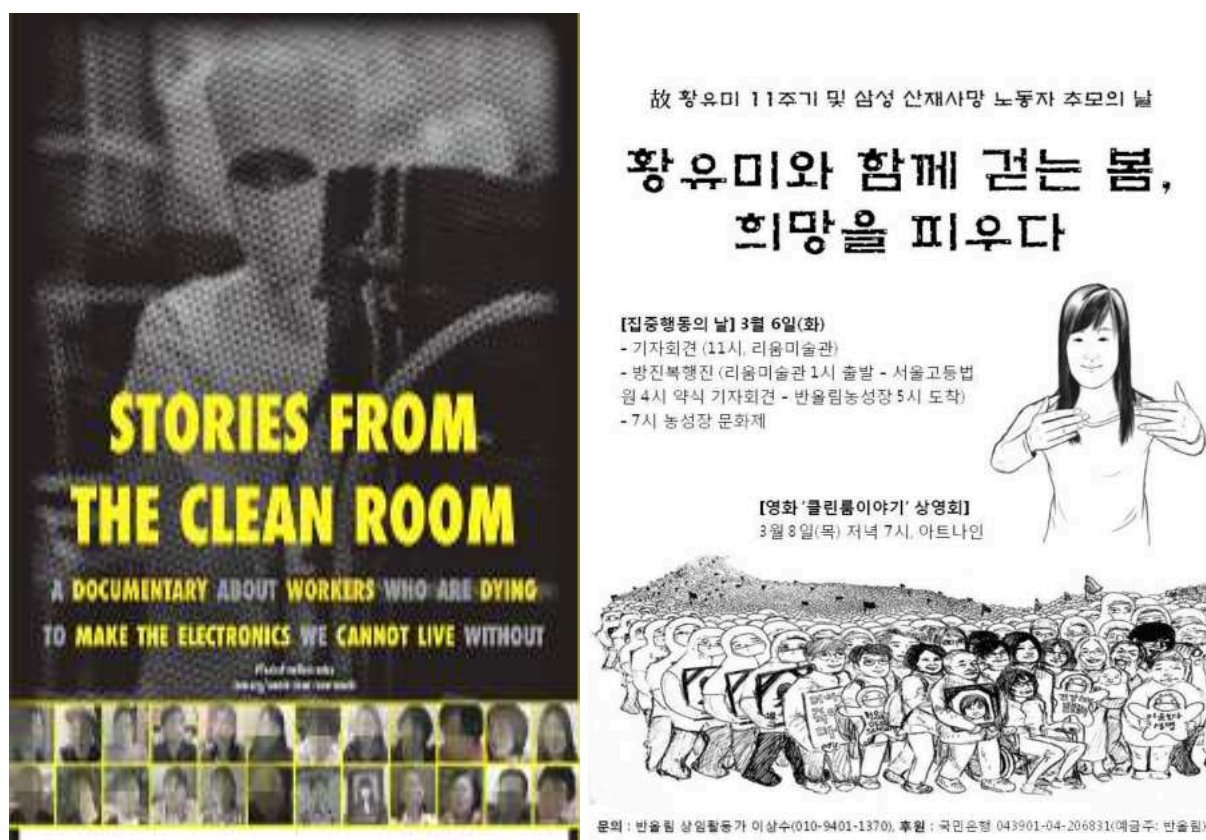


Figure 6-11 Stories from Clean Room (Joseph, 2017) and “the 11th anniversary of Hwang Yumi's death from leukaemia at work and the Samsung Workers' Memorial Day.”

The experiences of global screenings of “Stories from the Clean Room,” a documentary film that sheds light on the health risks faced by workers in the electronics manufacturing industry. The film features personal stories of workers and the impact of hazardous chemicals on their health. The article

highlights the importance of raising awareness about these issues and advocating for better working conditions and protections for workers in the industry.²⁰



Figure 6-12 Another Promise “I will never give up you as I am father”

This is a South Korean film which depicts the story of a single father struggling to make ends meet while caring for his daughter, who suffers from a serious illness. The father works in the electronics manufacturing industry and develops cancer as a result of his exposure to hazardous chemicals in the workplace. The film sheds light on the impact of the industry on workers' health and the need for better protections and working conditions.

Moreover, I analysed Stories from Clean Room which provides vivid testimony from 21 former workers, spouses and parental survivors (IPEN, 2017) and Another Promise which is a 2014 the Republic of Korean film based on the true story about the legal battle between Samsung and its

²⁰ On 6th March, to recognise the 11th anniversary of Hwang Yoo-mi's death and the memory of Samsung workers who died in industrial accidents, I wore anti-dust cloths and participated in a march from Lium Museum of Art to the SHAPs sit-in from 11am to 7pm. Hwang Yoo-mi began working at Samsung Semiconductor's Giheung facility in October 2003, during her third year of high school. Unfortunately, she passed away on 6 March 2007 at the age of 23, after being diagnosed with acute myeloid leukaemia just one year and eight months later. Approximately 100 individuals participated in the march, which served as both a familial gathering and a social initiative. I viewed the documentary “Stories from Clean Room” (Joseph, 2017) alongside the locals on Thursday, March 8, 2018, at 7:00 PM.

employees who had been seriously injured or killed working in electronics production (Supporters for Health and Rights of People in Semiconductor Industry, 2014).

I also went to a children's cancer hospital to conduct field research, and one of the parents told I that she works in the semiconductor field and her daughter is currently being treated for leukaemia. Although I did not conduct a study to investigate the causal relationship between the disease and the industrial site, he said that she would investigate this further and look for similar cases (Fieldnote, 8th January 2018).

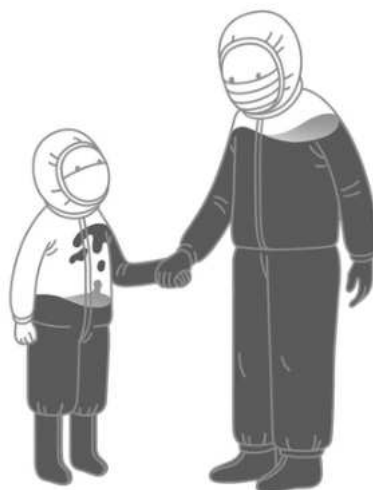


Figure 6-13 Workers Gave Birth to Children with Congenital Diseases

Im, (2014) reports that “Samsung Electronics semiconductor workers gave birth to children with congenital diseases as a result of exposure to hazardous substances during their working period. They applied for occupational disease recognition for their second-generation diseases.” Illustration by Jo Jae-seok (2014).

Case

Ellie Pearson had worked at the S Electronic Onyang plant for over 7 years, starting in 1991. Ellie explained: I worked on the production line coating semiconductor chips to protect them. There were many danger labels, such as skull and crossbones. Colleagues and I would often discuss whether the environment was really dangerous (skull and crossbones signs were quite scary). There was always a pungent smell coming from the production line, we would often say “this must be bad for us.” Just after I started working there, they had a massive shutdown of the production line. We were told to

evacuate the factory immediately, but after returning we were just told not to worry. I left the company when I was 3 months pregnant, I was in childbirth for over 4 hours, and when my child was born it had to undergo an emergency operation for an enlarged congenital colon. (Lee, 2022b)

Case

“Ms. Jung Mi-sun (pseudonym) resigned at 7 weeks pregnant. She had worked for 8 years at S Semiconductor’s Giheung and Onyang plants, where she worked on the mould line that applies a black coating to package chips. She worked without a dust mask in the black dust. She melted epoxy resin at temperatures over 180 degrees to mold the chips, which emitted strong smells and heat. During the early stages of pregnancy, when major organs of the fetus are formed, she was heavily exposed to harmful substances. Her son’s face swelled on the third day after birth, and he couldn’t move his bowels. He was diagnosed with congenital megacolon, a disease in which the end of the intestine becomes enlarged due to the inability to perform intestinal movements. He had to undergo surgery at S N Hospital to remove his hardened intestine-like cement. Ms. Jung also received diagnoses of thyroid cancer, rheumatism, epilepsy, and underwent surgery for cervical dysplasia.”. (JTBC, 2021)

Chronic diseases/ Life threatening disease	Cleft Etiologies
	Congenital Urinary Tract
	Occipital Lobe Epilepsy
	Aplastic Anemia
	Diabetes (type 1 and type 2) in children
	Hirschsprung disease
	Congenital Immunodeficiency Disorders Syndrome
	Heart Disease in Infants and Children

Table 6-14 Parents who have Children with LLCs and Used to Work in Electronics Production at Onyang,

Source from Kitak Im and Seunghoon Oh, 2014

Based on the healthcare system and holistic assessment (Im, 2014) there should have been a process to manage hazardous substances and enhance telling the truth about them.

In addition, the victim’s family members and/or survivors should have been supported (Eun, 2022; Lee, 2022), but there is no guidance on supporting and intervening in decision-making processes

for CYP with LLCs who need special care in addition to primary care, while ignoring SDOH and the management of hazardous substances²¹, demonstrating the critical importance of robust health and safety regulation and effective decision-making processes in relation to telling the truth. This situation revealed critical ethical failings in surrogate decision making, characterised by a transparency gap that had fatal consequences and highlighted systemic failings in the protection of vulnerable people. In addition, my research showed that there is no effective system to support decision-making in supportive, palliative and hospice care.

6.3.4 Asbestos-Contaminated Schools

Since November 2017, I have met with Gilsan Jang, a social worker investigating the humidifier disinfectant catastrophe. I had dinner with him and talked about his role in the investigation. He told me a story that changed his life.

Case

My father was diagnosed with asbestosis²² and passed away. Although I could not do anything at that time, I would like to prevent similar cases. At that time, I did not know what happened to my father, but recently I found many buildings, especially schools containing asbestos ... Upon discovering this I decided to participate in this social movement as a social worker. (Gilsan Jang, Social Work and Social Determinants of Health, 20/05/2018)

²¹ SHARPS, (2023) presents “The "Urging for Proper Enforcement Decree on Fatal Occupational Disease Law" Press Conference discussed the opinions of various individuals and groups on the issue of occupational diseases in South Korea. The speakers expressed concerns about the current enforcement decree, with labour attorney Jo Seung-kyu and Lee Hyang-choon, head of the Medical Solidarity Headquarters, criticising it for not fully reflecting potential harmful factors. Lee Tae-eui, deputy director of the Korean Confederation of Trade Unions, condemned the Ministry of Employment and Labour for not conducting adequate epidemiological research. Kim Eun-suk, a mother of a child with a congenital disease due to fatal occupational disease, emphasised the need for recognition of fatal occupational disease.

²² NHS (2020) defines “asbestosis is a serious long-term lung condition caused by prolonged exposure to asbestos. Asbestos is a whitish material that was used in buildings for insulation, flooring, and roofing in the past, but is now no longer used. While asbestos can be dangerous, it doesn't present a health risk if left undisturbed. But if material containing asbestos is damaged, it can release a fine dust that contains asbestos fibres. When the dust is breathed in, the asbestos fibres enter the lungs and can gradually damage them over time.”

Kelson's actions exemplify the evolving role of social workers, who are now engaged with community health issues on a broader scale. This entails not only addressing immediate social needs but also confronting significant public health challenges. The social worker investigates nearby communities living with hazardous substances, but asbestos is a Group 1 carcinogen set by the World Health Organization. The use of asbestos has been banned in Korea since 2009 (Kim, 2009).

In addition to Gilsan Jang, other professionals such as Gildong Roh, Vice-Chairman of the Environmental Network Social Disasters Commission, and Koretay Baek from Primary Health and Social Determinants of Health are also engaged in comparable initiatives. The collective endeavours of these professionals illustrate the expanding scope of social work, underscoring its critical role in addressing complex health determinants and advocating for safer living environments. Through engagement with Gilsan Jang, Social Work and Social Determinants of Health, Gildong Roh, Vice-Chairman of the Environmental Network Social Disasters Commission, and Koretay Baek from Primary Health and Social Determinants of Health, I was able to gain crucial insights into the issue of asbestos-contaminated schools. These professionals have been instrumental in identifying and addressing the health risks associated with asbestos in educational settings, underscoring the significant impact of environmental hazards on public health. Their dedicated efforts have not only raised awareness but also driven advocacy and action towards the creation of safer school environments for children and staff alike. Shin, Son, Hong, *et al.*, (2008): 287-294 investigated the materials containing asbestos in school buildings and the quantities of asbestos. Asbestos is easily found in everyday life. This is because building materials containing asbestos have been widely used since the 1970s and asbestos has excellent tensile tolerance and flexibility, and are cheap insulating materials, lagging materials and roof material (slate). The incubation period for diseases caused by asbestos is about 10 to 35 years, and a minimal amount of inhalation can cause more fatal diseases to children and adolescents than to adults. Most CYP spend their time in schools. Many primary schools have been built using asbestos, therefore the danger to health is obvious.

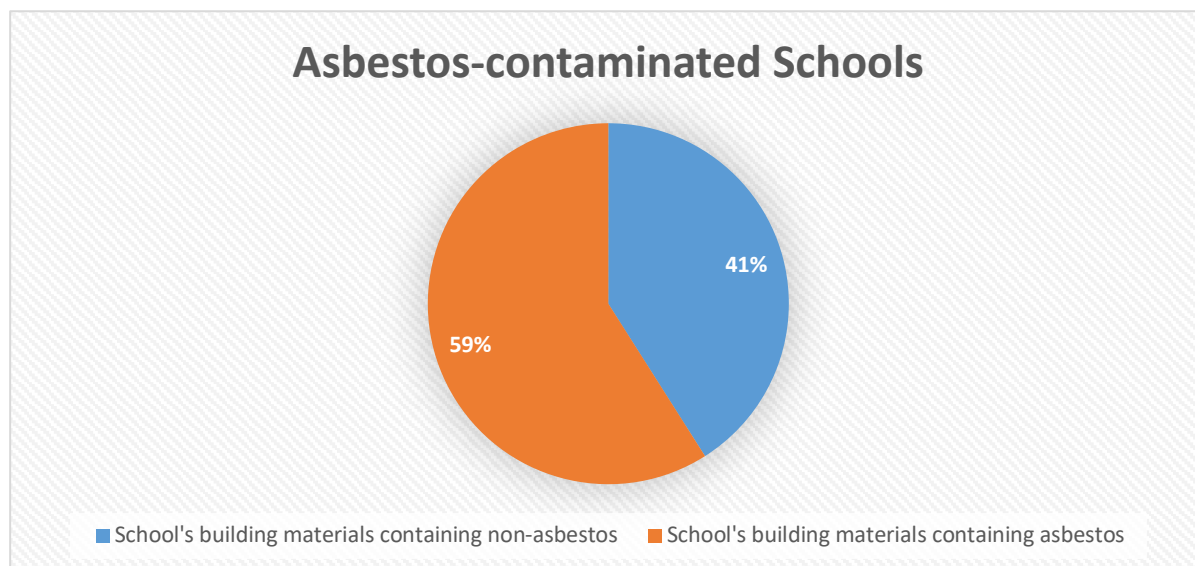


Figure 6-14 Asbestos-Contaminated Schools Pie Chart

Source from Asian Citizen's Center for Environment and Health and Ban Asbestos Network Korea, 2018

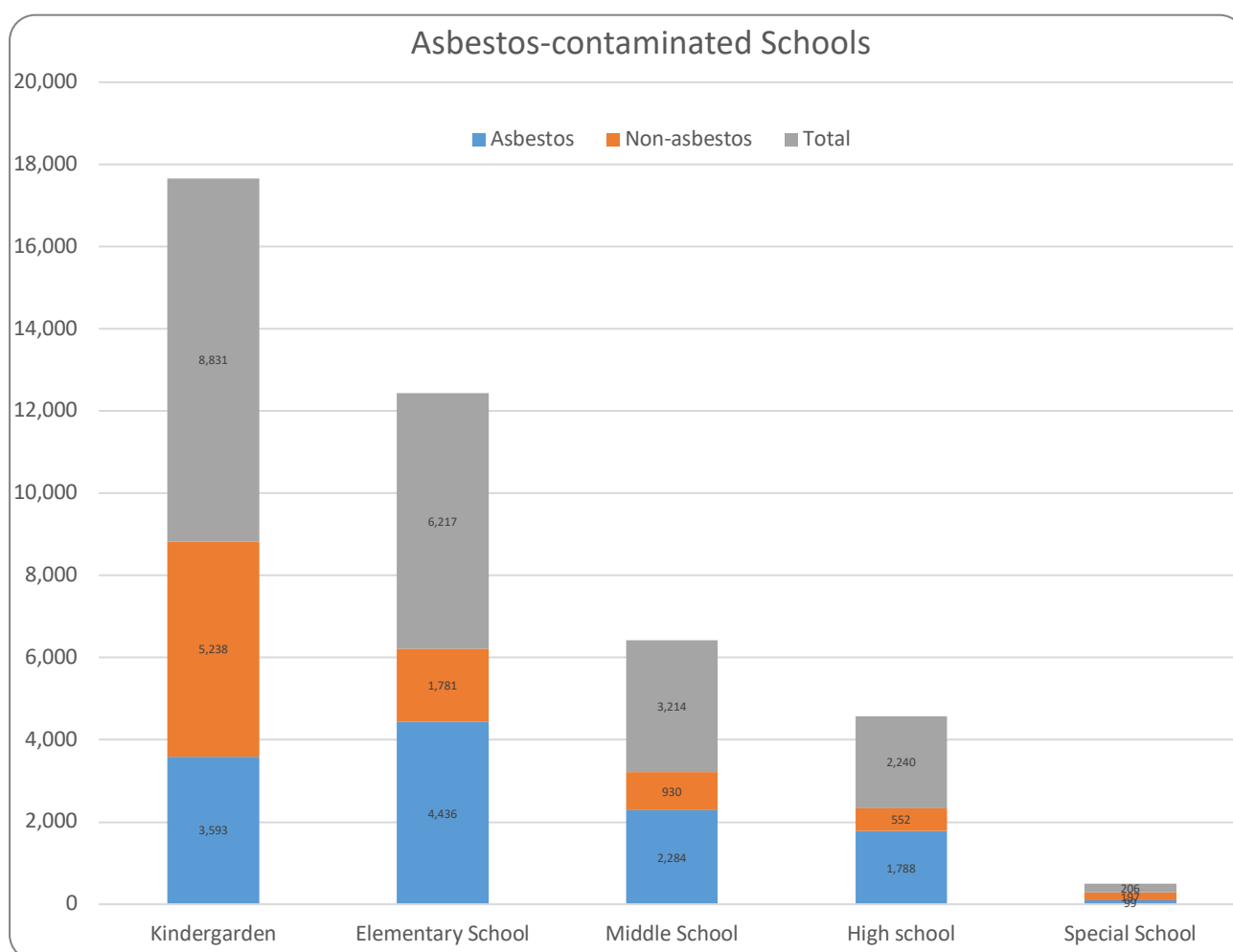


Figure 6-15 Asbestos-Contaminated Schools Bar Chart

Source from Asian Citizen's Center for Environment and Health and Ban Asbestos Network Korea, 2018

Asian Citizen's Centre for Environment and Health (2018) reported according to the Ministry of Education data, as of December 2017, 12,200 schools among 20,808 kindergartens, elementary and junior high schools, and special schools nationwide are asbestos schools. This represents 59%, and as many as 6 out of 10 schools are asbestos-contaminated buildings.

Social awareness on the risk of asbestos exposure remains low, and CYP with LLCs who stay longer in school do not know about the risk of asbestos. While planning, the mismanagement of hazardous substances and the SDOH should have been included in decision-making processes. Children require more oxygen than adults (Miller, Marty, Arcus, *et al.*, 2002: 405): when children breathe in asbestos fibres in schools over many years eventually this may cause scarring of the lungs. Therefore, considering the social awareness, the decision-making processes may lead to the unexpected situation although pursuing CYP with LLCs for the best interests. I emphasise the paramount significance of stringent health and safety regulations and efficient decision-making processes concerning telling the truth. I emphasise the paramount significance of stringent health and safety regulations and efficient decision-making processes concerning telling the truth.

6.4 Luck, Social Determinants of Health, or Oppression?

This section critically examines expectations of the role of the paediatric palliative care social worker, luck, social determinants of health and oppression at the structural level of decision making. At the structural level of decision making, not only is the role of the paediatric palliative care social worker unclear, but expectations are also higher. In terms of needs, I will consider some questions about how and why people attribute luck, social determinants of health or oppression to decision-making processes. At the structural level of decision-making processes, I will interpret the findings in terms of Emmanuel Levinas' phenomenology of violence and Pierre Bourdieu's symbolic violence. In understanding the limited options, the nature of the puzzles of surrogate decision making can reveal and distinguish between happiness, SDOH and oppression in the hidden web of decision-making processes.

6.4.1 Expectations from Paediatric Palliative Care Social Work?

At the structural level of the decision-making process, the role of the paediatric palliative care social worker is not clear in the Republic of Korea. However, according to the Association of Palliative Care Social Workers (APCSW, 2016) and Jones (2006), paediatric palliative care social workers seek to improve the care received by children and their families by providing information and emotional support for the decision-making process in a multidisciplinary palliative care team, including advance care planning, psychosocial and spiritual support, pain and symptom management, care at the time of death, financial burden on families of CYP with health care needs, funeral planning, respite and bereavement care.

Montreuil and Carnevale (2016: 8) present that the concept of children's agency has been applied to various circumstances regarding the role of paediatric palliative care social work for the patient's agency (Parker Oliver, Washington, Demiris, *et al.*, 2012: 4). Although the role of paediatric palliative care social work is not clear in the Republic of Korea, they have already been known to promote such practices amongst individuals, groups, and communities. Social work is not just about individuals and their families, but also the development of social policy and practice, influence change at three levels: micro, mezzo, and macro (Gwyther, Brennan & Harding, 2009).

At the structural level of decision-making processes, the role requires inter-agency and agencies. Ruth Gardner (2003: 137-138) suggested the following levels of cooperation in inter-agency policy planning and production: "communication, consultation, collaboration, bilateral planning and joint planning." Gardner (2003: 139) identified critical success factors for collaboration such as 'commitment and leadership in each organisation, good communication within and between collaborating agencies, consultation, training, time for planning and reflection and an infrastructure to provide these key elements of support'.

6.4.2 The Limitations of the Role and Ethical Challenge?

Regarding stage one as ethical challenge, paediatric palliative care social workers are oppressed. They should consider how to assess the risk and contribute to improving the quality of life for patients, there are limitations of assessment: who will assess the oppressed workers? To understand "the structural causes of social problems" (Adams, Dominelli, and Payne, *et al.*, 2009: 53; Smith, 2008b),

paediatric palliative care social workers should ponder what they face as a vicious circle in neoliberalism, but palliative care coordination in the community. Parker Oliver, Washington, Demiris, *et al.*, (2012: 4) pointed out that “the ambiguous nature of the role of social work in hospice care is due in part to the lack of standardised assessment across the hospice setting,” but in Korea, there is no palliative care coordination in community, and they cannot accommodate cooperation between inter-agency and agencies.

In addition, the separate assessment does not meet to understand the whole decision process regarding hidden SDOH. Even though the web of oppression was reported by individuals, families, communities, institutions, hospitals, and palliative care staff are linked with political, economic, social, and cultural aspects in decision-making processes. When the forms of oppression are hidden, blind luck is also hidden until unexpected results occur, and then they have their own interpretation. Considering the unpredictable results of surrogate decision-making, the substituted judgment standard is inevitable, and then an agency or inter-agency within the medical field will be taking praise or blame. Thus, there is no distinguishment between luck and the forms of oppression in the structural level of decision-making processes.

Not surprisingly, in supporting life-limited children and their families in “holistic and multi-disciplinary” approaches to paediatric palliative care, (Brown, Warr and Shribman 2007: 27).” A social worker should have pondered multi-disciplinary processes in the medical field. However, when some roles between medical team members overlap, I asked some social workers and then they answered me by saying that: *“That role is not mine but that of a medical doctor, so we just follow the given workload due to overworking hours.”* (Samuel Pyo, S Hospital Social Work, 17/05/2018)

The social worker faces three main barriers: overworked healthcare providers, insufficient provider training and incapable tracking of CYP with LLCs through the structural decision-making process. Because of this reason, I dedicated around 10 to 12 hours per day and 60 to 70 hours per week to conducting fieldwork and interviews.

However, the excessive workload exacerbates the problem of social workers failing to recognise the importance of paediatric palliative care within the context of neoliberalism, resulting in a damaging cycle of marginalised social workers and an inefficient bureaucratic system. Furthermore, the hidden forms of oppression are ignored when deciding on CYP with LLCs. Before defining

oppressive and non-oppressive decision making, I found that social workers and parents in paediatric palliative care have limited knowledge of surrogate decision makers. Social workers and parents in paediatric palliative care situations should understand those surrogate decision makers who did not understand why they had limited options in the decision-making process, but also internalised oppression when deciding for CYP with LLCs. For example, parents are confronted with different points in the decision-making process and the agreed transfer plan involving a hospital, school, community services and the family. Dominelli (2002: 8-9) emphasises that oppressive relationships are about limiting the range of options that subordinate individuals and groups can readily exercise. When making decisions about CYP with LLCs, it is essential to provide information about the different options and to support decision-making processes. However, there are no holistic approaches for surrogate decision-makers and their child or young person with LLCs. Unsurprisingly, there is no discussion of the overlap with multidisciplinary approaches in the medical field.

Therefore, social workers in paediatric palliative care cannot identify the ethical dilemmas that arise in surrogate decision making in terms of social injustice. Finally, they cannot reflect on ensuring safety, improving quality of life, avoiding futile treatments and pursuing the best interests of CYP with LLCs.

6.4.3 Blind Luck in Decision-Making Processes?

In stage one, the more difficult question is whether prudent parents might question the uncontrollable conditions of luck in the medical field when choosing CYP with LLCs. This is because not only are unexpected outcomes seen as luck, but blind luck can also cause serious conflict between a patient and a prudent parent due to the limitations of decision making in stage one.

Surrogate decision-makers are unable to see the vicious circle of neoliberalism in the decision-making process. Fragmented care, unnecessary duplication of services and inadequate training in paediatric palliative care all contribute to overburdened health professionals and unclear responsibilities. This critical situation calls for a thorough reassessment of roles and responsibilities in transitional care settings. Such an assessment is essential to address the inefficiencies and ethical dilemmas inherent in the current system. In terms of interpretation and context in decision-making processes, surrogate decision-makers believe that outcomes are linked to good or bad fortune. Interestingly, when making decisions for the best interest, they are unable to control blind luck when

planning ahead, which often involves blind luck and risk. This is because the outcomes have not yet happened and they believe their decision is going well. Planning ahead is not just about making decisions about advance care plans and advance decisions to refuse treatment, but can also include making funeral arrangements and a will (Macmillan Cancer Support, 2017; National End-of-life Care Programme, 2011; Henry N. Pollack, 2003: 13).

However, regardless of the given planning, there is an unexpected structural level of decision-making processes, and then luck can be understood as good or bad in terms of interpretation and context. Liu (2021: 85) insisted that “deciding by blind luck means exercising less control over outcomes.”

I traced the surrogate decision-makers pathway as to how they had access to information on the disease and participated in the process of decision-making, such as: starting the unknown journey, the unknown treatments, and the unknown end-of-life. In terms of EBM, palliative care staff provide certain information for patients and their family members, but they cannot ensure the result with responsibility. In the context of Emmanuel Levinas's philosophy, taking responsibility for ‘the Other’ implies an ethical imperative that should guide healthcare transitions. It suggests moving away from a fragmented approach, influenced by neoliberal priorities, towards an integrative model. This model would prioritize the best interests of CYP with LLCs, ensuring their care is both continuous and coordinated. This shift is essential for escaping the vicious circle of decision-making driven by neoliberal imperatives that often prioritise efficiency over individual care needs (Levinas, 1981: 300). Levinas's concept of responsibility extends beyond the mere provision of information to patients and their families. This entails healthcare professionals to reflect on the ethical implications of their decisions and actions, acknowledging their responsibility towards the Other in their entirety, extending beyond the clinical context. This shift is crucial for circumventing the vicious circle of decision-making driven by neoliberal imperatives, which frequently prioritise efficiency over individual care needs. In this sense, Levinas proposes a more compassionate and continuous engagement with the Other, rather than a utilitarian approach that reduces care to mere outcomes.

Two groups, one who knows the root cause of illness and the other, who does not, showed entirely different pathways after their child passed away. Both groups required more support in their decision-making processes, particularly when faced with unknown or unclear information about the illness. My observations revealed that decision-makers in both groups often sought additional guidance, but they struggled with a lack of sufficient resources and clarity. For the group without a clear understanding of the illness, this lack of knowledge exacerbated their difficulties, leading to greater emotional and ethical stress. Levinas’s notion of responsibility underscores that even amidst

uncertainty, surrogate decision-makers are ethically driven to act in the best interests of the child. However, without adequate support from the healthcare system, their ability to navigate this challenging process is compromised.

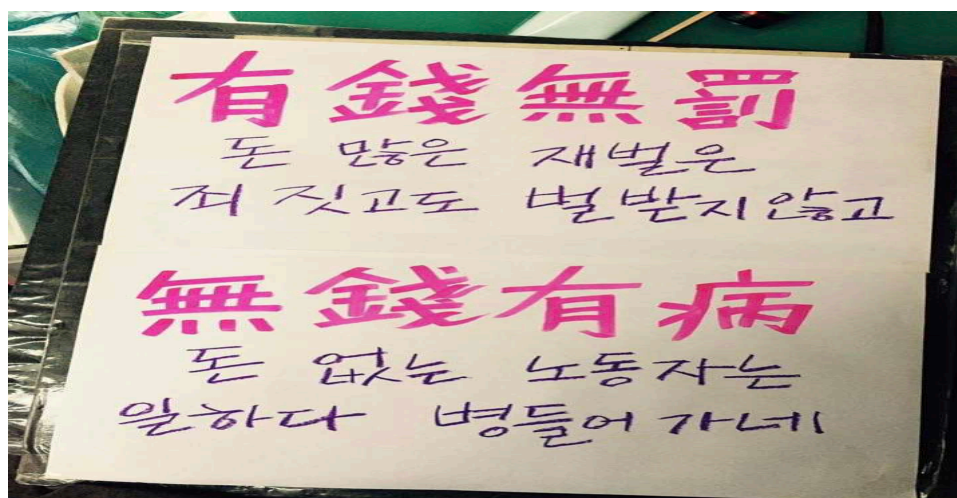


Figure 6-16 Rich chaebols are not punished for their sins, while poor workers get sick from working.

On 13 February 2018, I photographed the following phrase at a protest rally for workers injured and killed in a semiconductor industrial accident: “*Rich chaebols are not punished for their sins, while poor workers get sick from working.*” (Fieldnote, 13th February 2018). It revealed that many people are oblivious of the fortunate circumstances behind the electrical devices they use, as well as the happiness that seems to depend on luck. After fully comprehending the underlying causes, surrogate decision-makers display reluctance in accepting evidence-based medicine due to their own doubts.

The factors of blind luck, hidden social determinants, and forms of oppression remain unseen by surrogate decision-makers. Yet, they continue to strive to act in the best interests of the child under their care. Levinas (1969: 194) argues that ethical responsibility does not stem from full knowledge but rather from the act of responding to the Other, even amidst uncertainty. Despite these hidden forces, the weight of their decisions is heightened by the inherent complexity and ambiguity they face.

6.4.4 Hidden Social Determinants of Health?

Examining both blind luck and various cases of luck in decision-making are related to hidden social determinants. In stage two, exploring the decision-making processes in hidden SDOH is not only too difficult, but also understanding both environmental exposure and/or hazardous substance-

related diseases and knowing the root causes are complicated. Due to hidden SDOH, risk and luck in surrogate decision-making are possibly connected to perplexing problems or unexpected results.

This is because they cannot easily understand environmental exposures and/or diseases related to hazardous substances. As understanding toxic substances is closely related to telling the truth and health under oppression, I explored the mismanagement of toxic substances related to diseases in the home, workplace and school, and identified the hidden social determinants. Every year, at least 6,000 vulnerable people face an unwanted journey, making difficult choices and pursuing their best interests, but facing unexpected consequences. According to Emmanuel Levinas' phenomenology of the face of the other as the phenomenology of violence, the face of CYP with LLCs is directly asking for ethical demands; while their face is ignored and experiences real violence due to the hidden SDOH and hazardous substances. This is because the face of the other asserts the commandment: "You shall not kill".

Due to complicated environmental exposures and/or diseases related to hazardous substances, they blamed themselves, the government and others when they had poor outcomes. Even when they have good outcomes, their decision-making processes have already started in the hidden SDOH. In terms of risk analysis, uncertainty and rational decision making, exploring the practical implications of moral luck for decision making involves risks and uncertainties. Hidden mismanagement of hazardous substances ultimately leads to the worst decision outcomes for CYP with LLCs, even though they consider the best interests. As responding to the face of the other is an unreflective encounter with social and ethical responsibility, best-interest decision-making processes should have removed risks and considered health determinants. Although the understanding of both SDOH and hazardous substances is deeply connected to telling the truth and children's health, the decision-making processes ultimately lead to serious consequences while living in the face of the other. Planning for children's and adolescents' health begins in homes, schools, workplaces, neighbourhoods and communities, and is linked to a wide range of important issues that are not always addressed in decision-making processes.

Since surrogates did not concern and prepare for the worst results, they faced numerous barriers, especially the two groups who either knew the rooted cause of illness or did not. When exploring the structural level of decision-making processes, I found three hidden SDOH hindering to shared decision-making such as overworked healthcare providers, insufficient provider training and insufficient tracking of CYP with LLCs.

Therefore, because of the hidden information, finding the evidence of hazardous substances is not easy, and their decision-making processes eventually face brutal violence. Their understanding of hidden SDOH is related to the structural level of decision-making processes.

6.4.5 Oppression as Symbolic Violence?

The structural level of decision-making processes is linked to the free market through privatisation and deregulation: including stages one and two. Medical professionals and surrogate decision-makers have their own ‘misrecognition’ (Pierre Bourdieu, 1984: 86). Given the way in which symbolic violence is internalised within educational and social institutions, which makes it a pertinent analogy for health care settings, medical staff and surrogate decision-makers have not considered and prepared for the most unfavourable outcomes at the structural level of decision-making processes (Pierre Bourdieu, 1996: 32; 265-266).

In stage one, I found three main types of symbolic violence that hindered shared decision-making, such as overworked health care providers, inadequate training of providers, and inadequate tracking of CYP with LLCs through the structural decision-making process. Due to misunderstandings, medical staff accepted the decision-making processes in a vicious circle. In addition, surrogate decision makers were unable to recognise the multifaceted nature of the problem, which created major barriers to decision making when aggressive or futile treatments were highlighted. I reflected that three main symbolic violations are associated with overworked health care providers, inadequate training of providers, and inadequate tracking of CYP with LLCs by taking paediatric palliative care under neoliberal policies and distorted health care transitions (Pierre Bourdieu, 1996: 95-97).

In addition, because of the misperception of health in Stage Two, proxy decision-makers who know the root cause of illness face numerous barriers related to hidden SDOH and the biocide disaster in homes, workplaces and schools. According to the World Health Organization (2008), SDOH are “the conditions in which people are born, grow, work, live and age, and the broader set of forces and systems that shape the conditions of daily life”.

According to the two stages, two conceptual models such as "barriers and facilitators" (Boland, Graham, Légaré, *et al.*, 2019) and “discrimination” (Thompson, 2003; 2016) cannot explain the complex decision-making processes. The questions acknowledged that environmental causes and oppression were omitted, but people investigated some justifications and the soundness of the proxies.

Unsurprisingly, the emphasis was on individual choice and responsibility, and on the structural level of decision-making processes. For example, one of the main arguments is that we need to identify which of these principles should take precedence in each case. In the case of LLCs, it is common to question the soundness of the proxy in making decisions on behalf of the CYP.

Finally, one of the fundamental issues has led me to question the extent and nature of surrogate decision making under conditions of limited choice and oppression. Surrogate decision makers cannot anticipate outcomes and ensure the best interests of CYP with LLCs due to environmental exposures and/or hazardous substance related illnesses. In this way, interlocking systems of oppression as symbolic power leave individuals with the ‘responsibility’ to make their own decisions.

Therefore, oppression as symbolic power in stages one and two has been developed in neoliberal policies, distorted health care transitions and hidden SDOH. Since understanding this dynamic system of symbolic power is much more complicated, symbolic power at the structural level of decision-making not only supports neoliberalism, but also ignores holistic approaches to supporting decision-making and entails symbolic violence.

6.5 Conclusion: The Structural Level of decision-making processes- Oppression in the Hidden Social Determinants of Health of Decision-Making Processes

This chapter presents the structural level of decision-making processes: there are two levels, such as decision-making processes in a vicious circle and decision-making processes in hidden social determinants in Chapter 6. Since oppression at the structural level is defined as how oppression is institutionalised in society, I have explored oppressive decision-making processes in hidden social determinants, blind luck or oppression.

In section 6.2, I present stage one which is decision-making processes under a vicious circle. When exploring the processes of paediatric palliative care, there are complicated factors that are hidden, such as paediatric palliative care under neoliberal policies, distorted healthcare transition, lack of paediatric palliative care education, and struggling with work overload without responsibility.

Section 6.3 illustrates stage two as decision-making processes in hidden SDOH such as humidifier disinfectants, radon-emitting mattresses, the semiconductor industry and asbestos-contaminated schools. The decision-making processes ignored the fact that the health of CYP begins in their homes,

schools, workplaces, neighbourhoods and communities. The mismanagement of hazardous substances is linked to various diseases and the complicated decision-making processes in hidden social determinants, although decision-making processes can relate to the health of CYP, which starts in the homes, schools, workplaces, neighbourhoods and communities.

In terms of the structural level of decision-making processes, I interpreted the findings based on Emmanuel Levinas's Other and Pierre Bourdieu's symbolic violence in section 6.4. To find out about the decision-making processes of CYP with LLCs, I thought carefully about the structural level of decision-making processes: some questions about how and why people thought that luck or oppression was related to decision-making processes. To uncover the hidden web of oppression in decision-making processes, the role of paediatric palliative care social worker does not fit into the working conditions and the expectations are higher.

Furthermore, to explore the expectations of social workers and the role in paediatric palliative care in relation to decision-making processes for CYP with LLCs, I found that social workers did not recognise paediatric palliative care in neoliberalism as linked to a vicious circle of oppressed social workers and a bureaucratic system. They could not ensure safety, improve quality of life, avoid futile treatments and pursue the best interests of CYP with LLCs.

To discover the ethical challenges in the ethos of surrogate decision making, I showed that blind luck is hidden and unknown when surrogate decision makers consider the best interests, whereas there was no concept of blind luck, hidden social determinants or the hidden forms of oppression that had to be unfolded in two stages. Without an understanding of social inequality, I showed that decision-making processes cannot be focused on the structural level of decision-making, that oppression is institutionalised in society, and that interlocking systems of symbolic power leave individual choice and responsibility to struggle with.

The structural level of decision-making therefore reveals oppression in the hidden social determinants of health. Chapter 7 will highlight more individual choice and responsibility by focusing on the family-oriented level of decision-making processes. I explore the given issues that are relevant to how children with LLCs and their family members begin their journey.

Chapter 7: Family-Oriented Level of Decision-Making Processes: Blind Luck, and/or Ensuring Shared Decision Making?

7.1 Introduction

In this chapter, I will present the decision-making processes for CYP with LLCs in relation to paediatric palliative care and understanding the family-oriented level of decision-making processes. The findings from the literature review and from my fieldwork are related to ethical challenges which are associated with the rights of CYP, standards of decision-making, informed family consent, and ethical challenges of family-oriented decision-making, based on the following that:

- 1) to find out what are the processes of decision for CYP with LLCs: the family-oriented level.
- 2) to explore the expectations of social workers and the role in paediatric palliative regarding the processes of decision-making for CYP with LLCs.
- 3) to discover the ethical challenges in the ethos of surrogate decision-making.

To explore the findings from the field, I then move on to describe how many people face the unwanted journey as surrogate decision-makers in sections 7.2 and 7.3. In this section I will show what they face during the unwanted journey for their child with LLCs, focusing mainly on the medical and family-oriented perspectives. The family-oriented level of decision-making processes in Chapter 7 will present the complications of paediatric decision making, understanding the holistic journey that follows 1) diagnosis or recognition, 2) ongoing care and curative treatments, and 3) end of life. Exploring the unknown journey to a decision is presented in section 7.2. In this section I explore two types of diagnosis, difficult conversations about important news, and the timing of transition. While section 7.3 focuses mainly on the arduous journey that leads to a decision about a surrogate, many parents caring for a child with LLCs are unfamiliar with making decisions for their child. They do not know how to begin their arduous journey as surrogate decision makers.

In 7.4 I will present the expectations and ethical challenges for paediatric palliative care social workers when shared decision making for CYP with LLCs can be divided into three parts: curative

treatments, non-curative treatments and healthcare transitions such as hospital, hospice, home, school and community.

I conducted a total of 79 face-to-face interviews with parents and members of palliative care teams, including 50 interviews with cancer patients, 15 interviews with non-cancer patients, and 14 interviews with senior members of paediatric palliative care teams. The purpose was to explore how they support the best interests of CYP with LLCs and the role of luck or oppression in decision-making processes.

Section 7.5 will explore the unknown end-of-life of CYP with LLCs. In terms of the family-oriented level of decision-making processes, I will interpret the findings based on the Other from Emmanuel Levinas and authority from Polanyi and Neo-Confucian family-oriented decision-making processes. This section will present the limits of shared decision-making processes such as lack of consulting time, not enough places, and different perspectives of the best interests for CYP with LLCs, despite the importance of each of these stages.

7.2 Stage One: Into the Unknown Journey

In this section I will show what they face during the unwanted journey for their child with LLC, focusing mainly on both medical and family-oriented perspectives. Exploring two types of diagnosis helps to understand the unwanted journey. When people know the outcome of the diagnosis, this section explores the sharing or breaking of bad news before making important decisions, namely 1) diagnosis or recognition, 2) ongoing care and taking curative treatments, and 3) end of life.

I will then describe the process of moving from hospital to home or from a local hospital to a tertiary hospital. Shared decision making for children with life-limiting conditions can also be divided into three parts: curative treatments, non-curative treatments and healthcare transitions such as hospital, hospice, home, school and community.

Next, I will explore the process of knowing the outcome of the diagnosis, how to share or keep the bad news, knowing about transfer and liaison between hospital and community services. As this is the starting point for thinking about decision making, I will explore people embarking on the unknown journey, what they face and the choices available to them to support CYP with LLCs.

7.2.1 The Two Kinds of Diagnosis

Based on the total paediatric deaths such as the infants with 41.3 %, children with 21.3% and adolescents with 37.4% (Kim, Lim, Kim, *et al.*, 2017), there are two kinds of diagnosis: a clearly defined diagnosis and an undefined diagnosis. There are two main groups of children with life-limiting conditions: those with cancer and those with non-cancer conditions. In cancer centres for children, caregivers typically receive the diagnosis of their child's condition approximately two weeks to two months after the child first exhibits critical symptoms or signs of illness and following clinical assessments and evidence-based medical practices.

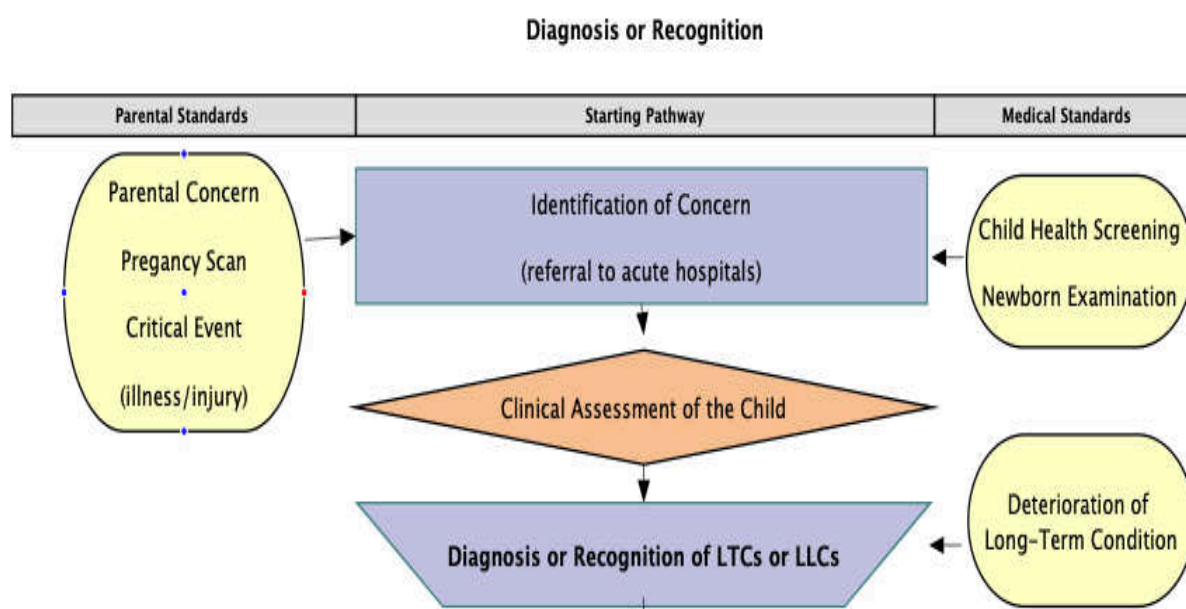


Figure 7-1 Starting Pathway: Diagnosis or Recognition of LLCs or LLCs:

Seunghoon Oh has adapted and expanded upon the framework originally presented Widdas, Street, Edwards, *et al.*, 2013.

In contrast, the diagnosticians of rare diseases, who are defined in fewer than 20,000 patients or those with an unknown prevalence, are struggling with the knowledge of the diagnosis. Because of the lack of information, diagnosis tools, and treatment options; research into discovering expert diagnosis is very challenging. According to the Korean Undiagnosed Diseases Program (KUDP) which was launched in January 2017 through a pilot project, there are four categories in the KUDP: I (undetermined due to the lack of medical and laboratory information), II (clinically undiagnosed with

low awareness), III (genetically undiagnosed due to extreme genetic heterogeneity or clinical diversity), and IV (unknown knowledge) (Kim, Lee, Lee, *et al.*, 2019: 68).

Furthermore, regarding cancer or non-cancer groups, it is crucial not only to know about the result of diagnosis but also the root causes of the diseases, based on social epidemiology. If the source of the main cause of rare diseases is discovered, there is a requirement to define social epidemiological factors and have long periods of evidence-based medicine. I investigated cases where the cause of illness was known and cases where it was not. Specifically, I met, interviewed and observed victims and survivors of hidden SDOH, such as air humidifiers, radon-emitting mattresses, the semiconductor industry and asbestos-contaminated schools.

However, without knowing the cause of the disease, most families and patients make the best decision to return to their daily lives, but when the social determinants of health are revealed, the lives of victims and survivors become more miserable. Instead of preparing for a more complex and challenging life, they sometimes engage in social behaviours that make life more difficult, and they see more of their lives disrupted and suffer. Worse still, it was difficult to see what good outcomes could easily be achieved, because the fact that the health of CYP begins at home, at school, at work, in the neighbourhood and in the community was hidden in the decision-making process. I found that survivors were finding it harder to return to normal life, and that families of the dead were demanding greater punishment from governments and corporations. I also found that victims' families and survivors experienced and appreciated the comfort they received from participating in social action with many citizens. I also experienced a sense of helplessness and unspeakable anguish while interviewing victims and survivors of hidden social determinants of health and observing their social behaviour, sometimes crying alone in the bathroom after interviews (Fieldnotes 2017 and 2018).

In the case of cancer, there are direct links to people diagnosed with leukaemia or other rare cancers who worked in the semiconductor factories. However, most of these factories have been relocated, making it very difficult to prove the causes of the diseases. Although there are many factors that need to be considered to prove the cause of the disease, it takes a lot of time and effort to find the evidence. For example, in the non-cancer group, one of my interviewees in the non-cancer group, after seeing the news about the toxic humidifier disinfectant that was classified as a biocide disaster, realised that the unknown death of her son was directly related to this event, even though it was 20 years later. (DiGangi, 2019). Once the causes of the illnesses were discovered and proven, the lives of the patients, if they were still alive, and their families were significantly changed (DiGangi, 2019).

Moreover, knowing the root causes, people are eager to find the answer to how to eliminate many difficulties. There is a huge gap between knowing and not knowing the causes of rare diseases, which undermines models of decision making, supportive decision making and interventions in palliative care. Finally, informal carers of a child with a rare disease often have to wait a relatively long time for the outcome of the diagnosis due to the difficulty of diagnosis. In these circumstances, the paediatrician or health professional may be reluctant to discuss this with the family. In order to provide appropriate decision-making and supportive palliative care, both formal and informal caregivers should be prepared for any unexpected events that CYP with LLCs may encounter as they embark on the unknown journey.

7.2.2 Diagnosis: Breaking or Keeping Bad News?

In semi-structured interviews with bereaved families who had lost their child with LLCs and non-bereaved families whose child had survived with LLCs, there were 50 families where the child had been diagnosed with cancer and 15 families where the child had not been diagnosed with cancer. Each family shared with me their experience of their child's or young person's diagnosis, how it changed their lives and described the overwhelming and devastating moment when they discovered the terrible truth. After learning the result of the diagnosis, CYP with LLCs and their family members experienced many changes. Based on my observations and interviews with health professionals, I found that knowing the results of the diagnosis requires essential virtues and sensitivity. I carefully considered a probing question: *“When did you know or recognise the disease?”* Although this is a simple question, they experienced great difficulty in coming to terms with the reality of the diagnosis.

If the diagnosis is given to the parents rather than the child or young person with LLCs, there is also the question of whether or not the child or young person knows. Some children or young people may have been given a diagnosis of a named condition by doctors or their parents, but most have not. According to Together for Short Lives (2013: 17), ‘at any point, the diagnosis or recognition of a life-limiting condition should be communicated to the family with the same level of care and sensitivity as for children whose prognosis was clear from the outset’.

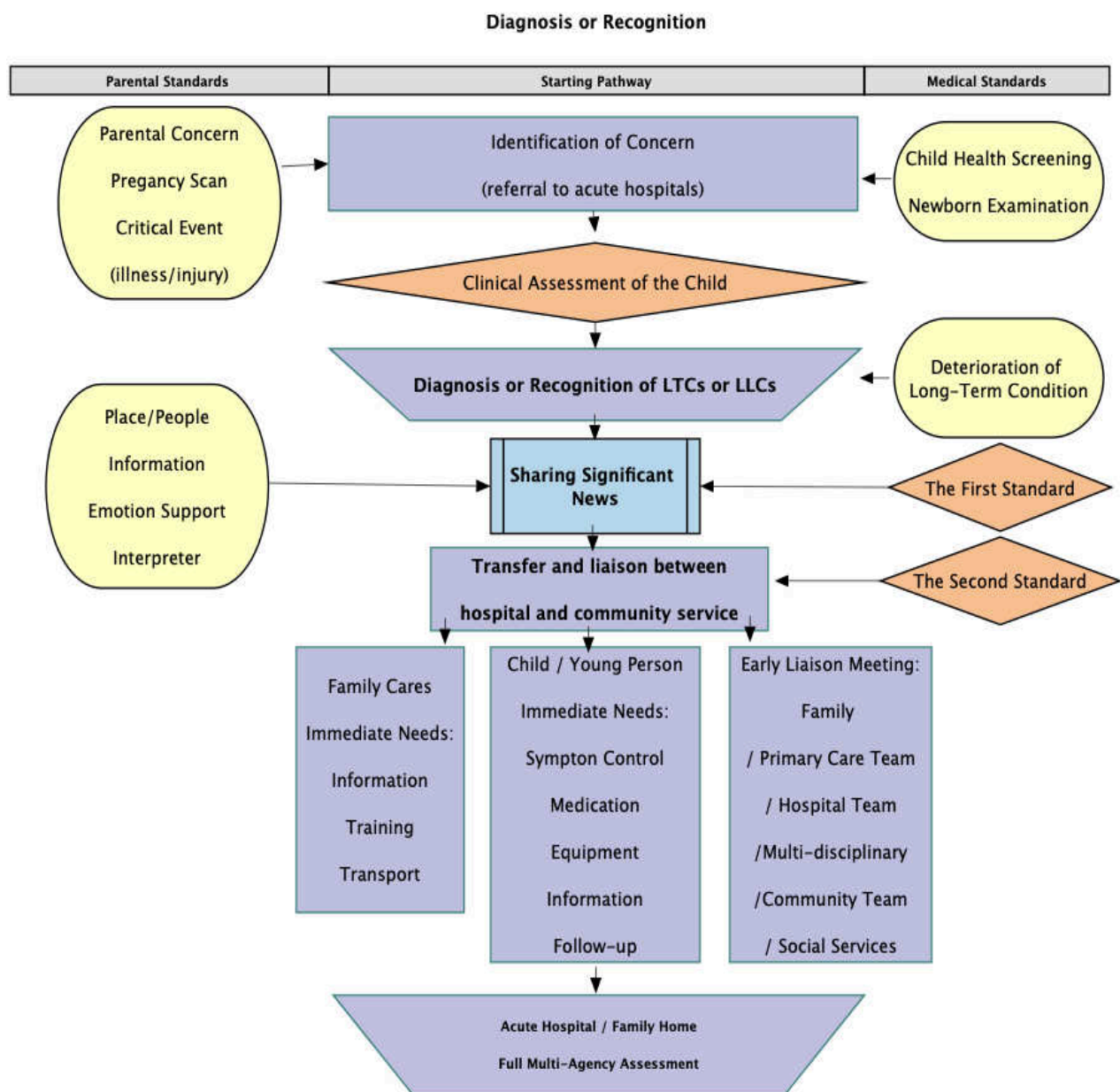


Figure 7-2 Diagnosis or Recognition

Seunghoon Oh has adapted and expanded upon the framework originally presented Widdas, Street, Edwards, *et al.*, 2013.

According to Together for Short Lives, (2013: 19), there are six keys' goals for the prognosis of sharing significant news:

1. News should be shared in a face-to-face discussion in privacy.

2. Written information should be provided to support verbal communication.
3. Emotional support should be available to families when significant news is being shared.
4. Information conveyed should be easy to understand for the individual.
5. Parents should be treated with openness and honesty.
6. If possible, families should be together to receive the news.

In reflecting on the six fundamental goals of optimal care, I identified a significant barrier as face-to-face interviews with parents - including 50 with cancer patients and 15 with non-cancer patients - only three families had fully informed their children about the diagnosis. A common theme emerged from the interviews: all parents understood the importance of informing their children about serious diagnoses, but they consistently expressed a preference for waiting until recovery was more certain before discussing it. By delaying treatment with openness and honesty, CYP with LLCs are already acknowledging their circumstances. One notable case was that of Sophia Taylors, who was diagnosed with leukaemia at the age of 18 and survived to the age of 22. She courageously confronted her mother, saying: *'I know I have leukaemia, so please don't be too sad'* although six months of effective treatment had passed, and she was still under observation. Even when their families are aware of the medical information, I contended that these young people's lack of direct involvement in understanding their own medical histories restricts their autonomy and makes it more difficult for them to actively participate in their lives. Through semi-structured interviews, a recurring theme of isolation emerged: families from all walks of life, whether dealing with the agony of loss or navigating the complexities of living with LLCs, expressed a profound struggle to access supportive communities willing to buffer their psychological distress. Sophia Taylors echoed this sentiment poignantly: *'I wish someone had told me what to expect with chemotherapy and what treatments were coming up. It would have been so helpful to have the support of someone who had been through it. It was incredibly hard to feel alone and isolated.'*

In 14 interviews with senior members of paediatric palliative care teams, all respondents concurred that it was of paramount importance to inform the child. Nevertheless, there was no consensus regarding the optimal timing for this disclosure. Although parents of CYP with LLCs face challenges in communicating in private face-to-face conversations, a paediatric doctor said that that *'their children were at an age when they would quickly forget their experiences and what was happening in their lives'* (Fieldnotes: 2017 to 2018) Through interviews with healthcare providers, I discovered that the cure rate for childhood malignancies is very high and sharing in a private face-to-face discussion

is not emphasised. However, I discovered that childhood cancer survivors use their smartphones in the hospital to access information that was previously unknown to them. During a snack break at a childhood cancer survivor event, a survivor asked about my research. In the course of our conversation, one of the children shared that, *'Both my parents and medical staff refused to share this information with me, so I resorted to using my phone to search for definitions and details about my location and prescribed medications'* (Fieldnotes: 15th December 2017) As a result, these clinicians do not perceive the outcome or communication of diagnosis as separate issues. When considering different options, it is inevitable that uncomfortable information will need to be disclosed at a later stage in life. However, for such young children, parents have chosen to withhold the distressing news.

7.2.3 At the Time of Transfer?

Through interviews and observations, I found that patients and families shared common characteristics. When parents found their child's abnormal symptoms through a referral from a local doctor or a children's hospital, they rushed to get their child admitted to the so-called Big Five hospitals²³ in Seoul. The transfer was faster than I thought: the paediatric cancer patients they interviewed were admitted to the university hospital for their main cancer treatment within seven to 10 days, and as little as a month. I found that patients and families felt that the speed with which children with cancer were admitted and treated meant that they had a relatively good prognosis (Fieldnotes, 2017 to 2018).

But there are some issues about transferring. While researching people with non-cancer or rare diseases, I came across a case. Moyamoya disease is an obscure condition with symptoms that baffle both patients and doctors. The parents suspected epilepsy, and specialists took some time to make a diagnosis. Momo was hospitalised for seizures, but after brain surgery he is immobile and requires ongoing therapy. Jaehee Kim who is Minhoo Kim's father said that it was difficult to continue his rehabilitation and to move him from a tertiary hospital to a secondary hospital and back to a tertiary hospital because of his poor health. However, it was equally difficult to find a tertiary hospital. Even

²³ The 'Big Five' hospitals are equipped with the latest technology and are affiliated with prestigious academic institutions. They include Severance Hospital, Asan Medical Centre, Samsung Medical Centre, Seoul National University Hospital and Seoul St. Mary's Hospital. According to Song (2018a), they have earned the nickname 'the black hole' of Korean healthcare due to their considerable attractiveness for medical services and personnel. The 'Big Five' are so named in part because of the degree of resource concentration and widespread recognition they enjoy.

when they are finally discharged and allowed to return home, they have to do so with a large bed that does not have enough room in the house, and they have to climb stairs without a lift. In other words, when their child is discharged from hospital, they have to move, which is not an easy task, the guardian told me. (Jaehye Kim, Minho Kim's father, 7th December 2018)

In South Korea, patients often prefer larger hospitals because of their advanced resources and specialised expertise. This preference can also lead to “doctor shopping” as patients seek the best possible care. The country's healthcare system is a single-payer model administered by the National Health Insurance Service (NHIS), where patients' out-of-pocket expenses can range from 30% to 60% for outpatient care. Despite the high coverage of the NHIS, there is still a significant reliance on private insurance due to these out-of-pocket expenses (McVay, 2024).

In terms of transition, decision making is not a one-off rational event where parents are confronted with various junctures in decision-making. In having an agreed transfer plan involving a hospital, school, community services or the family, decision making includes three precautionary steps: “to tolerate emotional distress, to gather information, and to select the best option” (Peter Kaye, 1999: 16).

I found that most parents made the decision for the best interests of their child or young person and struggled with emotional distress and lack of information (Fieldnotes, 7th December 2018). Without patient-centred care information interchange and consultation across the health system, it is impossible to improve the consistency and quality of outpatient care, even when patients visit various hospitals for the same condition. CYP with LLCs and family members did not know about the processes of healthcare transition, although they have a vague understanding of the conversations known between doctors and parents.

Second, patients discharged from the hospital do not receive adequate outpatient care to lower the risk of readmission. When leaving hospital via a rapid discharge pathway, families did not know how to access to an appropriate specialist or have the opportunity. Rogers, Brooks and Aizelwood, *et al.*, (2018:2) define “poor transition is frequently rushed and unsupported with little or no handover between professionals or support for young people and families.” Although the family-oriented level of decision-making processes is highlighted, palliative care at the time of an unexpected transition does not help to alleviate significant physical, and emotional stress on parents and patients. It is incredibly difficult to avoid needless, unexpected, and costly hospital admissions for patients. For starters, patients see several doctors, but no single doctor consistently collects and organises clinical information for them.

Third, patients with specific medical disorders do not have a single source for routine testing and medication management, and access to cannabidiol (CBD) is only through the Korea Orphan & Essential Drug Centre makes pain management more difficult. As a representative of the Medical Cannabis Legalisation Campaign told Is in an interview, *"It's ridiculous. Other medicines don't even take political decisions into account, but CBD does. Unlike other medicines, it's up to the Ministry of Food and Drug Safety to decide, and it's so embarrassing for patients and their families. We estimate that there are 300,000 to 400,000 people with epilepsy in Korea, and it's incomprehensible that the law has only just been passed to allow them to buy it with a prescription at one designated location in Seoul."* (Seokhyun Kwon, 15th May 2018)

I conclude that once diagnosed or recognised, children, young people and their parents do not receive adequate information and their needs cannot be reviewed at appropriate intervals, as this does not optimise the holistic care of the family in the decision-making process.

7.3 Stage Two: Into the Unknown End-of-life

As part of my fieldwork, I observed the NICU and PICU alongside medical staff. Families were not allowed to stay in the room with their children and were instead placed in a separate area. While no one wants to consider the possibility of their child entering the end-of-life phase, it is a potential outcome. Each time the code buzzer sounded, which occurred frequently during my research, I viewed it as a signal that this transition could be happening.

For most parents, accepting that their child or young person is transitioning into the end-of-life phase is incredibly difficult. A decision must then be made about whether to continue or stop all life-prolonging treatment, knowing that death is inevitable. It is essential that families receive care and support from professionals experienced in these situations, who have built a relationship with them.

However, it is notable that many children or young people die in the NICU or PICU. In these situations, I will explore the unknown end of life outcomes if they avoid the decision and why there is no cold room to support the child and family. They will need reassurance that pain and other symptoms will be well controlled and that family-oriented care will continue in the place of their choice, if that is practical. An advance care plan should be used to support the child and family regardless of age, gender and health status. In 7.3.2 I will look carefully at what guidance is provided. Finally, following

the death of the child or young person, 7.3.3 looks at the choices available to parents in relation to bereavement. Despite the importance of two stages, I will show how CYP with LLCs are excluded from decision-making processes.

7.3.1 Guideline of Advance Care Plans?

An Advance Care Plan should be applied regardless of age, gender, and health conditions.

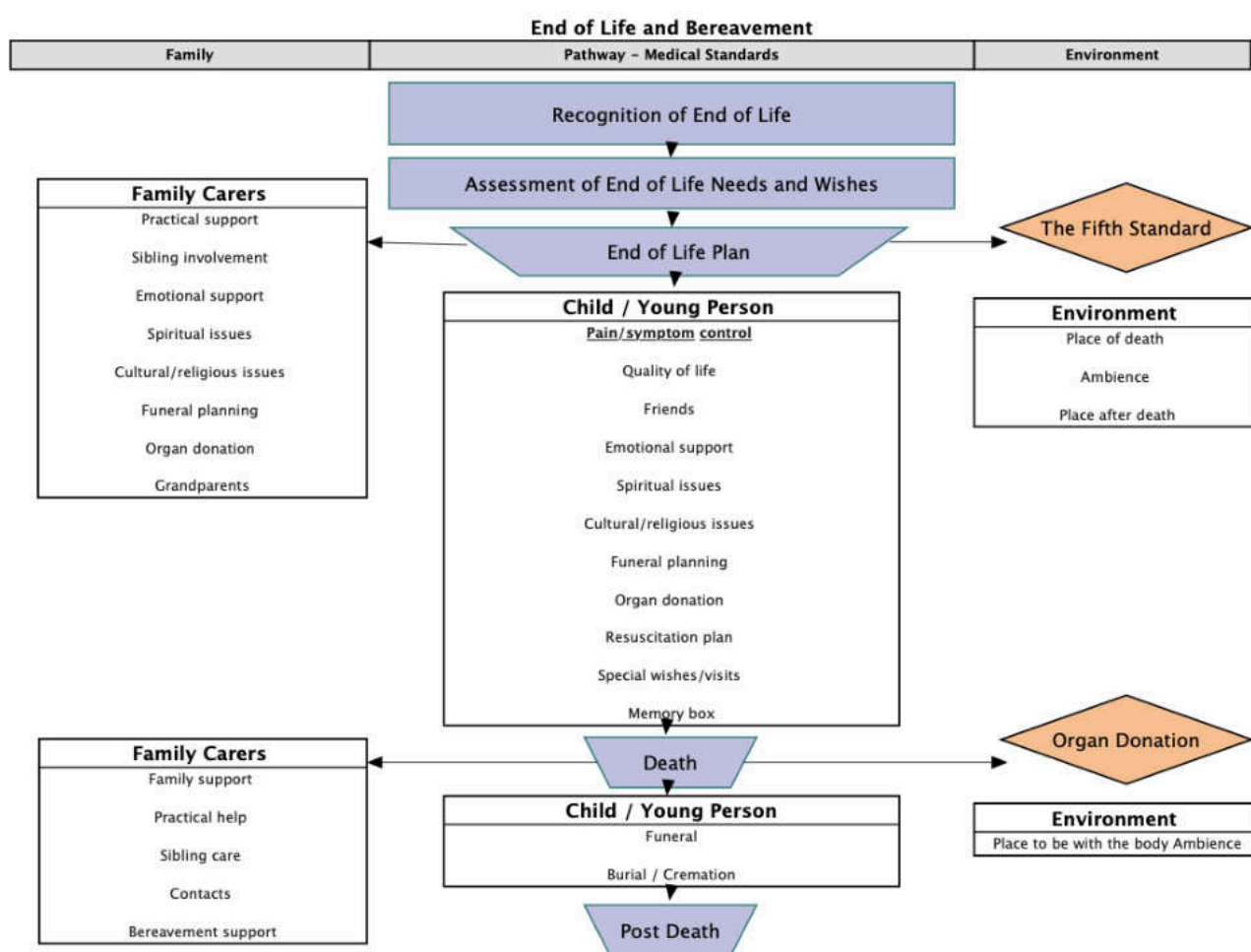


Figure 7-3 End-of-life and Bereavement

Seunghoon Oh has adapted and expanded upon the framework originally presented Widdas, Street, Edwards, *et al.*, 2013.

Widdas, Street, Edwards, *et al.*, (2013: 29) recommend that before dying a child with LLCs, “an Advance Care Plan (ACP) should be recorded including the most sensitive thoughts and feelings a child and family have about the care they wish to receive throughout their life and end-of-life.” The arduous journey facing the reality of their child’s death for the significant time requires key goals of the fifth standard for an end-of-life care plan:

1. Professionals should be open and honest with families when the approach to end-of-life is recognised.
2. Joint planning with families and relevant professionals should take place as soon as possible.
3. A written plan of care should be agreed and shared with emergency services, including decisions about methods of resuscitation.
4. Care plans should be reviewed and altered to take account of changes.
5. There should be 24 hours access to pain and symptom control including access to medication.
6. Those managing the control of symptoms should be suitably qualified and experienced.
7. Emotional and spiritual support should be available to the child and family.
8. Children and families should be supported in their choices and goals for quality of life to the end.
9. There needs to be clear understanding of the formal processes that are needed after death and the timing of these (Widdas, Street, Edwards, *et al.*, 2013: 29).

I interviewed family counsellors to find out how Widdas, Street, Edwards, *et al.*, (2013: 29) issues were being addressed and progress being made.

Minah Kim: Absolutely! There's a pressing need for clear, practical guidelines tailored specifically to the Korean setting. My training primarily focused on practices in the US, which doesn't translate directly here. This gap in applicable knowledge leaves us in a sort of limbo, unable to provide the full scope of information that our children and their families desperately need.

Families often find themselves wholly dependent on medical professionals for guidance. They come to us unprepared for the decisions they need to make, particularly when it comes to sensitive topics like Do Not Resuscitate (DNR) orders. It's still a challenging topic even among adults and professionals qualified to discuss it. (Minah Kim is Registered nurses- Counsellor 18th May 2018).

Following the criteria of an end-of-life care plan or Advance Care Planning (ACP), several elements need to be met, including obtaining informed consent from competent young people. Widdas, Street, Edwards, *et al.*, (2013: 28) highlight the need to recognise the end-of-life period as a key milestone in the care pathway, allowing both families and professionals to focus on planning and preparing for the child's death. ACP involves comprehensive multi-agency care planning that includes discussions about sensitive decisions such as organ or tissue donation, preferred settings for care at the time of death and beyond, and how the family wishes to care for their child's body after death (Widdas, Street, Edwards, *et al.*, 2013: 29).

However, despite their ability to make independent decisions, young people are frequently excluded from creating their own end-of-life care plans. The decision to support the family's decision to improve quality of life or to seek life-prolonging treatment is heavily influenced by the child's chronological or cognitive age. Reflecting on my previous experience in a palliative care setting where advance care planning is standard practice, I see a potential oversight in not involving young people more actively in these discussions. My previous work experience may have influenced my perspective and highlights the need for a more participatory approach to end of life planning for young people. Excluding CYP with LLCs from decision-making is not justified, as it has a direct impact on them. It is vital that CYP with LLCs understand what they want in terms of advance care planning (Fieldnotes, 18th May 2018). By understanding the death of CYP with LLCs, supporting their emotion, parents, siblings, grandparents, and other significant family members can be encouraged and supported to continue their caring role with the child (McNamara and Francis Edwards, 2013: 29).

ACP includes at least do-not-resuscitate (DNR) orders hematopoietic stem cell therapy and organ and tissue donation, but I observed that parents often said to me "my child may not need to have full information because they cannot understand all the medical information and they should have time to adjust to each aspect before receiving more specific information regardless of their physical or cognitive age." Parents tend to avoid discussing hematopoietic stem cell therapy, organ and tissue donation or DNR with their child due to their focus on medical treatments (Fieldnotes 18th May 2018).

I identified that the absence of established ACP guidelines presents several difficulties, including the impasse encountered by CYP with LLCs who are unable to make independent judgements.

“I overheard my mother and the doctor talking outside the door. My mother instantly began to sob, and their tone indicated that the situation was serious. I was told to remain outside the entrance, but I was in a nasty mood, so I tried to enter the outpatient section. However, the nurse denied me access. I forced the door open and shouted at the doctor. I feel driven to investigate the nature of my affliction and the source of my distress. I ask you to explain why you are reluctant to engage in conversation with me.” (2017120, Jamie Payne, Survivor)

I really wanted somebody to tell me what treatment I needed and what I needed to do in the worst case scenario, not some weird psychological test that didn't make any sense, but at least somebody to tell me what I needed to do and what I needed to prepare for in the course of treatment, and nobody told me, so I listened to what the doctor told me and I googled it, and I found out by googling it that there's a course of treatment. Fortunately, six months may be as short or as long as you want them to be, but it was a hard time for me. (20180207, Lydia Brooks, Survivor)

ACP guidelines for CYP with LLCs should adhere to human rights norms (Puybaret & UN General Assembly, 2008) and involve families in decisions. The BMA (2001: 122) states policies should specify when DNR orders are appropriate and clarify decision-making responsibilities and communication. ACP is not commonly practiced in cases involving CYP with LLCs.

Despite legal provisions for minors under the age of 16 to participate in organ donation, Confucian values of filial duty (孝) often exclude children from decision-making. Although these values underpin social care within families (Fan, *ed.*, 2015: 14;18), research suggests that the voices of CYP with LLCs are consistently overlooked under the guise of family paternalism (Fieldnotes 5th December 2017; 13th December 2017; 27th December 2017; 9th January 2018; 6th May 2018; 16th May 2018).

I have found that involving CYP with LLCs in advance care planning can seem overly complicated and easily hidden under the guise of family paternalism. By maintaining a family-oriented level of decision making, the overly complicated issues of CYP with LLCs can mask the complex issues at hand. Legal capacity does not always imply knowledge of important decisions such as DNR orders, which can lead to misunderstandings and disagreements, especially when conventional family roles and authority are challenged. It is believed that by addressing these issues at the family level, a

solution is more likely to be found. This belief in simple, family-level decision making, despite the apparent reluctance of families and the emotion shown by the 65 respondents, underlines the positive findings that family members do not want to win an internal solution.

7.3.2 Focuses on the Cremation but not Bereavement Care?

In general, people believe that after the death of a child, the end of the care pathway is completed rather than bereavement support and bereavement care.

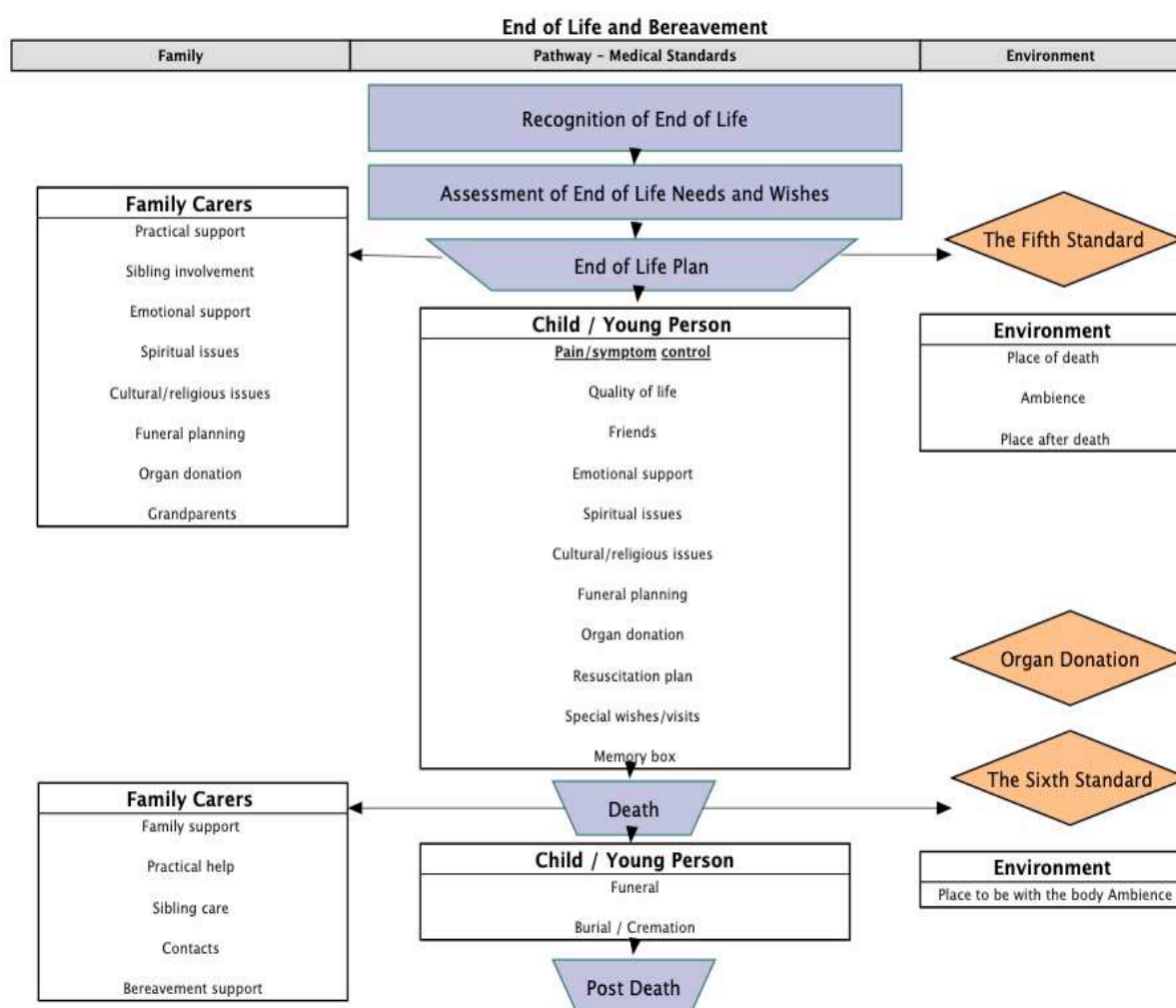


Figure 7-4 End-of-life and Bereavement

Seunghoon Oh has adapted and expanded upon the framework originally presented Widdas, Street, Edwards, *et al.*, 2013.

The arduous journey confronting the inevitability of their child's death for the final time requires key goals of the sixth standard for a child and family care plan following (Widdas, Street, Edwards, *et al.*, 2013: 36):

1. The family should be allowed time and privacy with their child.
2. Parents should feel in control of events before and after the death and should be able to follow their own choices and wishes.
3. Families should all be offered bereavement support, and this offer should be repeated as it may well not be heard or taken up in the first instance.
4. The bereavement needs of siblings should be recognised and supported.
5. The needs of care staff should be considered including supporting staff in ending their involvement with the family as part of agreed bereavement plans.

Widdas, Street, Edwards, *et al.* (2013: 35) emphasise that 'bereavement support should be provided along the care pathway and should continue throughout the child's death and beyond'. Bereavement support is linked to ACP. The NICU and PICU are closely associated with life and death. During my observations and interviews, I found that there are no concrete guidelines for ACP for children and their families, compared to advance care planning or ACP for adults.

Dealing with death in the NICU and PICU is very stressful because they should at least be preparing for rescue and death. I have observed that families often wait for user feedback on end-of-life care, whereas in the NICU and PICU providers have little opportunity to hear these perspectives. In the NICU and PICU, there should have been an essential discussion about end-of-life care in the ICU, including preparing for a discussion, conducting a discussion, and concluding a discussion about end-of-life care in the ICU. Due to the lack of prepared guidelines and toolkits for CYP with LLCs and their family members, bereavement care and support is not linked to decision-making in the NICU and PICU. From my point of view, there was a lack of discussion about end of life because managing death in the NICU and PICU could be difficult to support end of life care in the NICU and PICU, regardless of the focus on medical treatment. In the NICU and PICU, clinicians are challenged to simultaneously prepare for both survivorship and death as possible outcomes for their patients; they did not have enough time and resources to achieve both outcomes.

Characteristics	CCCs	Non-CCCs	Total pediatric deaths
Total No. (%) of subjects	12,515 (34.0)	24,293 (66.0)	36,808 (100.0)
Sex			
Male	56.6	61.2	59.6
Female	43.4	38.8	40.4
Age, yr			
Infant (< 1)	45.2	39.3	41.3
Children (1–9)	24.5	19.7	21.3
Adolescent (10–19)	30.2	41.0	37.4
Region			
Metropolitan	44.6	40.4	41.8
Non-metropolitan	55.4	59.6	58.2
Location of death			
Hospital	85.5	57.9	67.3
Home	8.4	13.6	11.9
Other ^a	6.0	28.2	20.6
Unknown	0.1	0.3	0.2

Values are presented as number of patients (%) or percentage.

CCC = complex chronic condition.

^aWelfare facilities, on the way to hospital, road, etc.

Table 7-1 Total Scale of Paediatric Deaths from 2005 to 2014 According to Demographic Factors

Source from Kim, Lim, Kim, *et al.*, (2018: 4)

Table 7-3 shows that the main place of death is the hospital with 67.3%. Babies are both born and die in hospital. In contrast, Carter (2016: 136) notes that in the UK, statistics on place of death (Office of National Statistics 2011) show hospice with 5% (NHS and non-NHS), residential home with 18% (local authority and private), home with 21% and hospital with 53%. Although hospital is an important place of death, my observations in the Republic of Korea suggest that most deaths in NICUs and PICUs may involve the withholding or withdrawal of multiple life-sustaining therapies when parents are reluctant to pursue the best interests of their children. Spending at least ten days in the NICU or PICU during their final hospitalisation may be a setting for dying and place of death management for CYP with LLCs. After the patient has died, the doctor can remove the ventilator: the patient's head, face and arms are now free from all kinds of medical equipment, as most CYP with LLCs did not have DNR consent.

Many Koreans believe that the place to die should be at home because people believe it is associated with a good death. (Kendall & Dix 1987: 75) shows that dying at home surrounded by family members is considered a good death, whereas people believe that Gaegsa 客死 which means dying away from home is an unfortunate and bad death. Despite the beliefs about the place of death, the most significant change in the place of death is from home to hospital. Usually, the body is transferred quickly from the NICU or PICU to the hospital mortuary. There are many decisions to be made after the death of a child, such as funeral planning, respite and bereavement care.

After death, the body is taken to the hospital mortuary or funeral home. Funeral planning for CYP with LLCs includes reflection on their lives, bereavement support for family and friends, and observance of funeral rites. In general, funeral rites may be conducted by family members of spiritual leaders, and hospital chaplains may provide assistance. Adult funerals usually consist of a three-day service during which family and friends visit the deceased's home to pay their respects, but when a child or young person dies, people are generally uncomfortable with the prospect of visiting the bereaved. Superstitions abound when a child dies before their parents, even to the point of believing that bad luck will befall any pregnant woman or child who attends the service. This can cause great anxiety for parents who are responsible for arranging the funeral of their children, with some even taking the distressing decision not to have a funeral service or ceremony, but only a private cremation.

Contemporary funeral culture in the Republic of Korea has undergone enormous changes in recent years, such as the location of the deceased's body prior to burial and the method of burial. Traditionally, the body of the deceased remained in the family home, but it is now the norm for the body to 'lie in state' in a funeral hall or undertaker's premises, where family and friends can visit and pay their respects. There has also been a big move away from burial to cremation. When it comes to CYP with LLCs, their parents generally opt for a service/ceremony at home, but the preference for the actual place of death has shifted from home to hospital/hospice.

Park (2010) notes two changes in location from home to hospital since home funerals were common until the mid-1980s. It is the place of remembrance, where parents and family members are reminded of where the child died.

	Dying	Funeral	Disposal method	
Until 1980s	Home	Home	Burial	
1990s	Hospital	Mortuary	Burial	
2000s	Hospital	Funeral Hall	Cremation	Deposition with multiple choice

Table 7-2 Korea Gallup Surveys on the Changing Location of Dying, the Changing Funeral Venues and Disposal Methods since the 1980s. Source from Park (2010: 26)

Table 7-4 shows that not only did the place of death change from the home to the hospital, but funerals also took place in hospital morgues or funeral parlours. Until the 1980s, the body of the deceased remained at home for neighbours and friends to view until the funeral, which was attended by all, including children. During the 1980s there were significant socio-cultural factors and phenomena such as urbanisation, industrialisation, individualism, the dissolution of the extended family and the

formation of the nuclear family (Lee, 1996: 54). Due to the shortage of burial sites, the Korean government introduced a burial-to-cremation disposal method and encouraged the construction of crematoria. Also, thanks to a high degree of commercialisation/marketing and media saturation (Park, 2010: 33), there have been three dramatic changes since the 1990s: the place of death, the place of burial and the method of disposal. The new pattern of funeral practice from the mid-1980s onwards was to die at home, be buried in the hospital morgue and then be interred in a public cemetery or family graveyard.

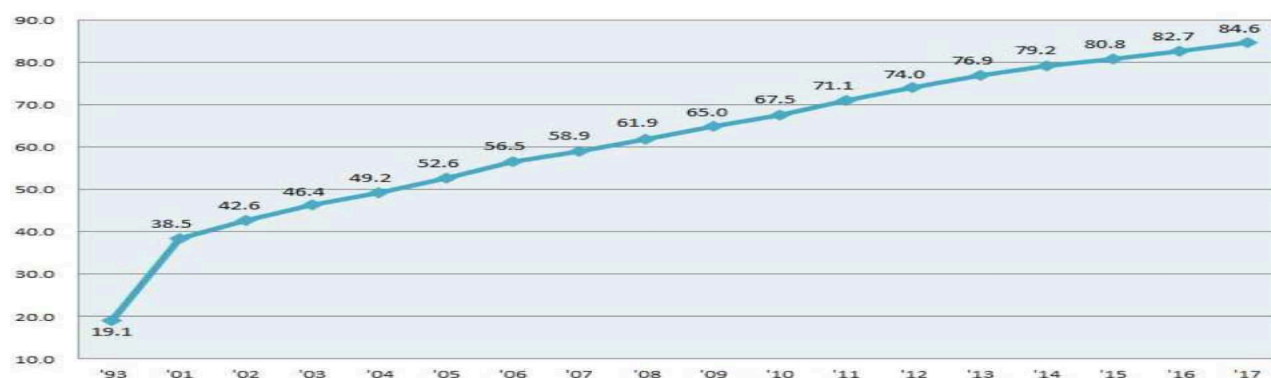


Figure 7-5 Korea Gallup Surveys on the Nationwide Cremation Rates 1993–2017

Age	Under 9 years	10s	20s	30s	40s	50s	60s	70s	80s
Rate of Cremation	94.6	99.5	98.2	97.0	97.3	95.4	91.6	84.6	78.1

Table 7-3 Korea Gallup Surveys Rate of Cremation based on Age

Although families have the option of committal, burial, or cremation, most parents preferred cremation after the brief funeral service. In fact, cremation was the choice of over 90% of parents in the under-60 age group.

Furthermore, parents should consider one of three methods of dealing with the remains (ashes) of the deceased, such as keeping in a safekeeping box at a cemetery (*Napgoljang* 納骨堂); scattering at a favourite location on a river, mountain, or at sea (*Sangol* 散骨); or calling eco-dying a natural burial, place under or around a tree within a memorial park (*Sumokjang* 樹木葬). In terms of death with dignity, processing of the funeral is crucial and significantly sensitive. Supporting the family during the planning and arranging of the funeral is connected to starting the bereavement care. The fundamental forms of funerary practices maintained in the later period of Confucian Korea (1392–

1910) continued until the 1980s and some similarities from Confucianism remain into funerary rites and customs despite the three dramatic changes during the last two decades.

This is a particularly distressing time for the parents of a child in the NICU or PICU who is dying. By ignoring APC or AD, family members usually do not have time to consider end-of-life decisions and often do not have the opportunity for privacy with their child as they focus on the medical treatments available. Because of the initial shock and sense of utter despair, those who have lost their loved one are confused about what to do next. Support should include written information about procedures and entitlements such as the death certificate, advice about benefits or entitlements and information about the child death review process.

7.4 Expectations and Ethical Challenges from Paediatric Palliative Care Social Work?

In this section, I explore the expectations of the role of paediatric palliative care social workers in terms of family oriented and/or interpersonal level of decision, especially a concern for the psychological and social issues of patients and their families in 7.4.1.

CYP with LLCs should have been afforded rights despite a child's reduced cognitive capacities, and their lack of rational decision-making claims a traditional argument for denying children rights. I will show that every single year at least 6,000 vulnerable people face their unwanted journey of having to make hard choices. In contrast, the findings from the study show that the faces of CYP with LLCs in healthcare settings are quickly forgotten. Therefore, this section presents that the role of paediatric palliative care social worker is not only unclear but also the expectation higher.

7.4.1 Expectations from Paediatric Palliative Care Social Work?

When enhancing the best interest for CYP with LLCs, the limitation of autonomy of the patient can be allowed (British Medical Association, 2001). Sonia Douek and Jewish Care (2003: 123) list four "key aspects of good practice for working with carers: effective and open communication, multi-disciplinary working, creative collaboration with voluntary and informal networks and advocating between different professionals to assist with access to services." In understanding the hard choices of

children and their parents, following family-oriented decision-making processes is useful. To improve the quality of care, I followed medical professional staff, who believe decision-making is at the heart of medical care and can inform children or young people and their family members of the result of the diagnosis, medical procedures, or treatments, and support the hard choices. Autonomy or shared decision-making has some controversial issues, such as medical, legal, and ethical aspects in the decision-making processes. Children's decision-making requires assessing capacity, competency, child autonomy and standard of best interests.

Based on the IFSW (2007), the rights of CYP with LLCs can be divided into at least three areas. First, CYP with LLCs have fundamental rights to survivors and to the fullest development in terms of health, social security, education, and play. The second is protection. When CYP with LLCs are subject to medical malpractice or medical futility, the state must intervene, protect, provide, and promote palliative care and quality of life. The third is the participation of CYP with LLCs in decision-making, especially near the end-of-life. Gwyther, Brennan and Harding (2009) insist that all children have their own views and a right to express their views.

The role of paediatric palliative care social worker as a part of the interdisciplinary team is associated with concern for the psychological and social issues for patients and their families, especially if parents make a poor decision. Paediatric palliative care social workers assess and support the role of the patient's parents or guidance who decides among three difficult choices: following, rejecting, or withholding. To support life-limited children and their families, shared decision-making (Gwyther, Brennan and Harding, 2009) is highlighted, but refusing life-sustaining treatment in cultural discourses or ignoring "participation of CYP" (Bell, 2011).

Child decision-making and participation of CYP are directly linked with children's rights. If they can participate in the decision-making, as well as express their opinion on how to increase their quality of life, logical arguments of the rights should be grounded such as who can decide on behalf of children and incapacitated patients and what decision-making standards or criteria are applicable.

However, there should be various options when suggesting the best interests for CYP with LLCs considering the ethical framework and established facets of practice within which questions of children's consent. Despite having the latest developments in medical treatments, hospital healthcare professionals' intentions in deal with parents who have a child with LLCs have numerous problems. Exploring the family-oriented level of decision-making processes is vital because I found that CYP with LLCs are excluded from decision-making processes. Assessing decision-making processes with

children or young people with LLCs is not only the structural level but also requires a family-oriented level, beginning with a critical event.

Thus, paediatric palliative care social workers face difficulties such as how to enhance the quality of life, ensure the safety and the best interest of incompetent patients, and avoid futile treatments in multi-disciplinary work. In the role of paediatric palliative care social worker, the expectations are not met to support decision-making processes due to the given workload (see 6.2.5).

7.4.2 Increasing the Number of Paediatric Patients with LLCs

Paediatric consent helps to integrate seemingly family and patient/child centred models, but the family in post-traditional societies is diverse and understanding trust as the moral basis of family relationships is not easy to support life-limited children and their families in the ‘holistic and interdisciplinary’ approach of paediatric palliative care (Brown, Warr & Shribman, 2007: 27).

Every single year at least 6,000 vulnerable people face their unknown journey and should ponder decision-making, whereas their face has been easily forgotten although summarised medical information can be accessed. According to 2016 National Cancer Control Plan, in the Republic of Korea, 1,353 patients under 18 years of age were diagnosed with childhood cancer in 2015²⁴. However, the data shows the population of childhood cancers but does not include non-cancer patients. Min Sun Kim at al (2018, 1) reported that “there were 36,808 cases of paediatric deaths in Korea during that 10-year period, one-third (12,515 cases, 34.0%) of which were due to complex chronic conditions (CCCs). In 2014, there were 1,044 cases of paediatric deaths due to CCCs (9.8 deaths per 100,000 children) in Korea.

²⁴ According to the 2016 National Cancer Control Plan, in The Republic of Korea, 1,353 patients under 18 years of age diagnosed with childhood cancer in 2015 increased every year, and cumulative paediatric and adolescent cancer cases are about 25,000. (National Cancer Centre 2021)

Characteristics	CCCs	Non-CCCs	Total pediatric deaths
Total No. (%) of subjects	12,515 (34.0)	24,293 (66.0)	36,808 (100.0)
Sex			
Male	56.6	61.2	59.6
Female	43.4	38.8	40.4
Age, yr			
Infant (< 1)	45.2	39.3	41.3
Children (1–9)	24.5	19.7	21.3
Adolescent (10–19)	30.2	41.0	37.4
Region			
Metropolitan	44.6	40.4	41.8
Non-metropolitan	55.4	59.6	58.2
Location of death			
Hospital	85.5	57.9	67.3
Home	8.4	13.6	11.9
Other ^a	6.0	28.2	20.6
Unknown	0.1	0.3	0.2

Values are presented as number of patients (%) or percentage.

CCC = complex chronic condition.

^aWelfare facilities, on the way to hospital, road, etc.

Table 7-4 Total Scale of Paediatric Deaths from 2005 to 2014 According to Demographic Factors

Source from Kim, Lim, Kim, *et al.*, (2017: 4)

According to Kim, Lim, Kim, et al. (2017: 4), the rate of paediatric deaths due to CCCs has decreased during this 10-year period. The total scale of paediatric deaths shows 36,808, divided into 12,515 with CCCs and 24,293 with non-CCCs from 2005 to 2014 according to demographic factors. Based on the total scale of paediatric deaths in the Republic of Korea from 2005 to 2014, the number of CYP with LLCs is at least 3,000 in each year according to demographic factors. Every single year at least 6,000 vulnerable people face unexpected life events and should ponder decision-making on how to go into the unknown life whether they have well prepared or not. Although the death toll has increased, the face of CYP with LLCs has been easily forgotten because new CYP with LLCs come to the acute hospital.

7.4.3 Following Footprints of Medical Perspective

To understand the medical perspective, I followed a paediatric doctor, who usually meets at least 100 to 180 patients per day, including inpatient and outpatient. I awoke early in the morning around 3 am, to prepare the planning of interviews and read some essential textbooks such as *Consent Rights and Choices in Healthcare for CYP* (2001), *Oxford Handbook of Paediatric* (2013), *Paediatric Palliative Medicine* (2016), *Oxford Textbook of Palliative Social Work* (2011) and *Palliative Care Nursing of CYP* (2018). It seemed like cramming for an exam because unless I knew the medical terms

and essential information about patients and their family members when I attended the case conference, I could not accurately catch basic concepts for patients. Before attending the case conference from 7 am to 8am, I had to understand how many patients were hospitalised and their medical situations.



Figure 7-6 Steps of Walking in an Acute Hospital from 6 am to 3 pm²⁵

Figure 7-10, which is based on the iPhone's Health app for the iPhone, depicts the itinerary for the day in question. I accompanied the medical staff on their rounds of the hospital wards with the objective of observing the interactions between the medical professionals, patients, and their families. I was afforded the opportunity to observe a medical school professor on his daily ward rounds, engaging with patients and their families from 7 a.m. to 1 p.m. During this period, I met with approximately 120 patients. Furthermore, he conducted outpatient consultations between 2 and 4 p.m. and interviews with individuals who had been referred by physicians. Subsequently, I proceeded to the location where the patients were congregating.

During the running of the case conference, paediatric fellows and residents, who mainly set up the computer equipment with the projector for the case conference, present current patients' issues, especially physical problems. Despite having an hour at best, they conducted the case conference intensively. In an hour, they discussed current patients' issues who are hospitalised from almost 60 patients to approximately 70 patients, excluding outpatients. There were usually two or three paediatric cancer specialists, a psychiatrist, four of five residents, three or four nurses, a play therapist, an art

²⁵ From about 11:00 pm to 1:00 am, I visited the sit-in demonstration site relating to semi-conduct industry.

therapist, a medical social worker, two medical interns, and me. I believe that the case conference remains the art of identifying the patients' problems, which are specialised considerations more than merely diagnosing his/her disease process. While attending the case conference, I tried to understand most cases whether I could fully understand medical jargon or not.

After the case conference ended, I followed a paediatric doctor with his fellows and medical staff such as residents, nurses, a translator, and social workers. Although I had a lot of questions which I was unable to ask, I quickly followed the medical staff when they met the patients and their parents. We visited paediatric intensive care units (PICU), neonatal intensive care units (NICU), hematopoietic stem cell transplantation units (HSCTU) and emergency rooms. When following the medical doctors during their usual morning rounds, I performed around 8,000 steps. Owing to having to visit a lot of patients, we walked at a brisk pace or almost ran to meet the patients in the largest hospital. After having lunch with medical staff from 12 pm to 1 pm, we then met a number of outpatients; During this period, I was given the opportunity to meet some patients and their parents when a paediatric doctor introduced me during their consultations. Despite having read textbooks and memorising essential concepts, I could not fully follow whole situations because it required more time and effort.

In the evenings, I attended gatherings of individuals who had been affected by the humidifier disinfectant disaster, as well as meetings with semiconductor workers who had been diagnosed with industrial illnesses. These experiences afforded invaluable insights into the challenges confronted by those afflicted with severe health conditions. Furthermore, I conducted interviews, investing a minimum of 60 hours and a maximum of 70 hours per week in fieldwork.

From the perspective of Emmanuel Levinas, this fieldwork can be seen as an ethical endeavour to engage with the Other. In his 1969 work, Levinas posits that ethical responsibility does not originate from comprehensive comprehension but rather from a willingness to acknowledge the needs and afflictions of the vulnerable. In this sense, healthcare workers, like myself during this fieldwork, are ethically obliged to respond to patients' suffering, even when certainty is absent. Levinas emphasises that this responsibility extends beyond mere knowledge, necessitating the navigation of ambiguity while striving to make decisions that serve the best interests of others (Levinas, 1969: 194).

By immersing myself in the decision-making processes of healthcare professionals and understanding the perspectives of patients and families, I aimed to reflect Levinas's ethical approach, focusing on the complexities of care and the human costs borne by those within the healthcare and industrial sectors.

7.4.4 Forgetting the Face

Every morning, I have to cram medical information and terms into my head, unable to focus on the children's faces because 3 minutes at best was not enough time to remember their faces. During these mornings I met about 100 patients, including inpatients and outpatients, their family members and about 40 medical staff in an acute hospital. The experience of meeting many patients and their parents enabled me to read the moods of the human face and to know the person by signs that I cannot describe. Among a million things, knowing a face is related to practical knowledge: knowing what and knowing how (Michael Polanyi and Amartya Sen: 1966, 7). When we speak of knowing, Polanyi said (Michael Polanyi and Amartya Sen: 1966, 4) I will rethink human knowledge by starting from the fact that we can know more than we can tell, which is the result of an active shaping of experience carried out in the pursuit of knowledge. Interestingly, we cannot always say how we recognise a face; we have made a large collection of pictures showing or illustrating a wide range of noses, mouths and other features, and the pieces can be put together to form a face (Michael Polanyi and Amartya Sen: 1966, 4-5).

In the afternoon and evening I tried to remember faces and names as I read their medical records. Although CYP with LLCs and their family members can remember me, I could hardly remember some of them after the day's observations and interviews. On the other hand, when interviewing their parents, I can remember their faces, which means not just a face, but also their narrative in context, having met them at least three or four times.

I followed the medical perspective for about six months and came to the conclusion that the faces of people who came to the acute hospital could easily be forgotten. The process is like running a huge department store, based on the process of meeting the doctor, the patient and their parents. If we read and retain a one-page profile, which is a summary of valuable information, we can remember their face.

On the other hand, the one-page profile without a face means that health professionals cannot imagine or describe: 1) what is really important to the child or young person with LLCs, and 2) how we should provide good and quick support, because they have to meet a lot of CYP with LLCs and their parents.

“The face is a living presence; it is expression. . . The face speaks.” (Levinas, Totality and Infinity, 66).

In *Totality and Infinity*, Levinas emphasises the human 'face', which means that an unreflective encounter with the face demands social and ethical responsibility, because the living presence of another person is exposed to me and expresses the child or young person simply by being there. As many patients were waiting to see the doctor, the faces of the patients showed us a wide range of important issues that they were experiencing. A living presence would include the most vulnerable and expressive aspects of the face, including verbal and non-verbal speech, gestures, behaviour and attitude. According to Levinas, the face makes direct ethical demands. Desperately, at least 6,000 vulnerable people face difficult choices every year. In contrast, their faces are easily forgotten, regardless of the medical treatment they receive.

7.5 Focusing on Family-Oriented Level of Decision-Making Processes?

Without enough information about the patient's condition or how the patient feels, surrogates are not readily able to conduct decision-making or presume their interests. The more difficult decision is that when surrogates do not know their interests, they might struggle with hard decision-making. The results can cause serious conflicts between a patient, and a surrogate(s) and a limitation of decision-making. Although a family-oriented level of decision-making processes can be possible, I found that there is a lack of consulting time, not enough place, and different perspectives of the best interests for CYP with LLCs.

7.5.1 "Three Minute" Consultation?

To make sense of the situation from the patient's point of view, firstly, the nature of the conflict is to tell the truth regardless of ethical dilemma, legal uncertainty, or clinical uncertainty. They would like to know what will happen and how they should take the next steps. Even though medical staff know this, they do not pass on the information. When meeting a doctor, parents and their child with LLCs should expect a long waiting time. This is vital for both patients and clinicians. For this reason, I followed one of families, showing that:

“To avoid a traffic jam, my daughter Melody McNeil and I left early in the morning. It took us about two hours to reach the hospital. Arriving early, we took a nap in the car and had something to eat before our appointment. Our meeting with the doctor lasted only about five minutes. I believe that Korea has excellent medical technology, but I don’t have faith in doctors. When we entered the room, the doctor barely glanced at Melody and me, focusing instead on the computer monitor. Despite having many questions, particularly about managing her osteosarcoma, which she was diagnosed with at the age of five, I was unable to ask them. Melody, now ten, has always dreamed of becoming a ballerina, but her condition necessitates special orthotic devices that make movement difficult, adding another layer of challenge to our visits.” (Heidi Chapman, Melody McNeil’s Mother, 05/02/2018)

For various reasons, parents and their child with LLCs should expect a long waiting time, but they do not have enough information from medical doctors. While following the perspective of patients and clinicians, a paediatric doctor usually meets at least 100 to 180 patients per day, including inpatient and outpatient. Although morning rounds are different among tertiary hospitals, based on the steps and times, I thought inpatient consultation time was approximately 5 minutes, but real outpatient consultation time was around 1 to 3 minutes.

In terms of outpatient consultation time, Chan Hee Lee, Hyunsun Lim, Younghan Kim et. (2014: 257) surveyed 1,105 patients of a single general hospital in Gyeonggi-do to discover imagined and actual outpatient consultation time from October 28 to November 27 in 2013. They show that each patient’s outpatient consultation time is at least 5.6 minutes, as demonstrated in the following comparison of outpatient consultation time.

Variable	Patient no. (mean patient no. in each section)	Real time (min)	Feeling time (min)	Satisfactory time (min)
Total	1,105	4.2 ± 2.7 ^{*,†}	5.1 ± 3.8	6.3 ± 4.1*
Gender				
Male	475	4.3 ± 2.9 ^{*,†}	5.4 ± 4.4	6.5 ± 4.3*
Female	630	4.1 ± 2.6 ^{*,†}	4.8 ± 3.3	6.2 ± 4.0*
Clinical department				
Gastroenterology	96 (38)	4.4 ± 2.2 ^{*,†}	5.2 ± 4.2	5.9 ± 3.3
Cardiology	105 (65)	3.5 ± 2.1 ^{*,†}	4.3 ± 3.0	5.9 ± 4.1*
Pulmonology	47 (39)	5.4 ± 2.1 [†]	5.4 ± 2.6	6.6 ± 3.1*
Endocrinology	55 (49)	4.0 ± 1.5 ^{*,†}	4.8 ± 3.2	5.4 ± 3.6
Nephrology	66 (36)	3.7 ± 2.1 ^{*,†}	4.6 ± 3.4	5.6 ± 4.5*
Hemato-oncology	41 (16)	3.4 ± 2.4 ^{*,†}	4.6 ± 3.3	6.4 ± 3.8*
Infection	28 (22)	7.0 ± 4.6	7.4 ± 4.8	7.9 ± 4.7
Rheumatology	60 (47)	2.6 ± 1.3 ^{*,†}	3.5 ± 2.2	4.5 ± 3.7*
Neurology	50 (38)	4.0 ± 2.2 ^{*,†}	5.2 ± 3.6	9.4 ± 5.3*
Neuropsychiatry	53 (49)	4.9 ± 4.7 [†]	5.8 ± 4.5	7.3 ± 4.8*
Surgery	81 (28)	4.5 ± 2.9 ^{*,†}	5.9 ± 4.3	6.8 ± 3.8*
Orthopedic surgery	88 (32)	4.0 ± 3.0 ^{*,†}	5.0 ± 3.8	5.9 ± 3.9*
Neurosurgery	40 (11)	4.7 ± 2.8 [†]	6.1 ± 5.0	8.0 ± 5.3*
Obstetrics-gynecology	43 (28)	5.1 ± 3.4 [†]	5.7 ± 3.7	6.5 ± 3.4
Pediatrics	80 (39)	3.6 ± 2.0 ^{*,†}	4.4 ± 3.6	5.6 ± 3.1*
Otorhinolaryngology	46 (33)	4.2 ± 3.1 [†]	4.5 ± 2.7	5.7 ± 3.2*
Dermatology	41 (39)	3.1 ± 2.0 [†]	3.7 ± 2.8	4.7 ± 3.1*
Rehabilitation	43 (32)	5.3 ± 2.7 ^{*,†}	7.3 ± 5.7	8.1 ± 5.6
Family medicine	42 (32)	4.8 ± 2.0 [†]	5.4 ± 4.1	7.1 ± 4.9*
Consultation hour				
A.M.	537	3.8 ± 2.3 ^{*,†}	4.6 ± 3.3	5.8 ± 3.6*
P.M.	568	4.5 ± 3.0 ^{*,†}	5.5 ± 4.2	6.8 ± 4.5*
Consultation type				
New patient	243	5.0 ± 3.4 [†]	5.4 ± 4.0	6.7 ± 4.2*
Established patient	862	4.0 ± 2.5 ^{*,†}	5.0 ± 3.8	6.3 ± 4.1*
Satisfaction				
Very good	722	4.3 ± 2.7 ^{*,†}	5.3 ± 3.7	6.0 ± 3.8*
Good	289	4.1 ± 2.8 ^{*,†}	4.7 ± 4.1	6.9 ± 4.6*
Common	83	4.0 ± 2.4 [†]	4.5 ± 3.7	7.0 ± 4.8*
Bad	10	3.2 ± 1.0 [†]	2.4 ± 1.6	7.1 ± 3.1*
Very bad	1	4.1	5.0	10.0
Revisiting intention				
Very good	749	4.2 ± 2.7	5.2 ± 3.8	6.1 ± 4.0
Good	311	4.2 ± 2.8*	4.8 ± 4.0	6.7 ± 4.4
Common	37	4.5 ± 3.0 [†]	4.8 ± 3.4	7.5 ± 4.4*
Bad	6	4.7 ± 2.0 ^{*,†}	3.2 ± 2.0	7.5 ± 2.7*
Very bad	2	3.1 ± 1.5 ^{*,†}	3.0 ± 2.8	5.5 ± 6.4*
Recommendation to others				
Very good	708	4.2 ± 2.7	5.2 ± 3.7	6.2 ± 4.0
Good	295	4.3 ± 3.0 [†]	4.9 ± 3.9	6.6 ± 4.4*
Common	78	3.8 ± 2.4 ^{*,†}	4.7 ± 4.4	6.7 ± 5.0*
Bad	19	3.7 ± 1.8 ^{*,†}	3.3 ± 2.2	6.7 ± 4.0*
Very bad	4	3.5 ± 1.1 ^{*,†}	3.0 ± 2.3	5.3 ± 3.7*

Values are presented as number or mean ± standard deviation.

*Statistically significance between feeling time and satisfactory time or real time. †Statistically significance between satisfactory time and real time.

Table 7-5 Comparison of Outpatient Consultation Time

Source from Lee, Lim, Kim, *et al.*, (2014: 257)

Ideally, patients and clinicians should have enough time to engage in shared decision making, and I would argue that about three minutes is not enough. By observing health professionals, patients and their parents, I measured how long a doctor spent communicating medical information, such as treatment planning, diagnosis and transitions in care, to a patient or their parent. For outpatients, the time spent on communication ranged from about 8 minutes to 2 minutes, because many patients wait to communicate with health professionals about treatment planning, especially about reviewing medical issues. Surrogate decision-makers may not always accept the information and may not know

what to do for their child. Understanding the right answer for people of all ages, genders and disabilities is not easy, and there is insufficient time for counselling and information gathering.

7.5.2 Enough Place for Neo-Confucian Family-Oriented Decision-Making Processes?

The places to be considered in decision making, which include a hospital, a home or a school, are only part of the process to be discussed with multi-professional staff in pursuit of the best interests. Yi-fu Tuan (1979: 387) defines that ‘place is not only a fact to be explained in the broader framework of space, but also a reality to be clarified and understood from the perspective of the people who have given it meaning’.

First, place is full of noise. When I visited a children's cancer centre in an acute hospital, the paediatric oncologist emphasised that children are not just miniaturised adults. In acute hospitals, there are two groups of patients: inpatients and outpatients. Observing both, I was disturbed by the noise in the children's cancer centre, although there were enough places and well-prepared facilities such as play therapy rooms, a big table and a big TV for patients and their parents. In the acute hospital, however, the high noise level was not under control because of the focus on medical treatment.



Figure 7-7 The Waiting Space for Outpatients for Children and Their Parents

The noise included babies crying and repeated calls for code blue, which means a medical emergency such as respiratory distress or cardiac arrest. I was disturbed by the noise, which made me depressed and anxious as I imagined what might happen to the child with LLCs and the nature of the emergency. Although I apologised to many people for any inconvenience, especially the loud noise, the parents had to put up with it. I observed and concluded that it is impossible to endure the noise level without wishing for medical miracles and keeping hope (Fieldnote 2017 to 2018).

Furthermore, there is a reality in this place that needs to be clarified and understood from the perspective of the people who have been given the meaning of the end of life (Yi-fu Tuan, 1979: 387). Up to 80% of childhood cancers can be treated with medical treatments, while the other cases and non-cancers cannot be treated. In terms of end of life, decisions about place should be considered, but parents cannot decide whether to have aggressive treatments in the PICU or to stop treatments because there is no cold room in acute hospitals.



Figure 7-8 Waiting Room

Source from Lee & Shin, 2020

While parents wait for their patient, they only see status information about the operation in progress, which does not prepare them for the possibility of the end of life. The place should include both the survivor and the dying. However, in terms of a connection to a cultural identity, surgery can mean life or death. I have observed and concluded that it is almost impossible for parents to wait without wishing for medical miracles and holding on to hope.

Inadequate communication between parents and the healthcare team can lead to unsatisfactory outcomes in terms of the best interests of CYP with LLCs. Decision-making processes that prioritise family involvement may not always lead to hospitalisation.

7.5.3 Different Perspectives of the Best Interests and the Voiceless of Children

On an uncertain journey, they may be a dynamic experience of changes in illness such as chronic illness, prognostication, transition, recurrence, survival, death, and bereavement care. Because of this, children, and young people with LLCs and their families require a unique kind of care to accommodate a wide range of needs and I heard frequently many parents “Because of you!” And “I love you!”

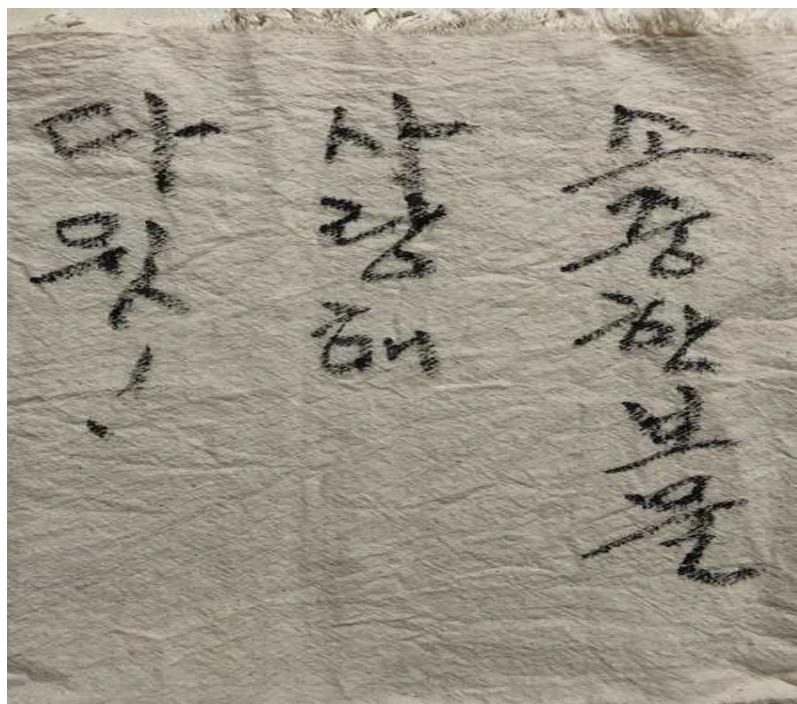


Figure 7-9 “My precious treasure! I love you, My David!”

(Before sending David it, a traditional calligrapher showed me a sample.)

During the interviews, parents mainly asked about their child's health and what would be in their best interest. In one instance, a grandmother and her grandchild asked me to create a calligraphic gift that read, “My precious treasure! I love you, My David.” Despite their love and commitment to

caring for a child or young person with LLCs, there was an information asymmetry when it came to determining what was in their best interest. While desiring their healthy life, the parents and their child make vital decisions. I found the different perspectives, by following Table 7-8.

Different Perspectives	
Physicians (Oncologists/Haematologists)	They will easily forget their experiences such as surgeries, medical treatments and so on. Because telling the truth will cause anxiety and some troubles , I could not talk about that. Lastly, parents do not want to be told truth. (Fieldnote, 7 th February 2018)
Nurses, Social Workers and Art Therapists	There is no formal or informal disclosure , and maybe medical doctors will deal with these issues. We do not have the authority to tell the truth. Medical doctors will deal with these issues. (Fieldnote, 8 th January 2018)
Parents	I was told that my child will easily forget their experiences such as surgeries, medical treatments and so on. I am unable to tell the truth . If I do, it will cause my child serious issues. I do withhold the truth from my child, to aid its recovery. (Fieldnote, 7 th November 2018)
Survivors from Cancer	I really wanted somebody to tell me what treatment I needed and what I needed to do in the worst case scenario, not some weird psychological test that didn't make any sense, but at least somebody to tell me what I needed to do and what I needed to prepare for in the course of treatment, and nobody told me, so I listened to what the doctor told me and I googled it, and I found out by googling it that there's a course of treatment. Fortunately, six months may be as short or as long as you want them to be, but it was a hard time for me. (2018/02/07, Lydia Brooks, Survivor)

Table 7-6 Different Perspectives for the Best Interests

Even though I was unable to interview CYP with LLCs owing to ethical issues, the findings from survivors, their families, physicians, nurses, social workers, and art therapists show CYP with LLCs hardly have the chance to ask about their diagnosis and rarely participate in decision-making with their family. When I scrutinised the whole process such as assessment, judgement, and the helping process, shared decision-making with CYP with LLCs has several limits, especially “participation of CYP” (Bell, 2011).

The importance of shared decision making is widely recognised by health professionals (Elwyn, Frosch, Thomson, *et al.*, 2012). I noted that in paediatric palliative care, social workers prioritise family-oriented decision-making processes and assess the involvement of children or young people with LLCs in these processes. However, it is often observed that the voices of these children are sidelined: the participation of CYP with LLCs in decision making processes is not disclosed and their right to consent or refuse medical treatment needs to be considered.

7.6 Conclusion: Family-Oriented Level of Decision-Making Processes - Failing to Ensure Shared Decision Making

This chapter has explored the family level of decision making. Those facing the unknown journey of decision making from diagnosis to end of life or survivorship should have the opportunity to choose from the wide range of options available. In order to understand the decision-making processes of CYP with LLCs, I have explored the unknown journey of decision making from diagnosis to end of life or survivorship and can suggest an assessment in terms of the family-oriented level. There are two stages, the beginning of the unknown journey and the unknown end of life.

In the first stage, I showed how the surrogate decision makers of CYP with LLCs and their parents tried to face the unknown journey. The results of this study show that social workers do not have the skills to give bad news to family members, whether it is recommending a move from home to school or hospital in the context of a clearly defined diagnosis, or an undefined diagnosis in the context of holistic care.

In the second stage, I explored the unknown end of life of CYP with LLCs and the use of the NICU and PICU, which does not provide a cold room. Despite the importance of these two stages, I found that CYP with LLCs are excluded from decision making processes in a critical event.

Section 7.4 highlighted the expectations and ethical challenges of paediatric palliative care social workers and their role in addressing psychological and social issues for patients and their families when telling the truth of CYP with LLCs is undervalued and bad news is not shared with them. Each year, at least 6,000 vulnerable people face an unwanted journey and difficult decisions. In contrast, the results of the study show that the faces and individualism of CYP with LLCs are quickly forgotten in health care settings.

Section 7.5 interprets the findings: family-oriented levels of decision making cannot ensure shared decision making and surrogates are not easily able to make decisions or assume their interests, based on Emmanuel Levinas' Other and Polanyi's and neo-Confucian family-oriented decision-making authority. There needs to be more time, more space and different perspectives on the best interests of CYP with LLCs.

Therefore, important findings of the study were revealed and confirmed. Firstly, CYP with LLCs were not involved in end-of-life decision making when they embarked on the unknown journey; secondly, the findings of this study are relevant to the unknown journey of decision making. Although

shared decision making is essential in paediatrics, there are complexities and limitations in the process, particularly in the involvement of CYP with LLCs. Chapter 8 carefully explores the tacit dimension of the decision-making process.

Chapter 8: The Tacit Dimensional Level of Decision-Making Processes: Internalised Oppression and/or the Psychology of Luck?

8.1 Introduction

This chapter aims to examine how social workers can identify the difficulties in the ethos of surrogate decision-making for CYP with LLCs through the following questions:

- 1) to find out the processes of decision-making for CYP with LLCs at the tacit dimensional level of decision-making processes.
- 2) to explore the expectations of social workers and the role in paediatric palliative regarding the processes of decision-making for CYP with LLCs.
- 3) to discover the ethical challenges in the ethos of surrogate decision-making.

Section 8.2 will reveal the reproduction of distorted beliefs in decision-making processes, oppression in the ethos of surrogate decision-making. Specific examples of biased beliefs, such as taboo, palliphobia²⁶, toxic faith, raising a child without medicine (*Anaki*), and avoidance of funeral preparations will also be described.

Regarding the distorted beliefs in deciding with the family, I will ponder perspectives such as the psychology of luck and the internalised oppression in decision-making processes in 8.3. For an understanding of the tacit dimensional level of decision-making processes, especially reproducing distorted beliefs, I will interpret the findings, based on the tacit dimension of Polanyi. When understanding the psychology of luck and the internalised oppression, finding the relationship between oppression, belief and luck can be possible in deciding with family. I conducted a total of 79 face-to-face interviews with parents and members of palliative care team members, including 50 interviews with cancer patients, 15 interviews with non-cancer patients, and 14 interviews with senior members of paediatric palliative care teams.

²⁶ According to Friedrichsdorf and Bruera (2018) “Delivering Paediatric Palliative Care: From Denial, Palliphobia, Pallilalia to Palliative” published in the Journal of Clinical Medicine, palliphobia refers to the fear of palliative care. It is a term used to describe the apprehension and reluctance that some healthcare professionals and patients' families may have towards discussing end-of-life care and implementing palliative care services. This fear may stem from a lack of understanding about the purpose and benefits of palliative care, as well as cultural and religious beliefs surrounding death and dying.

To understand decision-making processes with children or young people with LLCs, this chapter shows how social workers could identify the difficulties in the ethos of surrogate decision-making for CYP with LLCs through mainly understanding the tacit dimensional level of decision-making processes.

8.2 Reproducing Distorted Beliefs in Deciding with Family

This section illustrates that distorted beliefs in decision-making processes are associated with internalised oppression in the ethos of surrogate decision-making. Despite being irrational, surrogate decision-makers often hold onto distorted beliefs, such as linking denial and palliphobia to taboo and avoiding discussing a child's funeral. This section highlights the consequences of reproducing taboo in the decision-making process, which can ultimately hinder the best interests of CYP with LLCs as they face the unknown realities of end-of-life care.

8.2.1 Taboo: *Jaesu* - Tough Luck in Hospital

In the hospital, when talking about taboo people believe that “*Jaesue*” means to bring bad luck. If people believe that talking about death causes bad luck, this creates the taboo.



Figure 8-1 The Changed Number 4 as F in the Hospital

Although the Number 4 四 and the word death 死 are both pronounced *Sa*, their meanings are entirely different, because Korean people believe that the word is a reminder of death, the number was changed from 4 to F. When taking a left in any hospital, there is no “number 4”, but “F”. When talking about hospice or death, patients’ parents believe using the words will bring sudden death to their loved one. Instead of hospice or palliative care, palliative medicine is more common in an acute hospital. This is because those family beliefs related to “*Jaesue*” are classed as taboo and you should be careful what you wish for in the palliative care’s context.

During my research, one of the parents expressed a strong desire to protect their children from harsh realities, reflecting a deep protective instinct. One parent emphatically stated: "You should not tell my child the truth. They went on to explain their reluctance to have such conversations: "Even though I've heard that this is good research, I don't want to discuss it with my child. So I'm willing to take part in the interview, but I'm not willing to talk to my child about it. I am afraid that exposing them to such issues might have negative effects...".

This sentiment resonated with the Western proverbs "Be careful what you wish for" and "Don't jinx it! Stop saying such things! It's striking how similar these expressions are to the caution felt by parents, driven by an invisible force that made it almost impossible to discuss certain things openly. Many felt that talking about certain issues could bring bad luck or jinx the situation, as if mere words could bring misfortune. (Fieldnotes, 2nd November 2017.)

Parents like to hear we are just doing everything we can, whether it is western medicine, eastern medicine or praying. Shared decision-making requires to discuss informed consent, truth-telling, refusing treatments, withdrawing treatment and futility of treatment. Although informed consent and truth-telling are essential in decision-making processes, I found most parents are reluctant about how to start telling the truth.

It is my firm belief that when we decide to do something, we should hope for the best but also prepare for the worst. However, upon commencing fieldwork, I discovered that the use of taboo language, not only among carers but also among health professionals, led them to believe that preparing for the worst would result in worse outcomes. I translated life-limiting conditions as terminal illness. The families of the patients who read the article and the medical staff alike displayed a negative reaction,

“We don't have patients like that on our ward. How can you use such language?” (I could be heard muttering and gossiping behind his.) One of the family members was outraged and flatly

refused to be interviewed, saying, “*My son is not like this. I can't do this.*” (They used the pronoun *this* because they were reluctant to say the taboo words out loud.) (Fieldnotes 2nd November 2017).

Furthermore, I asked how much your child knows about these circumstances. The parents were unequivocal in their response: “My child does not know” and “You should not tell the truth because my child will be shocked” (Fieldnotes, 2nd November 2017). However, they frequently reconsider aggressive treatment in a desperate situation, believing it is their best option for their child. In PICU, one parent emphatically told a medical doctor, “We should do anything if there is any hope for my child!” With advice that suggests doing anything, regardless of feasibility, is beneficial for children, they sought aggressive treatments instead of “stopping such talk.”

Fifty-two bereaved family members declined to be interviewed, and only three were willing to meet and be interviewed. Only three family members were available to meet and interview the bereaved. On 22nd February, the doctor contacted the remaining families of the patients interviewed and expressed his frustration to me. During the interview with Mya Marsh on 16th November 2017, she mentioned that her child had received comprehensive care in the intensive care unit (ICU). However, she expressed her intention to file a complaint due to a comment made by the doctor Han that she found unsatisfactory. He told me that “sorry” was a forbidden word that should not be used with a patient’s family, as it implied that the doctor was at fault, which could lead to legal action²⁷.

Healthcare professionals are acutely aware of the challenges of decision-making and the vital importance of effective communication in caring for children and families. This includes active listening, honest responses and the provision of key information. However, there is a significant gap between the perspectives of parents and health professionals.

I found that some health professionals, particularly those holding *Jaesu* that discussions about the futility and withdrawal of treatment can lead to adverse outcomes. This clearly demonstrates the complex dynamics of surrogate decision-making, which are often further complicated by the hidden aspect of internalised oppression within the healthcare system. I have found that such topics are

²⁷ South Korea is currently discussing the implementation of an ‘Apology Law,’ similar to laws in countries like the United States, the United Kingdom, and Australia. These laws allow medical professionals to apologise to patients or their families without admitting legal liability, aiming to reduce conflicts and promote transparency. The Medical Reform Committee is also examining Japan’s model, where healthcare providers must explain the circumstances of a patient’s death to the family and report it to a dedicated support centre. (Seong-Soon Kwak, 2024)

typically seen as taboo, and there is a clear belief that addressing them directly can lead to serious repercussions.

8.2.2 Palliphobia

Although shared decision making in paediatrics should be linked to the highest quality evidence-based medicine, such as balancing the benefits and risks of different treatments and the clinical expertise and judgement of the clinician, patient and family preferences should not be undermined. In this section I will explore biased beliefs in the form of taboos. Surrogate decision making is related to the belief system of religion, attitudes, culture, superstition and stigma. Knowledge of the belief system can be analogous to action. Audi (2015: 27) says that “belief is profoundly analogous to action. Both are generally based on reasons; both are a basis for praising or blaming the subject; both are sensitive to changes in the environment; both can be properly described as objects of decision and deliberation, and beliefs can appear quite action-like when understood as formed by assent or acceptance”.

By observing medical settings and analysing testimonies, I identified ethical issues related to supportive, palliative and hospice care, informed consent, truth telling, refusal of medical treatment, and futility and withdrawal of treatment. Ethos is a Greek word that refers to a set of beliefs, the character of a person or community, the spirit, tone, attitude or custom that defines it. Before discussing these ethical issues, surrogate decision makers are reluctant to talk about palliative care and hospice due to biased beliefs of ‘denial’ and ‘palliphobia’ (Friedrichsdorf and Bruera, 2018). In this section, I will show that social workers in paediatric palliative care have not identified the ethical dilemmas that arise in the process of surrogate decision making, but that they are confronted with biased beliefs as taboo when making decisions, focusing mainly on a family-centred perspective.

To recruit interviewees for interviews, I posted flyers around the hospital. As the concept of hospice and palliative care needed to be translated into the Korean context, I also considered the history of the hospice and palliative care movement in Korea when selecting interviewees for the study. To recruit interviewees for interviews, I posted flyers in the hospital. As the concept of hospice and

palliative care had to be translated to the Korean context, I also considered the history of the hospice²⁸ and palliative care movement in Korea when selecting interviewees for the study.

아동 그리고 청소년과 함께 결정하는 것 한국 아동 호스피스 완화의료

Figure 8-2 Deciding with CYP in Korea's Children's Hospice and Palliative Medicine from 1st November 2017

Because hospice or end-of-life care is limited to those who are nearing the end of life, typically 6 months, 'palliative care' has been subsumed under 'end-of-life care' (Grinyer, 2012: 4). This should be applied as early as possible to any life-threatening condition to optimise quality of life, such as alleviating physical, psychosocial and spiritual pain. In other words, preparing for the end of life should start earlier than we expect.

I had some difficulties recruiting people for the study. I put up flyers in the hospital, but there was resistance when I used the word 'hospice'. Some medical staff were uncomfortable with the word and said it was not used in the hospital. I then encountered resistance when trying to recruit respondents from surrogate decision makers, even after being introduced to some parents by a doctor. When I asked probing questions about their experience of paediatric palliative care, I was met with anger and resistance. After hearing this, I spoke with the nurse in charge of paediatric patients. The nurse explained that patients and their carers felt a strong aversion to the word 'hospice'. We discussed this further over lunch. My experience showed me that the word 'hospice' is taboo in some hospital settings (Fieldnotes, 20 November 2017).

Interestingly, by using the word 'hospice', people are reminded of the fear of death at the end of life. Some medical staff read the flyer and said to me, "How can you use the word hospice?" It is not used in this hospital. I found out that the use of the word 'hospice' is forbidden, although palliative care does not exclude it. I had the opportunity to ask the interviewees a probing question: "Could you please describe whether your child was happy while receiving paediatric palliative care?" Despite an appreciation of the importance of this research, the detailed recollection of their facial expressions and

²⁸ The 'hospice movement' is an umbrella term for the growth of end-of-life and palliative care services in The Republic of Korea. In 1998, Korean society for hospice and palliative care was started to develop multi-disciplinary approaches, including both in the voluntary and statutory sectors.

emotional states remains with me. In response, they displayed uncontrolled anger, stating, “My child is not at that stage and is not about to die; how dare you!” I then took the opportunity to reassure the patient's carers and explain the terminology associated with palliative care. I emphasised that while active treatment was essential, palliative care also included the management of various types of discomfort. Essentially, the nurses lacked awareness of the scope of palliative care. Following my explanation, they reported feeling more comfortable and their anxiety, often referred to as ‘palliphobia’, was alleviated, allowing us to proceed with the interview (Fieldnotes, 20th November 2017). For 20 days, I was unable to find any interviewees among surrogate decision-makers because of the word ‘hospice’, although a doctor introduced me to some parents who had a child with LLCs. Through these experiences in an acute hospital, I found that the word ‘hospice’ can be taboo.



Figure 8-3 Deciding with CYP in Korea's Children's Palliative Medicine
from 20th November 2017

Eventually, the term ‘hospice’ was replaced in the flyer with ‘children's palliative care’. Field and Behrman (2003: 34) note that the term ‘end-of-life care’ lacks a precise definition. However, they argue that discussions about hospice care can precipitate or accelerate the process of dying. One of the medical social workers and nurses explained that in an acute hospital there are palliative care centres and cancer centres. However, adult patients and their families often believe that they will die if they are transferred to a hospice because of the taboo surrounding the word hospice. It is not uncommon for parents to describe a palliative care doctor as the ‘grim reaper’, which often leads to reluctance to meet them. As a result, the word ‘hospice’ seems to be taboo. When discussing hospice care, parents often claim that their child is not going to die imminently. Medical staff have indicated that parents tend to associate the term ‘hospice’ with a lack of hope and acceptance of fate.

8.2.3 Toxic Faith and/or 'Raising a Child Without Medicine (*Anaki*)'

Despite the general emphasis on EBM and shared decision making among health professionals, surrogate decision makers often struggle to determine the best course of action for CYP with LLCs. While evidence-based decision-making processes prioritise the best interests of CYP with LLCs, there is a challenge in reconciling this with the concept of 'wish fulfilment' (Welsh, 1994), particularly in the context of 'toxic faith' and/or the practice of 'raising a child without medicine *Anaki*'. These approaches advocate alternative methods, moving away from conventional medicine towards natural remedies and faith-based healing. This represents a clear ideological contrast, where the pursuit of best interests may diverge from traditional medical paradigms, creating complex decision-making for surrogate caregivers. I examined the influence of toxic faith and *Anaki* on decision-making, with a specific focus on the decision to pursue aggressive medical treatments or transition to survivorship. Most social workers and medical staff shared stories of their patients who practised toxic faith. The following is a social worker's experiences:

"While identifying the largest hospitals offering advanced medical treatments, it became evident that their faith often strengthened. I recall one individual stating that she held a strong belief that her son would resume a normal life after her preferred pastor offered prayers on his behalf. She mentioned that her child was currently undergoing treatment at the hospital but felt compelled to seek out this pastor for prayer. She was convinced that prayer alone would fully restore her child's health. Unfortunately, despite receiving the prayer, her child eventually passed away." (Junsu Son, Social Work, 21/03/2018)

People with unrealistic "wish fulfilment" in a religion agree to aggressive and/or futile medical treatments. In my fieldwork, documented on 2nd September 2017, I observed the profound impact of 'toxic faith' on a family coping with unexpected medical treatment outcomes. Initially seeking comfort and answers through their faith, the family increasingly allowed their religious practices to overshadow practical medical decisions, leading to a dysfunctional family environment. This case highlights how toxic faith can distort decision-making processes in critical health-related matters, particularly during medical crises. My field notes detail the gradual progression of her involvement in religious practices that promised healing and blessings, but ultimately exacerbated family dysfunction and led to misguided medical decisions.

The concept of ‘subtle forms of prosperity theology’ was particularly evident in an incident on the same day when I encountered a church’s ‘Ten Commandments of Faithful Living’, which promoted material blessings through spiritual acts. This observation raised concerns about how religious beliefs could exploit faith for material gain and influence decisions in sensitive areas such as paediatric palliative care. My subsequent research led to the book ‘Toxic Faith’, which provided a theoretical framework for understanding these observations. This book effectively linked my fieldwork findings to wider discussions about the negative impact of distorted religious beliefs on health practices, and highlighted the ethical issues this raises in medical decision-making.

Arterburn, Felton and Doucette (2001: 35) define ‘toxic faith’ as a destructive and dangerous involvement in a religion that controls a person’s life rather than fostering a genuine relationship with God. This type of faith often attracts individuals struggling with past trauma, dysfunctional family dynamics, unrealistic expectations or personal gain.

Another social worker shared her experience with me, and I found out about a phenomenon of raising a child with medicine called *Anaki*. Unlike palliphobia, *Anaki* is a kind of so-called ‘natural therapy.’ The family maintain distorted beliefs.

“My service user’s child was diagnosed with leukaemia... Due to Anaki, the child did not receive adequate medical treatment. After assessing all the circumstances, I reported it to the police.” (Minji Ahn, Executive Secretary/ Korean Association for Children with Leukaemia and Cancer, 13/02/2018)

The choice of *Anaki* in decision-making processes does not eliminate risk and does not guarantee natural therapy. The *Anaki* Movement provides children with potentially harmful folk remedies that have not been tested. When parents choose to involve their children in *Anaki*, they are often unaware of the potential for adverse effects on family dynamics and the well-being of their child or young person. In the course of my research, I examined the nexus between toxic faith and health perspectives in the context of paediatric cancer care. To this end, I drew upon insights gleaned from Mel Armstrong’s interview (2018), testimonies by An Jong-joo (Pressian, 2017), and an interview with Dr. Kim Hyo-jin, a proponent of the *Anaki* movement (JoongAng Ilbo, 2017).

The primary data for this research is derived from interviews with 50 cancer patients and 15 non-cancer patients, of whom 49 identified as Christians. The data set yielded instances of what could

be described as “toxic faith,” as defined by the framework established by Arterburn, Felton, and Doucette (2001). These observations are summarised in Table 8-1, ‘Toxic Faith and *Anaki*’, demonstrating how certain religious beliefs influence healthcare practices, with links to epistemic vice (Akrasia) through the interpretation of fieldnotes.

Toxic Faith	‘Raising a Child Without Medicine (<i>Anaki</i>)’
<p>“If I have real faith, God will heal my child. I must not stop meeting others’ needs. I must always submit to authority without doubt.” Fieldnotes 2nd September 2017</p> <p>“Having true faith means waiting for God to help me and doing nothing until he does.” Fieldnotes 7th November 2017</p> <p>“When believing the results will be fine and well; Should be joyful.” Fieldnotes 20th December 2017</p> <p>“A strong faith will protect and heal my child with LLCs from problems and pain.” Fieldnotes 2nd September 2018</p>	<p>“Charcoal feeding</p> <p>Chickenpox party</p> <p>Hot water therapy for burns, enema for a child with heat cramps</p> <p>For the treatment of colds in infants and children, fermented foods should be used.</p> <p>Burned children should be healed by bathing in warm water at 40 degrees Celsius.</p> <p>Essential vaccinations for infants and toddlers harm the child.” Fieldnotes 16th January 2018</p>

Table 8-1 Toxic Faith and *Anaki*

Furthermore, for those who combined toxic faith with *Anaki*, nobody could guarantee the best interests for CYP with LLCs. In addition, they believed that talking about dying or taking bereavement care is an extremely doubtful and distorted attitude. When meeting their “wish fulfilment” (Welsh, 1994), unsystematic and intuitive methods in decision-making processes came together. I found that there could be similar features in both toxic faith and *Anaki*, such as focusing on personal efforts and willingness and ignoring the evidence based on objectivity and probability.

Therefore, I found that the epistemic vice (Akrasia) is linked with interpretations in the community whether firmly holding toxic faith and/or *Anaki* in decision-making processes or focus on decision-making processes of medical treatments for the survivors for their child with LLCs.

8.2.4 To Avoid Child’s Funeral

On 16 November 2017, an interview was conducted with Mya Marsh, the mother of eight-year-old Minh Jeong. At the time of the interview, Minh Jeong was in the second stage of his illness, and Mya expressed optimism about his recovery, displaying a determined demeanour. However, in a

regrettable turn of events, as documented in my fieldnotes on (20th January 2018), I observed that Connor had sadly passed away subsequent to our initial discussion.

Subsequently, it was found that the remains of young people like Minho Jeong are usually taken to either a hospital mortuary or a funeral parlour. Funeral planning, which is an essential part of advance care planning for children with long-term conditions, involves a series of rituals carried out by family members and spiritual leaders. This process includes reflecting on the life of the deceased, supporting the bereaved family and friends, and finalising arrangements for the funeral and memorial service (Fieldnotes, 21st January 2018).

During this period of mourning, it was evident that the parents were experiencing deep grief. They were often crying and hiding their faces, indicating an inability to openly express their emotions at what was clearly the most distressing time of their lives. It was observed that a haematologist informed the researcher that many parents chose not to have a funeral because of deep-seated family taboos, although specific reasons were often not directly disclosed (Fieldnotes, 21st January 2018). I thought this insight was subsequently confirmed by further interviews with other bereaved families, which revealed that such decisions are significantly shaped by cultural beliefs about death and mourning, rooted in family ideas about taboos.

In contrast, the biggest unfilial piety should not follow in terms of Confucian ethics. One bereavement family shared their experience with me, observing that, “excluding my daughter, many parents avoided a child’s funeral. Parents who have lost their children are reluctant to prepare and conduct their child’s funeral. I was the first to conduct a funeral. Since my older brother runs a funeral house, I had the privilege.” Interestingly, I scrutinised the main textbooks such as 論語 The Analects of Confucius, 孝經 The Classic of Filial Piety and 擊蒙要訣 Kyōngmong yogyōl Key to Breaking Folly's Hold, which show the definition of filial piety and unfilial piety, but there is no principle, or any single case about banning a child’s funeral when a child dies before their parents because of the biggest unfilial piety. Although a child dying before its parents is the biggest unfilial piety, there are various causes of child’s funerals. Therefore, the belief of a child’s funeral is not unfilial piety, but it seems like ‘Chinese whispers.’

Lastly, due to superstitions, people will not attend a child’s funeral. Adult funerals usually consist of a 3-day service/ceremony. During this ‘mourning’ period, family members and friends visit the location of the deceased family to pay their respects. However, when a child or young person passes away, people are generally uncomfortable at the prospect of visiting the bereaved family. People believe that “you should not go to a child’s funeral” and “pregnant women and children should not go

to the rituals.” Superstition abounds when a child predeceases their parents, this even goes as far as believing bad luck will fall on any pregnant woman or child who attends the service/ceremony.

Therefore, overwhelming loss, the distorted belief of Confucian ethics about unfilial piety and superstitions may lead to an isolated funeral in the mourning process and bring taboo about CYP’ rituals. It may lead to a focus on the funeral service/cremation and place a barrier against bereavement care, which is a vital process to provide support to the bereaved. Not surprisingly surrogate decision makers did not only use appropriate guidelines, but also received useful intervention.

8.3 The Tacit Dimension in Deciding with Family: The Psychology of Luck and/or Internalised Oppression?

This section critically interprets the tacit dimension in deciding with family. This is because the findings are associated with the psychology of luck or internalised oppression in the ethos of surrogate decision-making. Considering the reproducing of distorted beliefs, I will present that the expectations for paediatric palliative care social workers are required to support and intervene in decision-making processes. It regards holistic care and improves quality of life. Regarding the expectations, paediatric palliative care social workers should understand reproducing distorted beliefs in deciding with family, this section presents two perspectives: the psychology of luck and internalised oppression in the ethos of surrogate decision-making.

In 8.3.2, considering the need for psychosocial support, the roles of nurses, social workers, and clinical psychologists overlap, especially in understanding about the psychology of luck in decision-making processes.

In 8.3.3, I found surrogate decision-makers hold their distorted beliefs regardless of the alleged relationship between oppression, distorted beliefs, and luck. Although the psychology of luck is undeniable, the hidden or unknown oppression was not revealed because there is no reason to hold and reproduce distorted beliefs in deciding with family. I employ Polanyi’s view of tacit knowing which has four aspects: the functional, the phenomenal, the semantic and the ontological as it enables the relationship in the decision-making processes between oppression, distorted beliefs, and luck. By showing both perspectives, I will reveal the relationship in the decision-making processes between oppression, distorted beliefs, and luck.

8.3.1 Expectations from Paediatric Palliative Care Social Work

There is an important expectation of medical staff: paediatric palliative social workers need to assess how best to share information, support or intervene in decision making with children. This is because, in 8.2, parents with distorted beliefs may project their values or beliefs and medical treatment preferences, while the best interests of the patient may be ignored. From a medical perspective, when a surrogate makes a poor decision, there should be some intervention or support in terms of the role of paediatric palliative care social work.

It is recommended that support is provided for decision-making processes that use holistic approaches, given the potential benefits in terms of informed choice and consideration of multiple factors. The complexity of decision making for CYP with LLCs arises when these vulnerable children are unable to communicate their thoughts and when their best interests are not taken into account in areas such as home care, school and the wider community, irrespective of medical treatments. The United Nations Convention on the Rights of the Child (UNCRC) (1989) states that individuals between the ages of 0 and 18 are considered to be children. However, the designation of 18 as the upper limit is a matter of debate among academics and practitioners. The International Federation of Social Workers (2015) asserts that social workers have a duty to provide optimal assistance without unjust discrimination based on factors such as gender, age, disability, colour, social class, race, religion, language, political opinion or sexual orientation. As might have been anticipated, this phenomenon was particularly evident in Confucian cultures, where unmarried individuals are often still regarded as children. This perspective was articulated during the course of discussions held at the Hospice and Palliative Care Association meeting (Fieldnote, 2nd December 2017).

The role also requires some intervention in decision-making processes. Social workers should be aware that distorted beliefs based on religious beliefs, attitudes, superstitions and cultural values may negatively influence the decision-making process of family members, potentially disregarding the best interests of CYP with LLCs. Children's decision-making and/or shared decision-making can be problematic in relation to vague notions of child and adult autonomy, as well as some conflicts between advocating for children's rights and reinforcing paternalism for 'child protection' (Bell, 2011). Where surrogate decision-making poses a risk to public health, it may be justified to restrict the exercise of autonomy. It is then difficult to know whether potential problems will arise, additional dilemmas will be created, or the right to autonomy will be restricted (de Graeff and Dean 2007). Due to these expectations and the oppression (see to section 6.4.5), I concluded that the two responsibilities of

paediatric palliative social work could not be harmonised. Although the misconceptions, namely the act of avoiding a child's funeral, may not have a direct impact on public health, parents experience illness and hidden grief and distress (see section 8.3.3.3). In terms of expectations, they should consider the psychological aspects of happiness and internalised oppression in surrogate decision-making. Surrogates may face moral issues in selecting CYP with LLCs due to biased views, different religious beliefs, cultures and superstitions. It is important for them to engage in critical thinking to overcome these challenges.

8.3.2 The Psychology of Luck?

Regarding the decision-making processes of surrogate decision-makers, where their ability, character or effort are underestimated, the uncontrolled outcomes may be more likely to be attributed to external factors, especially luck²⁹. There are some key issues to be considered in this part including the following:

- **“What factors influence when and why we attribute luck to some situations and not others? From a psychological perspective, what tend to be the markers of a luck event?**
- **Are people consistent in their luck attributions? If they are inconsistent, what accounts for their variance?**
- **How does assessment of lucky situations relate to assessment of risk?**
- **What role do our emotions play when we evaluate and respond to luck and risk? Does better emotional regulation correspond to better assessments?**
- **What factors influence how someone experiences luck? Is there any way to promote healthier responses to good or bad luck?”** (Church, I.M. and Hartman, R.J. *eds.*, 2019: 7-8).

I pondered the given questions which psychologists ask about how and why people attribute luck to certain situations when those who pursue the best interests for their child with LLCs, follow the tripartite analysis of belief in decision-making processes.

²⁹ Nagel (1979) mentioned that there are four kinds of cases such as “‘resultant luck’, ‘causal luck’, ‘circumstantial luck’, and ‘constitutive luck.’”

S decides on one of the given options.

S experiences the event after the decision.

S believes that the event is luck.

From a psychological perspective, I found that those who have distorted beliefs, inevitably face uncontrolled and unexpected results that may be interpreted as luck while deciding processes.

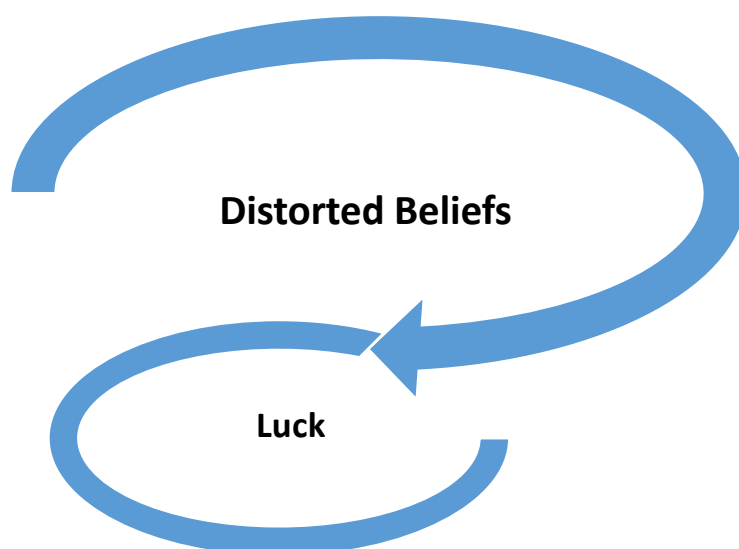


Figure 8-4 Distorted Beliefs and Luck

Figure 8-4, entitled 'Distorted Beliefs and Luck', reveals a noteworthy trend: patients from all social classes attribute their recovery and resumption of daily life to what they describe as 'medical luck'. This concept was elucidated through semi-structured interviews with families and paediatric palliative care teams, comprising physicians, nurses, art therapists, hospice chaplains, and social workers. The collective findings of the interviews, which included 50 interviews with families affected by cancer and 15 interviews with non-cancer affected families, both bereaved and non-bereaved, revealed a universal hope among caregivers and families for the patient's return to normalcy, regardless of the severity of their condition. This phenomenon was observed even when patients were transferred between intensive care units.

On 25th December, 2017, I revisited Lawrence J. Schneiderman's *Embracing Our Mortality: Hard Choices in an Age of Medical Miracles* (2008), focusing on the themes of medical miracles and

the role of ‘medical luck.’ Schneiderman critically examines how societal expectations and hospital marketing shape perceptions of medical miracles, influencing our views on fate and fortune in healthcare (2008: 89, 97). His work provides a vital theoretical framework for understanding the intricate relationship between ‘medical luck’ and ethical decision-making in medical settings (2008: 98-99).

During my fieldwork, I engaged extensively with stakeholders in paediatric palliative care, whose stories and insights painted a vivid picture of how beliefs in luck influence medical interactions. Documented meticulously in my fieldnotes, these encounters illuminated the nuanced role that ‘medical luck’ plays in the lives of families and caregivers navigating the uncertain paths of life-limiting conditions. The profound impact of these cultural beliefs on healthcare dynamics underscores the intricate ways in which luck is woven into the fabric of medical decision-making, shaping experiences and expectations in profound ways.

Surrogate decision makers have the capacity to understand and acknowledge the presence of epistemic luck. Surrogate decision makers need to consider internal elements while adopting a bottom-up approach that combines the best external evidence with their own clinical experience and conclusions. Surrogate decision makers may have epistemic luck due to variations in their ability to detect biased beliefs, which can be attributed to internal variables.

Although individuals may hold biased views and vary in their ability to detect biased beliefs, these internal characteristics can be attributed to their epistemic luck. When it comes to providing psychosocial support, there is considerable overlap between the roles of nurses, social workers and clinical psychologists, particularly in their understanding of the psychological aspects of decision making related to luck.

8.3.3 Internalised Oppression?

In examining decision-making processes for CYP with LLCs, I observed that surrogate decision-makers often harbour their own distorted beliefs, which appear to persist irrespective of the commonly acknowledged interplay between oppression, distorted beliefs, and luck. The influence of luck in psychological terms is undeniable; however, the covert or unrecognized forms of oppression remain undisclosed, as there seems no apparent justification for these distorted beliefs to continue influencing family decision-making dynamics. From an ethical and knowledge-based standpoint, the

concept of luck introduces a delicate paradox, creating a discord between moral and rational justifications in decision-making processes. Risk and the element of luck in surrogate decision-making can lead to complex dilemmas or unforeseen outcomes (Dickenson, 2003: 65). Hence, I employed Michael Polanyi's notion of tacit knowledge, which incorporates functional, perceptual, semantic, and ontological elements, in order obtain a deeper comprehension of the fundamental dynamics involved in decision-making that connect oppression, erroneous beliefs, and luck.

8.3.3.1 The Psychology of Luck and/ or Internalised Oppression?

Regardless of the age of most parents who are surrogate decision-makers, they desired a healthy life for their child rather than a hospitalised life but did not think about the unexpected results while going on the unknown journey of decision-making to tolerate emotional distress. When the results of decision-making and luck are connected and interpreted, risk and luck in decision-making can possibly lead to perplexing problems or unexpected results (Dickenson, 2003: 65). However, there should be a distinction between the psychology of luck and internalised oppression in decision-making processes.

When I asked, *"Could you describe the events if there were good communications between multidisciplinary palliative team members?"*, the responses from the majority of the 65 interviewees indicate a notable semantic aspect: while only four individuals demonstrated familiarity with hospice and palliative care, they nevertheless articulated their experiences and requirements regarding the provision of a cool room and support for family members. In contrast, the majority of respondents placed a higher value on prompt medical intervention and recovery, indicating a strong reliance on the authority of the physician, regardless of shared decision-making. This emphasis on prompt treatment reflects a pervasive cultural expectation that medical professionals' directives should be followed unquestioningly, thereby obscuring the potential benefits of comprehensive communication within multidisciplinary palliative care teams. This finding highlights a deeply entrenched belief in the primacy of curative efforts over the communicative processes that are integral to holistic palliative care. It illustrates a significant cultural and semantic gap in the understanding and acceptance of palliative care principles among the general population. Their preference for curative treatments over palliative care may limit the integration of palliative care into the care plan, which may lead to suboptimal outcomes for the child and family. While the shared decision-making model emphasises the importance of considering all available options, it may not always be practical in situations where curative treatments are perceived as the only viable option.

In the course of my observations during rounds with the medical team, I noted instances of misinterpretation of interactions between doctors and parents. One noteworthy occurrence took place outside the ICU, where the attending physician promptly conveyed the patient's current condition and impending alterations in their treatment plan. The parents did not pose any queries, indicating that they had not fully comprehended the specifics of the explanation. Subsequently, upon revisiting the parents in the ICU to ascertain whether they had comprehended the doctor's morning briefing, it became evident that a significant misunderstanding had occurred. The parents conceded that they had not fully grasped the information provided and expressed a passive acceptance of the medical process, stating, "We just have to believe." This emphasised a dependency on authority over an engagement in informed decision-making, thereby underscoring the vital necessity for effective communication within healthcare settings to empower patients and their families to make informed decisions, rather than fostering reliance on unchecked beliefs (Fieldnote, 18, November, 2017).

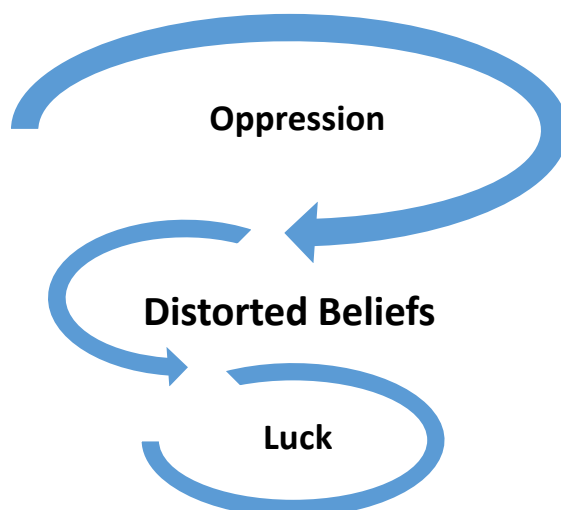


Figure 8-5 Oppression, Distorted Beliefs and Luck

Notwithstanding the recommendations set forth in the clinical guidelines published by the American Medical Association (2003: 58), which call for medical professionals to propose specific interventions, this case study revealed no evidence of such action. According to Figure 8-6, this oversight complicates the decision-making process, intertwining it with elements of oppression, distorted belief, and perceived luck. As a result, the process resembles less a balanced decision-making process and more a unilateral imposition by authoritative figures (Fieldnote, 18th November, 2017).

In 8.2, I provided an elaboration of the concept of distorted beliefs. Nevertheless, these beliefs persist, exerting a significant influence on the concept of medical luck, which can be understood

through Polanyi's concepts of focal and subsidiary awareness. In this context, focal awareness is directed towards the explicit outcomes of medical interventions, which are often subject to a degree of chance, and which occupy the immediate attention of decision-makers. Conversely, subsidiary awareness operates subtly in the background, influencing decisions through deeply ingrained, often unexamined beliefs about the nature of illness, treatment efficacy, and destiny (Polanyi, 1966: 20). These beliefs, operating as subsidiary elements, provide support and information to the focal awareness, resulting in decision-making where empirical evidence and rational judgement are overshadowed by reliance on fate and unchallenged assumptions (Polanyi, 1966: 135).

Furthermore, this situation exemplifies Polanyi's notion of the 'tacit dimension', which posits that unspoken elements of knowledge and belief have a significant impact on how medical communications are perceived and understood. These tacit elements, although often unnoticed, exert a significant influence on perceptions and interactions within complex systems like healthcare. This underscores the need for heightened awareness and critical examination of the underlying assumptions that influence medical decisions (Polanyi, 1966: 55). Polanyi would likely highlight that this misalignment could result in misunderstandings, errors, or oversights due to the presence of focal and subsidiary awareness. For example, if a medical decision-making process is unduly influenced by focal awareness such as relying exclusively on a specific clinical outcome without considering the broader patient needs or ethical considerations, it may fail to take into account important subsidiary inputs, such as patient values, past experiences, or non-verbal cues, which are essential for a fully informed decision.

By examining the functional aspects of decision-making within the context of paediatric palliative care, it emphasises the interplay between the psychology of luck and internalised oppression. Polanyi (1969: 146) articulates this through the concepts of focal and subsidiary awareness, which he describes as a dual structure of understanding (Polanyi, 1966: 135). Focal awareness refers to the primary objective of the surrogate decision-makers, namely, the restoration of the child's normal life. In contrast, subsidiary awareness pertains to the practical aspects of selecting medical treatments that optimise the child's well-being (Polanyi, 1969: 147).

Effective decision making requires the integration of both focal and subsidiary awareness in order to navigate the complex dynamics between chance and entrenched beliefs. This holistic approach ensures that decisions are not driven solely by overt outcomes or unchecked assumptions, but are informed by a balanced consideration of both explicit goals and underlying contextual factors.

Polanyi would suggest a re-evaluation of decision-making processes to ensure that neither form of consciousness is overlooked. He would suggest the implementation of training programmes and practical exercises designed to promote the recognition and balancing of both forms of consciousness. Such a shift may require a re-evaluation of prevailing cultural and institutional norms to increase the value placed on this integrated approach.

In addition, my research suggests that there is an urgent need for a critical examination of persistent distorted beliefs that can impede rational decision-making in this area (Smith, 2002: 171-176). Tsoukas (2005: 98) also advocates this perspective, emphasising the need for an integrated awareness of tacit knowledge for effective decision-making in complex and emotionally charged contexts.

8.3.3.2 Jeong (情) Based on Deciding with Family?

Decision making should be based on evidence-based medicine rather than other factors. Although surrogate decision makers believe that the event was lucky, they maintain irrational beliefs. decision-making processes are also associated with complicated and unexpected outcomes. Although the results are not their fault, pondering the complexity of physician paternalism, parental preference, and patient autonomy, and personal or family perspectives of luck. In pursuing the best interests of CYP with LLCs, surrogate decision-makers should have planned under uncertainty to better articulate the importance of patient-centred care and shared decision making, particularly ‘weighing benefits and burdens’ (British Medical Association 2012: 24). Echoing Polanyi’s ontological aspect of tacit knowledge, the concept of Jeong (情)³⁰ offers valuable insights into the structural dynamics of decision-making processes. This ontological perspective emphasises that *Jeong* is not simply an emotional expression; it is a fundamental element in the dialectical interplay of knowledge systems in

³⁰ During my fieldwork on 29 November 2017 in a hospital school, I was reading English children's books with the children. One child's mother asked if I could read to her child for about 30 minutes while she attended to an urgent matter. Afterwards, she thanked me repeatedly for spending time with 'our child'. This use of 'our' instead of 'mine' struck me deeply and led me to reflect on the unique collective sentiment embedded in the Korean term 'Jeong'. This concept, which Daniel Tudor translates as 'the invisible hug' in his book *Korea: The Impossible Country* (2012), resonated with my observations. It provided a crucial lens for understanding the interconnectedness and communal bonds that characterise Korean social and family relationships, and influenced my exploration of how Jeong influences decision-making in paediatric palliative care.

Korean culture. In this context, *Jeong* represents not only a reflection of shared emotional bonds but also a critical underpinning that influences how decisions are perceived and made. It encapsulates a multifaceted web of personal, familial, and societal elements, emphasising the significant influence of tacit knowledge on not only individual choices but also on this concept. This aligns with Polanyi's portrayal of tacit knowledge as a potent undercurrent that influences both individual and collective ethos, operating beyond the scope of explicit awareness (Polanyi, 1966: 4).

Firstly, *Jeong* influences Koreans' decision-making and social structures in Korean society, especially we-ness feelings and experiences. This is because it is very useful to understanding the Korean indigenous emotion and its relation between family and social structures.

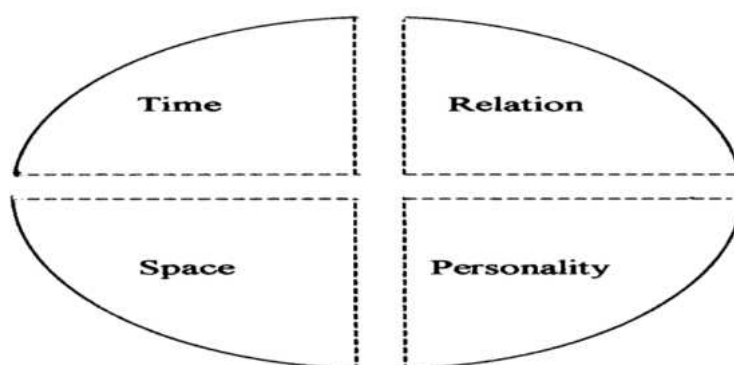


Figure 8-6 Structural Topography of Cheong properties

Source from Choi and Choi, 2001: 74.

Choi and Choi, (2001:76-78) found that the structural characteristics underpin the culture-bound concept of *Jeong*. Through the four dimensions of *Jeong*, time, space, personality and relationship (Choi and Choi, 2001), Koreans have *Jeong* feelings of we-ness and show the humanistic side. CYPs with LLCs are called 'our daughter' or 'our son' by medical staff, and they in turn are called 'our teachers'. Surrogate decision makers have experienced *Jeong* through time, space, relationship and personality as they embark on the unknown journey of decision making, such as the start of the unknown journey, the unknown treatments and the unknown end of life, resonating with Polanyi's assertion that tacit knowledge is segmentally articulated through personal and communal experiences (Polanyi, 1966: 17). They shared feelings and experiences of we-ness in the hospital. Calling our *woori* cannot be translated directly from Korean into English because in Western countries no one calls 'our child' but 'my child'. Choi (2007) insists that we-ness, calling 'our *woori*', does not

have a possessive meaning, but shows the relationship of social connection as a family group. It does not correspond to singular use and possessive meanings, but shows markers of group membership.

Rooted in the community-based concept of *Jeong*, families advocate for 24-hour access to paediatric palliative care specialists, paediatricians, or specially trained palliative care teams. This is driven by the cultural value placed on communal support and collective well-being, illustrating how *Jeong* shapes healthcare expectations and practices.

Interestingly, decision-making processes influenced by *Jeong* do not primarily engage with rational assessments, such as weighing benefits and burdens, typically expected in medical decisions. Medical staff who prioritize rationality in decision-making processes may exhibit they are said to be the characteristics of *Jeong*-less persons, such as cool-headed and apathetic characteristics. Polanyi's discussion on the tacit dimension demonstrates that such deeply held beliefs and practices, though seldom fully articulated, exert a significant influence on perceptions and actions within healthcare systems (Polanyi, 1966: 55-92). In contrast, becoming a *Jeong*-full person and showing altruistic tendencies and concern for the interests of others does not meet their wishes in decision-making processes. Because the priority of decision-making is to alleviate pain and improve quality of life, both the characteristics of a *Jeong* -full and *Jeong* -less persons are needed.

The Characteristics of a <i>Jeong</i> -full Person	The Characteristics of <i>Jeong</i> -less Persons
<ul style="list-style-type: none"> 1. Altruistic 2. Tender 3. Foolish-Kind 4. Concern for others 	<ul style="list-style-type: none"> 1. Lacks sympathy for others' pain and problems 2. Selfishness 3. Cool-headed 4. Apathetic

Table 8-2 Jeong -full vs Jeong -less Persons

Source from Choi and Choi, 2001: 78-79.

Over the course of eight months, I encountered significant challenges in securing interviews with bereaved family members. However, I conducted interviews with a total of 17 people who had successfully survived cancer within a period of just two months. I discovered that those who have lost a loved one experience a sense of disconnection, known as *Jeong*, in various aspects of their lives. Even among cancer survivors, feelings of isolation and detachment can be present in a variety of settings, including home, school, work, neighbourhood and community. Rather than prioritising rationality in their decision making, they prioritise their bonds within a family-oriented decision-making process. This cultural framework often leads to feelings of betrayal or profound frustration

when outcomes deviate from expectations, highlighting a significant emotional dimension in the decision-making process.

Furthermore, the absence of logical reasoning in decision-making processes is directly linked to the manifestation of internalised oppression in decision-making. This divergence is consistent with Polanyi's concept that tacit knowledge frequently results in actions that are not entirely rational but are significantly influenced by an internalised coherence of experiences and values (Polanyi, 1969: 141). This is because the maintenance of *Jeong* within the community, particularly in family-oriented decision-making processes, requires fundamental values such as trust, loyalty and commitment. The presence of irrationality in decision-making processes does not guarantee an improvement in trust, loyalty and commitment.

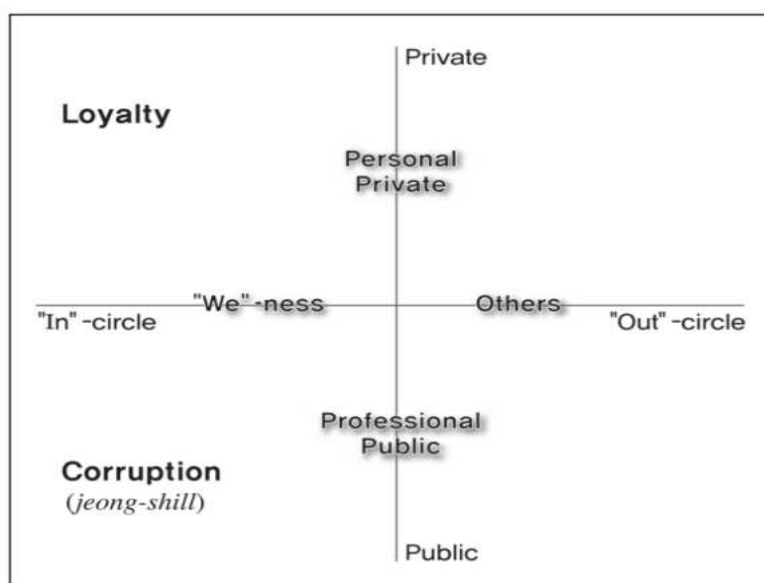


Figure 8-7 In-Circle vs. Out-Circle

Source from Chung and Cho (2006: 52)

When depending on *Jeong*, family members finally become betrayal or frustration. Chung and Cho, (2006: 50) show “*Jeong* becomes the intense psychological trauma of *Haan* (恨), and eventually *Hwabyung*, occurs where unquestionable loyalty and trust is expected and mandated. Therefore, only where *Jeong* has been strengthened and cultivated (in Korean terms, “*Jeong Eel Dondok Hee Ha Da*”) does *Haan* result as a reaction to its violation; *Jeong* is a basic Korean culture-specific emotion and a prerequisite to *Haan*.” Although maintaining irrational beliefs in decision-making processes is unreliable, because of *Jeong* in decision-making processes they believe that epistemic authority in relation, altruistic attitude and behaviour are more reliable than rationality.

From Polanyi's ontological perspective of tacit knowledge, it becomes evident that these cultural phenomena inform decision-making subconsciously. It can be posited that families influenced by *Jeong* may give precedence to decisions that serve to reinforce relational ties and collective well-being. This would illustrate how tacit knowledge operates through emotional connections, rather than through the application of articulated rules or principles. Similarly, decisions influenced by *Haan* often seek to alleviate or address deep-seated emotional scars, thereby demonstrating how tacit knowledge governs actions through the influence of deeply ingrained feelings and shared histories. This complex interweaving of *Jeong* and *Haan* within the context of family decision-making underscores the necessity for an approach that respects these tacit dimensions of knowledge, acknowledging their pivotal influence on the manner in which decisions are reached.

8.3.3.3 火病- “Fire Illness”

On 5 April 2018, I attended the tree planting ceremony for the Humidifier Disinfectant Victim Memorial Forest in Noonul Park, and on 5 March 2018, I attended the 11th anniversary of Yumi Hwang, and observed the deep grief of families at both annual events. After these events, although it was difficult to clearly describe their symptoms, Minah Kim, a nurse and counsellor, informed me on 18 May 2018 that many family members who lost their children were suffering from *Hwa-byung*. The examination of decision-making processes reveals the coexistence of two forms of knowledge: tacit and explicit. Polanyi (1966: 4) posits that there is a distinction between knowing and telling, whereby we can know more than we can tell. In the process of grappling with the intricacies of decision-making, the personal involvement therein reveals the existence of tacit knowing from a phenomenological standpoint. This phenomenon is consistent with Polanyi's description of the tacit dimension, whereby he posits that tacit knowledge encompasses the ancillary awareness that individuals possess regarding their corporeal experiences and emotional responses. This forms the foundation upon which more conscious actions and decisions are informed and shaped (Polanyi, 1966: 22). Polanyi (1983: 15) asserts that “our body is the ultimate instrument of all our external knowledge, whether intellectual or practical.” Tacit knowing refers to the knowledge of how to perform tasks, although surrogate decision-makers did not provide any information. This is a Korean culture-bound syndrome, characterised by symptoms that embody profound emotional and communal distress, yet often remain unarticulated (Polanyi, 1966).

From a phenomenological perspective, this can be considered a Korean culture-bound syndrome, which is prevalent among marginalised groups in Korea. The term 'invisible suffering', or *Hwa-byung* (화병) in Korean and 火病 in Chinese, denotes a condition characterised by a range of symptoms, including a sensation of a mass in the epigastrium or a fear of impending death. This phenomenon, as described by Polanyi (1967: 18), exemplifies a key aspect of tacit knowledge: it is known through personal experience and manifests in ways that can be challenging to communicate, yet are profoundly felt. This phenomenon is consistent with Polanyi's description of the tacit dimension, whereby he posits that tacit knowledge encompasses the subsidiary awareness that individuals possess regarding their bodily experiences and emotional responses. This subsidiary awareness informs and shapes the individual's more conscious actions and decisions (Polanyi, 1967: 22).

Christopher K. Chung and Samson J. Cho (2006: 46) define that “*Hwa-byung*³¹ is classified as a culture-bound syndrome with many somatic/anxiety symptoms, such as feelings of a mass in the epigastrium, fear of impending death, aches/pains, and palpitations by the DSM-5” The symptoms could be ineffable knowledge: when a disease is diagnosed through these symptoms, it becomes a phenomenon of tacit knowledge.

After facing unexpected results in decision-making processes, bereaved family members have some show *Hwa-byung*. While going into an uncertain journey, patients and surrogate decision makers have a dynamic experience of changes in illness such as chronic illness, prognostication, transition, recurrence, survival, death, and bereavement care (Wang, S.Y., Hsu, S.H., Aldridge, M.D *et al.*, 2019; Jindal-Snape, D., Johnston, B., Pringle, J., Kelly, *et al.*, 2019; Izumi, S., Noble, B.N., Candrian, C.B *et al.*, 2020; MacArtney, J.I., Broom, A., Kirby, E., Good, *et al.*, 2015; Killackey, T., Lovrics, E., Saunders, S. *et al.*, 2020).

I found that the phenomenon of tacit knowledge in paediatric palliative care allows a deeper understanding of these internal struggles, which may manifest as symptoms associated with *Hwa-byung*. Although the full extent and severity of symptoms could not be fully ascertained, among those who participated in the interviews, several individuals reported experiencing symptoms similar to

³¹ *Hwa-byung* and posttraumatic embitterment disorder seems like a similar Korean culture-bound syndrome. However, Soohyun Joe, Jung Sun Lee and Seong Yoon Kim (2017) present “Posttraumatic embitterment disorder (PTED) is characterized by states of “embitterment”, characteristically similar to “*hwa-byung*”, which is a Korean culture-bound syndrome. These results suggest that PTED may be a disorder category that is distinct from *hwa-byung*. PTED and *hwa-byung* have different clinical features. The study also suggests that embitterment is not merely a feeling of inner anger as is often associated with *hwa-byung*. *Hwa-byung* was related more to the suppression or partial expression of anger, while PTED was more associated with depression. Finally, the results indicate that PTED and *hwa-byung* is not an overlapping diagnosis.”

those of *Hwa-byung*. There was a visible display of symptoms similar to those of *Hwa-byung*. The depth of unspoken grief was often most evident in the tear-filled eyes of those who declined to share their stories, underscoring an unwillingness to share, or even partially unburden, their emotional turmoil. This reluctance reflects a profound impact of grief and suggests a communal sharing of grief that remains unarticulated, suggesting a collective experience of internalised oppression in the decision-making process. While these symptoms are important for diagnosis, they may also represent a form of inexpressible knowledge, reflecting internalised oppression within the decision-making process. This understanding highlights the emotional turmoil that lies beneath the surface, as observed in the tearful eyes of both participating and non-participating families, which speaks volumes without the need for words. Tacit knowledge in these cases becomes a vital tool in recognising and understanding the layers of suffering that lie beneath the surface, which is an integral part of paediatric palliative care. Thus, it can be connected to internalised oppression in decision-making processes from a phenomenological aspect.

8.3.3.4 Hidden Haan “恨”- “the Invisible Grief and Suffering”

Interview 7 April 2018: Minsu Choi, the father, talks about the loss of his daughter, Wonjun Choi, who died of chronic respiratory disease at just 50 days old. Even though she is no longer with us, I still keep our daughter close to my heart. I keep her photos close to me. She left this world far too early and I feel unable to share my grief with anyone. You tell me to keep her memory in my heart - but how easy is that to do?

Haan “恨” is a Korean culture-bound grief and suffering and can be easily found in Korea, especially in decision-making processes for marginalised groups, but due to *Haan* “恨” meaning “the invisible grief and suffering” in decision-making processes, the complicated mood is complexed when social workers assess and understand it. Kyong-Dong, K., (2017: 17) defines that *Haan*, which reads 한 in Korean and 恨 in Chinese, means “a complex mixture of the emotional sense of frustration and remorse, arousing feelings of regrets and revengefulness.” Chung and Cho (2006: 50) pointed that “*Haan* is key to the pathological process of the development of *Hwa-byung*,” having the signs of *Haan* (Chung and Cho, 2006; Min, Lee and Han, 1997) such as chest stuffiness/oppression, epigastric mass, sighing, tearing, and much talking (*Hasoyeon*). Regarding the complicated mood, Tudor (2012) translates the Korean words ‘*Haan*’ to invisible suffering and I added grief as well.

In terms of a semantic aspect of Polanyi, in order to understand both *Haan* 恨 and *Hwa-byung* 火病, Polanyi's framework provides a comprehensive insight into how tacit knowledge, through its functional and phenomenal aspects, affects the decision-making processes of surrogate decision-makers in healthcare. Polanyi (1983: 24) states that these aspects are not isolated; rather, they interact dynamically through a process he terms 'indwelling' (Polanyi, 1966: 4), which allows meanings to circulate and influence perception and decision-making. It is essential to understand this interaction in order to grasp how those acting as surrogates can successfully navigate the complex medical and ethical landscapes they encounter.

Cultural beliefs and values frequently prompt surrogate decision-makers to ascribe outcomes to what Polanyi characterises as 'moral luck'. This concept emphasises that outcomes are often perceived as dependent on factors beyond an individual's control, thereby illustrating a broader, culturally embedded tendency to blame. The assertion that one is powerless to affect the outcome, or that it is the will of a higher power, illustrates the extent to which deeply held beliefs influence medical decision-making processes and reflect a tendency to blame. The combination of functional awareness, which concentrates on the practical elements of medical data, with phenomenal awareness, which encompasses the cultural and emotional aspects, demonstrates Polanyi's perspective that knowledge is both individual and significantly affected by the social context (Polanyi, 1966). This fusion of perspectives is crucial in how surrogate decision-makers weigh clinical information against their personal and cultural insights.

Due to their luck attributions, surrogate decision-makers blamed themselves. However, the surrogate decision-makers do not know they are surrounded by forms of oppression while struggling with *Haan* 恨 and *Hwa-byung* 火病. In the guilty feeling, family-oriented preferences are highlighted, but there is no explanation of medical futility. Regardless of the discussion of futile treatments, CYP with LLCs are excluded from the decision-making process. Survivors shared with me their experiences when the CYP were not recognised as having a life-limiting condition, they were worried about the outcome. Armstrong-Dailey and Zarbock, (2009: 62) said that "Kubler-Ross said that children are not afraid of death—they are afraid of abandonment. When surrounded by love, joy, and hope, children hold on to their fragile lives." Interestingly, there were neither providing advance care planning nor the discussion of medical futility: emergency rooms, PICUs and emergency interventions, especially cardiopulmonary resuscitation CPR. The reasons will be more explored in next chapter.

In addition, when experiencing an overwhelming loss, some parents may struggle to share their grief and may choose to avoid holding a funeral. This may lead to a lack of emotional support during

the mourning process, leaving parents to bear the full burden alone without the aid of family or friends. Such individuals may feel isolated when dealing with the emotional weight of the situation. I found that that parents who have lost a child are often unable to share their overwhelming sense of loss with others, despite their attempts to seek relief from the uncontrolled pain that accompanies such a loss. This burden is often borne alone, without the support of family or friends, compounding the already difficult situation. When the child predeceased the parent, Koreans said it is *Chamcheog* 慘慼: ‘*Cham* (慘)’ means wrenching and ‘*Chuck* (慼)’ means lamentation. In Korean, a husband who has lost a wife is a widower (*Hol-abi*), a wife who has lost a husband is a widow (*Hol-eomi/ Gwabu*, 寡婦), and a child who has lost a parent is an orphan (*Goa*, 孤兒). However, there are no proper nouns to describe parents who have lost their children. According to a Korean Proverb, parents are buried in the ground, whereas children are buried in the heart.

Expression of both *Chamcheog* and burring in the heart of parents does not refer to the subject of suffering, but only describes the suffering situation. People believe that parents who have lost their child have to deal with the loss for themselves, taking the burden without support from others.

Furthermore, Koreans believe that it is the biggest unfilial piety when a child dies before their parents. Because filial piety is a cardinal cultural norm and Korea as an Asian society has been influenced by Confucian culture (Kim, Kim & Hurh 1991; Kim and Hurh, 1991; Koyano, 1996; Daisaku (1983). People believe unfilial piety should be avoided because filial piety is virtue, whereas unfilial piety is vice. Bereaved family members shared with me what they and their family experienced when preparing the funeral for their child or why they gave up, following that: “If a child dies before their parents, a funeral is not necessary because it is unfilial piety” and “preparing ritual services for children is blaspheming against our ancestors.” The norm of filial piety is highlighted when CYP are educated. Choi (2004) conducted a survey to explore the general public's perception of filial piety and its motivations in modern society. The survey identified desirable motivations for conducting filial piety, including love and affection for parents, respect for parents, gratitude for parental support, promotion of family harmony, and respect for human beings.

8.4 Conclusion: The Tacit Dimensional Level of Decision-Making Processes - Internalised Oppression

This chapter has explored the tacit dimension of decision making. In 8.2, the reproduction of distorted and/or irrational beliefs in decision-making processes, distorted beliefs are irrational, but surrogate decision-makers hold on to the distorted beliefs. Examples include taboos, linking denial and palliophobia, and avoiding a child's funeral. As a result of distorted beliefs, decision-making processes hinder the best interests of CYP with LLCs.

In 8.3 I have critically presented that the expectations of paediatric palliative care social workers are to support and intervene in decision-making processes in relation to holistic care to improve quality of life. By reflecting on the tacit dimension of decision making with the family, I found the relationship between oppression, belief and happiness in relation to decision making for CYP with LLCs: To understand the reproduction of distorted beliefs in decision-making processes, there are two perspectives: the psychology of luck and internalised oppression. In terms of the psychology of luck, I found that those with distorted beliefs inevitably face uncontrolled and unexpected outcomes that can be interpreted as luck in decision-making processes. Although the perspective reveals the relationship between distorted beliefs and luck, neither the maintenance of oppressive decision-making processes nor the reproduction of oppressive decision-making processes was included in the psychology of luck.

I employ Polanyi's view of tacit knowing, having four aspects: the functional, the phenomenal, the semantic and the ontological as it enables the relationship in the decision-making processes between oppression, distorted beliefs, and luck. Firstly, in terms of the functional aspect of Polanyi's tacit knowledge, the decision-making processes can be distinguished whether the psychology of luck or internalised oppression in decision-making processes. Secondly, based on Polanyi's ontological aspect of tacit knowledge, *Jeong* (情) reveals to reflect the structure of knowing and corresponds to knowing in a dialectical sense in decision-making processes. Thirdly, after facing unexpected results in decision-making processes, bereavement family members have some show *Hwa-byung*. The symptoms could be ineffable knowledge: when a disease is diagnosed by these symptoms, it becomes a phenomenon of tacit knowledge. Finally, in terms of a semantic aspect of Polanyi, in order to understand both *Haan* 恨 and *Hwa-byung* 火病, Polanyi (1983: 24) shows that functional and phenomenal aspects create meaning through the indwelling and circulating processes between functional and phenomenal awareness. Polanyi (1983: 15) says that "our body is the ultimate instrument of all our external knowledge, whether intellectual or practical". Tacit knowledge refers to the knowledge of how they did and should do things, although the surrogate decision makers did not say anything. I have critically explored the tacit dimensional level and can suggest an assessment of the tacit dimensional level of decision-making processes when deciding for the best interest.

In choosing CYP with LLCs, there is a psychology of luck and/or internalised oppression in the decision-making process. Due to the relationship between oppression, belief and luck, I have found that in making decisions for CYP with LLCs, internalised oppression is hidden in the decision-making process and people desire the psychology of luck. Thus, pursuing the best interests and making decisions for their CYP with LLCs is more complicated without understanding the tacit dimensional level. Without understanding the internalised oppression in decision making, social workers cannot recognise the difficulties in the ethos of surrogate decision making. In the next chapter, Chapter 9, the privilege level of decision making is carefully explored.

Chapter 9: The Privilege Level of Decision-Making Processes: Epistemic and Moral Luck and/or Social Inequality?

9.1 Introduction

During this time, I was constantly involved in observing and reflecting on the children's palliative care programmes and observing team meetings. Through observation and interviews, I found some similarities in both inpatient and outpatient care for cancer and non-cancer patients in terms of the level of privilege in decision-making processes. In order to understand the level of privilege in decision making, I will explore the level of privilege in best interest decision making by

- 1) To find out what the decision-making processes are for CYP with LLCs: the level of privilege in decision-making processes.
- 2) To explore the expectations of social workers and the role in paediatric palliative care in relation to decision-making processes for CYP with LLCs.
- 3) To explore the ethical challenges in the ethos of surrogate decision making.

I conducted a total of 120 face-to-face interviews with various interviewees, including 50 cancer patients, 15 non-cancer patients, 14 senior members of paediatric palliative care teams, and 41 interviewees from local, national and international decision-making contexts. During the interviews, I observed a unique expression used exclusively in Korea for childhood cancer survivors. Although the term 'survivor' is commonly used after five years of treatment, the preferred term remains 'complete recovery'. This nomenclature seemed to reinforce the privileged decision-making level of these individuals, in marked contrast to how bereaved families are referred to and treated. Surprisingly, interviews with survivors proceeded much more smoothly than with families who had experienced loss, highlighting the differences in ease and access within the decision-making processes.

This observation led me to focus more on the levels of privilege inherent in the decision-making processes. To interpret these findings, I will use Pierre Bourdieu's theoretical frameworks of capital, habitus and field, which will help to elucidate how social and cultural capital influences the dynamics within paediatric palliative care decision-making. In 9.2, I will show stage one what they experienced in the forms of privileged or underprivileged levels in surrogate decision-making such as geographical accessibility, financial burden, telling the truth and multi-disciplinary assessment or needs.

In 9.3, stage two will reveal decision-making processes in which surrogate decision-makers often continue to praise and/or blame the results in relation to the privilege level. They take on the financial burden while praising the results as doctor shopping in the decision-making process. Doctor shopping is inevitable in the decision-making process, even though aggressive medical treatments cannot guarantee the best interests of CYP with LLCs. And they believe in ‘hit and miss’ (福不福) in palliative care rehabilitation and education. Otherwise, in terms of end-of-life, they struggle with self-cultivation (各自圖生) of the final place.

Considering stages one and two, 9.4 illustrates that the expectations for paediatric palliative care social work require and what they focus on for their priority. Finally, the level of privilege of the decision-making processes can be divided into epistemic luck and/or social inequality in section 9.5. In terms of the level of privilege of the decision-making processes, I will interpret the findings based on capital, habitus and Bourdieu's field.

9.2 Stage One: The Privileged or Underprivileged

This section illustrates that the two groups faced with privileged and underprivileged decision-making processes differ in their sense of entitlement. In stage one, they experienced the privileged or underprivileged level in surrogate decision making, such as geographical accessibility, financial burden, multidisciplinary assessment or needs, and telling and sharing the truths for decision-making processes.

9.2.1 shows that their place of residence is the starting point of their privilege, as family members should have 24-hour access to a paediatric palliative care specialist, paediatrician or specially trained palliative care team. In 9.2.2, I describe how surrogate decision makers take on the financial burden based on the spoon categorisation of who has different privileges living in Hell-Joseon (Korea). In 9.2.3, multidisciplinary assessments based on developmental tasks should have been provided regardless of privilege, but there is no guideline. Regardless of privilege, geographical accessibility is important in planning care. 9.2.4 will present the conflicting perspectives between the ‘hiding the truth’ and ‘telling the truth’ of parents, palliative care staff and children or young people with LLC. Despite the lack of multidisciplinary assessments based on developmental tasks, conflicting views are

expressed. perspectives between ‘hiding the truth,’ and ‘telling the truth’ are related to privileged or underprivileged levels.

9.2.1 Geographical Accessibility: Child and Family Care Plan?

All professionals and agencies involved in planning for end-of-life care should be aware of the multidisciplinary assessment of the family's needs. Reviewing and discussing their wishes with the family at this stage covers a wide range of issues, particularly where they live. Symptoms and pain should be managed outside normal working hours, as family members have 24-hour access to a paediatric palliative care specialist, paediatrician or specially trained palliative care team.

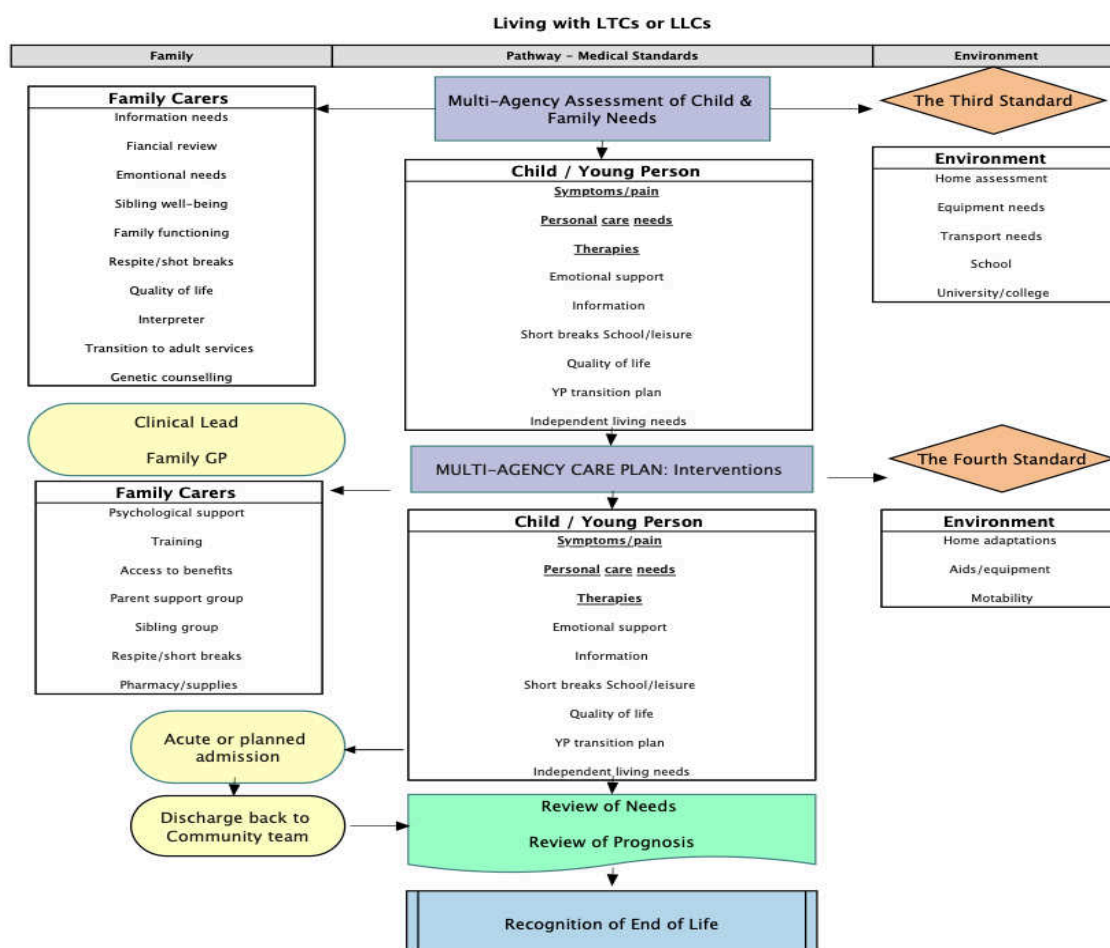


Figure 9-1 Living with LLCs or LLCs

Seunghoon Oh has adapted and expanded upon the framework originally presented Widdas, Street, Edwards, *et al.*, 2013.

To enhance family strengths and to meet their needs, a multi-disciplinary and multi-agency care plan should deliver co-ordinated care such as the child's community nursing team, allied health professionals, hospice, local acute and tertiary hospital services, education, social care and short break services (Widdas, Street, Edwards, *et al.*, 2013). The arduous journey facing the reality of their child's death for the first time requires key goals of the fourth standard for a child and family care plan following that:

1. Every family should have a team that uses key working principles to co-ordinate the plan.
2. Relevant and timely information should be available for the child and family.
3. The plan should take account of the whole family's need and wishes.
4. The plan should be comprehensive. (Widdas, Street, Edwards, *et al.*, 2013: 25)

In order to fulfil the four standards for a child and family care plan, they should access palliative care services at a location within two hours of their residential location.

Region	2005 (n = 1,524)	2006 (n = 1,476)	2007 (n = 1,522)	2008 (n = 1,281)	2009 (n = 1,177)	2010 (n = 1,157)	2011 (n = 1,141)	2012 (n = 1,124)	2013 (n = 1,069)	2014 (n = 1,044)
Seoul	226 (14.8)	280 (19.0)	253 (16.6)	259 (20.2)	235 (20.0)	218 (18.8)	214 (18.8)	190 (16.9)	192 (18.0)	200 (19.2)
Busan	105 (6.9)	106 (7.2)	109 (7.2)	91 (7.1)	67 (5.7)	70 (6.1)	76 (6.7)	60 (5.3)	72 (6.7)	69 (6.6)
Daegu	85 (5.6)	83 (5.6)	95 (6.2)	66 (5.2)	59 (5.0)	61 (5.3)	70 (6.1)	59 (5.2)	57 (5.3)	62 (5.9)
Incheon	84 (5.5)	74 (5.0)	93 (6.1)	61 (4.8)	65 (5.5)	61 (5.3)	62 (5.4)	76 (6.8)	55 (5.1)	58 (5.6)
Gwangju	37 (2.4)	31 (2.1)	44 (2.9)	49 (3.8)	38 (3.2)	33 (2.9)	38 (3.3)	39 (3.5)	23 (2.2)	23 (2.2)
Daejeon	60 (3.9)	42 (2.8)	57 (3.7)	38 (3.0)	46 (3.9)	41 (3.5)	34 (3.0)	40 (3.6)	38 (3.6)	38 (3.6)
Ulsan	45 (3.0)	38 (2.6)	38 (2.5)	32 (2.5)	29 (2.5)	26 (2.2)	25 (2.2)	34 (3.0)	22 (2.1)	22 (2.1)
Sejong	-	-	-	-	-	-	-	0 (0)	3 (0.3)	2 (0.2)
Gyeonggi	346 (22.7)	338 (22.9)	359 (23.6)	304 (23.7)	267 (22.7)	285 (24.6)	272 (23.8)	263 (23.4)	281 (26.3)	224 (21.5)
Gangwon	50 (3.3)	37 (2.5)	49 (3.2)	24 (1.9)	39 (3.3)	46 (4.0)	32 (2.8)	43 (3.8)	30 (2.8)	38 (3.6)
Chungbuk	51 (3.3)	55 (3.7)	52 (3.4)	31 (2.4)	51 (4.3)	31 (2.7)	35 (3.1)	34 (3.0)	26 (2.4)	42 (4.0)
Chungnam	64 (4.2)	60 (4.1)	57 (3.7)	55 (4.3)	44 (3.7)	52 (4.5)	44 (3.9)	53 (4.7)	53 (5.0)	44 (4.2)
Jeonbuk	65 (4.3)	49 (3.3)	62 (4.1)	57 (4.4)	54 (4.6)	38 (3.3)	53 (4.6)	59 (5.2)	49 (4.6)	36 (3.4)
Jeonnam	54 (3.5)	64 (4.3)	51 (3.4)	29 (2.3)	40 (3.4)	45 (3.9)	50 (4.4)	45 (4.0)	47 (4.4)	38 (3.6)
Gyeongbuk	108 (7.1)	76 (5.1)	87 (5.7)	80 (6.2)	57 (4.8)	59 (5.1)	61 (5.3)	51 (4.5)	49 (4.6)	58 (5.6)
Gyeongnam	125 (8.2)	116 (7.9)	87 (5.7)	87 (6.8)	71 (6.0)	71 (6.1)	64 (5.6)	65 (5.8)	53 (5.0)	73 (7.0)
Jeju	17 (1.1)	24 (1.6)	28 (1.8)	14 (1.1)	11 (0.9)	19 (1.6)	9 (0.8)	12 (1.1)	17 (1.6)	14 (1.3)
Foreign country	2 (0.1)	3 (0.3)	1 (0.1)	4 (0.4)	4 (0.4)	1 (0.1)	2 (0.2)	1 (0.1)	2 (0.2)	3 (0.3)

Values are presented as number of patients (%).

CCC = complex chronic condition.

Table 9-1 Regional distribution of paediatric death attributed to CCCs from 2005 to 2014

Source: Kim, Kim, Kim, *et al.*, 2016: 7.

When spending approximately an hour by public transportation, living in Seoul can make it easy to have the accessibility of children's hospitals or acute hospitals compared to non-metropolitan areas. Thus, more than half of the children dying due to LLCs were unable to access palliative care services at a location within two hours of their residential location.

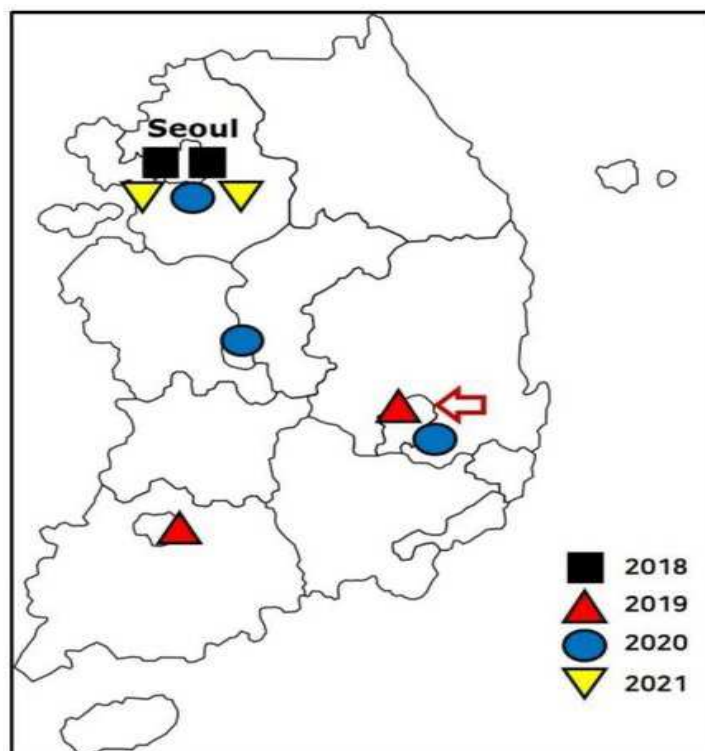


Figure 9-2 Paediatric Palliative Care Centres in the Republic of Korea.

Centres that opened in 2018 (■), 2019 (▲), 2020 (●), and 2021 (▼) are shown. The red arrow indicates the first local paediatric palliative care centre.

Source from Bae and Kim, (2022: 1270)

Sue Hyun Bae and Yeo Hyang Kim (2022: 127) highlight that despite Korea having 43 tertiary teaching hospitals, CYP with LLCs often struggle to access adequate services. These include well-trained healthcare professionals working in multidisciplinary teams and continuous home care services. My findings suggest that providing PPC requires more time and resources to be effective.

Spending Time	Home to Hospital/PPC	Reasons
2 hours	Anyang, Gyeonggi province	Due to poor public transport connections, they had to leave home in their car at 04 00 to enable them to arrive at the hospital for 06 00, this journey took place every single day during Carmen's treatment, at times they had to stop to take a nap as Carmen's immune system was very weak. (Ivanna Moran 19 th December, 2017)
4 hours	Jeju Island	Flights and public transport each week and having to stay in a hotel in the vicinity of the hospital during the treatment period. "We had to travel such a long way and then book a hotel near the hospital. Patients living in Seoul had a nearby hospital." (Mercedes Whitley 23 rd November 2017)
1 day or 3 days	Seoul	Taking a day off is difficult for my grandson with LLCs, although we live in Seoul nearby hospital. Because of the reason, I should find a helper for my grandson with LLCs. (Jasmine Blair 6 th February 2018)

Table 9-2 Different Accessibility of Hospital and Paediatric Palliative Centres

After the interviews, I reflect on the different accessibility of the hospital and the paediatric palliative care centres of my ethnography:

"I kept sighing as I thought of many images. I remember interviewing a teacher in one of the schools and hearing her sigh too. For an interview I visited the classroom where she used to be and I was reminded of the importance of the classroom where she worked and the space where the children lived. The child's mother is absent, the father is an alcoholic, and the grandmother takes care of the sick child, and while the grandmother also works and takes care of the child, she can hardly get leave to go to the hospital with the child. Even though the hospital is close to Seoul, it is not easy for the child to go to the hospital alone if the grandmother does not get leave..."

After the interview with the teacher, I started to think about who would be able to take care of the child and travel to the hospital for medical appointments, although there would also be geographical and economic considerations. Although the other child's mother is a professor and can fly to Seoul from Jeju Island in four hours with her child, it was heartbreaking to see that even though he lives in Seoul, he has to adjust the timing of his visits to the hospital if his grandmother cannot get time off work for his child. After visiting the school, I slowly walked out and googled public transport options for the child. It's about an hour from Sewol-dong in Seoul to the hospital. However, this is a distance that can take a child one to three days, depending on the support of their parents, and for some it is less than 30 minutes by car. As I walked out of the schoolyard, I put myself in the child's shoes and felt so frustrated and the invisible wall seemed so huge. (Fieldnote, 6th February 2018)"

Due to the different accessibility of the hospital and paediatric palliative care centres, I found that there are the two groups facing privileged and underprivileged decision-making processes are different, having a sense of entitlement regarding Table 9-2. When considering the accessibility of the hospital and the paediatric palliative care centre, the location of the place and transport are of primary importance, but it depends on the confrontation with privileged and underprivileged decision-making processes. At least, I have found that privileged groups can be favoured on the basis of social class and geographical location according to Table 9-2. Due to their underprivileged experiences, CYP with LLCs could not receive adequate health services.

In terms of the right to education, when CYP with LLCs are diagnosed, they should be enrolled in distance learning programmes that provide educational requirements for those who are unable to attend mainstream schools. (Fieldnote 2017 and 2018) They seem to like being hospitalised, but this cannot be generalised as the health conditions of CYP vary. In terms of the right to education, CYP with LLCs should not only have appropriate information, but also an appropriate learning environment for CYP with LLCs. They need both appropriate medical treatment or palliative care and flexibility in study schedules. On the other hand, due to their medical treatments and health conditions, they cannot maintain good organisation, self-motivation and time management skills. For these reasons, I found that online education was not suitable for CYP with LLCs. And I found Canteen School, which is based in Seoul and is supposed to provide appropriate educational programmes for CYP with LLCs.

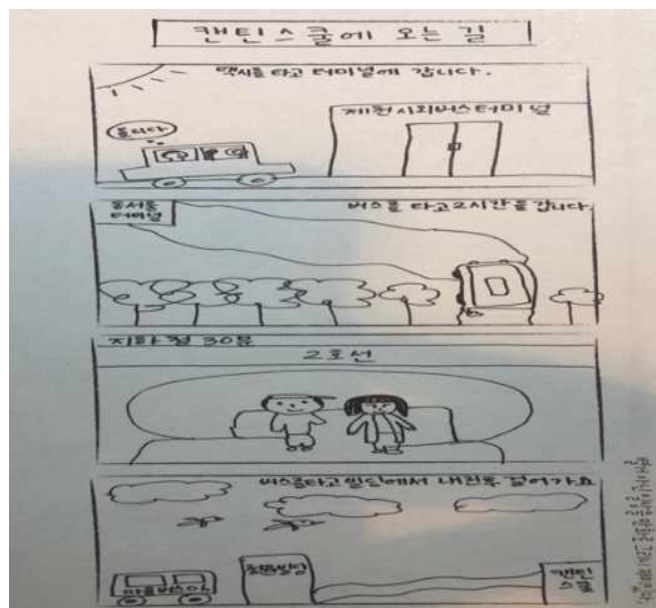


Figure 9-3 Going to Canteen School Source: Canteen School Note³²

1. By taking a cab, my mom and I went to Jochen Bus Station. “So sleepy!”
2. Spending around 2 hours... arriving at East Seoul Bus Station.
3. I was taking tube-green line around 30 mins.
4. Taking a bus and then walking from Changwon building to Canteen School.

“Making a cartoon is so much fun, showing not my special day but an ordinary day”.

In the notebooks given to the students at Canteen School, I saw a picture drawn by one of the students, and I could see their transformed stories from Figure 9-3. Despite a well-developed public transport system, parents of CYP with LLCs and a weak immune system are reluctant to use public transport. However, many would like to attend a mainstream school and be able to meet and interact with friends. While undergoing chemotherapy and anti-cancer therapy, many children attended

³² The Canteen School Note is a collection of writings and drawings by CYP with LLCs, collected through interviews and sessions at Canteen School. Unlike typical art exhibitions where artwork is displayed without context, Canteen School encourages these young participants to not only present their drawings, but also to describe their experiences directly. This approach provides a deeper understanding of their perspectives and captures their personal narratives alongside their artistic expressions. The notebook is written and illustrated by young people with cancer from Canteen School. I was given permission by Canteen School to use this notebook for research purposes. The following people contributed to this notebook Seyeon Kang (13, medulloblastoma), Junseo Ko (16, acute myeloid leukaemia), Ji-Ye Lee (13, Langerhans histiocytosis), Nayeon Kim (16, acute lymphocytic leukaemia), Nayeon Kim (16, acute lymphoblastic leukaemia), Minji Kim (19, medulloblastoma), Jungmin Kim (17, acute lymphoblastic leukaemia), Chaeun Kim (21, osteosarcoma), Haeyeon Noh (13, osteosarcoma), Minseo Moon (18, acute promyelocytic leukaemia), Jiwon Bang (16, acute lymphocytic leukaemia), Seoyeon Oh (17, acute lymphocytic leukaemia), Yusun Yang (18, HLH), Yunho Jang (13, Seonjin Chae (20, brain tumour), Tae Kyung Cho (18, brain tumour) These notes are not for sale but for distribution to children with cancer. I quoted some of the numbers in this note.

mainstream schools despite the risk to their health, some for the reasons mentioned above, but also because of the lack of alternative schools for CYP with LLCs.



Figure 9-4 The Bucket List

1. Trip with Mom
2. In front of Jeju Island's seaside, to Have Pizza with Mom
3. Let's Go Camping
4. Never be Sick Again
5. Speak English Fluently

Source from Canteen School Note: collected from young people with LLCs who wrote their experiences and drew pictures.

When confronted with privileged and underprivileged decision-making processes, the decision-making process becomes more complex. Taking into account age, gender and health status, I have mainly examined the geographical accessibility of hospitals, PPCs and training in terms of their multidisciplinary work and fundamental problems and can then conclude that CYP with LLCs face privileged and underprivileged decision-making processes with a sense of entitlement. The underprivileged CYP with LLCs do not have access to palliative care, end of life care and appropriate education.

9.2.2 In the “*Hell-Joseon (Korea)*” Financial Burden on Families

Even though the unknown journey of decision-making processes is very similar among CYP with LLCs, I found that there are two kinds of decision-making processes owing to having the privilege. I did not only look at how families and patients deal with medical costs. With regard to the decision-making processes that patients and their families in particular face when paying for hospital costs, I thankfully discovered a social solidarity organisation working on this issue (Fieldnote 5 December 2017; 13 December 2017; 27 December 2017; 9 January 2018; 6 May 2018; 16 May 2018). Although I was annoyed to observe two conflicting processes at the same time, they had different perspectives: doctors were adamantly against providing care that was deemed inappropriate, while social solidarity organisations supported capping hospital bills for children at one million won. At the press conference, I learned that hospital costs are a key factor in decision-making, following that:

“One of the stumbling blocks for doctors is that introducing a cap of 1 million won for children's hospital bills would not only ease their burden, but also cause moral damage to the use of medical care. Equity issues have also been raised, as it would undermine the universality of health insurance.

On the other hand, the head of the Coalition to Strengthen Hospital Coverage for Children said, “In 2017, hospital costs for children with rare and difficult diseases such as severe immune deficiency were about 380 million won, and the patient's burden reached 56.45 million won, but if Moon Jae-in's care is implemented, it will be reduced by 15.73 million won, but the patient will still have to pay 40.72 million won.” There are calls for the government to address the excessive medical costs of children under the age of 18.

Na Ae-rim, a parent of a child suffering from a germ cell tumour, cried out at a debate on the introduction of the “full 1 million won (about £650) cap” held by the Children's Hospital Expenses National Security Promotion Alliance (hereafter referred to as the Children's Hospital Expenses Alliance) on the 5th, saying that she had to sell her house to pay for her child's treatment, quit her job to take care of her child, causing her family to go bankrupt and breaking the tragic cycle of children and families not being able to live a normal life.

The financial resources required by the state to cover the costs of children's hospitals is 515.2 billion won per year. If the Moon Jae-in Care is implemented, it will be possible with 28 billion

won,” said Kim Jong-myung, head of the policy team at the Children’s Hospital Solidarity Alliance.”³³ (Fieldnote, 5th December 2017)

I followed most decision-making processes of the transfer from a hospital to a home or from a local hospital to a tertiary hospital. In the decision-making processes, I found income-related health inequalities across regions in Korea while following doctor shopping. Considering various options for patients such as curative treatments, aggressive treatments, surgical palliative care, or palliative surgery, the decision process is to pursue what medical treatments are available and how to manage the symptoms.

Hospitalisation Costs and Financial Burden on Families	
Medical Treatments	“My child has been blocked from the oesophagus since birth. The oesophagus connected to the bronchus. (Omitted) My child experienced 63 times of surgeries since birth. When my child had a transplant operation, the cost of medical expenses was 50 million won per month. (About £32,256) My child still has to do a lot of surgery...”
Supporting Care at Home	“Even if my child is discharged from the hospital and goes home, my family still needs to worry about spending money. My child needs all the medical equipment although staying at home. As you know, because general medical devices are not prescribed in hospitals, most devices are not affordable. The suction’s machine is basically about 1 million won. The sensor that checks the child’s breathing is about 1 million won. The child is discharged and cared for at home, and it cost about fifteen million won. (Omitted) The sterilized catheter and other disposable products are also at least 500 won (about 32 pence) per piece. Because the infection rate is high, it should not reuse.”
Limited Benefits from the Government	“My child has so much pain since taking normal painkillers and cannot control it. So, the doctor recommended that when putting a machine in the abdominal area, it automatically injects painkillers and then through the spine, the pain will be alleviated. (Omitted) Since this machine has been imported into Korea for about two years, he said that national medical insurance is unable to cover it. For controlling pain, the cost of the machine only is about 8 million won (around £5,100).”

Table 9-3 Hospitalisation Costs and Financial Burden on Families³⁴

Growing medical overburdens in the area of non-payment is inevitable due to statutory uninsured medical benefits, and arbitrary uninsured medical benefits according to Hospitalisation Costs and Financial Burden on Families.³⁵ I have followed the decision-making processes for various

³³ Following the presentation of viewpoints from both a doctor and a social worker, I raised doubts about the need for a “children’s hospice” system, emphasising the challenges of providing care and the financial burden of healthcare expenses. The speaker highlighted the lack of consideration given to children’s hospice, emphasising its potential to reduce escalating healthcare costs, unnecessary medical treatments, and unnecessary doctor shopping. (Fieldnote, 5th December 2017)

³⁴ On April 20, 2017, I was granted permission to use the proceedings of “Overburdened Medical Expenses of Children’s Households,” “Institutionalisation Proposal for National Coverage of Children’s Hospital Expenses,” and “Policy Discussion on National Coverage of Children’s Hospital Expenses” that she had received via email. Based on the presentation “Analysis of the Burden of Medical Expenses on Children’s Households: Focusing on Severe and Rare Diseases” from the Green Umbrella Children’s Foundation, I constructed the following table out of this.

³⁵ There are three types of benefits in the National Health Insurance Act of Korea such as the treatment benefit, statutory uninsured medical benefits, and arbitrary uninsured medical benefits. Non-wage benefits were reduced from health insurance as the expanding coverage of health insurance through the National Health Insurance which the government implemented a policy to expand the coverage of health insurance from 2016 until 2022.

social classes and there are two types: a having a proper time of transfer with privilege or financial burden because of out-of-pocket payments.

I have followed the decision-making processes for different social classes and there are two types: 1) having a proper time of transfer with privilege or 2) huge financial burden because of out-of-pocket payments. The financial burden leads to marginalisation as we easily fail to take into account the interests of oppressed groups and the values of CYP with LLCs. As there is no standard to require some key objectives for transfer and liaison between hospital and community services, and the start of planning for transfer is unclear, there are two decision-making processes: some can arrange transfer from hospital to home or from local hospital to tertiary hospital, while others take the financial burden as out-of-pocket payments.

While deciding for CYP with LLCs, they hope to have normal life, but I found that they struggled with living in the *Hell Choseon*. Youngmi Kim (2018: 1) defines that *Hell Choseon* is the widely used pejorative term used to compare current societal structure to class-based Joseon (also spelled as *Chosun*) Korea in the 19th and early 20th centuries.

Diamond Spoon	Assets: above 3 billion won Annual Income: 300 million won	Upper Class 0.1%
Gold Spoon	Assets: above 2 billion won Annual Income: 200 million won	Upper Class 1%
Silver Spoon	Assets: above 1 billion won Annual Income: 80 million won	Upper Class 3%
Bronze Spoon	Assets: above 500 million won Annual Income: 55 million won	Upper Class 7.5%
Dirt Spoon	Assets: below 50 million won Annual Income: below 20 million won	The rest

Note: One million won is US\$870.

Source: Ch'oe Ŭn-gyŏng, “‘Sujŏron’ sasillo ... sahoejŏk chiwi sesŭp simhwa” [“Spoon theory” becomes real ... succession of social status deepens], *Chosŏn ilbo*, January 31, 2016.

Table 9-4 Spoon Categorisation

Source from Kim (2017b: 845)

Based on table 9-4 spoon categorisation who have different privileges, there are 5 classes based on the spoon. Regarding the spoon theory, while conducting surrogate decision-making and growing up through illness, they faced uncontrolled problems. Bailey (2004, 302), who says, “without recognition of the role privilege plays in maintaining systems of domination, any understanding of oppression is

incomplete.” Bailey (2004, 302), who says, “without recognition of the role privilege plays in maintaining systems of domination, any understanding of oppression is incomplete.”

Choi Ki-chun and Lee Hyun-bok (2017: 30-31) state that the National Health Insurance in Korea does not provide adequate coverage, resulting in a large number of Koreans opting for private health insurance. The lack of a logical relationship between the National Health Insurance and private health insurance has led to several problems, such as problems arising from selective enrolment in private health insurance, negative effects on the finances of the National Health Insurance due to excessive use of medical services by policyholders, and a reduction in private health insurance expenditure due to the expansion of coverage provided by the National Health Insurance.

“At a childhood cancer survivorship meeting, a child was found to have a recurrence of cancer. The recommendation for immediate hospitalisation was hampered by expired medical insurance due to policy restrictions on illnesses occurring within the previous five years, leading to a tragic delay in treatment and the eventual death of the child, although the insurance was later renewed.” (This information was detailed by Maya Atkins, a registered nurse and counsellor, in an interview conducted on 18 May 2018.)

The shortcomings of the National Health Service have prompted many individuals to pursue the acquisition of private health insurance. The advent of the private health insurance market has brought about a number of advantages, while also giving rise to a number of challenges. The current role of private health insurance is to compensate for the shortcomings of public insurance coverage.

In light of these considerations, I have expanded the scope of my analysis to encompass the concept of privilege. Individuals who possess such advantages may experience a distinct form of disadvantage when their decisions are influenced by the privileges they hold. Conversely, those who are less privileged may eventually become marginalised and challenge the oppressive and non-oppressive decision-making processes that shape their lives.

9.2.3 Tasks: Multi-Disciplinary Assessment of Needs?

Most children with LLCs and their family desire to return to some kind of ‘normality’ with their peers. They should expect the best, such as: going back to school and enjoying social and leisure opportunities but avoid being prepared for the worst, primarily paediatric deaths. In recovering

normality, most parents consider how to treat their child or young person, when to treat, and when to cease treatment (Armstrong-Dailey, A., Zarbock, S.F. and Zarbock, S. eds., 2001: 72). For the child and family's hopes, wishes, and concerns, the required assessments should provide children with LLCs and their family. CYP with LLCs require a comprehensive plan such as pain management of the child's physical symptoms, the child's developmental stage and fears or worries, body images, sexual needs, dealing with isolation, psychosocial family concerns, separation from parents, loss of autonomy, the adolescent's developing autonomy, cultural influences on the family, spiritual belief system, social and leisure opportunities, and immobilisation.

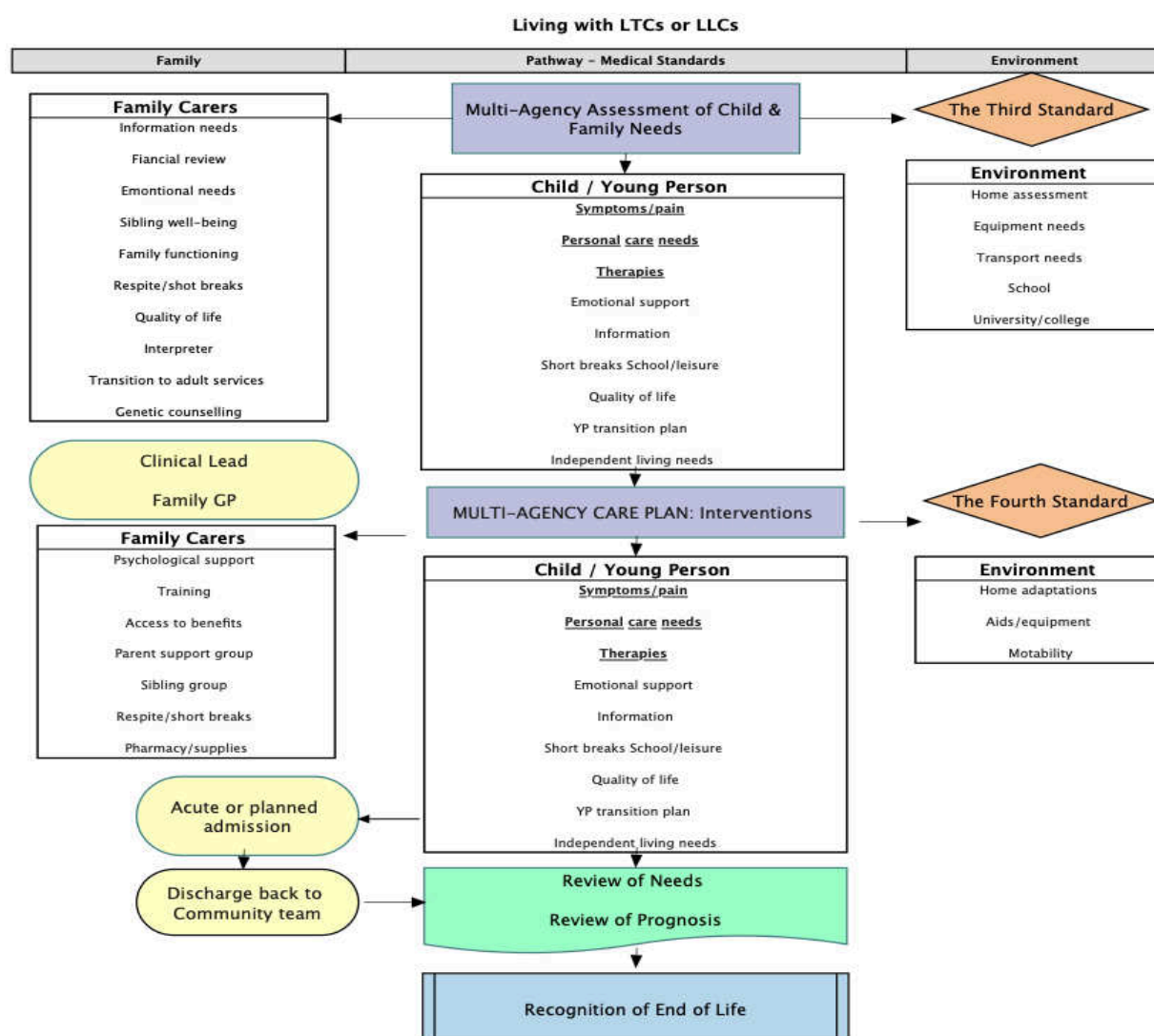


Figure 9-5 Living with LLCs or LLCs

Seunghoon Oh has adapted and expanded upon the framework originally presented Widdas, Street, Edwards, *et al.*, 2013.

In Figure 9-5, the types of needs have been set down in three sections: in the middle column I found what the medical standards underlined rather than paediatric palliative care; the most needs of family

are shown in the left column but ignored; and factors concerning the family's environment are shown in the right column. According to Widdas, Street, Edwards, *et al.*, (2013: 29), the third standard requires the key goals for multi-disciplinary assessment of needs, following:

1. Those undertaking assessments should be skilled in the assessment of children with palliative care needs.
2. Children and families should have their strengths, needs, and wishes assessed as soon as possible after diagnosis or recognition in partnership with the family.
3. A holistic, multi-disciplinary and multi-agency approach should be used to avoid the need for multiple assessments.
4. The child or young person should be the central focus of the assessment.
5. Care should be taken to include the strengths and needs of fathers, siblings, and the wider family.
6. To enable shared assessment, consent needs to be gained and confidentiality assured.
7. Assessment information should be part of a family held document.

Widdas, Street, Edwards, *et al.*, (2013) present that the assessment of the family's needs involves ongoing rather than one-time, in-depth gathering, recording, and sharing of information with the child and family at the heart of the process. Unlike dying, which involves many physical, social, emotional, and symbolic losses, the CYP with LLCs and their family require a multidisciplinary assessment of needs which should be seen as an ongoing process rather than a single event. The assessment may take days or weeks to complete and should be recorded systematically and stored securely for planning as well as should be transferable to different care settings.

In the Republic of Korea, the total number of paediatric deaths gradually decreased from the rate of 12.2 deaths per 100,000 individuals observed in 2005. Interestingly, the proportion of paediatric death due to CCC has continually declined in children and adolescents, whereas the rate of infant mortality shows an almost unchanged trend.

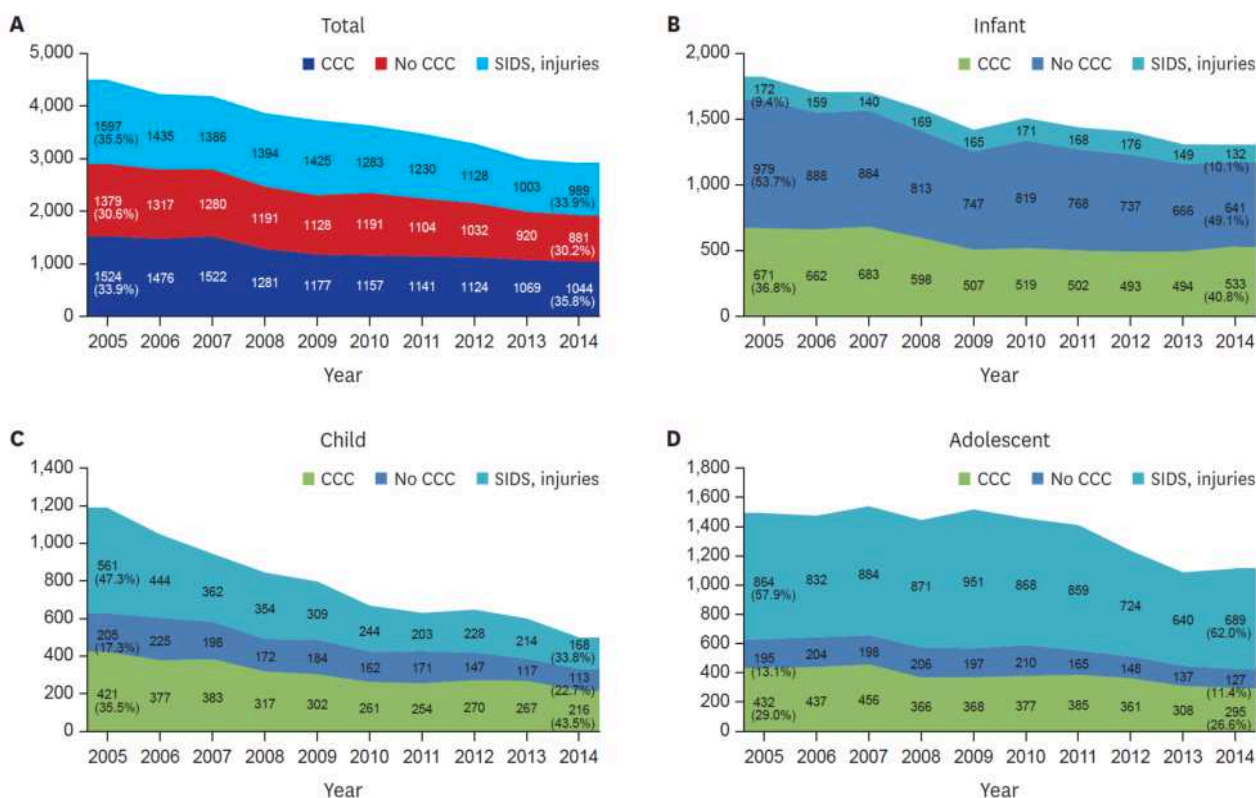


Figure 9-6 Trends in Paediatric Deaths from 2005 to 2014 in Korea by Age Categories. (A) Total, (b) Infant, (c) Child, and (d) Adolescent (crude number)

Source from: Kim, Kim and Lee (2020: 4)

Kim, Kim and Lee (2020: 4) identified that there were 36,808 cases of paediatric deaths in Korea during that 10-year period and the paediatric deaths below the age of 20 years were categorised into following groups: the death of infants (below one year of age), children (between 1–9 years of age), and adolescents (10–19 years of age). Thus, about 35,000 CYP and their families per year struggle with the devastating experience of loss of a child.

By exploring interviews and observation, I categorised neonates, infants, toddlers, pre-schoolers, school-age children, and adolescents to understand various developmental tasks. With a figure of around 35,000 deaths of children each year, I assume that about 1,000,000, including CYP with LLCs, and their parents, have been struggling with the unexpected journey. Because they do not know how to deal with their tasks, they require a multidisciplinary assessment for urgent issues.

Knowing multidisciplinary assessment of needs is connected to eventual medical treatments, although aiming at whole-person paediatric care for CYP with LLCs. The practice of encouraging a holistic, multidisciplinary, and multi-agency approach highlighted, but multiple assessments did not highlight and shared with CYP with LLCs in terms of medical treatments. Children and families have

had their strengths, needs, and wishes assessed as soon as possible after diagnosis or recognition in partnership with the family, whereas there was no alternative plane. For instance, when their health is deteriorating rapidly and CYP with LLCs could not participate in the decision-making processes at the end-of-life, it is inevitable that their parents become responsible for making the decisions for the best interests of CYP with LLCs. Regarding medical treatments, the best interests can be considered that several distressing symptoms can be managed effectively and promptly.

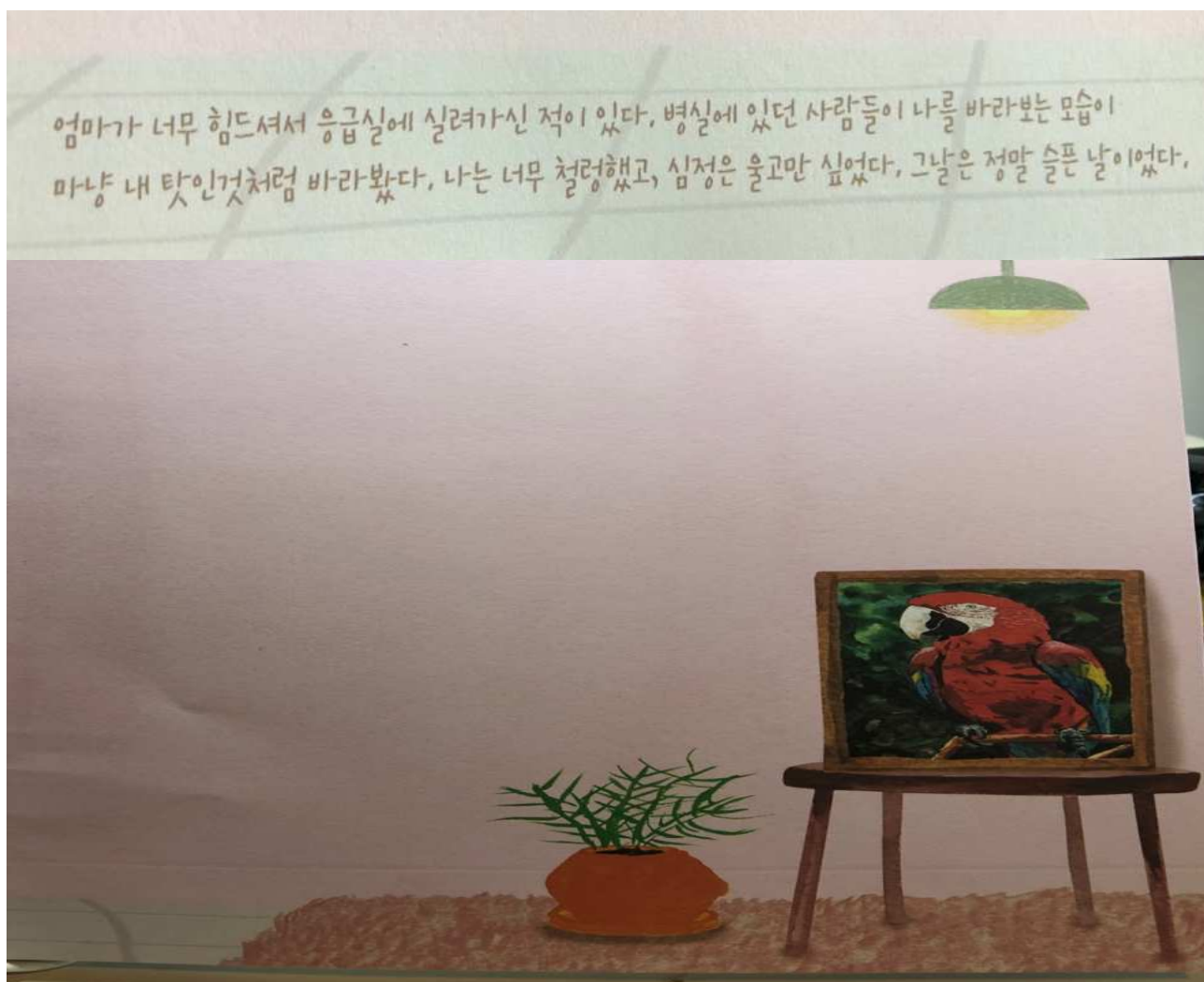


Figure 9-7 The Saddest Day of My Life

“My mom fell and had to be carried to the emergency room because of being too tired. In my room other patients did not say anything, but their disturbed eyes made me feel that it was my fault. I was heartbroken and felt like crying. It was the saddest day of my life.”

Source: The Canteen School Note is a collection of writings and drawings by CYP with LLCs, collected through interviews and sessions at Canteen School. Unlike typical art exhibitions where artwork is displayed without context, Canteen School encourages these young participants to not only present their drawings, but also to describe their experiences directly. This approach provides a deeper understanding of their perspectives and captures their personal narratives alongside their artistic expressions.

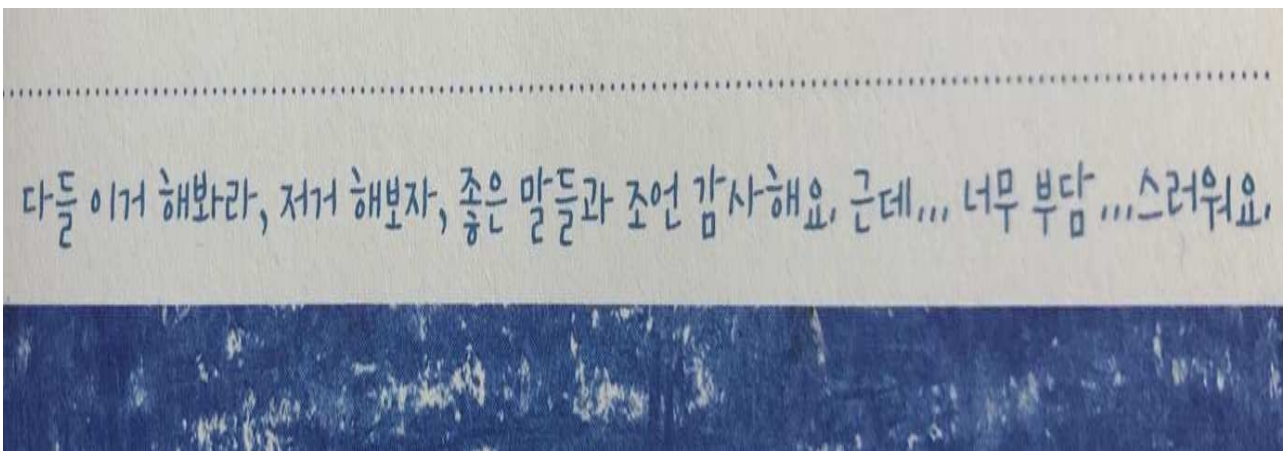


Figure 9-8 I Feel ... Too Much Burden.

People give me some advice: This is so good for you! That is very suited for you! Thank you for giving me your opinion. But ... I feel ... too much burden.

Source: The Canteen School Note is a collection of writings and drawings by CYP with LLCs, collected through interviews and sessions at Canteen School.

The social worker who provided the canteen school notes told me that she had collected each of the children's drawings and wanted to include the stories that the children referred to in the drawings

and made the notes available for the purposes of the study. The notes were looked at carefully, I was concerned that the whole-person approach to supportive and palliative care could easily be ignored, as evidenced by the survivors' experiences in Figures 9-8 and 9-9.

At the Korean Leukaemia and Lymphoma Society, one of the teachers gave me a book and showed me a passage: When you do a general art exhibition, you don't know what the children are trying to say, so I asked them to write or tell me what they wanted to say along with their drawings. I thought that was very important because we don't want to get a distorted understanding of their thinking When you do a general art exhibition, you don't know what the children are trying to say, so I asked them to write or tell me what they wanted to say along with their drawings. I thought this was very important because we don't want to get a distorted understanding of their minds.

They laughed at me. I couldn't cry in front of them, only in front of my mother when I got home. Even with my hat on, I'm small, and when I take it off, I can see everything..." Today my heart has been in my throat all day. I'm saddened by the pain, but I can't fathom the feelings of the children because of the discrimination and hatred. I am so saddened by the situation of Korean students who live with hatred and discrimination as a matter of course, and if you can think of anything, please pray for the improvement of this miserable reality. (Fieldnote, 13th February)

Survivors' stories, as detailed in my findings, underline the importance of a holistic, person-centred approach. These narratives vividly illustrate how illness affects an individual's sense of identity, dignity and social connections, and argue for a system that recognises and addresses these broader aspects of care beyond medical treatment.

My investigation reveals a lack of comprehensive, multidisciplinary assessments for treatment, care and support across medical specialties in Korea from 2016 to 2021. Although each hospital has its own assessment tool, none adequately addresses the multifaceted needs of children and families. The study advocates for mandatory, holistic assessments that take into account the preferences of the child and family, as well as the expertise of a broad multidisciplinary team. This approach is crucial for the development of personalised care plans, yet it's been found that access to such care varies significantly according to socio-economic status.

From my findings up to this point, the privileged or underprivileged level of decision-making processes is different. Although the privileged group did not take the multidisciplinary assessment, they can manage well. While spending time in a hospital where they stayed in VIP (Very Important Person) wards³⁶, private wards, wards for five persons, and others, they experienced the privileged or underprivileged level. I found that regardless of the multidisciplinary assessment, the level can ensure a strong or weak relationship between medical staff, parents and CYP with LLCs. Eventually, in terms of the privileged or underprivileged level of decision-making processes, one set of groups are marginalised, whereas the other groups can manage their essential tasks. It has still required full multi-agency assessment. Privileged families navigate the healthcare system more effectively, even without multidisciplinary assessments, because they have access to better hospital facilities and stronger relationships with medical staff. This disparity not only marginalises less privileged groups, but also undermines the ethos of equitable care. I highlight survivors' narratives, which underline the vital need for a holistic, person-centred approach to support and palliative care. These accounts reveal the profound impact of illness on personal identity, dignity and social isolation. It is argued that every child and family facing LLCs deserves a comprehensive, multidisciplinary and multi-agency assessment of their needs, focusing not just on medical treatment but on overall wellbeing. This call for a universal standard of care, regardless of social status, aims to ensure that all individuals receive the support they need to navigate their healthcare journey.

My analysis identifies a critical gap in the care of CYP with LLCs in Korea. It highlights the lack of standardised, multidisciplinary assessment across medical specialties, which is fundamental to the development of tailored care plans. Although each hospital has its own assessment tool, there is a notable lack of a unified approach that addresses the multiple needs of children and their families.

In a broader context, section 6.3 of my thesis examines the risks associated with hazardous substances found in homes, workplaces and schools. It identifies specific hazards posed by products such as disinfectants for humidifiers, radon-emitting mattresses and asbestos. Stressing the urgent need for comprehensive assessments, I advocate mandatory holistic assessments. These should take into account the preferences of the child and family, a detailed medical history and the findings of a thorough multidisciplinary team. Such assessments should inform personalised care plans, ensuring

³⁶ I was not allowed to attend rounds with the medical staff of the VIP (Very Important Person) ward, but I did go to a café with one of professors on the so-called Royal Floor. (Fieldnote, 26 May 2018).

that all families, irrespective of their socio-economic status, receive comprehensive support from diagnosis through to palliative care.

9.2.4 Decision Processes with Unheard Voices or Not?

While there is a consensus among health professionals and parents that the voices of CYP with LLCs are crucial to the decision-making process, practical difficulties often prevent their full participation. These include multi-agency assessments, which, although comprehensive in scope, may not adequately capture the unique perspectives of CYP with LLCs due to workload constraints on health professionals and the intermittent involvement of part-time or temporary staff. Furthermore, while health professionals are well trained in palliative care assessment, the reality of a disproportionate number of patients per social worker limits the depth of individual engagement. Consequently, despite the intention to include CYP with LLCs voices in assessments from diagnosis through to disease progression, systemic challenges may mean that these critical voices remain unheard. To mitigate this, even temporary paediatric palliative care staff should adopt triage strategies that prioritise understanding the experiences and needs of both the patient and their family to ensure that these essential voices inform care decisions. I specifically requested an extension to the fieldwork period in order to meet and interview more bereaved families.

However, I experienced 97 refusals, 49 of which were attempts to interview bereaved families. During a fieldwork interview conducted on 13th February 2018, social worker Minji Ahn from the Korean Association for Children with Leukaemia and Cancer shared insightful observations about the profound challenges families face in the Korean healthcare system, especially those dealing with serious chronic diseases such as cancer. Minji Ahn explained: *“In our work, we often see families who are desperate for cancer treatment and come to us when the cost of a single injection can be fifty to a hundred million won. It's a huge financial burden that many are not prepared for.”* She described the emotional and financial struggle of one particular case: a mother whose daughter was diagnosed with intestinal epithelial dysplasia, a rare and serious condition affecting only a few people in Korea. From the time of her daughter's diagnosis at birth until her death at the age of six, the mother was immersed in a relentless search for treatment, navigating a healthcare system that allows direct access to specialists without the need for referrals from primary care. This ease of access, while seemingly beneficial, often leads to ‘doctor shopping’, where care becomes fragmented as patients seek multiple

opinions and treatment options without coordinated oversight. Reflecting on the mother's experience, Minji Ahn shared her poignant words: *"I cried for a whole month when I was told I only had one month left with my daughter. If only I had someone to guide and support me through the healthcare maze, someone to talk to about the complexities of her care. Had I known we had only a few days left, I would have stopped all the treatments, put my daughter in a pram and just cherished our moments together, walking around our neighbourhood."* While positive outcomes from treatment are the hoped-for ideal, it is imperative to acknowledge the realm of medical futility, where interventions may lead not to meaningful recovery, but to a prolonged process lacking in quality. In such cases, what constitutes the 'best interests' of the patient must be rigorously examined. This account not only underscores the personal agony and potential financial devastation families may face but also punctuates the critical need for a more integrated healthcare management approach. It highlights the urgent need for comprehensive palliative care services that provide not only medical but also robust emotional support to ensure that families are not left to navigate this difficult journey alone.

Simply conducting assessments without considering the potential for medical futility risks ignoring what is truly in the best interests of CYP with LLCs. It is not enough to carry out assessments and believe that we have heard their voices. We need to go deeper and ensure that our medical interventions do not inadvertently overshadow their real needs and wishes. This means actively seeking out what will improve their quality of life, not just what will prolong it, and putting this at the heart of our ethical and clinical considerations. Medical futility emerges in the narratives not merely as a clinical concept but as a lived experience of grappling with the limits of medicine in the face of mortality. These stories are not anomalies but symptomatic of a system where the dominance of a medical model often overlooks the value of palliative approaches and open dialogue about end-of-life desires. They expose the harsh reality of patients' internal battles with treatments that may extend life but at the cost of its quality.

In terms of privilege, some may have been able to access multi-agency assessment not only because they had been diagnosed with a named condition by doctors or their parents, but also because they had had the opportunities: growing up with illness, communicating with others, having their own experiences: social development and social relationships. For example, a mother and her daughter told me that the child, who had all the information, was involved in most decisions, especially about medical treatment.

However, In interviews with 50 children and young people with cancer and 15 children and young people without cancer and their families, I found that most CYP with LLCs not only knew the

outcome of the diagnosis, but also did not expect their child to face a difficult life: neurological changes, personality changes, endocrinological changes, changes in body image, changes in family dynamics, quality of life and long-term prognosis. For this reason, survivors who are Jamie Payne and Sophia Taylors have told me that “*I made the decision for myself, but I was not involved in the decision*”. Most children grow into adulthood without experiencing serious illness, but CYP with LLCs face an unexpected life. This is because not only were CYP with LLCs involved in the decision-making processes, but people also believed in the right of CYP with LLCs not to know who they thought was making the decision without their input.

Unsurprisingly, CYP with LLCs did not receive proper multidisciplinary assessments based on developmental tasks. Finally, opposing perspectives between ‘hiding the truth’ and ‘telling the truth’ are related to privileged or underprivileged levels. As decision making is not a single rational event and parents are confronted with different points in the decision-making process, it is privileged to know their voice. In terms of privilege, there are two groups of surrogate decision-makers: hiding the truth and telling the truth.

9.3 Stage Two: Praising and Blaming the Results

This section mainly focuses on blaming the results after deciding. I traced the surrogate decision-makers’ pathway as to how they had access to information on the disease and participated in the process of decision-making such as starting the unknown journey, the unknown treatments, and the unknown end-of-life on.

In stage two, following healthcare transitions is linked to the doctor shopping with privilege or not in 9.3.1. Thanks to more easily accessible hospital’s being available, many parents who have CYP with LLCs have praised the results after deciding while transferring from home to hospitals. In 9.3.2, I will carefully examine what hit and miss (福不福) in palliative care rehabilitation and education are in decision-making processes. This is because although becoming survivors is not finished in the decision-making processes, they should ponder both palliative care rehabilitation and education. In 9.3.3, I found that they felt powerless because of *Gakjadosaeng* (各自圖生) which literally translates into “self-cultivating and is an idiom meaning “each person plans a way to live their own lives.” After the death of the child or young person, what decisions are available to the parents regarding bereavement care in 7.3.3.

When going to doctor shopping, arising blame and praise in decision-making processes, surrogate decision makers experience powerless: hit-and-miss *BokbulBok*(福不福), and *Gakjadosaeng* (各自圖生) which literally translates into “self-cultivating and is an idiom meaning “each person plans a way to live their own lives.” When praising and/or blaming in the decision-making processes, parents and CYP with LLCs do not recognise the complicated decision-making processes as the privileged level. Besides, knowing of praising and/or blaming the results, social workers in paediatric palliative care can understand the privileged level of decision-making processes.

9.3.1 Doctor Shopping: Following Medical Miracle or Not?

I will investigate doctor shopping in this section when CYP with LLCs are required to decide on active medical treatments. CYP with LLCs do not only know how to start their arduous journey as surrogate decision-makers but also how to share or inform various options when suggesting the best interests for CYP with LLCs.

Doctor shopping in Korea is notably influenced by its distinctive healthcare system, characterised by a government-run national health setup that allows clinics to offer inpatient services and local hospitals to provide a comprehensive range of treatments. Unique to Korea's system is the freedom for patients to access any medical services directly, without the need for referrals from primary care physicians. This aspect is critical in understanding the prevalence of doctor shopping in the country.

A significant factor contributing to doctor shopping is the widespread misconception about the role of primary care among both patients and doctors, as noted by Ock *et al.*, (2014). In many healthcare systems, primary care acts as a gatekeeper, guiding patients through the healthcare journey and providing referrals to specialists. However, in Korea, this gatekeeping role is diminished. Patients often bypass primary care, directly seeking specialist opinions, especially for chronic or serious conditions. This behaviour is rooted in a belief that hospital services are more effective for certain ailments, an assumption that aligns with the greater trust placed in hospital-based treatment.

Research indicates that one of the fundamental issues contributing to doctor shopping is the lack of a robust primary healthcare system that can provide comprehensive and continuous care. This gap in the healthcare delivery system encourages patients to seek care from multiple providers, often without coordination, resulting in fragmented care and unnecessary duplication of services. Despite

this problem, people believe that innovative treatments can deliver better medical outcomes for CYP with LLCs.

Regarding the innovative treatment of decision-making for children, there is a case of stem cells in the innovative procedure, calling Hannah Warren's Story. Most patients with incurable or irreversible diseases cling to hopes that advanced medical technology will lead us to discover methods to increase life expectancy. The stem cell technique has been previously used to produce body parts and could be a stepping-stone in treating other birth defects and childhood diseases. 'In August 2013 in Seoul, the Republic of Korea, Hannah Warren, a two-year-old girl, born without a windpipe was given an artificial trachea, grown from stem cells.



Figure 9-9 Girl with Stem Cell Trachea Repair.

Reprinted from a two-year-old girl born without a windpipe receives artificial trachea grown from stem cells

Source from Mele, 2013: 505.

The stem cells used came from Hannah's bone marrow, it would take 9 hours for the trachea transplant procedure to be completed. It was approved by the Food and Drug Administration under rules that permit experimental operations, although the patient has little to no chance of survival' (Mele, 2013: 504-507). In discussing the role of surrogate decision-makers in Hannah's story, it is important to note their determination to seek what they saw as a potential medical miracle. This determination is

sometimes misinterpreted as doctor shopping. This is because Hannah Warren's case, often seen as a medical miracle, does not fit the conventional definition of doctor shopping. Worley & Hall (2012: 263) define that doctor shopping encompasses a variety of behaviours in which patients seek multiple medical opinions or prescriptions, often motivated by financial incentives, the pursuit of better care, or the complexities of the healthcare market. In contrast, Hannah's treatment consisted of a highly specialised and innovative procedure - the creation of an artificial trachea from her own stem cells. This procedure, approved under FDA experimental protocols for her life-threatening condition, was conducted with full transparency and strict medical oversight, and required full parental consent. It is an example of medical innovation focused purely on preserving life, as opposed to the secretive and exploitative nature of doctor shopping, although the narrative does not extensively cover the palliative care provided after her surgery.

I found two groups of patients particularly interesting. One group had been urgently transferred from general hospitals to university hospitals when immediate hospitalisation was required. Another group, initially treated in local hospitals, travelled from Jeju to hospitals in Seoul in the hope of better treatment for their child's leukaemia. They endured weekly flights and public transport and stayed in hotels near the hospital while receiving treatment. We had to travel a long way and then book a hotel near the hospital. Patients living in Seoul had the convenience of a nearby hospital," said Mercedes (Whitley on 23 November 2017).

On the other hand, I explored opposite case taking palliative care and hospice care: one of my interviewees shared with me her daughter's story; Dain Oh was a 13-year-old woman with stage IV leukaemia cell lung cancer, she had been hospitalised suffering from increased pain. Haeun Seo who is Dain Oh's Mother, said to me that

When my daughter went into semi-coma, the medical professor said your daughter does not have enough time and you should be prepared for your daughter to pass away. I refused to send my daughter into PICU since there was no possible medical treatment available to her and asked a doctor to allow her to remain where she was. I used to be a medical nurse and knew that she would be given medical treatments if my daughter was admitted into PICU, I just wanted to spend what little time my daughter had left watching over her. It was my first experience in the hospital, I thought it seems like many of the medical staff were very confused. I was adamant that my daughter was not resuscitated in the event of a cardiac arrest, and we did not wish she was to be given vasopressors or to be intubated. (Haeun Seo, Age: Diagnosed aged 11, died aged 13, Dain Oh's Mother, 09/04/2018)

I found that the case of Dain Oh for receiving palliative and hospice care is valuable, but the case is rare case. Still, there are some difficulties in applying to general decision-making for CYP with LLCs. Transferring from the local hospital to an acute hospital, it is that their prime consideration should have focused on alleviation of pain and the management of the child's symptoms and becoming survival. They hope to be assured that their child's pain suffering and symptoms will be minimised, and they will demand ongoing support and assistance to achieve symptom management. Parents focusing on medical treatments can pursue their CYP with LLCs to have a normal life rather than caring for the whole family in palliative care. Eventually the decision-making processes show gives use doctor shopping to bring a medical miracle.

I noted a pattern in which 'doctor shopping' is mainly focused on curative treatments, while palliative care is often overlooked for children and young individuals with life-limiting illnesses (Fieldnote, 2017 to 2018). However, García (2016:165) argues that both curative therapies and palliative care can be given concurrently to CYP with LLCs, rather than selecting one over the other.



Figure 9-10 To Choose Between the Two?

Image from García, 2016: 166³⁷

³⁷ Palliative care for children with chronic and serious illnesses aims to improve their quality of life and can be offered alongside curative treatment. Patients and families do not have to choose between the two, as both can proceed together. It is about "hoping for the best but planning for the worst".

In the context, where private hospitals represent the predominant form of healthcare provision and there is a debate about the necessity of healthcare reform, the reality observed from my perspective may indicate a trend where patients seek multiple medical opinions primarily for curative therapies, with palliative care often overlooked for CYP with LLCs. Despite government claims of improved coverage and support for both types of care, the focus on primary care reform and innovation remains largely absent from discussions. As a result, there's a discrepancy between the advocated simultaneous provision of curative and palliative care and the actual healthcare practices observed. According to Armstrong-Dailey and Zarbock (2009: 74-75), there is a dearth of training resources for palliative care social workers, both in terms of trainers and training programmes (Lee, 2013: 67-68). This is problematic considering the importance of psychosocial and emotional support towards the end of life. Regarding the lack of knowledge, totalizing thought can relate to understanding non-cancer patients and their family members and then precisely attention to the neediness and suffering of the other cannot be possible based on the Other of Emmanuel Levinas. According to Levinas (1991: 214), the face of the Other demands a response to the command for responsibility for the Other. Due to the lack of knowledge, palliative care social workers cannot only conduct to serve an essential role in helping patients overcome psychological and social issues, but also support their decision-making regarding holistic approaches. It is difficult for palliative care social workers to conduct supportive decision-making due to the lack of systematic training programs to obtain practical knowledge and skills.

In my interviews with various key figures across the healthcare and social work sectors in Korea, I observed a consistent theme: social workers are primarily engaged in supportive or fundraising roles. While these roles are crucial, they often limit their capacity to advocate for or implement innovative care strategies. The interviewees included:

- *Nari Gwon, Chairman of the Korean Association of Hospice and Palliative Care, struggles with policy constraints but strives to shape impactful hospice care initiatives.*
- *Isabelle Shin, Representative of the Korean Association of Medical Social Workers, is focused on enhancing the professional development and advocacy capabilities of social workers within medical settings.*
- *LeonardMoon, Representative of the Korean Association of Social Workers, is committed to integrating social work practices more deeply within healthcare systems.*
- *Minseo Son, Executive Secretary at Han Bit Love for Children with Cancer, is primarily involved in fundraising and administrative support, crucial for sustaining the NGO's operations.*
- *Vinseok Ryu and Samuel Pyo from S Hospital's Social Work department deal directly with patient care, yet find their roles constricted by the hospital's operational policies.*
- *Junsu Son of Seoul Social Work champions community-based initiatives, aiming to bridge the gap between hospital care and community support.*

Therefore, supporting decision-making for surrogate decision-makers has been ideal even if highlighting compassion as ‘the nexus of human subjectivity’ and the ‘supreme ethical principle by Levinas.

The quest often manifested itself as a form of ‘doctor shopping’, where parents, driven by hope and despair, sought multiple opinions and treatments, akin to the quest for medical miracles (Schneiderman, 2011). This relentless pursuit, though rooted in love, sometimes bordered on the ethical dilemmas Schneiderman describes, where the line between benefiting the child and potentially prolonging suffering becomes blurred. The many interviews I conducted were not only about capturing what these children and their families were willing to express explicitly, but also about tuning into the unspoken aspects of their experiences which the silent often overlooked voice of their lives. During the fieldwork I was confronted with the diverse expressions and cries of CYP with LLCs. This endeavour was an attempt to respond more deeply to what Emmanuel Levinas describes as the face of the Other.

In engaging with these faces, I came to understand that the response required was not just an academic exercise, but a moral imperative. Levinas teaches that the face of the Other commands us to respond, and in the context of these interviews, the faces of these CYP demanded a deep ethical engagement. Their expressions of joy, anguish and hope were not just fleeting moments of research; they were profound calls to action, demanding a response that went beyond mere observation. This approach is deeply rooted in the Levinasian philosophy that every face presents an ethical demand that compels us to acknowledge and respond to the vulnerability and subjectivity of the other. In this way, the interviews went beyond being a mere methodological tool - they became a means of ethically engaging with the lives and experiences of young people, of hearing and responding to their silent pleas.

Doctor shopping therefore appears to be an excellent method of obtaining advanced medical treatment. There is a widespread belief that receiving specialist care in hospitals leads to better outcomes, which has led to an increasing tendency to consult many doctors for treatment. My conclusion is that misconceptions about the importance of primary care contribute to weakening its gatekeeper role and exacerbating health inequalities. Doctor shopping is a notable problem in South Korea due to several factors, including the lack of a well-established primary care system, convenient

access to higher-level hospitals, and a healthcare system that encourages frequent visits due to the relatively affordable cost of medical services (Kwon 2003; Chun et al. 2009; Ock *et al.*, 2014).

9.3.2 Hit and Miss (福不福) in Education for Children and Young People

While following doctor shopping, surrogate decision makers have believed what they want to have their own hope or a small story of medical results. Despite becoming survivors, I found that the decision-making processes of surrogate decision makers and CYP with LLCs are still not finished for taking education.

Parents and others wanted to ensure that children and young people had the right to an education, even if they were receiving treatment in a hospital. In Korea, education is considered a significant faith or religion. I noted that the majority of the age group that the hospital school would like to connect with is between 3 and 14 years old, but felt it was vital to engage with both older and younger age groups as well. However, despite the fact that there is a hospital school where children can be educated, additional social assistance cannot be provided. Furthermore, the majority of the instruction is done online, resulting in a significant drop in attendance. The school is labelled a school, but it actually has small classes, and many of the teachers are volunteers. The irony is that many individuals believe that education is essential for children and young people, but they are not receiving the education they need. Survivors told me that “the right to education is like hit and miss” (Fieldnote 8th January)

I questioned that “the right to education is like hit and miss.” I found that it appears to be a lucky and wonderful opportunity for certain people, but it cannot guarantee the right to an education, even though accessing remote learning programmes is appropriate for CYP with LLCs.

Case Disconnected Education: My daughter is very depressed and cried in her room. While she has still been taking medical treatments, she just allows to access distance learning programmes rather than attending school. My daughter missed her friends, so she went there. Due to taking the distance

learning programmes, she was banned to go to school. (Namsu Lee, Seongmin Lee's Father, 30/11/2017)

In Children's Hospital, there is an interesting phenomenon of education for CYP with LLCs. While taking distance learning programmes, they should take one of options: distance learning and attending school. Due to disconnecting the opportunity for attending school of CYP with LLCs, their life has been changed and cannot take their ordinary life such as not wearing school uniform, not taking exam, and only taking distance learning programmes.

Despite becoming a survivor, some survivors, living with a disability are inevitable due to side effects. There are over 90,000 students with disabilities, but there are only 175 special schools. Park jongkwan (2019) reported that "among students enrolled in special schools, 44.6% of the students take more than an hour to commute to and from school. 7.4% of students take more than two hours to commute from home to school." A teacher at a special school in Seoul said, "It is not easy for a student with a disability to commute alone for more than an hour round trip."

After going back to their normal life, going to school is like a hit-and-miss. Although it is a special school newly established in Seoul after about 17 years, this caused regional conflict. An open forum was held to resolve the conflict over the issue of opening a school in 2017. At this time, parents of children with disabilities knelt in front of residents and appealed to their children to go to the special school safely and comfortably.

During the press conference, I was frustrated, astonished and incredulous to see a group of people kneeling. Many of those present were sympathetic to the call for a national Oriental medicine hospital, hiding their desire for higher profits from their own property prices and land, while the faces of the parents desperately pleading for a school for the disabled brought tears to their eyes. I wrote: 'My child has to travel two hours from home to school just because he is disabled; he has to travel two hours to school to get an education, and then he has to travel two hours back home, so we're begging you to build a school for the disabled here in Gangseo district. If you curse me, I will take it; if you insult me, I will accept it; if you hit me, I will take it; but you will never build a special school for my child. Disabled students in Gangseo County have the right to be educated in county schools. We will try to communicate with you about the children's rights; all we ask is that you open your minds a little and consider them as students first, not their disabilities, and create a space for them to learn. (Fieldnote, 6th September 2017).

This study found that the following photo presented an open forum, showing two groups got down on their knees and begging for the establishment of a special school and the establishment of a national oriental hospital in Gangseo-gu, Seoul: about 50 parents were kneeling for appalling the establishment of a special school in Gangseo-gu, Seoul (Figure 9-11 the top photo). In contrast, at that time, about 10 residents who opposed the establishment of a special school (Figure 9-11 the bottom photo) were kneeling. Hyunghee Hwang, 2016 and Chunha Hwang, 2018 reported that as Kim Seong-tae, member of parliament ran as Kang Seo-eul, Seoul as a candidate in the general election for the National Assembly in April and put forward the establishment of a national oriental medicine hospital as a pledge. Because of a pledge, residents have demanded the establishment of an oriental medicine hospital instead of a special school.



Figure 9-11 Two Groups Got Down on Their Knees and Begged

Photo from (Kang, 2017)

Parents and CYP with LLCs did not ponder their education when becoming a survivor with a disability. Because of the reason survivors believe that the accessibility of education is like a hit-and-miss. According to Lee, Kim and Shin (2020: 30) reported that recent healthcare systems in Korea are not well-organised for CYP with LLCs, which results in fragmented, uncoordinated, and emergency-driven care. Fewer opportunities for the right to education and a very hit-and-miss system even though going back to normal life.

9.3.3 Self-cultivating (各自圖生) of Final Place

According to my observation and medical staff's experience, most parents who lost their child or young person with LLCs avoid the funeral (see 7.3.3). Most children or young people die at the NICU or the PICU, but one of my interviewees refused at the NICU and took VIP wards, private wards for providing well-qualified medical services. Regarding these situations, I will explore their unknown end-of-life when avoiding the decision, and why there is no cool room for supporting the child and young people with LLCs and their family.

Although there are 43 tertiary hospitals in the Republic of Korea, as of 2018, only two in Seoul had established multidisciplinary teams specifically for CYP with LLCs. In addition, there were no dedicated children's hospices and no hospitals or medical institutions specialising in paediatric palliative care for CYP with LLCs. However, by 2021, the number of institutions with specialised teams had increased to nine.

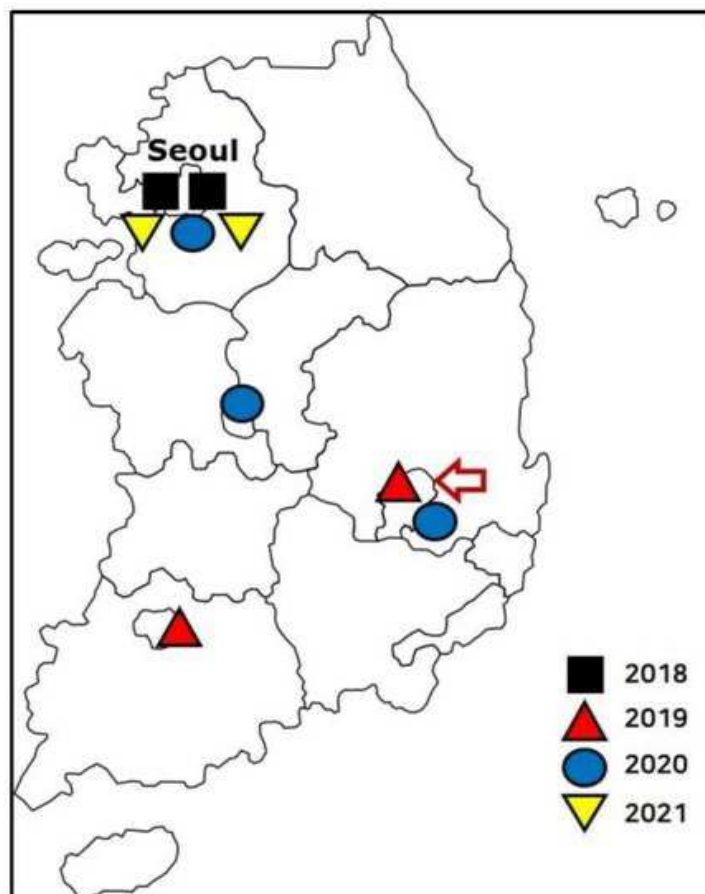


Figure 9-12 Pediatric palliative care centers in the Republic of Korea.

Centers that opened in 2018 (■), 2019 (▲), 2020 (●), and 2021 (▼) are shown. The red arrow indicates the first local pediatric palliative care center.

Source from Bae, S.H. and Kim, Y.H., 2022: 127

Based on the above map showing tertiary hospitals, which I observed one of two places in 2018³⁸ and interviewed medical staff who work in both places, there is no cool room for CYP with LLCs. For instance, even though medical staff inform suggestions for talking to children about death and dying, infants and toddlers are unable to articulate communication with others. Understanding their unspoken languages such as hand gestures, eye gaze and facial expressions can be ignored because their final place for CYP with LLCs eventually is at the NICU or the PICU and there is no cool room. I have found this in the bereavement processes of the families that have followed:

³⁸ From February 3, 2022, a pilot project for paediatric palliative care will begin at 9 institutions. (4 in Seoul, 1 in Gyeonggi, 2 in Daegu, 1 in Daejeon and 1 in Jeonnam), National Hospice Centre, (2022).

1. *Dain Oh, Cancer (leukaemia), Age: Diagnosed aged 11, died aged 13*

Bereavement: Despite initial reluctance from others about the need for a funeral, believing that cremation alone would suffice, a funeral was held. However, there was no known structured bereavement care afterwards, highlighting a gap in ongoing support for the grieving family.

2. *Eli Jang, moyamoya disease, Age: Diagnosed and died aged 18 from sudden complications of illness*

Bereavement care: A school social worker facilitated the attendance of Elliot's classmates at the funeral, addressing cultural taboos about children attending such services in Korea. Following the funeral, the involvement of social workers in providing therapeutic programmes for the bereaved siblings and counselling for the family was particularly effective in helping them to understand and process their grief.

3. *Seondeok Kim, Age: Diagnosed aged 19, died aged 22*

Bereavement support: No details of bereavement support are given, suggesting a possible lack of formal support following her death.

4. *Jenny Choi: Died aged 22*

Bereavement Care: No specific details of bereavement care or funeral arrangements are available, suggesting a lack of documented support.

5. *Wonjun Choi, Chronic respiratory disease, Age: Died at 50 days*

Bereavement care: There is no specific information regarding a funeral or bereavement care, suggesting a possible lack of formal bereavement support.

6. *Viha Shin, Chronic respiratory disease, Diagnosed aged 15 Died aged 39*

Bereavement care: The lack of specific bereavement or funeral details suggests a lack of structured support systems.

7. *Namsu Park, Condition: Chronic respiratory disease, Age: Diagnosed aged 19, Died aged 40*

Bereavement care: There is no information on whether formal bereavement support was provided, highlighting a potential gap in support.

8. *Seokjin Roh, Chronic respiratory disease Age: Diagnosed aged, Died aged 42*

Bereavement care: No details of funeral or bereavement care are provided, suggesting a potential oversight in the provision of necessary support services.

Reflecting on the interviews, I was struck by the notion of *Gakjadosaeng* (各自圖生)³⁹ which literally translates into “self-cultivating and is an idiom meaning “each person plans a way to live their own lives.” It underscored the autonomy that families should make the best decisions for their children and themselves, without standardised guidance in paediatric palliative care. This insight was poignant given the lack of nationalised standards and facilities, such as cold rooms, in tertiary hospitals, despite the availability of multidisciplinary CYP teams. Reflecting on ‘*Gakjadosaeng*’, I was reminded of the need for individuals to take charge of their own end-of-life care in difficult circumstances. Regardless of their hope, a relapse may occur, and they may struggle with the prospect of facing an early death, whether from cancer or non-cancer. After the child or young person has died, what choices are available to parents in relation to bereavement care? In exploring the whole decision-making process, I found that people were reluctant to involve the CYP in the funeral. Only two of the bereaved families I interviewed had the privilege of attending their children's funerals. This exploration of the decision-making process reveals a disturbing truth: despite differences in social class and access to resources, parents often feel disempowered, their autonomy limited not by choice but by circumstance. This limitation is not necessarily due to a lack of medical or palliative care options, but rather to the absence of a coherent, supportive framework that would enable parents to make informed decisions without bearing the entire emotional and logistical burden alone.

I bring to light the stark reality of surrogate decision-makers who find themselves resorting to concepts of luck when faced with outcomes that defy expectations. In cases where the child’s trajectory leads to an early death, whether from cancer or other LLCs, the concept of ‘luck’ surfaces in parental narratives, a poignant testament to the vulnerability and helplessness felt at these moments. Although there are different social classes, surrogate decision-makers believe in and accept luck when unexpected outcomes occur, following blame and/or praise. The interplay of blame and praise following an unexpected medical outcome highlights the critical role of social support structures in shaping parents' responses to their child's illness trajectory.

³⁹ Oh & Ardit (2009: 21) highlight that self-cultivation in Korean Neo-Confucianism focuses on personal moral and spiritual development, with the aim of aligning one's character with universal principles. Traditionally, community support through education, ritual and obligation has been crucial in supporting these personal efforts. However, in modern contexts where individualism predominates and traditional structures are weakening, this analysis suggests that the absence of community support makes it more difficult for children and young people with life-limiting conditions to maintain discipline and feel validated in their decision-making processes. Such isolation could hinder personal growth and the practical application of Neo-Confucian principles.

9.3.4 Virtual Reality in Bereavement Care?

Throughout the fieldwork, I described one of the most difficult aspects as interacting with and interviewing grieving relatives. It proved incredibly difficult to find good storylines for these people. I have extensive experience in adult hospice care and have developed long-term relationships with bereaved families over the course of more than a decade. However, the experiences of CYP interviewed were far from good. Their memories were marked by a tremendous sadness and a reluctance to remember such difficult times. (Fieldnote, 20th May 2018)

Observing my daughter's enjoyment of virtual reality (VR) and augmented reality games and playful pastimes, as well as literature indicating the growing prevalence of augmented reality in the lives of developing CYP, I believe that the adoption of new technologies may become an inherently familiar tool for this generation. This discussion includes the possible alteration of grief care for families as it connects with developing technologies.



Figure 9-13 Researcher's Child Explores Marine Life with Augmented Reality

Source from Fieldnote, 20th May 2018

The chance grows much stronger when one considers that today's children regard their mobile phones. Considering the extensive research into children's interaction with smartphones by experts in various fields, it is clear that smartphones are becoming an increasingly important part of children's

daily experiences. From as young as two years old, children engage with these devices, mastering tactile interactions and progressing to more complex tasks such as navigation and the use of educational applications as they grow⁴⁰ (Yadav & Chakraborty 2021).

The vast amount of images and videos archived on websites raises a crucial question: how can we preserve these digital artefacts and how should those left behind care for them? During the long, home-bound months of COVID-19, I found that a VR bereavement programme. The feelings generated were warm and comforting, but also led me to think deeply about the possibility of highlighting privileged access to VR technologies.



Figure 9-14 I, Mother, Meet You Source from MBC: 2020

Despite the uncertainty of the professional ‘duty of care’, Audrey Agnew, Roger Manktelow, Tommy Haynes and Louise Jones (2011: 112) emphasise that ‘palliative care extends beyond the treatment of the patient to include ongoing support for the bereaved’. Kim Jong-woo, the programme

⁴⁰ Yadav & Chakraborty (2021) note that applications designed with consideration can enhance child development in areas such as communication, creativity, and learning. However, they also caution that excessive smartphone use is associated with negative outcomes, including disturbances in sleep patterns and an increased risk of obesity in children.

director of MBC, is the author of *I met you* (2022)⁴¹ and has undertaken a documentary project using new technology to turn history into a virtual reality for people. During the COVID-19 crisis, the Virtual Reality Human Documentary launched virtual bereavement support for families who were unable to say goodbye to their daughter. Thanks to VR in Bereavement, many people were drawn to the aftermath of a moving programme about a mother's virtual reunion with her deceased daughter. MBC life (2020) created the video “Mother reunites with deceased daughter using VR Mum, ‘I won’t make you cry’” by Kim Jong-woo. In the immersive field of VR applied to mourning, the digital environment has received much attention, especially with the release of a film in which a mother is reunited with her deceased daughter in virtual space. In the moving video “Mother reunited with deceased daughter using VR”, the mother says: “Mum, I won't make you cry. I will love you more and miss you less,” eloquently captures the emotional impact of VR. This video can be viewed on YouTube, where it has received a high number of likes, indicating that it has touched many people's hearts. The video has received over 770,000 likes and is available in other languages. The tremendous response prompted researchers to investigate the dual value of integrating technology and human emotion.

VR has provided a virtual venue for people to express their shared empathy and, potentially, a cathartic release. This notion has been empirically validated by my own first-hand experience. The “*I Met You*” project exemplifies the potential of integrating wearable technology and virtual reality to create a realistic experience of presence, touch, and conversation. Such integration has the potential to have a profound impact on the audience on a visceral level, which may be measured in terms of its effect on the body and the emotions. Watching a devastated mother converse with a supposedly tangible representation of her lost daughter is more than a simulation; it is a deeply intimate moment of connection and closure. This virtual encounter encourages reflection on the many ways in which technology interacts with human emotions and grieving processes. VR has the potential to bridge the gap between memory and presence, resulting in a digital memorialisation that seems almost physical.

Kim, Jongwoo (2022) explained the challenges of identifying the optimal type of support and timing, given the reliance on virtual reality and the ‘metaverse’, whereas the ethical challenge of virtual

⁴¹ In 2019, PD Jongwoo Kim planned a virtual reality called “I, Mother, Meet You. Although the fieldwork was over at the time, I heard about the project through Facebook and KakaoTalk from patients, family members and many others, especially when one family member told me that he was disappointed because he wanted to participate in the project. In particular, he mentioned that he was sad not to be able to say goodbye to his beloved daughter and that the creation of the virtual reality in Bereavement was a comfort to him. After the broadcast, I was able to read a detailed history of the Nayeon family, from the planning of the project by the police to the book *I met you* by Kim Jong-woo. When he read about his loved ones, he was inspired to try to reconnect with them through the power of technology. In the book, we see Nayeon involved in new projects with other families, not just her own. I learned that the project has been going on for several seasons and will continue to be rewritten in the future.

reality technology lies in the taboo of meeting the dead. Kim (2022) suggested the next research should support distinguishing between reality and virtual reality after participating in the virtual reality of bereavement care, to help cope with trauma.

9.4 Expectations from Paediatric Palliative Care Social Work and Under Oppression as Ethical Challenges?

Considering stage one and two, in 9.4.1 I will present that the expectations of paediatric palliative care social work require enhancing holistic care to improve quality of life and promoting fundraising. However, in 9.4.2 I found that they could not carry out at least the two given roles of paediatric palliative care social work but concentrated on fundraising.

9.4.1 Expectations in the Privilege Level of Decision Process?

In terms of the privilege level of decision-making processes, one of significant expectations from the role of paediatric palliative care social work is that the processes of holistic care for improving quality of life, although to ponder medical treatments is not the role for weighing benefits and burdens for the patient's best interests. Since holistic care, including healthcare transition such as hospital, hospice, home, school, and community is vital, the expectation for paediatric palliative care social work requires how to enhance holistic care to improve quality of life. By understanding the privilege level of decision-making processes, social workers in paediatric palliative care can suggest how to assess decision-making processes with children or young people with LLCs. This is because decision-making processes including educational opportunities, housing, healthcare, and food should guarantee the safety or security of children with LLCs when concentrating on holistic approaches.

Secondly, the expectation for paediatric palliative care social workers asks fundraising since the most medical social worker is mainly to deal with solving economic problems for their service users (Choi and Kim, 2017: 158).

Maybe I am the first medical social worker in Korea and contributed in many ways, especially systematic fundraising. In addition, I believe that the role of the medical social worker is not only to set up systematic fundraising in their hospital but also to make resource networking. I think medical social workers should devise various methods for patients who cannot afford the hospital bills. (Isabelle Shin, Representative/ The Korean Association of Medical Social Worker, 28/11/2017)

According to Isabelle Shin's experience, the involvement of social workers in fundraising is inevitable. In terms of the privileged level of decision-making processes, it is crucial that the expectations of both improving holistic care and systematic fundraising for social workers in paediatric palliative care are met. Eventually, social workers in paediatric palliative care do have enough time to understand the psychology of luck and internalised oppression in decision-making processes.

9.4.2 Depending on Donation and/or Ignored Social Inequality or Epistemic Luck?

In stage two, most parents of CYP with LLCs struggle with the financial burden of taking medical treatments while engaging in doctor shopping. While interviewing patients and their family members, a social worker asked me, *why do they have to rely on donations instead of improved healthcare?* A single question was put forward for consideration. This raises the question of why these families are forced to rely on donations rather than being able to afford enhanced healthcare support. Not only myself, but also these key stakeholders in paediatric palliative care see this as an example of social injustice. A coalition of social welfare organisations, including Social Workers for Changing the World, My Welfare State, Korean Patients Association, Walking With Children, and various regional social worker associations across Korea, from Seoul to Ulsan, have united to propose a significant policy initiative. Each participant provided a critical analysis of the over-reliance on community fundraising and the urgent necessity for structured healthcare support. An alliance comprising approximately 70 agencies was established with the objective of advocating for enhancements to the Children's Health Insurance Programme. To gain further insight into this systemic issue, interviews were conducted with senior members of renowned NGOs that are actively engaged in healthcare policy reform for CYP with LLCs. To gain deeper insights into this issue, four senior members from notable NGOs who are deeply involved in efforts to reform healthcare policies for CYP

with LLCs were interviewed. To address the issue of institutionalising national coverage for children's medical expenses, interviews were conducted with representatives of key NGOs, including Green Umbrella and the Children's Cancer Society. These discussions, part of the Welfare State of My Making initiative, focused on different strategies and perspectives on health policy reform. The insights shared by the participants have significantly shaped the narrative of this coalition's efforts to advocate for systemic change without extensive public campaigning.

I could not stop a question. Why should we, especially CYP with LLCs depend on donations? This question started to establish the alliance for enhancing Children's Health Insurance with around 70 agencies. Although we did not make a huge slogan, many people participated in petitions and made these enormous achievements. However, policymakers did not concern with promoting paediatric palliative care until now. (Joonmyun Ham, Co-Representative/ My Welfare (NGO) for Changing Social Policy, 23/12/2018)

Notwithstanding the absence of a catchphrase, the initiative witnessed considerable community involvement and the submission of numerous petitions, which represent notable achievements in the field of advocacy. Each participant emphasised the critical issue of over-reliance on community fundraising and the necessity for structured healthcare support. Nevertheless, as Jeremy Hamilton observed on 23 December 2018, there is a discrepancy between the recommendations of the experts and the actions of the policymakers, who continue to disregard the crucial necessity of promoting paediatric palliative care. The head of the policy team at the Children's Hospital Fee Alliance posited that a state guarantee of children's hospital expenses would necessitate an annual allocation of approximately 515.2 billion won. The implementation of strategic policies such as the Moon Jae-in Care Initiative has the potential to reduce this financial burden to 280 billion won, thereby empowering. This campaign demonstrates the efficacy of a community-driven approach to healthcare reform, whereby various stakeholders collaborate to advocate for substantial policy changes. It is evident that the collective endeavours of these organisations and their representatives are instrumental in advocating for legislative reforms that seek to establish a more equitable healthcare system in Korea.

Furthermore, while the primary focus is on fundraising, it is challenging to prioritize developmental tasks for CYP with LLCs and their siblings. This is due to the fact that social workers specialising in paediatric palliative care are subjected to a significant degree of oppression (for further details, please refer to Chapter 4). Eventually, the oppressed social workers did not intentionally ignore

the cultural transmission of social inequality. However, some service users and social workers face the form of oppression and even reproduce blaming (see stages one and two in this chapter). The absence of guidelines for CYP with LLCs results in parents focusing on life-prolonging treatments, regardless of whether these are in the best interests of the CYP with LLCs or not. The findings of this study demonstrate that every family should receive a child- and family-oriented, multidisciplinary and multi-agency assessment of their needs as soon as possible after diagnosis or recognition, and that these assessments should be repeated at appropriate intervals. The act of asking people to choose among options is, in fact, the root cause of the problem in decision-making. This phenomenon leads to the avoidance of social injustice and social inequality.

9.5 Epistemic and Moral Luck and/or Social Inequality in Decision-Making Processes?

Even though paediatric palliative care social workers cannot focus on holistic approaches because they are oppressed (see Chapter 6.2.5), they should understand the difference between oppression, epistemic luck and social inequality when making the decision. Meanwhile, parents as surrogate decision makers believe in good or bad luck after deciding on unexpected results.

As surrogate decision-makers do not know epistemic luck but also social inequality, social workers in paediatric palliative care should identify that the privilege level of the decision-making processes can be divided into epistemic luck and/ or social inequality in Section 9.5.

In 9.5.1, I will explore epistemic and moral luck such as pseudo-science, arising blame, and praise. In addition, there are problems of luck which are not only linked to the epistemological aspect, but also ethical problems in decision-making processes. After taking the result, arising blame and praise can be related to moral in decision-making processes. Lastly, in 9.5.2, I will investigate how the interplay among habitus, capitals and field constitutes social inequalities in decision-making processes based on Pierre Bourdieu.

9.5.1 Epistemic and Moral Luck in Decision-Making Processes?

While pondering the decision making in complexity, surrogate decision-makers select a course of action to solve a specific problem for their child with LLCs. In researching decision-making processes

for CYP with LLCs, I would consider how levels of decision-making, particularly by palliative social workers, could potentially lead to misunderstandings, epistemic luck in pseudo-science and moral luck in assigning blame or praise. All of these elements must be carefully navigated in order to maintain the autonomy of those involved in the decision-making process. It is essential to ensure that decision-making respects the informed and considered choices of patients and their families, balancing scientific rigour with ethical sensitivity.

In this section, I will explore perspective and interpretation. EBM and/ or epistemic luck in pseudo-science can be easily distinguished when having the privilege. This is to identify the ethical challenge encountered within the processes of surrogate decision-making.

9.5.1.1 Focusing on Evidence-Based Decision Making?

In terms of evidence-based decision making (EBDM), what else should health care providers consider when making decisions in situations like the one described above? It is doubtful that the answer will be a simple number. When I observed evidence-based communication among medical doctors, parents, and interviewed professional medical staff, their answers show the following:

Seeking for Certainty	Medical Uncertainty
<i>"What do I do, then?" 5th December 2017</i>	<i>"The surgery could be longer if there is a complication.", 5th December 2017</i>
<i>"Are you sure?" 5th December 2017</i>	<i>"I cannot guarantee 100%." 5th December 2017</i>
<i>"Doctor, is my son's surgery that serious?" 21st December 2017</i>	<i>"There are a lot of variables during surgery" 21st December 2017</i>
<i>"Doctor, please save my son! I won't be able to live, if he is gone." 29th November 2017</i>	<i>"We can't be sure yet" 29th November 2017</i>
<i>"Please save Dave." 20th November 2017</i>	<i>"We don't know yet" 29th November 2017</i>
	<i>"We need to observe a bit more." 20th November 2017</i>
	<i>"We will do my best" 20th November 2017</i>

Table 9-5 Seeking for Certainty and Medical Uncertainty

Health care professionals need to balance the need to offer hope with the need to communicate the uncertainties of medical treatments. Caregivers often seek definitive answers and reassurance,

especially in critical care settings such as the PICU. I summarised some observations regarding a dialogue between a professor of haematology and caregivers in front of the PICU and shared with the professor on 22nd January 2018. The two talked for a short while over coffee, during which he shared what he had observed. During the conversation, I noted that caregivers seek definitive answers when making difficult medical decisions, and expressions of commitment such as “*we will do our best*” carry significant weight. This can lead to a gap between expectations and clinical reality. Medical professionals strive to reduce uncertainty and improve outcomes by thoroughly exploring all medical options. Meanwhile, caregivers' hopes are centred on their desired outcomes.

Owing to the gap between the perspectives, the interpretations of main problems and gathering information are different. This is because there is a considerable discrepancy of understanding among medical doctors, patients, and their parents. Regarding the gap between understanding and misunderstanding groups, many professional medical workers are unable to give clear answers for their patients but only give vague ones. As most palliative care workers were trained, health workers and family can take both curative treatments and palliative care concomitantly rather than one action for CYP with LLCs (García, 2016:165). According to Geoffrey’s definition, there are palliative care, palliative medicine, surgical palliative care, palliative surgery, and hospice care (Dunn, 1997; Dunn and Johnson, *eds.*, 2004; Dunn, Sugantha Ganapathy and Chan, 2012) at the end-of-life, despite showing apparently similar concepts.

Palliative care	Medical care provided by an interdisciplinary team, including the professions of medicine, nursing, social work, chaplaincy, counselling, nursing assistant, and other healthcare professions, focused on the relief of suffering and support for the best possible quality of life for patients facing serious life-threatening illness and their families. It aims to identify and address the physical, psychological, spiritual, and practical burdens of illness.
Palliative medicine	Palliative medicine is the study and management of patients with active, progressive, and far-advanced disease, for which the prognosis is limited, and the focus of care is the quality of life.
Surgical palliative care	Surgical palliative care is the treatment of suffering and the promotion of quality of life for patients who are seriously or terminally ill under surgical care.
Palliative surgery	A surgical procedure used with the primary intention of improving quality of life or relieving symptoms caused by advanced disease. Its effectiveness is judged by the presence and durability of patient-acknowledged symptom resolution.
Hospice	Hospice is variably used to describe a (1) philosophy of care, (2) a place of care, or (3) an insurance benefit, such as the Medicare Hospice Benefit. Hospice describes supportive care for patients and their families during the patients’ final phase of life-limiting illness. The traditional goal of hospice care is to enable patients to be comfortable and free of pain, so that they live each day as contentedly as possible.
Aggressive Treatment	Benefits or risks associated with mortality outcomes.

Table 9-6 Palliative Care Definitions

Source from Dunn, Sugantha Ganapathy and Chan, 2012: 18

Some of the measures most widely referred to are: average total spending, PICU days, and hospital inpatient days for these patients. Firstly, in terms of diversity, cancer and non-cancer causes are different. In cancer cases, there is a wide range. Where people anticipate and prefer the peaceful dying with family members is not common. Secondly, “aggressive medical treatments” (Wright, Keating, Ayanian, *et al.*, 2016: 291), “surgical palliative care” and “palliative surgery” (Dunn, Sugantha Ganapathy and Chan, 2012: 18) should be distinguished, in spite of various family perspectives on the given definitions. Despite taking the given options, Jaspreet and Bidhu, (2011: 23) say that “the treatment phases of a patient will depend upon the disease condition/stage, the patient’s general health, and the preference of the patient and family.”

Sackett, Rosenberg, Grey, *et al.*, (1996) further stated that EBM should not be regarded as “cookbook” medicine. Furthermore, Haby and Reveiz (2022: 2) highlight that evidence-informed decision-making (EIDM) acknowledges the complex and diverse aspects of patient care. EIDM acknowledges that although EBM offers a robust framework grounded in meticulous research, healthcare decisions frequently necessitate a more customised approach that accounts for the unique circumstances, preferences, and values of the individual patient.

Field notes, 12-13 April 2018: Over two days, I engaged (interviewed on 12 April 2018) and Hiroki Takahashi (interviewed on 13 April 2018) of the Bioethics Research Interdisciplinary Group in discussions focused on decision-making processes involving patients and families, particularly in relation to evidence-based medicine (EBM) and evidence-informed decision making (EIDM). In extending these discussions to paediatric settings, both bioethicists expressed significant reservations, pointing out that even adult discussions lack depth and paediatric considerations are even less developed. At a dinner with a Korean scholar who participated in the interviews, the scholar cynically noted the unrealistic expectations within South Korea's fast-track healthcare system. This insight highlights a critical gap in the literature on the specific attitudes and practices of South Korean clinicians towards EBM and EIDM, and suggests the need for more focused research on how these decision-making frameworks are perceived and implemented by local medical professionals.

EIDM entails making treatment decisions based on the most reliable and current evidence, taking into account individual factors and the feasibility of implementing various treatment alternatives. This approach transcends the dichotomy between “ineffective” and “innovative” remedies and attempts to acknowledge the intricacies and diversity that are intrinsic to the field of healthcare. EIDM endeavours to deliver care that is attuned to the unique requirements and circumstances of each

patient by incorporating clinical proficiency, patient values, and the most reliable research data. This approach enhances the responsibility and efficacy of healthcare determinations. Adopting a more comprehensive viewpoint is of utmost importance when confronted with uncertainty, as it can aid in averting the types of errors that result from an overly rigorous application of evidence-based guidelines.

9.5.1.2 Epistemic Luck in Pseudo-Science

In the emotionally charged process of making decisions for CYP with LLCs, parents grapple with the delicate balance between hope for their child's improvement and the practicalities of care. Despite the challenges, they strive to make decisions that are in the best interests of their child.

Doctor	Family Caregivers of Child or Young Person with LTCs
"A patient of mine had a similar condition to you and had the treatment and did very well."	"My son had a similar illness and took the treatment. After taking the treatments he did very well."

Table 9-7 Storytelling Source from 9th January 2018 Fieldnotes

I observed that the narratives shared by healthcare providers, such as "A patient of mine had a similar condition and improved significantly after treatment," or "My son faced a similar illness and recovered well post-treatment," serve to humanise the medical discourse (9th January 2018 Fieldnotes). These stories provide solace to parents, fostering hope and personalising the treatment experience. Such anecdotes may indeed influence parents' decision-making, as they often seek assurance through relatable outcomes that envision the best interest of their child. *Laurel Wagner* shared me her experience that it is not uncommon for patients to seek personal guidance by asking,

"If you were in my position, what would you do?" It is important for healthcare professionals to be open and honest about what they believe would be the optimal decision in such

circumstances. It is also important to reiterate that whatever choice is made, it is not about right or wrong, but about making the best possible decision in the situation. (2nd/3/2018 Nara Jang)

EIDM, as described by Haby and Reveiz (2022), emphasises the integration of reliable evidence, clinical expertise and patient preferences as a priority. It is a disciplined technique that places a high value on data obtained through careful investigation, systematic observation and extensive analysis. Doherty (2005: 307) highlights a discrepancy between EBM and the approach he discusses. He suggests that EBM downplays the importance of intuition, anecdotal clinical experience and pathophysiological thinking in making therapeutic judgements. Instead, EBM emphasises the importance of data derived from clinical research. EIDM recognises and values this perspective, while also recognising the importance of individual patient stories. It integrates these stories into a scientifically rigorous framework to guide decisions that are both evidence-based and patient-centred.

Although stories can have a powerful influence on decision-making, surrogate decision-makers may grasp at them like “a drowning man catching at a straw.” While stories can assist in considering options and the pros and cons of outcomes, they cannot guarantee certainty. Instead, they can be used to pursue what one wants to believe when feeling confused. The crux of the matter lies in the tendency for the worst decisions to arise when evidence is either omitted, exaggerated, or biased, often driven by a pursuit of epistemic luck. This phenomenon underscores the dangers of pseudo-science creeping into decision-making processes, where the desire for certain narratives can overshadow the importance of evidence-based medicine. Surrogate decision-makers and CYP with LLCs would benefit from a clear understanding of these dynamics, emphasising the importance of evidence and informed decision-making to avoid falling into the trap of epistemic luck in pseudo-scientific realms.

Pseudoscience is a risky and dangerous practice that often presents exaggerated or unsubstantiated claims without the scientific method. Surrogate decision-makers, while seeking information, may mistakenly believe in pseudoscience as an accurate explanation for certain illnesses, such as the use of radon-emitting mattresses and humidifier disinfectants.



Figure 9-15 Negative ion, germanium products are sold on the internet. Souce from Juhee Yoo, 2021

Pseudoscience refers to activities or beliefs that claim to be scientific but lack empirical evidence, adherence to the scientific method, or acceptance by the scientific community. Cases such as radon-emitting mattresses and germanium bracelets illustrate this phenomenon by claiming unproven health benefits and distorting scientific concepts to appear more credible. The intersection of hidden SDOH and pseudoscience, particularly in the context of economic policy, can have significant implications for public health and well-being. When certain social determinants are deliberately omitted or obscured, this can pave the way for pseudoscientific beliefs to take hold, with potentially harmful consequences. Unfortunately, many CYP with LLCs have been exposed to these harmful practices. Lack of transparency in the decision-making process and unavailable evidence make it difficult for surrogate decision-makers to find accurate facts. Despite the emphasis on EBM, this review explores why surrogate decision-makers may rely on epistemic luck, which can significantly influence their decisions about continuing healthcare.

I emphasise that the prevalence of pseudoscientific beliefs hinders informed healthcare decisions and highlights the need to distinguish between treatments that are scientifically validated and those that are based on unsubstantiated claims. When it comes to EBDM, it's important for healthcare providers to consider factors beyond empirical data. While EBDM values empirically supported therapies, effective care goes beyond mere statistics or rigid protocols. EBDM requires that treatments be tailored to each patient, taking into account their medical history, preferences, values and social circumstances to ensure optimal care.

9.5.1.3 Moral Luck: Arising Blame and Praise

The decision-making landscape for CYP with LLCs is complex. Parents consider not only immediate medical decisions, such as treatment options, but also comprehensive end-of-life planning. This includes organising funerals, making wills and considering organ and tissue donation (Macmillan Cancer Support, 2015; National End-of-Life Care Programme, 2012; Henry N. Pollack, 2003: 13).

Decision Processes

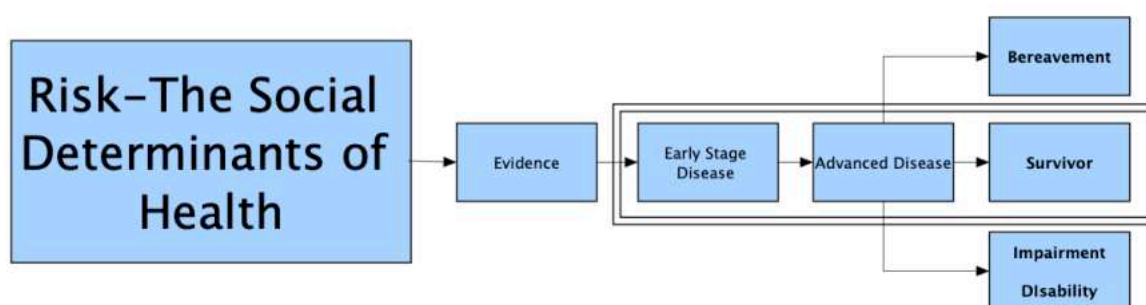


Figure 9-16 Focusing on Becoming Survivors in decision-making processes

Observing the two groups, I found that in cases where the treatment was successful and the cancer did not return for a period of five years, the survivors were more likely to express positive opinions about the medical outcome. However, in cases where the treatment was unsuccessful and the child died, there was a significant amount of guilt, anger and blame.

I made a poignant discovery when I regularly visited several wards with seriously ill patients and interacted with both patients and their families. The tacit acceptance of grief as a form of defeat creates a growing and unbridgeable gap between those who have lost loved ones and the grieving families. I observed that grieving families expressed feelings of guilt and shame when interacting with medical professionals in the hospital.

Haeun Seo, Dain Oh's mother, (09/04/2018 interview) told me, "*Avoid overemphasising treatments. Occasionally it is necessary to interrupt or stop certain activities.*" She expressed to me, "*I would like to visit the hospital and deliver this message, but unfortunately I will never have the opportunity to do so.*"

I expressed concern that there is no formal procedure for CYP with LLCs to refuse unnecessary treatment, unlike adults who can do so through advance care planning. Despite the establishment of children's and young people's palliative care units, these are only located in university hospitals.

The notion of moral luck refers to situations in which an individual is held accountable or praised for the consequences of their actions, despite not having control over them. In healthcare, moral luck can arise when unexpected outcomes receive moral judgment. For example, a doctor may be criticized for failing to cure a patient, even though the outcome was outside of their control. Dickenson (2003) further argues that moral luck can also arise when unexpected results involving risks and contingencies receive moral praise or blame. This can lead to ethical dilemmas for healthcare professionals and decision-makers.

Thus, epistemic and moral luck in decision-making processes are quite different aspects, but in terms of knowledge and ethics, the problem of luck is intertwined with the fragile concept by setting up a disagreement between moral justification and rational justification. Risk and luck in surrogate decision making may have led to perplexing problems or unexpected outcomes. (Dickenson, 2003: 65) It leads to moral differences such as blame and praise.

Ethical dilemmas can be the result of moral luck as well as patient preferences and needs. For example, a surrogate decision maker may be faced with the dilemma of whether to pursue curative treatment or palliative care for a child with a life-limiting illness. Conflicting beliefs and values can also create dilemmas, as different communities may have different views on what constitutes the 'best interests' of the patient. Prudent decision-making can be hampered by these conflicting beliefs, leading to conflicts between what is considered to be in the best interests of the patient and the prudence of authorities. Discussions about decision making in health care therefore need to consider the possibility of moral luck and the potential for blame and praise in decision making, especially when making difficult decisions for children with LLCs.

9.5.2 Decision Processes with Habitus, Capital, and Field?

Understanding decision-making processes in social inequality, I employ Bourdieu who insisted three interlinked concepts enable the analysis of decision-making processes: habitus, capital, and field. For understanding the complicated decision-making processes leading to marginalisation, paediatric palliative care social workers can focus on holistic approaches such as the interests of the oppressed

groups and the values of CYP with LLCs. And they can understand in a dynamic decision process, regarding a class phenomenon.

In 9.5.2.1, I will interpret that telling the truth with habitus can assist with theorising health choices. Telling the truth requires knowing both essential information and how to share significant news for their child with LLCs. This section presents that there are two opposite decision-making processes whether telling the truth with habitus or hiding the truth with habitus.

In 9.5.2.2, by using a Bourdieu-based interpretation, I will explore linguistic, social, and economic capital. Because of the forms of capital, there is a huge discrepancy in decision-making processes.

In 9.5.2.3, I will present that health choices in decision-making processes can be understood between epistemic luck and social inequality. However, this section presents critical points that due to social inequality as external factors of uncontrolled decision-making processes, focusing on becoming survivors in decision-making processes reproduces ‘unequal class relations and its structures of social inequality, but may not relate to epistemic luck. It can help enhancing holistic care including healthcare transition such as hospital, hospice, home, school, and community.

9.5.2.1 *Telling the Truth with Habitus*

While observing parents at an acute hospital and listening to the unheard voices of CYP with LLCs, I initially perceived that surrogate decision-makers were not adequately informed or involved in the diagnostic and decision-making processes. However, my findings delineated two distinct groups: those who disclose the diagnosis to the child and those who choose to conceal it.

While exploring parents having a child came an acute hospital, I tried observing unseen faces and listening to their unheard voices from CYP with LLCs. Before starting observation, I thought that surrogate decision makers for CYP with LLCs had not been given diagnosis and participation in decision-making processes. However, the findings revealed two opposite groups: those who disclose the diagnosis to the child and those who keep it hidden from them.

Telling truth to CYP with LLCs in decision-making processes has linked the privilege: delivering the communication requires appropriate time and place between patients, their family members and health workers. Besides, it should not only require knowing diagnosis in starting pathway and next processes but also having supporting groups for decision-making processes in terms of privilege.

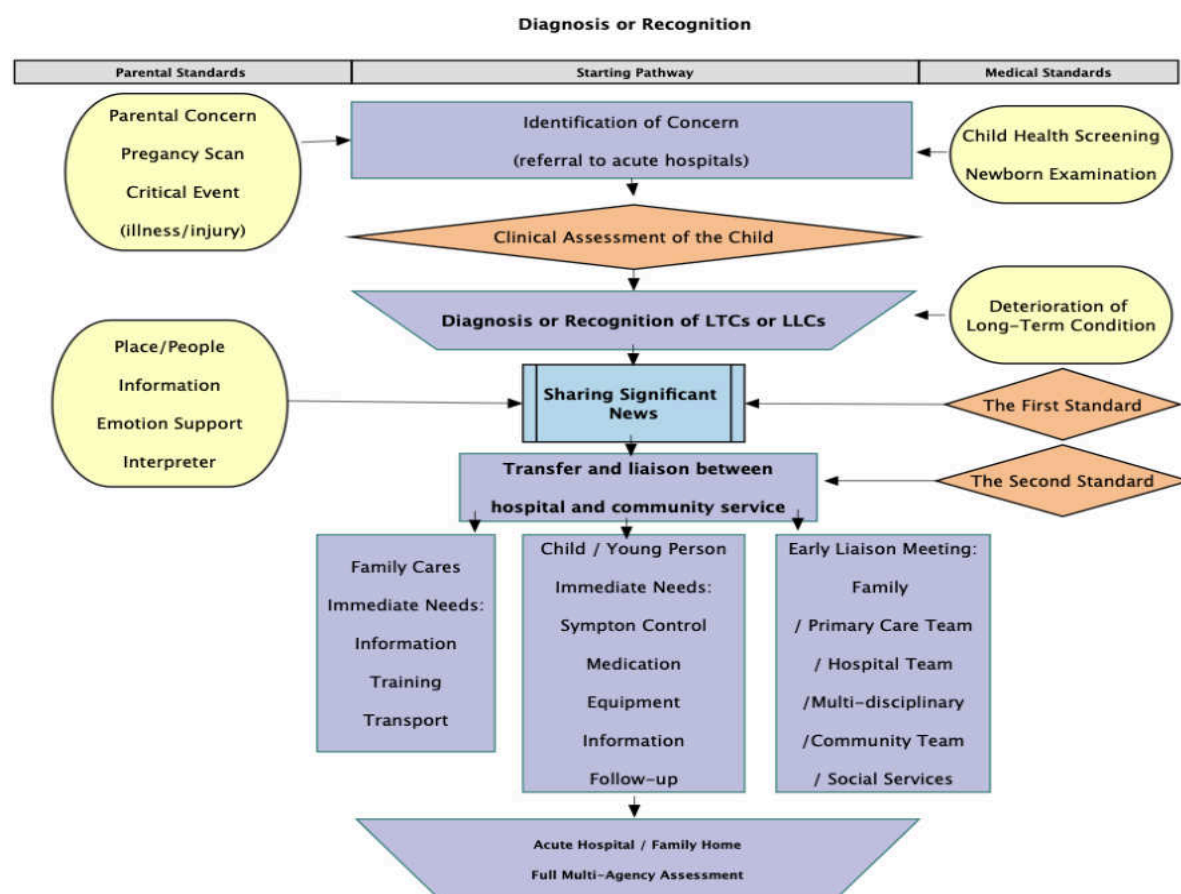


Figure 9-17 Starting Pathway: Diagnosis or Recognition of LLCs or LLCs:

Seunghoon Oh has adapted and expanded upon the framework originally presented Widdas, Street, Edwards, *et al.*, 2013.

Bourdieu (1994: 63) mentioned people have their own habitus which has their own embodied experiences that how people have the formation of thought, perception, judgement, and values within the community which are differentiated from other communities. Garth Stahl (2019:70) insist that “habitus is intended to extend our understandings of internalised behaviours, perceptions and beliefs that individuals carry with them and which, in part, are translated into practices.” According to Bourdieu, individuals navigate the social world based on their habitus, which predisposes them to act in certain ways, often unconsciously. In the context of palliative care, this manifests in how surrogate decision-makers communicate with CYP with LLCs. Some may choose transparency, while others

prefer protection from harsh realities, reflecting their underlying habitus formed by their cultural, social, and economic capitals (Bourdieu, 1986:101).

However, the other groups are struggling with unexpected disability following brain tumour surgery that has resulted in significant vision loss due to optic nerve damage.

'Let me die with my mother': Samsung to compensate sick workers, but many will never recover



Former workers and their families vow to fight on for safe working conditions

CBC Radio - January 29



Figure 9-18 Han Hye-kyung eats with the help of her mother, Kim Sinyeo, left. The 40-year-old has lived with a disability since 2005, following a surgery to remove a brain tumour. Han's family believes it was caused by her time working in a Samsung factory.

(Jean Chung/Getty Images) (Sandra Bartlett 2019)

- *Deborah Oh was diagnosed with the condition at the age of 19 and subsequently interviewed at the age of 40. The successful surgical removal of the brain tumour resulted in significant vision loss due to damage to the optic nerve. Her work in the semiconductor industry may have contributed to the exacerbation of her health problems, thereby illustrating the complex interplay between occupational hazards and health outcomes. The challenges faced by these individuals in re-entering social and professional life demonstrate the far-reaching socio-economic impact of cancer, extending beyond the medical prognosis.*
- *Bumsoo Seo was 16 years of age at the time of diagnosis and 21 years of age at the time of interview. Despite undergoing successful treatment, Branden experienced irreversible vision loss,*

which had a profound impact on his independence and daily functioning. His case serves to highlight the serious and often unexpected long-term effects of cancer treatment, and underscores the necessity for comprehensive post-treatment care and support systems.

In addition, the non-cancer group of 15 people analysed in the humidifier disinfectant tragedy includes people with chronic and rare diseases such as moyamoya and chronic respiratory diseases, each of which presents unique challenges.



Figure 9-19 Dong Hyun Yi, 2, whose lungs were destroyed by a humidifier steriliser in 2006, is pictured in hospital with a nose tube before surgery for a pneumothorax (top left) and smiling after the operation when he can breathe easier (top right). The photos above, from right to left, are used as the cover of *Stolen Breath* and as a symbol of humidifier damage. /Park Ki-yong (yellow jacket), who took part in a commemorative performance at Seoul City Hall on 31 August to mark the fifth anniversary of the humidifier disaster, sits on a large hanging painting of his son Dong-hyun (below) /Provided by Ahn Jong-joo (Ahn Jong-joo, 2016)

Firstly, telling the truth requires acknowledging that for many people, long-term management is a critical issue, requiring ongoing care that profoundly affects their lifestyle and overall wellbeing. This ongoing need for medical care not only disrupts their daily routines, but also shapes their habitus and dispositions developed in response to their living conditions. These dispositions, formed through

prolonged experiences of health care, influence how individuals perceive their health and manage their care, often solidifying a habitus of resilience or resignation dependent on their socio-medical interactions (Bourdieu, 1990:53).

Secondly, telling the truth means that the need for social and emotional support is pronounced, highlighting the chronic nature of their conditions and the constant adaptations required. The constant struggle to adapt to changing health conditions requires considerable social support, which shapes the social capital to which individuals have access. Bourdieu's concept of habitus here explains the deeply rooted perceptions and expectations individuals develop about receiving support, which can significantly influence their engagement with health care providers and their personal networks (Bourdieu, 1986:101).

In terms of echoes from the field, several participants in this study expressed concerns that reflect these theoretical insights. Their narratives reveal an acute awareness of how their ongoing health struggles and need for adaptive change affect their daily lives. These experiences, as articulated by the participants, not only reflect their individual habitus, but also illustrate the broader social and cultural dispositions that shape their responses to chronic health challenges. (Bourdieu, 1984:170-171).

The privileged people know telling the truth is essential as habitus is to tie the 'objective' with the 'subjective' social world. According to Widdas, Street, Edwards, *et al.*, (2013: 19), there are two different habitus: one group has their own standards despite no six keys' goals for the prognosis and shared significant news, whereas the other group believes in hiding the news with family members. "Paternalistic decision-making" (Roeland, Cain, Onderdonk, *et al.*, 2014; Santoro and Bennett, 2018) is related to the voicelessness of CYP with LLCs: surrogate decisions excluding the voice of children and undermining for the autonomy of the patients.

At the hospital, I met two groups of surrogate decision-makers: hiding the truth or telling the truth. On 7 February 2018, I conducted an interview with Taeyeon Koo, a hospital interpreter with a medical background, who primarily assists Russian expatriates. Due to language barriers, direct interviews with Russian speakers or other foreigners were not feasible, which underscored the importance of Taeyeon Koo's insights. She shared with me that many Russian parents prefer to conceal their children's medical conditions, adhering to a belief in hiding the truth. These parents voiced their worries about the potential lack of support if the truth came to light. *"Please never tell our child about the illness,"* implored one parent through Taeyeon Koo. *"They claim that if the chemotherapy is successful, it could be over in six months, but we'd rather our child remain unaware."*

Additionally, on 16 November 2017, I interviewed with the mother of Minhø Jeong, an eight-year-old diagnosed earlier that day with a Stage II condition. I recorded an unplanned meeting with his mother, Minji Park, on 8 January (fieldnote), during which we further discussed this conversation. In the hospital ward, she confided, *“I still haven’t told our child anything about the illness.”*

I found that one group believed that they could never reveal the disease to their children. Thus, they mentioned hiding the truth but did not know how to replace them when their children were told the truth or who could help our family.

In contrast, the other group explained all the situations to their children and told them how to recognise and deal with the situation together. In interviews conducted from February to May 2018 with 17 families of cancer survivors, a common pattern emerged: while many parents initially chose not to discuss the diagnosis with their children, the truth about the illness invariably came to light, either through deliberate disclosure by the parents or discovery by the children themselves. This consistent observation across multiple cases, such as with Bumsoo Seo, a 21-year-old survivor, and Daun Kang, an 8-year-old whose family initially struggled with how to handle the disclosure, highlights a crucial shift from secrecy to transparency.

I discovered that the act of telling the truth depends on several conditions, which underlines the importance of being prepared for both favourable and unfavourable consequences. This belief goes beyond the attainment of psychological and emotional stability, as it includes the resolution of any obstacles that may arise. This transition often turned honesty into a vital tool for these families, aiding in problem-solving and preparing both parents and children to face the realities of the illness. As a result, two opposing factions emerge due to their different methods of communicating the facts. Telling the truth requires knowing both essential information and how to communicate important news to your child with LLCs. For this reason, there are two opposing decision-making processes, whether to tell the truth with habitus or to hide the truth with habitus. Thus, the opposite perspectives between ‘hiding the truth’ and ‘telling the truth’ among parents, palliative care staff and children or young people with LLCs may be related to privileged or unprivileged habitus.

9.5.2.2 Forms of Capital and the Gap of Decision-Making Processes

By using a Bourdieu-based interpretation, I will explore linguistic, social, and economic capital. Because of the forms of capital, there is a huge discrepancy in decision-making processes. The inequalities created by these forms of capital are profound and shape how decisions are approached and implemented. Bourdieu's theory of capital and field provides a nuanced understanding of these processes, highlighting how different forms of capital confer power and influence within the health sector (Bourdieu, 1986: 241). In general, surrogates know their interests to respect the autonomy and then they just follow the patient's decision-making for the best interests. When making the decision is one of these options: following, refusing, or withholding a patient's opinion. There could be a problem: when medical treatment has been recommended, especially moving to PICU, and it is met by a refusal from a surrogate decision-maker, this is always a serious situation that needs to be given very careful attention, following that:

A mother who lost her daughter from leukaemia told me about her experience. "I used to be a nurse and have received hospice palliative care training, so I know the importance of end-of-life care for my daughter. A doctor has recommended moving my daughter to ICU, but my daughter and my family carefully thought before coming to this situation as further treatment may be futile and bring more harm to my daughter. Not only that, I thought it would only be more painful if the child went to the ICU and there would be a little real benefit to the treatment. There is no reason to choose to cause more pain to the child. Although moving to the transition to palliative care was not available, we asked to have a private ward. The doctor told me that my refusal of treatment was a first for this hospital. He has been a professor and practicing for over ten years, and it appears there have been no such refusals before. I did not want my daughter to undergo harsh treatments. I refused treatment for the first time, and my family and daughter had the last farewell in the single room ward." (Haeun Seo, Dain Oh's Mother, 09/04/2018)

Firstly, Haeun Seo, a former nurse trained in hospice care, used her professional knowledge and experience to navigate the medical discourse that enabled her to make an informed decision against moving her daughter into intensive care, reflecting her considerable linguistic capital (Bourdieu, 1991:66) in decision-making processes. There are two opposite decision-making processes with linguistic capital: choosing a preferred course of action for the patient's preferences is linked with doctor shopping, whereas weighing benefits and burdens for the patient's best interests is led to

refusing potentially life-prolonging treatment. Understanding uncertainty in decision-making processes means whether who have linguistic capital or not while taking essential information from medical staff in 3 minutes. When parents have informed of the given explanations based on the probability such as patients' symptoms and current situation, they are confused: they are unfamiliar with statisticians and the probability. As every medical treatment has some risks and brings various possible outcomes, medical staff cannot guarantee 100%. It could be whether they misunderstood or understood the given information from medical staff. Without NICE guidance (Villanueva, Murphy, Vickers, *et al.*, 2016: 355), surrogate decision-makers who have linguistic capital can ponder various contexts for pursuing the best interests for CYP with LLCs.

The second is economic capital. During an interview, Minah Kim, a nurse and counsellor, shared a poignant story about one of her patients. On 18 May 2018, she recounted how a family had come to participate in a survivor program for cancer patients, five years after the patient had completed their initial treatment. Despite their hopes, visible signs of recurrence, such as bruising, were apparent. The patient's mother was in the process of securing life insurance and cancer coverage when the patient's condition deteriorated, eventually leading to their death. Families of CYP with LLCs often face complexities when weighing curative treatments against palliative care options. Despite her informed choice, the limitations of available care options and the need for a private ward highlight the intersection of economic and social capital. Families often face complex choices in which economic resources can limit or enable access to preferred care options, significantly influencing outcomes (Bourdieu, 1986:184). The range of choices can be confusing, leading some to engage in 'doctor shopping' to assert autonomy in decision making. In Korea, this practice, while understandable, can add to the confusion and may not be the most cost-effective approach. As a result, parents and CYP with LLCs are faced with multiple options and sometimes struggle to navigate their choices effectively. During the decision-making processes for children and young with LLCs, the family members take huge financial burdens as out-of-pocket payments, showing before and after changed income.

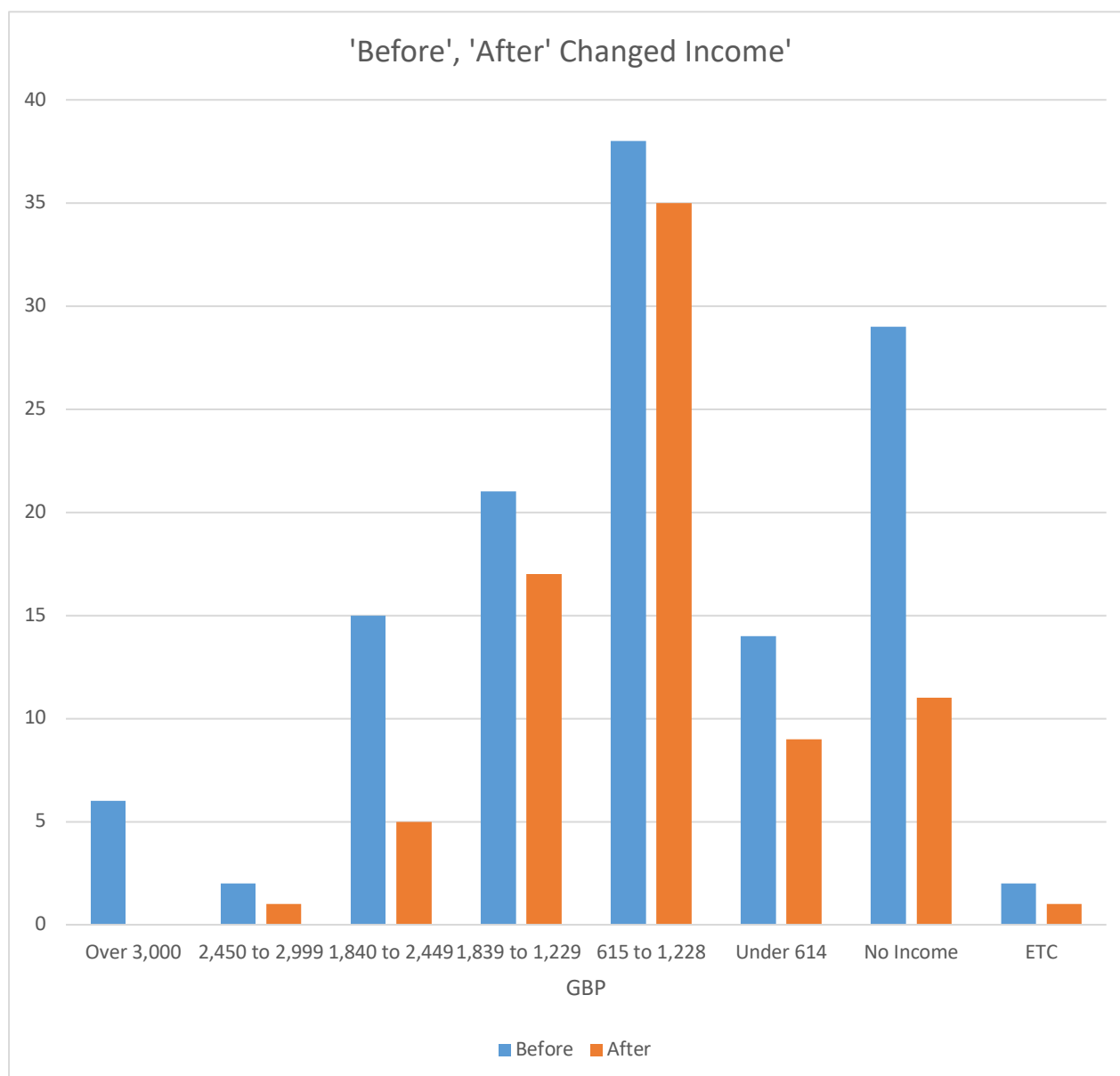


Figure 9-20 Before and After Changed Income Due to Doctor Shopping

Source from Park and Shin, (2016)

When CYP with LLCs are hospitalised and focus on doctor shopping, there is a huge gap between different economic capitals, according to the figure. To alleviate the financial burden, medical social workers help to improve systematic fundraising. Surrogate decision-makers with economic capital can use doctor shopping to pursue the best interests of CYP with LLCs, whereas most parents struggle with financial burdens. The range of choices can be confusing, leading some to doctor shop to assert autonomy in decision making. In Korea, the practice of doctor shopping reflects an assertion of autonomy in decision-making influenced by economic capital. While this practice allows for a thorough exploration of treatment options, it also adds complexity and often increases the financial

burden on families. This dynamic illustrates the crucial role of economic capital in navigating health care choices and the inequalities it can create between families with different financial resources (Bourdieu, 1986:241). In Korea, this practice, while understandable, can exacerbate confusion and may not be the most cost-effective approach. As a result, parents and CYP with LLCs are faced with multiple options and sometimes struggle to navigate their choices effectively. The third is social capital. When surrogates know their child's best interests, they just follow the best interests. Deciding for the best interests requires supporting groups as supporting decision-making processes.

I found that CYP with LLCs and their family members rarely participate in decision-making processes related to professional involvement in the care of a child. The low level of involvement may be influenced by covert SDOH and/or oppression, as well as decision-making processes guided by *Jeong's* theory-based decision-making processes. (See Chapters 6.3 and 8.3.3.2.) However, an individual's social capital may influence their ability to successfully manage the developmental responsibilities of parenting a child with LLCs. For example, they may be better prepared to manage tasks such as changing hospitals and coordinating between hospital and community services. They may also be better able to assess the child's and family's reactions to their care. However, parents who lack social capital may not have access to these choices and may have to rely on their own judgement to maintain their independence. These challenges can be particularly difficult for parents with limited financial resources, who may have fewer opportunities to make informed decisions about their child's care. The role of social capital is critical as it shapes the support systems that families have access to and enhances their ability to make informed decisions. Families with strong social networks are better able to navigate the health care system, coordinate support at critical decision points and potentially secure better health care outcomes (Bourdieu, 1986:248).

It is therefore crucial to consider the potential ethical dilemmas and complexities that may arise in health care decision making, and to explore methods of supporting parents and families to make optimal decisions for CYP with LLC, particularly how different forms of capital influence these processes.

9.5.2.3 *Epistemic Luck or Social Inequality of Fields?*

Although medical staff partly admit the privileged level of decision-making processes, they believe that “*parents have their own beliefs, so they believe what they see and want*” which is related

to misunderstanding EBM and epistemic luck in pseudo-science in 9.5.1.2. This is because surrogates, who decide on behalf of a patient, face the lack of control conditions of luck in the medical field, which cause unexpected results. Statman (1991: 146) accounts for good and bad luck, stating that “good luck occurs when something good happens to an agent P, its occurrence being beyond P’s control. Similar, bad luck occurs when something bad happens to an agent P, its occurrence being beyond his/her control.” Regarding their beliefs, when evidential and doxastic epistemic luck is combined, a necessary condition for knowledge may boost “wish fulfilment” (Welsh: 1994).

However, there may be internal and external factors of uncontrolled decision-making processes. Focusing on epistemic luck in decision-making processes highlights internal factors related to the beliefs of surrogate decision makers rather than external factors of uncontrolled decision-making processes. Although it might be assumed that unpredictable outcomes in healthcare are merely instances of epistemic luck, Bourdieu’s concept of social fields provides a more comprehensive and nuanced explanation. This theory suggests that what may be perceived as “luck” is, in fact, the consequence of complex interactions within a field that is shaped by power dynamics and capital distribution. In the context of healthcare, decisions are not solely influenced by the knowledge or beliefs of individuals (such as surrogate decision makers). Furthermore, their positions within the field are shaped by their access to various forms of capital, including social, economic, and cultural capital. These positions determine their capacity to exert influence and navigate the healthcare system, thereby significantly impacting decision-making processes and outcomes. Consequently, what may initially appear to be randomness or ‘luck’ is, in fact, deeply rooted in the structured inequalities of the healthcare field. Bourdieu’s field theory highlights how dynamic interactions within social spaces are shaped more by the relationships between entities than by the entities themselves. In health care, actors with different levels of capital - social, cultural or economic - actively influence these dynamics, either seeking to maintain or change the existing distribution of power and resources (Hilgers & Mangez, 2015: 34). This theory is particularly relevant when making decisions for CYP with LLCs, where serious conflicts can arise. When deciding for CYP with LLCs, the results can cause serious conflicts in terms of Bourdieu’s third concept in the “healthcare field” (Fran M Collyer, Karen F Willis, Marika Franklin, 2006), following the figure:

Decision Processes

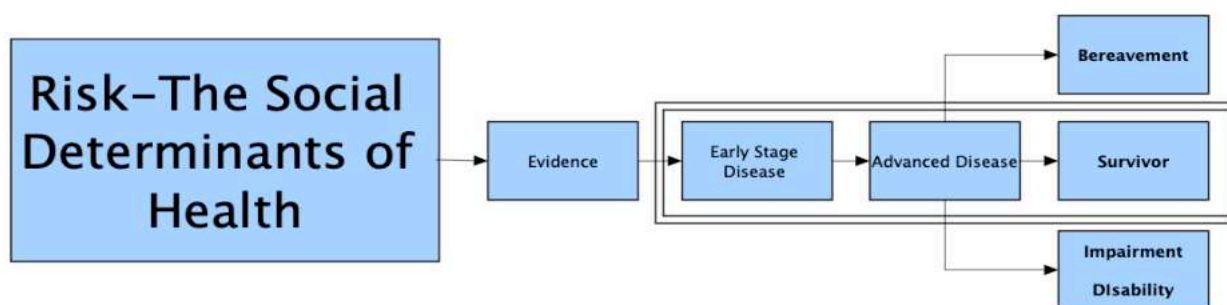


Figure 9-21 Focusing on becoming survivors in decision-making processes

Figure 9-21 synthesises the decision-making processes of 50 individuals diagnosed with cancer and 15 individuals without cancer, revealing a predominant focus on becoming survivors. The figure illustrates that, despite their concentration on survival, surrogate decision-makers often fail to consider critical aspects such as the financial burden, proving the evidence of diseases, bereavement care or rehabilitation care, which are nevertheless important elements of the decision-making process. Furthermore, in their pursuit of solutions pertaining to SDOH, some have resorted to unverified pseudo-science, thereby exacerbating the challenges and potentially worsening the patient's condition.

All CYP with LLCs hope to go back to their normal life as a survivor. The “healthcare field” (Collyer, Willis, Franklin, *et al.*, 2015) of decision-making processes is structured by the opposition between bereavement and survivor (who have different groups whether going back to normal life, requiring rehabilitation, or living with a disability). The “healthcare field” (Collyer, Willis, Franklin, *et al.*, 2015) of decision-making processes implicitly may show a site of struggle and contestation (Collyer, 2014), especially doctor shopping, which is dominated by the logic of the economic level. Due to having unequal capital and focusing on becoming survivors in decision-making processes reproduces ‘unequal class relations and its structures of inequality’ (Moore, 2008: 103–104). The opposite fields between bereavement and survivor struggle with social inequality, mainly accessing social capital in decision-making processes. After following doctor shopping, most family members are vulnerable to easily become a marginalised group (see Figure 9-20 Before and After Changed Income Due to Doctor Shopping). Bourdieu's theory emphasises the pivotal role of social fields and their intrinsic structures in influencing interactions and outcomes. When applied to the field of healthcare, this perspective demonstrates how decision-making processes extend beyond the

boundaries of individual and clinical judgments. Instead, they are profoundly shaped by the pervasive social and structural inequalities that define the healthcare sector. These disparities determine access, influence and power, and thus have a profound impact on patient outcomes and treatment options (Bourdieu & Wacquant 1992: 39-43;185).

When it comes to decision making in holistic approaches, it is important to take into account various settings such as hospitals, schools, intercommunities, and households, as indicated by Villanueva, Murphy, Vickers, *et al*, (2016:355). While survivor care planning is absent, the lack of a discernible health sector is cause for concern. The procedures necessitate the identification and assessment of conditions that restrict life expectancy, the first phases of such conditions, the development of care plans, the provision of care, end-of-life support, and bereavement care. The NICE guidance summary states that the decision-making procedures in the holistic approach encompass various healthcare settings.

Therefore, social workers in paediatric palliative care evaluate choice processes involving CYP with LLCs by comprehending their privilege level. When examining the importance of decision-making processes, I identified two viewpoints: epistemic chance or social inequity. The emphasis is placed on uncertainty and risk in decision-making processes for CYP with LLCs within the family, rather than on addressing systemic injustice and oppression, while also downplaying the significance of social inequality. As a result of social inequality, which is an external element that influences decision-making, prioritising the goal of survival in choice processes perpetuates unequal class relations and the structures of social inequality. However, this focus may not necessarily be connected to epistemic luck. Furthermore, it can be associated with a self-perpetuating cycle in the underlying factors of societal disparity, and it cannot be included into collaborative decision-making that prioritises remedial interventions.

9.6 Conclusion: The Privilege Level of Decision-Making Processes - Social Inequality

In this chapter, I explored the privilege level of decision-making processes because decision-making processes are not a one-off rational event and parents are confronted with various junctures in decision-making processes.

In 9.2, I showed that in stage one, they experienced the forms of privileged or underprivileged level in surrogate decision-making such as financial burden, telling the truth, multi-disciplinary assessment or needs and geographical accessibility.

In 9.3, stage two showed that the results of decision-processes often keep praising and/or blaming the results on the privilege level. Parents and CYP with LLCs do not always recognise signs of oppressive decision-making, non-oppressive decision-making, or multi-layered oppression in doctor shopping, the hit and miss (福不福) in palliative care rehabilitation and education, and self-cultivating (各自圖生) of final place. This is because there are rare opportunities of palliative care rehabilitation, avoiding funerals, and victim-blaming. Stage two will show that the results of decision-processes often keep praising and/or blaming the results regarding the privilege level.

Regarding stages one and two, 9.4 revealed that the expectations for paediatric palliative care social work require enhancing holistic care to improve quality of life and encourage fundraising, but in fact, focusing on fundraising is more important than other works.

Section 9.5 identifies the ethical dilemmas encountered within the privilege level of the decision-making processes' perspectives: epistemic luck and/ or social inequality. On the one hand, when misunderstanding evidence-based medicine and/ or epistemic luck in pseudo-science, epistemic luck may happen in decision-making processes while pursuing the best interest for CYP with LLCs.

On the other hand, to understand the complicated decision-making processes leading to marginalisation, I employ the triad of concepts such as habitus, capital, and field from Bourdieu: the three interlinked concepts that enable the analysis of decision-making processes. Firstly, telling the truth in decision-making processes can be divided into two opposite decision-making processes whether habitus with the truth or hiding the truth with habitus. Secondly, in the forms of capital such as linguistic, social, and economic, there is a huge discrepancy in decision-making processes. Lastly, in terms of Bourdieu's third concept as the "healthcare field", focusing on becoming survivors in decision-making processes reproduces 'unequal class relations and its structures of inequality, but may not relate to epistemic luck. Owing to the privilege level of the decision-making processes, this rise in social inequality, which lies at the centre of pursuing the best interest of CYP with LLCs may be the cause of heated national debate.

Chapter 10: Conclusion

10.1 Introduction

In this thesis, I aimed to critically explore the multi-dimensional decision-making processes from lived experiences. A critical ethnographic approach, combining methods of observations and interviews enabled the study objectives to be met and facilitated the exploration of the multi-dimensional decision-making processes from lived experiences. This doctoral thesis has been a collective effort that has involved CYP with LLCs and many people, such as senior members of paediatric palliative care teams, and local, national, and international disciplinary contexts in decision-making where I learnt more about the decision-making processes. My previous experiences working in hospices inspired the research idea, but the scoping review in chapter 2 highlighted the ethical challenges, decision-making processes, and the role of paediatric palliative care social workers.

Research is often discussed, showing the multi-dimensional decision-making processes that I navigated during the holistic decision-making processes. In Section 10.2, I was able to provide a deep theoretical and methodological exploration of the multi-dimensional decision-making processes from a range of perspectives. Employing this theoretical framework illuminated the lived realities. To investigate some connections among barriers, facilitators, discrimination, oppression, and luck in multi-dimensional decision-making processes, I drew from the Other of Emmanuel Levinas, from the tacit dimension of Michael Polanyi, and from the field, habitus and doxa of Pierre Bourdieu.

The novel contributions that this Thesis makes to knowledge are presented in Section 10.3. The key findings of this thesis are arranged in four sections below focused on the key areas: the structural level, the family-oriented level, the tacit dimensional level, and the privilege level of decision-making processes. Each level of decision-making processes includes ethical challenges such as oppression, distorted beliefs, luck as social inequality. Limitation and implications present in section 10.4 and recommendations for future research are proposed in Section 10.5.

10.2 Theoretical and Methodological Considerations

Exploring the multi-dimensional processes for CYP with LLCs, critical ethnography was the methodology employed within this thesis to answer my question of “finding out the multi-dimensional processes for CYP with LLCs in the Republic of Korea.” Employing methods of 120 semi-structured interviews, fieldnotes, participant observation and document analysis, I constructed empirical data in the given places and time. The observation and interviews used in this study were limited to hospital healthcare professionals in the capital, Seoul. Thus, critical ethnography allowed me to answer my question by focusing on the processes of decision-making for CYP with LLCs. In specific, three research questions were presented in the methodology chapter (Section 1.4):

- 1) to find out what are the processes of decision-making for CYP with LLCs: the structural level, family-oriented level, the tacit dimensional level, and the privilege level of decision-making processes.
- 2) to explore the expectations of the role of social workers in paediatric palliative regarding the processes of decision-making for CYP with LLCs.
- 3) to discover the ethical challenges in the ethos of surrogate decision-making.

My research was embedded in the Other from Emmanuel Levinas, which required I conduct myself in a manner that explores the multi-dimensional processes for CYP with LLCs, regarding supportive care, palliative care, and hospice care.

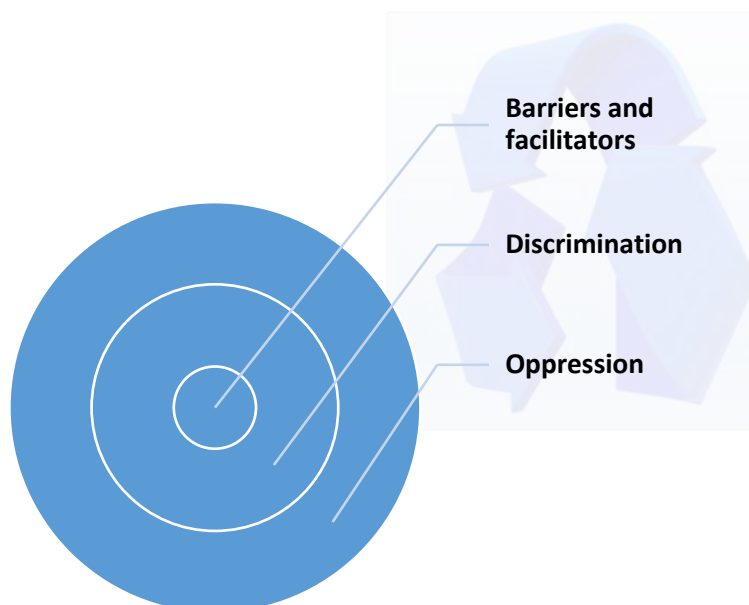


Figure 10-1 Barriers and Facilitators, Discrimination and Oppression

Since CYP with LLCs are excluded in decision-making, and supporting surrogate decision-making is not highlighted, I found three conceptual models, showing Figure 10-1: “barriers and facilitators” (Laura Boland, Ian D. Graham and France Légaré, 2019), “discrimination” (Thompson, 2003; 2016) and “oppressions” (Dominelli, 2002; Smith, 2008; 2010) when pondering multi-dimensional decision-making processes. Employing the concept of “oppression” (Dominelli, 2002; Smith, 2008; 2010) helped me to navigate the multi-dimensional decision-making processes. The decision-making processes with CYP with LLCs are rather often at the centre of the problems about human rights, health inequalities, and other forms of injustice.

In addition, I found luck as one of ethical challenges in the ethos of surrogate decision-making for CYP with LLCs, while also engaging a methodology that attempts to link the detailed analysis of ethnography to wider social structures (Madison, D.S., 2005). Nagel’s notion of ‘lack of control’ (this case of moral luck occurs whenever luck makes a moral difference) is to find a connection between structural issues in community and “tacit dimension” (Polanyi, 1967). The field has understood luck in decision-making processes, but the more I read and analysed my work alongside luck and social inequalities concepts, the more I began to scrutinise crossovers in key phrases: patient-centred care and shared decision-making. After taking unexpected results which can be linked to their interpretation, whether it is good or bad luck, they experienced to be blamed by their self-and/or others. Parents making decisions on behalf of their child were devastated mainly, whether deciding on futile treatments or aggressive treatments. When tolerating emotions, the guilty feeling after taking unexpected results may be avoidable.

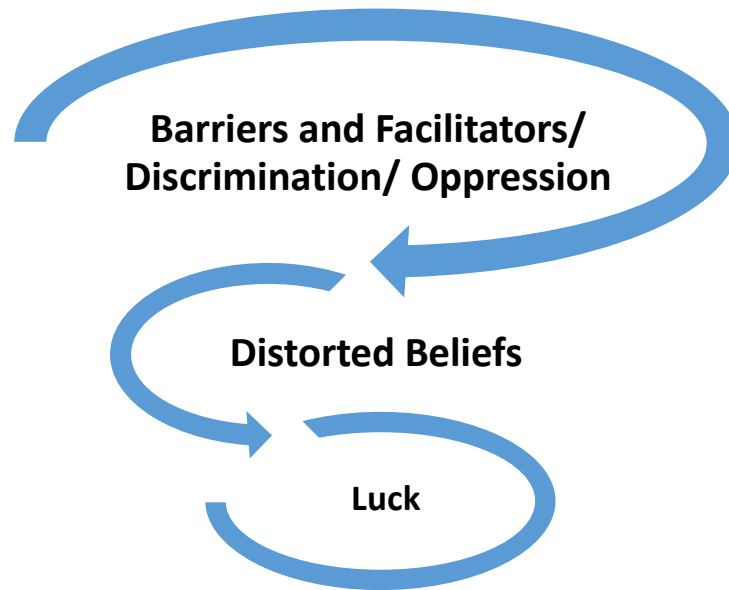


Figure 10-2 Barriers, Facilitators, Discrimination, Oppression, and Luck

I have focused on the relationship among barriers, facilitators, discrimination, oppression, and luck in multi-dimensional decision-making processes. Epistemic and moral luck are totally different aspects, but in terms of knowledge and ethics, the problem of luck intertwines within a fragile notion by setting up a disagreement between moral justification and rational justification. Risk and luck in surrogate decision-making possibly led to complexed problems or unexpected results (Dickenson, 2003, 65). To investigate some connections among barriers, facilitators, discrimination, oppression, and luck in multi-dimensional decision-making processes, I draw from the Other of Emmanuel Levinas (1906-1995), from the tacit dimension of Michael Polanyi (1891-1976), and from field, habitus and doxa of Pierre Bourdieu (1930-2002), following this table.

Emmanuel Levinas (1906-1995)	Michael Polanyi (1891-1976)	Pierre Bourdieu (1930-2002)
“The Ethics of the Other” “Ethics as first philosophy” (To face the Other is to have the idea of Infinity)	The Tacit Dimension	Habitus
Responsibility for the Other	Commitment and Fiduciary: act in affirmation of truth	Capital
The face-to-face relation “the subject into “giving and serving” the Other.”	Conviviality	Field - Social Class
The phenomenology of violence	Power	Symbolic Violence

Table 10-1 Emmanuel Levinas, Michael Polanyi and Pierre Bourdieu

While understanding multi-dimensional decision-making processes from the Other of Levinas, from the tacit dimension of Polanyi, and from field, habitus and doxa of Bourdieu was perhaps somewhat uncommon, it was my attempt to critically explore multi-dimensional decision-making processes regarding holistic approaches (Dominelli, 2002). Although Levinas, Polanyi, Bourdieu have different perspectives, during the analysis of my fieldwork, I wondered whether there is, or is about to be in multi-dimensional decision-making processes for CYP with LLCs. I have used a complex theoretical framework for deeply interpreting multi-dimensional decision-making processes for CYP with LLCs. This is perhaps the interesting part about pursuing a theoretical framework: exploring what theoretical perspectives may help to understand together and what others are not well suitable for new understandings in our fields of research.

Crucially, the framework embraces the multi-dimensional decision-making processes for CYP with LLCs, if going to explore the decision-making processes in which participants are unaware of the reasons for their choice.

Blind Luck:	External Factors	Structural Level of decision-making processes
	Internal Factors	Family-Oriented Level of decision-making processes
The Psychology of Luck		The Tacit Dimensional Level of decision-making processes
Epistemic Luck		The Privilege Level of decision-making processes
Moral Luck		

Table 10-2 Luck and Different Levels of decision-making processes

Hence, theoretical frameworks contributed to the overall understanding of barriers, facilitators, discrimination, oppression, and luck in multi-dimensional decision-making processes for CYP with LLCs.

10.3 Key Findings as Novel Contribution

Following the analysis process articulated from Chapter 6 to Chapter 9, the findings will present data from the semi-structured interviews and observations. The findings reported in this chapter, will

illuminate ethical challenges and the multi-dimensional level of decision-making processes. This research project aims to critically explore the decision-making processes for CYP with LLCs regarding ethical challenges and the complexed level of decision-making processes, following table 10-3:

Ethical Challenges in decision-making processes	Hidden or Unknown Oppression			
	Distorted Beliefs			
	Luck as Social Inequality			
The Multi-Dimensional Level of decision-making processes	The Structural Level of decision-making processes	The Family-Oriented decision-making processes	The Tacit Dimensional Level of decision-making processes	The Privilege Level of decision-making processes

Table 10-3 Ethical Challenges and the Multi-Dimensional Level of decision-making processes

This thesis has two important features: this kind of research has not been done before, for the multi-dimensional decision-making processes for CYP with LLCs and it contributes to the multi-dimensional decision-making processes for CYP with LLCs: the structural level, family-oriented level, the tacit dimensional level, and the privilege level of decision-making processes. Each level of decision-making processes includes ethical challenges such as oppression, distorted beliefs, luck as social inequality.

The key findings of this thesis are arranged in four sections below focused on the key areas: the structural level, the family-oriented level, the tacit dimensional level, and the privilege level of decision-making processes. This is a first study of its kind in the Republic of Korea exploring the multi-dimensional decision-making processes for CYP with LLCs. It was indicated in the literature review (Chapter 2) that there needs to be a study on the multi-dimensional decision-making processes for CYP with LLCs.

10.3.1 The Structural Level of Decision-Making Processes

In Chapter 6, I further explored the structural level of decision-making processes as introduced in the two stages: decision-making processes under a vicious circle and decision-making processes in hidden SDOH. Looking in more detail explored the structural level of decision-making processes to find out the processes of decision for CYP with LLCs. I explicitly addressed the lack of attention as

the structure level of decision-making processes includes two stages: decision-making processes under a vicious circle and decision-making processes in hidden SDOH.

Stage one is decision-making processes under a vicious circle. In exploring the processes of paediatric palliative care, there are complicated factors that remain hidden, such as paediatric palliative care under neoliberal policies and distorted healthcare transitions. Research suggests that one of the fundamental issues contributing to doctor shopping is the lack of a robust primary health care system that can provide comprehensive and continuous care. This gap in the health care system encourages patients to seek care from multiple providers, often without coordination, resulting in fragmented care, unnecessary duplication of services, lack of paediatric palliative care education and struggling with work overload without responsibility.

Decision Processes

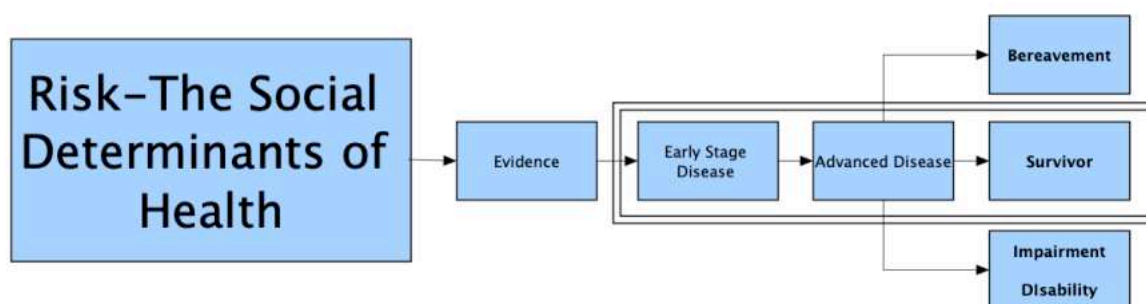


Figure 10-3 Focusing on Becoming Survivors in decision-making processes

Stage two is decision-making processes in hidden SDOH such as humidifier disinfectants, radon-emitting mattresses, semi-conduct industry and asbestos-contained schools. This is because decision-making processes are ignored the health of children and young starts in the homes, schools, workplaces, neighbourhoods, and communities.

Besides, knowing the rooted causes is not only too difficult to understand, but also parents and CYP with LLCs cannot easily understand environmental exposure and/or hazardous substances-related diseases, following the given table.

	Hazard Substances
Home	PHMG, PGH, CMIT, MIT from Humidifier disinfectants
	Radon-Emitting Mattresses

Work	Hazard Substances from Semi-conduct industry
School	Asbestos

Table 10-4 Environmental Exposure and Hazardous Substances-Related Diseases

Based on Table 10-4 Environmental Exposure and Hazardous Substances-Related Diseases, I found out that hidden social determinants of health continuously happen. The mismanagement of hazardous substances is related to various diseases and the complicated decision-making processes in hidden social determinates.

In terms of the structural level of decision-making processes, I tried interpretation of the findings, based on the Other of Emmanuel Levinas, and the symbolic violence of Pierre Bourdieu. I examined the expectations of social workers and their role in paediatric palliative care regarding the processes of decision-making for CYP with LLCs. One of questions is about how and why people attribute whether luck or oppression connect to decision-making processes. To explore the expectations of social workers and the role in paediatric palliative regarding the processes of decision-making for CYP with LLCs, I found that the social workers do not recognise paediatric palliative care in neoliberalism, linking a vicious circle of oppressed social workers and a bureaucratic system. They cannot ponder ensuring safety, increasing the quality of life, avoiding futile treatments, and pursuing the best interests of CYP with LLCs. I found out that the role of a paediatric palliative care social worker is not only unclear but also the expectation is higher.

To discover the ethical challenges in the ethos of surrogate decision-making, I revealed that blind luck is hidden and unknown when surrogate decision-makers ponder the best interests, and issues, such as: moral luck, hidden social determinants and the hidden forms of oppression are not known at all without unfolding them in two stages. Because oppression at the structural level of decision-making processes is not clearly known and is institutionalised in society, interlocking systems in symbolic power, as well as individual choice and responsibility are emphasised and struggle with the structural level of decision-making processes. Therefore, the structural level of decision-making processes reveals oppressive decision-making processes in hidden social injustice and the hidden web of oppression in decision-making processes.

10.3.2 The Family-Oriented Level of Decision-Making Processes

In Chapter 7, I found the family-oriented level of decision-making processes: those who face the unknown journey of decision-making from diagnosis to end-of-life or being survivors should have the opportunity to choose from the wide range of decisions available. To understand of decision-making processes with CYP with LLCs, I explored the unknown journey of decision-making from diagnosis to end-of-life or being survivors and can suggest assessment in terms of family-oriented level. There are the two stages in the unknown journey of decision-making processes, such as starting the unknown journey and the unknown end-of-life, mainly focusing on medical and family-oriented perspectives.

In stage one as the unknown journey, I showed how the surrogate decision makers of paediatric patients with LLCs and their parents, attempted to confront the unwanted journey.

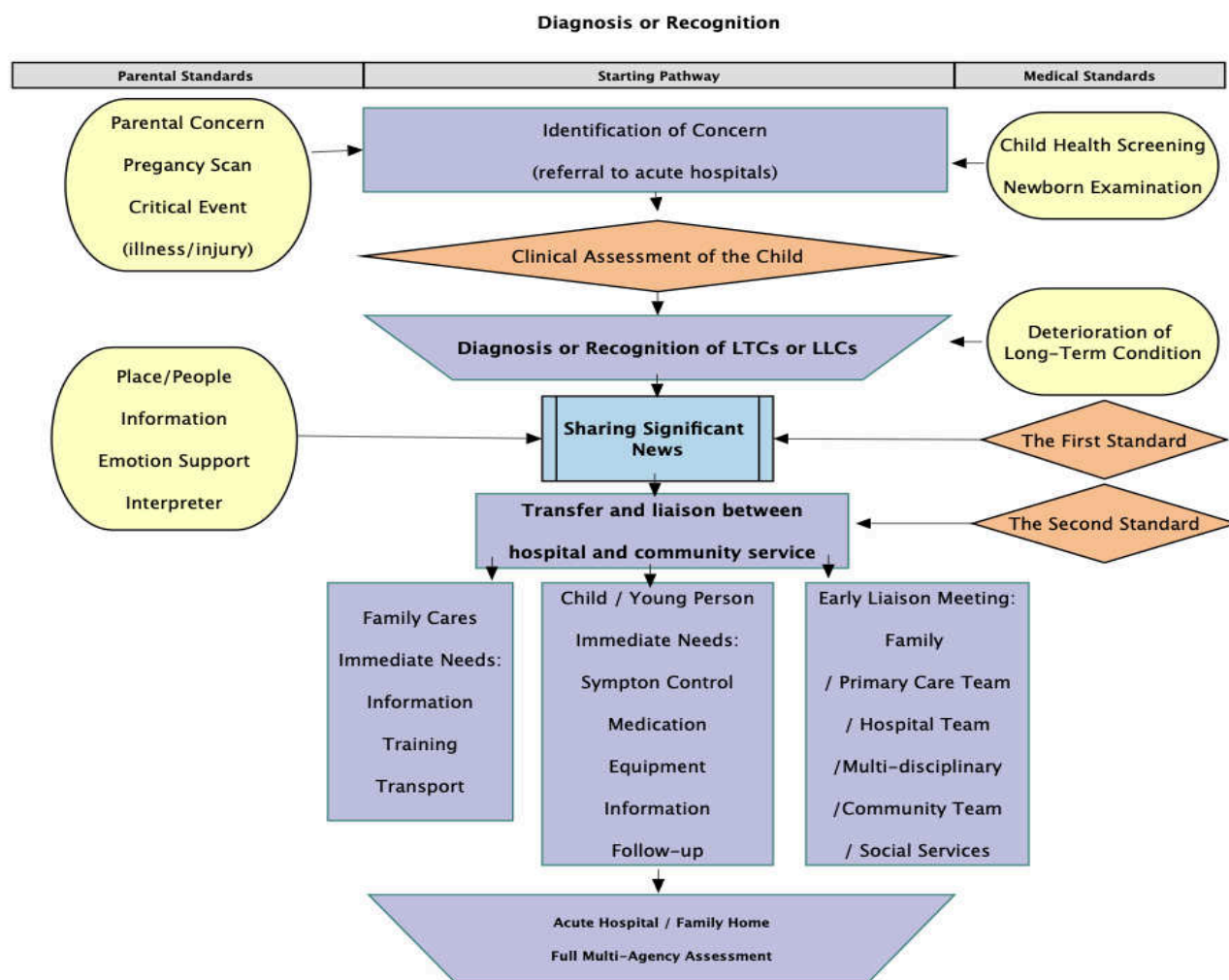


Figure 10-4 Diagnosis or Recognition

Seunghoon Oh has adapted and expanded upon the framework originally presented Widdas, Street, Edwards, *et al.*, 2013.

The findings from this study demonstrate when starting the arduous journey of decision-making, the social carers do not have the competencies on how to break bad news to the family members, and whether to recommend transfer from home to school or hospital regarding a clearly defined diagnosis and an undefined diagnosis regarding holistic care.

In stage two as the unknown end-of-life, I explored the unknown end-of-life of CYP with LLCs. The rise of the unknown end-of-life promotes the use of the NICU and the PICU but does not provide a cool room.

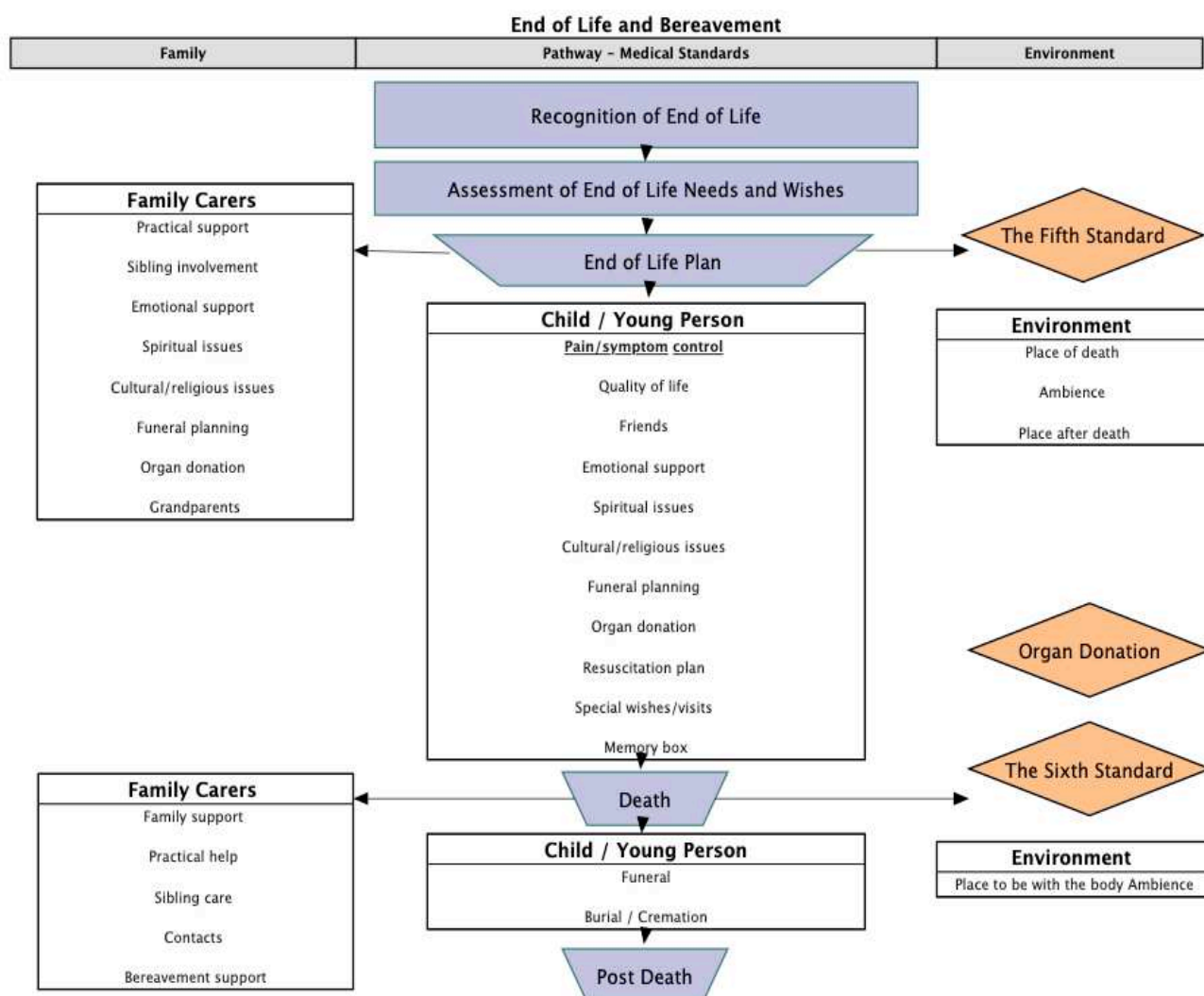


Figure 10-5 End-of-Life and Bereavement

Seunghoon Oh has adapted and expanded upon the framework originally presented Widdas, Street, Edwards, *et al.*, 2013.

Despite the importance of two stages: the unknown journey and the unknown end-of-life, beginning with a critical event, I found that CYP with LLCs are excluded from decision-making processes. The study examined CYP with LLCs who require a multidisciplinary framework. It identified a lack of ACP guidelines, which severely affects the decision-making processes for these children. They are unable to consent independently, and therefore, the lack of guidelines has a significant impact on their wellbeing. The study advocates for immediate policy reform to address these critical challenges.

Section 7.4 revealed expectations and ethical challenges from paediatric palliative care social workers. The role of paediatric palliative care social worker may be associated with concern for the psychological and social issues for patients and their families because telling the truth for CYP is undervalued when not sharing bad news with them. Every single year at least 6,000 vulnerable people face their unwanted journey having to make hard choices. In contrast, the findings from the study show the faces of CYP with LLCs in healthcare settings are quickly forgotten.

Section 7.5 interpreted the findings, the limits of shared decision-making in family-oriented levels of decision-making processes, based on the Other of Emmanuel Levinas and authority from Polanyi and Neo-Confucian family-oriented decision-making processes. There are lack of consulting time, not enough place, and different perspectives of the best interests for CYP with LLCs. This deficiency points to a broader systemic flaw that leaves both CYP with LLCs and their families ill-equipped to face the formidable emotional and logistical challenges presented by their conditions, cancerous or otherwise.

Therefore, major study findings were revealed and confirmed: firstly, CYP with LLCs were not involved in the processes of decision making at the end-of-life when they start on the unknown journey. Although family-oriented level of decision-making processes can be possible, I found that there are lack of consulting time, not enough place, and different perspectives of the best interests for CYP with LLCs.

10.3.3 The Tacit Dimensional Level of Decision-Making Processes

In Chapter 8, I explored the tacit dimension while deciding for the best interests. In 8.2 reproducing distorted beliefs in decision-making processes, distorted beliefs are irrational, but surrogate decision-makers maintain the distorted beliefs. There are some examples such as taboo, linking denial and palliphobia, and avoiding a child's funeral. Because of distorted beliefs, decision-making processes hinder the best interests of CYP with LLCs. I presented reproducing distorted beliefs in decision-making processes: it can reveal about oppression in the ethos of surrogate decision-making and describe what surrogate decision-makers take distorted beliefs: biased beliefs as taboo, palliphobia, toxic faith and/or raising child without medicine (*Anaki*), and to avoid preparing a child's funeral.

Regarding the distorted beliefs in deciding with family, I pondered both perspectives such as the psychology of luck and the internalised oppression in decision-making processes in 8.3. For an understanding of the tacit dimensional level of decision-making processes, especially reproducing distorted beliefs, I interpreted the findings, based on the tacit dimension of Polanyi. When understanding the psychology of luck and the internalised oppression, finding the relationship between oppression, belief and luck could be possible in deciding with family.

To understand decision-making processes with children or young people with LLCs, this chapter showed how social workers could identify the difficulties in the ethos of surrogate decision-making for CYP with LLCs through mainly understanding the tacit dimensional level of decision-making processes and the psychology of luck and /or internalised oppression in decision-making processes. Due to the relationship between oppression, belief, and luck, while deciding for CYP with LLCs, I found that internalised oppression in decision-making processes is hidden, and people desire luck. Thus, pursuing the best interests and making decisions for their CYP with LLCs are more complicated without understanding the tacit dimensional level. Without understanding the internalised oppression in decision-making processes, social workers cannot identify the difficulties in the ethos of surrogate decision-making processes.

In 8.3, I critically presented that the expectations for paediatric palliative care social workers are required to support and intervene in decision-making processes, regarding holistic care to improve quality of life. By pondering the tacit dimension in deciding with family, I found the relationship between oppression, belief, and luck, relating to deciding for CYP with LLCs: To understand reproducing distorted beliefs in decision-making processes, there are two perspectives: the psychology

of luck and internalised oppression. In terms of the psychology of luck, I found that those with distorted beliefs, inevitably faced uncontrolled and unexpected results that may be interpreted as luck while deciding processes. Although the perspective revealed the relationship between distorted beliefs and luck, neither maintaining oppressive decision-making processes, nor reproducing oppressive decision-making processes were in the psychology of luck.

I employ Polanyi's view of tacit knowing through its four aspects: the functional, the phenomenal, the semantic and the ontological as it enabled the relationship in the decision-making processes between oppression, distorted beliefs, and luck. Firstly, in terms of the functional aspect of Polanyi's tacit knowledge, the decision-making processes could be distinguished, whether on the psychology of luck or internalised oppression in decision-making processes. Secondly, based on Polanyi's ontological aspect of tacit knowledge, *Jeong* (情) revealed to reflect the structure of knowing and corresponded to knowing the dialectical sense in decision-making processes. Thirdly, after facing unexpected results in decision-making processes, bereavement family members showed *Hwa-byung*. The symptoms could be ineffable knowledge: when a disease is diagnosed through these symptoms, it becomes a phenomenon of tacit knowledge. Lastly, in terms of a semantic aspect of Polanyi, in order to understand both *Haan* 恨 and *Hwa-byung* 火病, Polanyi (1983: 24) showed functional and phenomenal aspects created meaning through the indwelling and circulating processes between the functional and the phenomenal awareness. Polanyi stated (1983: 15) that "our body is the ultimate instrument of all our external knowledge, whether intellectual or practical" Tacit knowing refers to knowledge of how they did things, although surrogate decision-makers did not say anything. I critically explored the tacit dimensional level and suggested how an assessment of the tacit dimensional level of decision-making processes could help in deciding for the best interests.

Not surprisingly, due to undervaluing the tacit dimensional level of decision-making processes, they did not know about hidden moral dilemmas which could arise towards near the end-of-life and be associated with beliefs, luck, and oppression, connecting risks, contingencies and the best interests.

10.3.4 The Privilege Level of Decision-Making Processes: Why Luck but Not Social Inequality?

In chapter 9, I explored the privilege level of decision-making processes because decision-making processes are not a one-off rational event, and parents were confronted with various junctures in decision-making processes.

In stage one, they experienced the forms of privileged or underprivileged level in surrogate decision-making. I found the two groups confronting privileged and underprivileged decision-making processes were different, having a sense of entitlement. While deciding for CYP with LLCs, they experienced the privileged or underprivileged level in surrogate decision-making such as: geographical accessibility, financial burden, multi-disciplinary assessment or needs, and telling and sharing the truths for decision-making processes. In terms of geographical accessibility, the living space is the starting point of their privilege as the family members should have 24-hour access to a paediatric palliative care specialist, paediatrician, or specially trained palliative care team. While deciding for CYP with LLCs, the financial burden represented the spoon categorisation of who has the different privileges living in the *Hell-Joseon* (Korea). In addition, multi-disciplinary assessments based on developmental tasks should have been provided regardless of privilege, although there is no guideline. Despite not having multi-disciplinary assessments based on developmental tasks, opposite perspectives between ‘hiding the truth,’ and ‘telling the truth’ were related to privileged or underprivileged levels.

In stage two, I described that the results of decision-processes often kept praising and/or blaming the results regarding the privilege level. When praising and/or blaming the results, parents and CYP with LLCs did not recognise between oppressive decision-making, non-oppressive decision-making, or multi-layered oppression from options such as: doctor shopping, hit and miss (福不福) in palliative care rehabilitation and education, and self-cultivating (各自圖生) of final place. This is because there are rare opportunities of palliative care rehabilitation, avoiding funerals, and victim-blaming. Stage two showed that the results of decision-processes often kept praising and/or blaming the results regarding the privilege level.

Regarding stages one and two, I revealed that the expectations for paediatric palliative care social work required enhancing holistic care to improve the quality of life and to encourage fundraising, but in fact, they focused on fundraising, which was more important than other works.

Furthermore, I identified the ethical dilemmas encountered within the privilege level of the decision-making processes’ perspectives: epistemic luck and/ or social inequality. On the one hand, misunderstanding evidence-based medicine and/ or epistemic luck in pseudo-science could lead to epistemic luck in decision-making processes while pursuing the best interest for CYP with LLCs.

One the other hand, to understand the complicated decision-making processes, leading to marginalisation, I employed the triad of concepts such as habitus, capital, and field from Bourdieu: three interlinked concepts which enabled the analysis of decision-making processes. Firstly, telling the

truth in decision-making processes could be divided into two opposite decision-making processes whether habitus with the truth or hiding the truth with habitus. Secondly, in the forms of capital such as linguistic, social, and economic capital, there was a huge discrepancy in decision-making processes. Lastly, Bourdieu's third concept of the "healthcare field" focusing on becoming survivors in decision-making processes reproduced 'unequal class relations and its structures of inequality but may not relate to epistemic luck.

Following the figure of the decision-making processes in Korea, decision-making processes are linked to the privilege level of decision-making processes and reveal the understanding of social inequality. Owing to the privilege level of the decision-making processes, this rise in social inequality lies at the centre of pursuing the best interest of CYP with LLCs may be heated national debate.

10.4 Limitation and Implications

Following the main findings, I discuss the need for further research and make some final comments. This research employed critical ethnography to access and articulate the subtle, often unspoken decision-making processes among CYP with LLCs and their families. The empirical data collected through this approach has been instrumental in highlighting the need for systemic reforms and informing the development of recommendations to enhance paediatric palliative care. Without this qualitative insight, the study might have overlooked essential aspects of the human experience, which are critical for understanding and improving the delivery of care in these sensitive and complex situations. I could not find holistic assessments from diagnosis or recognition, through ongoing care, taking curative treatments and to the end of life, although medical assessments essentially provide this, although I tried to find it. Given the limitations, this thesis considers oppression and serendipity in decision-making processes but cannot develop how paediatric palliative care social workers ethically intervene or support decision-making.

In addition, the theoretical frameworks contributed to the overall understanding of barriers, facilitators, discrimination, oppression and luck in multidimensional decision-making processes for CYP with LLCs. However, I did not develop the arguments around barriers, facilitators, discrimination, oppression and luck in multidimensional decision-making processes. The research findings underline the urgency of systemic reforms that empower families to communicate more effectively and support their children through the harrowing journey of living with LLCs.

To understand the complex level of decision-making in a holistic approach, the government should implement the policy of Palliative Care Coordination Centres and train social workers in palliative and end-of-life care. Palliative care co-ordination centres can suggest how to improve the co-ordination and provision of care packages for CYP with LLCs at the end of life. Their families can not only enable them to be cared for and to die in a place of their choice, but also to find their own connection from home to their local community. The centre will provide innovative services that work as an integrated part of health and social care for CYP with LLCs and manage resources effectively to ensure equity of access to services and equity of services available in their locality. It is also essential to introduce and improve training for social workers in palliative and end-of-life care. This is an innovative training programme designed for health social workers by social workers who can promote the integration of primary palliative care skills into clinical practice and understand holistic decision-making processes. The focus on treatment planning obscures the unheard voices and unseen faces of CYP with LLC. The impact of the unheard voices and unseen faces of CYP with LLC can be profound, and the multidisciplinary team, both in the hospital and in the community, will work closely with family members alongside the social worker.

The findings of this research have significant implications for healthcare professionals and policymakers who work to support CYP with LLCs and their families. The study identified four levels of decision-making processes: structural, family-oriented, tacit dimensional, and privilege level. Based on these levels, the following social policy suggestions can be made:

At the structural level of decision-making, doctor shopping is indeed a significant problem in South Korea, resulting from a combination of factors including the absence of a well-established primary care system, easy access to higher level hospitals, and a healthcare system that incentivises frequent visits due to the relatively low cost of medical services. This phenomenon is exacerbated by the absence of a gatekeeping system where patients can directly seek specialist care without referral, leading to congestion in tertiary hospitals and inefficient use of medical resources. To address the problem of doctor shopping and improve the efficiency of the health system, a key approach is to strengthen the role of primary care providers as gatekeepers who can manage patients' health comprehensively and coordinate their care across different levels of the health system. Doctor shopping in South Korea reflects deeper systemic problems within the health care system that require comprehensive reforms to strengthen primary care, ensure coordinated and continuous care, and address the challenges posed by medical dualism and commercialisation.

In addition, it is important to recognise that neoliberalism (Navarro, 2007) may lead to a vicious circle of oppressed social workers and a bureaucratic system. Healthcare professionals and policymakers should be educated about anti-oppressive social policy to ensure that they understand the needs and experiences of CYP with LLCs (Pfund, 2007) and their families. Such education could help in developing social policies (Bonner, 2017) and practices that are more effective in supporting families and healthcare professionals in decision-making.

At the family-oriented level of decision-making, the participation of CYP with LLCs in decision-making is crucial. However, the study found that CYP with LLCs were not involved in the processes of decision-making at the end-of-life when they started on the unknown journey. It is important to recognise the complexities and limitations in the shared decision-making process, particularly in the participation of CYP (Monroe & Oliviere, 2003). Policies should be put in place to ensure that CYP with LLCs are involved in decision-making processes.

At the tacit dimensional level of decision-making, it is crucial to develop assessment tools to understand the internalised oppression in decision-making processes. Surrogate decision-makers often hold onto distorted beliefs, such as the taboo of discussing hospice and palliative care, linking denial and palliophobia, and avoiding a child's funeral. Without understanding the internalised oppression in decision-making processes, social workers cannot identify the difficulties in the ethos of surrogate decision-making processes. Therefore, social policies should focus on developing assessment tools (Al-Khabbaz, Nkosi and Nakawesi, 2020) to identify such internalised oppression and develop training programs to educate healthcare professionals on how to address these issues.

At the privilege level of decision-making, social inequality is an external factor that can affect decision-making processes. It is crucial to recognize the systemic factors that contribute to social inequality (Richard Gerald Wilkinson, 2005; Wilkinson, 2008; Bartley, 2004; Navarro, 2007) and focus on fundraising to optimize the delivery of palliative and end-of-life care. Social policies should prioritize holistic care, including healthcare transitions such as hospital, hospice, home, school, and community. Such policies can help to address the social inequality that affects decision-making processes and promote more equitable access to palliative and end-of-life care.

In conclusion, this study has highlighted the complex decision-making processes involved in supporting CYP with LLCs and their families. Social policies and practices should be developed to support the participation of CYP with LLCs in decision-making processes, recognise the internalised oppression in decision-making processes, and address the systemic factors that contribute to social

inequality. By tackling social inequality, healthcare professionals and policymakers can work to optimise the delivery of palliative and end-of-life care for CYP with LLCs and their families.

10.5 Future Work and Research

The current study investigated the complex decision-making processes for CYP with LLCs, deeply influencing my fieldwork experiences and future research ambitions in palliative care. My ongoing work will focus on the role of virtue in anti-oppressive practice, the cultural aspects of decision-making, and the anti-oppressive social policy surrounding medical cannabis. Additionally, there is a pressing need to improve decision-making support for CYP with LLCs and their families and to define crucial training for paediatric palliative care social workers, areas that will be central to my future research and training initiatives in palliative social work.

10.5.1 The Cultural Level of Decision-Making Processes

In my thesis, I extensively explored the tacit dimensions of decision-making processes, advocating for an expansion into the cultural aspects of these decisions (see Chapter 8). To support CYP with LLCs and their families, it is essential to implement an Advance Care Plan tailored to each individual, irrespective of age, gender, or health condition. This plan should ensure effective pain and symptom management and uphold family-oriented care within their chosen cultural context.

The next phase of research should delve into the complex conflicts encountered in determining what is in the best interest of these individuals, enhancing our understanding of the cultural dimensions involved. This deeper understanding is crucial in developing culturally sensitive assessments and interventions, assisting in decisions about therapeutic and non-therapeutic medical research, and innovative or futile treatments.

Furthermore, this knowledge can aid in crafting guidelines for schools and communities, acknowledging the oppressive structures that influence decision outcomes. In Chapter 8, I highlighted the absence of discussions on ‘hate speech’ violence experienced by CYP with LLCs and their families, which exacerbates the challenges in decision-making. School social workers, by understanding these

cultural processes, can better identify and address the ethos of surrogate decision-making, leading to more holistic assessments and effective interventions.

Recognising these factors is vital for policymakers and healthcare professionals to support medical staff effectively, breaking the cycle of poor decision-making and enhancing the care for CYP with LLCs and their families. This foundational research is instrumental for the next project, focusing on creating assessments, guidelines, and interventions that consider the cultural level of decision-making processes.

10.5.2 Virtue in Anti-Oppressive Practice

The research will suggest a model of anti-oppressive surrogate decision-making in paediatric palliative care when a paediatric palliative care social worker considers supporting decision-making processes for CYP with LLCs. In the next project, virtue-theoretic approaches to ethics and epistemology focus on how moral and intellectual virtues can be applied in surrogate decision-making based on virtue theory and anti-oppressive practice that a combination of rigorous philosophical arguments might address a number of compelling issues related to the determination of competence and the institutional arrangements needed to make decisions.

Anti-oppressive decision-making processes in paediatric palliative care are essential, where social workers ethically support decision-making, drawing on moral and epistemic virtues. These virtues reflect the belief that a good person embodies moral and intellectual virtues within a supportive community, aiding transformational practices (Adams, Dominelli and Payne *et al.*, 2009: 53). However, despite the lack of practical guidelines across different settings for CYP with LLCs, an interdisciplinary educational approach is vital for healthcare professionals to accurately assess their situations.

While virtue ethics emphasises individual character and interpersonal relations, it often overlooks broader social inequalities and oppression (Clifford and Burke, 2008 and 2014). Julia Driver (2000: 125) differentiates between the goals of moral virtues aimed at others' well-being and intellectual virtues aimed at truth. The forthcoming project will explore how virtue-theoretic approaches in ethics and epistemology can address surrogate decision-making, potentially illuminating "the structural causes of social issues" (Adams, Dominelli, and Payne *et al.*, 2009: 53; Smith, 2008b).

This research will propose a model of anti-oppressive surrogate decision-making in paediatric palliative care, emphasising the application of moral and intellectual virtues in decision-making processes, providing a philosophical framework to tackle issues of competence and necessary institutional arrangements for effective decision-making.

10.5.3 Anti-Oppressive Social Policy of Medical Cannabis

Skye Cochran, CEO of the Korea Medical Cannabis Organization, explained in an interview with I that South Korea passed legislation on medical cannabis in mid-2017, but it wasn't until the passage of a new law on psychotropics in medicine in 2018 that a legal framework was established for its use. The Korea Medical Cannabis Organization played an important role in advocating for the legalisation of medical cannabis in South Korea. They worked closely with policy makers to submit research and evidence in support of medical cannabis. On November 23, 2018, the bill passed, legalising medical cannabis in South Korea. This legislative change aimed to protect patients, especially children and families, so that they could obtain legality for the use of medical cannabis.

Despite the legalisation of medical cannabis in South Korea, its use remains highly restricted, and access to it is limited. Strict controls have been placed on its production, importation, and prescription, with only a limited number of hospitals authorised to prescribe it. Patients must meet strict criteria to qualify for medical cannabis, and doctors must obtain special permission from the government to prescribe it. Patients are only allowed to use non-smokable forms of medical cannabis, such as oils, tinctures, and pills. These strict controls on medical cannabis in South Korea suggest the need for critical ethnography to research and critique the social policies related to medical cannabis. Critical ethnography can help to identify how these policies may be shaped by power relations and social inequalities and their impact on the lives of patients and their families.

Research by Nimalan, Kawka, Erridge *et al.* (2022) confirms the efficacy of cannabis-based medicinal products in managing chemotherapy-induced nausea and vomiting, crucial for enhancing quality of life in palliative care. Expanding access to medical cannabis and further research into its benefits and safety are essential. Skye Cochran of the Organisation of Legalising Medical Cannabis highlights the social taboos and oppression surrounding its use in South Korea, suggesting a need for anti-oppressive policies to improve accessibility. Multi-disciplinary research could help shape informed, equitable social policies on medical cannabis. While its legalisation marks progress in South

Korea, the restricted access calls for more comprehensive policies and research to understand its full potential and widen its availability.

10.6 Conclusion

This Thesis has made significant contributions towards our understanding of multi-dimensional decision-making processes. This contribution is both a deep theoretical and methodological exploration of the multi-dimensional decision-making processes from a range of perspectives. Medical staff have come to understand the multi-dimensional decision-making processes to define belief, luck, barriers, discrimination, and oppression to suggest a problem-solving intervention to be considered, along with the potential impact upon CYP with LLCs

The findings from chapter 6 to chapter 9 were presented and discussed in the previous chapter. The key findings of this thesis are arranged in four sections below focused on the key areas: the structural level, the family-oriented level, the tacit dimensional level, and the privilege level of decision-making processes. In finding data and in terms of setting guidelines of the multi-dimensional decision-making processes that can be made to clinical practice, it can now be explored to try to understand how the journey of decision-making processes for CYP with LLCs might arise from the hidden paediatric decision-making processes where marginalised voices will now be heard throughout guidelines of the multi-dimensional decision-making processes.

In this final chapter, the unique contribution of this thesis summarises the findings in 10.3, limitations the research outlined, implications for practice, and research and outcomes of the research in section 10.4 and Section 10.5 concludes with suggestions for future research steps.

References

- Abrecht, P. (1979) *Faith, science, and the future*. Philadelphia, Fortress Press.
- Adam, B.D. (1978) Inferiorization and ‘Self-Esteem’. *Social Psychology*. [Online] 41 (1), 47. Available at: doi:<https://doi.org/10.2307/3033596> (Accessed: 4 April 2019).
- Adams, R., Dominelli, L. and Payne, M. (2009) *Social Work: Themes, Issues and Critical Debates*. Red Globe Press.
- Adriaan Theodoor Peperzak (1996) *Ethics as first philosophy : the significance of Emmanuel Levinas for philosophy, literature and religion*. New York ; London, Routledge.
- Ahn Jong-joo 안종주 환경보건시민센터 운영위원(<빼앗긴 숨> 저자 (2016) ‘*엄마, 숨이 안 쉬어져, 도와줘*’... 가슴기 살균제에 두 번 죽을 뻔한 동현이. [Online]. 3 September 2016. 경향신문. Available at: <https://www.khan.co.kr/national/national-general/article/201609031818021> (Accessed: 13 September 2024).
- Ahn, J.-J. (2022) Occupational and Environmental Safety Issues in South Korea and Their Implications for Health Experts. *Journal of Environmental Health Sciences*. [Online] 48 (1), 19–27. Available at: doi:<https://doi.org/10.5668/jehs.2022.48.1.19> (Accessed: 9 April 2022).
- Aidoo, E. and Rajapakse, D. (2018) End of life care for infants, children and young people with life-limiting conditions: planning and management: the NICE guideline 2016. *Archives of disease in childhood - Education & practice edition*. [Online] edpract-2017-312767. Available at: doi:<https://doi.org/10.1136/archdischild-2017-312767>.
- Al-Khabbaz, E., Nkosi, B. and Nakawesi, J.S. (2020) Holistic Assessment. *Children’s Palliative Care: An International Case-Based Manual*. [Online] 39–49. Available at: doi:https://doi.org/10.1007/978-3-030-27375-0_4.
- Altilio, T. and Otis-Green, S. (2011) *Oxford textbook of palliative social work*. Oxford; New York, Oxford University Press.
- Alvesson, M. (2003) Methodology for Close up Studies: Struggling with Closeness and Closure. *Higher Education*. [Online] 46 (2), 167–193. Available at: https://www.jstor.org/stable/3447465?casa_token=-nVyZ4-4v4kAAAAA%3A9QuhAWF-E02X7yFeVWM5fN3AJGjYyfKsKUtGQSvoDhBVuHBS3a4VoUssnH-rQyUYImOr9K-W3IfR8FebtfSh-asYSxJSGdbu8g6QHxLo1qpmPo_Q4D8 (Accessed: 1 March 2023).
- Ariès, P. (1975) *Western Attitudes toward Death: From the Middle Ages to the Present*. [Online]. JHU Press. Available at:

- https://books.google.com/books?hl=en&lr=&id=3sZJN3wojesC&oi=fnd&pg=PR9&dq=western+attitudes+towards+death&ots=1u_R0-Uf0V&sig=jeVRtbMn_uHdaBEzAeIN8fawUNM (Accessed: 28 February 2023).
- Arksey, H. and O'Malley, L. (2005) Scoping studies: Towards a Methodological Framework. *International Journal of Social Research Methodology*. 8 (1), 19–32.
 - Armstrong-Dailey, A. and Zarbock, S.F. (2009) *Hospice care for children*. Oxford; New York, Oxford University Press.
 - Arterburn, S., Felton, J. and Doucette, M. (2001) *Toxic faith experiencing healing over painful spiritual abuse*. Westminster] Waterbrook.
 - Asian Center for Environmental Health (2018) <http://eco-health.org/> 환경보건시민센터 보고서 315 호 2018 년-14 호 'Environmental Health Citizens' Center Report No. 315, No. 14 of 2018: Disclosure of List and Related Information of 625 Schools for Asbestos Removal During the 2018 Summer Vacation.' 2018 년도 여름방학 석면철거 625 개 학교 명단 및 관련정보 공개. [Online]. 2018. Asian Center for Environmental Health & Causes. Available at: <http://www.asiancenter.asia/> (Accessed: 4 March 2023).
 - Atkinson, P., Coffey, A., Delamont, S., Lofland, J., et al. (2014) *Handbook of ethnography*. Los Angeles London New Delhi Singapore Washington Dc Sage Los Angeles London New Delhi Singapore Washington Dc Sage.
 - Atkinson, P. and Hammersley, M. (2012) *Strategies of qualitative inquiry*. Norman K Denzin and Yvonna S Lincoln (eds.). Thousand Oaks, Sage Publications, Inc.
 - Audi, R. (2015) *Rational Belief*. Oxford University Press.
 - Badarau, D.O., Ruhe, K., Kühne, T., De Clercq, E., et al. (2016) Decision making in pediatric oncology: Views of parents and physicians in two European countries. *AJOB Empirical Bioethics*. [Online] 8 (1), 21–31. Available at: doi:<https://doi.org/10.1080/23294515.2016.1234519> (Accessed: 11 June 2020).
 - Bae, S.H. and Kim, Y.H. (2022) The First Step to Initiate Pediatric Palliative Care: Identify Patient Needs and Cooperation of Medical Staff. *Healthcare*. [Online] 10 (1), 127. Available at: doi:<https://doi.org/10.3390/healthcare10010127> (Accessed: 8 February 2022).
 - Banks, S. and Gallagher, A. (2008) *Ethics in Professional Life*. Bloomsbury Publishing.

- Barnoff, L. and Moffatt, K. (2007) Contradictory Tensions in Anti-Oppression Practice in Feminist Social Services. *Affilia*. [Online] 22 (1), 56–70. Available at: doi:<https://doi.org/10.1177/0886109906295772>.
- Barrett, W. (2006) Luck and Decision. *Journal of Applied Philosophy*. [Online] 23 (1), 73–87. Available at: doi:<https://doi.org/10.1111/j.1468-5930.2006.00321.x> (Accessed: 6 February 2023).
- Bartley, M. (2004) *Health inequality: an introduction to concepts, theories and methods*. Cambridge, UK; Malden, Ma, Usa, Polity.
- Bauer, M.W. (2010) *Qualitative researching with text, image and sound: a practical handbook*. Los Angeles Sage Publ.
- Beauchamp, T.L. and Childress, J.F. (2019) *Principles of Biomedical Ethics*. 7th edition. New York, Oxford University Press.
- Beaune, L., Leavens, A., Muskat, B., Ford-Jones, L., et al. (2014) Poverty and Pediatric Palliative Care: What Can We Do? *Journal of Social Work in End-Of-Life & Palliative Care*. [Online] 10 (2), 170–185. Available at: doi:<https://doi.org/10.1080/15524256.2014.906375> (Accessed: 6 September 2019).
- Beck, C. and Shue, V. (2003) Surrogate Decision-Making and Related Issues. *Alzheimer Disease & Associated Disorders*. [Online] 17S12. Available at: https://journals.lww.com/alzheimerjournal/Abstract/2003/04001/Surrogate_Decision_Making_and_Related_Issues.3.aspx (Accessed: 24 February 2023).
- Bell, D., Caplan, P. and Wazir Jahan Karim (2013) *Gendered Fields*. Routledge.
- Bell, M. (2009) *Anger, Virtue, and Oppression*. [Online]. 2009. PhilPapers. Available at: <https://philpapers.org/rec/BELAVA-2> (Accessed: 22 February 2023).
- Bell, M. (2011) *Promoting children's rights in social work and social care: a guide to participatory practice*. London ; Philadelphia, Pa, Jessica Kingsley Publishers.
- Bell, V. (2001) On ethics and feminism: Reflecting on Levinas' ethics of non-(in)difference. *Feminist Theory*. [Online] 2 (2), 159–171. Available at: doi:<https://doi.org/10.1177/146470010100200203>.
- Bennett, H. (2014) *A Guide to End of Life Care End of life planning series 2 A Guide to End of Life Care 3 A Guide to End of Life Care Care of children and young people before death, at the time of death and after death* [Online]. Available at: <https://www.togetherforshortlives.org.uk/app/uploads/2018/01/ProRes-A-Guide-To-End-Of-Life-Care.pdf>.

- Bennett, H., Bennett, H., Duke, S. and Richardson, A. (2020) *Parents' Experience of Advance Care Planning: A Grounded Theory of Re-constructing Meaning Through Advance Care Planning*. [Online]. 17 July 2020. eprints.soton.ac.uk. Available at: <https://eprints.soton.ac.uk/452354/> (Accessed: 6 March 2023).
- Benuto, L.T. (2020) *Prejudice, stigma, privilege, and oppression : a behavioral health handbook*. Cham, Switzerland, Springer.
- Berger, A., Shuster, J.L. and Von Roenn, J.H. (2013) *Principles and practice of palliative care and supportive oncology*. 3rd edition. Philadelphia, Lippincott Williams & Wilkins.
- Berges, S. (2015) *A Feminist Perspective on Virtue Ethics*. [Online]. New York: palgrave macmillan. Available at: <https://philpapers.org/rec/BERAFP> (Accessed: 22 February 2023).
- Bernasconi, R. and Critchley, S. (2002) *The Cambridge Companion to Lévinas*. [Online]. Cambridge University Press. Available at: <https://philpapers.org/rec/BERTCC-11> (Accessed: 1 March 2023).
- Bernasconi, R. and Wood, D. (2002) *The Provocation of Levinas*. Routledge.
- Berry, G.R. (2007) Adding ethical consideration to the decision-making process: A leadership challenge. *Journal of Leadership Studies*. [Online] 1 (1), 45–50. Available at: doi:<https://doi.org/10.1002/jls.20007> (Accessed: 13 March 2019).
- Biermann, O., Mwoka, M., Ettman, C.K., Abdalla, S.M., et al. (2021) Data, Social Determinants, and Better Decision-making for Health: the 3-D Commission. *Journal of Urban Health: Bulletin of the New York Academy of Medicine*. [Online] 98 (Suppl 1), 4–14. Available at: doi:<https://doi.org/10.1007/s11524-021-00556-9>.
- Bluebond-Langner, M. (2020a) *In the Shadow of Illness*. Princeton University Press.
- Bluebond-Langner, M. (2020b) *The Private Worlds of Dying Children*. Princeton University Press.
- Boland, L., Graham, I.D., Légaré, F., Lewis, K., et al. (2019) Barriers and facilitators of pediatric shared decision-making: a systematic review. *Implementation Science*. [Online] 14 (1). Available at: doi:<https://doi.org/10.1186/s13012-018-0851-5>.
- Bonner, A. (2017) *Social determinants of health An interdisciplinary approach to social inequality and wellbeing*. Bristol University Press.
- Bordini, B.J. and Kliegman, R.M. (2020) Undiagnosed and Rare Diseases in Perinatal Medicine: Uncommon Manifestations or Mimics of Neonatal Disorders. *Clinics in Perinatology*. [Online] 47 (1), xxi–xxii. Available at: doi:<https://doi.org/10.1016/j.clp.2019.12.001> (Accessed: 22 October 2021).

- Bourdieu, P. (1984) *Distinction: a Social Critique of the Judgement of Taste*. London, Routledge, Taylor & Francis Group.
- Bourdieu, P. (1991) *Language and symbolic power*. Cambridge, Polity.
- Bourdieu, P. (1977) *Outline of a Theory of Practice*. Cambridge, Cambridge University Press.
- Bourdieu, P. (2000) *Pascalian meditations*. Cambridge, Uk, Polity Press.
- Bourdieu, P. (1998) *Practical reason : on the theory of action*. Cambridge, Polity Press.
- Bourdieu, P. (2008) *Sketch for a Self-analysis*. University of Chicago Press.
- Bourdieu, P. (1990) *The Logic of Practice*. Cambridge, Polity Press.
- Bourdieu, P. (2009) *The weight of the world: social suffering in contemporary society*. Cambridge Polity Press.
- Bourdieu, P. and Wacquant, L.J.D. (1992) *An Invitation to Reflexive Sociology*. Cambridge; Malden, Mass., Polity Press.
- British Medical Association (2001) *Consent, rights, and choices in health care for children and young people*. London, Bmj Books.
- British Medical Association (2012) *Medical Ethics Today*. John Wiley & Sons.
- Broncano-Berrocal, F. (2015) Luck as Risk and the Lack of Control Account of Luck. *Metaphilosophy*. [Online] 46 (1), 1–25. Available at: doi:<https://doi.org/10.1111/meta.12114> (Accessed: 9 June 2019).
- Broström, L. (2007) *The Substituted Judgment Standard. Studies on the Ethics of Surrogate Decision Making*. [Online]. 2007. lup.lub.lu.se. Available at: <https://lup.lub.lu.se/search/publication/599023> (Accessed: 22 February 2023).
- Brown, E., Warr, B. and Shribman, S. (2007) *Supporting the child and the family in paediatric palliative care*. Philadelphia, Jessica Kingsley Publishers.
- Browning, D.M. and Solomon, M.Z. (2005) The Initiative for Pediatric Palliative Care: An Interdisciplinary Educational Approach for Healthcare Professionals. *Journal of Pediatric Nursing*. [Online] 20 (5), 326–334. Available at: doi:<https://doi.org/10.1016/j.pedn.2005.03.004> (Accessed: 12 December 2019).
- Bruce Lawrence Berg and Lune, H. (2012) *Qualitative research methods for the social sciences*. 8th edition. Boston Etc., Pearson, Cop.
- Bruera, E., Higginson, I.J., von Gunten, C.F. and Morita, T. (2021) *Textbook Of Palliative Medicine And Supportive Care*. 3rd edition. S.L., Crc Press.
- Bryman, A. (2016) *Social Research Methods*. 5th edition. Oxford, Oxford University Press.

- Buchanan, A.E. and Brock, D.W. (1989) *Deciding for others: the ethics of surrogate decision making*. Cambridge England ; New York, Cambridge University Press.
- Burggraef, R. (1999) Violence and the Vulnerable Face of the Other: The Vision of Emmanuel Levinas on Moral Evil and Our Responsibility. *Journal of Social Philosophy*. [Online] 30 (1), 29–45. Available at: doi:<https://doi.org/10.1111/0047-2786.t01-1-00003>.
- Byram, A.C. (2019) *A proposed paradigm shift for surrogate decision-making in ICU*. [Online]. 2019. open.library.ubc.ca. Available at: <https://open.library.ubc.ca/soa/cIRcle/collections/ubctheses/24/items/1.0380901> (Accessed: 22 February 2023).
- Cadell, S., Johnston, M., Bosma, H. and Wainright, W. (2010) An overview of contemporary social work practice in palliative care. *Progress in Palliative Care*. [Online] 18 (4), 205–211. Available at: doi:<https://doi.org/10.1179/096992610x12775428636700>.
- Cadell, S., Kennedy, K. and Hemsworth, D. (2012) Informing Social Work Practice Through Research With Parent Caregivers of a Child With a Life-Limiting Illness. *Journal of Social Work in End-Of-Life & Palliative Care*. [Online] 8 (4), 356–381. Available at: doi:<https://doi.org/10.1080/15524256.2012.732021> (Accessed: 21 June 2019).
- Cai, X., Robinson, J., Muehlschlegel, S., White, D.B., et al. (2015) Patient Preferences and Surrogate Decision Making in Neuroscience Intensive Care Units. *Neurocritical Care*. [Online] 23 (1), 131–141. Available at: doi:<https://doi.org/10.1007/s12028-015-0149-2>.
- Calder, M., Mckinnon, M. and Sneddon, R. (2012) *National Risk Framework to Support the Assessment of Children and Young People 2012* [Online]. Available at: <https://dera.ioe.ac.uk/16053/1/00408604.pdf> (Accessed: 24 February 2023).
- Cambridge (2023a) *luck*. [Online]. 7 February 2023. dictionary.cambridge.org. Available at: <https://dictionary.cambridge.org/dictionary/english/luck> (Accessed: 7 February 2023).
- Cambridge (2023b) *medical miracle collocation | meanings and examples of use*. [Online]. February 2023. @CambridgeWords. Available at: <https://dictionary.cambridge.org/example/english/medical-miracle> (Accessed: 7 February 2023).
- Carnelley, K.B. and Janoff-Bulman, R. (1992) Optimism about Love Relationships: General vs Specific Lessons from One's Personal Experiences. *Journal of Social and Personal Relationships*. [Online] 9 (1), 5–20. Available at: doi:<https://doi.org/10.1177/0265407592091001>.

- Carpenter, J., Patsios, D., Szilassy, E. and Hackett, S. (2011) Outcomes of Short Course Interprofessional Education in Parental Mental Illness and Child Protection: Self-efficacy, Attitudes and Knowledge. *Social Work Education*. [Online] 30 (2), 195–206. Available at: doi:<https://doi.org/10.1080/02615479.2011.540394>.
- Carroll, K.W., Mollen, C.J., Aldridge, S., Hexem, K.R., et al. (2012) Influences on Decision Making Identified by Parents of Children Receiving Pediatric Palliative Care. *AJOB Primary Research*. [Online] 3 (1), 1–7. Available at: doi:<https://doi.org/10.1080/21507716.2011.638019> (Accessed: 23 August 2021).
- Carter, M. (2016) *Helping children and adolescents think about death, dying, and bereavement*. London ; Philadelphia, Jessica Kingsley Publishers.
- Caulkins, J.P., Morrison, E.L. and Weidemann, T. (2007) Spreadsheet Errors and Decision Making. *Journal of Organizational and End User Computing*. [Online] 19 (3), 1–23. Available at: doi:<https://doi.org/10.4018/joeuc.2007070101>.
- Cave, E. (2013) Competence and authority: adolescent treatment refusals for physical and mental health conditions. *Contemporary Social Science*. [Online] 8 (2), 92–103. Available at: doi:<https://doi.org/10.1080/21582041.2012.751502>.
- Cave, E. (2014) Goodbye Gillick? Identifying and resolving problems with the concept of child competence. *Legal Studies*. [Online] 34 (1), 103–122. Available at: doi:<https://doi.org/10.1111/lest.12009>.
- Chalier, C. (1993) Emmanuel Levinas: Responsibility and Election. *Royal Institute of Philosophy Supplement*. [Online] 3563–76. Available at: doi:<https://doi.org/10.1017/s1358246100006251> (Accessed: 6 November 2021).
- Chan, C.W.H., Wong, M.M.H., Choi, K.C., Chan, H.Y.L., et al. (2019) What Patients, Families, Health Professionals and Hospital Volunteers Told Us about Advance Directives. *Asia-Pacific Journal of Oncology Nursing*. [Online] 6 (1), 72–77. Available at: doi:https://doi.org/10.4103/apjon.apjon_38_18 (Accessed: 28 March 2020).
- Chanter, T. (2001) *Feminist Interpretations of Emmanuel Levinas*. Re-Reading the Canon.
- Charon, R. (2001a) Narrative Medicine. *JAMA*. [Online] 286 (15), 1897. Available at: doi:<https://doi.org/10.1001/jama.286.15.1897>.
- Charon, R. (2001b) Narrative Medicine: Form, Function, and Ethics. *Annals of Internal Medicine*. [Online] 134 (1), 83. Available at: doi:<https://doi.org/10.7326/0003-4819-134-1-200101020-00024>.

- Cherny, N.I. (2009) Stigma associated with ‘palliative care’. *Cancer*. [Online] 115 (9), 1808–1812. Available at: doi:<https://doi.org/10.1002/cncr.24212> (Accessed: 21 June 2019).
- Cho, J. and Winzer, P.J. (2019) Probabilistic Constellation Shaping for Optical Fiber Communications. *Journal of Lightwave Technology*. [Online] 37 (6), 1590–1607. Available at: doi:<https://doi.org/10.1109/jlt.2019.2898855> (Accessed: 28 August 2020).
- Cho, J.H. (2019) Association between the Use of Humidifier Disinfectants and Bronchiolitis and Allergic Rhinitis Diagnoses in Korean Children. *www.e-jehs.org*. [Online] 45 (4), 381–393. Available at: doi:<https://doi.org/10.5668/JEHS.2019.45.4.381> (Accessed: 4 April 2024).
- Choi, Hong-Lim. (2007) PR meets Hong Bo: An alternative approach to international public relations. *The University of Iowa ProQuest Dissertations Publishing*. 1–193.
- Choi, J.-Y. and Kim, J.-H. (2013) What Factors Are Linked to Profitability among Hospitals?: A Review on the Research Trends. *Health Policy and Management*. [Online] 23 (4), 397–414. Available at: doi:<https://doi.org/10.4332/kjhpa.2013.23.4.397> (Accessed: 6 March 2023).
- Choi, K. (2015) The Ideal of Autonomy and Its Misuse. *Philosophy and Medicine*. [Online] 83–91. Available at: doi:https://doi.org/10.1007/978-3-319-12120-8_5.
- Choi, K. and Cho, J.K. (2020) Statistical Analysis Using Living Radiation Survey Data on Processed Products. *Journal of Radiological Science and Technology*. [Online] 43 (2), 123–128. Available at: doi:<https://doi.org/10.17946/jrst.2020.43.2.123> (Accessed: 3 March 2023).
- Choi, K. and Kim, J. (2017) 의료사회복지사의 역할 불일치와 직무만족 Role Discrepancy and Job Satisfaction on Medical social workers. *한국사회/복지/행정학*. [Online] 19 (4), 133–158. Available at: <https://www.dbpia.co.kr/Journal/articleDetail?nodeId=NODE07271867> (Accessed: 7 March 2023).
- Choi, S.-J. (2004) Development of a new concept of filial piety in modern Korean society. *Geriatrics and Gerontology International*. [Online] 4 (s1), S72–S73. Available at: doi:<https://doi.org/10.1111/j.1447-0594.2004.00155.x> (Accessed: 7 November 2021).
- Choi, S.C. and Choi, S.H. (2001) Cheong: The socioemotional grammar of Koreans. *International Journal of Group Tensions*. [Online] 30 (1), 69–80. Available at: doi:<https://doi.org/10.1023/a:1026606217152> (Accessed: 15 December 2020).
- Choi, Y.J. and Jeon, M.S. (2019) How Business Interests and Government Inaction Led to the Humidifier Disinfectant Disaster in South Korea: Implications for Better Risk Governance.

- Risk Analysis*. [Online] 40 (2), 240–253. Available at: doi:<https://doi.org/10.1111/risa.13400> (Accessed: 13 May 2020).
- Chung , C.K. and Cho , S.J. (2006) Conceptualization of jeong and dynamics of hwabyung. *Psychiatry Investigation*,. 3 (1), 46–54.
 - Chung, Y.-I. (2007) *South Korea in the fast lane: economic development and capital formation*. Oxford, Oxford Univ. Press.
 - Church, I.M. and Hartman, R.J. (2019) *The Routledge Handbook of the Philosophy and Psychology of Luck*. Routledge.
 - Clifford, D. and Burke, B. (2014) *Anti-oppressive ethics and values in social work*. Houndmills, Basingstoke, Hampshire ; New York, Ny, Palgrave Macmillan.
 - Collyer, F.M. (2014) Practices of conformity and resistance in the marketisation of the academy: Bourdieu, professionalism and academic capitalism. *Critical Studies in Education*. [Online] 56 (3), 315–331. Available at: doi:<https://doi.org/10.1080/17508487.2014.985690> (Accessed: 22 November 2019).
 - Collyer, F.M., Willis, K.F., Franklin, M., Harley, K., et al. (2015) Healthcare choice: Bourdieu’s capital, habitus and field. *Current Sociology*. [Online] 63 (5), 685–699. Available at: doi:<https://doi.org/10.1177/0011392115590082> (Accessed: 16 October 2019).
 - Contro, N.A. (2004) Hospital Staff and Family Perspectives Regarding Quality of Pediatric Palliative Care. *PEDIATRICS*. [Online] 114 (5), 1248–1252. Available at: doi:<https://doi.org/10.1542/peds.2003-0857-1> (Accessed: 19 April 2020).
 - Coombes, L.H., Wiseman, T., Lucas, G., Sangha, A., et al. (2016) Health-related quality-of-life outcome measures in paediatric palliative care: A systematic review of psychometric properties and feasibility of use. *Palliative Medicine*. [Online] 30 (10), 935–949. Available at: doi:<https://doi.org/10.1177/0269216316649155>.
 - Corbin, J. and Morse, J.M. (2003) The Unstructured Interactive Interview: Issues of Reciprocity and Risks when Dealing with Sensitive Topics. *Qualitative Inquiry*. [Online] 9 (3), 335–354. Available at: doi:<https://doi.org/10.1177/1077800403009003001>.
 - Corbin, J.M. and Strauss, A.L. (2015) *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*. 4th edition. Los Angeles, Sage.
 - Creswell, J.W. and Creswell, J.D. (2018) *Research design: Qualitative, quantitative, and Mixed Methods Approaches*. 5th edition. Thousand Oaks, California, SAGE Publications.
 - Cropley, A. (2006) In Praise of Convergent Thinking. *Creativity Research Journal*. [Online] 18 (3), 391–404. Available at: doi:https://doi.org/10.1207/s15326934crj1803_13.

- Cross, R. (1991) THE NEED FOR CUSTOM MIRRORS: BLIND LUCK = BAD LUCK. *Commercial Carrier Journal*. [Online] 148 (9). Available at: <https://trid.trb.org/view/517544> (Accessed: 27 February 2023).
- Cudd, A.E. (2006) *Analyzing oppression*. New York, Oxford University Press.
- D Soyini Madison (2019) *Critical ethnography : method, ethics, and performance*. 3rd edition. Thousand Oaks, California, Sage.
- Daisaku, M. (1983) *APA PsycNet*. [Online]. 1983. psycnet.apa.org. Available at: <https://psycnet.apa.org/record/1984-22964-001> (Accessed: 7 March 2023).
- Dalberg, T., Jacob-Files, E., Carney, P.A., Meyrowitz, J., et al. (2013) Pediatric oncology providers perceptions of barriers and facilitators to early integration of pediatric palliative care. *Pediatric Blood & Cancer*. [Online] 60 (11), 1875–1881. Available at: doi:<https://doi.org/10.1002/pbc.24673> (Accessed: 20 May 2019).
- Dalberg, T., McNinch, N.L. and Frieber, S. (2018) Perceptions of barriers and facilitators to early integration of pediatric palliative care: A national survey of pediatric oncology providers. *Pediatric Blood & Cancer*. [Online] 65 (6), e26996. Available at: doi:<https://doi.org/10.1002/pbc.26996>.
- Dalrymple, J. and Burke, B. (2006) *Anti-oppressive Practice: Social Care and the Law*. Maidenhead Open University Press.
- Daniels, N. (1979) Wide Reflective Equilibrium and Theory Acceptance in Ethics. *The Journal of Philosophy*. [Online] 76 (5), 256–282. Available at: doi:<https://doi.org/10.2307/2025881>.
- Daudt, H.M., van Mossel, C. and Scott, S.J. (2013) Enhancing the scoping study methodology: a large, inter-professional team’s experience with Arksey and O’Malley’s framework. *BMC Medical Research Methodology*. [Online] 13 (1). Available at: doi:<https://doi.org/10.1186/1471-2288-13-48>.
- David, D., Lynn, S.J. and Ellis, A. (2010) *Rational and Irrational Beliefs: Research, Theory, and Clinical Practice*. [Online]. Oxford University Press, USA. Available at: <https://books.google.com/books?hl=en&lr=&id=bxxnDAAAQBAJ&oi=fnd&pg=PA3&dq=A+Ibert+Ellis> (Accessed: 28 February 2023).
- Day, L. and Maltby, J. (2003) Belief in Good Luck and Psychological Well-Being: The Mediating Role of Optimism and Irrational Beliefs. *The Journal of Psychology*. [Online] 137 (1), 99–110. Available at: doi:<https://doi.org/10.1080/00223980309600602>.

- de Graeff, A. and Dean, M. (2007) Palliative sedation therapy in the last weeks of life: a literature review and recommendations for standards. *Journal of Palliative Medicine*. [Online] 10 (1), 67–85. Available at: doi:<https://doi.org/10.1089/jpm.2006.0139> (Accessed: 9 June 2020).
- Deber, R.B., Kraetschmer, N., Urowitz, S. and Sharpe, N. (2007) Do people want to be autonomous patients? Preferred roles in treatment decision-making in several patient populations. *Health Expectations*. [Online] 10 (3), 248–258. Available at: doi:<https://doi.org/10.1111/j.1369-7625.2007.00441.x>.
- Demiris, G., Parker Oliver, D., Wittenberg-Lyles, E., Washington, K., et al. (2012) A Noninferiority Trial of a Problem-Solving Intervention for Hospice Caregivers: In Person versus Videophone. *Journal of Palliative Medicine*. [Online] 15 (6), 653–660. Available at: doi:<https://doi.org/10.1089/jpm.2011.0488> (Accessed: 13 September 2020).
- Dickenson, D. (1991) *Moral Luck in Medical Ethics and Practical Politics*. Avebury.
- DiGangi, J. (2019) A Tragic Case Study in Hazardous Chemicals in Consumer Products. *Journal of Environmental Health Sciences*. [Online] 45 (4), 396–399. Available at: doi:<https://doi.org/10.5668/JEHS.2019.45.4.396> (Accessed: 3 March 2023).
- DiGangi, J. (2017) *Stories from the Clean Room | IPEN*. [Online]. 20 June 2017. ipen.org. Available at: <https://ipen.org/news/stories-clean-room> (Accessed: 4 March 2023).
- Doherty, S. (2005) Evidence-based medicine: Arguments for and against. *Emergency Medicine Australasia*. [Online] 17 (4), 307–313. Available at: doi:<https://doi.org/10.1111/j.1742-6723.2005.00753.x> (Accessed: 13 July 2020).
- Dolan, P. and Frost, N. (2017) *The Routledge handbook of global child welfare*. Abingdon, Oxon, Routledge, an imprint of the Taylor & Francis Group.
- Dominelli, L. (2002) *Anti-oppressive social work theory and practice*. Basingstoke, Palgrave Macmillan.
- Dominelli, L. (1996) Deprofessionalizing Social Work: Anti-Oppressive Practice, Competencies and Postmodernism. *British Journal of Social Work*. [Online] 26 (2), 153–175. Available at: doi:<https://doi.org/10.1093/oxfordjournals.bjsw.a011077>.
- Dominelli, L. (2005) Social inclusion in research: reflecting on a research project involving young mothers in care. *International Journal of Social Welfare*. [Online] 14 (1), 13–22. Available at: doi:<https://doi.org/10.1111/j.1468-2397.2005.00335.x> (Accessed: 11 January 2020).

- Dominelli, L. (2004) *Social work : theory and practice for a changing profession*. Cambridge, Uk ; Malden, Ma, Polity Press.
- Downing, J. ed. (2020) *Childrens Palliative Care: An International Case-Based Manual*. Cham, Springer International Publishing, Imprint Springer.
- Dreesens, D., Veul, L., Westermann, J., Wijnands, N., et al. (2019) The clinical practice guideline palliative care for children and other strategies to enhance shared decision-making in pediatric palliative care; pediatricians' critical reflections. *BMC Pediatrics*. [Online] 19 (1). Available at: doi:<https://doi.org/10.1186/s12887-019-1849-0> (Accessed: 4 September 2020).
- Duneier, M., Carter, O. and Hakim Hasan (2001) *Sidewalk*. New York New York, Farrar, Straus And Giroux.
- Dunn, G.P. (1997) Surgery, palliative care, and the American College of Surgeons. *Annals of Palliative Medicine*. 4 (1), 5–9.
- Dunn, G.P. and Johnson, A.G. (2004) *Surgical Palliative Care*. Geoffrey P. Dunn and Alan G. Johnson (eds.). [Online]. Oxford, New York, Oxford University Press. Available at: <https://global.oup.com/academic/product/surgical-palliative-care-9780198510000?cc=gb&lang=en&> (Accessed: 2 March 2023).
- Dunn, G.P., Sugantha Ganapathy and Chan, V.W.S. (2012) *Surgical palliative care and pain management*. Philadelphia, Pa., Saunders.
- Dunn, S. (2005) A conceptual framework for patient-professional communication: an application to the cancer context. *Psycho-Oncology*. [Online] 14 (10), 810–811. Available at: doi:<https://doi.org/10.1002/pon.986> (Accessed: 19 April 2021).
- Dworkin, R. (1985) *A mother of principle*. London, Harvard University Press.
- Edwards, A., Glyn Elwyn, Wood, F., Atwell, C., et al. (2005) Shared decision making and risk communication in practice: A qualitative study of GPs' experiences. *British Journal of General Practice*. [Online] 55 (510), 6–13. Available at: <https://bjgp.org/content/55/510/6> (Accessed: 30 December 2019).
- Elisabeth Louise Thomas (2004) *Emmanuel Levinas : ethics, justice and the human beyond being*. New York, Routledge.
- Elliott, J. (2005) *Using narrative in social science research : qualitative and quantitative approaches*. London, Sage.

- Elwyn, G., Edwards, A. and Thompson, R. (2016) *Shared decision-making in health care : achieving evidence-based patient choice*. Oxford, United Kingdom ; New York, Ny, United States Of America, Oxford University Press.
- Elwyn, G., Frosch, D., Thomson, R., Joseph-Williams, N., et al. (2012) Shared Decision Making: A Model for Clinical Practice. *Journal of General Internal Medicine*. [Online] 27 (10), 1361–1367. Available at: doi:<https://doi.org/10.1007/s11606-012-2077-6>.
- Emanuel, E.J. and Emanuel, L.L. (1992) Four Models of the Physician-Patient Relationship. *JAMA: The Journal of the American Medical Association*. [Online] 267 (16), 2221. Available at: doi:<https://doi.org/10.1001/jama.1992.03480160079038>.
- Emmel, N., Greenhalgh, J., Manzano, A., Monaghan, M., et al. (2018) *Doing realist research*. London ; Los Angeles, Sage.
- English, V., Sommerville, A., Brannan, S., British Medical Association, et al. (2012) *Medical ethics today: the BMAs handbook of ethics and law*. Chichester, West Sussex ; Hoboken, Nj, Wiley-Blackwell.
- Economic and Social Research Council (2015) Framework for Research Ethics. Available online: <https://esrc.ukri.org/files/funding/guidance-forapplicants/esrc-framework-for-research-ethics2015/>
- Eun , Y. (2019) *알지 못하는 아이의 죽음 Unknown Child Who Died*. 돌베개.
- Eun, H. (2022) *문제를 문제로 만드는 사람들 'People who make a problem into a problem.'* May's Spring.
- Fagan, M. (2009) The Inseparability of Ethics and Politics: Rethinking the Third in Emmanuel Levinas. *Contemporary Political Theory*. [Online] 8 (1), 5–22. Available at: doi:<https://doi.org/10.1057/cpt.2008.20> (Accessed: 2 March 2021).
- Fan, R. ed. (2015) *Family-oriented informed consent: East Asian and American perspectives*. Cham, Springer.
- Feenstra, B., Lawson, M.L., Harrison, D., Boland, L., et al. (2015) Decision coaching using the Ottawa family decision guide with parents and their children: a field testing study. *BMC Medical Informatics and Decision Making*. [Online] 15 (1). Available at: doi:<https://doi.org/10.1186/s12911-014-0126-2> (Accessed: 8 January 2021).
- Feudtner, C. (2007) Collaborative Communication in Pediatric Palliative Care: A Foundation for Problem-Solving and Decision-Making. *Pediatric Clinics of North America*. [Online] 54

- (5), 583–607. Available at: doi:<https://doi.org/10.1016/j.pcl.2007.07.008> (Accessed: 24 October 2019).
- Feudtner, C., Carroll, K.W., Hexem, K.R., Silberman, J., et al. (2010) Parental Hopeful Patterns of Thinking, Emotions, and Pediatric Palliative Care Decision Making. *Archives of Pediatrics & Adolescent Medicine*. [Online] 164 (9). Available at: doi:<https://doi.org/10.1001/archpediatrics.2010.146> (Accessed: 2 December 2020).
 - Fineberg, I.C. (2010) Social work perspectives on family communication and family conferences in palliative care. *Progress in Palliative Care*. [Online] 18 (4), 213–220. Available at: doi:<https://doi.org/10.1179/096992610x12624290277105>.
 - Francesco Lo Piccolo and Thomas, H. (2009) *Ethics and planning research*. Farnham, England ; Burlington, Vt, Ashgate Pub.
 - Friedland, N. (1992) On luck and chance: Need for control as a mediator of the attribution of events to luck. *Journal of Behavioral Decision Making*. [Online] 5 (4), 267–282. Available at: doi:<https://doi.org/10.1002/bdm.3960050404> (Accessed: 8 September 2020).
 - FRIEDMAN, M. (2008) Virtues and Oppression: A Complicated Relationship. *Hypatia*. [Online] 23 (3), 189–196. Available at: doi:<https://doi.org/10.1111/j.1527-2001.2008.tb01213.x> (Accessed: 15 August 2019).
 - Friedrichsdorf, S. and Bruera, E. (2018) Delivering Pediatric Palliative Care: From Denial, Palliphobia, Pallilalia to Palliative. *Children*. [Online] 5 (9), 120. Available at: doi:<https://doi.org/10.3390/children5090120> (Accessed: 3 July 2020).
 - FUJIMURA, M., TOMINAGA, T., KURODA, S., TAKAHASHI, J.C., et al. (2022) 2021 Japanese Guidelines for the Management of Moyamoya Disease: Guidelines from the Research Committee on Moyamoya Disease and Japan Stroke Society. *Neurologia medico-chirurgica*. [Online] 62 (4), 165–170. Available at: doi:<https://doi.org/10.2176/jns-nmc.2021-0382> (Accessed: 19 May 2022).
 - García, WendyC.G. (2016) Pediatric palliative care: Comprehensive support for children. *Acta Medica International*. [Online] 3 (2), 165. Available at: doi:<https://doi.org/10.5530/ami.2016.2.32> (Accessed: 2 March 2023).
 - Gardner, R. (2003) *Supporting Families*. John Wiley & Sons Incorporated.
 - Gelwick, R. (2004) *The way of discovery: an introduction to the thought of Michael Polanyi*. Eugene, Ore., Wipf & Stock Publishers.
 - Gilbert, B. (2003) Consent, rights, and choices in health care for children and young people: British Medical Association. British Medical Association, 2001, 19.95 (BMA

- members 18.95), pp 266 + xix. ISBN 0-7279-1228-3. *Journal of Medical Ethics*. [Online] 29 (4), 13e13. Available at: doi:<https://doi.org/10.1136/jme.29.4.e13> (Accessed: 23 October 2019).
- Gillam, L. and Sullivan, J. (2011) Ethics at the end of life: Who should make decisions about treatment limitation for young children with life-threatening or life-limiting conditions? *Journal of Paediatrics and Child Health*. [Online] 47 (9), 594–598. Available at: doi:<https://doi.org/10.1111/j.1440-1754.2011.02177.x> (Accessed: 13 January 2020).
 - Goldenberg, M.J. (2006) On evidence and evidence-based medicine: Lessons from the philosophy of science. *Social Science & Medicine*. [Online] 62 (11), 2621–2632. Available at: doi:<https://doi.org/10.1016/j.socscimed.2005.11.031> (Accessed: 10 February 2020).
 - Goldman, A., Hain, R. and Liben, S. (2021) *Oxford textbook of palliative care for children*. 3rd edition. Oxford ; New York, Oxford University Press.
 - Goodley, D. (2000) *Self-advocacy in the lives of people with learning difficulties: the politics of resilience*. Buckingham, Open University Press.
 - Gordon, E.J. and Levin, B.W. (2007) Contextualizing Ethical Dilemmas: Ethnography for Bioethics. *Empirical Methods for Bioethics: A Primer*. [Online] 83–116. Available at: doi:[https://doi.org/10.1016/s1479-3709\(07\)11004-9](https://doi.org/10.1016/s1479-3709(07)11004-9) (Accessed: 1 March 2023).
 - Gorer, G. (1977) *Death, Grief, and Mourning*. [Online]. 1977. eweb:17914. Available at: <https://repository.library.georgetown.edu/handle/10822/775385>.
 - Gorer, G. (1955) The Pornography of Death. *Encounter*. 5 (4), 49–53.
 - Greener, I. (2011) *Designing social research: a guide for the bewildered*. London, Sage Publications.
 - Gries, C.J., Curtis, J.R., Wall, R.J. and Engelberg, R.A. (2008) Family Member Satisfaction With End-of-Life Decision Making in the ICU. *Chest*. [Online] 133 (3), 704–712. Available at: doi:<https://doi.org/10.1378/chest.07-1773> (Accessed: 4 February 2020).
 - Grinyer, A. (2012) A bereavement group for parents whose son or daughter died from cancer: how shared experience can lessen isolation. *Mortality*. [Online] 17 (4), 338–354. Available at: doi:<https://doi.org/10.1080/13576275.2012.730684> (Accessed: 12 March 2020).
 - Gwyther, L., Brennan, F. and Harding, R. (2009) Advancing Palliative Care as a Human Right. *Journal of Pain and Symptom Management*. [Online] 38 (5), 767–774. Available at: doi:<https://doi.org/10.1016/j.jpainsymman.2009.03.003> (Accessed: 4 October 2019).

- Gwyther, L.P., Altilio, T., Blacker, S., Christ, G., et al. (2005) Social Work Competencies in Palliative and End-of-Life Care. *Journal of Social Work in End-Of-Life & Palliative Care*. [Online] 1 (1), 87–120. Available at: doi:https://doi.org/10.1300/j457v01n01_06.
- Haby, M.M. and Reveiz, L. (2022) *A Guide for Evidence-Informed Decision-Making, Including in Health Emergencies*. [Online]. Pan American Health Organization. Available at: <https://investigadores.unison.mx/en/publications/a-guide-for-evidence-informed-decision-making-including-in-health> (Accessed: 5 April 2024).
- Hackett, S. and Taylor, A. (2013) Decision Making in Social Work with Children and Families: The Use of Experiential and Analytical Cognitive Processes. *British Journal of Social Work*. [Online] 44 (8), 2182–2199. Available at: doi:<https://doi.org/10.1093/bjsw/bct071> (Accessed: 1 June 2020).
- Hain, R., Goldman, A., Rapoport, A. and Meiring, M. (2021) *Oxford Textbook of Palliative Care for Children*. Oxford University Press.
- Hain, R. and Satbir Singh Jassal (2016) *Oxford specialist handbook of paediatric palliative medicine*. Oxford, United Kingdom, Oxford University Press.
- Hamilton, K. and Catterall, M. (2007) Cooperation and Conflict in Family Decision Making. *ACR European Advances*. [Online] E-08. Available at: <https://www.acrwebsite.org/volumes/13941/eacr/vol8/E-08> (Accessed: 28 February 2023).
- Hand, S. (2014) *Facing the Other: The Ethics of Emmanuel Levinas*. [Online]. Routledge. Available at: https://books.google.com/books?hl=en&lr=&id=IRtIAwAAQBAJ&oi=fnd&pg=PP1&dq=Emmanuel+levinas+feminism&ots=_mgdjpBDU&sig=MaKUyPXa5f3vjqHxBWL-av1Y5rc (Accessed: 1 March 2023).
- Haraway, D. (1988) Situated Knowledges: the Science Question in Feminism and the Privilege of Partial Perspective. *Feminist Studies*. 14 (3), 575–599.
- Hardy, M.A. and Bryman, A. (2009) *Handbook of data analysis*. Los Angeles ; London, Sage.
- Haridimos Tsoukas (2005) *Complex knowledge: studies in organizational epistemology*. New York, Oxford University Press.
- Health and Medical Services statutes of the Republic of Korea (2000) *Statutes of the Republic of Korea*. [Online]. 2000. elaw.klri.re.kr. Available at: https://elaw.klri.re.kr/eng_service/lawView.do?hseq=54790&lang=ENG (Accessed: 2 March 2023).

- Henry, C. (2011) National End of Life Care Programme: progress and future directions. *Together for Short Lives*. [Online] Available at: <https://www.togetherforshortlives.org.uk/abstract/national-end-of-life-care-programme-progress-and-future-directions/> (Accessed: 5 March 2023).
- Henry, S.G. (2006) Recognizing Racit Knowledge in Medical Epistemology. *Theoretical Medicine and Bioethics*. [Online] 27 (3), 187–213. Available at: doi:<https://doi.org/10.1007/s11017-006-9005-x> (Accessed: 9 January 2023).
- Hilgers, M. and Mangez, E. (2015) *Bourdieu's Theory of Social Fields: Concepts and Applications*. Hoboken, Taylor and Francis.
- Hill, A. (1998) Multiprofessional teamwork in hospital palliative care teams. *International Journal of Palliative Nursing*. [Online] 4 (5), 214–221. Available at: doi:<https://doi.org/10.12968/ijpn.1998.4.5.9099>.
- Hinds, P.S., Menard, J.C. and Jacobs, S.S. (2012) The child's voice in pediatric palliative and end-of-life care. *Progress in Palliative Care*. [Online] 20 (6), 337–342. Available at: doi:<https://doi.org/10.1179/1743291x12y.0000000035> (Accessed: 22 March 2021).
- Honjo, K. (2004) Social Epidemiology: Definition, History, and Research Examples. *Environmental Health and Preventive Medicine*. [Online] 9 (5), 193–199. Available at: doi:<https://doi.org/10.1265/ehpm.9.193> (Accessed: 1 March 2023).
- Houston, S. (2002) Reflecting on Habitus, Field and Capital. *Journal of Social Work*. [Online] 2 (2), 149–167. Available at: doi:<https://doi.org/10.1177/146801730200200203>.
- Hui, D., De La Cruz, M., Mori, M., Parsons, H.A., et al. (2012) Concepts and definitions for 'supportive care,' 'best supportive care,' 'palliative care,' and 'hospice care' in the published literature, dictionaries, and textbooks. *Supportive Care in Cancer*. [Online] 21 (3), 659–685. Available at: doi:<https://doi.org/10.1007/s00520-012-1564-y>.
- Hutchens, B.C. (2004) *Levinas : a guide for the perplexed*. New York, Continuum.
- Hwang, H. (2018) '내가 잔 침대에서도..' 케모포비아 확산.. 소비자 '분통'. [Online]. 2018. 언론사 뷰. Available at: <https://v.daum.net/v/20180525111633443?f=m&rcmd=rn> (Accessed: 3 March 2023).
- Hymes, D. (2003) *Ethnography, Linguistics, Narrative Inequality*. Taylor & Francis.
- IFSW (2002) *The best interest of the child – International Federation of Social Workers*. [Online]. 2002. www.ifsw.org. Available at: <https://www.ifsw.org/the-best-interest-of-the-child/> (Accessed: 23 February 2023).

- Im, K. (2014) 2 세 선천성 질환 증가추세... 정부차원 상세한 조사 필요. [Online]. 12 November 2014. www.hani.co.kr. Available at: <https://www.hani.co.kr/arti/society/labor/664288.html> (Accessed: 4 March 2023).
- Indaimo, J.A. (2015) *The Self, Ethics and Human Rights : Lacan, Levinas & Alterity*. Abingdon, Oxon [UK], Routledge.
- International Federation of Social Workers (2012) *Human rights – International Federation of Social Workers*. [Online]. 20 February 2012. Ifsw.org. Available at: <https://www.ifsw.org/human-rights-policy/> (Accessed: 24 February 2023).
- International Federation of Social Workers (2019) *HUMANISM AND ETHICS IN SOCIAL WORK*. [Online]. 2019. Ifsw.org. Available at: <https://www.ifsw.org/>.
- Iris Marion Young (2022) *Justice And The Politics Of Difference*. S.L., Princeton University Pres.
- Israel, Barbara , Schulz, Amy, et al. (2001) *ProQuest | Better research, better learning, better insights*. [Online]. 2001. www.proquest.com. Available at: <https://www.proquest.com/scholarly-journals/community-based-participatory-research-policy/docview/2258169865/se-2>. (Accessed: 28 February 2023).
- J Randall Curtis and Rubinfeld, G.D. (2001) *Managing death in the ICU : the transition from cure to comfort*. Oxford ; New York, Oxford University Press.
- Jaspreet, K. and Bidhu, M. (2011) Transition from curative to palliative care in cancer - ProQuest. *Indian Journal of Palliative Care*. [Online] 17 (1), 1–5. Available at: <https://www.proquest.com/openview/2df30be18f5e76dbd43a0d1239738e17/1?pq-origsite=gscholar&cbl=226506> (Accessed: 2 March 2023).
- Jaycox, M.P. (2016) The Civic Virtues of Social Anger: A Critically Reconstructed Normative Ethic for Public Life. *Journal of the Society of Christian Ethics*. [Online] 36 (1), 123–143. Available at: doi:<https://doi.org/10.1353/sce.2016.0008> (Accessed: 13 December 2019).
- Jones, B.L. (2006) Pediatric palliative and end-of-life care: The role of social work in pediatric oncology. *Journal of Social Work in End-of-Life & Palliative Care*. 1 (4), 35–62.
- Jonsen, A.R., Siegler, M. and Winslade, W.J. (2010) *Clinical ethics a practical approach to ethical decisions in clinical medicine /*. New York, N.Y., Mcgraw-Hill Education Llc., C.
- Joo, Y. (2022) *공기살인 TOXIC*. [Online]. 22 April 2022. 다음 영화. Available at: <https://movie.daum.net/moviedb/main?movieId=143705> (Accessed: 4 March 2023).

- Jovchelovitch, S. and Bauer, M. (2007) *Narrative Interviewing*. [Online]. 2007. [www.semanticscholar.org](https://www.semanticscholar.org/paper/Narrative-Interviewing-Jovchelovitch-Bauer/088c059a6e274293f9adfcba9b465085957301c1). Available at: <https://www.semanticscholar.org/paper/Narrative-Interviewing-Jovchelovitch-Bauer/088c059a6e274293f9adfcba9b465085957301c1> (Accessed: 1 March 2023).
- Ju, H.Y., Moon, E.-K., Lim, J., Park, B.K., et al. (2018) Second malignant neoplasms after childhood cancer: A nationwide population-based study in Korea Samir M. Dalia (ed.). *PLOS ONE*. [Online] 13 (11), e0207243. Available at: doi:<https://doi.org/10.1371/journal.pone.0207243> (Accessed: 21 October 2021).
- Jünger, S., Pestinger, M., Elsner, F., Krumm, N., et al. (2007) Criteria for successful multiprofessional cooperation in palliative care teams. *Palliative Medicine*. [Online] 21 (4), 347–354. Available at: doi:<https://doi.org/10.1177/0269216307078505>.
- Kang, D.-M., Kim, J.-E., Kim, Y.-K., Lee, H.-H., et al. (2018) Occupational Burden of Asbestos-Related Diseases in Korea, 1998–2013: Asbestosis, Mesothelioma, Lung Cancer, Laryngeal Cancer, and Ovarian Cancer. *Journal of Korean Medical Science*. [Online] 33 (35). Available at: doi:<https://doi.org/10.3346/jkms.2018.33.e226> (Accessed: 2 March 2023).
- Kang, G. (2017) ‘특수학교 반대’ 강서구민들께... ‘막연한 거부를 거둬주세요’ ‘To the Gangseo residents who are against “special education schools”... please reconsider your vague rejection.’ [Online]. 23 October 2017. 오마이뉴스. Available at: http://www.ohmynews.com/NWS_Web/View/at_pg.aspx?CNTN_CD=A0002370367.
- Kathryn Strother Ratcliff (2017) *The Social Determinants of Health Looking Upstream*. Newark Polity Press.
- Kaye, E.C., Rubenstein, J., Levine, D., Baker, J.N., et al. (2015) Pediatric palliative care in the community. *CA: a cancer journal for clinicians*. [Online] 65 (4), 316–333. Available at: doi:<https://doi.org/10.3322/caac.21280>.
- Kaye, P. (1999) *Decision Making in Palliative Care*. Johnson Johnson Medical.
- KCDC (2011) *Hospital based case-control study on lung injury with unknown causes*. [Online]. 2011. Public Health Weekly Report (in Korean). Available at: https://scholar.google.com/scholar?cluster=954624160740146097&hl=en&as_sdt=2005&sciodt=0,5 (Accessed: 3 March 2023).
- Kendall, L. and Dix, G. (1987) *Religion and Ritual in Korean Society*. University of California Inst of East.
- Kim, Hyunchul (2023) *경제학이 필요한 순간 When you need economics*. 김영사.

- Kim, Jongwoo MBC <I met you> the producer (PD) of the MBC program (2020) *너를 만났잖아 I met you*. [Online]. 슬로디미디어. Available at: <https://m.yes24.com/Goods/Detail/113791132> (Accessed: 30 August 2024).
- Kim, B.-G., Jeong, K.-H. and Shin, H.-K. (2019) EVALUATION OF DOSE IN SLEEP BY MATTRESS CONTAINING MONAZITE. *Radiation Protection Dosimetry*. [Online] 187 (3), 286–299. Available at: doi:<https://doi.org/10.1093/rpd/ncz163> (Accessed: 3 March 2023).
- Kim, C.G. (2017a) Hospice & Palliative Care Policy in Korea. *The Korean Journal of Hospice and Palliative Care*. [Online] 20 (1), 8–17. Available at: doi:<https://doi.org/10.14475/kjhpc.2017.20.1.8> (Accessed: 22 April 2020).
- Kim, C.G. (2019) The History of Hospice and Palliative Care in Korea. *The Korean Journal of Hospice and Palliative Care*. [Online] 22 (1), 1–7. Available at: doi:<https://doi.org/10.14475/kjhpc.2019.22.1.1> (Accessed: 3 June 2020).
- Kim, E. and Byeong Cheon I (2006) *Developmental dictatorship and the Park Chung-hee era : the shaping of modernity in the Republic of Korea*. Paramus, Nj Homa & Sekey Books.
- Kim, H. (2017b) ‘Spoon Theory’ and the Fall of a Populist Princess in Seoul. *The Journal of Asian Studies*. [Online] 76 (4), 839–849. Available at: doi:<https://doi.org/10.1017/s0021911817000778>.
- Kim, H., Kim, D. and Lee, C. (2020) Analysis of the Government’s Policy Responses to the Incident of Radiation in the Natural Environment in Korea: Focused on Radon-emitting Mattress Case. *Journal of Safety and Crisis Management*. [Online] 10 (2), 33–46. Available at: <https://www.dbpia.co.kr/Journal/articleDetail?nodeId=NODE10693220> (Accessed: 3 March 2023).
- Kim, H., Lee, J.S., Lee, Y., Kim, S.Y., et al. (2019) Diagnostic Challenges Associated with GLUT1 Deficiency: Phenotypic Variabilities and Evolving Clinical Features. *Yonsei Medical Journal*. [Online] 60 (12), 1209. Available at: doi:<https://doi.org/10.3349/ymj.2019.60.12.1209> (Accessed: 6 March 2023).
- Kim, H.R. (2009) Overview of Asbestos Issues in Korea. *Journal of Korean Medical Science*. [Online] 24 (3), 363–367. Available at: doi:<https://doi.org/10.3346/jkms.2009.24.3.363> (Accessed: 4 March 2023).

- Kim, J. (2022) [기획] 국내서도 싹트는 ‘소아청소년 완화의료’... 뿌리 내리려면?
[Online]. 20 January 2022. 청년의사. Available at:
<http://www.docdocdoc.co.kr/news/articleView.html?idxno=2018144> (Accessed: 2 March 2023).
- Kim, K.C. and Hurh, W.M. (1991) The extended conjugal family: family-kinship system of Korean immigrants in the United States. *ehrafworldcultures.yale.edu*. [Online] (14), 115–133. Available at: <https://ehrafworldcultures.yale.edu/document?id=n019-017> (Accessed: 7 March 2023).
- Kim, K.C., Kim, S. and Hurh, W.M. (1991) Filial Piety and Intergenerational Relationship in Korean Immigrant Families. *The International Journal of Aging and Human Development*. [Online] 33 (3), 233–245. Available at: doi:<https://doi.org/10.2190/y91p-ungr-x5e1-175k> (Accessed: 5 March 2022).
- Kim, K.W., Ahn, K., Yang, H.J., Lee, S., et al. (2014) Humidifier disinfectant–associated children’s interstitial lung disease. *American journal of respiratory and critical care medicine* . 189 ((1)), 48–56.
- Kim, K.W., Ahn, K., Yang, H.J., Lee, S.Y., et al. (2013) Humidifier Disinfectant-Associated Children’s Interstitial Lung Disease. *American Journal of Respiratory and Critical Care Medicine*. [Online] 189 (1), 131107125401005. Available at: doi:<https://doi.org/10.1164/rccm.201306-1088oc> (Accessed: 17 December 2021).
- Kim, M.J. (2023) Unintended consequences of healthcare reform in South Korea: evidence from a regression discontinuity in time design. *Health research policy and systems*. [Online] 21 (1), 60. Available at: doi:<https://doi.org/10.1186/s12961-023-00993-9>.
- Kim, M.S., Lim, N.G., Kim, H.J., Kim, C., et al. (2017) Pediatric Deaths Attributed to Complex Chronic Conditions over 10 Years in Korea: Evidence for the Need to Provide Pediatric Palliative Care. *Journal of Korean Medical Science*. [Online] 33 (1). Available at: doi:<https://doi.org/10.3346/jkms.2018.33.e1> (Accessed: 15 October 2021).
- Kim, S., Sohn, M., Moon, S., Yoon, H., et al. (2017) Financial integrity strategies for sustainable development of local public medical centers: focused on financial efficiency and publicness 지방의료원의 재무적 효율성과 공공성 향상을 위한 관련 요인 분석 1)
*국립중앙의료원 신경외과, **고려대학교 대학원 보건과학과 BK21PLUS 인간생명-
사회환경 상호작용 융합사업단, ***고려대학교 보건과학대학 보건정책관리학부

- Financial Integrity Strategies for Sustainable Development of Local Public Medical Centers: Focused on Financial Efficiency and Publicness. *Korea Journal of Hospital Management*. [Online] 22 (2), 44–57. Available at: <https://www.koreascience.or.kr/article/JAKO201719951667829.pdf>.
- Kim, S.-Y., Kim, Y.-C., Kim, Y. and Hong, W.-H. (2016) Predicting the mortality from asbestos-related diseases based on the amount of asbestos used and the effects of slate buildings in Korea. *Science of The Total Environment*. [Online] 5421–11. Available at: doi:<https://doi.org/10.1016/j.scitotenv.2015.10.115> (Accessed: 2 March 2023).
 - Kim, Y.H., Kim, K.W., Lee, K.E., Lee, M.-J., et al. (2015) Transforming growth factor-beta 1 in humidifier disinfectant-associated children's interstitial lung disease. *Pediatric Pulmonology*. [Online] 51 (2), 173–182. Available at: doi:<https://doi.org/10.1002/ppul.23226> (Accessed: 5 July 2022).
 - Kinley, J., Stone, L., Butt, A., Kenyon, B., et al. (2017) Developing, implementing and sustaining an end-of-life care programme in residential care homes. *International Journal of Palliative Nursing*. [Online] 23 (4), 186–193. Available at: doi:<https://doi.org/10.12968/ijpn.2017.23.4.186> (Accessed: 14 March 2021).
 - Kissane, D. and Al, E. (2017) *Oxford textbook of communication in oncology and palliative care*. Oxford, Oxford University Press.
 - Kissane, D.W., Bultz, B.D., Butow, P.N., PhD, C.L.B., et al. (2017) *Oxford Textbook of Communication in Oncology and Palliative Care*. Oxford University Press.
 - Klosterman, R.E. (1985) Arguments for and against planning. *Town Planning Review*. [Online] 56 (1), 5. Available at: doi:<https://doi.org/10.3828/tpr.56.1.e8286q3082111km4>.
 - Kong, J.O. (2012) 반도체 산업의 작업환경과 질병의 경험들 Working Environment and Experiences of Diseases in Semiconductor Industry. *J Korean Soc Occup Environ Hyg.* 22 (1), 32–41.
 - KOREA GALLUP. (2017) *한국갤럽조사연구소 Gallup report: Korean funeral culture*. [Online]. 2017. www.gallup.co.kr. Available at: <https://www.gallup.co.kr/>.
 - Korean Organization for Rare Diseases (2023) 2023. [Kord.or.kr](http://kord.or.kr). Available at: <https://www.kord.or.kr/index.php> (Accessed: 1 March 2023).
 - Koyano, W. (1996) Filial Piety and Intergenerational Solidarity in Japan. *Australian Journal on Ageing*. [Online] 15 (2), 51–56. Available at: doi:<https://doi.org/10.1111/j.1741-6612.1996.tb00203.x>.

- Labov, W. (1972) *Language in the inner city : studies in the Black English vernacular*. Philadelphia, Pa., University Of Pennsylvania Press.
- Ladou, J. and Bailar, J.C. (2007) Cancer and Reproductive Risks in the Semiconductor Industry. *International Journal of Occupational and Environmental Health*. [Online] 13 (4), 376–385. Available at: doi:<https://doi.org/10.1179/oeht.2007.13.4.376>.
- Larcher, V., Craig, F., Bhogal, K., Wilkinson, D., et al. (2015) Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice: *Archives of Disease in Childhood*. [Online] 100 (Suppl 2), s1–s23. Available at: doi:<https://doi.org/10.1136/archdischild-2014-306666>.
- Lawton, J. (2005) *The dying process: patients' experiences of palliative care*. London; New York, Routledge.
- Lee, W. and Shin, W. (2020) *Hospital Playlist Season 1st episode*. [Online]. 2020. www.netflix.com. Available at: <https://www.netflix.com/title/81239224> (Accessed: 7 March 2023).
- Lee, C.H., Lim, H., Kim, Y., Park, A.H., et al. (2014) Analysis of Appropriate Outpatient Consultation Time for Clinical Departments. *Health Policy and Management*. [Online] 24 (3), 254–260. Available at: doi:<https://doi.org/10.4332/kjhpa.2014.24.3.254> (Accessed: 6 January 2022).
- Lee, C.W. and Kim, H.R. (2022) SPATIAL DISTRIBUTION ANALYSIS AND DOSE ASSESSMENT OF THE RADON EMITTED FROM THE MONAZITE-CONTAINING MATTRESS IN GENERAL RESIDENTIAL SPACE BY CFD METHODS. *Radiation Protection Dosimetry*. [Online] 198 (1-2), 8–15. Available at: doi:<https://doi.org/10.1093/rpd/ncab181> (Accessed: 3 March 2023).
- Lee, H. (2022a) ‘공기살인’, 결말을 알고 봐도 실화의 힘이 막강하니 [TF 씨네리뷰] : "Even knowing the ending, the power of the true story behind 'Toxic is so strong" - TF Cinema Review. [Online]. April 2022. 언론사 뷰. Available at: <https://v.daum.net/v/20220416070014004> (Accessed: 4 March 2023).
- Lee, H.-E., Kim, E.-A., Park, J. and Kang, S.-K. (2011) Cancer Mortality and Incidence in Korean Semiconductor Workers. *Safety and Health at Work*. [Online] 2 (2), 135–147. Available at: doi:<https://doi.org/10.5491/shaw.2011.2.2.135> (Accessed: 29 March 2020).
- Lee, H.S. (1996) Change in Funeral Customs in Contemporary Korea. *Korea Journal*. [Online] 36 (2), 49–60. Available at:

- <https://www.dbpia.co.kr/Journal/articleDetail?nodeId=NODE09373730> (Accessed: 7 March 2023).
- Lee, I. (2015a) Filial Duty as the Moral Foundation of Caring for the Elderly: Its Possibility and Limitations. *Philosophy and Medicine*. [Online] 137–147. Available at: doi:https://doi.org/10.1007/978-3-319-12120-8_9 (Accessed: 28 February 2023).
 - Lee, J., Kim, M.S. and Shin, H.Y. (2020) Integrative care for children with medical complexity. *Clinical and Experimental Pediatrics*. [Online] 63 (2), 32–33. Available at: doi:<https://doi.org/10.3345/kjp.2019.00717> (Accessed: 16 May 2022).
 - Lee, J.-H., Kim, Y.-H. and Kwon, J.-H. (2012) Fatal Misuse of Humidifier Disinfectants in Korea: Importance of Screening Risk Assessment and Implications for Management of Chemicals in Consumer Products. *Environmental Science & Technology*. [Online] 46 (5), 2498–2500. Available at: doi:<https://doi.org/10.1021/es300567j> (Accessed: 13 May 2020).
 - Lee, J.-W. and Park, C.-H. (2015) Factors affecting the hospital profitability (Focusing on the convergence of differences in financial performance of the surplus and deficit hospital). *Journal of Digital Convergence*. [Online] 13 (11), 267–276. Available at: doi:<https://doi.org/10.14400/jdc.2015.13.11.267> (Accessed: 1 April 2021).
 - Lee, J.Y. and Kim, S.-K. (2007) Update of Moyamoya Disease. *Journal of the Korean Medical Association*. [Online] 50 (12), 1109. Available at: doi:<https://doi.org/10.5124/jkma.2007.50.12.1109> (Accessed: 5 September 2020).
 - Lee, K.-M. and Lee, J.M. (2014) Crohn’s disease in Korea: past, present, and future. *The Korean Journal of Internal Medicine*. [Online] 29 (5), 558. Available at: doi:<https://doi.org/10.3904/kjim.2014.29.5.558> (Accessed: 28 March 2023).
 - Lee, P.-S. (2015b) Basic Law on Service Industry Development and medical privatization. *Journal of the Korean Medical Association*. [Online] 58 (2), 86–88. Available at: doi:<https://doi.org/10.5124/jkma.2015.58.2.86> (Accessed: 2 March 2023).
 - Lee, Y. (2022b) [책과 삶] ‘난 왜 아프게 태어났어?’... 삼성반도체 노동자 아이들의 물음에 답하다 [Books and Life] “Why was I born sick?” Answering the questions of children of Samsung semiconductor workers.’ [Online]. 14 October 2022. m.khan.co.kr. Available at: <https://m.khan.co.kr/culture/book/article/202210141611001> (Accessed: 4 March 2023).

- Lee, Y.S. (2013) The Past, Present and Future Strategies of Korean Social Work in Hospice and Palliative Care. *The Korean Journal of Hospice and Palliative Care*. [Online] 16 (2), 65–73. Available at: doi:<https://doi.org/10.14475/kjhpc.2013.16.2.065> (Accessed: 7 April 2020).
- Leem, J.H. and Kim, H.-C. (2020) Mitochondria disease due to humidifier disinfectants: diagnostic criteria and its evidences. *Environmental Analysis Health and Toxicology*. [Online] 35 (2), e2020007. Available at: doi:<https://doi.org/10.5620/eaht.e2020007> (Accessed: 5 October 2020).
- Levinas, E. (2008a) *Outside the subject*. New York, Ny, Continuum.
- Levinas, E. (2008b) *Time and the other: (and additional essays)*. Pittsburgh, Duquesne University Press.
- Levinas, E. (1980) *Totality and Infinity*. 3rd edition. Dordrecht, Kluwer Academic Publishers.
- Levinas, E. and Lingis, A. (1991) *Otherwise than being or beyond essence*. Dordrecht Springer.
- Levinas, E. and Philippe Nemo (2011) *Ethics and infinity : conversations with Philippe Nemo*. Pittsburgh, Duquesne University Press.
- LEWIS , S. (2016) *South Korean Victims of Toxic Disinfectant File Lawsuit*. [Online]. 17 May 2016. Time. Available at: <https://time.com/4338272/oxy-dehumidifier-disinfectant-reckitt-benckiser-korea/> (Accessed: 23 February 2023).
- Liben, S., Papadatou, D. and Wolfe, J. (2008) Paediatric palliative care: challenges and emerging ideas. *The Lancet*. [Online] 371 (9615), 852–864. Available at: doi:[https://doi.org/10.1016/s0140-6736\(07\)61203-3](https://doi.org/10.1016/s0140-6736(07)61203-3).
- Liu, C. (2021) In luck we trust: Capturing the diversity bonus through random selection. *Journal of Organization Design*. [Online] 10 (2), 85–91. Available at: doi:<https://doi.org/10.1007/s41469-021-00100-8> (Accessed: 6 July 2021).
- LOGAN, J. and GRAHAM, I.D. (1998) Toward a Comprehensive Interdisciplinary Model of Health Care Research Use. *Science Communication*. [Online] 20 (2), 227–246. Available at: doi:<https://doi.org/10.1177/1075547098020002004> (Accessed: 17 May 2020).
- Longacre, R.E. (2020) *An anatomy of speech notions*. [Online]. Walter de Gruyter GmbH & Co KG. Available at: https://books.google.com/books?hl=en&lr=&id=qCMTEAAQBAJ&oi=fnd&pg=PA6&dq=longacre+1976+anatomy+of+speech&ots=qtU9CYSVQk&sig=9AJH_75O5vjV95Uq5v68s1L5TaA (Accessed: 1 March 2023).

- Lovell, A. and Yates, P. (2014) Advance Care Planning in palliative care: A systematic literature review of the contextual factors influencing its uptake 2008–2012. *Palliative Medicine*. [Online] 28 (8), 1026–1035. Available at: doi:<https://doi.org/10.1177/0269216314531313>.
- MacIntyre, A. (1981) The Nature of the Virtues. *The Hastings Center Report*. [Online] 11 (2), 27. Available at: doi:<https://doi.org/10.2307/3561072>.
- Macmillan Cancer Support (2017) Impact Brief: Best cancer care—Macmillan’s one-to-one support workers, 2/2. *British Journal of Healthcare Assistants*. [Online] 11 (11), 542–547. Available at: doi:<https://doi.org/10.12968/bjha.2017.11.11.542> (Accessed: 30 May 2019).
- Marshall, P.L. and Koenig, B.A. (2001) *Ethnographic Methods*. [Online]. 2001. eweb:225762. Available at: <https://repository.library.georgetown.edu/handle/10822/942277> (Accessed: 28 February 2023).
- Martins, D.C., Babajide, O., Maani, N., Abdalla, S.M., et al. (2021) Integrating Social Determinants in Decision-Making Processes for Health: Insights from Conceptual Frameworks—the 3-D Commission. *Journal of Urban Health*. [Online] 98 (S1), 51–59. Available at: doi:<https://doi.org/10.1007/s11524-021-00560-z> (Accessed: 8 June 2022).
- Martyn Hammersley and Atkinson, P. (2019) *Ethnography: principles in practice*. London; New York, Routledge. Copyright.
- Matyas, T.A. and Ottenbacher, K.J. (1993) Confounds of insensitivity and blind luck: Statistical conclusion validity in stroke rehabilitation clinical trials. *Archives of Physical Medicine and Rehabilitation*. [Online] 74 (6), 559–565. Available at: doi:[https://doi.org/10.1016/0003-9993\(93\)90152-z](https://doi.org/10.1016/0003-9993(93)90152-z) (Accessed: 8 July 2022).
- MBC (2020) [VR Human Documentary] Mother meets her deceased daughter through VR technology *YouTube*. [Online]. Available at: <https://www.youtube.com/watch?v=uflTK8c4w0c> (Accessed: 2020).
- MBCLife (2020) [VR 휴먼다큐멘터리 - 너를 만났다] 세상 떠난 딸과 VR 로 재회한 모녀 | ‘엄마 안 울게. 그리워하지 않고 더 사랑할게’ (ENG/SPA subbed). [Online]. 6 February 2020. [www.youtube.com](https://www.youtube.com/watch?v=uflTK8c4w0c&list=PLFxvoUuf8_Ub8zQ1483GSaj8h0X9eII9I&index=1). Available at: https://www.youtube.com/watch?v=uflTK8c4w0c&list=PLFxvoUuf8_Ub8zQ1483GSaj8h0X9eII9I&index=1 (Accessed: 6 February 2020).
- McVay, D. (2024) *South Korea: Health System Coverage and Costs for Consumers*. [Online]. 9 April 2024. World Health Systems Facts. Available at:

- <https://healthsystemsfacts.org/national-health-systems/national-health-insurance/south-korea/south-korea-health-system-coverage-and-costs-for-consumers/>.
- Mele, C. (2013) Tissue Engineering With Stem Cells: An Innovative Technological Treatment in Pediatrics Disorders. *Journal of Pediatric Nursing*. [Online] 28 (5), 504–507. Available at: doi:<https://doi.org/10.1016/j.pedn.2013.07.002> (Accessed: 15 September 2020).
 - Merriam, S.B. and Tisdell, E.J. (2016) *Qualitative research: A guide to design and implementation*. 4th edition. San Francisco, Ca, Jossey-Bass, Cop.
 - Methley, A.M., Campbell, S., Chew-Graham, C., McNally, R., et al. (2014) PICO, PICOS and SPIDER: a Comparison Study of Specificity and Sensitivity in Three Search Tools for Qualitative Systematic Reviews. *BMC Health Services Research*. [Online] 14 (1). Available at: doi:<https://doi.org/10.1186/s12913-014-0579-0>.
 - Miller, D.T., Turnbull, W. and McFarland, C. (1990) *Counterfactual Thinking and Social Perception: Thinking about What Might Have Been*. [Online]. 1 January 1990. ScienceDirect. Available at: <https://www.sciencedirect.com/science/article/pii/S0065260108603226>.
 - Miller, M.D., Marty, M.A., Arcus, A., Brown, J., et al. (2002) Differences Between Children and Adults: Implications for Risk Assessment at California EPA. *International Journal of Toxicology*. [Online] 21 (5), 403–418. Available at: doi:<https://doi.org/10.1080/10915810290096630> (Accessed: 17 April 2020).
 - Milstein, J. (2005) A Paradigm of Integrative Care: Healing with Curing Throughout Life, ‘Being with’ and ‘Doing to’. *Journal of Perinatology*. [Online] 25 (9), 563–568. Available at: doi:<https://doi.org/10.1038/sj.jp.7211358> (Accessed: 9 May 2021).
 - Min, S.-K., Lee, J.-S. and Han, J.-O. (1997) A Psychiatric Study on Hahn. *Journal of Korean Neuropsychiatric Association*. [Online] 603–611. Available at: <https://pesquisa.bvsalud.org/portal/resource/pt/wpr-98389> (Accessed: 7 March 2023).
 - Mishler, E.G. (1986) ‘The analysis of interview-narratives’ *Narrative psychology: The storied nature of human conduct*. T. R. Sarbin (ed.). [Online]. Praeger Publishers/Greenwood Publishing Group. Available at: <https://psycnet.apa.org/record/2001-18244-012>.
 - Mitchell, G. (2008) *Palliative care: a patient-centered approach*. Oxford, Radcliffe.
 - Mohanti, B. and Kaur, J. (2011) Transition from curative to palliative care in cancer. *Indian Journal of Palliative Care*. [Online] 17 (1), 1. Available at: doi:<https://doi.org/10.4103/0973-1075.78442> (Accessed: 6 August 2020).
 - Monroe, B. and Oliviere, D. (2003) *Patient Participation in Palliative Care*. OUP Oxford.

- Montreuil, M. and Carnevale, F.A. (2016) A concept analysis of children's agency within the health literature. *Journal of Child Health Care*. [Online] 20 (4), 503–511. Available at: doi:<https://doi.org/10.1177/1367493515620914> (Accessed: 5 December 2019).
- Morgaine, K. and Moshoula Capous-Desyllas (2014) *Anti-oppressive social work practice : putting theory into action*. Thousand Oaks, Sage Publications, Inc.
- Morse, J.M. (2001) Using Shadowed Data. *Qualitative Health Research*. [Online] 11 (3), 291–292. Available at: doi:<https://doi.org/10.1177/104973201129119091> (Accessed: 25 October 2021).
- Morse, J.M., Barrett, M., Mayan, M., Olson, K., et al. (2002) Verification Strategies for Establishing Reliability and Validity in Qualitative Research. *International Journal of Qualitative Methods*. [Online] 1 (2), 13–22. Available at: doi:<https://doi.org/10.1177/160940690200100202>.
- Mullaly, R.P. (2018) *Challenging oppression and confronting privilege : a critical approach to anti-oppressive and anti-privilege theory and practice*. Oxford University Press.
- Nagel, T. (2012) *Mortal Questions (Canto Classics)*. [Online]. Cambridge University Press. Available at: [https://books.google.co.uk/books?id=pSfbnl-E5QgC&printsec=frontcover&dq=Nagel+\(1979\)+luck&hl=ko&sa=X&redir_esc=y#v=onepage&q&f=false](https://books.google.co.uk/books?id=pSfbnl-E5QgC&printsec=frontcover&dq=Nagel+(1979)+luck&hl=ko&sa=X&redir_esc=y#v=onepage&q&f=false) (Accessed: 27 February 2023).
- National Cancer Centre (2021) 국립암센터. [Online]. 2021. Ncc.re.kr. Available at: https://www.ncc.re.kr/main.ncc?uri=manage01_1 (Accessed: 7 March 2023).
- National Hospice Centre (2022) 공지사항 > 열린광장 > 중앙호스피스센터. [Online]. 2022. Hospice.go.kr. Available at: <https://hospice.go.kr:8444/index.html?menuno=36&bbsno=481&boardno=8&ztag=rO0ABXQANzxjYWxsIHR5cGU9ImJvYXJkIiBubz0iOCIGc2tpbj0iaG9zcGljZV9ub3JtYWwiPjwvY2FsbD4%3D&siten=1&act=view> (Accessed: 7 March 2023).
- Navarro, V. (2007) *Neoliberalism, Globalization, and Inequalities*. Routledge.
- Ng, A.S., Dodd, H.F., Gamble, A.L. and Hudson, J.L. (2012) The Relationship Between Parent and Child Dysfunctional Beliefs About Sleep and Child Sleep. *Journal of Child and Family Studies*. [Online] 22 (6), 827–835. Available at: doi:<https://doi.org/10.1007/s10826-012-9637-6> (Accessed: 5 October 2021).
- Nimalan, D., Kawka, M., Erridge, S., Ergisi, M., et al. (2022) UK Medical Cannabis Registry palliative care patients cohort: initial experience and outcomes. *Journal of Cannabis*

- Research*. [Online] 4 (1). Available at: doi:<https://doi.org/10.1186/s42238-021-00114-9> (Accessed: 16 January 2022).
- Nuclear Safety and Security Commission (NSSC) (2018) *원자력안전위원회 매인*. [Online]. 2018. www.nssc.go.kr. Available at: <https://www.nssc.go.kr/> (Accessed: 3 March 2023).
 - 뉴스 J. (2020) *아픈 아이 낳은 반도체 노동자들... ‘엄마가 미안해’* “Semiconductor workers who gave birth to sick children...” ‘Mom is sorry’. [Online]. 16 July 2020. news.jtbc.co.kr. Available at: https://news.jtbc.co.kr/article/article.aspx?news_id=NB11959968 (Accessed: 4 March 2023).
 - Nzira, V. and Williams, P. (2009) *Anti-oppressive practice in health and social care*. Los Angeles, Sage.
 - O’Campo, P. and Dunn, J.R. (2011) *Rethinking Social Epidemiology: Towards a Science of Change*. [Online]. Springer Science & Business Media. Available at: [https://books.google.com/books?hl=en&lr=&id=LqV0YeIrGY0C&oi=fnd&pg=PR3&dq=Patricia+O%E2%80%9999Campo+and+James+R.+Dunn+\(201&ots=xn0b2P4mkW&sig=WEoi9LQKXSlaOQYHWWX4g7cqFE](https://books.google.com/books?hl=en&lr=&id=LqV0YeIrGY0C&oi=fnd&pg=PR3&dq=Patricia+O%E2%80%9999Campo+and+James+R.+Dunn+(201&ots=xn0b2P4mkW&sig=WEoi9LQKXSlaOQYHWWX4g7cqFE) (Accessed: 1 March 2023).
 - OH SEUNG HOON (2007) The Personal knowledge of M. Polanyi and Virtue Epistemology. *Studies in Philosophy East-West*. [Online] null (45), 223–245. Available at: doi:<https://doi.org/10.15841/kspew.45.200709.223> (Accessed: 26 August 2020).
 - Oh, J., Lee, J.-S., Choi, Y.-J., Park, H.-K., et al. (2011) Struggle against privatization: a case history in the use of comparative performance evaluation of public hospitals. *International Journal of Health Services: Planning, Administration, Evaluation*. [Online] 41 (2), 371–388. Available at: doi:<https://doi.org/10.2190/HS.41.2.j> (Accessed: 25 February 2022).
 - Oh, M. and Ardit, J. (2009) Self-Cultivation as a Microphysics of Reverence: Toward a Foucauldian Understanding of Korean Culture. *Philosophy East and West*. [Online] 60 (1), 20–39. Available at: doi:<https://doi.org/10.1353/pew.0.0094> (Accessed: 12 January 2020).
 - Oh, S. (2012) *Analysis of the Concept of Belief in Michael Polanyi*. [Online]. 2012. 학술논문검색사이트 KISS. Available at: <https://kiss.kstudy.com/Detail/Ar?key=3132391> (Accessed: 28 February 2023).
 - Oh, S. (2008) 레비나스의 타자개념과 대리인의 사후 장기기증 Levinas’s concept of the other and cadaveric organ donation for other directions. *Korean Society For Phenomenology*.

- [Online] 38157–188. Available at:
<https://www.dbpia.co.kr/journal/articleDetail?nodeId=NODE01059970> (Accessed: 28 February 2023).
- Oh, S. (2005) 레비나스의 타자개념과 사전의사결정 Levinas's concept of the Other and Advance Directives. *Korean Society of Hospice Care*. (7)213–244.
 - Oh, S.-M., Lee, H.-J., Kim, G.-S. and Park, K.-D. (2013) Factors Affecting Social Adjustment of Childhood Cancer Survivors. *Child Health Nursing Research*. [Online] 19 (3), 238. Available at: doi:<https://doi.org/10.4094/chnr.2013.19.3.238> (Accessed: 1 March 2021).
 - Olesen, T. (2005) *International Zapatismo: The Construction of Solidarity in the Age of Globalization*. Zed Books.
 - Oliviere, D., Monroe, B. and Payne, S. (2011) *Death, dying, and social differences*. Oxford; New York, Oxford University Press.
 - Orasanu, J., Martin, L., Davison, J. and Null, C.H. (1998) *Errors in Aviation Decision Making: Bad Decisions or Bad Luck?* [Online]. 1 January 1998. ntrs.nasa.gov. Available at: <https://ntrs.nasa.gov/citations/20020063485> (Accessed: 27 February 2023).
 - Pandita, S. (2019) Building Environmental Health Movement in Asia: Lessons from Korea. *J Environ Health Sci*. [Online] 45 (4), 400–404. Available at: doi:<https://doi.org/10.5668/JEHS.2019.45.4.400> (Accessed: 24 February 2023).
 - Park, C.-W. (2010) Funerary transformations in contemporary South Korea. *Mortality*. [Online] 15 (1), 18–37. Available at: doi:<https://doi.org/10.1080/13576270903537559> (Accessed: 26 February 2020).
 - Park, J.J., Yang, S.-K., Ye, B.D., Kim, J.W., et al. (2017) Second Korean Guidelines for the Management of Crohn's Disease. *The Korean Journal of Gastroenterology*. [Online] 69 (1), 29. Available at: doi:<https://doi.org/10.4166/kjg.2017.69.1.29> (Accessed: 21 March 2023).
 - Park, S. and Shin, S. (2016) *아이가 아프면 모두가 아프다 'When a child is sick, everyone is sick.'* 2016.
 - Parker Oliver, D., Washington, K., Demiris, G., Wittenberg-Lyles, E., et al. (2012) Problem Solving Interventions: An Opportunity for Hospice Social Workers to Better Meet Caregiver Needs. *Journal of Social Work in End-Of-Life & Palliative Care*. [Online] 8 (1), 3–9. Available at: doi:<https://doi.org/10.1080/15524256.2012.650669> (Accessed: 18 February 2020).

- Patrick, D.L. and Deyo, R.A. (1989) Generic and Disease-Specific Measures in Assessing Health Status and Quality of Life. *Medical Care*. [Online] 27 (3), S217–S232. Available at: https://www.jstor.org/stable/3765666?casa_token=y0kLIAMmeq4AAAAA:UwDwhcLI84TWWy9YXWm3KWAmrEZE1VXdJileDPDY5SGn4R3CcXei8RYQpChFV8CCv6n1N1-joKsJqk9iGZxfn07wsU4lq7x9aPgLaA30td_H2qLBJg4 (Accessed: 1 March 2023).
- Patton, M.Q. (2002) *Qualitative Research and Evaluation Methods*. 3rd edition. Thousand Oaks, Calif., Sage Publications.
- Paul, S. (2019) Is Death Taboo for Children? Developing Death Ambivalence as a Theoretical Framework to Understand Children’s Relationship with Death, Dying and Bereavement. *Children & Society*. [Online] 33 (6). Available at: doi:<https://doi.org/10.1111/chso.12352>.
- Payne, M. (2010) Inequalities, end-of-life care and social work. *Progress in Palliative Care*. [Online] 18 (4), 221–227. Available at: doi:<https://doi.org/10.1179/096992610x12624290277187> (Accessed: 4 January 2021).
- Payne, M. (2006) *What is professional social work?* Bristol, Policy.
- Perpich, D. (2008) *The ethics of Emmanuel Levinas*. Stanford, Calif., Stanford University Press.
- Petr, C.G. (2008) *Multidimensional Evidence-Based Practice Synthesizing Knowledge, Research, and Values*. Routledge.
- Pfund, R. (2007) *Palliative care nursing of children and young people*. Oxford; Seattle, Radcliffe.
- Phil Francis Carspecken (1996) *Critical ethnography in educational research: a theoretical and practical guide*. New York; London, Routledge, Cop.
- Polanyi, M. (1948) *Full Employment and Free Trade*. Cambridge.
- Polanyi, M. (1969) *Knowing and Being*. Routledge & Kegan Paul Books.
- Polanyi, M. (2012) *Personal Knowledge*. Routledge.
- Polanyi, M. (2017) *Society, Economics, and Philosophy*. Routledge.
- Polanyi, M. (1940) *The Contempt of Freedom*. Watts & Company.
- Polanyi, M. (2010) *The logic of liberty: reflections and rejoinders*. London, Routledge, Imp.
- Polanyi, M. (2013) *The tacit dimension*. Chicago, Ill, The University Of Chicago Press.
- Pollack, H.N. (2005) *Uncertain Science ... Uncertain World*. Cambridge University Press.
- Popejoy, E., Almack, K., Manning, J.C., Johnston, B., et al. (2021) Communication strategies and persuasion as core components of shared decision-making for children with life-limiting

- conditions: A multiple case study. *Palliative Medicine*. [Online] 36 (3), 026921632110689. Available at: doi:<https://doi.org/10.1177/02692163211068997> (Accessed: 18 February 2022).
- Popper, K.R. (1979) *Objective knowledge an evolutionary approach*. Oxford Clarendon Pr.
 - Post, S.G. (2004) *Encyclopedia of Bioethics, 3rd edition*. Stephen G. Post (ed.). MacMillan Reference.
 - Postier, A., Catrine, K. and Remke, S. (2018) Interdisciplinary Pediatric Palliative Care Team Involvement in Compassionate Extubation at Home: From Shared Decision-Making to Bereavement. *Children*. [Online] 5 (3), 37. Available at: doi:<https://doi.org/10.3390/children5030037> (Accessed: 24 August 2019).
 - Pran Tiku (2008) *Six Sizzling Markets*. John Wiley & Sons.
 - Price, J. and Mcneilly, P. (2009) *Palliative care for children and families: an interdisciplinary approach*. Basingstoke; New York, Palgrave Macmillan.
 - Pritchard, D. (2011) *Epistemic luck*. New York, Oxford University Press.
 - Pritchard, D. and Smith, M. (2004) The psychology and philosophy of luck. *New Ideas in Psychology*. [Online] 22 (1), 1–28. Available at: doi:<https://doi.org/10.1016/j.newideapsych.2004.03.001>.
 - Puybaret, E. and United Nations. General Assembly (2008) *Universal declaration of human rights*. Paris, United Nations.
 - Rawls, J. and Kelly, E. (2001) *Justice as fairness: a restatement*. Cambridge, Mass., Harvard University Press.
 - Reeves, S., Kuper, A. and Hodges, B.D. (2008) Qualitative research methodologies: ethnography. *BMJ*. [Online] 337a1020–a1020. Available at: doi:<https://doi.org/10.1136/bmj.a1020>.
 - Reith, M. and Payne, M. (2009) *Social work in end-of-life and palliative care*. Chicago, Ill, Lyceum Books.
 - Resnik, D.B. and Kennedy, C.E. (2010) Balancing Scientific and Community Interests in Community-Based Participatory Research. *Accountability in Research*. [Online] 17 (4), 198–210. Available at: doi:<https://doi.org/10.1080/08989621.2010.493095> (Accessed: 15 May 2019).
 - Rhee, J.-C. (2002) *The State and Industry in South Korea*. Routledge.
 - Richard Gerald Wilkinson (2005) *The impact of inequality: how to make sick societies healthier*. Abingdon, Routledge, Impr., Cop.

- Roeland, E., Cain, J., Onderdonk, C., Kerr, K., et al. (2014) When Open-Ended Questions Don't Work: The Role of Palliative Paternalism in Difficult Medical Decisions. *Journal of Palliative Medicine*. [Online] 17 (4), 415–420. Available at: doi:<https://doi.org/10.1089/jpm.2013.0408>.
- Rogers, J., Brooks, L., Aizelwood, L. and Kaehne, A. (2018) The 10 Steps Transition Pathway: Improving Transition for Children in Hospital Settings. *INTERNATIONAL JOURNAL OF NURSING*. [Online] 5 (2). Available at: doi:<https://doi.org/10.15640/ijn.v5n2a1> (Accessed: 26 March 2020).
- Rost, M., Wangmo, T., Niggli, F., Hartmann, K., et al. (2017) Parents' and Physicians' Perceptions of Children's Participation in Decision-making in Paediatric Oncology: A Quantitative Study. *Journal of Bioethical Inquiry*. [Online] 14 (4), 555–565. Available at: doi:<https://doi.org/10.1007/s11673-017-9813-x> (Accessed: 15 December 2022).
- Roumbanis, L. (2019) *Blind luck - could lotteries be a more efficient mechanism for allocating research funds than peer review?* [Online]. 11 December 2019. Impact of Social Sciences Blog. Available at: <https://eprints.lse.ac.uk/103417/> (Accessed: 27 February 2023).
- Rózsa, S. (2021) Introducing the brief version of the Dysfunctional Attitude Scale (DAS-14) based on a large clinical sample. *Mentálhigiéné és Pszichoszomatika*. [Online] 22 (4), 395–417. Available at: doi:<https://doi.org/10.1556/0406.22.2021.014> (Accessed: 8 January 2022).
- Rycroft-Malone, J. and Bucknall, T. (2010) *Models and frameworks for implementing evidence-based practice : linking evidence to action*. Chichester, Wiley-Blackwell.
- Ryu, S., Park, D., Lee, E., Park, S., et al. (2019) Humidifier disinfectant and use characteristics associated with lung injury in Korea. *Indoor Air*. [Online] 29 (5), 735–747. Available at: doi:<https://doi.org/10.1111/ina.12585> (Accessed: 10 March 2022).
- Sackett, D.L., Rosenberg, W.M.C., Gray, J.A.M., Haynes, R.B., et al. (1996) Evidence based medicine: what it is and what it isn't. *BMJ*. [Online] 312 (7023), 71–72. Available at: doi:<https://doi.org/10.1136/bmj.312.7023.71>.
- Salmon, A. (2017) *Was Park Chung-hee a dictator?* [Online]. 31 July 2017. koreatimes. Available at: http://www.koreatimes.co.kr/www/opinion/2018/09/351_233945.html (Accessed: 23 February 2023).
- Sandra Bartlett (2019) *'Let me die with my mother': Samsung to compensate sick workers, but many will never recover* | *CBC Radio*. [Online]. 29 January 2019. CBC. Available at: <https://www.cbc.ca/radio/thecurrent/the-current-for-january-29-2019-1.4995965/let-me-die->

- [with-my-mother-samsung-to-compensate-sick-workers-but-many-will-never-recover-1.4996212](#).
- Santoro, J. and Bennett, M. (2018) Ethics of End of Life Decisions in Pediatrics: A Narrative Review of the Roles of Caregivers, Shared Decision-Making, and Patient Centered Values. *Behavioral Sciences*. [Online] 8 (5), 42. Available at: doi:<https://doi.org/10.3390/bs8050042> (Accessed: 10 July 2019).
 - Schneiderman, L.J. (2011) Defining Medical Futility and Improving Medical Care. *Journal of Bioethical Inquiry*. [Online] 8 (2). Available at: doi:<https://doi.org/10.1007/s11673-011-9293-3>.
 - Schneidewind, D.K. (2016) *Economic Miracle Market South Korea: A Blueprint for Economic Growth in Developing Nations*. Singapore, Springer Singapore.
 - Seo, E.K. (2013) Diagnosis and Treatment of Moyamoya Disease. *The Ewha Medical Journal*. [Online] 36 (1), 9. Available at: doi:<https://doi.org/10.12771/emj.2013.36.1.9>.
 - Seo, S., Ha, W.-H., Kang, J.-K., Lee, D., et al. (2019) Health effects of exposure to radon: implications of the radon bed mattress incident in Korea. *Epidemiology and Health*. [Online] 41e2019004. Available at: doi:<https://doi.org/10.4178/epih.e2019004> (Accessed: 14 November 2020).
 - Seo, S., Kang, J.-K., Lee, D. and Jin, Y.W. (2019) Health effects and consultations about radon exposure. *Journal of the Korean Medical Association*. [Online] 62 (7), 376. Available at: doi:<https://doi.org/10.5124/jkma.2019.62.7.376> (Accessed: 10 May 2022).
 - Seong-Soon Kwak (2024) *의료사고처리특례 앞서 ‘의료분쟁 조정제도’ 혁신나선 政*. [Online]. 11 July 2024. 청년의사. Available at: <https://www.docdocdoc.co.kr/news/articleView.html?idxno=3019061> (Accessed: 11 September 2024).
 - Shim, H.-Y. and Chang, Y.-J. (2015) Development of e-learning Education Programs for Social Workers in Hospice and Palliative Care. *The Korean Journal of Hospice and Palliative Care*. [Online] 18 (1), 9–15. Available at: doi:<https://doi.org/10.14475/kjhpc.2015.18.1.9> (Accessed: 10 December 2019).
 - Shin, Y.-C., Son, B.-H., Hong, W.-H. and Lee, J.-S. (2008) A Study on the Estimation about Amount of the Amelioration Districts for Optimum Process of Designated Wastes. *Proceeding of Spring/Autumn Annual Conference of KHA*. [Online] 285–290. Available at: <https://koreascience.kr/article/CFKO200810335353263.page> (Accessed: 4 March 2023).

- Silvermint, D. (2018) Resisting for other reasons. *Canadian Journal of Philosophy*. [Online] 48 (1), 18–42. Available at: doi:<https://doi.org/10.1080/00455091.2017.1332257> (Accessed: 6 March 2020).
- Smith, L.C. and Shin, R.Q. (2015) Negotiating the Intersection of Racial Oppression and Heteronormativity. *Journal of Homosexuality*. [Online] 62 (11), 1459–1484. Available at: doi:<https://doi.org/10.1080/00918369.2015.1073029> (Accessed: 20 March 2020).
- Smith, R. (2009) *A Universal Child?* Palgrave Macmillan.
- Smith, R. (2008a) *Social work and power*. Basingstoke; New York, Palgrave Macmillan, Cop.
- Smith, R. (2008b) *Social Work with Young People*. John Wiley & Sons.
- Smith, R. (2010) Social work, risk, power. *Sociological Research Online*. 15 (1), 37–46.
- Smith, R. (2004) *Values and Practice in Children's Services*. Bloomsbury Publishing.
- Smith, S., Mitchell, C. and Bowler, S. (2008) Standard versus patient-centred asthma education in the emergency department: a randomised study. *European Respiratory Journal*. [Online] 31 (5), 990–997. Available at: doi:<https://doi.org/10.1183/09031936.00053107> (Accessed: 5 August 2022).
- Smith, T., David Allan Sonnenfeld, Pellow, D.N. and Al, E. (2006) *Challenging the chip : labor rights and environmental justice in the global electronics industry*. Philadelphia, Temple University Press, Cop.
- Smith, V., Oppression, and Resistance Struggles Trevor William (2015) *Virtue, Oppression, and Resistance Struggles*. [Online]. Available at: https://epublications.marquette.edu/dissertations_mu/551/ (Accessed: 22 February 2023).
- social disasters commission (2022) *사회/적참사특별조사위원회 가습기살균제 분야(1) 종합보고서(6 권)*. [Online]. 2022. Available at: http://eco-health.org/bbs/board.php?bo_table=sub02_04&wr_id=415 (Accessed: 3 March 2023).
- Song , S. (2018a) *Big-5 hospitals dominate patient care*. [Online]. 14 March 2018. KBR. Available at: <https://www.koreabiomed.com/news/articleView.html?idxno=2778>.
- Song , S. (2018b) *Neonatal intensive care units in dire state*. [Online]. 1 February 2018. KBR. Available at: <https://www.koreabiomed.com/news/articleView.html?idxno=2482> (Accessed: 6 March 2023).

- Statman, D. (1991) MORAL AND EPISTEMIC LUCK. *Ratio*. [Online] 4 (2), 146–156. Available at: doi:<https://doi.org/10.1111/j.1467-9329.1991.tb00036.x> (Accessed: 21 February 2020).
- Stevens, S.S. (1946) On the Theory of Scales of Measurement. *Science*. [Online] 103 (2684), 677–680. Available at: doi:<https://doi.org/10.1126/science.103.2684.677>.
- Supporters for Health and Right of People in Semiconductor Industry (SHARPS) (2023) [22.11.28.] 제대로 된 태아산재법 시행령 촉구 기자회견: 반올림 논평 및 자료 ‘[11/28/22] Press Conference Urging for Proper Enforcement Decree on Fetal Occupational Disease Law: Commentary and Materials by SHARPS.’ [Online]. 30 January 2023. sharps.or.kr. Available at: <https://sharps.or.kr/statement/?q=YToxOntzOjEyOiJrZXI3b3JkX3R5cGUiO3M6MzoiYWxsIjt9&bmode=view&idx=14096339&t=board> (Accessed: 4 March 2023).
- Tahmasebi-Birgani, V. (2014) *Emmanuel Levinas and the politics of non-violence*. Toronto, University Of Toronto Press.
- Tatterton, M., Honour, A., Billington, D., Kirkby, L., et al. (2022) Care after death in children’s hospices: recommendations for moving and handling, and for managing physiological deterioration. *Nursing Children and Young People*. [Online] 34 (5). Available at: doi:<https://doi.org/10.7748/ncyp.2022.e1412> (Accessed: 17 March 2022).
- Taylor, B. (2013) *Professional Decision Making and Risk in Social Work*. London, Sage Publications.
- the Association of Palliative Care Social Workers (2016) *The role of social workers in palliative, end of life and bereavement care Association of Palliative Care Social Workers in collaboration with the former College of Social Work and Making Waves Lived Experience Network/OPEN FUTURES Research, with support from the British Association of Social Workers and Hospice UK* [Online]. Available at: <https://www.apcsw.org.uk/wp-content/uploads/2016/03/The-Role-of-social-workers-in-palliative-end-of-life-and-bereavement-care.pdf>.
- The International Federation of Social Workers (IFSW) (2015) *The BASW Code of Ethics for Social Work* [Online]. Available at: https://www.basw.co.uk/system/files/resources/basw_code_of_ethics_-_2021.pdf#:~:text=Social%20workers%20have%20a%20responsibility%20to%20challenge%20oppression (Accessed: 7 March 2023).

- the Korea Legislation Research Institute (2013) *Statutes of the Republic of Korea*. [Online]. 2013. elaw.klri.re.kr. Available at: https://elaw.klri.re.kr/eng_mobile/viewer.do?hseq=29060&type=part&key=36#:~:text=Recovery%20and%20a%20transplant%20of%20organs%2C%20etc.%20shall (Accessed: 6 March 2023).
- the Nuclear Safety and Security Commission (2020) *Nuclear Safety and Security Commission News > Press Releases*. [Online]. 7 April 2020. www.nssc.go.kr. Available at: https://www.nssc.go.kr/en/cms/FR_BBS_CON/BoardView.do?MENU_ID=90&CONTENTS_NO=1&SITE_NO=3&BOARD_SEQ=1&BBS_SEQ=45914 (Accessed: 30 March 2023).
- the Nuclear Safety and Security Commission (2018) *원자력안전위원회 알림마당 > 보도자료*. [Online]. 10 May 2018. www.nssc.go.kr. Available at: https://www.nssc.go.kr/ko/cms/FR_BBS_CON/BoardView.do?SITE_NO=2&BOARD_SEQ=5&BBS_SEQ=44238&MENU_ID=190&CONTENTS_NO= (Accessed: 30 April 2024).
- Thomas, J. (1993) *Doing critical ethnography*. Newbury Park, Calif., Sage.
- Thomas, K., Lobo, B. and Detering, K. (2018) *Advance care planning in end of life care*. Oxford, United Kingdom, Oxford University Press.
- Thompson, N. (2003) *Promoting Equality*. Jo Campling (ed.). [Online]. London, Macmillan Education UK. Available at: doi:<https://doi.org/10.1007/978-0-230-21647-1>.
- Thompson, N. (2016) *The professional social worker: meeting the challenge*. London, Palgrave/Macmillan Education.
- Together for Short Lives (2013) *A Core Care Pathway for Children with Life-limiting and Life-threatening Conditions*. [Online]. 28 February 2013. www.basw.co.uk. Available at: <https://www.basw.co.uk/resources/core-care-pathway-children-life-limiting-and-life-threatening-conditions> (Accessed: 4 April 2022).
- Tomlinson, A. (2004) Pierre Bourdieu and the Sociological Study of Sport: Habitus, Capital and Field. *Sport and Modern Social Theorists*. [Online] 161–172. Available at: doi:https://doi.org/10.1057/9780230523180_11.
- Tomlinson, D., Bartels, U., Hendershot, E., Constantin, J., et al. (2007) Challenges to participation in paediatric palliative care research: a review of the literature. *Palliative Medicine*. [Online] 21 (5), 435–440. Available at: doi:<https://doi.org/10.1177/0269216307077173> (Accessed: 27 November 2020).

- Topolski, A. (2014) Relationality as a ‘Foundation’ for Human Rights: Exploring the Paradox with Hannah Arendt and Emmanuel Levinas. *Theoria and Praxis: International Journal of Interdisciplinary Thought*. [Online] 2 (1). Available at: <https://theoriandpraxis.journals.yorku.ca/index.php/theoriandpraxis/article/view/39373> (Accessed: 1 March 2023).
- Torke, A.M., Alexander, G.C. and Lantos, J. (2008) Substituted Judgment: The Limitations of Autonomy in Surrogate Decision Making. *Journal of General Internal Medicine*. [Online] 23 (9), 1514–1517. Available at: doi:<https://doi.org/10.1007/s11606-008-0688-8> (Accessed: 24 October 2019).
- Towle, A., Godolphin, W., Grams, G. and LaMarre, A. (2006) Putting informed and shared decision making into practice. *Health Expectations*. [Online] 9 (4), 321–332. Available at: doi:<https://doi.org/10.1111/j.1369-7625.2006.00404.x>.
- Trachsel, M., Mitchell, C. and Biller-Andorno, N. (2013) Decision-making incapacity at the end of life: conceptual and ethical challenges. *Bioethica Forum*. [Online] 6 (1). Available at: doi:<https://doi.org/10.24894/bf.2013.06007> (Accessed: 13 October 2021).
- Tricco, A.C., Lillie, E., Zarin, W., O’Brien, K.K., et al. (2018) PRISMA extension for scoping reviews (PRISMA-ScR): Checklist and explanation. *Annals of Internal Medicine*. [Online] 169 (7), 467–473. Available at: doi:<https://doi.org/10.7326/m18-0850>.
- Tsai, A.C., Kohrt, B.A., Matthews, L.T., Betancourt, T.S., et al. (2016) Promises and pitfalls of data sharing in qualitative research. *Social Science & Medicine*. [Online] 10 (8), 191–198. Available at: doi:<https://doi.org/10.1016/j.socscimed.2016.08.004>.
- Tudor, D. (2012) *Korea : the impossible country*. Tuttle Pub, Rutland, Vt.
- Ugwudike, P. (2016) Understanding Compliance Dynamics in Community Justice Settings. *International Criminal Justice Review*. [Online] 27 (1), 40–59. Available at: doi:<https://doi.org/10.1177/1057567716679231> (Accessed: 16 October 2019).
- UNICEF (1989) *UN Convention on the Rights of the Child (UNCRC)* - Unicef UK. [Online]. 1989. UNICEF. Available at: <https://www.unicef.org.uk/what-we-do/un-convention-child-rights/> (Accessed: 24 February 2023).
- Valdez-Martinez, E., Noyes, J. and Bedolla, M. (2014) When to stop? Decision-making when children’s cancer treatment is no longer curative: a mixed-method systematic review. *BMC Pediatrics*. [Online] 14 (1). Available at: doi:<https://doi.org/10.1186/1471-2431-14-124> (Accessed: 4 May 2020).

- van de Poel, I. and Zwart, S.D. (2009) Reflective Equilibrium in R & D Networks. *Science, Technology, & Human Values*. [Online] 35 (2), 174–199. Available at: doi:<https://doi.org/10.1177/0162243909340272> (Accessed: 23 June 2019).
- Vig, E.K., Taylor, J.S., Starks, H., Hopley, E.K., et al. (2006) Beyond Substituted Judgment: How Surrogates Navigate End-of-Life Decision-Making. *Journal of the American Geriatrics Society*. [Online] 54 (11), 1688–1693. Available at: doi:<https://doi.org/10.1111/j.1532-5415.2006.00911.x> (Accessed: 19 November 2020).
- Villanueva, G., Murphy, M.S., Vickers, D., Harrop, E., et al. (2016) End of life care for infants, children and young people with life limiting conditions: summary of NICE guidance. *BMJ*. [Online] 335i6385. Available at: doi:<https://doi.org/10.1136/bmj.i6385> (Accessed: 28 March 2019).
- Viswambharan, A.P. and Priya, K.R. (2015) Documentary analysis as a qualitative methodology to explore disaster mental health: insights from analysing a documentary on communal riots. *Qualitative Research*. [Online] 16 (1), 43–59. Available at: doi:<https://doi.org/10.1177/1468794114567494> (Accessed: 15 February 2020).
- Welsh, A. (1994) *Freud's Wishful Dream Book*. Princeton University Press.
- Wgenaar, W.A. and Kerenm, G.B. (1988) Cance and luck are not the same. *Journal of Behavioral Decision Making*. [Online] 1 (2), 65–75. Available at: doi:<https://doi.org/10.1002/bdm.3960010202> (Accessed: 3 November 2021).
- White, D.B., Jonsen, A. and Lo, B. (2012) Ethical Challenge: When Clinicians Act as Surrogates for Unrepresented Patients. *American Journal of Critical Care*. [Online] 21 (3), 202–207. Available at: doi:<https://doi.org/10.4037/ajcc2012514> (Accessed: 21 May 2021).
- White, H.C., Bourdieu, P. and Emanuel, S. (1997) The Rules of Art: Genesis and Structure of the Literary Field. *Contemporary Sociology*. [Online] 26 (5), 638. Available at: doi:<https://doi.org/10.2307/2655669> (Accessed: 18 November 2019).
- Widdas, D., Street, B., Edwards, F. and McNamara, K. (2013) A core care pathway for children with life-limiting and life-threatening conditions. *Together for Short Lives*. [Online] Available at: <https://www.togetherforshortlives.org.uk/resource/core-care-pathway/>.
- Wilkinson, D.J.C. and Truog, R.D. (2013) The luck of the draw: physician-related variability in end-of-life decision-making in intensive care. *Intensive Care Medicine*. [Online] 39 (6), 1128–1132. Available at: doi:<https://doi.org/10.1007/s00134-013-2871-6> (Accessed: 30 September 2020).

- Wilkinson, R.G. (2008) *평등해야 건강하다: 불평등이 어떻게 사회를 병들게 하는가*/. 후마니타스.
- William Paul Simmons (2011) *Human rights law and the marginalized other*. New York, Cambridge University Press.
- Wong, G., Derthick, A.O., David, E.J.R., Saw, A., et al. (2013) The What, the Why, and the How: A Review of Racial Microaggressions Research in Psychology. *Race and Social Problems*. [Online] 6 (2), 181–200. Available at: doi:<https://doi.org/10.1007/s12552-013-9107-9>.
- World Health Organization (2020) *Palliative care*. [Online]. 5 August 2020. World Health Organization. Available at: <https://www.who.int/news-room/fact-sheets/detail/palliative-care> (Accessed: 26 February 2023).
- World Health Organization (2022) *Social Determinants of Health*. [Online]. 2022. World Health Organisation . Available at: https://www.who.int/health-topics/social-determinants-of-health#tab=tab_1 (Accessed: 28 February 2023).
- Worley, J. and Hall, J.M. (2012) Doctor Shopping: A Concept Analysis. *Research and Theory for Nursing Practice*. [Online] 26 (4), 262–278. Available at: doi:<https://doi.org/10.1891/1541-6577.26.4.262> (Accessed: 28 January 2021).
- Wright, A.A., Keating, N.L., Ayanian, J.Z., Chrischilles, E.A., et al. (2016) Family Perspectives on Aggressive Cancer Care Near the End of Life. *JAMA*. [Online] 315 (3), 284. Available at: doi:<https://doi.org/10.1001/jama.2015.18604> (Accessed: 17 October 2019).
- Wright, B., Aldridge, J., Wurr, K., Sloper, T., et al. (2009) Clinical dilemmas in children with life-limiting illnesses: decision making and the law. *Palliative Medicine*. [Online] 23 (3), 238–247. Available at: doi:<https://doi.org/10.1177/0269216308099958> (Accessed: 29 August 2020).
- Wu, F., Zhuang, Y., Chen, X., Wen, H., et al. (2020) Decision-making among the substitute decision makers in intensive care units: An investigation of decision control preferences and decisional conflicts. *Journal of Advanced Nursing*. [Online] 76 (9), 2323–2335. Available at: doi:<https://doi.org/10.1111/jan.14451>.
- Yadav, S. and Chakraborty, P. (2021) Child–smartphone interaction: relevance and positive and negative implications. *Universal Access in the Information Society*. [Online] 21. Available at: doi:<https://doi.org/10.1007/s10209-021-00807-1>.

- Yang, J.-H. (2016) A Comparative Analysis of Business Performance of University Hospitals for the Past 10 Years. *The Korean Journal of Health Service Management*. [Online] 10 (3), 13–25. Available at: doi:<https://doi.org/10.12811/kshsm.2016.10.3.013> (Accessed: 18 November 2021).
- Yang, S. and Kim, T. (2021) Derivation of the ‘Principles of Transboundary Crisis Communication’ Based on the Reinterpretation of the ‘Ten Best Practices of Crisis Communication’ - Focusing on the Radon Bed Case -위기 커뮤니케이션 원칙의 재해석에 기반한 ‘탈경계적 위기 커뮤니케이션 원칙’의 도출과 검증 - 라돈침대사태 사례에의 적용을 중심으로 -. *Crisisonomy*. [Online] 17 (5), 159–185. Available at: <https://www.dbpia.co.kr/Journal/articleDetail?nodeId=NODE10658206> (Accessed: 3 March 2023).
- Yin, R.K. (1999) Enhancing the quality of case studies in health services research. *Health services research*. [Online] 34 (5 Pt 2), 1209–1224. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1089060/>.
- Yoon, L. (2022) *South Korea: national health insurance total expenditure 2019*. [Online]. 20 December 2022. Statista. Available at: <https://www.statista.com/statistics/978817/south-korea-national-health-insurance-total-expenditure/>.
- Yoon, W. (2020) *서울대병원, 국내 최초 ‘어린이 완화의료센터’ 건립 추진*. [Online]. 29 October 2020. *청년 의사*. Available at: <http://www.docdocdoc.co.kr/news/articleView.html?idxno=2004296> (Accessed: 2 March 2023).
- Yüncü, V. and Fidan, Ü. (2019) Integrating Organizational Reputation Mechanism to Decision-Making Processes: Facebook Case. *Yönetim Bilimleri Dergisi*. [Online] 98 (Suppl 1). Available at: doi:<https://doi.org/10.35408/comuybd.425271> (Accessed: 10 December 2019).
- Yung, L.Y.Y. (2015) The East Asian Family-Oriented Principle and the Concept of Autonomy. *Philosophy and Medicine*. [Online] 107–121. Available at: doi:https://doi.org/10.1007/978-3-319-12120-8_7 (Accessed: 22 December 2022).

Appendix A: Publications associated with this research

Publications

1. Oh, seunghoon. (2012) "Analysis of the Concept of Belief in Michael Polanyi", *Korean Society of Christian Philosophy, Vol.15*: 57-89.
2. Oh, seunghoon. (2008) "Levinas Concept of the Other and Cadaveric Organ Donation for Other Directions", *Korean Society for Phenomenology, Vol.38*: 157-188.
3. Oh, seunghoon. (2007) "The Personal Knowledge of Michael Polanyi and Virtue Epistemology", *Korean Society for Philosophy East-West, Vol. 45*: 223-245.
4. Oh, seunghoon and Choi, taeyeon. (2005) "Levinas Concept of the Other and Advance Directives" *Christian Philosophy Vol. 04*: 213-244.

International Conference

1. "Anti-Oppressive Health Care and the Right to Know: Unveiling the Hidden Health Impacts of Social Determinants of Health" the World Cancer Congress 17 to 19, September, 2024 (Geneva, Switzerland)
2. "Multi-Dimensional Decision-Making: Navigating Challenges in Decision-Making for Children and Young People with Life-Limiting Conditions" the World Cancer Congress 17 to 19, September, 2024 (Geneva, Switzerland)
3. "Hidden Oppression, Silent Victims and Dying: The intersection of mismanaged hazardous substances and social determinants of health" as an Oral presentation *International conference "Death and Dying in the 21st Century: Interdisciplinary Perspectives"*, 18 –19th April 2024 (Durham, UK)
4. "Exploring Decision Processes for Children and Young People with Life-Limited Conditions" as an Oral presentation *the 13th World Research Congress of the European Association for Palliative Care*, 16-18 May 2024 (Barcelona, Spain).
5. "Navigating Structural Challenges in Decision-Making: A Study on Paediatric Palliative Care in Korea" as an e-poster *the 13th World Research Congress of the European Association for Palliative Care*, 16-18 May 2024 (Barcelona, Spain).
6. "Survivor and Bereavement Care are Following Biocide Disaster and the Role of Social Work" as an Oral presentation *the JCECC International Conference on Community End-of-Life Care: Sustainable Development and New Frontier to be held virtually on June 17-18, 2021*, (Hong Kong, China)
7. "Anti-Oppressive Health Care against the Disaster of Hazardous Substances" A poster presentation *the SWESD 2021* from June 28th to July 1st, 2021, (Rimini, Italy)
8. "Anti-Oppressive Practice in Palliative Care and Mismanagement of Hazardous substances" A poster presentation *11th World Research Congress of the EAPC*. 14th to 16th May 2020, (Palermo, Italy)
9. "The Disaster of Biocide and Anti-Oppressive Practice for the Right to Know: exploring the victims and the survivors by using toxic disinfectant for humidifiers in South Korea" as an Oral presentation *IFSW EUROPEAN Conference*. 8th to 11th September 2019, (Vienna, Austria)
10. "Moral and Epistemic Virtues in Anti-Oppressive Surrogate Decision-Making with Children and Young People with Life-Limiting Conditions in South Korea" A poster presentation *the 16th World Congress of the European Association for Palliative Care*. 23rd to 25th May 2019, (Berlin, Germany)
11. "Bereavement care following biocide disaster and the role of social work" A poster presentation *the 16th World Congress of the European Association for Palliative Care, Germany*. 23rd to 25th May 2019, (Berlin, Germany)
12. "Beliefs, luck, and oppression associated with paediatric palliative care in South Korea: Implications for a model of anti-oppressive surrogate decision-making" as an Oral presentation *4th Global Gathering - Maruzza Congress on Paediatric Palliative Care*, 24th to 27th October 2018, (Rome, Italy)
13. "Anti-Oppressive Practice for the Right to Know- A Qualitative Study Exploring the Views of Korean Federation for Environmental Movement" A poster presentation *Social Work, Education and Social Development, ENVIRONMENTAL AND COMMUNITY SUSTAINABILITY: HUMAN SOLUTIONS IN EVOLVING SOCIETIES*, 2018 (Dublin, Ireland)
14. "Bereavement following man-made disaster and Anti-Oppressive Practice" A poster presentation *Social Work, Education and Social Development, ENVIRONMENTAL AND COMMUNITY SUSTAINABILITY: HUMAN SOLUTIONS IN EVOLVING SOCIETIES*, 2018. (Dublin, Ireland)

Appendix B: A Participant Information Sheet

Information Sheet

Research Project:

Deciding for Minors: Clinical Judgment and Anti-Oppressive Virtue Ethics in Moral Luck and Health Inequalities.

Seunghoon Oh
Durham University, England

Introduction

My name Seunghoon Oh, and I am conducting a study under the supervision of Professor Lena Dominelli and Professor Roger Smith in the School of Applied Social Sciences at the University of Durham in the United Kingdom. I am seeking to find out about people's experiences of making decisions about palliative care for children. It is hoped that the project could provide us to suggest a possible ethical model of decision making for practical ways in which there are the problems, associating with surrogate decision-making for terminally ill children in health inequalities, moral lucks and oppressions when paediatric palliative care social workers ethically intervene the decision-making.

Background

As you may be aware, Paediatric Palliative Care social workers assess and support that the role of patient's proxy or surrogate decision-makers has to make a decision among three difficult choices: following, rejecting or withholding patient's opinion. When a palliative care social worker considers the moral dilemmas of hospital or hospice in interdisciplinary work, serious epistemic and ethical issues can be identified in terms of its effectiveness in ensuring the safety, increasing quality of life, avoiding futile treatments and pursuing the best interest of incompetent patients. In addition, there are two problems of the role of palliative care social work: some overlaps between medical team members and in the hospital or clinical setting the lack of standardised assessments. For supporting patient's surrogate and informing many variables, the role of palliative care social worker will be reconsidered. This is because informed consent and forecasted medical results are always not identical due to many variables, namely moral luck.

AIMS

The purpose of this research is to answer the question of how anti-oppressive virtue ethics can help us to suggest possible ethical model of decision making for practical ways in which there are the problems, associating with surrogate decision-making for terminally ill children in health inequalities, moral luck and oppressions when paediatric palliative care social workers ethically intervene the decision-making.

PROCEDURE

We will arrange a time to meet, which is convenient for you and in your home if that is appropriate. By signing this consent form, there will be one, single interview with myself during which I will ask you questions. During the interview, you will be asked to share your experiences in your role as a paediatric palliative care social worker with patients and families near the end of life within your healthcare organisation. The interview will focus primarily on the role of paediatric palliative care social work, professional and personal reflections on supporting decision making, death and knowledge gaps. The time and

location of the interview will be arranged at your convenience. The meetings will be audiotaped. When I have completed the study, I will produce a summary of the findings and a transcription to send you if you are not reluctant. The audiotapes will not be shared with anyone and will be destroyed by supervisors and academic staff once the study is finished.

SAFEGUARDS FOR PARTICIPANTS

All of your remarks during the interviews will be kept completely confidential. A code number assigned at the time the interviews are conducted will identify all information about you and any data collected will be kept in a locked file during the study, and then destroyed by supervisors and academic staff when the study will be done. Participation in this study is entirely voluntary and is not a condition of employment. You may end your participation at any time you desire and do not have to answer any question you do not want to, nor will you incur any penalty for withdrawing from the study should you decide not to participate. Participation in this study will not involve any medical procedures. If you ever feel uncomfortable about any part of this research and do not wish to take part in a certain aspect of the research then you are free to withdraw. I would like to present my research in reports, journal articles and presentations after it is completed. All names and identifying characteristics will be changed to maintain anonymity.

RISKS / BENEFITS

Participation in a study such as the present one provides a new experience for the individual. Such an experience may offer possibilities for continuing professional and personal growth and development, both socially and psychologically. Participating in this study does carry the possibility of some distress in talking about providing care near the end-of-life although I anticipate that this will be minimal. In addition to personal benefits, it is believed that findings of studies such as the present one help to enrich our knowledge about effective ways of supporting social workers who work with patients facing the end of life.

If you have any questions about your rights as a participant, contact me, Seunghoon OH at 07460 838238 seunghoon.oh@durham.ac.uk at the School of Applied Social Sciences Durham University 32 Old Elvet Durham DH1 3HN

Tel: (07460 838238)

Email: seunghoon.oh@durham.ac.uk

Thanking you in advance for your time.

Best regards,

Seunghoon Oh

연구 프로젝트 설명서:

아동을 위해 결정하는 것: 임상 판단 그리고 보건 불평등과 도덕적에 있어서 반억압적 덕윤리
오승훈

Durham University, England

서론

저의 이름은 오승훈이며 그리고 레나 도미넬리 교수님과 로저 스미스 교수님의 지도 아래 영국에 위치한 더럼대학교의 응용사회과학부에서 사회복지학을 공부하고 있습니다. 저는 아동 완화의료적 의사결정에 대한 선생님의 고귀한 경험들과 그에 대한 이야기를 듣고자 합니다. 이 연구프로젝트는 윤리적인 모델을 제시하고자 하는 차원에서 진행하고 있습니다.

아동호스피스완화의료사회복지사들이 대리인의 의사결정에 있어서 관여하게 될 때 이들이 억압, 도덕적 윤 그리고 보건 불평등의 현실 가운데 대리인의 의사결정의 문제점들이 있을 것입니다. 이와 같은 문제점들을 해결하고자 실질적인 방법을 고려해서 윤리적인 모델을 제시하고자 하는 것입니다.

배경

선생님께서도 인지하시는 것처럼, 아동호스피스완화의료 사회복지사들은 환자의 대리인의 역할이 평가되거나 거 지지하게 됩니다. 이들의 역할은 환자의 의견을 수용하거나 아니면 거부하는 것입니다. 호스피스완화의료 사회복지사들은 다학제간의 업무안에 있는 병원이나 혹은 호스피스에서 윤리적인 딜레마를 고려하게 됩니다. 여기에는 심각한 인식론적 그리고 윤리적인 이슈들이 규명 할 수 있습니다. 호스피스완화의료 사회복지사들은 이때, 환자의 안전을 보장하고 삶의 질을 높이며 무의미한 치료들을 피하도록 하고 환자의 최선의 이익을 추구하도록 하는 차원에서 이를 규명하고 고려합니다. 또한, 호스피스완화의료 사회복지사들은 두 가지 문제에 직면해 있습니다. 먼저, 많은 의료팀들 사이에서의 업무가 중복되어 있습니다. 그리고 호스피스와 병원 현장에서의 규범화된 사정(Assessments)이 결여 되어있습니다. 환자대리인의 권리를 지지하고 또한 그 결정에는 다양한 변수가 있다는 것 알리려면, 호스피스완화의료 사회복지사의 역할은 재고 되어야 할 것입니다. 왜냐하면 충분한 정보제공된 동의와 예견된 의료적 결과들이 다양한 변수 즉 윤으로 인해 언제나 일치하지 않습니다.

목적

이연구의 목적은 어떻게 반역압적 덕윤리가 실질적으로 의사결정에 있어서 가능한 제안을 줄 수 있는지를 대답하고자 하는 것입니다. 아동호스피스완화의료사회복지사들이 대리인의 의사결정에 있어서 관여하게 될 때 이들이 억압, 도덕적 윤 그리고 보건 불평등이 만연한 현실에서 대리인의 의사결정의 문제점들이 있을 것입니다. 이와 같은 문제점들을 해결하고자 실질적인 방법을 고려해서 윤리적인 모델을 제시하고자 하는 것입니다.

진행절차

만약 이것이 적절하다면은 우리는 당신에게 편리한 그리고 당신에게 아늑한 장소에서 만날 약속을 잡을 것입니다. 동의이 형식에 사인함으로써, 저와 함께 선생님께서는 단회성의 인터뷰를 가질 것입니다. 이 인터뷰 동안에 선생님 기관에서 아동호스피스완화의료 사회복지사의 역할에 있어서 환자 그리고 그 가족들이 삶의 마지막에 있었던 경험을 나누는 질문을 받게 될 것입니다. 이 인터뷰는 종적으로 아동 호스피스 완화의료 사회복지의 역할 그리고 전문성 혹은 개인적인 성찰에 대한 부분인 의사결정을 원조한 다는 것과 죽음 그리고 지식의 차이에 있어서 전문성 혹은 개인적인 성찰에 대해서 묻게 될 것입니다. 이 이 인터뷰의 장소와 시간은 선생님의 편의에 따라서 조정될 것입니다. 만나게 될 때 모든 내용은 녹음 될 것입니다. 선생님께서 꺼려하시지 않는다면, 제가 이 모든 연구가 끝나게 될 때, 제가 찾게 된 것 부분들의 요약본을 만들게 될 것이며 녹취록을 선생님에게 보내게 될 것입니다. 이 모든 녹취된 자료는 타인과 공유되지 않을 것이며 연구가 끝나게 될 때, 필히 지도교수님들과 행정처분들에 의해서 삭제될 것입니다.

참여자를 위한 보호

인터뷰가 진행되는 동안의 선생님께서의 언급들은 전적으로 기밀을 유지하게 될 것입니다. 인터뷰가 진행되는 동시에 당신에 대한 모든 정보는 코드화 되어 질 것이며 그리고 모든 데이터가 연구가 진행되는 동안 암호화되어서 보관 될 것이고 연구가 끝나게 될 때, 지도교수님과 행정담당자에 의해서 데이터가 완전히 삭제 될 것입니다. 이 연구에 있어서 참여는 전적으로 자발적인 것이며 고용의 의한 조건은 아닙니다. 선생님께서는 어느때든 원하신다면 선생님이 참여하는 것을 그만 둘 수 있습니다. 또한 원하지 않으신다면 그 어떤 질문에도 대답하지 않으셔도 좋습니다. 만약 선생님께서 하지 않는다고 하더라도 이 연구로부터의 철회가 그 어떤 불이익에 선생님에게 발생되지 않을 것입니다. 이 연구의 참여는 그 어떤 의료적 치료과정에는 진행되지 않습니다. 만약 선생님께서 이연구에 있어서 어떤 부분이라도 불편한 부분이 있다거나 이 연구에 있어서 어떤 부분이 원치 않는다고 한다면,

자유롭게 거절할 수 있습니다. 저는 이것이 끝난뒤에 저의 연구에서 보고서들 논문의 저널에 발표하길 원합니다. 모든 이들을 언급된 특징모두가 익명으로 처리될 것입니다.

위험과 이익

이 연구에 참여하는 참여자는 개인적으로 새로운 경험을 제공받을 수 있습니다. 그 경험을 나눔으로 전문적 개인적 성장과 발전을 지속하는 가능성들을 얻게 됩니다. 이 연구에 참여하게 되면 선생님께서 환자들에게 임종시 제공된 돌봄에 관해서 언급하게 되고 그로인한 스트레스가 발생할 수 있습니다. 이것은 경미한 부분이라 예상됩니다. 또한 개인적인 이익들이 더해진다면, 이후에 삶 마지막에 직면한 환자들을 돕고자하는 사회복지자들에게 효과적인 방법에 대한 우리의 지식을 풍성하게하는데 도움이 되는 것을 제공하는 것이라고 생각합니다.

만약 선생님께서 참여자로서 선생님의 권리에 관한 어떤 질문이 있다면, 저에게 연락 주세요.

Tel: (010 2089 3115)

Email: seunghoon.oh@durham.ac.uk

오승훈 the School of Applied Social Sciences Durham University 32 Old Elvet Durham DH1 3HN

Informed Consent Form

I, the undersigned, confirm that (please tick the box if you agree):

No		Yes	No
1.	I have read and understood the information about the project, as provided in the Information Sheet dated _____ Day, _____ Month, _____ Year.	<input type="checkbox"/>	<input type="checkbox"/>
2.	I have been given the opportunity to ask questions about the project and my participation and am satisfied with the answers given.	<input type="checkbox"/>	<input type="checkbox"/>
3.	I voluntarily agree to participate in the project.	<input type="checkbox"/>	<input type="checkbox"/>
4.	I understand I can withdraw at any time without giving reasons and that I will not be penalised for withdrawing nor will I be questioned as to why I have withdrawn.	<input type="checkbox"/>	<input type="checkbox"/>
5.	The procedures regarding confidentiality and anonymity have been clearly explained (e.g. use of names, pseudonyms, anonymisation of data, etc.) to me.	<input type="checkbox"/>	<input type="checkbox"/>
6.	I have given consent for my interview to be audio or video recorded and other forms of data collection have been explained and offered to me.	<input type="checkbox"/>	<input type="checkbox"/>
7.	The use of the data in research, publications, sharing and archiving has been explained to me and I consent to their use for such purposes.	<input type="checkbox"/>	<input type="checkbox"/>
8.	I understand that the audiotapes will not be shared with anyone and will be destroyed by supervisors and academic staff once the study is finished.	<input type="checkbox"/>	<input type="checkbox"/>
9.	<p>Select only one of the following:</p> <ul style="list-style-type: none"> I would like my name used and understand what I have said or written as part of this study will be used in reports, publications and other research outputs so that anything I have contributed to this project can be recognised. I do not want my name used in this project. 	<input type="checkbox"/>	<input type="checkbox"/>
		<input type="checkbox"/>	<input type="checkbox"/>
10.	I, along with I, agree to sign and date this informed consent form.	<input type="checkbox"/>	<input type="checkbox"/>

Participant:

Name of Participant Signature Date

Researcher:

Name of Researcher Signature Date

동의서

나는 다음과 같이 서명하는 것에 대해서 확신하며 동의하는 부분에 있어서 표기합니다.

No		예	아니요
1.	나는 이 연구에 관한 제공된 정보를 읽고 이해했습니다. 2016년 월 .	<input type="checkbox"/>	<input type="checkbox"/>
2.	나는 이 연구에 관해서 질문할 수 있는 기회를 가졌으며 나의 참여와 그 대답들에 있어서 만족합니다.	<input type="checkbox"/>	<input type="checkbox"/>
3.	나는 자발적으로 이 연구에서 참여하는 것에 동의합니다.	<input type="checkbox"/>	<input type="checkbox"/>
4.	나는 그 어떠한 이유없이 철회할 수 있습니다. 나의 인터뷰 거부에 대해서 질문 또한 받지 않을 수 있으며 거부하는 것에 대해서 처벌 역시 없는 것을 이해했습니다.	<input type="checkbox"/>	<input type="checkbox"/>
5.	비밀과 익명성에 대한 절차들이 명료하게 설명되어 졌습니다. 예를 들면 이름 사용, 익명성 그리고 날짜의 익명들을 나에게 언급했습니다.	<input type="checkbox"/>	<input type="checkbox"/>
6.	나는 이 인터뷰가 자료 수집을 위한 형태이며 그리고 녹음 되는 것에 대해서 충분한 설명을 듣고 제공 받은 것에 있어서 동의했습니다.	<input type="checkbox"/>	<input type="checkbox"/>
7.	연구자는 학술 연구 그리고 출간 및 정보가 공유되는 것과 보관 되는 것에 있어서 이 자료가 사용되는 것을 나에게 설명하였으며 그와 같은 목적에 의해서 이것이 사용되는 것에 동의합니다.	<input type="checkbox"/>	<input type="checkbox"/>
8.	나는 이 모든 녹취된 자료는 타인과 공유되지 않을 것이며 연구가 끝나게 될 때, 필히 지도교수님들과 행정처 분들에 의해서 삭제될 것이라는 것을 이해했습니다.	<input type="checkbox"/>	<input type="checkbox"/>
9.	둘중에 하나를 선택해 주세요. 나는 나의 이름을 사용되길 바랍니다. 그리고 내가 어떤 이야기를 언급했고 기록되는 것에 있어서 이해합니다. 그리고 이 연구에서 출간되는 모든 부분에 있어서 알고 있습니다. 따라서 내 이름이 연구에 기여하는 것을 인지시키고 싶기 때문에 나의 이름을 사용하길 원합니다.	<input type="checkbox"/>	<input type="checkbox"/>
	나는 이 연구 프로젝트에 나의 이름이 사용되는 것을 원치 않습니다.	<input type="checkbox"/>	<input type="checkbox"/>
10.	나는 이 연구자와 함께 동의서에 날짜와 서명하는 것에 동의합니다.	<input type="checkbox"/>	<input type="checkbox"/>

참여자:

참여자 이름 _____ 서명 _____ 날짜 _____

연구자:

연구자 이름 _____ 서명 _____ 날짜 _____

Appendix C: Interview Guide for Interview

Interview Guide for Interview with Paediatric Palliative Care Social Worker

Hello, my name is Seounghoon Oh. Thank you very much for agreeing to meet with me. Could I just tell you a bit more about the project that I am involved with and that I am asking you to help us with? The aim of this project is to answer the question of how anti-oppressive virtue ethics can help us to suggest possible ethical model of decision making for practical ways in which there are the problems, associating with surrogate decision-making for terminally ill children in health inequalities, moral luck and oppressions when paediatric palliative care social workers ethically intervene the decision-making. This project will contribute to service users to have a chance to say what they think about the service they receive from social workers who specialise in working in hospice and palliative care and what they would like in the future.

This interview will probably last between one and one-and-a-half hours. But if you need to break or finish, whenever you can have a break or finish. If this is not enough and needed more, I will meet again. Is that okay? Can I just add there are no right or wrong answers; I just want to hear what you think.

I should inform you that the project, and I are entirely independent and separate from the team working with you. It will be completely confidential and anonymous and names will not be used. Is that okay?

For this interview I need to have an accurate record and make a transcript. I will give you a copy of the consent form(s) and information sheet to keep. If you would like one we can send you the consent form(s), information sheet, a copy of the audio and a transcript to correct. Could you read information sheet and the consent form through and sign that for me? I will also try and keep people in touch with what I am doing. Are there any questions? Are you happy to start? [put audio-recorder on]

Initial Open-ended Questions

- 1) Could you tell me what made you decide to become paediatric palliative care social worker?

Intermediate Questions

- 2) Regarding your experience, what did you find terminal children and their family member are afraid of?
- 3) Tell me about your thoughts and feelings what you learned after conducting your role in improving the quality of life for children and their family?
- 4) Tell me about your experience how did paediatric palliative care social workers intervene or support the surrogates' decision making through the multidisciplinary palliative team based on the given assessment?

- 5) What are some of the barriers to conducting your role in improving the quality of life for children and their family?
- 6) Could you describe the events if there were miscommunications between multidisciplinary palliative team members?
- 7) Could you describe the events that there might be conflict over between multidisciplinary palliative team members who concern what is taken to be in the best interest of terminally ill children and opinions of surrogates who individually pursue the prudence? Due to various beliefs in their community surrogates might hinder prudential decision-making.
- 8) After making the decision some people can be blamed or praised, what if luck made differences in a person's moral worth during bereavement care. What do you think about luck if the parents considered new medical marketing?
- 9) Have ever experienced oppressions due to social policy when you want to support the decision making? Could you describe one of the events that you have experienced?
- 10) Would you mind to tell me your experience that you felt some moral responsibility in luck, what if after decision making there were the potential problems such as unexpected cause-effect relationships in other contexts?

Ending Questions

- 11) After having these experiences, what advice would you give to people who want to become paediatric palliative care social workers?
- 12) Could I ask if there are any other comments, ideas or suggestions you would like to offer?

Thank you for all this help with the interview. I will shortly send you a copy of this audio file and a copy of the transcript to correct if you would like one.

If at any time you would like to make contact, if any problems or issues have been highlighted today, please contact.

Seunghoon Oh 07460 838238

seunghoon.oh@durham.ac.uk

School of Applied Social Sciences

Durham University

32 Old Elvet

Durham DH1 3HN

Email only is best:

If you have any complaints about the way in which I have conducted this interview, or research project, please contact my supervisor, Professor Lena Dominelli at lena.dominelli@durham.ac.uk

아동호스피스 사회복지사와 함께하는 인터뷰 가이드

안녕하세요. 저의 이름은 오승훈입니다. 저의 연구에 동의해주신 것에 대해서 대단히 감사드립니다. 제가 이 연구에 대해서 포함된 부분과 그리고 질문할 부분에 대해서 약간 설명해도 될까요? 이 연구의 목적은 어떻게 반역압적 덕윤리가가 실질적으로 의사결정에 있어서 가능한 제안을 줄 수 있는지를 대답하고자 하는 것 입니다.

아동호스피스완화의료사회복지사들이 대리인의 의사결정에 있어서 관여하게 됩니다. 이때 억압, 도덕적 윤 그리고 보건 불평등이 만연한 현실 가운데 대리인의 의사결정의 문제점들이 다양하게 야기됩니다. 이와 같은 문제점들을 파악하고 해결하고자 실질적인 방법을 고려해서 윤리적인 모델을 제시하고자 하는 것입니다. 이 연구는 이후에 호스피스 이용대상자들이 호스피스 사회복지사들로부터 호스피스 서비스에 대한 부분이 무엇인지를 생각하게 하는 것이며 향후 이들이 무엇을 선호할지에 대한 것을 기여하게 될 것입니다.

이 인터뷰는 아마도 한시간에서 혹은 한시간 반 정도 소요 될 것입니다. 그러나 만약 선생님께서 휴식이 필요하거나 아니면 종결을 원하신다고 하면 어느때든지 쉴 수 있으며 종결 할 수 있습니다. 만약 이 인터뷰가 충분하지 않다거나 혹은 더 필요로 할 경우, 제가 다시 만날 수 있습니다. 그래도 괜찮으신가요? 선생님의 답변에는 옳고 그름도 없다는 것을 꼭 언급하고 싶습니다. 저는 단지 선생님이 무엇을 생각하는지를 듣고자 하는 것입니다. 제가 이 프로젝트에 대해서 언급해야되는 되는 것이 있는데, 이것은 전적으로 독립된 연구이고 선생님이 일하는 팀과도 아무런 관련이 없습니다. 그리고 이것은 전적으로 비밀이 유지되며 무기명이고 처리 될 것입니다. 괜찮으신가요?

정확한 인터뷰를 위해서 명확한 기록이 요구되고 녹취록 역시 만들어야 됩니다. 저는 이 프로젝트를 위해서 보관을 목적으로 동의서와 연구에 대한 설명지를 드릴 것입니다. 그리고 선생님께서 다음과 같은 부분을 원하실 경우에 인터뷰의 내용이 맞는지 확인하기 위해서 오디오 파일과 녹취록 그리고 연구동의서 및 설명서를 보내드리도록 하겠습니다. 그럼 연구 설명서와 연구동의서를 읽어주시고 이를 위해서 서명해 주시겠습니까? 또한 저는 제가 무슨 연구를 계속 진행하고 있는지에 대해서 선생님에게 연락을 취하도록 할 것입니다. 이제 모든 것이 명료한가요? 혹시 저에게 하시고 싶은 질문이 있으신가요? 그럼 시작해도 될까요?

초기개방형 질문

- 1) 아동호스피스 사회복지사가 되고자 결심 했던 계기가 있었다면 이야기해 주실 수 있을까요?

중기 개방형 질문

- 2) 선생님의 경험에 비추어서, 임종이 임종이 임박한 아이들과 그들의 가족들이 두려워 하는 것이 무엇이었나요?
- 3) 아이들과 그들의 부모의 삶의 질을 향상시키기 위해서 선생님이 역할을 수행한 뒤에 무엇이 알렸던 감정이나 생각을 언급해 주실 수 있을까요?
- 4) 어떻게 아동호스피스 사회복지사들이 사정에 기반해서 다양한 완화의료팀들을 통해서 대리인의 의사결정을 지지하거나 혹은 관여 했던 경험에 대해서 이야기 해줄 수 있으신가요?
- 5) 그들의 삶의 질을 높이기위해서 선생님의 역할을 수행함에 있어서 걸림돌들이 있었다면 무엇이었나요?
- 6) 다양한 완화의료팀들 간에 의사소통의 문제가 있었던 일이 있었다면 그 일을 좀 설명해 주실 수 있나요?
- 7) 다양한 완화의료팀들은 환자의 최선의 이익을 고려할 것이고 환자의 대리인도 개인적으로 신중하게 고려하는 가운데 의사결정의 갈등이 야기 될 수 있을 것입니다. 그러나 대리인이 속한 공동체에 다양한 믿음이 대리인의 신중한 의사결정을 방해할 수 있습니다. 이와 같은 일들을 경험한 적이 있다면 이야기 해주실 수 있으신가요?
- 8) 만약 윤이 사별가족 돌봄가운데 이와 같은 사람의 도덕적 가치의 차이를 만든다면 의사결정 이후에 일부 사람들은 비난 받을 수 있고 칭송 받을 수 있습니다. 그 가족들이 새로운 의료 마케팅을 고려했다고 한다면 윤에 대해서 어떻게 생각하시나요?
- 9) 의사결정을 돕길 원했을 때 사회정책때문에 억압을 받았던 적은 없나요?

- 10) 의사결정 이후 잠정적 문제가 있을 수 있습니다. 그문제는 다른 맥락 안에서 전혀 고려할 수 없었던 인과관계와 같은 문제가 발생할 때, 그 발생한 운에 있어서 도덕적 책임을 느낀 적이 있나요? 그렇다면 그 이야기를 해주실 수 있나요?

끝맺는 질문

- 11) 이와 같은 경험을 기반으로 이후 아동호스피스 사회복지사가 되고자 하는 자들에게 조언을 주실 수 있나요?
- 12) 코멘트나 혹은 아이디어 그리고 제안하고 싶은 부분이 있으시다면 물어봐도 될까요?

인터뷰에 응해주셔서 감사드립니다. 선생님이 필요하시다면, 제가 녹취록과 오디오 파일을 짧은 시간안에 보내드리고록 하겠습니다.

만약 어느때든지 연락하기를 원하시거나 혹은 오늘 언급된 문제가 강조 되어 된다고 여길 시에 언제든지 연락 주세요.

오승훈 010 2089 3115

seunghoon.oh@durham.ac.uk

School of Applied Social Sciences

Durham University

32 Old Elvet

Durham DH1 3HN

만약 선생님께서 이와 같은 인터뷰 방식에 있어서나 이 연구 프로젝트에 대해서 불만이 있다고 할 경우 저의 지도교수님이신 레나 도미넬리교수님에게 이메일로 연락하시면 됩니다.
lena.dominelli@durham.ac.uk

Interview Guide for Interview with Palliative Care Social Worker

Hello, my name is Seounghoon Oh. Thank you very much for agreeing to meet with me. Could I just tell you a bit more about the project that I am involved with and that I am asking you to help us with? The aim of this project is to answer the question of how anti-oppressive virtue ethics can help us to suggest possible ethical model of decision making for practical ways in which there are the problems, associating with surrogate decision-making for terminally ill children in health inequalities, moral luck and oppressions when paediatric palliative care social workers ethically intervene the decision-making. This project will contribute to service users to have a chance to say what they think about the service they receive from social workers who specialise in working in hospice and palliative care and what they would like in the future.

This interview will probably last between one and one-and-a-half hours. But if you need to break or finish, whenever you can have a break or finish. If this is not enough and needed more, I will meet again. Is that okay? Can I just add there are no right or wrong answers; I just want to hear what you think.

I should inform you that the project, and I are entirely independent and separate from the team working with you. It will be completely confidential and anonymous and names will not be used. Is that okay?

For this interview I need to have an accurate record and make a transcript. I will give you a copy of the consent form(s) and information sheet to keep. If you would like one we can send you the consent form(s), information sheet, a copy of the audio and a transcript to correct. Could you read information sheet and the consent form through and sign that for me? I will also try and keep people in touch with what I am doing. Are there any questions? Are you happy to start? [put audio-recorder on]

Initial Open-ended Questions

- 1) Could you tell me what made you decide to become palliative care social worker?

Intermediate Questions

- 2) Regarding your experience, what did you find the differences between terminal children and their family member are afraid of, and adults their family member are afraid?
- 3) Considering adult hospices what are some of the barriers to conducting your role in improving the quality of life for children and their family?
- 4) Tell me about your thoughts and feelings what you learned after referring to children hospice in improving the quality of life?
- 5) Could you describe the events if there were miscommunications between multidisciplinary palliative team members?

- 6) Could you describe the events that there might be conflict over between multidisciplinary palliative team members who concern what is taken to be in the best interest of terminally ill adults and opinions of surrogates who individually pursue the prudence? Due to various beliefs in their community surrogates might hinder prudential decision-making.
- 7) After making the decision some people can be blamed or praised, what if luck made differences in a person's moral worth during bereavement care. What do you think about luck if the surrogates considered new medical marketing?
- 8) Have ever experienced oppressions due to social policy when you want to support the decision making? Could you describe one of the events that you have experienced?
- 9) Would you mind to tell me your experience that you felt some moral responsibility in luck, what if after decision making there were the potential problems such as unexpected cause-effect relationships in other contexts?

Ending Questions

- 10) After having these experiences, what advice would you give to people who want to become paediatric palliative care social workers?
- 11) Could I ask if there are any other comments, ideas or suggestions you would like to offer?

Thank you for all this help with the interview. I will shortly send you a copy of this audio file and a copy of the transcript to correct if you would like one.

If at any time you would like to make contact, if any problems or issues have been highlighted today, please contact.

Seunghoon Oh 07460 838238

seunghoon.oh@durham.ac.uk

School of Applied Social Sciences

Durham University

32 Old Elvet

Durham DH1 3HN

Email only is best:

If you have any complaints about the way in which I have conducted this interview, or research project, please contact my supervisor, Professor Lena Dominelli at lena.Dominelli@durham.ac.uk

호스피스 사회복지사와 함께하는 인터뷰 가이드

안녕하세요. 저의 이름은 오승훈입니다. 저의 연구에 동의해주신 것에 대해서 대단히 감사드립니다. 제가 이 연구에 대해서 포함된 부분과 그리고 질문할 부분에 대해서 약간 설명해도 될까요? 이 연구의 목적은 어떻게 반역압적 덕윤리가가 실질적으로 의사결정에 있어서 가능한 제안을 줄 수 있는지를 대답하고자 하는 것 입니다.

아동호스피스완화의료사회복지사들이 대리인의 의사결정에 있어서 관여하게 됩니다. 이때 억압, 도덕적 윤 그리고 보건 불평등이 만연한 현실 가운데 대리인의 의사결정의 문제점들이 다양하게 야기됩니다. 이와 같은 문제점들을 파악하고 해결하고자 실질적인 방법을 고려해서 윤리적인 모델을 제시하고자 하는 것입니다. 이 연구는 이후에 호스피스 이용대상자들이 호스피스 사회복지사들로부터 호스피스 서비스에 대한 부분이 무엇인지를 생각하게 하는 것이며 향후 이들이 무엇을 선호할지에 대한 것을 기여하게 될 것입니다.

이 인터뷰는 아마도 한시간에서 혹은 한시간 반 정도 소요 될 것입니다. 그러나 만약 선생님께서 휴식이 필요하거나 아니면 종결을 원하신다고 하면 어느때든지 쉴 수 있으며 종결 할 수 있습니다. 만약 이 인터뷰가 충분하지 않다거나 혹은 더 필요로 할 경우, 제가 다시 만날 수 있습니다. 그래도 괜찮으신가요? 선생님의 답변에는 옳고 그름도 없다는 것을 꼭 언급하고 싶습니다. 저는 단지 선생님이 무엇을 생각하는지를 듣고자 하는 것입니다. 제가 이 프로젝트에 대해서 언급해야되는 되는 것이 있는데, 이것은 전적으로 독립된 연구이고 선생님이 일하는 팀과도 아무런 관련이 없습니다. 그리고 이것은 전적으로 비밀이 유지되며 무기명이고 처리 될 것입니다. 괜찮으신가요?

정확한 인터뷰를 위해서 명확한 기록이 요구되고 녹취록 역시 만들어야 됩니다. 저는 이 프로젝트를 위해서 보관을 목적으로 동의서와 연구에 대한 설명지를 드릴 것입니다. 그리고 선생님께서 다음과 같은 부분을 원하실 경우에 인터뷰의 내용이 맞는지 확인하기 위해서 오디오 파일과 녹취록 그리고 연구동의서 및 설명서를 보내드리도록 하겠습니다. 그럼 연구 설명서와 연구동의서를 읽어주시고 이를 위해서 서명해 주시겠습니까? 또한 저는 제가 무슨

연구를 계속 진행하고 있는지에 대해서 선생님에게 연락을 취하도록 할 것입니다. 이제 모든 것이 명료한가요? 혹시 저에게 하시고 싶은 질문이 있으신가요? 그럼 시작해도 될까요?

초기 개방형 질문

- 1) 호스피스 사회복지사가 되고자 결심 했던 계기가 있었다면 이야기 해줄 수 있을까요?

중기 개방형 질문

- 2) 선생님의 경험에 비추어서, 임종이 임박한 아이들과 그들의 가족들이 두려워 하는 것과 성인 그리고 그 가족들이 두려워 하는 것의 차이는 무엇이었나요?
- 3) 성인호스피스에서 그들의 삶의 질을 높이기위해서 선생님의 역할을 수행했을 때 걸림돌이 있었다면 무엇이었나요?
- 4) 아이들과 그들의 부모의 삶의 질을 향상시키기 위해서 선생님이 어린이 호스피스로 의뢰했을 때 알겠된 감정이나 생각을 언급해 주실 수 있을까요?
- 5) 다양한 완화의료팀들 간에 의사소통의 문제가 있었던 일이 있었다면 그 일을 좀 설명해 주실 수 있나요?
- 6) 다양한 완화의료팀들은 환자의 최선의 이익을 고려할 것이고 환자의 대리인도 개인적으로 신중하게 고려하는 가운데 의사결정의 갈등이 야기 될 수 있을 것입니다. 그러나 대리인이 속한 공동체에 다양한 믿음이 대리인의 신중한 의사결정을 방해할 수 있습니다. 이와 같은 일들을 경험한 적이 있다면 이야기 해주실 수 있으신가요?
- 7) 만약 윤이 사별가족 돌봄가운데 이와 같은 사람의 도덕적 가치의 차이를 만든다면 의사결정 이후에 일부 사람들은 비난 받을 수 있고 칭송 받을 수 있습니다. 그 대리인들이 새로운 의료 마케팅을 고려했다고 한다면 윤에 대해서 어떻게 생각하시나요?
- 8) 의사결정을 돕길 원했을 때 사회정책으로 때문에 억압을 받았던 적은 없나요?

- 9) 의사결정 이후 잠정적 문제가 있을 수 있습니다. 그문제는 다른 맥락 안에서 전혀 고려할 수 없었던 인과관계와 같은 문제가 발생할 때, 그 발생한 운에 있어서 도덕적 책임을 느낀적이 있나요? 그렇다면 그 이야기를 해주실 수 있나요?

끝맺는 질문

- 10) 이와 같은 경험을 기반으로 이후 아동호스피스 사회복지사가 되고자 하는 자들에게 조언을 주실 수 있나요?

- 11) 컨멘트나 혹은 아이디어 그리고 제안하고 싶은 부분이 있으시다면 물어봐도 될까요?

인터뷰에 응해주셔서 감사드립니다. 선생님이 필요하시다면, 제가 녹취록과 오디오 파일을 짧은 시간안에 보내드리고록 하겠습니다.

만약 어느때든지 연락하기를 원하시거나 혹은 오늘 언급된 문제가 강조 되어 된다고 여길 시에 언제든지 연락 주세요.

오승훈 010 2089 3115

seunghoon.oh@durham.ac.uk

School of Applied Social Sciences

Durham University

32 Old Elvet

Durham DH1 3HN

만약 선생님께서 이와 같은 인터뷰 방식에 있어서나 이 연구 프로젝트에 대해서 불만이 있다고 할 경우 저의 지도교수님이신 레나 도미넬리에게 이메일로 연락하시면 됩니다.

lena.Dominelli@durham.ac.uk

Interview Guide for Interview with Children and Young People's Parents or Guardians / Bereaved Family Members

Hello, my name is Seounghoon Oh. Thank you very much for agreeing to meet with me. Could I just tell you a bit more about the project that I am involved with and that I am asking you to help us with? The aim of this project is to answer the question of how anti-oppressive virtue ethics can help us to suggest possible ethical model of decision making for practical ways in which there are the problems, associating with surrogate decision-making for terminally ill children in health inequalities, moral luck and oppressions when paediatric palliative care social workers ethically intervene the decision-making. This project will contribute to service users to have a chance to say what they think about the service they receive from social workers who specialise in working in hospice and palliative care and what they would like in the future.

This interview will probably last between one and one-and-a-half hours. But if you need to break or finish, whenever you can have a break or finish. If this is not enough and needed more, I will meet again. Is that okay? Can I just add there are no right or wrong answers; I just want to hear what you think.

I should inform you that the project, and I are entirely independent and separate from the team working with you. It will be completely confidential and anonymous and names will not be used. Is that okay?

For this interview I need to have an accurate record and make a transcript. I will give you a copy of the consent form(s) and information sheet to keep. If you would like one we can send you the consent form(s), information sheet, a copy of the audio and a transcript to correct. Could you read information sheet and the consent form through and sign that for me? I will also try and keep people in touch with what I am doing. Are there any questions? Are you happy to start? [put audio-recorder on]

Initial Open-ended Questions

- 1) Could you tell me when did you did your children receive palliative care for improving the quality of life?
- 2) Regarding your experience, what did you find the differences between adult hospice and children hospice?

Intermediate Questions

- 3) Tell me about your thoughts and feelings after referring to children hospice in improving the quality of life?
- 4) Could you describe one of the events that you have experienced oppressions due to financial reason when did you want to make your children the decision for improving quality of life?

- 5) Can you tell me what you have found most helpful in palliative care social work when you were struggling with making decision for your children?
- 6) Could you describe the events if there were good communications between multidisciplinary palliative team members?
- 7) Could you describe one of the events that when you have been oppressed?
- 8) Could you describe one of the events that you have ever experienced oppressions due to phycological reason when did you want to make your children the decision for improving quality of life?
- 9) After making the decision some people can be blamed or praised. Would you mind to tell me you have ever experienced the admirable decision making for your children?
- 10) Could you tell me your experience that you have ever experienced oppressions due to social policy when did you want to make your children the decision for improving quality of life?

Ending Questions

- 11) After having these experiences, what advice would you give to people who want to become paediatric palliative care social workers?
- 12) Could I ask if there are any other comments, ideas or suggestions you would like to offer?

Thank you for all this help with the interview. I will shortly send you a copy of this audio file and a copy of the transcript to correct if you would like one.

If at any time you would like to make contact, if any problems or issues have been highlighted today, please contract.

Seunghoon Oh 07460 838238

seunghoon.oh@durham.ac.uk

School of Applied Social Sciences

Durham University

32 Old Elvet

Durham DH1 3HN

Email only is best:

If you have any complaints about the way in which I have conducted this interview, or research project, please contact my supervisor, Professor Lena Dominelli at lena.dominelli@durham.ac.uk

사별가족 / 가족과 함께하는 인터뷰 가이드

안녕하세요. 저의 이름은 오승훈입니다. 저의 연구에 동의해주신 것에 대해서 대단히 감사드립니다. 제가 이 연구에 대해서 포함된 부분과 그리고 질문할 부분에 대해서 약간 설명해도 될까요? 이 연구의 목적은 어떻게 반역압적 덕윤리가가 실질적으로 의사결정에 있어서 가능한 제안을 줄 수 있는지를 대답하고자 하는 것 입니다.

아동호스피스완화의료사회복지사들이 대리인의 의사결정에 있어서 관여하게 됩니다. 이때 억압, 도덕적 윤 그리고 보건 불평등이 만연한 현실 가운데 대리인의 의사결정의 문제점들이 다양하게 야기됩니다. 이와 같은 문제점들을 파악하고 해결하고자 실질적인 방법을 고려해서 윤리적인 모델을 제시하고자 하는 것입니다. 이 연구는 이후에 호스피스 이용대상자들이 호스피스 사회복지사들로부터 호스피스 서비스에 대한 부분이 무엇인지를 생각하게 하는 것이며 향후 이들이 무엇을 선호할지에 대한 것을 기여하게 될 것입니다.

이 인터뷰는 아마도 한시간에서 혹은 한시간 반 정도 소요 될 것입니다. 그러나 만약 선생님께서 휴식이 필요하거나 아니면 종결을 원하신다고 하면 어느때든지 쉴 수 있으며 종결 할 수 있습니다. 만약 이 인터뷰가 충분하지 않다거나 혹은 더 필요로 할 경우, 제가 다시 만날 수 있습니다. 그래도 괜찮으신가요? 선생님의 답변에는 옳고 그름도 없다는 것을 꼭 언급하고 싶습니다. 저는 단지 선생님이 무엇을 생각하는지를 듣고자 하는 것입니다. 제가 이 프로젝트에 대해서 언급해야되는 되는 것이 있는데, 이것은 전적으로 독립된 연구이고 선생님이 일하는 팀과도 아무런 관련이 없습니다. 그리고 이것은 전적으로 비밀이 유지되며 무기명이고 처리 될 것입니다. 괜찮으신가요?

정확한 인터뷰를 위해서 명확한 기록이 요구되고 녹취록 역시 만들어야 됩니다. 저는 이 프로젝트를 위해서 보관을 목적으로 동의서와 연구에 대한 설명지를 드릴 것입니다. 그리고 선생님께서 다음과 같은 부분을 원하실 경우에 인터뷰의 내용이 맞는지 확인하기 위해서 오디오 파일과 녹취록 그리고 연구동의서 및 설명서를 보내드리도록 하겠습니다. 그럼 연구 설명서와 연구동의서를 읽어주시고 이를 위해서 서명해 주시겠습니까? 또한 저는 제가 무슨

연구를 계속 진행하고 있는지에 대해서 선생님에게 연락을 취하도록 할 것입니다. 이제 모든 것이 명료한가요? 혹시 저에게 하시고 싶은 질문이 있으신가요? 그럼 시작해도 될까요?

초기개방형 질문

- 1) 아동호스피스에 언제 선생님의 자녀분께서 삶의 질을 향상시키기 위해서 아동호스피스돌봄을 받았나요?

중기 개방형 질문

- 2) 선생님의 경험에 비추어서, 아동호스피스와 성인호스피스의 차이가 무엇인지 경험하셨나요? 있다면 그 이야기를 좀 해주실 수 있나요?
- 3) 삶의 질을 높이기 위해서 어린이 호스피스로 의뢰된 이후에 느낌과 생각에서 대해서 이야기 해주실 수 있으신가요?
- 4) 선생님의 자녀의 삶의 질을 높이하고자 의사결정을 하고자 할 때 경제적인 이유 때문에 억압됨을 경험한 적이 있다면 이야기 해주실 수 있으신가요?
- 5) 선생님께서 아이들을 위해서 의사결정을 하려고 고분고투하려고 하는데 사회복지사가 도움을 주었던 것을 이야기 해줄 수 있나요?
- 6) 호스피스피 완화의료 팀들 간에서 좋은 의사소통이 있었다면 어떤 것이 있었는지 이야기 해주실 수 있으신가요?
- 7) 선생님께서 의사결정시 억압이라고 생각했던 것은 어떤 것인지 설명해 주실 수 있으신가요?
- 8) 삶의 질을 높이하고자 선생님의 자녀의 의사결정을 하고자 할 때 심리적인 이유 때문에 억압을 받은 경험은 무엇이 있는지 이야기해줄 수 있나요?
- 9) 의사결정 이후 일부사람들은 비난을 받거나 칭송을 받기도 합니다. 선생님의 자녀를 위해서 칭찬받을 만한 결정을 이야기 해주실 수 있으신가요?

- 10) 의사결정을 하려고 하는데 사회정책으로 인해서 억압을 받은 경험은 무엇이 있는지 이야기해줄 수 있나요?

끝맺는 질문

- 11) 이와 같은 경험을 기반으로 이후 아동호스피스 사회복지사가 되고자 하는 자들에게 조언을 주실 수 있나요?
- 12) 코멘트나 혹은 아이디어 그리고 제안하고 싶은 부분이 있으시다면 물어봐도 될까요?

인터뷰에 응해주셔서 감사드립니다. 선생님이 필요하시다면, 제가 녹취록과 오디오 파일을 짧은 시간안에 보내드리고록 하겠습니다.

만약 어느때든지 연락하기를 원하시거나 혹은 오늘 언급된 문제가 강조 되어 된다고 여길 시에 언제든지 연락 주세요.

오승훈 010 2089 3115

seunghoon.oh@durham.ac.uk

School of Applied Social Sciences

Durham University

32 Old Elvet

Durham DH1 3HN

만약 선생님께서 이와 같은 인터뷰 방식에 있어서나 이 연구 프로젝트에 대해서 불만이 있다고 할 경우 저의 지도교수님이신 레나 도미넬리에게 이메일로 연락하시면 됩니다.

lana.dominelli@durham.ac.uk

Interview Guide for Interview with Palliative Care Medical Members

Hello, my name is Seounghoon Oh. Thank you very much for agreeing to meet with me. Could I just tell you a bit more about the project that I am involved with and that I am asking you to help us with? The aim of this project is to answer the question of how anti-oppressive virtue ethics can help us to suggest possible ethical model of decision making for practical ways in which there are the problems, associating with surrogate decision-making for terminally ill children in health inequalities, moral luck and oppressions when paediatric palliative care social workers ethically intervene the decision-making. This project will contribute to service users to have a chance to say what they think about the service they receive from social workers who specialise in working in hospice and palliative care and what they would like in the future.

This interview will probably last between one and one-and-a-half hours. But if you need to break or finish, whenever you can have a break or finish. If this is not enough and needed more, I will meet again. Is that okay? Can I just add there are no right or wrong answers; I just want to hear what you think.

I should inform you that the project, and I are entirely independent and separate from the team working with you. It will be completely confidential and anonymous and names will not be used. Is that okay?

For this interview I need to have an accurate record and make a transcript. I will give you a copy of the consent form(s) and information sheet to keep. If you would like one we can send you the consent form(s), information sheet, a copy of the audio and a transcript to correct. Could you read information sheet and the consent form through and sign that for me? I will also try and keep people in touch with what I am doing. Are there any questions? Are you happy to start? [put audio-recorder on]

Initial Open-ended Questions

- 1) Could you tell me what made you decide to become paediatric palliative care members?

Intermediate Questions

- 2) Regarding your experience, what did you find terminal children and their family member are afraid of?
- 3) Tell me about your thoughts and feelings what have you experienced the role of hospice social worker for improving the quality of life?
- 4) Tell me about your experience how did palliative care workers intervene or support the surrogates' decision making through the multidisciplinary palliative team based on the given assessment?

- 5) What are some of the barriers to conducting your role in improving the quality of life for children and their family?
- 6) Could you describe the events if there were miscommunications between multidisciplinary palliative team members?
- 7) Could you describe the events that there might be conflict over between multidisciplinary palliative team members who concern what is taken to be in the best interest of terminally ill children and opinions of surrogates who individually pursue the prudence? Due to various beliefs in their community surrogates might hinder prudential decision-making.
- 8) After making the decision some people can be blamed or praised, what if luck made differences in a person's moral worth during bereavement care. What do you think about luck if the parents considered new medical marketing?
- 9) Have ever experienced oppressions due to social policy when you want to support the decision making? Could you describe one of the events that you have experienced?
- 10) Would you mind to tell me your experience that you felt some moral responsibility in luck, what if after decision making there were the potential problems such as unexpected cause-effect relationships in other contexts?

Ending Questions

- 11) After having these experiences, what advice would you give to people who want to become palliative care social workers?
- 12) Could I ask if there are any other comments, ideas or suggestions you would like to offer?

Thank you for all this help with the interview. I will shortly send you a copy of this audio file and a copy of the transcript to correct if you would like one.

If at any time you would like to make contact, if any problems or issues have been highlighted today, please contact.

Seunghoon Oh 07460 838238

seunghoon.oh@durham.ac.uk

School of Applied Social Sciences

Durham University

32 Old Elvet

Durham DH1 3HN

Email only is best:

If you have any complaints about the way in which I have conducted this interview, or research project, please contact my supervisor, Professor Lena Dominelli at [lena.Dominelli@durham.ac.uk](mailto:lana.Dominelli@durham.ac.uk)

완화의료팀과 함께하는 인터뷰 가이드

안녕하세요. 저의 이름은 오승훈입니다. 저의 연구에 동의해주신 것에 대해서 대단히 감사드립니다. 제가 이 연구에 대해서 포함된 부분과 그리고 질문할 부분에 대해서 약간 설명해도 될까요? 이 연구의 목적은 어떻게 반역압적 덕윤리가가 실질적으로 의사결정에 있어서 가능한 제안을 줄 수 있는지를 대답하고자 하는 것 입니다.

아동호스피스완화의료사회복지사들이 대리인의 의사결정에 있어서 관여하게 됩니다. 이때 억압, 도덕적 윤 그리고 보건 불평등이 만연한 현실 가운데 대리인의 의사결정의 문제점들이 다양하게 야기됩니다. 이와 같은 문제점들을 파악하고 해결하고자 실질적인 방법을 고려해서 윤리적인 모델을 제시하고자 하는 것입니다. 이 연구는 이후에 호스피스 이용대상자들이 호스피스 사회복지사들로부터 호스피스 서비스에 대한 부분이 무엇인지를 생각하게 하는 것이며 향후 이들이 무엇을 선호할지에 대한 것을 기여하게 될 것입니다.

이 인터뷰는 아마도 한시간에서 혹은 한시간 반 정도 소요 될 것입니다. 그러나 만약 선생님께서 휴식이 필요하거나 아니면 종결을 원하신다고 하면 어느때든지 쉴 수 있으며 종결 할 수 있습니다. 만약 이 인터뷰가 충분하지 않다거나 혹은 더 필요로 할 경우, 제가 다시 만날 수 있습니다. 그래도 괜찮으신가요? 선생님의 답변에는 옳고 그름도 없다는 것을 꼭 언급하고 싶습니다. 저는 단지 선생님이 무엇을 생각하는지를 듣고자 하는 것입니다. 제가 이 프로젝트에 대해서 언급해야되는 되는 것이 있는데, 이것은 전적으로 독립된 연구이고 선생님이 일하는 팀과도 아무런 관련이 없습니다. 그리고 이것은 전적으로 비밀이 유지되며 무기명이고 처리 될 것입니다. 괜찮으신가요?

정확한 인터뷰를 위해서 명확한 기록이 요구되고 녹취록 역시 만들어야 됩니다. 저는 이 프로젝트를 위해서 보관을 목적으로 동의서와 연구에 대한 설명지를 드릴 것입니다. 그리고 선생님께서 다음과 같은 부분을 원하실 경우에 인터뷰의 내용이 맞는지 확인하기 위해서 오디오 파일과 녹취록 그리고 연구동의서 및 설명서를 보내드리도록 하겠습니다. 그럼 연구 설명서와 연구동의서를 읽어주시고 이를 위해서 서명해 주시겠습니까? 또한 저는 제가 무슨

연구를 계속 진행하고 있는지에 대해서 선생님에게 연락을 취하도록 할 것입니다. 이제 모든 것이 명료한가요? 혹시 저에게 하시고 싶은 질문이 있으신가요? 그럼 시작해도 될까요?

초기개방형 질문

- 1) 아동호스피스 완화의료진 되고자 결심 했던 계기가 있었다면 이야기해 주실 수 있을까요?

중기 개방형 질문

- 2) 선생님의 경험에 비추어서, 임종이 임종이 임박한 아이들과 그들의 가족들이 두려워 하는 것이 무엇이었나요?
- 3) 아이들과 그들의 부모의 삶의 질을 향상시키기 위해서 선생님이 역할을 수행한 뒤에 무엇이 알겠된 감정이나 생각을 언급해 주실 수 있을까요?
- 4) 어떻게 아동호스피스 사회복지사들이 사정에 기반해서 다양한 완화의료팀들을 통해서 대리인의 의사결정을 지지하거나 혹은 관여 했던 경험에 대해서 이야기 해줄 수 있으신가요?
- 5) 그들의 삶의 질을 높이기위해서 선생님의 역할을 수행함에 있어서 걸림돌들이 있었다면 무엇이었나요?
- 6) 다양한 완화의료팀들 간에 의사소통의 문제가 있었던 일이 있었다면 그 일을 좀 설명해 주실 수 있나요?
- 7) 다양한 완화의료팀들은 환자의 최선의 이익을 고려할 것이고 환자의 대리인도 개인적으로 신중하게 고려하는 가운데 의사결정의 갈등이 야기 될 수 있을 것입니다. 그러나 대리인이 속한 공동체에 다양한 믿음이 대리인의 신중한 의사결정을 방해할 수 있습니다. 이와 같은 일들을 경험한 적이 있다면 이야기 해주실 수 있으신가요?
- 8) 만약 윤이 사별가족 돌봄가운데 이와 같은 사람의 도덕적 가치의 차이를 만든다면 의사결정 이후에 일부 사람들은 비난 받을 수 있고 칭송 받을 수 있습니다. 그 가족들이 새로운 의료 마케팅을 고려했다고 한다면 윤에 대해서 어떻게 생각하시나요?

- 9) 의사결정을 돕길 원했을 때 사회정책 때문에 억압을 받았던 적은 없나요?
- 10) 의사결정 이후 잠정적 문제가 있을 수 있습니다. 그문제는 다른 맥락 안에서 전혀 고려할 수 없었던 인과관계와 같은 문제가 발생할 때, 그 발생한 운에 있어서 도덕적 책임을 느낀 적이 있나요? 그렇다면 그 이야기를 해주실 수 있나요?

끝맺는 질문

- 11) 이와 같은 경험을 기반으로 이후 아동호스피스 사회복지사가 되고자 하는 자들에게 조언을 주실 수 있나요?

- 12) 코멘트나 혹은 아이디어 그리고 제안하고 싶은 부분이 있으시다면 물어봐도 될까요?

인터뷰에 응해주셔서 감사드립니다. 선생님이 필요하시다면, 제가 녹취록과 오디오 파일을 짧은 시간안에 보내드리고록 하겠습니다.

만약 어느때든지 연락하기를 원하시거나 혹은 오늘 언급된 문제가 강조 되어 된다고 여길 시에 언제든지 연락 주세요.

오승훈 010 2089 3115

seunghoon.oh@durham.ac.uk

School of Applied Social Sciences

Durham University

32 Old Elvet

Durham DH1 3HN

만약 선생님께서 이와 같은 인터뷰 방식에 있어서나 이 연구 프로젝트에 대해서 불만이 있다고 할 경우 저의 지도교수님이신 레나 도미넬리에게 이메일로 연락하시면 됩니다.

[lena.Dominelli@durham.ac.uk](mailto:lana.Dominelli@durham.ac.uk)

Interview Guide for Interview with Paediatric Palliative Care Medical Members

Hello, my name is Seounghoon Oh. Thank you very much for agreeing to meet with me. Could I just tell you a bit more about the project that I am involved with and that I am asking you to help us with? The aim of this project is to answer the question of how anti-oppressive virtue ethics can help us to suggest possible ethical model of decision making for practical ways in which there are the problems, associating with surrogate decision-making for terminally ill children in health inequalities, moral luck and oppressions when paediatric palliative care social workers ethically intervene the decision-making. This project will contribute to service users to have a chance to say what they think about the service they receive from social workers who specialise in working in hospice and palliative care and what they would like in the future.

This interview will probably last between one and one-and-a-half hours. But if you need to break or finish, whenever you can have a break or finish. If this is not enough and needed more, I will meet again. Is that okay? Can I just add there are no right or wrong answers; I just want to hear what you think.

I should inform you that the project, and I are entirely independent and separate from the team working with you. It will be completely confidential and anonymous and names will not be used. Is that okay?

For this interview I need to have an accurate record and make a transcript. I will give you a copy of the consent form(s) and information sheet to keep. If you would like one we can send you the consent form(s), information sheet, a copy of the audio and a transcript to correct. Could you read information sheet and the consent form through and sign that for me? I will also try and keep people in touch with what I am doing. Are there any questions? Are you happy to start? [put audio-recorder on]

Initial Open-ended Questions

- 1) Could you tell me what made you decide to become palliative care medical members?

Intermediate Questions

- 2) Regarding your experience, what did you find the differences between terminal children and their family member are afraid of, and adults their family member are afraid?
- 3) Considering adult hospices what are some of the barriers to conducting your role in improving the quality of life for children and their family?
- 4) Tell me about your thoughts and feelings what you learned after referring to children hospice in improving the quality of life?
- 5) Could you describe the events if there were miscommunications between multidisciplinary palliative team members?

- 6) Could you describe the events that there might be conflict over between multidisciplinary palliative team members who concern what is taken to be in the best interest of terminally ill adults and opinions of surrogates who individually pursue the prudence? Due to various beliefs in their community surrogates might hinder prudential decision-making.
- 7) After making the decision some people can be blamed or praised, what if luck made differences in a person's moral worth during bereavement care. What do you think about luck if the surrogates considered new medical marketing?
- 8) Have ever experienced oppressions due to social policy when you want to support the decision making? Could you describe one of the events that you have experienced?
- 9) Would you mind to tell me your experience that you felt some moral responsibility in luck, what if after decision making there were the potential problems such as unexpected cause-effect relationships in other contexts?

Ending Questions

- 10) After having these experiences, what advice would you give to people who want to become paediatric palliative care social workers?
- 11) Could I ask if there are any other comments, ideas or suggestions you would like to offer?

Thank you for all this help with the interview. I will shortly send you a copy of this audio file and a copy of the transcript to correct if you would like one.

If at any time you would like to make contact, if any problems or issues have been highlighted today, please contact.

Seunghoon Oh 07460 838238

seunghoon.oh@durham.ac.uk

School of Applied Social Sciences

Durham University

32 Old Elvet

Durham DH1 3HN

Email only is best:

If you have any complaints about the way in which I have conducted this interview, or research project, please contact my supervisor, Professor Lena Dominelli at lena.dominelli@durham.ac.uk

호스피스 완화의료진과 함께하는 인터뷰 가이드

안녕하세요. 저의 이름은 오승훈입니다. 저의 연구에 동의해주신 것에 대해서 대단히 감사드립니다. 제가 이 연구에 대해서 포함된 부분과 그리고 질문할 부분에 대해서 약간 설명해도 될까요? 이 연구의 목적은 어떻게 반역압적 덕윤리가가 실질적으로 의사결정에 있어서 가능한 제안을 줄 수 있는지를 대답하고자 하는 것 입니다.

아동호스피스완화의료사회복지사들이 대리인의 의사결정에 있어서 관여하게 됩니다. 이때 억압, 도덕적 윤 그리고 보건 불평등이 만연한 현실 가운데 대리인의 의사결정의 문제점들이 다양하게 야기됩니다. 이와 같은 문제점들을 파악하고 해결하고자 실질적인 방법을 고려해서 윤리적인 모델을 제시하고자 하는 것입니다. 이 연구는 이후에 호스피스 이용대상자들이 호스피스 사회복지사들로부터 호스피스 서비스에 대한 부분이 무엇인지를 생각하게 하는 것이며 향후 이들이 무엇을 선호할지에 대한 것을 기여하게 될 것입니다.

이 인터뷰는 아마도 한시간에서 혹은 한시간 반 정도 소요 될 것입니다. 그러나 만약 선생님께서 휴식이 필요하거나 아니면 종결을 원하신다고 하면 어느때든지 쉴 수 있으며 종결 할 수 있습니다. 만약 이 인터뷰가 충분하지 않다거나 혹은 더 필요로 할 경우, 제가 다시 만날 수 있습니다. 그래도 괜찮으신가요? 선생님의 답변에는 옳고 그름도 없다는 것을 꼭 언급하고 싶습니다. 저는 단지 선생님이 무엇을 생각하는지를 듣고자 하는 것입니다. 제가 이 프로젝트에 대해서 언급해야되는 되는 것이 있는데, 이것은 전적으로 독립된 연구이고 선생님이 일하는 팀과도 아무런 관련이 없습니다. 그리고 이것은 전적으로 비밀이 유지되며 무기명이고 처리 될 것입니다. 괜찮으신가요?

정확한 인터뷰를 위해서 명확한 기록이 요구되고 녹취록 역시 만들어야 됩니다. 저는 이 프로젝트를 위해서 보관을 목적으로 동의서와 연구에 대한 설명지를 드릴 것입니다. 그리고 선생님께서 다음과 같은 부분을 원하실 경우에 인터뷰의 내용이 맞는지 확인하기 위해서 오디오 파일과 녹취록 그리고 연구동의서 및 설명서를 보내드리도록 하겠습니다. 그럼 연구 설명서와 연구동의서를 읽어주시고 이를 위해서 서명해 주시겠습니까? 또한 저는 제가 무슨

연구를 계속 진행하고 있는지에 대해서 선생님에게 연락을 취하도록 할 것입니다. 이제 모든 것이 명료한가요? 혹시 저에게 하시고 싶은 질문이 있으신가요? 그럼 시작해도 될까요?

초기 개방형 질문

- 1) 호스피스 사회복지사가 되고자 결심 했던 계기가 있었다면 이야기 해줄 수 있을까요?

중기 개방형 질문

- 2) 선생님의 경험에 비추어서, 임종이 임박한 아이들과 그들의 가족들이 두려워 하는 것과 성인 그리고 그 가족들이 두려워 하는 것의 차이는 무엇이었나요?
- 3) 성인호스피스에서 그들의 삶의 질을 높이기위해서 선생님의 역할을 수행했을 때 걸림돌이 있었다면 무엇이었나요?
- 4) 아이들과 그들의 부모의 삶의 질을 향상시키기 위해서 선생님이 어린이 호스피스로 의뢰했을 때 알겠된 감정이나 생각을 언급해 주실 수 있을까요?
- 5) 다양한 완화의료팀들 간에 의사소통의 문제가 있었던 일이 있었다면 그 일을 좀 설명해 주실 수 있나요?
- 6) 다양한 완화의료팀들은 환자의 최선의 이익을 고려할 것이고 환자의 대리인도 개인적으로 신중하게 고려하는 가운데 의사결정의 갈등이 야기 될 수 있을 것입니다. 그러나 대리인이 속한 공동체에 다양한 믿음이 대리인의 신중한 의사결정을 방해할 수 있습니다. 이와 같은 일들을 경험한 적이 있다면 이야기 해주실 수 있으신가요?
- 7) 만약 윤이 사별가족 돌봄가운데 이와 같은 사람의 도덕적 가치의 차이를 만든다면 의사결정 이후에 일부 사람들은 비난 받을 수 있고 칭송 받을 수 있습니다. 그 대리인들이 새로운 의료 마케팅을 고려했다고 한다면 윤에 대해서 어떻게 생각하시나요?
- 8) 의사결정을 돕길 원했을 때 사회정책으로 때문에 억압을 받았던 적은 없나요?

- 9) 의사결정 이후 잠정적 문제가 있을 수 있습니다. 그문제는 다른 맥락 안에서 전혀 고려할 수 없었던 인과관계와 같은 문제가 발생할 때, 그 발생한 운에 있어서 도덕적 책임을 느낀적이 있나요? 그렇다면 그 이야기를 해주실 수 있나요?

끝맺는 질문

- 10) 이와 같은 경험을 기반으로 이후 아동호스피스 사회복지사가 되고자 하는 자들에게 조언을 주실 수 있나요?

- 11) 컨멘트나 혹은 아이디어 그리고 제안하고 싶은 부분이 있으시다면 물어봐도 될까요?

인터뷰에 응해주셔서 감사드립니다. 선생님이 필요하시다면, 제가 녹취록과 오디오 파일을 짧은 시간안에 보내드리고록 하겠습니다.

만약 어느때든지 연락하기를 원하시거나 혹은 오늘 언급된 문제가 강조 되어 된다고 여길 시에 언제든지 연락 주세요.

오승훈 010 2089 3115

seunghoon.oh@durham.ac.uk

School of Applied Social Sciences

Durham University

32 Old Elvet

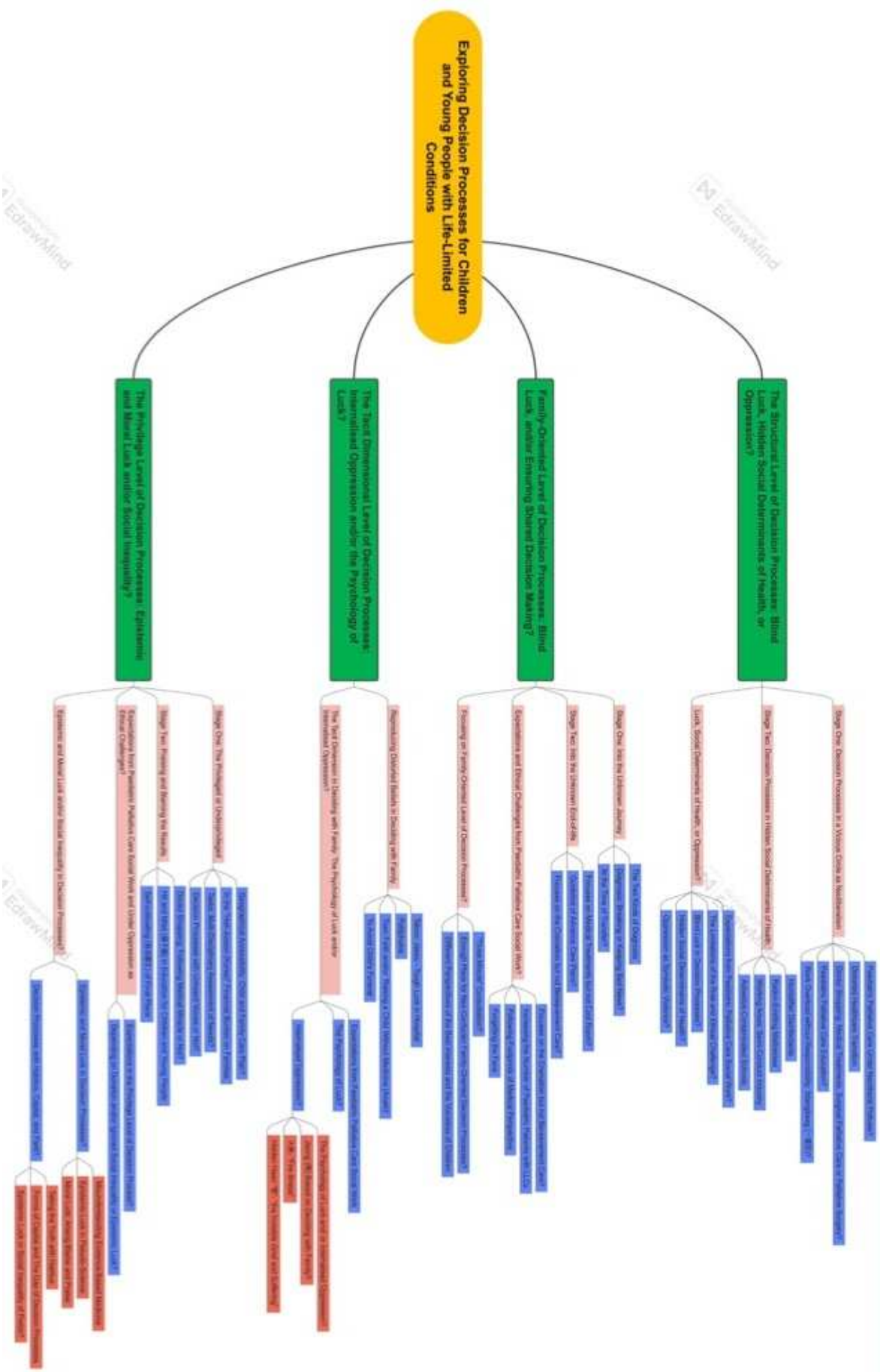
Durham DH1 3HN

만약 선생님께서 이와 같은 인터뷰 방식에 있어서나 이 연구 프로젝트에 대해서 불만이 있다고 할 경우 저의 지도교수님이신 레나 도미넬리에게 이메일로 연락하시면 됩니다.

lena.dominelli@durham.ac.uk

Using Atlas.ti to Generate Codes for Qualitative Data Analysis

Code Manager			
Children and Young People with LLCs for Decision Processes			
Codes		Groups	Comment
No document group			
<input type="radio"/> Ethics in VR	1	0	0
<input type="radio"/> Ethics of Labour	1	0	0
<input type="radio"/> Job dissatisfaction and career mo...	1	0	0
<input type="radio"/> Life-Threatening Conditions	1	0	0
<input type="radio"/> Raising Child without Medicine - A...	1	0	0
<input type="radio"/> Sexual harassment	1	0	0
<input type="radio"/> Team Work as Ethics of Labour?	1	0	0
<input type="radio"/> The Psychology of Luck	1	0	0
<input type="radio"/> Virtue	1	0	0
<input type="radio"/> Blind Luck	2	0	0
<input type="radio"/> National Core Technology	2	0	0
<input type="radio"/> School Social Work	2	0	0 School Social Workers do not know what they...
<input type="radio"/> Jeong—The Invisible Hug from Ch...	3	0	0 2/29/24, 3:26 PM, merged with 정?
<input type="radio"/> VR in Bereavement Care	3	0	0
<input type="radio"/> Cremation but not Berevement Care	4	0	0
<input type="radio"/> Palliphobia	4	0	0
<input type="radio"/> Taboo Jaesu	4	0	0
<input type="radio"/> EBM but How to explain for people?	5	0	0
<input type="radio"/> Epistemic Luck	5	0	0
<input type="radio"/> Moral Luck	5	0	0
<input type="radio"/> The Right of Treatment and Rehabi...	5	0	0
<input type="radio"/> the right to receive comfortable tr...	5	0	0
<input type="radio"/> Asbestros	6	0	0
<input type="radio"/> Blind Luck or Health Inequality	6	0	0
<input type="radio"/> Internalised Oppression	6	0	0
<input type="radio"/> Self-Cultivating of Final Place	6	0	0
<input type="radio"/> The Right of Enhanced Health	6	0	0
<input type="radio"/> The Right to Adaptation	6	0	0
<input type="radio"/> Industrial health services	7	0	0 "Industrial health services must protect worker...
<input type="radio"/> Discriminated Words in Korea	9	0	0
<input type="radio"/> Survivors with Cancers	9	0	0
<input type="radio"/> Compassion	10	0	0



Seunghoon, I completed this course and condensed the material into a concise summary of the SBR Investigator/Researcher - Basic Course. Subsequently, I underwent an examination. Upon receiving the outcome, he becomes eligible to submit a research project, following the result.

Report of Institutional Review Board

Requester: Durham University

This letter is to inform you of the results of your confidential.

Type of Review	<input type="checkbox"/> Initial Review <input checked="" type="checkbox"/> Response for Approved with Modification <input type="checkbox"/> Deferred <input type="checkbox"/> Tabled <input type="checkbox"/> Modification <input type="checkbox"/> cancellation of protocol <input type="checkbox"/> end of study report <input type="checkbox"/> final report <input type="checkbox"/> interim report <input type="checkbox"/> others		
IRB No.	4-2017-0866	Date of approval	Nov.3 rd ,2017
Title of Proposal	Deciding with Children and Young People: Korean Paediatric Palliative Care		
	Protocol No.	Version No.	
Investigator	-Principal Investigator: Jung Woo Han, MD / Assistant Professor / Pediatric Hematology and Oncology/ Yonsei University College of Medicine -Sub Investigator: Seung hoon Oh / Researcher / Durham University		
Generic name	-	Brand Name	-
Phase	<input type="checkbox"/> Phase I <input type="checkbox"/> Phase II <input type="checkbox"/> Phase III <input type="checkbox"/> Phase IV <input type="checkbox"/> Biological equivalence test <input checked="" type="checkbox"/> Others		
Proposed period of study	Approval date of IRB ~ for 24 months		
Contents of Review	* A written answer of review result * List of change on protocol review 1. Application Form 2. Study Protocol 3. Case Report Form 4. Informed Consent Form 5. Recruitment announcement 6. CV for Investigator		
Date of Review	Nov.3rd,2017		
Result of Review	<input checked="" type="checkbox"/> Approved <input type="checkbox"/> Approval with Modification <input type="checkbox"/> Deferred <input type="checkbox"/> tabled		
Comment	None		

Severance Hospital IRB is organized and operates according to ICH-GCP and the applicable laws and regulations

Nov 3rd 2017
 Seung Min Kim, MD, PhD
 Chairperson of Institutional Review Board
 Severance Hospital
 Yonsei University, College of Medicine
 Seoul 03722, Korea

SBR Investigator/Researcher - Basic Course

1 History and Ethical Principles - SBR

Lisa Robinson Bailey, MA Duke University

This module discusses the three key ethical principles of the *Belmont Report* as they relate to research in the social and behavioral sciences, education, and the humanities.

Introduction

Research with human subjects has a long and often troubled history in the U.S. and throughout the world. Chances are you have already heard of some of the most egregious-and famous-examples of unethical research in the biomedical sciences, such as the experiments conducted by Nazi doctors and scientists on concentration camp prisoners during World War II and the Tuskegee Study of Untreated Syphilis in the Negro Male, conducted by the U.S. Public Health Service. These abuses led to the creation of codes of research ethics in Europe and the U.S. In the wake of the Second World War, the Subsequent Nuremberg Trials on war crimes produced the Nuremberg Code, which outlined ten points for conducting ethical research with human subjects. Nearly two decades later, the World Medical Association developed a code of research ethics, known as the Declaration of Helsinki, published in 1964 and subsequently revised. This document built on both the Nuremberg Code and physicians' code of ethics known as the Declaration of Geneva by adapting the existing guidelines to address the growing field of clinical research.

In the U.S., news that researchers deceived and withheld treatment from subjects in the Tuskegee Study, led to the creation of the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. The National Commission was charged with the establishing a code of research ethics for U.S. research with human subjects. In 1979, the Commission issued the *Belmont Report*, the foundational document of the current system of U.S. human subjects protections. The *Belmont Report* outlines three key ethical principles for conducting research with human subjects: respect for persons, beneficence, and justice. The *Belmont Report*, in turn, informed the U.S. Department of Health and Human Services' (HHS) Code of Federal Regulations (45 CFR 46), created in 1974 and later revised. In 1991, Subpart A of these regulations (Basic HHS Policy for the Protection of Human Research Subjects) was adopted by 15 federal agencies and became known as "the Common Rule."

Landmark social sciences studies such as Milgram's Obedience to Authority Study, Zimbardo's Stanford Prison Experiment, and Humphreys's Tearoom Trade Study, made it clear that social and behavioral research may carry risks of harm related to psychological wellbeing, violations of autonomy and privacy, and reputational damage. Despite good intentions and best efforts, researchers are not always able to anticipate risks of harm. This module aims to bring human subjects protections into focus for investigators in the social and behavioral sciences, education, and the humanities by examining the complex issues raised by research with human subjects and how these issues may be addressed using the ethical principles outlined in the *Belmont Report*.

Excerpts of the *Belmont Report* appear below in italics. The full report (approximately seven pages long) provides the conceptual foundation for the federal regulations and the conduct of research with human subjects and is recommended reading.

Learning Objectives

By the end of this module, you should be able to:

- Understand the historical context of the *Belmont Report*
- Identify the three ethical principles described in the *Belmont Report*
- Perceive the relationship between the Belmont principles and the federal regulations
- Provide examples of how the ethical principles can be applied to research in the social and behavioral sciences, education, and the humanities

Ethical Principles of the *Belmont Report*

The ethical principles described in the *Belmont Report*, also known as the Belmont principles, lay out the fundamental ethical considerations for research with human subjects. The principles can readily be applied to non-medical and medical research alike.

Respect for Persons

Respect for persons incorporates at least two ethical convictions: first, that individuals should be treated as autonomous agents, and second, that persons with diminished autonomy are entitled to protection. The principle of respect for persons thus divides into two separate moral requirements: the requirement to acknowledge the autonomy and the requirement to protect those with diminished autonomy.

Autonomy

Autonomy means that people must be empowered to make decisions concerning their own actions and wellbeing. According to the principle of respect for persons, researchers must acknowledge the "considered opinions and choices" of research subjects—in other words, individuals must be given the choice whether to participate in research or not, and they must be provided with sufficient information and possess the mental competence to make that choice.

Mental Capacity

Respect for persons also recognizes that some individuals may not be capable of making decisions or choices that are in their own best interest. Individuals with "diminished decision-making capacity" may lack the ability to comprehend study procedures or how participating in a study might adversely affect them. Special care should be taken to protect those with diminished capacity to the point of excluding individuals who are not able to give meaningful consent to participate in research.

Children are a class of research subject with limited autonomy. Typically, a parent or guardian must give permission for a child to participate in a study. Researchers should also ask child subjects for their assent by explaining the study in terms they can understand.

Respect for persons demands that subjects enter into research voluntarily and with adequate information.

Voluntariness

Voluntariness is an essential component of respect for persons. Research subjects must be free to choose to participate in research and to end their participation for any reason, without consequences.

Voluntariness means more than offering people the choice to participate in or withdraw from research. Researchers should be aware of situations in which prospective subjects might feel pressured to participate in a study. In situations where a relationship between the investigator and subjects already exists, such as when a volunteer at a homeless shelter decides she wants to conduct research with that population, the lines between voluntariness and undue

influence may be blurred. People might be reluctant to decline participation if they have come to know the investigator in another, more personal capacity.

Other examples of situations in which researchers may exert undue influence because of being in a position of authority:

- Employer conducting research in which subjects are employees
- Professor conducting research in which the subjects are his students

Informed Consent

A prospective research subject's autonomy is honored through the process of informed consent. The Office for Human Research Protections (OHRP) offers these guidelines: "The informed consent process involves three key features: (1) disclosing to potential research subjects information needed to make an informed decision; (2) facilitating the understanding of what has been disclosed; and (3) promoting the voluntariness of the decision about whether or not to participate in the research" (U.S. Department of Health and Human Services 2011).

Researchers must provide certain essential points of information, such as the purpose of the research, a description of what the subject will be asked to do, any foreseeable risks of harm, and that the study is voluntary and subjects are free to withdraw at any time.

Informed consent must also be comprehensible to prospective subjects. Comprehension is the ability to understand what one is being asked to do, as well as the implications of any risks of harm associated with participating in the research. Comprehension may refer to an individual's mental capacity, but it also relates to the comprehensibility of the informed consent document, or, in the case of oral consent, the script. Investigators should create consent processes that are at an appropriate language level for the subject population. Study information can be presented in a conversational style that is easily understood by a wide range of individuals. In general, an 8th grade reading level or lower is advised.

When conducting research in a language other than the investigator's native language, the investigator needs to ensure that the translation is accurate and addresses idiomatic expressions that may not make sense in another language.

The Principles in Practice

In Laud Humphreys's study, detailed in his book *Tearoom Trade: Impersonal Sex in Public Places*, the researcher observed men meeting other men for casual sexual encounters in public restrooms. Humphreys, then a sociology graduate student, gained the confidence of the men by pretending to be a participant and acting as a lookout. While Humphreys eventually revealed himself as a researcher to some of the men and was able to interview them openly, he withheld his identity from many others, recording the license plate numbers of a subset of 100 other tearoom regulars in order to contact them for interviews later. A year after completing the observational part of the study, Humphreys followed up with these subjects, including them in separate social health study that enabled him to conduct in-home surveys and gather data about their family relationships and religious background. In a 1970 article taken from his book, Humphreys maintained that the researcher's obligation to protect respondents from harm was a critical ethical assumption. To avoid being recognized by the interview subjects, Humphreys changed his appearance and the kind of car he drove.

I already knew that many of my respondents were married and that all were in a highly discreditable position and fearful of discovery. How could I approach these covert deviants for interviews? By passing as deviant, I had observed their sexual behavior without disturbing it. Now, I was faced with interviewing these men (often in the presence of their wives) without destroying them (Humphreys 1970).

Although the resulting book, based on Humphrey's dissertation, may have been beneficial in dispelling some stereotypes, the research violated the autonomy of the individuals who became part of Humphreys's study without their knowledge.

Humphreys's research occurred in a different regulatory environment, prior to the creation of the National Commission and the codification of federal regulations protecting human subjects. A more recent example of research that obtained personal information about individuals without their knowledge is the Harvard "Tastes, Ties, and Time (T3)" study (2006-2009). Sociologists at Harvard University gleaned voluminous and detailed personal information from the Facebook profiles of an entire class of undergraduates and followed those students over four years. The research team created an extensive data set that included students' gender, home state, major, political and group affiliations, friend networks, photographs, and tastes in music, books, and film. In 2008, the researchers made the data publicly available through the Dataverse Network Project. Although no students were identified by name, some of data were specific enough to allow for re-identification of students by an outside researcher (Zimmer 2010; Parry 2011).

In both of these studies, the ethical concerns are invasion of privacy, lack of informed consent, and a failure to protect against deductive disclosure of identity.

Beneficence

Persons are treated in an ethical manner not only by respecting their decisions and protecting them from harm, but also by making efforts to secure their well-being. Such treatment falls under the principle of beneficence. The term 'beneficence' is often understood to cover acts of kindness or charity that go beyond strict obligation. In this document, beneficence is understood in a stronger sense, as an obligation. Two general rules have been formulated as complementary expression of beneficent actions in this sense: (1) do not harm and (2) maximize possible benefits and minimize possible harms.

Most research in the social and behavioral sciences, education, and the humanities does not provide direct benefit to subjects, and risks of harm tends to be minimal. The most common risks of harm are psychological distress surrounding sensitive research topics and inadvertent disclosure of private information. Studies of sexuality, mental health, interpersonal violence, and illegal activities expose subjects to possible feelings of distress as well as risk of embarrassment and reputational harm if private information that would not ordinarily be shared with a stranger or outsider becomes public. Researchers may choose to use pseudonyms in an effort to protect the confidentiality of subjects, but other bits of information, taken alone or in combination, may be enough to allow for re-identification of subjects.

A great deal of research in the social and behavioral sciences, however, involves minimal risk procedures, such as gathering and reporting on aggregate data using surveys and interviews. Some research involves manipulations and deception, both of which are permissible if investigators provide justification for such measures in the protocol. The protocol should also contain adequate debriefing procedures when the research involves deception.

Frequently, it is not the nature of the data collected but what the researcher does with the data that carries the most risk of harm for subjects. Data security and the very notion of privacy have changed dramatically with the explosion of social media, cloud storage, data mining of web-based information, and re-identification techniques.

Refraining from collecting subject names is a simple way of reducing risk of harm due to inadvertent disclosure of private information. As we have seen from the Harvard T3 study, however, it is rarely sufficient as data re-identification has emerged as growing computer science specialization. Latanya Sweeney, director of the Data Privacy Lab at Harvard, has demonstrated that 87% of Americans can be uniquely identified by only three bits of demographic information: five-digit zip code, gender, and date of birth (Sweeney 2000).

The Principles in Practice

Some studies in social and behavioral sciences have the potential to cause psychological and even physical distress. The "Stanford Prison Experiment," Philip Zimbardo's 1971 landmark psychological study of the human response to captivity and, in particular, prison life, assigned roles to normal male student volunteers to create groups of "prisoners" and "guards." The research became so intense as physical and psychological abuse of "prisoners" by "guards" escalated that several of the subjects experienced distress less than 36 hours after the study began. Zimbardo's study, like Humphreys's, occurred in a different regulatory environment, before the advent of the *Belmont Report*. Zimbardo did submit his protocol to an ethics board, but the consent process contained no provisions allowing subjects to withdraw at will, and no risks of harm beyond loss of privacy were addressed. According to Zimbardo (2012), the consent form signed by the subjects only allowed them "to be released from participation for reasons of health deemed adequate by the medical advisers to the research project or for other reasons deemed appropriate by Dr. Philip Zimbardo..." Zimbardo did not stop the experiment until six days had passed.

Other risks of harm may be social or reputational. Upon the publication of the 20th anniversary edition of her 1977 book, *Saints, Scholars and Schizophrenics: Mental Illness in Rural Ireland*, ethnographer Nancy Scheper-Hughes's reflected upon failing to protect the confidentiality and dignity of her subjects, who felt that she had violated their trust and depicted the community in an unflattering light. Scheper-Hughes commented that, in retrospect, the use of pseudonyms and misleading indirect identifiers was inadequate as a confidentiality measure, because the subjects were easily able to identify themselves and their neighbors in Scheper-Hughes's written account.

I would be inclined to avoid the 'cute' and 'conventional' use of pseudonyms. Nor would I attempt to scramble certain identifying features of the individuals portrayed on the naïve assumption that these masks and disguises could not be rather easily de-coded by the villagers themselves. I have come to see that the time-honored practice of bestowing anonymity on 'our' communities and informants fools few and protects no one—save, perhaps, the anthropologist's own skin (Scheper-Hughes 2000).

Studies focusing on political violence or other illicit activities may expose subjects to legal harms. The ongoing legal issues surrounding the Boston College Oral History Archive of the Troubles in Northern Ireland demonstrate the difficulty of promising confidentiality to subjects. Former members of the Irish Republican Army who agreed to be interviewed only if their accounts would remain sealed until their deaths have found themselves subject to prosecution by the British government for the murder of an informant, based on details shared by themselves and other IRA members (Dwyer 2011).

Justice

Who ought to receive the benefits of research and bear its burdens? This is a question of justice, in the sense of 'fairness in distribution' or 'what is deserved.' An injustice occurs when some benefit to which a person is entitled is denied without good reason or when some burden is imposed unduly. Justice requires that the benefits and burdens of research are equitably distributed—that is, no single individual or population are exposed to risks of harm while other individuals or populations receive the benefits. One example is cited in the Belmont Report: "During the 19th and early 20th centuries the burdens of serving as research subjects fell largely upon poor ward patients, while the benefits of improved medical care flowed primarily to private patients." The Tuskegee Syphilis Study and Nazi experiments on concentration camp inmates are well-documented examples of research injustices.

Similarly, researchers are discouraged from using prisoners, literally a captive population, as research subjects merely because they are a convenient study population. To conduct research with prisoners, the onus is on researchers to demonstrate that the subjects, as members of broader society, stand to benefit at least indirectly from the proposed study.

In the context of examples such as the Tuskegee Study and the Nazi experiments, injustice is obvious. In non-medical research, however, the issue of justice presents in more nuanced ways. Lawrence O. Gostin, a professor of global health law at Georgetown University, speaks to an ethical duty to research subjects that goes beyond non-harming. "In thinking about justice toward subjects, researchers need to consider equitable selection so that individuals are chosen on the basis of factors clearly relevant to the problems being studied. Researchers also need to consider

equitable distribution of advantages to research subjects and others who could benefit from the knowledge gained by the research" (Gostin 1991).

Psychologist Joan E. Sieber maintains that the research question itself, as well as the interpretation of the data, may contain an inherent bias that singles out a particular group of subjects and leads to or reinforces unjust treatment of that group: "One historically sensitive area of the application of research findings is examining racial differences. Another example relates to the use of psychological test results in order to promote a policy of sterilization for the mentally retarded population" (Sieber 1988). On the issue of justice, Sieber summarizes, "Justice and equitable treatment refer to issues of procedural and distributive justice that may arise at any stage of the research process. An idea that creates prejudices against some sector of society is unfair. An experimental treatment is also unfair if resources known to be vital to subjects' well-being are withheld from subjects in one group and given to those in another" (Sieber 1988).

The Principles in Practice

In some kinds of research, for example, in educational research testing a new curriculum or teaching method, subjects in the treatment group may derive benefits from the intervention while subjects in the control group do not have access to that intervention. If the program being tested is specific to that age group, the control group participants would not have the opportunity to benefit from that intervention in the future.

Balancing the Three Principles

It was the Commission's intention that each of the three principles should have equal moral force. This means that in some situations, the three principles might be in conflict with one another. For example, we might derive from the principle of respect for persons that we should limit the involvement of children in research because children are unable to choose for themselves. However, we might derive from the principle of justice that we must involve children in studies so that children will have the opportunity to benefit from the research. The *Belmont Report* states that one principle does not always outweigh another. Rather, we are required to consider each case separately and on its own merits while seeking to uphold all three principles.

The issue of deception in research illustrates this tension between principles: when an Institutional Review Board (IRB) feels the use of deception is justified and the risks of harm are minimal, beneficence and justice override the principle of respect for persons. For example, in studies of social rejection, experimental manipulations may be used to make subjects feel rejected in order to obtain valid data.

The Belmont Report and the Common Rule

The regulations list criteria (45 CFR 46.111) for IRB approval of a research protocol that are directly related to the three Belmont principles as follows:

Beneficence

- "Risks to subjects are minimized: (i) By using procedures which are consistent with sound research design and which do not unnecessarily expose subjects to risk, and (ii) whenever appropriate, by using procedures already being performed on the subjects for diagnostic or treatment purposes."
- "Risks to subjects are reasonable in relation to anticipated benefits, if any, to subjects, and the importance of the knowledge that may reasonably be expected to result. In evaluating risks and benefits, the IRB should consider only those risks and benefits that may result from the research (as distinguished from risks and benefits of therapies subjects would receive even if not participating in the research). The IRB should not consider possible long-range effects of applying knowledge gained in the research (for example, the possible effects of the research on public policy) as among those research risks that fall within the purview of its responsibility."

- "When appropriate, the research plan makes adequate provision for monitoring the data collected to ensure the safety of subjects."
- "When appropriate, there are adequate provisions to protect the privacy of subjects and to maintain the confidentiality of data."

Justice

- "Selection of subjects is equitable. In making this assessment the IRB should take into account the purposes of the research and the setting in which the research will be conducted and should be particularly cognizant of the special problems of research involving vulnerable populations, such as children, prisoners, pregnant women, mentally disabled persons, or economically or educationally disadvantaged persons."

Respect for Persons

- "Informed consent will be sought from each prospective subject or the subject's legally authorized representative, in accordance with, and to the extent required by §46.116."
- "Informed consent will be appropriately documented, in accordance with, and to the extent required by §46.117."
- "When appropriate, there are adequate provisions to protect the privacy of subjects and to maintain the confidentiality of data."
- "When some or all of the subjects are likely to be vulnerable to coercion or undue influence, such as children, prisoners, pregnant women, mentally disabled persons, or economically or educationally disadvantaged persons, additional safeguards have been included in the study to protect the rights and welfare of these subjects."

Summary

Historical events and contemporary abuses inform the development of ethics related to the protection of human research subjects. The *Belmont Report*, along with federal regulations and professional codes of ethics, offer guidance for IRB review, based on three key ethical principles: respect for persons, beneficence, and justice.

Sources Cited

- Dwyer, Jim. 2011. "[Secret Archive of Ulster Troubles Faces Subpoena](#)." *New York Times*, May 13.
- Gostin, Lawrence. 1991. "Ethical Principles for the Conduct of Human Subject Research: Population-Based Research and Ethics." *The Journal of Law, Medicine & Ethics* 19 (3-4): 191-201.
- Humphreys, Laud. 1970. "Tearoom Trade: Impersonal Sex in Public Places." *Society* 7 (3): 10-25. doi: 10.1007/BF02812336.
- Parry, Marc. 2011. "[Harvard Researchers Accused of Breaching Students' Privacy](#)." *The Chronicle of Higher Education*, July 10.
- Scheper-Hughes, Nancy. 2000. "Ire in Ireland." *Ethnography* 1 (1):117-140.

- Sieber, Joan E., and Barbara Stanley. 1988. "Ethical and professional dimensions of socially sensitive research." *American Psychologist* 43 (1): 49-55. doi: 10.1037/0003-066X.43.1.49.
- Sweeney, Latanya. 2000. "[Simple Demographics Often Identify People Uniquely](#)." Data Privacy Working Paper 3: 1-34.
- U.S. Department of Health and Human Services, Code of Federal Regulations, 45 CFR § 46 (2009).
- U.S. Department of Health and Human Services. 2011. "[What is informed consent and when, why, and how must it be obtained?](#)" Informed Consent - FAQs. Last modified January 20.
- Zimbardo, Philip. 2012. "[Stanford Prison Experiment](#)". Date Accessed June 6.
- Zimmer, Michael. 2010. "'But the data is already public': on the ethics of research in Facebook." *Ethics and Information Technology*. 12:313-325. doi: 10.1007/s10676-010-9227-5.

2 Defining Research with Human Subjects – SBR

Lorna Hicks, M.S., CIP Duke University

Introduction

One of the first questions researchers must ask is if the activity they propose to conduct is, in fact, research. If they determine it is research, the next question is to ask is if the activity involves human subjects. These are important because the answers determine if the activity is subject to IRB oversight. Federal regulations for protecting research subjects provide basic definitions of "research" and of "human subjects." This module will interpret words and phrases used in the definitions from the perspective of research in the social and behavioral sciences and the humanities.

Learning Objectives

By the end of this module, you should be able to:

- Explain the definition of research
- Explain the definition of human subject
- Describe the differences between private and public information and behavior

Defining "Research"

Research is defined by the federal regulations, as "a systematic investigation including research development, testing and evaluation, designed to develop or contribute to generalizable knowledge."

"Systematic investigation"

A great deal of research in the social and behavioral sciences uses what is commonly thought of as the scientific method. However, the interpretation of the term "systematic investigation" depends largely upon discipline-specific methods. It is possible for research to be systematic without conforming in every respect to the elements of the conventional scientific method. For example, when ethnographers study communities, they may not have *a priori* hypotheses, but many aspects of their research may be systematic including the selection of subjects, decisions about what observations to record, and their interview process.

"Including research development, testing, and evaluation"

Pilot studies, feasibility studies, and other preliminary studies clearly fall under the definition of research. Both of the following preliminary components of a study constitute research with human subjects:

- A focus group of Latino immigrants to help researchers develop a questionnaire about how sexually transmitted diseases are transmitted across borders.
- Pilot testing of a questionnaire before the administration of the questionnaire and analysis of the results.

"Designed to develop or contribute to generalizable knowledge"

To generalize is to derive general conclusions from particulars. Generalizable knowledge is a goal of most basic research. Even research about the most narrowly defined topic, such as an individual case study or the study of an isolated community, may be intended to contribute to a body of knowledge such as the function of culture, the expression of gender, or the political views of marginalized community members.

Some researchers in the social and behavioral sciences and humanities contend that the regulations were designed to govern only biomedical research. They then, reasonably, assume that "generalizable knowledge" is only that which is hypothesis driven, quantitative, and replicable. While it is true that abuses in biomedical research drove the development of the current regulations, the regulations were designed to cover all research with human subjects. The regulations specifically refer to interviews, oral history, focus groups, and other qualitative methods. Therefore, the concept of "generalizable knowledge" has to be broadened. (The development of drugs, biologics, and medical devices is governed by a separate set of regulations developed by the U.S. Food and Drug Administration.)

An essential consideration is whether it was the intent of the researcher to contribute to generalizable knowledge. Some activities that involve interactions with humans and data gathering may not fit the definition of research with human subjects, because they are designed to accomplish something else, such as in-house quality improvement. For example, a survey of college students about university counseling services may be designed strictly to improve service delivery for students on that campus, and thus does not meet the definition of generalizability.

Publication of results in a peer-reviewed journal is sometimes used as a measure of whether research is generalizable, but this is too narrow a measure for several reasons. First, not every study will produce results worthy of publication. Second, there are multiple ways in which results can be made available to others without being published in a peer-reviewed journal. Results may be presented at a conference or made the subject of a seminar. They may be shared with colleagues through the Internet or appear in a dissertation.

Defining "Human Subject"

According to the regulations, a human subject is a "living individual about whom an investigator (whether professional or student) conducting research obtains:

Data through intervention or interaction with the individual, or Identifiable private information."

The following four sections will consider key words and phrases in the definition.

"A living individual"

Research about people who are deceased, such as historical research, does not meet the definition of research with human subjects.

"About whom"

Most research in the social and behavioral sciences involves gathering information **about** individuals. However, some research that involves interactions with people does not meet the regulatory definition of research with human subjects because the focus of the investigation is not the opinions, characteristics, or behavior of the individual. In other words, the information being elicited is not about the individual ("whom"), but rather is about "what".

For example, if a researcher calls the director of a shelter for battered women and asks her for the average length of stay of the women who use the shelter, that inquiry would not meet the definition of research with human subjects because the information requested is not "about" the director. If the researcher interviewed the director about her training, experience, and how she defines the problem of battering, then the inquiry becomes about her - and thus "about whom."

"Interactions"

Interactions include communication or interpersonal contact between the subject and the researcher. Communication does not have to be face to face, and may even exist entirely on paper or in electronic realms. Participant observation is a variant of interaction, often including both formal and informal interviews in addition to observation.

"Interventions"

Interventions include physical procedures through which data are gathered, such as measuring brain function to supplement paper and pencil inquiries into the development of language and behavioral interventions such as experimental education programs or unproven psycho-social therapies. They also include manipulation of the subject or the subject's environment performed for research purposes, for example, studies investigating the effect of music on memory.

"Identifiable private information"

As defined in the regulations, private information includes:

- Information about behavior that occurs in a context in which an individual can reasonably expect that no observation or recording is taking place

- Information which has been provided for specific purposes by an individual and which the individual can reasonably expect will not be made public (for example, a school record).

The regulations further state that private information must be individually identifiable (that is, the identity of the subject is or may be readily ascertained by the researcher or associated with the information) in order for obtaining the information to constitute research with human subjects.

The following two sections will expand on the definition of identifiable private information.

Observing and Recording Private Behavior

It is important to keep in mind that whether a setting is public is, by federal definition, determined in large part by the potential subjects' expectations of privacy, rather than any absolute distinctions between public and private spaces. For example, one might expect that certain behavior, even if conducted in public spaces, is in fact private, such as a conversation in a public park. It is reasonable to assume that one might expect not to be taped while dining with a date at a restaurant.

Researchers who wish to obtain information in a context in which subjects would have a reasonable expectation of privacy may choose to use covert observation (concealed recording devices and videotaping or use of a one-way mirror) or assume a role in the setting or group being studied. Such studies raise significant concerns about violation of privacy and require additional protections and safeguards for subjects. Observational studies in quasi-public places, for example, hospital emergency rooms or state psychiatric hospital wards, may also raise such concerns.

Private Information Provided by Individuals for Specific Purposes

Individuals provide personal information with the expectation that it not be made public in a variety of settings, for example, at work, at school, when receiving health care, or as a member of an organization.

Some of this information is protected by law. For example, school records are protected by the Family Education Rights and Privacy Act (FERPA). Similarly, private health information is protected by the privacy provisions of the Health Insurance Portability and Accountability Act (HIPAA). Generally, although there are exceptions, school and medical records can only be released with express written permission.

Data files including identifiable private information are compiled and maintained by both public and private institutions. Owners of identifiable data impose restrictions on the use of the data. They may release de-identified data publicly, but only release identifiable data to investigators with IRB-approved data protection plans.

Summary

The definitions of "research" and "human subject" are essential for determining which research activities are subject to regulation and review. Important concepts include generalizability, identifiability, and public versus private information.

3 The Regulations and The Social and Behavioral Sciences

– SBR

Lorna Hicks, M.S., CIP Duke University

Introduction

Researchers in the social and behavioral sciences and the humanities often assert that the regulations for the protection of human research subjects do not really apply to the kind of research that they do, believing that the rules were written exclusively for biomedical research. There is a kernel of truth in this because revelations in the early 1970s about egregious medical experiments provided the impetus for developing federal standards for protecting human research subjects.

However, a close reading of the regulations will find mention of research methods and topics of inquiry relevant for researchers in the social and behavioral sciences and the humanities. Methods include surveys, interviews, focus groups, oral history, participant observation, observations of public behavior, and the analysis of existing data. Topics include research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior.

In addition to explicitly identifying these methods, the regulations include provisions that allow for appropriate review of social science, humanities, and behavioral research. For example, the regulations:

- Identify research activities that are low risk, for example, a survey in which no identifiers are collected, and that are thus exempt from the remaining provisions of the regulations, such as the requirement for continuing review.
- Identify research activities with no more than minimal risk that can be reviewed by one or more Institutional Review Board (IRB) members, rather than at a convened IRB meeting.
- Allow for waivers of the requirement to obtain written consent, for example, in a study of undocumented workers.
- Include provisions that permit researchers to withhold information in the consent process. This provision is important when some degree of deception is required in order to obtain valid results.
- Allow for the amendment of approved protocols. This process can be used effectively when it is not possible to know at the outset how a study will evolve, for example when the study employs community-based participatory research methods.
- Require that IRBs have the necessary competence to review specific research activities.

This module will provide an overview of the federal regulations so that researchers can become conversant with their basic provisions. The full [text of the regulations](#) is available on line. For a complete discussion about the flexibility in the regulations regarding the consent process, see the module Informed Consent.

Learning Objectives

By the end of this module, you should be able to:

- Determine whether research is exempt from the regulations or not
- Describe the criteria for expedited and full board review
- Summarize the authority of an IRB
- Describe the kinds of review that approved research may need

Title 45 Code of Federal Regulations Part 46: Protection of Human Subjects

The Department of Health and Human Services (DHHS) regulations are sometimes referred to as 45 CFR 46, a label that identifies their location in the Code of Federal Regulations. You will probably see 45 CFR 46 quoted in your institution's policies and resource materials.

Subpart A of 45 CFR 46 is often referred to as the "Common Rule." Although these regulations were first drafted and adopted by DHHS, most departments that fund research in the social and behavioral sciences, including the National Science Foundation and the Department of Education, subsequently adopted the regulations as part of their own Codes of Federal Regulations.

Additional Protections for Vulnerable Subjects

Three subparts have been added to the basic provisions, Subpart A, of the federal regulations:

- Subpart B: Pregnant women, human fetuses, and neonates
- Subpart C: Prisoners
- Subpart D: Children

Note: The additional protections for prisoners and children are covered in other modules and will not be discussed here. The additional protections for pregnant women, human fetuses, and neonates are most relevant in biomedical research.

Some federal agencies that adopted the Common Rule have also adopted some or all of the other subparts of the DHHS regulations, but others have not. For example, while the Department of Education has adopted the additional protections for children, the National Science Foundation has not.

Assurances with the Office for Human Research Protections

Every institution conducting research with federal support is required to enter into an agreement called an "assurance." Most assurances are negotiated with the DHHS' Office for Human Research Protections (OHRP). An assurance identifies the regulations for protecting research subjects that the institution will follow and the ethical principles it will adopt. In the United States these are the Common Rule and the Belmont Report. The assurance also states how broadly the institution will apply the Common Rule and the additional subparts. Some institutions apply the Rule to all research regardless of the source of funding. This means that the Rule would apply to research funded by foundations, associations, internal award programs, all other sources of research support, and even when research is not funded. Some institutions also choose to apply the additional Subparts B, C, and D, to all research regardless of the source of funding. Others choose to apply the subparts only to federally funded research.

Content of the Federal Regulations

The federal regulations for protecting research subjects describe:

- What research must be reviewed
- Who must review it
- What questions should be addressed during a review
- What kinds of review need to take place during the life of a project

It is important to note that the federal regulations are intended to provide minimum standards and may be supplemented by institutional policy.

What Must Be Reviewed

The first step in deciding whether a project needs review is to determine whether it meets the definition of research with human subjects. If it doesn't meet the definition, it doesn't require review by an IRB, although there may be ethical issues that must be addressed by the researcher's institution.

See the module Defining Research with Human Subjects for a discussion about how to apply the following definitions:

Research means a systematic investigation, including research development, testing and evaluation, designed to develop or contribute to generalizable knowledge.

Human subject means a living individual about whom an investigator (whether professional or student) conducting research obtains

1. Data through intervention or interaction with the individual, or
2. Identifiable private information.

Once it has been determined that a project meets the definition of research with human subjects, the next step is to determine the type of review it needs. The type of review usually determines who will conduct the review.

Research Eligible for Exemption

Of significant interest to social and behavioral researchers is the fact that there are activities that do meet the definition of research with human subjects but are exempt from the provisions of the Common Rule. They do not require review as described in the Rule.

While these studies do not require review in accordance with the Rule, some procedure is necessary to make the determination that they are eligible for exemption. Institutional procedures vary, but most commonly it is the institution, not the investigator that makes the determination.

Research may be eligible for exemption from the Common Rule if all the activities associated with the research fall into one or more of six categories. Of the six categories, three are frequently used by social and behavioral scientists. They are:

1. Research conducted in established or commonly accepted educational settings, involving normal educational practices.
2. Research involving survey procedures, interview procedures, or observation of public behavior provided that any disclosure of identifiable information outside the research setting would not place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, or reputation.

NOTE: If Subpart D applies, either by sponsor requirement or institutional choice, the following activities with children cannot be exempt: interviews, surveys, and participant observation.

3. Research involving the collection or study of existing data (collected prior to the research for purposes other than the research) if the data are publicly available or recorded by the investigator in such a manner that the subjects cannot be identified.

A complete list of research activities eligible for exemption is provided at [45 CFR 46.101](#).

Expedited or Full Review

If research is not eligible for exemption, the remaining options are expedited or full review.

To be eligible for expedited review research must meet two criteria:

1. Pose no more than minimal risk to subjects.

"No more than minimal risk" means that "the probability and magnitude of harm or discomfort anticipated in the research are not greater in and of themselves than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests."

2. Consist only of one or more research activities specified in the regulations as eligible for expedited review.

Eligible activities are similar to those for exempt research (some surveys, interviews, and data analysis) with the addition of some minor or non-invasive medical procedures, such as blood pressure readings, weight

measurements, and blood draws that are used occasionally by researchers in the social and behavioral sciences.

The preamble to the list of specified activities notes that if the primary risk to subjects is a breach of confidentiality and the risk can be managed to no more than minimal, then the research may be reviewed through an expedited process.

Institutional policy, local conditions, and subject vulnerability may require review by a convened IRB even for a study with no more than minimal risk, such as a study of decisionally-impaired individuals. If research involves more than minimal risk and/or does not fall into one of the categories of research eligible for expedited review, it must be reviewed by a convened IRB. This review involves consideration by a larger, more diverse group, thus bringing more perspectives and more experience to the review.

Who Must Review Research with Human Subjects

As prescribed in the regulations and implemented by institutional policy there are three possible sets of reviewers:

1. Individuals identified by the institution to screen research for exempt status.
2. One or more IRB members conducting expedited reviews.
3. Members of a convened IRB for studies requiring full review.

Description of an Institutional Review Board

An Institutional Review Board is a review committee established to ensure that the rights and welfare of human research subjects are protected. Although federal regulations use the term IRB, institutions may choose a different name for the committee, such as Research Ethics Board.

Membership

The minimum size and required composition of an IRB is spelled out in detail in the regulations. An IRB must have at least five members. Its membership must be diverse including considerations of race, gender, and cultural background. The committee is expected to be sensitive to community attitudes; have knowledge and experience with vulnerable populations; and to be conversant with applicable regulations, state and local laws, and standards of professional conduct.

The most important requirement is that an IRB must have the expertise and professional competence to evaluate research. One or more members must have familiarity with the discipline and methods under consideration. If not, the IRB must seek that expertise through consultation. For example, if an IRB is to review research on sensitive topics using web-based surveys, it must have expertise about security issues in the Internet environment or seek outside consultation.

Authority of the Institutional Review Board

Federal regulations stipulate that an IRB can:

- Approve research
- Disapprove research
- Require modifications to proposed research
- Conduct continuing reviews
- Observe/verify changes
- Suspend or terminate approval
- Observe the consent process and the research procedures

The regulations also require that IRBs develop procedures for handling noncompliance

Other Institutional Reviews

Research approved by an IRB may be subject to further review and approval or disapproval by officials of the institution (for example, department heads, deans, research directors). However, if an IRB has disapproved the research, the institution cannot override that determination.

What Questions Must Be Addressed During a Review

Exempt Research

When research is exempt from the provisions of the Common Rule, it follows that the review criteria provided for expedited and full review would not apply. However, all research should abide by the three basic ethical principles elucidated in the Belmont Report: respect for persons, beneficence, and justice. For example, the principle of respect for persons would entail securing informed consent from research subjects. Therefore, many institutions have developed forms designed to gather sufficient information to determine not only that a project is exempt, but that it is being conducted in accordance with the basic ethical principles.

Review Criteria for Expedited and Full Review

IRB members who are conducting an expedited review, or the convened IRB conducting a full review, must ask the following questions:

1. Have the risks to subjects been minimized using procedures that are consistent with sound research design?
2. Are the risks reasonable in relation to anticipated benefits?
3. Is the selection of subjects equitable?
4. Are adequate procedures in place to ensure privacy and confidentiality?
5. Is there a plan to monitor the data and safety of the subjects, if necessary?
6. Will informed consent be sought and appropriately documented? Do proposed alterations or waivers of informed consent meet the criteria for approval?
7. Are safeguards in place to protect vulnerable populations?

Comparison of Expedited and Full Review

Review procedures for expedited review and full review are similar in several ways:

- The review criteria are the same.
- Expediting reviewers and the full IRB can request modifications to research plans and approve the plans.
- Expediting reviewers and the IRB must specify when a research plan must be reviewed again. By regulation it must be within twelve months, but shorter review periods may be required.

A key difference between the two processes is that expedited reviewers cannot disapprove a research plan. They must refer research plans they cannot approve to the full IRB. All IRB members must be advised about protocols, continuing reviews, and amendments approved through expedited review procedures. Any member of the IRB may request that such approvals be reconsidered by the full IRB.

Approved Research: Additional Reviews

Once a research plan has received initial approval through expedited or full review procedures, it must be reviewed again within twelve months of its approval date, via continuing review. In addition, changes to approved research plans must be reviewed and approved before implementation. Reports of unanticipated problems must also be reviewed through procedures described by the institution conducting the research. Problems of particular concern are unanticipated risks of harm to subjects or others, such as family members.

Continuing reviews and reviews of proposed amendments to approved research may be reviewed by the full IRB or may be expedited. The determination about what type of review is appropriate is based on a number of factors, including the level of risk and the extent of proposed changes.

Continuing Review: Expedited or Full?

Federal regulations permit expedited review to be used for continuing review if the initial review was expedited and no new risks were identified. It may also be used when the initial review was conducted by a full IRB under some circumstances, such as 1) when no additional risks have been identified and during the initial review the IRB

determined and documented that the research involves no greater than minimal risk, or 2) the remaining activities are limited to data analysis.

The IRB or the expediting reviewer(s) must determine that all the requirements for initial review continue to be satisfied. OHRP notes that continuing review should cover specific information, including the number of subjects accrued, a summary of any relevant recent literature, a description of any unanticipated problems, and a copy of the current consent form.

Follow the link to view the latest guidance from the OHRP on Continuing Review.

Amending Approved Protocols

Changes to approved protocols must be approved prior to their implementation. The regulations state that expedited review procedures may be used to approve "minor changes in previously approved research during the period (of one year or less) for which approval is authorized." Consult with your IRB about your institution's policies and procedures regarding these reviews and about what constitutes a "minor" change.

Reports of Unanticipated Risks or Harms

Institutions conducting research under the auspices of an assurance with OHRP are required to develop written procedures for reporting and reviewing unanticipated problems involving risks or harms to research subjects.

Other Issues

The regulations cover other issues not addressed in this module such as working with collaborators, both domestic and international, required record keeping, and suspension and termination of IRB approved research.

Summary

Federal regulations define what research requires IRB review, the types of review, who conducts the review, and the criteria for review. Since the federal regulations establish a minimum standard it is important to check with your institution to find out if there are additional procedures and criteria.

4 Assessing Risk - SBR

Tracy Arwood, M.S. Clemson University and Sangeeta Panicker, Ph.D. American Psychological Association

Introduction

One of the most important and challenging tasks researchers and institutional review boards (IRBs) face is identifying and evaluating risks of harm associated with participation in research. Unlike biomedical research studies and clinical trials, in which the sources of risk may be more readily identifiable and quantifiable, potential harms associated with taking part in social and behavioral science research may be more ambiguous and less predictable, such as individual reactions to certain events or questions. However, identifying and assessing risks in such situations should be informed by a growing body of research literature on risks associated with research participation.

The risks of harm typically associated with social and behavioral research are social, psychological, economic, and legal in nature. However, in rare circumstances, the risks may involve physical harm. For example, those who study victims of domestic violence need to consider that individuals taking part in the study may become the victims of retaliatory violence if the subjects' involvement in the research is discovered.

It is also possible that when groups or communities rather than individuals are the focus of a study, the group as a whole may be at risk of harm. For example, research on the prevalence of HIV-infected individuals in communities may stigmatize the community being studied.

Identification, assessment, and minimization of risk are paramount to the conduct of ethical social and behavioral research.

Learning Objectives

By the end of this module, you should be able to:

- Identify risks of harm associated with participation in social and behavioral sciences research
- Distinguish between probability and magnitude of harm when assessing risk
- Apply the concepts of minimizing and managing risk

Identifying Risks Associated with Participation in Social and Behavioral Sciences Research

Risk of harm in social and behavioral sciences generally fall in three categories:

- Invasion of privacy
- Breach of confidentiality
- Study procedures

Invasion of Privacy

Invasions of privacy can occur if personal information is accessed or collected without the subjects' knowledge or consent. For example, if a researcher studying interaction patterns in an online support group joins the group and does not reveal her true identity online, the support group participants could feel that their privacy had been invaded by the researcher, if or when her true identity is revealed to the group.

Invasions of privacy can also occur if a subject's participation in a study is revealed despite assurances that this would not happen. For example, a researcher is studying emotional reactivity in women who have experienced sexual abuse. The research is conducted in a designated university lab on a particular day each week. Another university staff person sees an acquaintance entering the meeting room and therefore discovers that his acquaintance has experienced sexual abuse.

Breach of Confidentiality

Perhaps the primary source of potential harm in the social and behavioral sciences is that information obtained by researchers could adversely affect subjects if disclosed outside the research setting. Confidentiality can be compromised through an unauthorized release of data, which could have a negative impact on the subjects' psychological, social, or economic status. For example:

- An unintended disclosure of a subject's health status could result in the subject's loss of employment or health insurance coverage.
- Public revelations of data collected about sexual orientation could result in a loss of social status.
- Workers asked to share their attitudes about the effectiveness of their managers could lose their jobs or be denied promotions if the information is not adequately protected.
- Information about illegal activities or immigrant status can have serious legal consequences for subjects.

Study procedures

In some cases, simply taking part in research can put subjects at risk. For example, if a researcher is conducting interviews with individual gang members, it may be necessary to find places to meet where other members of the gang could not observe the interaction.

Another situation in which merely taking part in research might pose some risk to subjects is when there is a potential for a breach of confidentiality, not because of inadequate confidentiality procedures on the part of the research team, but from subjects themselves when data are collected in a group setting such as a focus group. Even though participants are typically cautioned not to share information outside the data collection setting, subjects should be made aware that the researcher cannot guarantee confidentiality.

Often it is assumed that the very nature of the research inquiry can pose risk to subjects. For instance, when reviewing protocols that involve asking subjects questions about trauma or abuse, IRBs are often concerned about re-traumatization. However, current research findings indicate that, when appropriate protections are built into the study design, such as ensuring that interviewers are trained to ask questions in a supportive, respectful manner as well as to respond to subjects' reactions appropriately, very few subjects were upset. In fact, most subjects, including those who may have experienced fleeting negative emotions, reported feeling good about taking part in the study (Cromer & Newman, 2011). Thus, it is important to review the literature in a given field to determine what, if any, risk of harm the research topic or design might pose to the participant and what, if any, additional protections may be necessary.

Assessing Risk

Probability and Magnitude of Harm

When assessing risks of harm associated with participation in a research study, there are two distinct elements of risk that must be considered. One is the probability of harm? The likelihood that a specific harm might occur. The fact that not all possible harms are equally probable should be taken into consideration when assessing risk. The second element of risk is the magnitude or severity of harm should it occur. The interaction between these two elements is a crucial factor in determining the level of risk of harm in a study.

Often there is disparity between the probability and the magnitude of harm in a study. For example, a researcher wants to do a web-based survey of college students to collect information about their sexual behavior and drug use. Direct identifiers will not be collected; however, IP addresses may be present in the data set. Although the probability that an individual subject could be identified is low, the magnitude of the possible harm is high given the sensitivity of the information. (For more information on managing risks in Internet-based research, see the module entitled Internet Research - SBE.)

Situation and Time Risks in research participation are specific to time, situation, and culture. What may be a socially sensitive issue or topic at one time or place may not be so at another time or place. For example, asking women if they have had an abortion would carry very different risks in a country where abortion is a routine medical practice, a country where it is illegal, and a country in which it is legal but the issue is fraught with religious and political controversy.

Subject Population Risks will differ according to the subject population, too. Consider this case: A study on the efficacy of a behavioral intervention for smoking cessation involves both adults and teenagers. Purchasing tobacco products is generally illegal for persons under 18 years of age. For adults, however, it is a health hazard, but not an illegal activity. Thus, any assessment of the risk for teenagers will have to consider that the research focuses on an illegal activity.

Similarly, a survey about sexually transmitted diseases would carry different risks for middle class suburban men, clergy, and gang members.

Assessing Risk Objectively

Researchers

People, including researchers, may underestimate risks involved in activities with which they are familiar and overestimate the benefit of things that are important to them.

Potential Subjects

Regardless of the true probability of harm, research indicates that when potential harms are severe, people tend to overestimate the probability. When potential harms are less severe, such as embarrassment, people tend to underestimate the probability.

An independent assessment of risk is critical. One function of Institutional Review Boards (IRBs) is to provide this independent assessment.

Balancing Risks and Potential Benefits

Federal regulations, based on the ethical principle of beneficence, require that risks of harm associated with research are reasonable in relation to the potential benefits.

A great deal of research in the social and behavioral sciences offers little potential for direct benefits to the subjects themselves. The benefits of the research often lie in the importance of the knowledge to be gained, the contributions it makes to science, or the contributions to society in general. There might also be cases in which a specific community, rather than individual subjects, benefits from the research. This should be balanced with the fact that most research in the social and behavioral sciences poses little or no risk to the individual subject.

Federal regulations stipulate that risks of harm must be minimized to the extent possible, consistent with sound research design. Potential research subjects need to be given sufficient information to make a decision about whether they are willing to accept risks. If questions will be of a sensitive nature, subjects need to be forewarned. Subjects also need to know what steps will be taken to protect confidential information, including disposition of recorded material. Any limits to the extent to which a researcher can protect identifiable personal information should be clearly explained. State and local laws may limit confidentiality, such as reporting requirements for child and elder abuse. Confidentiality cannot be guaranteed for information shared in a focus group.

Minimizing and Managing Risk

When the Primary Source of Risk is the Data

When a possible disclosure of subjects' responses is the primary source of potential harm, collecting data anonymously may provide the best protection. For example, a mailed survey can be constructed without a follow up procedure, thereby negating the need for identifiers.

If, however, the study design makes the collection of identifiers necessary, for example a longitudinal study, safeguarding the data from unauthorized access can be accomplished in various ways, including:

- Remove all direct identifiers as soon as possible
- Substitute codes for identifiers
- Maintain code lists and data files in separate secure locations

- Use accepted methods to protect against indirect identification, such as aggregate reporting or pseudonyms
- Use and protect computer passwords
- Encrypt transmitted and stored data
- Access and store data on computers without Internet connections
- Obtain a Certificate of Confidentiality

In the past, when data were usually recorded and stored on paper and or devices such as floppy disks, researchers restricted access to data by storing the records in locked file cabinets in locked offices. With increasing use of digital technologies to acquire, transmit, analyze, and store data, data security has become much more complex. Researchers are not often information technology (IT) experts. Therefore, research teams should consult with their institutional IT security contacts for guidance regarding the most secure means of obtaining, transferring, analyzing and storing data when the primary source of risk stems from a security breach.

Certificates of Confidentiality

Certificates of Confidentiality are issued by the National Institutes of Health (NIH) to protect identifiable research information from compelled disclosure. Certificates of Confidentiality may be obtained for any research, regardless of funding. Certificates of Confidentiality may be granted for studies collecting information that, if disclosed, could have adverse consequences for subjects or damage their financial standing, employability, insurability, or reputation. A Certificate of Confidentiality will allow the researcher, and others who have access to research records, to be protected from required disclosure of identifying information on research participants in

- Civil,
- Criminal,
- Administrative,
- Legislative, or
- Other proceedings, whether at the federal, state, or local level.

The kinds of information that can be protected include:

- Substance abuse or other illegal behaviors
- Sexual attitudes, preferences, or practices
- Genetic information
- Psychological health

Certificates of Confidentiality do not override the requirement to report the suspicion of child abuse or neglect, or any other state mandated reporting requirements, such as elder abuse.

Other federal agencies, such as the Department of Justice, provide agency-specific protections that apply to research conducted by or funded by the agency.

When the Primary Source of Risk Is the Consent Document

Subjects may be placed at risk if others know that they are taking part in a study of a stigmatizing or illegal activity. If the consent form is the only document that links the participants to the study, one way to diminish their risk of exposure is to consider applying to the IRB for a waiver of the requirement to document consent. A waiver of documentation of consent does not imply that any of the required elements of consent are waived. The elements of consent must be provided in some fashion such as in a cover letter, informational sheet, or verbal script. See the module Informed Consent - SBE for more information about waivers.

Summary

Common social and behavioral science methodologies such as surveys, questionnaires, and interviews are considered (sometimes erroneously) low risk because they do not involve physically invasive procedures with associated risk of physical harm. However, it is not the procedures per se that engender potential harm but the interaction of different factors. It is necessary to assess both the probability and magnitude of harm as well as the context (situation, place, and time) of the research as it relates to the particular study population.

References

Cromer, L. D. & Newman, E. (2011). Research ethics in victimization studies: Widening the lens. *Violence Against Women*, 17(12) 1536-1548

5 Informed Consent

Content Author

- **Lorna Hicks, MS, CIP** Duke University

Introduction

There is general consensus on the importance of informed consent in research. Most people have the expectation that they will be treated with respect and as autonomous individuals. They also expect that they have the right to make decisions about what will and will not be done to them and about what personal information they will share with others.

However, researchers also are aware that there are circumstances in which obtaining and documenting consent in social and behavioral research may be a complex, and often challenging, process. For instance, potential subjects may be fluent in a language but not literate. Researchers may need to deceive research subjects in order obtain scientifically valid data. Asking subjects to sign consent forms linking them to a study about illegal activities could put them at risk of harm.

The federal regulations provide sufficient flexibility to address some of these concerns, particularly for research posing no more than minimal risk of harm. For example, the regulations allow waivers of and alterations in the requirements for the consent and documentation processes.

Learning Objectives

By the end of this module you should be able to:

- Distinguish between consent as a process and the documentation of consent.
- Recognize the elements of consent.
- Determine when waivers are appropriate.
- Identify methods for ensuring comprehension of consent.

Overview of Informed Consent

Federal regulations require researchers to obtain legally effective informed consent from the subject or the subject's legally authorized representative (LAR). There are two parts to informed consent. The first is the process of providing information to prospective subjects. The second is documentation that the process took place and is a record of the subjects' agreement to take part in the study. In practice, informed consent forms often are used as a means to provide information about a study, and, when signed, serve as documentation of consent. However, in some cases, an oral consent process without documentation may be approved by an Institutional Review Board (IRB).

The Process

Informed consent is a process that begins with the recruitment and screening of a subject and continues throughout the subject's involvement in the research. It includes:

- Providing specific information about the study to subjects in a way that is understandable to them.
- Answering questions to ensure that subjects understand the research and their role in it.
- Giving subjects sufficient time to consider their decisions.
- Obtaining the voluntary agreement of subjects to take part in the study. The agreement is only to enter the study, as subjects may withdraw at any time, decline to answer specific questions, or complete specific tasks at any time during the research.

Documentation

Documentation of consent provides a record that the consent process took place. It generally consists of a consent form signed by the subject or the subject's LAR. In practice, this document often is used as a tool for engaging in the consent process. Informed consent may be documented by other means, such as audio or video recording, as approved by an IRB.

Information That Must Be Provided to Subjects

Federal regulations at 45 CFR 46 (Protection of Human Subjects 2009) about informed consent list specific elements of information that must be provided to subjects. The elements are divided into two categories. The first includes basic elements to be provided to subjects. The second lists elements that must be included if appropriate. The two lists are provided below with comments.

Basic Elements

- A statement that the study involves research, an explanation of the purposes of the research and the expected duration of the subject's participation, a description of the procedures to be followed, and identification of any procedures which are experimental.
- A description of any reasonably foreseeable risks or discomforts to the subject.
- A description of any benefits to the subject or to others, which may reasonably be expected from the research. If there are no direct benefits, the researchers may tell subjects what they hope to learn, how that knowledge will contribute to the field of study or how the knowledge might benefit others if such a case can be made.
- A disclosure of appropriate alternative procedures or courses of treatment, if any, that might be advantageous to the subject. This requirement is primarily relevant for biomedical research. However, it might be applicable to social and behavioral research if behavioral interventions, such as novel teaching or therapeutic methods, are proposed.
- A statement describing the extent, if any, to which confidentiality of records identifying the subject will be maintained. The description must include a full disclosure of any state-mandated reporting requirements, such as suspicion of child abuse and/or neglect or harm to others, when warranted by the topic under investigation. State requirements vary, so IRBs and researchers must be aware of state-specific information. For research involving more than minimal risk, an explanation as to whether any medical treatments are available if injury occurs and, if so, what they consist of, what compensation will be provided, and where further information may be obtained.
- An explanation of whom to contact for answers to pertinent questions about the research and research subjects' rights, and whom to contact in the event of a research-related injury to the subject. In some field research, there may not be any way for subjects to call or email anyone about their questions and concerns. Alternative means of communication must be established, such as a local contact on the research team.
- A statement that participation is voluntary, refusal to participate will involve no penalty or loss of benefits to which the subject is otherwise entitled, and the subject may discontinue participation at any time without penalty or loss of benefits to which the subject is otherwise entitled. Most researchers in the social and behavioral sciences are not in a position to impose penalties.
- However, specific study-related assurances that there will be no negative consequences associated with choosing not to take part might be appropriate. For example, parents may need to be assured that if they choose not to participate in a school-based, school-approved study their children's grades or placement will not be affected.

Additional Elements

Depending upon the nature of the research and the risks involved, there may be additional required elements, including:

- A statement that the particular treatment or procedure may involve risks to the subject (or the embryo or fetus, if the subject is or may become pregnant), which are currently unforeseeable.

- Anticipated circumstances under which the subject's participation may be terminated by the investigator without regard to the subject's consent.
- Any additional costs to the subject that may result from participation in the research.
- The consequences of a subject's decision to withdraw from the research and procedures for orderly termination of participation by the subject.
- Subjects need to know, for example, how their compensation will be affected if they choose not to complete an interview. Discussion of what happens to data already collected if they withdraw midway through the study also may be addressed in this section.
- A statement that significant new findings developed during the course of the research which may relate to the subject's willingness to continue participation will be provided to the subject.
- This requirement applies primarily to biomedical research involving new treatments and procedures, but also may apply to research on experimental behavioral interventions.
- The approximate number of subjects involved in the study.

Incentives

Incentives are payments or gifts offered to subjects as reimbursement for their participation. These must be described during the consent process as well as the conditions under which subjects will receive partial or no payment.

Recruitment

Recruitment is part of the consent process because it begins the process of providing information about the study. All recruitment strategies such as fliers, email messages, newspaper advertisements, phone scripts, and so on must be reviewed and approved by an IRB before they are used.

Exculpatory Language

Subjects may not be asked to waive or even appear to waive any of their legal rights. They may not be asked to release a researcher, sponsor, or institution from liability for negligence. Institutions may provide information about how liabilities will be covered.

Ensuring Comprehension of Consent Information

Researchers are required to provide information in a manner understandable to the subjects. This requires preparing material in the subjects' language at the appropriate reading level. When a study is complex and/or the reading or educational level of the prospective study population is low, the role of dialog and explanation becomes an even more crucial part of the consent process.

Ensuring Free Choice

The principle of respect for persons requires that participation in research be truly voluntary, free from coercion or undue influence. Even when a study is innocuous, subjects must be informed that they do not have to take part, and they may choose to stop participating at any time.

Setting and Time

Researchers should consider ways in which the setting of the consent process might include elements of undue influence. Potential subjects might not feel entirely free to choose whether to take part in a research study if they are:

- Adolescents whose parents are in the room
- Adolescents in a group of other adolescents being recruited for the same study
- Parents who receive a letter from the school principal asking them for permission to enroll their children in a study
- Athletes recruited by their coach
- Employees asked to take part by their employer

Subjects must be given adequate time to consider whether they wish to take part in a study. This is particularly true if the study procedures involve more than minimal risk or will require subjects to disclose sensitive information.

Compensation or incentives to participate may not be so high that they override other considerations for potential subjects. Determining whether incentives are unduly influential depends on the research context and the financial and emotional resources of the subjects.

Safeguards for Vulnerable Subjects during Consent

Federal regulations state that IRBs must ensure that appropriate safeguards are in place to protect the rights and welfare of subjects likely to be vulnerable to coercion or undue influence. Potentially vulnerable subjects include children, prisoners, pregnant women, mentally disabled persons, or economically or educationally disadvantaged persons. Additional safeguards for three of these groups are provided in subparts of the federal regulations for protecting research subjects: Subpart B for research on pregnant women, human fetuses, and neonates; Subpart C for prisoners; and Subpart D for children. Discussions of the additional protections for prisoners and children can be found in CITI Program modules "Research with Prisoners – SBE" and "Research with Children - SBE."

Safeguards employed for vulnerable subjects include, among many other strategies, assessing the decision-making capacity of potential subjects, requiring parental permission from both parents rather than just one parent for some studies with children, and ensuring that incentives are not coercive.

Informed Consent in Exempt Research

If an institution determines that a study meets the criteria for exempt research, the detailed regulatory requirements for informed consent in 45 CFR 46.116 do not apply. However, research that is exempt from federal regulations is still research with human subjects and the ethical principles as outlined in the Belmont Report still apply. Each institution or IRB decides how to handle informed consent in research that is eligible for exemption from the regulations.

Waivers of the Elements of Consent

Federal regulations allow IRBs to authorize researchers to modify the consent process by omitting one or more elements of information or to provide no information at all. The waiver or alteration of any or all of the elements of consent can be authorized only if these four criteria are met:

1. The research involves no more than minimal risk to the subjects.
 - "Minimal risk" means "the probability and magnitude of harm or discomfort anticipated in the research are not greater in and of themselves than those ordinarily encountered in the daily life or during the performance of routine physical or psychological examinations or tests" (Protection of Human Subjects 2009).
2. The waiver or alteration will not adversely affect the rights and welfare of the subjects.
 - In the absence of specific legal rights, this criterion is often difficult to apply because the federal regulations do not define "rights and welfare." Also, the parties involved in the research process (researchers, IRBs, and the community of subjects) may not always agree on how to define subjects' rights and welfare. When a waiver is required because the research involves deception, this requirement usually is interpreted to mean that subjects are not "tricked" into participating in a study that they would find objectionable.
3. The research could not practicably be carried out without the waiver or alteration.

- Impracticable does not mean time consuming, expensive, or inconvenient. It means that securing consent is not feasible, regardless of cost and time.
 - Impracticable may mean that without a waiver it would not be possible to answer the research question. Disclosing the purpose of the research may influence how subjects respond.
4. Whenever appropriate, the subjects will be provided with additional pertinent information after participation.
- This process often is referred to as debriefing. The debriefing process is an opportunity to provide subjects with information not disclosed during the initial consent process. It also provides an opportunity for subjects to withdraw and not have their identifiable data included in the research. Note: Debriefing is not required in situations in which debriefing would cause more harm than good, for example, if subject selection was based on an undesirable or unflattering characteristic.

Uses of Waivers

Deception: Outright deception can sometimes be justified as essential for investigating a particular phenomenon. For example, subjects may be told that a study is about perception of visual phenomenon, when in fact it is about susceptibility to peer pressure from the researcher's confederates.

Complete Non-Disclosure: If people know that they are being observed, they may alter their behavior in such a way that obtaining meaningful results is not possible. Covert observation requires a waiver of all of the elements of consent if the research takes place in a setting in which subjects could reasonably expect that their behavior was not being observed and recorded.

Waivers of Parental Permission and Child Assent

An IRB may waive the requirement to secure parental permission for children to take part in research, in accordance with the same criteria for waiving consent.

The regulations do not include a list of elements that must be included in a child assent process. It is up to an IRB to determine whether child assent is required, what elements must be included in the assent process, and whether the assent must be documented.

Documentation of Informed Consent

When documentation of informed consent is required, there are two methods available:

1. The subject or the subject's legally authorized representative signs a form containing all the required elements of consent and any additional information necessary to provide complete disclosure. The person who signed the consent form is given a copy as a reference and reminder of the information conveyed.
2. The consent is done orally in language understandable to the subject and is documented by an impartial witness. This process uses two documents: (1) a short- form written consent document stating that the required elements of consent have been presented orally to the subject or the subject's legally authorized representative, and (2) a written, IRB-approved summary of what will be said to the subject or the subject's representative. The subject signs the short form. The witness signs both forms. The person actually obtaining consent signs the summary. Copies of the short form and the summary are given to the subject.

Note: Illiterate English-speaking subjects can "make their mark" on the informed consent document, as long as it is consistent with applicable state or local laws.

Waivers of Documentation

Documentation of the consent process is not always required. Note, however, that waivers of documentation are not waivers of the consent process itself. For waivers of consent, see the criteria noted above.

Documentation may be waived under two circumstances:

1. The principal risks are those associated with a breach of confidentiality concerning the subject's participation in the research, and the consent document is the only record linking the subject with the research. For example:

- Research about women who have left abusive partners.
 - Research on the black market capitalist economy in Cuba in which illicit vendors will be interviewed in a safe space.
 - When the requirement for documentation is waived, the IRB may require the researcher to offer the subjects information about the study in writing.
2. Study participation presents minimal risk of harm to the subject and the research involves no procedures requiring consent outside the context of participation in a research study, for example, a telephone survey.

Summary

Informed consent includes both the process of sharing information and documenting that the process took place. To ensure that potential subjects can truly make informed decisions about whether to take part in research, issues of comprehension, language, and culture need to be considered in addition to the elements of information provided in the regulations. The regulations provide criteria for waiving any or all of the elements of information and the documentation of consent.

Reference

- Protection of Human Subjects, 45 CFR § 46 (2009).

6 Privacy and Confidentiality

- **Lorna Hicks, M.S., CIP** Duke University

Introduction

The Regulations for Protecting Research Subjects (the Common Rule) state that when reviewing protocols, IRBs must determine that there are adequate provisions for protecting the privacy of subjects and to maintaining the confidentiality of data.

The Common Rule is just one document that directs researchers to consider privacy and confidentiality when conducting research. The guidelines of the American Anthropological Association, the Oral History Association, the American Psychological Association, and the American Sociological Association identify protecting privacy and ensuring confidentiality as key components of respecting the safety and dignity of research subjects.

This module will define privacy and confidentiality and discuss their application in various research settings. It will also discuss applicable laws, other than the Common Rule.

Learning Objectives

By the end of this module, you should be able to:

- Distinguish between privacy and confidentiality
- Identify privacy risks associated with study designs
- Identify a range of procedures for ensuring confidentiality
- Identify relevant laws regarding collection of private information
- Identify laws that limit the ability to ensure confidentiality

Definitions

According to the IRB Guidebook, published by the Office for Human Research Protections, privacy can be defined in terms of having control over the extent, timing, and circumstances of sharing oneself (physically, behaviorally, or intellectually) with others. Confidentiality pertains to the treatment of information that an individual has disclosed in a relationship of trust and with the expectation that it will not be divulged to others in ways that are inconsistent with the understanding of the original disclosure without permission.

Thus it follows that privacy, a right, can be violated. Confidentiality, an agreement, can be breached. Confidentiality procedures, as described during the informed consent process, allow subjects to decide what measure of control over their personal information they are willing to relinquish to researchers.

It is not always the case that information provided by research participants must be protected from unauthorized or inadvertent disclosure. Some participants want to be identified and quoted. Some agree to have their photographs or audio- or video-tapes archived in collections available to the general public.

How can researchers determine which behaviors and information are private and which are public? The distinction is important because observation and/or recording of public behavior does not meet the definition of research with human subjects. The federal regulations define "private information" to mean "information about behavior that occurs in a context in which an individual can reasonably assume that no observation or recording is taking place, and information which has been provided for specific purposes by an individual and which he or she can reasonably expect will not be made public (for example, a medical record)." Although this definition includes the phrase

"reasonably assume" which requires interpretation, the definition does provide a yardstick for differentiating between public and private behavior.

It would be perhaps unreasonable to assume that behavior on a street corner is private, but reasonable to assume that behavior in our homes is private. However, individuals may identify private spaces in the midst of very public ones. For example, parents taking their children to a city park might consider it a violation of privacy if the interactions of their children were audio-taped using long-range recording devices.

"Reasonable assumptions" regarding privacy will vary from culture to culture and setting to setting. Individuals' ability to control access to their persons and to their personal information is determined by a variety of factors, including socioeconomic status, age, and circumstance. For example, information about welfare rolls is public information; information about personal stock portfolios is not. Minors have different rights to privacy than adults. Institutionalized persons may have significant limitations on their ability to control personal information.

While not an exhaustive list, the following material highlights some concerns about privacy in the context of research.

- Observational Studies
- Study Questions
- Communicating with Subjects
- Focus Groups
- Snowball Sampling

Observational Studies

Invasions of privacy can occur if subjects are asked questions that they find intrusive. If a survey instrument or an interview script contain questions that individuals are likely to find intrusive, they must be informed about the nature of the questions in advance. Studies about sexual behavior, childhood abuse, use of psychotropic medications, and other personal topics should include a disclosure in the consent form about the sensitive nature of the questions. The survey instrument or interview process must be designed so that subjects may choose not to answer questions that make them uncomfortable, or that they want to skip for any reason.

Although there is considerable variation in how people define the right to privacy, there are nonetheless community and cultural standards that should be taken into account when designing research. Topics that are considered appropriate in one setting may be offensive and off-limits in another.

Communicating with Subjects

If a study is obviously about stigmatizing conditions, illegal activities, or life experiences that subjects may not want others to know about, communications with the subjects should not reveal their participation in the study to others because to do so would violate the subjects' right to privacy. Study titles should be carefully considered; it is often best if the title alone is not sufficient to reveal sensitive information about participants. A method of communication that is of particular concern is e-mail. Employee e-mail is not secure and some home accounts may be accessed by anyone in the family. Telephone calls to subjects at home may also be of concern. It may be appropriate to script calls carefully so that no information is revealed about the caller or the subject to anyone other than the subject. In some cases it may be appropriate to educate subjects about how to prevent possible violations of their privacy in their homes. For example, researchers may counsel subjects to make sure their home computers are secure or to close their browsers after completing an on-line survey on a sensitive topic.

Focus Groups

Protecting privacy within research using focus groups often requires researchers to modify the kinds of promises of confidentiality that they give in one-on-one interviews. Even though researchers can emphasize to all participants that the comments made during the focus group session should be kept confidential (when the topic warrants), researchers need to inform participants that it is impossible for the researcher to promise that participants will not repeat comments outside the group at some time in the future. Because maintaining confidentiality is not entirely under the control of the researcher, participants need to be encouraged to be as honest and open as they can, but

remain mindful of the limits on the researcher's ability to protect confidentiality. In recruiting for focus groups, it is important to inform prospective participants how fellow participants are being selected. Privacy may or may not be an issue in the course of the group discussion, depending on whether individuals already know each other, and the topic. Participants need to know that information to help them decide about their comfort in being part of that group and dealing with the specific topics of the study.

Snowball Sampling

Snowball sampling is a recruitment technique in which research participants are asked to assist researchers in identifying other potential subjects. If the topic of the research is not sensitive or personal, it may be appropriate for subjects to provide researchers with names of people who might be interested in participation. If the topic is sensitive or personal, such as the fact that someone was adopted, care should be taken so that potential subjects' privacy is not violated. In this case, subjects assisting with recruiting could provide information about the research to potential subjects, rather than giving the researcher names of potential subjects.

Confidentiality

The ways in which data will be used and made available to others is part of the agreement researchers make with study participants and must be described during the informed consent process. The following questions are some of those that may be used to guide the design of study-specific confidentiality procedures.

1. Are identifiers really needed or could data be collected anonymously?
2. Can identifiers be destroyed, thus anonymizing data?
3. If identifiers are needed, can coded IDs be created to use for data collection, merging, and analysis, with identifiers kept entirely separate and secure?
4. If subjects were chosen for the study due to a sensitive or stigmatizing condition or participation in illegal activities, are procedures in place from the very beginning to protect identities, such as a waiver of the requirement to document consent?
5. Once identifiers are used to create codes to identify various data, can actual identifiers and the list linking them with the code be destroyed, thus anonymizing the data?
6. How will the data be protected from inadvertent disclosure or unauthorized access during collection, storage, and analysis? Would password protection be sufficiently protective, or would data encryption be necessary in addition? Would the use of stand-alone computers, without network access help prevent access by unauthorized users?
7. Are de-identified data sufficiently protected from re-identification?
8. Should data be manipulated in specific ways to reduce specificity, by collapsing data into categories with small numbers of individuals, reducing age or geographic specificity, etc.
9. Does sensitive data need to be protected from subpoena by third parties? Should a **Certificate of Confidentiality** be obtained?
10. In studies where it is an issue, are there limits to the promises of confidentiality that the researcher can make to subjects due to state laws requiring researchers to report suspected child abuse or neglect?
11. How will data be reported? In aggregate? Using pseudonyms? Using real names? Answers to these questions should be shared with participants so they can decide if they are comfortable with the plan.
12. Does permission need to be obtained to attribute quotations to subjects in a way that reveals their identity?
13. Who else, besides the researchers, will have access to the data in the present AND in the future?
14. If audiotapes or videotapes are made, what will be done with them during and after the research? Will they be shown at scholarly conferences? If so, will all subjects be asked if they are willing for the tapes to be shown? Will audiotapes or videotapes be archived? Do releases need to be obtained for archiving material? Will the tapes be saved in case they have an as-yet-unknown, research use?

Privacy and Reporting Laws

Federal Privacy Law

Federal laws protect the disclosure of educational records (FERPA) and of private health information (HIPAA).

Generally, the disclosure of these records to researchers involves securing written authorizations from the potential subjects, although in certain clearly defined circumstances the requirement to secure authorizations may be waived.

The module Research in Public Elementary and Secondary Schools provides more information about the use of educational records. Researchers in the social and behavioral sciences and the humanities usually do not generate private health information covered by HIPAA, rather they ask for it to be disclosed to them, usually by asking subjects to sign authorizations permitting the disclosure. Most institutions covered by HIPAA have models of authorization forms that they expect researchers to use.

State Reporting Requirements

State reporting laws may limit the promises of confidentiality that researchers can offer subjects. Most state laws identify individuals who must report suspected child abuse and neglect. This requirement should be described when child abuse and neglect might be revealed in a research study. Such studies could involve at-risk youth, school-based interventions, or parenting practices, among others.

On the other hand, there are many studies in which it is extremely unlikely that the topic would arise or that the researcher would be in a position to observe neglect or abuse. For example, a study of decision-making strategies using computer-based activities would not generate information about child abuse and there would be no need to discuss reporting requirements during the consent process.

State reporting laws may cover such matters as specific communicable diseases, the intent to harm oneself or others, and elder abuse. Consult with your IRB about the laws in your state.

International Privacy Laws

Researchers conducting research abroad should identify privacy laws at the research site that may be relevant for the conduct of research with human subjects.

Certificates of Confidentiality

Certificates of Confidentiality are issued by the National Institutes of Health (NIH) to protect identifiable research information from forced disclosure. Certificates of Confidentiality may be granted for studies collecting information that, if disclosed, could have adverse consequences for subjects or damage their financial standing, employability, insurability, or reputation. A Certificate of Confidentiality will allow the investigator and others who have access to research records to refuse to disclose identifying information on individual research participants in civil, criminal, administrative, legislative, or other proceedings, whether at the federal, state, or local level.

Information that can be protected includes, but is not limited to:

- Substance abuse or other illegal behaviors.
- Sexual attitudes, orientation, or practices.
- Genetic information.
- Psychological well-being.

Certificates of Confidentiality may be secured for any sensitive research, regardless of funding source. In fact, the research does not have to be funded.

Summary

Although privacy and confidentiality deal with different aspects within a study design, how these two issues are handled translate to issues of trust and security for a research participant.

7 Research with Children - SBR

- **Lorna Hicks, M.S., CIP** Duke University

Based on concern for the welfare of children as research subjects, protections for children that exceed those for adults were incorporated into the federal regulations for protecting research subjects. At the same time regulators recognized that some research presents no more than minimal risk to children and allowed for flexibility in the parental permission and child assent processes. This module will describe both the required additional protections and the options for flexible application of the regulations. In addition, the module includes a case study about a waiver of parental permission for children to participate in research.

Learning Objectives

By the end of this module, you should be able to:

- Know how the federal regulations define "children"
- Identify the federal regulations for protecting research subjects that apply to research with children
- Describe when research with children may be exempt from the regulations and when it may be expedited
- Outline the parental permission and child assent processes
- Apply the criteria for waivers of parental permission and child assent
- Understanding the requirements for documenting parental permission and child assent

Defining "Children"

According to the federal regulations, children are persons who have not yet attained the legal age of consent under the applicable laws in the jurisdiction in which the research will be conducted. Generally, though not always, the age of consent is the age at which minors reach the age of majority and are considered adults. In the United States, state law dictates the age of majority. In most states, the age of majority is 18. This means that a 17 year old may be considered a child when applying the federal regulations for protecting research subjects.

Investigators should be aware that the age of majority might be quite different in other countries. It is also possible that a nation may have no legal definition of majority. In such cases investigators will have to rely on community standards. For example, a researcher in Sierra Leone found that adulthood for the male population he wished to study was conferred through a Shamanic initiation process.

In the United States, some states have a legal process of emancipation that confers adult status on those who are younger than the age of majority. The conditions under which children may be released from parental authority vary from state to state. For example in some states emancipated minors may have the legal authority to provide permission for their own children to become research subjects, but may not be able to consent for themselves unless the requirement for parental permission is waived by an IRB. Consult with your IRB if these issues are relevant to your research.

Regulations That Apply to Research with Children

1. The basic federal regulations for protecting research subjects known as the Common Rule: Department of Health and Human Services (DHHS) Regulations, Subpart A, adopted by numerous federal agencies and departments.
2. The provisions of Subpart D, of the DHHS regulations, Additional Protections for Children Involved as Subjects in Research. The provisions of Subpart D must be applied to all research funded by the DHHS (which includes NIH). However, not all federal agencies that have adopted the Common Rule have also adopted Subpart D. In addition to DHHS, only the Food and Drug Administration and the Department of Education have adopted it. Institutions may elect to apply the subpart to all research, regardless of the source of funding.
Subpart D includes:
 - Restrictions on the applicability of the criteria for exemption when children are the subjects.
 - A hierarchy of four levels of risk and associated benefits.
 - Specifications for parental permission and child assent requirements at each level.
 - Criteria for waivers of parental permission and child assent.
3. State and local law and institutional policy, as applicable. For example, provisions for waiving parental permission for neglected or abused children cannot violate federal, state, or local law. The permissibility of such waivers may also be governed by institutional policies.

Exempt Research with Children as Subjects

The Common Rule describes activities that, although they **do** meet the definition of research with human subjects, are **not** subject to the provisions of the rule. Research eligible for exemption must include only activities that fall in one or more of **six categories**. (Following a link will open a new window in your browser. To return to the module, close the new window.)

Subpart D restricts the use of exemptions with children as subjects

The exemption categories that may be used with children include:

1. Research conducted in established or commonly accepted educational settings, involving normal educational practices.
2. Research about educational tests.
3. Observations of children in public settings, providing the researcher does not participate in the activities being observed.
4. Studies using existing data about children, (a) if the data are publicly available, or (b) if they are recorded in such a way by the investigator that the identity of the children cannot be determined either directly or indirectly.
5. Studies conducted by federal departments or agencies about government programs, such as welfare programs.
6. Taste and food quality evaluations and consumer acceptance studies, under some circumstances.

According to Subpart D, exemptions may **not** be used for any of the following:

1. Research involving interviews.
2. Research involving surveys.
3. Observation in which the researcher participates in the activities observed.

Note: Consult your IRB about your institution's exemption policies and procedures.

Expedited Review When Children Are Subjects

Expedited review is an option when the research activities pose no more than minimal risk to subjects and fall within **explicitly defined categories of activity**. The categories cover a range of activities, including research on individual behavior using interviews and questionnaires and the use of cheek swabs to collect genetic material. With the exception of limits on the amount of blood that may be drawn, there are no regulatory restrictions on using the expedited review process when children are subjects. Institutions are free to have more restrictive policies specifically for children.

Parental Permission and Child Assent

The General Process

The basic consent model when working with children is that parents (or legal guardians) provide permission for their children (or wards) to participate in research and for the researcher to contact the children. Children then provide their assent to become subjects. Assent is a child's affirmative agreement to participate. The absence of dissent should not be construed as assent when the child is old enough that this is meaningful. Generally, parental permission can only override a child's dissent when the health of the child is at stake.

Although particulars vary, it is generally assumed that children (minors) have limited rights to decide what will happen to them, based on their age and maturity. On one end of the age and maturity continuum are infants and toddlers who are not capable of making a decision about whether to participate, although they may evidence dissent if they become distressed. On the other end of the continuum are older adolescents who are both capable of making a decision and actively assenting or dissenting to participate in research.

No guidelines can replace a researcher's knowledge about the children to be recruited for a study. Researchers should be prepared to support their proposed assent process either with data or experience-based evidence, particularly if the children involved have vulnerabilities other than their youth, or live in a country, community, or society unfamiliar to the IRB.

How Much Information to Give Children

The federal regulations specifying what must be included in an adult consent process also apply to the parental permission process. However, there are no regulations that require specific elements or define the content or format of the child assent process.

Research about children's decision-making skills supports the common practice of using different assent processes for children and for adolescents, with the level of disclosure increasing as children grow older. Mature adolescents should generally be provided with study information comparable to that provided to adults.

Cultural Differences

Investigators may need to take into account the nationality, ethnicity, and socio-economic status of their potential subjects in order to design appropriate parental permission and child assent processes.

Cultural assumptions about the rights of children vary widely. In some countries or subgroups it may be inappropriate and perhaps offensive to ask children to make research-related decisions.

Longitudinal Studies

In order to respect the emerging maturity and autonomy of child and adolescent subjects in longitudinal studies, some researchers advocate revising the assent and permission processes appropriately and reaffirming assent as the child grows older. Once the child reaches the age of majority (typically 18) he or she may sign a consent form for adults.

Parental Permission, Child Assent, and Risk Level

Categorizing Risk Level

According to Subpart D, research with children can be divided into four categories of risk and related benefits. Each category carries specific review requirements as well as parental permission and child assent requirements. As levels of risk increase and benefits to individual children decrease, review criteria become more stringent and the requirements for permission and assent increase.

Most research in the social and behavioral sciences will fall into the first two of the four research categories.

1. **Research with no more than minimal risk.**(1). Adequate provisions must be made for securing permission of one parent and assent of the child, as appropriate. The regulations allow for waivers of some or all of the provisions of consent parental permission and child assent, under defined circumstances.
2. **Research involving more than minimal risk but presenting the prospect of direct benefit to the children participating in the study.** The parental permission and child assent requirements are the same as those for studies with no more than minimal risk. The risk must be justified in relationship to the anticipated benefits.

The two remaining categories primarily cover research on therapy for a disease or condition. They are:

1. Research involving greater than minimal risk and no prospect of direct benefit to individual subjects, but likely to yield generalizable knowledge about the subject's disorder or condition.
2. Research not otherwise approvable which presents an opportunity to understand, prevent, or alleviate a serious problem affecting the health or welfare of children.

Waivers of Parental Permission and Child Assent

An IRB may decide that child assent is not required because a child is not capable of providing assent. The regulations offer the following guideline: "In determining whether children are capable of assenting, the IRB should take into account the ages, maturity, and psychological status of the children involved."

In addition, Subpart D allows waivers of some or all of the required elements of consent for the parental permission and child assent processes, according to criteria established in the Common Rule. The criteria are:

1. The research involves no more than minimal risk to subjects.
2. The waiver will not adversely affect the rights and welfare of the subjects.
3. The research could not practicably be carried out without the waiver.
4. Whenever appropriate, the subjects will be debriefed after the study.

In addition to permitting waivers of parental permission and child assent in accordance with the Common Rule, Subpart D includes provisions for waiving the requirement to secure parental or guardian permission if an IRB determines that a research protocol is designed for conditions or for a subject population for which permission is not a reasonable requirement to protect the subjects. For example, an important area of inquiry is why and how certain teenagers come to live on the streets. An anthropologist wishing to interview teenagers who are runaways or who have severed ties with their families could not do so if parental permission were required.

Case Study: Waiver of Parental Permission

Prevention of Sexually Transmitted Diseases (STDs) in Adolescents

Researchers wish to contact minors who have accessed the services of a clinic for treatment of STDs. In the state in which the research is being conducted, minors are legally permitted to access these services without parental consent. The goal of the research is to identify the kinds of information the teenagers had before they acquired the STD and whether and how possessing the information affected their sexual behavior. The researchers are asking for a waiver of parental permission to interview teenagers who, based on full disclosure of the study's goals, are willing to take part in the research. The request is based on the grounds that if parental permission were required, it would pose a serious threat to the subjects' privacy and further, the adolescents' concerns about potential loss of confidentiality would limit enrollment and make the research impracticable. No identifiers will be collected.

Based on the regulations, the following questions would have to be asked to determine whether the study meets the criteria for a waiver of parental permission:

1. Is the level of risk more than minimal?

- **Considerations:** The researchers want to interview teenagers who have already sought treatment. The research does not involve medical treatment, but is limited to an interview. The teenagers will be fully informed about the research goals and the kinds of questions they will be asked. Identifiers will not be collected. Therefore, it can be argued that the probability and magnitude of harm or discomfort are not greater in and of themselves than those ordinarily encountered in daily life or routine physical or psychological exams; that is, that the research involves no more than minimal risk.

2. Would the waiver affect the rights and welfare of the subjects?

- **Considerations:** Assent will be obtained from the adolescents. Therefore, their right to make decisions about whether they will become research subjects will not be adversely affected. Parents' rights to make decisions about whether their child becomes a research subject may be limited when adolescents have been granted the right to privacy in certain matters by state law.

3. Could the study practicably be conducted without the waiver?

- **Considerations:** If the minors needed to get permission from their parents they would have to reveal that they are sexually active and that they have contracted a venereal disease, the answer to the question would probably be "no". While some parents might be aware of their child's health status, the researchers are familiar enough with the community in which the research is taking place to know that this is not likely.

4. Is debriefing possible and will it be conducted?

- **Considerations:** No demographics will be collected for any follow-up. The purpose of the study will be explained in the consent process. Notifying parents after participation would not be helpful and would jeopardize the minors' privacy.

Based on the answers to these questions, an IRB might conclude that parental permission could be waived under the regulations. IRBs could come to different conclusions, based on institutional policy, community standards, and state law. IRBs could require that additional procedures be put in place to protect the subjects. For example, an IRB could request that a research project have a child advocate who could assess whether an adolescent should participate. This would be someone not associated with the research team and with whom an adolescent could discuss his or her involvement.

Documentation of Parental Permission and Child Assent

Documentation of parental or guardian permission for children to become research subjects is required unless waived by an IRB in accordance with the regulations, as described below. Documentation of child assent is not required by the federal regulations for protecting research subjects. Institutional Review Boards have the discretion to determine the appropriate manner, if any, of documenting child assent.

If adolescents are involved in research where a consent form would have been used if the subjects were adults, it would generally be appropriate to use a similar form to document an adolescent's assent.

Waivers of the requirement to document parental or guardian permission may be approved by an IRB in accordance with the same regulations that govern waivers of the requirement to document adult consent. Thus, such waivers may be permitted under the following two conditions:

1. The documentation of consent is the only record linking the child to the research, **and** the principal risk would be potential harm resulting from a breach of confidentiality. If subjects wish to have a signed consent form, their wishes will govern.
2. The research involves procedures for which consent is not normally required outside the research environment.

When the requirement for documentation is waived, the IRB may require the investigator to present each subject (or parent or guardian) with a written statement regarding the research.

Summary

The federal regulations include special protections for children that include specific criteria for the kinds of review that may be used. When conducting research with children, researchers must develop parental permission and appropriate child assent processes. Requests to waive the requirements to secure parental permission and child assent and of the requirement to document parental permission may be approved by an IRB.

Footnote

1. "Minimal risk means that the probability and magnitude of harm or discomfort are not greater in and of themselves than those ordinarily encountered in the daily life or during the performance of routine physical or psychological examinations or tests." Daily life refers to the daily life of normal children.

8 Research in Public Elementary and Secondary Schools

- SBR

- **Lorna Hicks, M.S., CIP** Duke University

Introduction

Conducting research in public schools is a complex endeavor. Researchers must contend with a wide range of issues including the availability of school time and resources for research and the difficulty of securing parental permission. They must also contend with a number of federal regulations and laws that govern research in the schools. This module will outline those regulations and laws and their implications for researchers.

Learning Objectives

By the end of this module, you should be able to:

- List the regulations and laws that apply to research in the public schools
- Understand the impact on research of the Family Educational Rights and Privacy Act (FERPA) and the Protection of Pupil Rights Amendment (PPRA)
- Apply the additional safeguards for research with children included in Subpart D of 45 CFR 46
- Describe the requirements for parental permission and child assent
- Identify state and local reporting requirements

Overview of Regulations that Apply to Research in the Public Schools

In addition to the general provisions of the Common Rule (the federal regulations for protecting research subjects) the following regulations also govern research in the public schools:

- **The Family Educational Rights and Privacy Act (FERPA)**, sometimes referred to as the Buckley Amendment, gives parents certain rights over the content of their children's educational records.
- **The Protection of Pupil Rights Amendment (PPRA)**, amended by the "No Child Left Behind Act" of 2001, is designed to provide parental control over the content of surveys, instructional materials, analyses, and evaluations of minor students. Two levels of control are provided, based upon how the research is funded.
- **Subpart D of the federal regulations, "Additional Protections for Children Involved as Subjects in Research,"** when applicable: Some federal agencies that have adopted the Common Rule have not adopted the other subparts to the DHHS regulations. For example, while the Department of Education has adopted Subpart D; the National Science Foundation has not. Thus, when research is funded by the Department of Education, the provisions of the subpart apply. They do not apply when research is funded by the National Science Foundation.

Institutions are free to choose to apply Subpart D to all research, regardless of the source of funding.

The Family Educational Rights and Privacy Act

The Family Educational Rights and Privacy Act (FERPA) gives parents certain rights with respect to their children's education records. The rights transfer to students, or former students, who have reached the age of 18 or are attending any school beyond the high school level. Generally, schools must have written permission from the parent or eligible student before releasing any identifiable information from a student's record. Information in school records may include religious affiliation, citizenship, disciplinary status, attendance, gender, ethnicity, grades/exam scores, test scores (for example, the SAT), and progress reports.

FERPA **does** allow schools to disclose records without consent to certain parties, including organizations conducting research. Such disclosures may be used by researchers **only** when a school, school district, or state department of instruction initiates a study.

Schools may disclose, without consent, "directory" information such as a student's name, address, telephone number, date and place of birth, honors and awards, and dates of attendance. However, schools must tell parents and eligible students that directory information is not protected, and they must allow parents and eligible students a reasonable amount of time to request that the school not disclose directory information about them.

Researchers who themselves are employed by the schools, such as teachers returning for graduate degrees, must be aware of their dual roles. As researchers, they do not have legitimate access to information that they may consult daily as teachers.

The Protection of Pupil Rights Amendment

Protection of Pupil Rights Amendment (PPRA) gives parents some level of control over their child's participation in third-party survey research or exposure to instructional materials developed by researchers. PPRA identifies eight sensitive topics and includes two provisions for parental approval of surveys and materials that cover any of the eight topics. Each provision is associated with a Department of Education funding mechanism: 1) direct funding of a particular research topic by the Department, or 2) general school funding from the Department. (The following sections explain how PPRA is applied based on the funding mechanism.)

The eight topics are:

- Political affiliations or beliefs of the student or the student's parent.
- Mental and psychological problems of the student or the student's family.
- Sexual behavior or attitudes.
- Illegal, anti-social, self-incriminating, or demeaning behavior.
- Critical appraisals of other individuals with whom respondents have close family relationships.
- Legally recognized privileged or analogous relationships, such as those with lawyers, physicians, and ministers.
- Religious practices, affiliations, or beliefs of the student or student's parents.
- Income (other than that required by law to determine eligibility for participation in a program or for receiving financial assistance under such program).

Direct Funding of Research by the U. S. Department of Education

If research conducted under an "applicable program" of the Department of Education asks students to provide information about any of the eight topics listed above, parental permission for the students to participate cannot be waived.

An "applicable program" means "any program for which the Secretary or the Department has administrative responsibility as provided by law or by delegation of authority pursuant to law." This means any survey that is funded in whole or in part by any program administered by the U.S. Department of Education.

General Funding from the U. S. Department of Education

In 2001, parents were given additional rights with regard to the content of any surveys administered in public schools, not just those funded directly through a Department of Education program. Every public school system that accepts money from the Department of Education (all public elementary and secondary schools) must develop a policy that informs parents of their rights to inspect third-party surveys and related instructional materials and to ask that their children not participate.

PPRA does not require written parental permission for the use of surveys and related instructional materials when such use is not funded directly by the Department of Education. However, the Common Rule does require that parental permission be either secured or waived in accordance with criteria established in the Rule. (See below.) Note that even if an IRB waived the requirement to secure parental permission in accordance with the Common Rule, PPRA requires that, in accordance with school system procedures, parents must be notified about the research to take place and given the opportunity to ask that their children not take part.

FERPA and PPRA in Private Schools

If research is conducted under an applicable program of the U. S. Department of Education in a private school, PPRA applies. A private school that does not receive any federal funding is not subject to the provisions of FERPA and PPRA.

Subpart D, Additional Safeguards for Children as Research Subjects

Subpart D includes:

- Restrictions on the applicability of the criteria for exemption when children are the subjects.
- A hierarchy of four levels of risk and associated benefits, with specifications for parental permission and child assent requirements at each level.
- Criteria for waivers of parental permission and child assent.

Some institutions have chosen not to apply the provisions of the subpart unless required by a funding agency, so its provisions do not apply universally.

With regard to social and behavioral research, salient portions of Subpart D include 1) limits on the use of exemptions when children are research subjects and 2) an additional provision for waivers of parental permission when it is not a reasonable requirement, for example, when the children are neglected or abused. (Note: Such a waiver cannot violate PPRA, when applicable.)

Activities That May Qualify for Exemption in Accordance with the Common Rule

The Common Rule describes activities that do meet the definition of research with human subjects, but are not subject to the provisions of the rule. These activities pose little or no risk to the potential subjects and are called "exempt." Consult your IRB about your institution's exemption policies and procedures.

Subpart D limits the use of exemption criteria for research involving children. The following activities likely to take place in the public schools may qualify for exemption:

1. "Research conducted in established or commonly accepted educational settings, involving normal educational practices, such as (i) research on regular and special education instructional strategies, or (ii) research on the effectiveness of or the comparison among instructional techniques, curricula, or classroom management methods." *It is important to note that the definition of a normal educational practice varies over time and from community to community. For example, many school districts have adopted programs designed to improve interpersonal skills, such as the widely used "Second Step" curriculum. In those schools, role-playing to explore conflict resolution strategies may be considered a normal educational strategy. Therefore, the application of the exemption criteria regarding classroom activities will be affected by local context.*
2. Research using educational tests (unless an inadvertent disclosure of identifiable data would create the potential for harm).
3. Observation of public behavior in which the researchers do not participate in the activities being observed, for example, playground activities.
4. Research involving the collection or study of existing data or records if the data are publicly available, for example, aggregate system-wide data about student or school performance, or data recorded without identifiers.
5. Food and taste test studies.

The following activities with school children do not qualify for exemption under Subpart D:

- Research involving surveys.
- Research involving interviews.
- Observation of public behavior when the researcher participates in the activities being observed.

The following two case studies illustrate how the exemption criteria can be applied.

Case Study 1: Reading Comprehension

Elementary school teachers are interested in whether they can improve students' reading comprehension by teaching them how fiction and non-fiction texts are organized. Rising third-graders at schools A and B are tested for reading comprehension in their school district. Before the new school year begins, teachers at school A participate in a developmental workshop where a widely available program of instructional strategies for teaching students about fiction and non-fiction text structures is presented. Teachers at school A implement the new strategies in their classrooms. School A outcomes for reading comprehension will be compared with a comparable population in school B at the end of the third grade year. Teachers from school B will participate in the same workshop the following year if reading comprehension increases for the third-graders at school A.

Does this study meet the exemption criteria?

Yes, because it involves commonly accepted educational practices in a commonly accepted educational setting.

Case Study 2: Coping with Grief

A researcher wants to study how guided writing and drawing help elementary school children cope with divorce. She wants to interview children as part of the study.

Does this study qualify for an exemption?

No, because Subpart D states that interviews with children cannot be exempt.

Parental Permission and Child Assent

The consent paradigm for research with children requires that parents or legal guardians give permission for their children to become research subjects. The children, when appropriate for their developmental stage, provide assent.

Obtaining Parental Permission

A challenging issue for researchers in the public schools is the difficulty of securing parental permission. Sending home permission forms is unreliable. The forms may never make it out of the students' packs or may end up in stacks of papers for busy parents to get to later. And forms mailed to parents may not be read. Investigators report response rates as low as 50%. Without a high response rate, it may be impossible to obtain scientifically valid results or to assess interventions.

These difficulties create tension between the ethical principle of respect for persons, manifested in obtaining parental permission, and the ethical principle of beneficence. Benefits to both individuals and communities can only occur if research results are meaningful. There is also tension between the ethical principles of respect for persons and of justice. It is possible that those families who already are burdened by poverty or lack of education are less likely to provide permission for their children to be involved in research that might provide some direct benefit to them. If that is the case, there may not be enough of their children enrolled to get data that are meaningful for those children.

Waivers of Parental Permission

Because some institutions have requirements for waivers of parental permission that are stricter than the federal regulations, investigators should consult their IRBs for guidance.

The Common Rule provides four criteria for waivers of any or all of the elements of informed consent, as described below. Subpart D allows waivers of parental permission and child assent in accordance with the four criteria of the Common Rule. In addition, the subpart allows for waivers of parental or guardian permission when permission is not a reasonable requirement to protect subjects (for example, neglected or abused children) provided an appropriate mechanism for protecting the children is substituted.

In order to waive any or all of the elements of informed consent in accordance with the Common Rule, an IRB must find and document that the following criteria have been met:

1. **The research involves no more than minimal risk to the subjects.** *"Minimal risk" means that "the probability and magnitude of harm or discomfort anticipated in the research are not greater in and of themselves than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests." Research with more than minimal risk would introduce risks not normally part of the daily experience of school children.*
2. **The waiver or alteration will not adversely affect the rights and welfare of the subjects.** Some parental rights are defined by law, including FERPA and PPRA, as described above. But neither "rights and welfare" or "adversely affect" is defined in the regulations protecting research subjects, so an IRB must interpret what they mean in the local context. As always, the IRB may consult with the investigator, the schools, or other experts.
3. **The research could not practicably be carried out without the waiver or alteration.** The researcher must explain the reasons why the waiver is essential to the study. Inconvenience and expense are not acceptable factors in making a determination about "practicability".
4. **Whenever appropriate, the subjects will be provided with additional pertinent information after participation.** This process is usually referred to as "debriefing".

Many IRBs require that researchers tell parents about a study, even when it has approved a waiver of parental permission. In essence, parents may be offered the option of entering into a permission process even though it is not required.

Child Assent

The IRB is responsible for deciding whether child assent is required in proposed research activities. The IRB should require child assent unless it can be appropriately waived, or if the child is not capable of providing assent. The regulations identify three circumstances in which an IRB may determine that waiver of children's assent is appropriate:

- If the capability of some or all of the children is so limited that they cannot reasonably be consulted.
- If the intervention or procedure involved in the research holds out the prospect of direct benefit to the health or well-being of the children and is available only in the context of the research.
- If the research meets the same conditions as those for waiver or alteration of informed consent in research involving adults and parents, as described in the previous section.

Care should be taken so that children do not feel pressured into participating in research. Younger children may need to be reassured that their teacher will not be mad at them if they choose an alternate activity provided by the researcher rather than participating in the research. Adolescents who might be vulnerable to peer pressure, either to participate or not participate, may need privacy to make their decisions.

Child Abuse and Neglect Reporting

Researchers must be aware of their state and local reporting requirements when they suspect child abuse and neglect. If warranted by the research topic, they must also inform parents and older children that the confidentiality they can provide may be limited by the reporting requirements. While researchers need to alert subjects that they will make reports as required, they may wish to find ways to do so that will not discourage children from talking about their experiences.

Summary

Research in public schools is covered not only by the federal regulations for protecting human subjects, but by additional federal protections for children as research subjects. Federal acts and regulations further define students' and parents' rights in educational settings. Nonetheless, there are flexibilities in the regulations that make it possible to conduct research in the schools while ensuring the protection of students' rights and welfare, such as waivers of parental permission for some kinds of research.

9. Unanticipated Problems and Reporting Requirements in Social and Behavioral Research

Jeffrey M. Cohen, Ph.D., CIP
The HRP Consulting Group

Introduction

The federal regulations refer to events that increase the risks of harm to research subjects as “unanticipated problems involving risk to subjects or others” and require that such problems be promptly reported to the IRB.

Learning Objectives

By the end of the module, you should be able to:

- Define an unanticipated problem
- Describe the reporting requirements associated with unanticipated problems
- Identify the types of actions an Institutional Review Board (IRB) may take in response to an unanticipated problem

What are Unanticipated Problems?

The Office for Human Research Protections (OHRP) in its Guidance on Reviewing and Reporting Unanticipated Problems Involving Risks to Subjects or Others and Adverse Events noted that unanticipated problems, in general, include any incident, experience, or outcome that meets all of the following criteria:

1. unexpected (in terms of nature, severity, or frequency) given (a) the research procedures that are described in the protocol-related documents, such as the IRB approved research protocol and informed consent document; and (b) the characteristics of the subject population being studied;
2. related or possibly related to participation in the research (in this guidance document, possibly related means there is a reasonable possibility that the incident, experience, or outcome may have been caused by the procedures involved in the research); and
3. suggests that the research places subjects or others at a greater risk of harm (including physical, psychological, economic, or social harm) than was previously known or recognized.

Although the definition of unanticipated problems says that the problems may affect research subjects or “others,” OHRP does not provide guidance about what categories of persons are considered “others.” It is up to the

institution/IRB to determine what groups should be considered, for example, they may be close relatives of the research subjects or members of the research team. The determination may be research context dependent. The institution/IRB should have policies and procedures that speak to this issue.

Reporting Requirements

The reporting of an unanticipated problem by the researcher to the IRB begins the process of assessing the unanticipated increased risk(s) to subjects or others, and determining what course of action should be taken to protect the subjects. Each institution's IRB must have policies on what constitutes "prompt" reporting, and procedures for submitting and responding to reports. OHRP guidance states that "The regulations at 45 CFR 46.103(a) and (b) (5) do not specify a time frame for reporting, except to say this must be done "promptly." For a more serious incident, this may mean reporting to OHRP within days. For a less serious incident, a few weeks may be sufficient." Researchers should check with their local IRB to determine their institution's procedures.

IRB Actions

Actions that an IRB may take include, but are not limited to:

- Require modifications to the protocol
- Modify the consent document or consent process
- Require that current subjects be re-consented
- Provide additional information to current and/or past subjects
- Require additional training of the researcher and/or study staff

10 Research with Prisoners - SBR

Introduction

The history of conducting research with prisoners has been problematic. As a group, prisoners have been a population of convenience – researchers knew where they were and would be, often for many years. In addition, prisoners lived under controlled conditions conducive to research. It was generally accepted to use prisoners as research subjects, testing medicines, drugs, and medical devices without regard to the risks, benefits, and rights of those individuals.

As documented in *Acres of Skin: Human Experiments at Holmesburg Prison* (Hornblum, 1998), prisoners were used in lieu of laboratory animals to test the toxicity of cosmetics. In other experiments, they were irradiated in research conducted by the Atomic Energy Commission, rendering some sterile and others badly burned.

In 1978, the U.S. Department of Health and Human Services (DHHS) issued additional regulations providing safeguards for prisoners as research subjects, Subpart C: Additional Protections Pertaining to Biomedical and Behavioral Research Involving Prisoners as Subjects. These regulations address the fact that prisoners are under constraints that could affect their ability to make truly voluntary and un-coerced decisions to participate in research. Subpart C imposes strict limits on the involvement of prisoners as research subjects. **In essence, the only research that may be conducted with prisoners as subjects is research that is material to the lives of the prisoners.**

Learning Objectives

By the end of this module, you should be able to:

- Examine and apply the definition of "prisoner in the regulations
- List the four categories of permissible research allowed by the regulations
- Identify issues to consider when designing research to be conducted with prisoners
- Identify issues related to accessing prison populations
- Describe the regulatory obligations of an IRB reviewing prison research

Defining "Prisoner"

Subpart C defines a "prisoner" as follows:

"Prisoner means any individual involuntarily confined or detained in a penal institution. The term is intended to encompass individuals sentenced to such an institution under criminal or civil statute, individuals detained in other

facilities by virtue of statutes or commitment procedures which provide alternatives to criminal prosecution or incarceration in a penal institution, and individuals detained pending arraignment, trial, or sentencing."

Included in this definition are those individuals in hospitals or alcohol and drug treatment facilities under court order. Individuals in work-release programs and under house arrest programs also qualify as prisoners. The definition applies to minors as well as to adults.

Research Allowed Under the Regulations

The regulations allow prisoners to be involved in four categories of research. Most social and behavioral science research falls into the first two categories:

1. Studies of the possible causes, effects, and processes of incarceration, and of criminal behavior, provided that the study presents no more than minimal risk and no more than inconvenience to the subjects.
2. Studies of prisons as institutional structures or of prisoners as incarcerated persons, provided that the study presents no more than minimal risk and no more than inconvenience to the subjects.
3. Research on conditions particularly affecting prisoners as a class (for example, vaccine trials and other research on diseases such as hepatitis and HIV which are more prevalent in prisons than elsewhere; and research on social and psychological problems such as alcoholism, drug addiction, and sexual assaults).
4. Research on practices, both innovative and accepted, which have the intent and reasonable probability of improving the health or well being of the subjects. In cases in which those studies require the assignment of prisoners to control groups in which they may not benefit from the research, the study may require federal-level review.

Examples of social and behavioral science research in the categories listed above include:

- Age at first arrest as a predictor of adult criminal history
- Effects of over-crowding on prison populations
- The influence of prison-awarded incentives, such as promotions in custody level, on retention in substance abuse treatment programs
- The use of true crime/detective stories as bibliotherapy
- Social support systems in prisons
- The functioning of pseudo-families in prison

Designing Prison Research

Consent Issues

Free Choice

Informed consent requires the ability to choose freely, without coercion and without undue influence. Because the autonomy of prisoners is necessarily limited, the regulations include provisions designed to reduce any undue

influence on prisoners' decisions to participate in research. For example, each prisoner must be clearly informed that the decision to take part in research will have no effect on an inmate's parole.

The Use of Incentives

Incentives to take part in research should be appropriate to the research setting and subject population. Prison cultures and prison structures are such that incentives that might seem trivial in the outside world could carry great significance within a prison. For example, a researcher offered women photographs of themselves and their visiting children that would be taken and framed by a professional photographer. In a prison environment, where women are deprived of their children and do not have cameras that particular form of compensation might be an undue influence. Another example involves money as an incentive. In many states, the maximum wage for an offender is \$1.00 per day. Offering \$25.00 for participation in research would be comparable to five weeks pay and might thus prove to be an undue influence.

The presence of incentives in research is not always clear within the prison culture. As such, the regulations require the IRB to consider "(a)ny possible advantages accruing to the prisoner through... participation in the research, when compared to the general living conditions, medical care, quality of food, amenities and opportunities for earnings..." within the prison. The IRB should determine that these types of incentives do not impair the prisoner's ability to make an informed choice.

Descriptions of Confidentiality

Researchers should describe, in detail and at the appropriate reading level, how they will protect data provided by prisoners. The consent form should also clarify the types of information the researcher will give to correctional staff, such as a "final report containing group data without names."

The consent form should clarify the type of information the researchers will give to correctional staff, such as a final report containing aggregate data but not information that would identify individuals.

Limits to Confidentiality

Investigators need to specify the limits of confidentiality. Consent forms should clearly state what information can never be confidential within a prison such as prisoners' threats to hurt themselves or others and professed plans to escape and must be reported to the prison authorities. Investigators need to be aware of the circumstance in which even having a copy of the consent form may lead to a breach of confidentiality.

Assessing Risk

Harm in Asking Questions

There is often a limited support system within a prison that an offender can use to "debrief" following involvement in research. Prisoners often have limited means and skills to work through issues and feelings. Strategies use to cope with stress that are available outside prison, such as telephoning a friend or going for a run may be restricted in the prison setting. Investigators, in conjunction with prison staff, need to develop strategies for managing the risks presented when inmates are asked potentially emotionally charged questions, such as the events leading to their incarceration or questions about their current emotional health and relationships.

Breach of Confidentiality

This section includes examples of potential breaches of confidentiality unique to the prison setting and some strategies for managing that risk.

Nature of Conviction

Scenario:

A researcher is studying child abuse history of pedophiles in order to develop treatment strategies for use within the prisons. He wants to call 25 pedophiles out of the general prison population for interviews.

Discussion:

There is a great deal of offender information that is freely available to the public: an inmate's name, age, race, sex, conviction, court where sentenced, length of sentence, etc.

However, some of this information, though publicly available in free society, becomes private within the prison. Within prisons some crimes are more "acceptable" than others. Given the culture of a prison, the identification of a research participant as a pedophile may expose that individual to harm. Even though convictions are public information, researchers do not have the right to disclose information about a person's conviction to other prisoners.

A possible strategy for managing this particular risk is to interview 50 people who had committed a variety of crimes so that 25 pedophiles included among the 50 would not be identified to other prisoners.

Health Status

Scenario:

A researcher is studying quality of life issues in inmates who have a positive HIV status.

Discussion:

Prisoners who take part may risk a breach of confidentiality regarding what should be private health information. Prisoners have little privacy and, in many facilities, there is still stigma attached to a positive HIV status. As in the previous scenario, the investigator needs to consider study design strategies to keep the subject matter confidential, perhaps by interviewing prisoners with a range of health conditions that includes a positive HIV status.

It would be easier to maintain confidentiality when conducting this type of research outside the prison setting: one could arrange to conduct the interview in a private setting so that no one but the researcher would know his or her health status.

Prison Life

Scenario:

A researcher proposes to conduct focus groups with women prisoners. The goal is to develop an understanding of the kinds of services incarcerated women will need in order to break the cycle of repeated arrests.

Discussion:

Investigators need to be mindful of the inability to guarantee confidentiality within focus groups. One possible consequence in this case, among many, is that a woman might mention something in the focus group that could be used against her by other group members. It is difficult to ensure that group members will not talk outside of group; other inmates or staff may try to persuade members to share information. The researcher needs to ensure that all members understand this risk. In the absence of such assurances, it may be preferable for the researcher to acquire data about needed services through individual interviews.

Institutional Review Board Review of Prison Research**Required Composition of the IRB**

A majority of the IRB members must have no association with the prison(s) involved, apart from their membership on the IRB.

At least one member of the IRB must be a prisoner, or a prisoner representative with appropriate background and experience to serve in that capacity. The prisoner representative must be a voting member of the IRB with a close working knowledge and understanding and appreciation of prison conditions from the prisoner's perspective. If a research project is being reviewed by more than one IRB, only one IRB must satisfy this requirement. Suitable board members would include former prisoners, prison chaplains, prison psychologists, prison social workers, other prison service providers, persons who have conducted advocacy for the rights of prisoners, and other individuals who are qualified to represent the rights and welfare of prisoners by virtue of appropriate background and experience with prisons and prisoners.

Required IRB Findings

For research involving prisoners, the IRB must make additional determinations before approving the research. The IRB must determine that:

- The research under review falls into one of the four categories of permitted research listed above.
- Any benefits to the prisoner that may result from being in the research when compared to the general living conditions, medical care, quality of food, amenities, and opportunity for earnings in the prison, do not impair his or her ability to weigh the risks of the research against the benefits in the prison environment.
- The risks involved in the research are commensurate with risks that would be accepted by non-prisoner volunteers.
- Procedures for the selection of subjects within the prison are fair to all prisoners. Control subjects must be selected randomly from the group of available prisoners who meet the characteristics needed for that particular research project.
- The study information is presented in language that is understandable to the subject population.
- Each prisoner must be clearly informed in advance that participation in the research will have no effect on his or her parole.
- Adequate provisions have been made for follow-up examination or care and prisoners are informed that the provisions have been made.

Exempt and Expedited Review of Prison Research

Research conducted in prisons may not be exempt under 45 CFR 46.101(b). Although the regulations permit expedited review of prisoner research, the Office for Human Research Protections (OHRP) strongly discourages the

use of expedited review procedures as an acknowledgement of the vulnerability of prisoners as a class. It is recommended that all prisoner research be reviewed by the convened IRB with a prisoner representative present for the review.

The Use of Waivers in Prison Research

Research involving prisoners may be approved with a waiver or alteration of informed consent. However, even if documentation of informed consent is waived or altered, Subpart C of 45 CFR part 46 still requires that the subjects be clearly informed in advance that participation in the research will have no effect on their parole.

Federal Review of Prison Research

Prison research funded by the Department of Health and Human Services (DHHS), including NIH, must be certified by OHRP. In addition, research with prisoners that falls into categories 3 and 4, described earlier in this module, requires federal consultation and approval. If research is not conducted or supported by DHHS, these requirements do not apply.

When Enrolled Subjects Become Prisoners

If a human subject involved in ongoing research becomes a prisoner during the course of the study, the researcher must notify the IRB promptly. All research activities with the now incarcerated prisoner/subject must be suspended immediately. The only exception to this rule is when it is in the best interests of the subject to remain in the study. This exception is most often invoked when the subject is taking part in clinical research, and involves the administration of drugs or medicine involving a prospect for direct benefit to the subject. The research must then be reviewed by the investigator's IRB using Subpart C to make the required determinations about the permissibility of the research and, where applicable, OHRP must certify that the research may be conducted.

Accessing Prisoners

Jurisdiction

The jurisdiction over a correctional facility may exist at the local, state, or federal level. Within a state, policies may vary from county to county. Juvenile correctional systems are usually separate from other state facilities and may have their own rules and policies. Therefore, accessing prisoners might involve an entirely different process, depending upon the facility housing the prisoners. There are also various phases of incarceration, from pre-sentencing to work release, with differing restrictions on access to the prisoners. Investigators will need to identify the jurisdiction with authority over access to the prisoners they wish to study and become familiar with its procedures.

Gaining Access

A few general comments may be made about accessing prison populations:

- Correctional systems on the state level will have a review process. It may be administrative, a permissions board, but could include a review comparable to that of an IRB. Investigators who want to do research in a state facility will need approval from their local IRB and with the equivalent committee from the state

Department of Correction. Depending upon the type and category of research, it may also require certification from DHHS.

- Approval by an institutional IRB is frequently not sufficient to get an investigator inside a state prison. The Superintendent has the final authority to allow a researcher access to prisoners.
- An essential step in preventing problems entails establishing a collaborative relationship with departmental staff while still in the research design stage. In fact, this step is essential. Staff with whom to establish collaborations include prison social workers, psychologists, and custody staff. Investigators should consider how their proposed studies might help further the mission/goals of a specific department. For instance, if prison staff are worried about or experiencing trouble with gangs, the investigator might consider how the research may lead to information about how to handle gang activity.
- As an administrative issue, many penal institutions are willing to provide access provided that the research is not disruptive to the institution. Administrators will be concerned with protecting the safety of researchers, the prison population, and the prison staff. In addition to safety concerns, there are operational concerns. Is there office space? Are there enough officers assigned? Are the prisoners occupied in treatment or work during interview times?
- If a study disrupts prison operations, it may not be allowed even if it is ethically sound and might yield useful results.
- Local and county jails are less likely to have a formal review process for proposed research. In the absence of structural protections for the inmates, the researcher must assume the sole responsibility for ensuring the ethical conduct of research. As one official noted, "If the second shift lieutenant says you're in, you're in." Thus, access is dependent upon local personnel and could vary significantly.
- Juvenile correctional systems may or may not have a formal review process. If formal processes do exist, they may reside either at the state level, at the level of the local facility, or both. Research in juvenile facilities involves additional ethical considerations under subpart D pertaining to children as well as those of prisoners.

Summary

Persons who are confined or detained by court order have lost significant rights, and their ability to freely consent is hampered. When research is conducted with prisoners, researchers and their IRBs have significant responsibilities, as outlined in the regulations, to take steps to ensure that they safeguard the rights prisoners retain and those protected by regulations. Prisoners must be allowed to choose whether to participate in research that is relevant to their lives and their privacy and the confidentiality of their research data must be protected to the extent possible.

12 International Research - SBR

- **Lorna Hicks, M.S., CIP**
Duke University
- **Mary Simmerling, M.A.**
University of Chicago

Introduction

Social and behavioral scientists conduct research around the globe. Ethnographers immerse themselves in communities in the developing world and study minority enclaves in Western Europe. Environmentalists study the practices of multi-national corporations in South America. Linguists, demographers, historians, sociologists, and educators all conduct research abroad and collaborate with foreign institutions.

Wherever research is conducted, it must be carried out in a way that honors the autonomy and dignity of all persons and embodies the principles of respect for persons, beneficence, and justice.

Learning Objectives

By the end of this module, you should be able to:

- Recognize the value of understanding the local context
- Determine where research should be reviewed
- Identify when institutions are engaged in research

Applicable Regulations and Guidelines

The federal regulations for protecting research subjects include stipulations about how collaborations with foreign institutions must be conducted. The Office for Human Research Protections (OHRP) has acknowledged the importance of understanding the local research context.

Non-regulatory guidance about the design and conduct of research is available from a variety of sources, including professional associations. For example, the American Anthropological Association has formal guidelines about the ethical obligations of international researchers.

The Importance of the Local Research Context

It is essential that researchers have sufficient knowledge of the local research context to be able to design and carry out research in a way that protects the rights and welfare of the subjects. The local research context includes

socioeconomic, political, and cultural factors, and influences every aspect of the research design. An effective child assent process requires understanding how relationships between parents and their children are defined. Questions that may be innocuous in the United States could be offensive elsewhere. Different cultures have different authority structures that will influence how researchers handle potential coercion.

Even when the federal regulations do not require review by an Institutional Review Board or ethics committee in the country or region where the research will take place, local review of some sort may be the norm in some countries. Consider these examples:

An ethnographer conducting research in a village in Northern Togo needed clearance, first, from the Togolese government's Ministère de la Recherche Scientifique; then, from the Préfet of the canton in northern Togo; then, from the Chef (chief) du Canton, the Chef du Village, and the Chef du Quartier. Then the researcher secured the consent of the subjects.

In Israel, the Spokesperson's Unit of the Ministry of Defense must process all requests to interview Israeli soldiers.

Researchers may wish to consult with community leaders and stake holders who may be able to provide important insights about the local research context, including information about local customs, norms, and laws. Similarly, IRBs must have sufficient information to meaningfully evaluate the proposed research and may engage consultants to supplement its expertise. Researchers and IRBs may find it useful to work together to gather information about the proposed research site.

Determining Where Research Should Be Reviewed

If research involves collaboration with an institution that is "engaged" in research in the foreign country (See below for a discussion of "engagement in research"), the collaborating institution will need to have procedures in place that ensure that subjects will be protected in a manner commensurate with the Common Rule, including review by an independent committee comparable to an IRB. These procedures must be described in an agreement called an "assurance of compliance" with OHRP.

The federal regulations acknowledge that local customs, norms, and laws where the research will take place may differ from the Common Rule and provide options for listing different standards in foreign assurances of compliance. Optional standards include, among others, the Canadian Tri-Council Policy, the Indian Council of Medical Research, and the CIOMS International Ethical Guidelines (biomedical). Foreign collaborators may have their own IRBs or comparable review committees. If not, they may designate another IRB willing to review the research as the IRB of record. That IRB could be the U.S. investigator's IRB or another IRB in the foreign country.

Specific procedures for approving such substitutions may be found in the Common Rule [\(1\)](#). Instructions and application forms for foreign institutions to secure assurances of compliance may be found on the [OHRP website](#). Sometimes an individual who is not affiliated with an institution collaborates with a U.S. investigator. In such cases, an unaffiliated investigator agreement may be appropriate. Consult your IRB if you anticipate such a collaboration. If a collaborating institution, or unaffiliated individual, is not "engaged" in the research as described below, foreign assurances of compliance are not required.

"Engagement" in Research

Collaborating institutions are either engaged or not engaged in research as described in OHRP [guidance documents](#). Briefly, an "engaged" foreign institution is one that recruits and secures consent from subjects, conducts research procedures, or receives or shares private, identifiable information.

Institutions are not engaged if their employees or agents: (i) inform prospective subjects about the availability of research; (ii) provide prospective subjects with written information about research (which may include a copy of the relevant informed consent document and other IRB-approved materials) but do not obtain subjects' consent or act as authoritative representatives of the investigators; (iii) provide prospective subjects with information about contacting investigators for information or enrollment; or (iv) obtain and appropriately document prospective subjects' permission for investigators to contact them. For a full description of the concept of "engagement" see the OHRP guidance documents noted above.

Research without Foreign Collaborators

Some international research is carried out without the involvement of collaborators. For example, political scientists may interview people on the street in Germany or environmental scientists may interview fisherman in Panama. Federal regulations do not require on-site review in such cases. As noted above, even when research does not require review at a foreign research site, local review of some sort may be normal in some countries. Again, the researcher's and IRB's knowledge about the local research context are essential.

Exempt Research

A great deal of research in the social and behavioral sciences poses little or no risks to subjects and may qualify for exemption, depending upon institutional policy. If a proposed study qualifies for exemption, federal regulations do not require review at the foreign site where it will be conducted. OHRP guidance documents about engagement in research and knowledge of local research context do not apply to exempt research. Institutional policy will determine how exempt research conducted abroad will be reviewed and the required qualifications of reviewers.

Informed Consent

The points to consider when obtaining informed consent in non-U.S. settings include:

- Sometimes, in non-U.S. communities, people other than the individual taking part in the research may be required to give permission before the potential subject may be asked to participate. These individuals may include a spouse, a head of household, or a group leader. The investigator must design a consent process that honors local custom. However, another individual's permission should not substitute for a subject's voluntary informed consent unless that consent process has been waived by an IRB or equivalent local review committee.
- What is the appropriate language for the consent? In many settings, there may be several languages, such as an "official" state language and a local language or dialect. Consent is best obtained using the language that is most familiar to the subject.
- Should consent be oral or written? In some instances, the language used to obtain informed consent is not a written language. In other instances, the people who are considering whether or not to take part in the research may not read the language, even if it is written. There may be some settings in which signing a document has connotations that would make a written documentation of consent problematic. The investigator should gather information about what the situation is in the research setting and propose an appropriate approach to obtaining and documenting consent.

- Who can act as interpreter? Ideally, the research team is fluent in the local language. If this is not the case, the investigator must have individuals to assist who are fluent. However, the investigator must carefully consider, especially in a small population, the relationship between the interpreter and the subjects. While most IRBs agree that using children as interpreters is not appropriate, there may be disagreement about whether adult relatives, residents of a small village, or others already known to the subjects may be employed in this role. The issues used to determine who can interpret include the possibilities for undue pressure or influence, selection bias, and the extent to which the chosen interpreter can relay information between investigator and subjects in a clear and unbiased manner. For example, it is not unusual for interpreters to simply leave out information they believe is unpleasant or culturally inappropriate.
- What is the age of majority in the country where the research is taking place? Do the parental permission and child assent processes reflect local norms?
- Is there a local contact person? When research is conducted in the United States, investigators are required to provide contact information for their IRB should subjects have questions or concerns regarding the research in which they are participating. In an international study it may be important to have a local contact identified by the investigator in consultation with the community and the IRB.

Additional Information for IRB Review

Investigators who will be conducting research internationally will want to provide the IRB with at least the following information:

- Information about where the research will be conducted (both the geographic location and the performance site, where applicable).
- A copy of local IRB or equivalent ethics committee approval, when required.
- Information about the investigator's knowledge of the local research context, including the current social, economic, and political conditions.
- Information about whether there are any additional risks subjects might face as a result of the population being studied and/or the local research context.
- The language(s) in which consent will be sought from subjects and the research will be conducted, as well as whether the investigator is fluent in this language, or whether an interpreter will be used. If an interpreter will be used, it should be clear what risks, if any, this might pose for subjects, as well as how the risks will be minimized.
- Copies of the translated informed consent documents and instruments, including verification of the accuracy of the translation(s).
- Information on how the investigator will communicate with the IRB while in the field.

Summary

Research conducted abroad may need review only by the researchers' institution; however, some research with collaborators may need multiple kinds and levels of review depending upon the funding source and the nature of

the collaboration. These reviews are focused on applying ethical principles to research methods and interactions with human subjects in the context in which the research takes place.

Footnote

1. 46.101(h) When research covered by this policy takes place in foreign countries, procedures normally followed in the foreign countries to protect human subjects may differ from those set forth in this policy. [An example is a foreign institution which complies with guidelines consistent with the World Medical Assembly Declaration (Declaration of Helsinki amended 1989) issued either by sovereign states or by an organization whose function for the protection of human research subjects is internationally recognized.] In these circumstances, if a department or agency head determines that the procedures prescribed by the institution afford protections that are at least equivalent to those provided in this policy, the department or agency head may approve the substitution of the foreign procedures in lieu of the procedural requirements provided in this policy. Except when otherwise required by statute, Executive Order, or the department or agency head, notices of these actions as they occur will be published in the Federal Register or will be otherwise published as provided in department or agency procedures.

13 Hot Topics

- **Margaret Rankovic, MEd, CIP**
CITI Program

Welcome to the CITI Program's "Hot Topics" module. The following information has been prepared to keep you updated on regulatory issues, new policies, and hot topics in human subjects research. The module is revised annually or more frequently as needed.

Final Revisions to the Common Rule

On 19 January 2017, the U.S. Department of Health and Human Services (HHS) and 15 other federal agencies issued a final rule to update the current regulations 45 CFR 46 Subpart A "Federal Policy for the Protection of Human Subjects" (the Common Rule). These are the first substantial changes to the regulations since 1991. The revisions aim to reduce administrative and regulatory burden through operational updates, as well as improve protections for human subjects through emphasizing understandability in informed consent, and eliminate duplicative Institutional Review Board (IRB) review by requiring a single review for cooperative multi-site research. The regulatory definitions of "research" and "human subject" were expanded and a new definition was added for "clinical trial" that aligns with the National Institutes of Health's (NIH) definition.

The final rule was preceded by the Notice of Proposed Rulemaking (NPRM) which received over 2,100 comments and the Advanced Notice of Proposed Rulemaking (ANPRM). Many of the more controversial changes proposed by the NPRM and those that were not fully developed (for example, the exemption tool) were not included in the final rule.

Additional final rule revisions include:

- Improving the informed consent document and process to increase subject understanding
- Requiring that consent forms for certain federally funded clinical trials be posted on a public website
- Requiring single Institutional Review Board (IRB) review for cooperative research for some studies
- Allowing the use of broad consent for future research for secondary studies on stored identifiable data or identifiable biospecimens
- Eliminating continuing review for certain minimal risk research
- Establishing additional exempt categories of research based on level of risk posed to subjects
- Adopting the definition of "Clinical Trial" that includes behavioral health-related outcomes

The changes affect all areas and members of the research community – including investigators, IRB members and administrators, subjects, and organizational officials, and both biomedical and social behavioral research.

The pre-2018 rule will be replaced by the final rule effective on January 19, 2018. The compliance date for this rule, except for cooperative research is January 19, 2018. The compliance date for cooperative research is January

19, 2020. The final rule does not adopt the proposal that was mentioned in the NPRM to allow institutions and investigators to implement provisions in the final rule 90 days after publication of the final rule. After the effective date, however, institutions may choose on a study-specific basis to apply either the pre-2018 rule or the final rule to research initiated before the effective date. All research initiated after the effective date of the final rule must comply with the final rule. This final rule will apply to all 15 federal agencies that have adopted the Common Rule.

Single IRB

National Institutes of Health (NIH) Policy

On June 21, 2016, the NIH issued its final policy on the Use of a Single IRB (sIRB) for Multi-Site Research that requires the use of a single IRB (sIRB) of record for multi-site research that is NIH-funded, multi-site (more than one site) and non-exempt human subjects research conducted in the U.S. (HHS 2016). This policy takes effect September 25, 2017 (the NIH extended the effective date from May 25, 2017). NIH is officially promoting the use of a single IRB for large, multi-site clinical trials in order to avoid duplication of effort, decrease approval times, and be more cost effective.

Common Rule Requirements per 45 CFR 46.114

Effective January 19, 2020, as published in 45 CFR 46.114 Cooperative Research, single IRB review is required for research that takes place within the U.S. The final rule states that all U.S. institutions engaged in cooperative research will have to rely on a single IRB for the portion of the research that takes place within the U.S., with certain exceptions (Protection of Human Subjects 2017). The exceptions include when more than sIRB review is required by law (for example, tribal law), and when any federal department or agency supporting or conducting the research determines and documents sIRB review is not appropriate for the study.

Updated NIH Policies

Two recent rules affect specimen research, consent, and IRB review for NIH-funded human subjects research.

The [Newborn Screening Saves Lives Reauthorization Act of 2014](#)

Affects federally funded research with dried blood spots collected after 18 March 2015. It requires that the IRB review this research, that the use of dried blood spots cannot be considered non-human subjects research even though they are non-identifiable, and that the IRB cannot waive the requirements for parental permission. More information is available in the [NIH guidance about research with newborn dried blood spots](#). However, with the recently published final rule, this Act will no longer be effective as of January 19, 2018.

The [Genetic Data Sharing \(GDS\) Policy](#)

Extends and replaces the 2007 Genome-Wide Association Studies (GWAS) data sharing policy. It applies to NIH-funded research and affects researchers who are sharing data through the NIH database (dbGaP) / repository, as well as researchers who plan to access the data and samples in the database / repository. The GDS policy has implications for IRB review of research, including requiring IRBs to review the researcher's data sharing plan and informed consent document - even if the use of the specimens would not be considered human subjects research by the 2008 Office for Human Research Protections (OHRP) guidance. More information about the GDS policy is available [here](#) and in the [NIH Points to Consider for IRBs and Institutions](#).

Phase I Research - BIA 10-2474 Trial Disaster

In January 2016, a phase I research trial in France made worldwide news when one subject died after receiving the study drug (BIA 10-2474) and five others were hospitalized. Phase I subjects are generally healthy volunteers who are testing the drug's safety in humans. According to reports, the French phase I trial was being conducted according to all regulatory rules. However, in the aftermath of this human subjects research tragedy, there are calls for additional legislation to further protect subjects (Callaway and Butler 2016). The French government is taking first steps via France's General Inspectorate of Social Affairs (IGAS), which in May 2016 issued a report ([Enquête sur des incidents graves survenus dans le cadre de la réalisation d'un essai clinique - Rapport définitif](#)) saying that all clinical trial centers in the country will be inspected by France's Regional Health Agencies together with the National Agency for Medicines and Health Products Safety (ANSM) (Enserink 2016).

Mobile Health (mHealth) Technology in Human Subjects Research

According to industry estimates, 500 million smartphone users worldwide will be using a health care application by 2015, and by 2018, 50 percent of the more than 3.4 billion smartphone and tablet users will have downloaded [mobile health applications](#). These users include health care professionals, consumers, and patients (FDA 2015).

Smartphone apps in research have grown in use over the last few years. Searching "smartphone" in [clinicaltrials.gov](#) turns up 491 registered trials (as of 1 June 2016).

There is limited guidance on the use of smartphone apps and mobile technology for research, and IRBs and researchers may not have a lot of experience with this new technology. The FDA has published [draft guidance on mobile medical apps](#), and the FDA and OHRP have published [draft guidance on the use of electronic informed consent](#) in clinical investigations.

There are four government agencies that may have a hand in regulating mobile apps.

- U.S. Food and Drug Administration (FDA)
- Office of the National Coordinator for Health Information Technology (ONC)
- Office for Civil Rights (OCR)
- Federal Trade Commission (FTC)

For example, the FTC charged the marketer of a "vision improvement" app for false claims, because the app developers did not have scientific evidence to support their marketing (FTC 2015). There is now an [online tool](#) provided by these agencies to help app developers find out which federal laws they need to follow.

Incidental Findings in Research

Incidental findings (which include unexpected results, secondary findings, or discovery findings) are information discovered unintentionally and are usually unrelated to the test being performed or the condition being treated (Presidential Commission 2013). Incidental findings affect all areas of research, from standard of care CT scans to genetic sequencing to social and behavioral interviews.

There are no specific regulations in the U.S. on how researchers should handle incidental findings. However, there have been steps taken by the [Presidential Commission for the Study of Bioethical Issues](#) and professional organizations (for example, the American College of Medical Genetics and Genomics) to develop guidance and recommendations for researchers.

Organizations may also offer their own guidance regarding incidental findings. At the University of Kentucky (UK), a committee collaboration between the IRB and an NIH- funded Center for Clinical and Translational Sciences resulted in recommendations on incidental findings for researchers and IRB members, and template language for the informed consent document.

Draft Federal Guidance: IRB Written Procedures

U.S. Department of Health and Human Services (HHS) and U.S. Food and Drug Administration (FDA) regulatory requirements mandate that IRBs have written procedures. In August 2016, HHS 'Office for Human Research Protections (OHRP) and FDA issued draft guidance [Institutional Review Board \(IRB\) Written Procedures: Guidance for Institutions and IRBs](#). While still in draft stage, it may be helpful to review both the guidance and its accompanying checklist during the development of organizational procedures.

Federal Guidance: Electronic Consent

The Department of Health and Human Services '(HHS) Office for Human Research Protections (OHRP) and the U.S. Food and Drug Administration (FDA) have provided finalized joint guidance on using electronic systems to obtain informed consent for both HHS-regulated human research and FDA-regulated clinical investigations of medical products. The guidance is for IRBs, investigators, and sponsors on the use of electronic systems to obtain informed consent. The guidance (FDA and HHS 2016) focuses on the procedures to be followed when using eIC. The FDA and HHS (2016) guidance also makes it clear that the responsibility for obtaining the subject's consent ultimately lies with the investigator, and cannot be delegated to an electronic system.

Additional Educational Resources

FDA

The [FDA website](#) includes educational tutorials and training about the drug and device approval process.

NIH

The [NIH website](#) includes [research and training](#) resources.

OHRP

OHRP provides leadership in the protection of the rights, welfare, and well-being of subjects involved in research conducted or supported by the HHS. Their website includes information on training and **educational resources**.

OHRP also produces educational videos, which are available on the HHS YouTube channel. The videos are accessible through the **OHRP playlist** and include:

- "Research Use of Human Biological Specimens and Other Private Information"
- "Reviewing and Reporting Unanticipated Problems and Adverse Events"
- "Institutional Review Board (IRB) Membership"
- "General Informed Consent Requirements Parts I (Research Investigator) and II (Research Subject)"

In order to help the public better understand the goals and affects of the new proposals, OHRP has developed **six webinars covering key aspects of the NPRM**. The webinars aim to explain the NPRM proposals that are most relevant to each topic. As such, there is a fair amount of overlap in content and material covered in the webinars.

Presidential Commission for the Study of Bioethical Issues

The Presidential Commission for the Study of Bioethical Issues was appointed by President Barack Obama in 2009 and issued reports and educational materials for researchers, administrators, and the community. As of January 15, 2017, the complete work of the Bioethics Commission, including all reports, materials, meeting transcripts, Ethically Sound podcast series, study guides, and educational materials can be found by visiting links below:

- **Website** <https://bioethicsarchive.georgetown.edu/pcsbi/>
- **Blog** <https://bioethicsarchive.georgetown.edu/pcsbi/blog/>

Recent reports included:

- "Ethics and Ebola"
- "Gray Matters"
- "Anticipate and Communicate"
- "Protecting our Children"

PRIM&R

Public Responsibility in Medicine and Research (PRIM&R) provides educational resources through their website, webinars, and conference programs.

14 Students in Research

- **Jackie Galvez**
University of Southern California
- **Susan L. Rose, Ph.D.**
University of Southern California
- **Jennifer Hagemann**
University of Southern California
- **Monica Aburto**
University of Southern California

This module was revised and adapted from the original module authored by:

- **Maristela Cho, M.A.**
Ed.D. Candidate, Rossier School of Education
University of Southern California
- Edited By
Susan L. Rose, Ph.D.
University of Southern California

Introduction

This module is designed as a "one-stop shop" for students who may be involved in human subjects research as an investigator and/or a subject. It is intended for research studies that qualify as no greater than "minimal risk."

Degree requirements in undergraduate, master's, or doctoral programs often require students to conduct or assist in research projects that include human subjects. These projects, which provide students with an opportunity to learn various research techniques appropriate to their disciplines, must follow ethical principles and guidelines set forth in the federal regulations and institutional policies for protecting human subjects. This module provides student investigators and student research assistants with a brief overview of the research regulations, the Institutional Review Board (IRB) review process, and ethical considerations in research involving human subjects.

In addition, students may be asked or "required" to participate as subjects in research projects. This module describes what students can expect when participating as research subjects, and describes their rights as research subjects.

Student researchers and student research subjects can benefit from the other Resources for Students section.

Learning Objectives

By the end of this module, you should be able to:

- Describe the historical development of regulations associated with the protection of human subjects
- Identify the required elements of informed consent
- Describe the different categories of exempt research
- Determine when research requires IRB review

History of the Ethical Regulations

The history of the ethical regulations in human subjects research began in the 1940s with the Nuremberg Code. Since then, the U.S. federal government has increased the awareness to protect the rights and welfare of human subjects by establishing regulatory codes and regulations. This section serves to provide a brief background on the history of the ethical regulations when human subjects are involved in research projects.

What is the Nuremberg Code?

The Nuremberg Code was developed following the Nuremberg Military Tribunal, which judged human experimentation conducted by the Nazis. The Code encompasses many of the basic principles governing the ethical conduct of human subjects research today. The Nuremberg Code states that "the voluntary consent of the human subject is absolutely essential" and it further explains the details implied by this requirement: capacity to consent, freedom from coercion, no penalty for withdrawal, and comprehension of the risks and benefits involved.

What is the Declaration of Helsinki?

In 1964, the World Medical Association established recommendations guiding medical doctors in biomedical research involving human subjects. The Declaration governs international research ethics and defines rules for "research combined with clinical care" and "non-therapeutic research." The Declaration of Helsinki was revised in 1975, 1983, 1989, and 1996, and is the basis for Good Clinical Practices used today.

Issues addressed in the Declaration of Helsinki include:

- Research with humans should be based on the results from laboratory and animal experimentation
- Research protocols should be reviewed by an independent committee prior to initiation
- Informed consent from research participants is necessary
- Research should be conducted by medically/scientifically qualified individuals
- Risks should not exceed benefits

What is the Federal Policy for the Protection of Human Subjects? (Common Rule)

In 1981, the Department of Health and Human Services (DHHS) codified the Policy for the Protection of Human Subjects (45 CFR 46). Subpart A of these regulations, is also called the "Common Rule," provides for the basic foundation of the Institutional Review Boards. This Federal Policy has been codified by the federal agencies that conduct, support, or otherwise regulate human subjects research, hence the title "Common Rule." Additional subparts of 45 CFR 46 provide protections to vulnerable populations such as pregnant women, fetuses, and neonates (Subpart B), prisoners (Subpart C), and children (Subpart D) involved in human subjects research. Many federal agencies and departments have not adopted subparts B, C, and D. Therefore only Subpart A is known as the "Common Rule."

What is the *Belmont Report*?

In 1978, the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research created *The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research*. The Belmont Report sets forth the basic ethical principles required for research involving human subjects. The Belmont Report encompasses three key principles: **respect for persons (autonomy), beneficence, and justice.**

Respect for Persons

"Respect for persons incorporates at least two ethical convictions: first, that individuals should be treated as autonomous agents, and second, that persons with diminished autonomy are entitled to protection. The principle of respect for persons thus divides into two separate moral requirements: the requirement to acknowledge autonomy and the requirement to protect those with diminished autonomy." This states that the person must be capable of making an informed decision on whether or not to participate in a human subjects research project.

Beneficence

"Persons are treated in an ethical manner not only by respecting their decisions and protecting them from harm, but also by making efforts to secure their well-being." Such treatment falls under the principle of beneficence. The term "beneficence" is often understood to cover acts of kindness or charity that go beyond strict obligation. In this document, beneficence is understood in a stronger sense, as an obligation. Two general rules have been formulated as complementary expressions of beneficent actions in this sense:

1. Do not harm and
2. Maximize possible benefits and minimize possible harms.

Justice

"Who ought to receive the benefits of research and bear its burdens? This is a question of justice, in the sense of "fairness in distribution" or "what is deserved." An injustice occurs when some benefit to which a person is entitled is denied without good reason or when some burden is imposed unduly. Another way of considering the principle of justice is that equals ought to be treated equally. However, this statement requires explication. Who is equal and who is unequal? What considerations justify departure from equal distribution? Almost all commentators allow that distinctions based on experience, age, deprivation, competence, merit and position do sometimes constitute criteria

justifying differential treatment for certain purposes. It is necessary, then, to explain in what aspects people should be treated equally. There are several widely accepted formulations of just ways to distribute burdens and benefits. Each formulation mentions some relevant property on the basis for which burdens and benefits should be distributed. These formulations are:

1. To each person an equal share.
2. To each person according to individual need.
3. To each person according to individual effort.
4. To each person according to societal contribution.
5. And to each person according to merit.

Students as Researchers

When participating in or conducting human subjects research, student investigators and student research assistants must adhere to the guidelines and principles set forth by the U.S. federal regulations and institutional policies and procedures. This section of the module provides an overview of the information a student must know prior to conducting a research project.

What is an IRB?

The IRB is an independent committee comprised of at least five members from relevant academic disciplines or experiences. At least one member must be not affiliated with the institution. The IRB must be diverse and must include at least one member whose primary concern is in a scientific area and one who is not a scientist. The members may include faculty, staff, students, as well as members from the local community. The IRB functions as a type of "human subjects advocate" whose role is to protect subjects participating in research. The IRB committee reviews research projects submitted by researchers (students, faculty, or staff). The committee has the authority to approve, require changes to the study procedures, or disapprove proposed research projects. Officials at an institution may disapprove an IRB approved project but cannot approve a project that has been disapproved, suspended, or terminated by the IRB.

IRB members must have the necessary experience and expertise to evaluate proposed research projects. IRBs must be diverse in terms of race, gender, cultural backgrounds, and include members from the community.

The IRB is charged with reviewing all projects involving human subjects for compliance with institutional policies and state, local, and federal laws, as well as the ethical principles contained in the *Belmont Report* (that is, respect for persons, beneficence, and justice).

The IRB is part of a bigger system, the Human Research Protection Program (HRPP), in charge of the protection of research subjects. The HRPP may include the Office for the Protection of Research Subjects, the Office of Compliance, the Office of Contracts and Grants, and other Institutional officials and committees (for example, a community outreach program).

IRB Approval Required

The IRB is charged with the responsibility of reviewing and overseeing human subjects research. The IRB review process is designed to protect the rights and welfare of human subjects by ensuring equitable subject selection, assuring adequate informed consent, assessing and minimizing risks, and maintaining privacy and confidentiality. Human subjects research projects cannot be conducted without the approval of the IRB, or exemption by the individual or group identified by the organization or the IRB.

IRB approval is valid for one year or for a shorter interval determined by the IRB based on risks involved. If the research continues beyond a year, a continuing review application must be submitted to extend approval for the next year.

Note that certain projects may be required to be reviewed more frequently based on the risk involved in the study.

Types of IRB Review

Research projects are reviewed at three different levels: **exempt, expedited, and full board**. Minimal risk projects generally fall under the review categories of exempt or expedited review. For studies that are deemed more than minimal risk, a full/convened board review is required. An explanation of each type of review is found below. Student investigators should consult with the IRB/faculty advisor if they are unsure of which review applies to their study.

- **Exempt Review** - Exempt research is research with human subjects that generally involves no more than minimal risk. However, it is "exempt" from the provisions stated in 45 CFR 46, Subpart A (Common Rule). An exempt research project does not require ongoing review by the IRB, unless the project is amended in such a way that it no longer meets the exemption criteria. However, institutional policy may have different requirements for obtaining consent as well as continuing review of exempted protocols. Student investigators should consult with their IRB regarding these matters. The IRB is required to determine if a research project falls under one of the following six exempt categories listed in the federal regulations (45 CFR 46.101(b)):
 1. Research conducted in established or commonly accepted educational settings, involving normal educational practices, such as
 - a. Research on regular and special education instructional strategies.
 - b. Research on the effectiveness or the comparison among instructional techniques, curricula, or classroom management methods.
 2. Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures (of adults), interview procedures (of adults) or observation of public behavior, unless:
 - a. Information obtained is recorded in such a manner that human subjects can be identified, directly or through identifiers linked to the subjects. AND
 - b. Any disclosure of the human subjects' responses outside the research could reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, or reputation.
 3. Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior that is not exempt under paragraph (2) if:
 - a. The human subjects are elected or appointed public officials or candidates for public office.
 - b. Or the research is conducted for the Department of Justice under Federal statute 42 U.S.C. 3789g, or for the National Center for Education Statistics under Federal statute 20 U.S.C. 12213-1, which provide certain legal protections and requirements for confidentiality.

4. Research involving the collection or study of existing data, documents, records, pathological or diagnostic specimens, if these sources are publicly available or if the information is recorded by the investigator in such a manner that subjects cannot be identified, directly or through identifiers linked to the subjects.
5. Research and demonstration projects which are conducted by or subject to the approval of department or agency heads, and which are designed to study, evaluate, or otherwise examine:
 - a. Public benefit or service programs.
 - b. Procedures for obtaining benefits or services under those programs.
 - c. Possible changes in or alternatives to those programs or procedures. OR
 - d. Possible changes in methods or levels of payment for benefits or services under those programs.
6. Taste and food quality evaluation and consumer acceptance studies, if
 - a. Wholesome foods without additives are consumed or
 - b. A food is consumed that contains a food ingredient at or below the level and for a use found to be safe, or agricultural chemical or environmental contaminant at or below the level found to be safe, by the Food and Drug Administration or approved by the U.S. Environmental Protection Agency or the Food Safety and Inspection Service of the U.S. Department of Agriculture.
- **Expedited Review** - If the research presents no more than minimal risk, the IRB may determine it qualifies for an expedited review. The expedited review covers the same elements as a full/convened committee review but can be conducted by the IRB chair or a designated experienced reviewer rather than the whole convened committee. There are nine expedited categories in the federal regulations (45 CFR 46.110):
 1. Clinical studies of drugs and medical devices only when condition (a) or (b) is met.
 - a. Research on drugs for which an investigational new drug application (21 CFR Part 312) is not required.
 - b. Research on medical devices for which
 - i. An investigational device exemption application (21 CFR 812) is not required.
 - ii. Or, the medical device is cleared/approved for marketing and the medical device is being used in accordance with its cleared/approved labeling.
 2. Collection of blood samples by finger stick, heel stick, ear stick, or venipuncture as follows:
 - a. From healthy, nonpregnant adults who weigh at least 110 pounds. For these subjects, the amounts drawn may not exceed 550 ml in an 8 week period and collection may not occur more frequently than 2 times per week.
 - b. Or from other adults and children, considering the age, weight, and health of the subjects, the collection procedure, the amount of blood to be collected, and the frequency with which it will be collected. For these subjects, the amount drawn may not exceed the lesser of 50 ml or 3 ml per kg in an 8 week period and collection may not occur more frequently than 2 times per week.
 3. Prospective collection of biological specimens for research purposes by noninvasive means.
 4. Collection of data through noninvasive procedures (not involving general anesthesia or sedation) routinely employed in clinical practice, excluding procedures involving x-rays or microwaves. Where medical devices are employed, they must be cleared/approved for marketing. (Studies intended to evaluate the safety and effectiveness of the medical device are not generally eligible for expedited review, including studies of cleared medical devices for new indications).
 5. Research involving materials (data, documents, records, or specimens) that have been collected or will be collected solely for non-research purposes (such as medical treatment or diagnosis). (NOTE: Some research in this category may be exempt from the HHS regulations for the protection of human subjects 45 CFR 46.101(b)(4). This listing refers only to research that is not exempt.)
 6. Collection of data from voice, video, digital, or image recordings made for research purposes.
 7. Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies. (NOTE: Some research in this category may be exempt from the HHS regulations for the protection of human subjects 45 CFR 46.101(b)(4). This listing refers only to research that is not exempt.)

* Note: The following apply to the continuing review of research:

1. Continuing review of research previously approved by the convened IRB as follows:
 - a. Where:
 - i. The research is permanently closed to the enrollment of new subjects.
 - ii. All subjects have completed all research-related interventions.
 - iii. And the research remains active only for long-term follow-up of subjects.
 - b. Or where no subjects have been enrolled and no additional risks have been identified.
 - c. Or where the remaining research activities are limited to data analysis.
2. Continuing review of research, not conducted under an investigational new drug application or investigational device exemption where categories two (2) through eight (8) do not apply but the IRB has determined and documented at a convened meeting that the research involves no greater than minimal risk and no additional risks have been identified.
 - **Full Board (Convened) Review** - Studies that involve more than minimal risk require full board review at a convened meeting at which a quorum of IRB members is present. For the research to be approved, it must receive the approval of a majority of those members present. While federal regulations do not specifically list categories that would fall under full board review, below are certain criteria that may require a study to have full board review:
 1. Studies using vulnerable populations
 2. Studies taking place internationally (particularly those with little or no provisions for protection of human subjects)
 3. Studies where information may be disclosed that could require mandatory legal reporting (e.g., child/elder abuse, drugs, etc.)
 4. Studies involving deception which raises the risk level of the subjects
 5. Studies that fall under the jurisdiction of the Food and Drug Administration

Student research projects are generally reviewed the same as any other human subjects research conducted by faculty or staff. Student investigators, after consultation with their faculty advisor, who are planning on conducting a research project involving human subjects must obtain approval from their IRB. IRB approval must be given prior to any research activity/study procedures. There is no retroactive approval for data previously collected for the current study. **Failure to seek approval for thesis or dissertation research may invalidate the study and/or result in a delayed graduation.**

What is Human Subjects Research?

The IRB has been charged, by the federal regulations, with the responsibility of reviewing and monitoring human subjects research. Therefore, the first question with respect to IRB review of a project is a determination of whether the project fits the definition of human subjects research. In support of the Institution's mission to protect human subjects who are involved in research and the potential regulatory consequences of not obtaining IRB review and approval, the student investigator should choose to err on the side of caution and consult the IRB when he/she is uncertain whether the study is human subjects research.

Ask, "Is It Research?"

Federal regulations define **research** as "**a systematic investigation, including research development, testing, and evaluation, designed to develop or contribute to generalizable knowledge**" (45CFR46.102(d)). As described in the Belmont Report "...the term 'research' designates an activity designed to test a hypothesis [and]

permit conclusions to be drawn... Research is usually described in a formal protocol that sets forth an objective and a set of procedures to reach that objective."

"Research" generally does **not** include operational activities such as practice activities in medicine, psychology, social work, and public health (for example, routine outbreak investigations and disease monitoring) and studies for internal management purposes such as program evaluation, quality assurance, quality improvement, fiscal or program audits, marketing studies, or contracted-for services. It generally does not include journalism or political polls. However, some of these activities may include or constitute research in circumstances where there is a clear intent to contribute to generalizable knowledge.

Ask, "Does It Involve Human Subjects?"

A **human subject** is defined by federal regulations as **"a living individual ABOUT whom an investigator (whether professional or student) conducting research obtains (1) data through intervention or interaction with the individual, or (2) identifiable private information."** (45 CFR 46.102(f)(1),(2))

Living individual - The specimen(s)/data/information must be collected from live subjects. Cadavers, autopsy specimens or specimens/information from subjects now deceased are not human subjects.

"About whom" - a human subject research project requires that the data received from the living individual is **about** the person.

Intervention includes physical/psychological procedures, manipulations of the subject, or manipulations of the subject's environment for research purposes.

Interaction includes communication between the investigator and the subject. This includes face-to-face, mail, and phone interaction as well as any other mode of communication.

Identifiable private information "includes information about behavior that occurs in a context in which an individual can reasonably expect that no observation is taking place," (such as a public restroom) "and information which has been provided for specific purposes by an individual and which the individual can reasonably expect will not be made public (for example, a health care record)" (45 CFR 46.102(f)(2)). **"Identifiable" means the information contains one or more data elements that can be combined with other reasonably available information to identify an individual (ex: Social Security #).** Student investigators should consult the IRB if they are unsure about certain issues such as identifiable cadaver materials needing review or certain state laws regarding human subjects.

Observational studies of public behavior (including television and public Internet chat rooms) do not involve human subjects as defined when there is no intervention or interaction with the subjects and the behavior is not private. Also, studies based on data collected for non-research purposes may not constitute human subjects research if individual identities are not available (for example, programmatic data such as service statistics, school attendance data, crime statistics, or election returns).

Studies based on data that are individually identifiable but are also publicly available may not constitute human subjects research. However, the term "publicly available" is intended to refer to record sets that are truly readily available to the broad public, such as census data. An investigator should not assume information qualifies as "publicly available" merely because it has been posted on an electronic website and can be accessed without authorization.

What follows are examples of types of studies that qualify as not human subjects research and those that are human subjects research. Student investigators may use this as guidance on whether a project is submitted as human subjects research or may receive the not human subjects determination. However, it is recommended that the student consult with the IRB and/or the faculty advisor on this matter.

Studies that are not human subjects research:

- **Data collection** for internal departmental, school, or other institutional administrative purposes is not human subjects research. Examples: teaching evaluations, customer service surveys
- **Information-gathering interviews** where questions focus on things, products, or policies rather than about people or their thoughts regarding themselves are not human subjects research. Example: canvassing librarians about inter-library loan policies or rising journal costs
- **Course-related activities** designed specifically for educational or teaching purposes, where data is collected from and about human subjects as part of a class exercise or assignment, but are **not** intended for use outside of the classroom may not be human subjects research. Students are advised to contact their local IRB as certain course-related activities may require IRB review. Example: instruction on research methods and techniques. Note: The IRB is only required to review studies that meet the Federal definitions of engagement*, research, and human subject
- **Biography or oral history** research involving a living individual that is not generalizable beyond that individual may not be considered human subjects research. Researchers are advised to contact their local IRB as these studies may be subject to local interpretation.
- **Research involving cadavers**, autopsy material or bio-specimens from deceased individuals is not human subjects research. *Note: Some research in this category, such as genetic studies providing private or medical information about live relatives, may need IRB review. Please contact the IRB for further information*
- **Case histories** which are published and/or presented at national or regional meetings are often **not** considered research if the case is limited to a description of the clinical features and/or outcome of a single patient and do not contribute to generalizable knowledge. However, researchers are advised to contact their local IRB as these studies may be subject to local interpretation.
- **Publicly available data** do **not** require IRB review. Examples: census data, labor statistics. *Note: Investigators should contact the IRB if they are unsure if their data qualifies as "publicly available."*
- **Coded specimens and/or data sets** that were **not** collected for the currently proposed projects do not need IRB review as long as the investigator receiving the data/specimens cannot link the data/specimens back to individual subjects. If the data/specimen provider can ascertain the identity of the subjects (for example, subjects' names, addresses, etc.), the investigator must enter into an agreement with the data/specimen provider that states under no circumstances will the identity of the subjects be released to the investigator. Note: Investigators are not allowed to make this determination. These **projects** require verification from the IRB or the IRB liaison/designee.
- **Non-Engagement* in Research** occurs when an institution's employees or agents act as consultants on research but at no time obtain, receive, or possess identifiable private information, perform commercial services for the investigators, or inform prospective subjects about the availability of research. Note: the

examples above are not an all inclusive listing. Please see the following [website](#) for further information.* An institution becomes "engaged" in human subjects research when its employees or agents (i) intervene or interact with living individuals for research purposes; or (ii) obtain individually identifiable private information for research purposes.

Studies that are human subjects research:

- Studies that involve human subjects to test or develop devices, products, or materials that have been developed through research for human use.
- Studies that collect data through intervention or interaction with individuals. Examples of this type of research include the evaluation of teaching methods and programs, Internet surveys about alcohol consumption, studies that involve deception, research involving risky behaviors or attitudes, and open-ended interviews with minors about family values in a foreign country that contribute to generalizable knowledge. Data collection using non-identifiable information may be exempt. (Students are advised to discuss with the applicable IRB the process for determining exemptions.)
- Studies using private information that can be readily identified with individuals, even if the information was not collected specifically for the study in question.
- Studies that use bodily materials such as cells, blood, urine, tissues, organs, hair, or nail clippings, even if these were not collected for research purposes. However, such research may be considered exempt or Not Human Subjects Research if the materials/data are coded and the investigator does not have access to the coding systems.
- Studies that intend to produce generalizable knowledge about categories or classes of subjects from individually identifiable information.
- Studies that involve retrospective analysis of existing individually-identifiable private information.
- Studies that use human beings to evaluate environmental alterations, for example, weatherization options or habitat modifications

Research belonging to any of the above categories must comply with the Federal Regulations and the Institution's policies for the protection of human subjects.

*Please visit the [Office for Human Research Protections \(OHRP\) website](http://www.hhs.gov/ohrp/humansubjects/guidance/45cfr46.html) for the code of federal regulations. www.hhs.gov/ohrp/humansubjects/guidance/45cfr46.html

What are the Steps in the IRB Process?

To obtain an IRB approval for a study, most student researchers have certain steps to follow:

1. Student research preparation:

The IRB application is completed under the guidance of the student's faculty advisor. The student's advisor is responsible for guiding the student investigator in the development of the research plan as well as the conduct of the research project. The faculty advisor/committee will refine the project and once it is approved by the committee, they should indicate the expected level of review (exempt, expedited, or full board review). (Please note that the final determination of review category will be made by the IRB.) The advisor also assists students in a design to maximize the benefits and minimize the risks involved in the research, and assure the ethical conduct of the project. The Institution's IRB staff is also available to aid student applicants.

2. Departmental/Faculty review and approval:

Depending on the Institution's policy, the department chair/faculty advisor must review and sign off on the application before it is submitted to the IRB for review. This signoff may address issues of scientific merit, availability of resources, institutional policies, or other issues at the department level.

3. Application submitted to IRB for review:

The IRB staff may conduct the initial screening of an application to assist in the future review either for exemption or for further levels of review. The IRB grants the final approval. In some institutions, a designated reviewer/department or school may conduct a pre-review of the application before it is submitted to the IRB for review. If a study is exempt or does not qualify as human subjects research, a designee may determine this and no further approval is required. (The IRB/designee may provide a letter stating that the study qualified as exempt or as not human subject research.)

4. IRB review outcomes:

The IRB will notify the researcher with one of the following once the application has been reviewed:

- Approval - the application is complete, the risks to subjects are minimal/minimized, and the procedures are appropriate. The IRB gives approval for the research to be conducted.
- Approval with Contingencies/Stipulations - the application is complete but there are issues/changes that must be addressed before the project can begin. Once a satisfactory response to these contingencies is received and approved by the IRB, the review is complete.
- Deferred - applications that are found to have deficiencies (risk to subjects, unclear procedures, serious omissions, ethical issues, or major contingencies) will be deferred. The researcher is sent a memorandum listing the concerns that must be addressed for approval to proceed. The researcher's response is reviewed by the IRB and will be approved or deferred until all issues are addressed satisfactorily.
- Non-Approval - Applications that are found to have risks that outweigh the potential benefits to subjects and/or society will receive a non-approval and the research will not be allowed to be conducted. Institutional administrative officials may not override this decision.

5. Conduct of research and reporting:

Once the application is approved, the researcher may begin recruiting subjects and conducting study procedures. However, the researcher must let the IRB know if any of the following occurs:

- Modifications and Amendments to the approved protocol (changes to the original submitted study must be reviewed and approved by the IRB before they are implemented)
- Adverse Events/Effects and Unanticipated Problems involving risks to subjects or others (the IRB must be notified immediately if any undue harms result from the study)
- Complaints Regarding Human Subjects Research (the IRB must be notified immediately if any complaints, either from the subjects or the study staff, are made regarding the research study)
- Breach of Confidentiality (If any personal/confidential data has been inappropriately disclosed by any member of the study staff, the IRB must be notified immediately)

6. Status Report (Renewal or Closeout):

Prior to the expiration of a study, the IRB will require submission of a status report to assess the study's progress or a final report when the study is completed. Either the student or the faculty advisor may submit the final report.

What are Some "Other Considerations" in the IRB Submission?

Student investigators need to be aware of some "other considerations" with regard to their human subjects research. Many of these terms will be useful to know when completing the IRB application as well as during the research process.

Health Insurance Portability and Accountability Act (HIPAA) / Privacy Rule

The Health Insurance Portability and Accountability Act "Privacy Rule" (HIPAA) is a federal law that generally prohibits health care providers (such as physicians or other health care practitioners, hospitals, nursing facilities and clinics) from using or disclosing "protected health information" (PHI) without written authorization from the patient.

If a student investigator intends to use or release to others (e.g., sponsors, other investigators, collaborators) any identifiable health information in connection with their research, he/she must indicate that in the IRB application.

- Protected health information (PHI) is health information transmitted or maintained in any form or medium that includes ALL of the three following characteristics:
 - identifies or could be used to identify an individual; and
 - is created or received by a healthcare provider, health plan, or healthcare clearinghouse; and
 - relates to the past, present, or future physical or mental health or condition of an individual; the provision of healthcare to an individual; or the past, present, or future payment for the provision of healthcare to an individual.
- Examples include: name, social security number, telephone number, etc

The full text of the Privacy Rule can be found at the HIPAA privacy website of the Office for Civil Rights (OCR): <http://www.hhs.gov/ocr/hipaa>

Informed Consent

Informed consent is the process of informing potential subjects about the key facts of a research study and what their participation will involve. The human subjects in the study must participate willingly, after having been adequately informed about the research. If the subjects are from a vulnerable population*, such as prisoners or children, additional protections may be required. (*See the [Code of Federal Regulations](#)). Students are advised to discuss research that may include such populations, as institution specific requirements may also exist. The IRB office as well as dissertation chairs or advisers may be helpful in providing information.

Consent documents must be clearly written and understandable to subjects. The language must be non-technical (comparable to the language in a newspaper or general circulation magazine). Scientific, technical, and medical terms must be plainly defined. Depending on the study population, it is often recommended that the informed consent be written at the sixth to eighth grade reading level. Assent forms for minors and study recruitment materials must reflect the reading level of the minors. *The informed consent must be translated into the primary language of the subject if he/she is not fluent in English.

What elements should be included in an informed consent?

For human subjects to participate in a research study, they need to have enough information to give a truly voluntary informed consent. Information subjects must be given include:

- Purpose of the research
- Procedures involved in the research

- Alternatives available should a subject decide not to participate in the research
- All foreseeable risks and discomforts to the subject. *Note that these include not only physical injury but also possible psychological, social, or economic harm, discomfort, or inconvenience.
- Benefits of the research to society and possibly to the individual human subject
- Length of time the subject is expected to participate
- Payment for participation (if applicable)
- Person to contact for answers to questions or in the event of a research-related injury or emergency
- Statement that participation is voluntary and that refusal to participate will not result in any consequences or any loss of benefits that the person is otherwise entitled to receive
- Subjects' right to confidentiality and right to withdraw from the study at any time without any consequences

There are two types of consent that may be required:

Consent - An adult capable of giving permission to participate in a study can provide consent. In most states, the subject must be 18 years of age and competent to make the decision to participate. Parents/legal guardians of minors can also provide consent to allow their children to participate in a study. Check with your local IRB for your state's requirement.

Assent - In most states if the subject is under 18 years of age, assent must be obtained. Assent is a child's affirmative agreement to participate in research. The assent form must include simple language written at the appropriate reading level of the youngest subject in the youth age range. An assent form may also be used if the subject is cognitively impaired. Researchers are advised to contact their local IRB regarding this matter.

Privacy/Confidentiality

The protection of privacy and confidentiality are important issues in the protection of human research subjects. Protection of human research subjects' privacy and confidentiality are extensions of the principles of autonomy (respect for persons) and beneficence from the Belmont Report.

- **Privacy** can be defined in terms of having control over the extent, timing, and circumstances of sharing oneself (physically, behaviorally, or intellectually) with others.
- **Confidentiality** pertains to the treatment of information that an individual has disclosed in a relationship of trust and with the expectation that it will not be divulged to others in ways that are inconsistent with the understanding of the original disclosure without permission.

The investigator must describe plans to protect the subject's identity as well as the confidentiality of the research records. Care should be taken to explain the mechanisms that have been devised to protect the privacy of the subjects, for example, the use of numbering or code or safely locked files in private offices. Furthermore, the investigator should describe who has access to the data and under what circumstances a code may be broken. Without appropriate safeguards, problems may arise with long-term retention of records. In special circumstances requiring additional safeguards to prevent potential criminal civil prosecution of the participating human subject, the IRB may require the destruction of all data that can identify the subjects. Subjects should be informed of whether the data collected will be retained, and if so, for what purpose, what period of time, or whether and when data will be de-identified or destroyed.

A special situation arises for video or taped data and photographs since these media provide additional potential means for subject identification. Investigators must secure subject consent explicitly mentioning these practices. They should also explain plans for final disposition or destruction of such records.

Risk/Benefit

Risk

Risk is the probability of harm or injury (physical, psychological, social, or economic) occurring as the result of participation in a research study. Both biomedical and social and behavioral research may entail some level of risk to a person's health, physical, psychological, or socioeconomic well being. Student researchers must consider the following risks when conducting their studies:

Risk Resulting from Study Questions/Surveys

In human subjects research, particularly social and behavioral projects, subjects may feel stress caused by the research questions or procedures. Perhaps questions raise painful memories or unresolved issues. Interviews of survivors of personal or state violence, for example, may be very stressful. Questions about at-risk behaviors may cause embarrassment, feelings of guilt, or legal liability when that behavior is generally illegal or socially unacceptable.

Most psychological risks are minimal and transitory, but investigators must be aware of the potential for serious psychological harm.

Breach of Confidentiality

A breach of confidentiality is often the greatest risk to participants in social and behavioral human subjects research. Reputations or employment may be damaged or jeopardized if confidentiality is not maintained.

Information about subjects' activities may place them at risk of legal action. For example, if a researcher asks parents how they discipline their children, information about child abuse may be obtained and must be reported. Similarly, if subjects divulge information about illegal or stigmatizing activities, any disclosure of that information could place the subjects at risk of significant harm.

The kind and level of risk is determined by context. For example, research regarding political activism in some countries may put subjects in serious jeopardy, while it would not in other countries.

In many cases risk to privacy/confidentiality can be eliminated or reduced by careful procedures for ensuring confidentiality. Psychological support and referrals can be built into studies when emotional distress may be an outcome. Consent forms describing the kinds of questions the researcher will ask allow participants to choose whether they wish to divulge certain types of information or explore certain issues.

Benefits

Potential benefits for individual subjects may be easy to define in studies offering interventions for behavioral, psychological, or physical problems. However, research is often conducted as part of a faculty member or graduate student investigation into a specialized field of study. The research may provide no direct benefit to the subjects.

Furthermore, it may be many years before the results of the research are publicly known and made useful to society or to groups of people. Vague promises to benefit science or society are not adequate descriptions of benefit in a consent form or a research application. When there is no direct benefit to subjects, they must be told what the researcher is trying to learn and why. (The only exception would be a study in which deception is a necessary, and IRB-approved, element of the design.)

Note that compensation to subjects is not considered a benefit in the risk/benefit analysis, nor is the fact that participants may find it rewarding to be helpful.

International Studies

Procedures normally followed outside the United States for research involving human subjects may differ from those set forth in federal regulations and institutional policies. These may result from differences in language, cultural and social history, and social mores. In addition, national policies such as the availability of national health insurance, philosophically different legal systems, and social policies may make U.S. forms and procedures inappropriate. In federally funded research, research activities in a foreign country may be approved if the ethical protections adhered to by a foreign institution are equivalent or greater to those in the U.S.

If protections are deemed equivalent, requests to review or waive some standard elements of U.S. approvals may be considered. However, protections afforded subjects must approximate those provided to subjects in the United States. The investigator is encouraged to contact the Chair of the appropriate IRB to discuss these issues. Investigators will be required to obtain approval from an independent ethics committee (IEC), the IRB equivalent, for research done internationally for studies that are more than minimal risk. Many institutions outside of the United States have Ethics Committees who can review and approve the research. For studies that are minimal risk, the IRB equivalent to an approval letter or permission letter from the research site may be acceptable; however, it will be reviewed on a case-by-case basis. Students proposing to conduct research outside of the U.S. should also be aware that some countries may have more stringent regulations or policies associated with human subjects research.

International research studies must adhere to recognized ethics codes such as: 45 CFR 46, Nuremberg Code, The Declaration of Helsinki, and The Belmont Report. Consent and recruitment documents must be in the language that is readable and understandable by the subjects or the short form and translator method may be used. Additionally, the following issues should be addressed in the IRB application or be considered in the IRB discussion.

- Risks/Benefits to Subjects/Community
- Language Sensitivity
- Community spokesperson or tribal leaders

- Infrastructure development/availability
- Cultural sensitivities
- Justify Use of Population
- Genetics/Homogeneity/Validity of data to Other Populations
- Ethics Body Equivalent Approval (Research Ethics Review Board/IRB)
- Potential Coercion
- Paternalism
- "Helicopter" Research (data/sample collection & leaving site with no follow-up or benefit)
- Literacy Assessment

Students as Research Subjects

In an academic institutional setting, students play an integral role as subjects in certain research situations (for example, research dealing with teaching methods, curricula, and other areas related to the scholarship of teaching and learning). An underlying principle of the regulations governing the involvement of human subjects in research is that the subject's participation is voluntary and based upon full and accurate information.

Consistent with an overall concern that research subjects should not be coerced, student and faculty researchers should take particular care to avoid the unintentional or subliminal coercion that may occur when potential subjects are also students. For this reason, faculty researchers, in particular, must avoid involving their own students as research subjects. Faculty who wish to involve their own students as subjects should be able to provide a good scientific reason, rather than convenience, for selecting those students as research subjects. The research project should be relevant to the topic of the class, and participation should be part of the learning experience for the students.

In instances where investigators can provide a good reason for involving their own students in their research, the IRB generally requires that someone other than the investigator (instructor) obtain informed consent and collect the data. When this is not possible, the IRB will consider other methods for obtaining consent and collecting data that would not reveal to the instructor whether or not a specific student participated in the research project until after final grades have been determined. The students should be informed of what these procedures are in the informed consent form. In addition, it is generally recommended that the investigator/professor provide a recruitment flyer or letter to a student pool, general student population, or both so that the student may be the one who initiates contact with the investigator/researcher.

If a student feels he/she has been coerced to participate in a study, he/she should immediately inform the institution's compliance office and/or the IRB.

Extra Credit (Alternative for student subjects)

The IRB may approve projects that give extra credit to students who participate in a research project only when alternative means of obtaining equivalent extra credit with equivalent effort is made available to students who do not wish to volunteer as research subjects. The IRB carefully reviews the alternatives to ensure that students are not being coerced to participate. The informed consent form should clearly state that there is an option to withdraw at any point without consequences (for example, extra credit should be given despite withdrawal).

Student "Subject Pools"

"Subject pools" are often used where students enrolled in introductory courses are recruited by investigators from within the department/school for participation in research projects. The department/school may impose its own standards for the type of research that may be conducted in this setting and specify who may have access to such subjects and how access is obtained. Investigators who recruit from "subject pools" are required to submit the research studies to the IRB for review and approval.

Beyond the considerations outlined above, academic units may impose their own additional constraints on using students as research subjects. The possibility of undue influence on students (grades or faculty pressure) must be addressed and avoided. The IRB may pay special attention to studies using student "subject pools."

What Should a Student Expect as a Subject?

All students have certain rights as a research subject. These rights, such as the right to be free from any coercion, can be found below:

Consent Form

In accordance with the principles of free and informed consent, privacy, and confidentiality, and in consideration of the vulnerable nature of students as research subjects, students have the right to a consent form that addresses key points of the study. Please refer to the Important Terms/Parts of the IRB Application section of this module under "What are the Steps in the IRB Process?"

Recruitment of Subjects

Students have the right to be free from any coercion or bias that might result when a researcher is also evaluating them in a course. Therefore, the person recruiting the subjects should be someone other than an instructor of the students. This is to reduce any perception of coercion and to reduce the possibility of bias by the person evaluating the students resulting from knowing who is or isn't participating in the research project.

Obtaining Subjects' Names

Students have the right to privacy of personal information. Under the institution's privacy guidelines, the institution may not supply a researcher with the names of students for research purposes. Also, a researcher with knowledge of student names as a result of teaching or other institution-related activity may not be permitted to use that knowledge to generate a list of student names for research purposes. (There may be some exceptions - please check with the applicable IRB.) The researcher may create a written form describing the kind of subjects being recruited and why, which can be:

- Distributed in class (it would be important for the researcher to be absent at the time of distribution to reduce any perception of coercion).
- Posted in a place where potential subjects will see it.
- Distributed via a class e-mail listserv (not using individual student names). If this option is employed, the use of the e-mail listserv should be "at arm's length." In other words, the listserv should either list students

in the class of a third party or, if the listserv lists students in the researcher's own class, students should be directed to respond to a third party.

Research During Class Time

Students have the right to have class time devoted to classroom activities appropriate to meeting the objectives for the scheduled course. Institutions discourage the use of class time for the investigator's research activities. If class time is to be used for research, the researcher must make a case to the IRB as to why the research is directly relevant to course content. A student can participate in the research activity without having his or her responses included in publishable data by withholding their consent or saying at the onset that their data may not be used.

How Can Coercion Be Avoided?

Whenever possible, researchers should avoid involving their own students if another population of subjects is equally suited to the research question (e.g., another class section not taught by the researcher, recruitment by another instructor, or blinded/coded data collected by an associate so that subjects are not identified to the instructor). Students should be given an opportunity to decline participation without jeopardy.

Unless the research question is directly related to class material, or the study process is being used as a teaching opportunity, such as in a research methods class, the use of class time to recruit subjects or class time used to complete study instruments is discouraged.

Resources for Student Researchers and/or Student Subjects

In an institutional setting, there are various resources that are available for student researchers and student subjects.

What is the Role/Expectation of the Faculty Advisor?

Faculty advisors may be chosen by the student investigator or assigned to the student. Their role as the advisor is to guide students through the IRB process by discussing general principles of research ethics with the class/student prior to the initiation of any project involving human subjects.

Faculty members who supervise student research are responsible for the protection of human subjects and are required to:

1. Be familiar with the ethical and regulatory requirements of human subjects research.
2. Determine whether projects require IRB review and assist students with the process. (If the project involves research in a non-US setting, then considerations of local regulations and customs must be understood and satisfied.)
3. Discuss research ethics with the students.
4. Advise students conducting international studies on understanding the local customs and ethics.
5. Monitor student projects, paying special attention to maintaining confidentiality, privacy, level of risk, voluntary participation and withdrawal, and informed consent.

6. Assure that any unexpected or adverse events are reported to the IRB.

*Responsibilities for faculty that uses students as subjects in research can be found in Section 3.

Complaints

Student researchers and student subjects must have access to reporting complaints regarding faculty when there are issues such as ethical concerns, coercion of student subjects, misguidance on research projects, or other issues that a student may find offensive or wrongful. Students can contact the appropriate department, the IRB office, the Office of Compliance, or the institution's ethics' office to report and address their concerns. More information can be found at [DHHS Office of Research Integrity's website](#) (especially the section on mentoring).

What is the Role of the IRB Office?

The institution's IRB office, and its staff, can also be a valuable resource for student investigators. They can assist student in completing the human subjects application and understanding human subjects ethics, regulations, and the review process. They help the student comply with requirements and regulations to assure the protection of human subjects research and to help facilitate smooth completion of the research projects.

What is the Role of the Office of Compliance?

In response to continuing scrutiny from government regulators and an increasingly complex statutory and regulatory environment, most institutions have an established institutional compliance program. The compliance program is a central office intended to enforce the institution's commitment to comply with all applicable laws and regulations, detect and correct compliance violations promptly and eliminate misconduct and other wrongdoing. The compliance office is also a resource for information on laws and regulations pertaining to human subjects research.

What Bibliographic Resources Are Available For Student Researchers?

There are many informational resources available on research with human subjects. Most Institutions have a website and their own policies and procedures dedicated to research with human subjects. On these websites, the student investigator will find information about the Belmont Report, the human subjects research review process, and/or human subject educational opportunities. Institutions provide training throughout the year and the Institution's IRB can be contacted for more information.

Listed are a few internet websites for student investigators and student subjects on human subjects research:

- [DHHS Office of Human Research Protections \(OHRP\)](#)
- [OHRP guidance documents](#)
- [OHRP compliance references](#)
- [DHHS Food and Drug Administration \(FDA\)](#)
- [FDA guidance documents](#)
- [FDA compliance references](#)
- [Engagement of Institutions in Human Subjects Research](#)

- [Coded Private Information or Biological Specimens](#)
- [University of Southern California Office for the Protection of Research Subjects website](#)
- [University of Minnesota Institutional Review Board website](#)
- [Vanderbilt University Institutional Review Board website](#)
- [University of Las Vegas Office for the Protection of Research Subjects website](#)
- [The Collaborative Institutional Training Initiative \(CITI\) Course in the Protection of Human Research Subjects website](#) (Please check if your institution is a member of CITI.)
- [Public Responsibility in Medicine & Research \(PRIM&R\)](#)

Common Terminology

Minimal Risk

The probability and magnitude of harm or discomfort anticipated in the research are not greater in and of themselves than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests. (Note that this definition of minimal risk does not apply to research involving prisoners, which has its own definition of what constitutes minimal risk).

Primary vs. Secondary Data

Primary data collection involves direct contact with, or observation of, one or more people for the purpose of collecting data about them.

Secondary data collection involves accessing information that has already been obtained about humans, either individually or in aggregate form. Secondary data which contains personal identifiers are subject to the requirements set forth under the institution's research policies. Secondary data, which do not contain personal identifiers, are exempt from these requirements. Secondary data - whether they do or do not contain personal identifiers - may be used only when original consent allows the information to be used in this manner.

Subject Recruitment

Recruitment is the process by which potential subjects are informed about the study. Recruitment materials, such as fliers, email messages, newspaper ads, and phone calls, must be true, non-coercive, and must not highlight any potential monetary compensation. These materials must be approved by the IRB before they are implemented in the study.

Identifiable Personal Information

Identifiable personal information is any information that can allow researchers to ascertain the identity of the subject. Researchers must take caution in recording personal information and/or collecting certain types of data to ensure that the privacy and confidentiality of the subjects are maintained.

Coded Private Information or Biological Specimens

Coded means:

1. identifying information (such as name or social security number) that would enable the investigator to readily ascertain the identity of the individual to whom the private information or biological specimens pertain has been replaced with a number, letter, symbol, or combination thereof (i.e., the code); and
2. a key to decipher the code exists, enabling linkage of the identifying information to the private information or specimens.

Engagement of Institutions in Research

An institution becomes "engaged" in human subjects research when its employees or agents

1. Intervene or interact with living individuals for research purposes
2. Or obtain individually identifiable private information for research purposes. Please see the federal guidance, *Engagement of Institutions in Human Subjects Research: OHRP Guidance (2008)*.

Deception Studies

Deception is the intentional misleading of subjects or the withholding of full information about the nature of the study. Misleading or omitted information might include the purpose of the research, the role of the researcher, or what procedures in the study are actually experimental. Deception increases ethical concerns, because it interferes with the ability of the subject to give informed consent. However, deception is arguably necessary for certain types of behavioral research. Because humans act differently depending on circumstances, full knowledge by the subject might bias the results.

Subjects have the right to full disclosure as soon as possible. In exceptional circumstances, the full or true purpose of the research may not be revealed to the subjects until the completion of data collection. In such cases, subjects should not be exposed to undue stress or embarrassment and must have the right to full disclosure of the purpose of the study as soon as possible after the data have been collected. This process is known as debriefing. Note that techniques of this type are contrary to the policy of full advanced disclosure in the informed consent process and document. Deception techniques should be used with discretion and may only be employed with the approval of the IRB. Deception in some social and behavioral research where meeting the minimal risk provision is involved is often part of study designs in some fields of research.

Vulnerable Populations

Certain populations are considered to be vulnerable in human subjects research. People who cannot competently understand the information regarding a study and cannot give true consent. Such populations may include individuals with psychiatric, cognitive, or developmental disorders and substance abusers. It is critical that investigators evaluate whether subjects may be vulnerable and whether they are competent to consent.

While any individual who may fit the above category can be considered vulnerable, federal regulations specifically define three groups of people: pregnant women, fetuses, and neonates (Subpart B), prisoners (Subpart C), and children (Subpart D).

- ***Pregnant women, fetuses, and neonates (Subpart B)*** Pregnant women, fetuses, and neonates are considered vulnerable because they may be at a greater risk than others. Special protections, however, are geared more toward medical research than social/behavioral research.
- ***Prisoners (Subpart C)*** Prisoners are considered to be vulnerable in that they may be under constraints because of their incarceration which could affect their ability to make a truly voluntary and uncoerced decision on whether or not to participate as subjects in research.
- ***Children (Subpart D)*** Children are considered vulnerable because they may not be able to completely understand the information presented about a study.

Conclusion

The purpose of this module was to assist both students researchers and student subjects with the IRB process. It included information that students in undergraduate, masters, or doctoral degree programs may encounter as investigators and/or subjects.

The information contained in this module provided general guidance in protecting human subjects as set forth by U.S. federal regulations and institutional policies. Students are advised to contact their own Institution's IRB for any additional policies and procedures.

15 Are You Thinking About Being In A Research Study?

- Cheryl Savini, CIP
- Judy Matuk, MS
- Diane Paul, MS, RN
- Alavy Sos, BA, BS, CIP

I. Introduction

The goal of this module is to:

1.Help you understand what research is, 2.Provide you with the information you need to help you make your decision about participating in a research study, or 3.To help you understand research in order for you to help someone other than yourself (such as a family member) make a decision about taking part in research.

At the end of this module, you will find a list of definitions to help you familiarize yourself with some of the words used in research, and links to other websites and organizations that may provide you with more in-depth information.

At the bottom of this page, you will find a link to important federal regulations.

What is research?

Research is the collection of information (data) to obtain more knowledge or to answer a specific question about a certain topic. For the information to be helpful in better understanding the topic, the gathering of information or the testing of an idea must be done in a very organized manner. A researcher or investigator is the person who conducts research.

What is research involving human subjects?

When research calls for getting personal information from, or about people, then the researcher is doing research involving human subjects. Research can involve such things as asking simple questions about the foods people like, or it can involve looking at the good and bad effects of one or many drugs for treating a disease. Studies can also get information about people without directly speaking to them, or asking them to do things. For example, a study may take personal information from medical or school records in order to answer a research question.

[Definitions of Commonly Used Terms](#)

Links to Additional Information

Regulations

What are my rights as a human subject?

As a subject in a research study, protecting your rights is one of the most important jobs a researcher has. Before you enter a study, **you have the right to be given all the information you need to make an informed decision about being in the study.** We will be discussing the information you should know in this module.

Some examples of what you must be told are:

- Why the study is being done.
- Your option to withdraw from the study at anytime without any penalty and without having to give a reason.
- What is expected of you.
- What will be done to you for research reasons.
- How long you will be in the study.
- The bad things and good things that could happen to you in the study.

You have the right to be given all this information in words that you can **understand**.

You also have the right to be **given as much time as you need to make your decision.**

Another right you have is to **ASK QUESTIONS** and have a detailed conversation about the study with the person asking you to volunteer! That is what helps you make informed decisions about whether to be in a study, or continue once you have said yes. You may ask as many questions as you like, as many times as you like, to make sure you understand what is being told to you. The person who is asking you to be in the study may also ask you questions to make sure you understand what was explained.

What questions should I ask before I decide about being a human subject?

Here are some of the questions you might want to ask while you are deciding whether or not you want to be a human subject. Remember, of course, that you can ask any question that you want to make sure you understand what is being told to you, and you can ask the same question as many times as you want.

General Questions:

- Why is the study being done?

- What will be done to me if I say yes to be in the study?
- How long will I have to be in the study?
- What can I do instead of being in this study? What other choices do I have?
- Do I get paid to make up for the time and effort I will put in by being in the study? If yes, how much? How often?
- What are the bad effects (?risks?) that can happen to me if I?m in this study? How often can the bad things happen (rarely? A lot?)? Do the bad effects go away after I stop being in the study?
- Are there good effects (?benefits?) that can happen to me if I?m in this study? What are they?
- Is being in the study going to cost me anything?
- Will my being in a study affect any of my family members?
- What happens to the information I give you or any information you find out about me?
- Will you share my information with anyone who is not part of the study team?
- Who will know that I?m in the study?
- Will I find out my own study results, if tests are done?
- Will I find out the results of the whole study?
- Who do I call if I have questions?
- What if I want to stop taking part in the research study? Will anything bad happen to me?

Additional Questions for Bio-medical Studies:

- Do I have to stay in the hospital? For how long?
- How will being in this study affect my life?
- Will I have to make extra trips to the doctor?s office?
- Has this drug/device/treatment been tested before in people?
- Do I have to stop taking any medications I am already taking?
- Should my regular doctor know that I am in the study?
- Should my regular doctor get my test results from this study?
- Will my insurance company have to pay for any costs I have for being in this study?
- If my insurance pays for standard care costs, what will be my out-of-pocket expenses?
- Who will pay if I am injured while on the study?

How do I decide about being a research subject?

After you have asked all your questions and you have been told about the research study, you now have to ask yourself:

- Could this research help me personally?

- Do I still want to be a part of the research study even if the study won't help me personally, but may help others?
- Do I understand what the research is about and what is expected of me?
- Am I comfortable with what's going to happen to me?
- Do I have the time to commit to the research study?
- How does my family feel about my being in a research study?
- Can I agree to take the chance that the bad things (?risks?) they have told me might happen to me?
- Do I feel confident that the people who are conducting the study respect me, treat me kindly, and will do everything possible to keep me safe during the study?
- If I am treated on the study, will my health insurance cover medical expenses that are not covered by the study itself?

Finally, depending on the type of study, and the amount of time that will be needed, you may want to speak with your family about helping you make the decision about being in the study.

What about people who are not able to decide for themselves about being a human subject?

You can see that it's a very important decision you have to make when thinking of becoming a human subject. There are research studies that need to answer questions involving:

- children, who are not able to make decisions to be in research because they are too young, OR
- adults who are not able to make decisions because they may be too sick, either mentally or physically to do so.

Children are protected when it comes to being in research studies because there are special rules in place that make sure, with very few exceptions, that:

- Parents give their permission,
- The child agrees, and
- A special committee, called an Institutional Review Board (IRB), makes sure the study is ok for children to be in.

Adults who are too sick to decide to be in research studies are protected under specific research rules too. Only someone who is allowed by law to make decisions for another person can give the researcher permission to include the person in the study. Who is or is not allowed by law to make decisions on behalf of another person depends on state or local laws. If you are asked to give permission on behalf of someone who cannot consent for him or herself, you have to make sure to learn and understand as much as possible about the research so that you can make the best decision. Always ask the question: "Would the person want to be a human subject in this study?"

What is the informed consent process?

The process that involves being given important details, and asking and answering questions about the study, is called the informed consent process. You may also be asked to sign a form that has all the information you've discussed with the researcher. That form is called the Informed Consent Form, and you have the right to be given a copy of it

after you've signed it. This is a good thing, since it will also contain names and phone numbers you can call if you have questions later. [\(Click here for more information about the informed consent form.\)](#)

Being a volunteer in a research study is a choice. This means you never have to be in, or continue to be in, a research study if you don't want to. You have the right to say "No, I don't want to be in this study", or "I said yes to being in this study but now I've changed my mind" without having to give a reason, and without any penalties. If you don't want to start, or finish, something you have been asked to do, that's ok. If, for example, you are uncomfortable about answering a certain question, or doing a certain task, simply tell the researcher as soon as you can. Even though you can leave a study if you want to, sometimes the researcher needs to take certain steps so that you can be removed from the study safely. This really matters in studies where it may be dangerous for you to simply stop a study procedure (For example, if you are going to stop taking a study drug). You may need to slowly withdraw from the study, or come back for a safety visit to make sure you're ok now that you're out of the study.

While you are in a study, **you have the right to be given any new information that the researcher finds out that might make you change your mind about being in the study.** For example, during the study, it may be found that there are bad side effects happening in other subjects that were not known at the time you went in the study. Or, the researcher may decide that she/he wants to do an extra test, or have you come in for an extra visit.

What is expected of you after you have said "yes" to being a human subject?

After saying yes to being in the study, you have to follow the directions given to you as best you can. For example, if you have agreed to come in for a study visit at a certain time, you need to show up on the day and time you were asked to come.

If you have been asked to give information about yourself, you need to be sure that you are telling the truth. If you don't, you may not only hurt the study (that may need certain kinds of people with certain kinds of qualities in order to answer the research question) but you may also put yourself at risk. One of the goals of any study is to keep safe those who are subjects in it. That is why the types of people who can and cannot be in a study are very carefully looked at and approved before a study starts. [\(Click here for more information about the recruitment and screening of potential research subjects\)](#)

During the study, the researcher needs you to tell them if anything begins to bother you, or if you do not feel well during your time in the study. Say, for example, you are answering questions that are very personal and you start to become upset. You should let the person asking the questions know that you are becoming upset. That person will stop asking the questions, and will try to help you feel better. **Or**, if you are taking a **drug** and you start to feel funny or become sick, it is important that you let the researcher know **as soon as you can**. It is more important, however, that at any time you feel the need, you should go to the nearest emergency room, just as you would if you were not in a study.

Who protects people who agree to be research subjects?

Many groups work together to make sure research subjects are protected when they are in research studies. The main groups are:

The **Researchers**, who make sure your rights are protected and also make sure you are kept as safe as possible the whole time you are in the study. Your safety and rights are more important to the researcher than finding out the answer to the research question.

Researchers are required to be knowledgeable about how to conduct a research study and how to protect those who have volunteered to participate.

The **Institutional Review Board (IRB)**, which is a group of people that are not a part of the research study team, who are specially trained to review, approve, and watch over studies that involve human subjects. This group can be called different names in different places, but they all have to follow the same laws to make sure that the amount of protection they give research subjects is the same.

The State and Federal Government that makes the laws and rules that researchers must follow if they want to do research involving human subjects, and IRBs must follow if they want to be able to approve research involving human subjects.

16 Cultural Competence in Research

- **Roderick King, MD, MPH** Harvard Medical School
- **Julian Jane Atim, MBChB, MPH** Uganda Health Marketing Group (UHMG)
- **Stephanie Cantu** Harvard Medical School
- **Jonelle Wright, PhD, RN** University of Miami

Introduction

This module consists of four (4) sections. After completing the training, you will take a short quiz on the training content. After completing the quiz, we ask you to answer a few optional questions to give your view of this training module.

Learning Objectives

By the end of this module, you should be able to:

- Describe the concept of Cultural Competence in Research
- Explain the importance of Cultural Competence in Research
- Describe ways to enhance the engagement of diverse populations and communities in research
- Identify cultural competence challenges faced by researchers when working with culturally diverse populations

Cultural Competence in Research

Culture is fundamental to everyone's perceived identity. It is a mix of one's values, beliefs, standards, norms, behaviors, language, communication styles, and thinking patterns.[1] Cultural competence refers to understanding the importance of social and cultural influence on the beliefs and behaviors of the patient, student, colleague or client.[2] Cultural competence in health care describes the ability of systems and health care professionals to provide high quality care to patients with diverse backgrounds, values, beliefs, and behaviors, including communicating effectively and tailoring delivery to meet patients' social, cultural and linguistic needs and perspectives.[3] By definition, diversity can include differences in race, ethnicity, age, gender, size, religion, sexual orientation, and physical and mental ability.[4]

Many terms are used to describe cultural competence: awareness[5], responsiveness, safety[6] and sensitivity. But, unlike cultural responsiveness, sensitivity[7], or appropriateness, cultural competency requires more than simply being sensitive to or aware of cultural differences. It necessitates taking action to improve one's competence. Becoming culturally competent is an on-going process of developing skills, values, and the capacity to function effectively in cross-cultural situations.[8] It is said that cultural competence starts with awareness, grows with knowledge, is enhanced with specific skills, and becomes polished through actual cross-cultural encounters.[1]

Cultural Competence in Research is the ability of researchers and research staff to provide high quality research that takes into account the culture and diversity of a population when developing research ideas, creating the theoretical and conceptual framework, designing the study, conducting research, interpreting and exploring the applicability of the research findings, and disseminating the results. Cultural Competence in Research plays a critical role in study design and implementation processes, including the development of research questions and hypotheses, outreach and recruitment strategies, consent activities, data collection protocols, analyzing and interpreting research findings, drawing conclusions and presenting the results. Altogether, cultural congruence in these research processes helps to ensure the research is applicable to diverse populations and if necessary can be adapted to meet the target population's social, cultural, and linguistic needs[9]. Cultural competence can be crucial to successfully recruiting and retaining diverse individuals as study subjects.[10]

Cultural competency standards can apply to all kinds of researchers (that is, basic and clinical scientists, health service and community based participatory researchers, social and behavioral researchers, and other research professionals, etc.). However, the direct or indirect applicability of cultural competence will vary for each type of researcher and for each study. For purposes of this training module, Cultural Competence in Research should be an expectation of any individual who conducts research with the goal of improving the health and well-being of all.

It is important to differentiate Cultural Competence in Research from Community Based Participatory Research and Community Engagement. We consider Cultural Competence in Research an overarching principle, which encompasses traditional modes of scientific research including, but not limited to, basic science research, clinical research (including clinical trials), community-based participatory research (CBPR), and community engagement.

CBPR, however, begins with a research topic of importance to a specific community, with the aim of combining knowledge and action for social change to improve community health and perhaps address health disparities[11]. Community engagement is a core element of CBPR research. It requires academic members to become part of the community and community members to become part of the research team, thereby creating a unique working and learning environment.[12] An understanding of Cultural Competence in Research is thus not only required for successful and culturally safe CBPR and community engagement, but also for effective research design, implementation, and recruitment of research participants for traditional modes of scientific research.

Importance of Cultural Competence in Research

It is important that research keeps pace with and is fully responsive to the challenges that arise as a result of the rapidly increasing diversity of U.S. demographics. Research findings from studies conducted only in homogenous populations are not always applicable to diverse groups. That is why it is important that a study's subject enrollment reflect as closely as possible the population of those affected by the health problem being studied.

While the general health of our nation has improved, health disparities disproportionately affect minority populations and the medically underserved. It is clear that good health is connected to ethnicity, gender, and cultural factors.[13] The actual focus of the research should also address cultural factors and their effect on the health of diverse populations. Today's dramatic demographic shifts require researchers to understand, clearly, how cultural differences

among groups influence the actual process of designing and conducting research. Researchers will need to learn how best to understand and perhaps engage diverse populations in study design, implementation, analysis, and data interpretation processes. Researchers who are culturally competent are in a better position to design research methodology, analyze and interpret results that may be influenced by cultural differences.

Engaging Diverse Individuals, Populations, and Communities in Research

Federal Requirements for Minority Population Participation in Research

In 1994, the National Institutes of Health (NIH) established policy for the inclusion of women, children, and members of minority groups and their subpopulations in biomedical and behavioral clinical studies. Public Law 103-43 requires that women and minority subjects "be included in all clinical research studies, as appropriate for the scientific goals of the work proposed." [14] The goal is to ensure that minority individuals are included in clinical trials "in numbers adequate to allow for valid analyses of gender and/or racial/ethnic differences in intervention effects." [10] Further, investigators must develop outreach efforts to recruit these groups into clinical trials. [15]

As a result, researchers complying with these requirements will interact more than ever before with study subjects from diverse cultural perspectives. The quality of these interactions is extremely important. It will directly affect the overall equitability of the research, the quality and generalizability of data generated, subjects' willingness to complete the study, researchers' ability to translate research findings into practice, and ultimately, the public's willingness to accept research-based interventions.

Conducting Research Ethically-The Belmont Report[16]

In 1979, the National Commission for the Protection of Humans Subjects of Biomedical and Behavioral Research established ethical principles and guidelines for protecting human subjects in research. The three principles, respect for persons, beneficence, and justice, and their application, as outlined in the Belmont Report, require culturally competent research-related interactions with study participants.

Specifically, respect for persons requires researchers to assure autonomy and protect those with diminished autonomy. Researchers meet this obligation by allowing those who can to make informed choices about taking part in research and by instituting added protections for those who do not have the capacity to decide. In diverse communities, the former can only be accomplished when information is tailored to subjects' linguistic needs, comprehensible, and delivered in a culturally congruent manner.

Second, beneficence requires favorably balancing physical, emotional, economic, stigmatization, and confidentiality risks and potential benefits of research participation. Risks and benefits differ according to multiple factors and circumstances that vary widely across diverse communities and minority populations are more vulnerable to risks. Researchers need to engage community leaders in the process of estimating risk/benefit ratios to gain a full appreciation for how participation might affect individuals participating in studies conducted with diverse populations.

Third, justice for the individual requires fair recruitment practices. Researchers should be impartial when it comes to the enrollment of study subjects. No single group or populations should be favored. No group or population should be exposed to riskier interventions due to their circumstances. Social justice requires decisions be made by researchers in light of the ability of certain ethnic and economic classes to bear added burdens of research. Disadvantaged groups should be protected from being asked to participate in research for convenience or socioeconomic status. In such

cases, only less burdened groups should be asked to accept the risks of research except when the study relates directly to conditions specific to the disadvantaged group.

Trust, Transparency, and Impartiality

When conducting research with diverse communities, involving community members in decisions about key aspects of the research, promoting feelings of ownership within the community, maintaining public accountability and transparency, and assuring appropriate ethics oversight creates trust in study subjects.[17]

A poignant example of minority Americans being used to advance medical research without considering trust, transparency, and the need for consent from families or loved ones is the story of Henrietta Lacks. Scientists know her as HeLa. Born to a poor Southern tobacco farmer who worked the same land as her slave ancestors, her cells were taken without her or her family's knowledge and made into one of the most important research tools in medicine. Later, it was acknowledged that "HeLa cells were vital for developing the polio vaccine; uncovered secrets of cancer, viruses, and the effects of the atom bomb; helped lead to important advances like in vitro fertilization, cloning, and gene mapping; and have been bought and sold by the billions." [18]

The uncomfortable irony of this example is best stated by Henrietta's daughter Deborah, "Truth be told, I can't get mad at science, because it help people live, and I'd be a mess without it. I'm a walking drugstore! . . . But I won't lie, I would like some **health insurance** so I don't got to pay all that money every month for drugs my mother cells probably helped make." [18]

Unfortunately, there have been several examples of misconduct in cultural competence including the Tuskegee Syphilis Experiment [19], the unfortunate history of medical experimentation on slaves in the 18th and 19th centuries [20],[21] and Nazi physicians conducting experiments on Jewish prisoners. These scenarios demonstrate the importance of understanding historical contexts for study populations before initiating research. Culturally competent study design is critical in order to better develop trust and transparency with certain study populations. Diverse populations more easily adopt interventions that were developed in research in which they may have participated, developed trust through transparency, and was aligned as closely as possible to prevailing cultural factors. Study design should include (1) well-qualified researchers who are themselves from diverse racial and ethnic backgrounds as Principal and Co-Investigators, (2) incorporating diverse and culturally competent researchers into various levels, such as project coordinator who may work more closely with the study population as well as (3) ensuring adequate numbers of diverse participants to ensure that studies are effectively powered to produce meaningful results.

Improving behavioral and health outcomes

Appreciating and integrating culturally diverse perspectives among providers (health workers, educators, researchers, and others) improves communication and builds confidence among minority populations, thus increasing access to resources among minority populations. [22],[23] Increased access to health care and willingness to adopt culturally sensitive health interventions developed from research conducted by culturally competent researchers improves health outcomes. This process is vitally important in the success of translating basic science and clinical research to better health outcomes for patients.

Challenges in Cultural Competence in Research

Despite the importance of Cultural Competence in Research, its full integration in the conduct of research faces several challenges. Foremost, is the underestimation, often misunderstanding, of what it takes to ensure trust and

understanding in diverse individuals participating in research. Examples of common misperceptions are listed below with corresponding clarifying statements.

Common Misperception	Clarifying Statement
"My basic or preclinical research does not directly apply to diverse communities so this does not really apply to me." *	Some research may not hold immediate clinical relevance or application to practice, but such studies lay the scientific foundation for research that develops treatments or directly influences health interventions. It is important that early-phase studies build an understanding of, and take into account, differences that can be attributed to race, gender, age, and other cultural factors.
"Cultural competence is not that important because there are only a few minorities in the U.S."	The U.S. Census tells us that current minorities will make up the majority of the population in 2040.
"My research deals with a disease that affects mostly non Hispanic whites, so this does not apply to me."	Even in a disease affecting proportionally more Caucasian patients than minorities, the inclusion of minority patients is important both scientifically to explore the role of race and ethnicity on disease susceptibility, and to fulfill the ethical requirement of just conduct of research.
"Once we have designed our study and obtained the research funding needed, we will be able to dedicate the appropriate amount of time and effort required to do a good job at identifying and recruiting minorities for participation in our study."	Engaging diverse communities in research requires building trust and, as importantly, understanding, that can be developed only over time. Inclusion of diverse study subjects should occur early in the study development process to increase cultural congruence of study methods and likelihood of success in study recruitment and retention. (ref)
"Once we have designed the study and obtained the funding, we'll hire a minority research assistant who will help with recruiting minorities."	While a diverse research team can be a valuable component for the recruitment of minority patients, considerations about cultural sensitivity are important, and are better addressed at the study design and the budget process stages.
"Cultural competency is a new "concept" and it will interfere with how we currently conduct research."	Federal guidelines on inclusion of women and minorities in clinical research were established in 1994. [25] These requirements, which are now updated regularly, dramatically changed how research was designed and implemented in the 1990s and will continue to shape the way we conduct research in the future.
"I do not need to be concerned about cultural competence because my research does not involve interaction with study subjects."	Research-driven health interventions are more likely to be successful when they are culturally sensitive and congruent and take into consideration diverse target populations for which they may be designed.

**Quotes are a compilation of common themes and statements from researchers involved in the piloting of the module and members of the Advisory Committee that helped guide the development of the work in Harvard Catalyst.*

Summary

Essentials of Cultural Competence in Research

- We define Cultural Competence in Research as the ability of researchers and research staff to provide high quality research that takes into account the diversity of a study population's values, beliefs and behaviors when developing research ideas, conducting research and exploring applicability of their findings.
- Rapid changes in the US demographics and subsequently research study populations call for adjustments in research study design, analysis and interpretation processes.
- Understanding historical contexts for study populations before initiating research study design is critical.[26],[27]
- Building trust and understanding with specific populations that are being recruited to participate in research is critical. Having a working knowledge of the important customs, values, beliefs, and communication styles, without stereotyping, is of utmost importance.[28],[29],[30]
- Building the skills to communicate effectively to explore customs, values, and health beliefs will prepare one to develop inclusive study designs and enable one to work with a variety of study populations.

What can Institutional Review Boards (IRB's) and researchers do to support this work?

IRBs should:

- Review IRB membership to determine if there are large communities or cultures that participate in the research they approve and seek an IRB member that can help represent that community
- Seek consultants as needed to help them understand the cultural issues as they pertain to a particular protocol
- Consider educational initiatives on cultural competence
- When appropriate, as part of a protocol application, ask questions regarding what efforts the researcher has made to work with and understand the communities being studied

Researchers should:

1. Look for members of specific communities to help identify areas of concern for research
2. Seek guidance from representatives of the community when developing and implementing protocols with communities
3. Consider adding members with expertise in the community under study as part of the research team

Additional Resources

- [*Quality Interactions*](#): Quality Interactions is an e-learning program that provides case-based instruction on cross-cultural health care. This interactive program focuses on common clinical and/or cross-cultural scenarios that build a framework of knowledge and skills for delivering quality care to diverse patient populations
- [*Annotated Bibliography in Cultural Competence in Research*](#)
- [*The Joint Commission: Hospitals, Language and Culture*](#): The Joint Commission provides links and resources regarding cultural competence in research and health care, in the context of patient safety.

References

1. Agramonte, T. (2010). Suspending judgment: A key to being culturally competent. U. S. Department of Veterans Affairs. Retrieved 10 May 2010.
2. Betancourt, R. J., Green, A. R., & Ananeth-Firemong II, O. (2003). Defining cultural competence: A practical framework for addressing racial/ethnic disparities in health and health care. *Public Health Reports*, 118, 293-302.
3. Betancourt, J, Green, A, & Carrillo, E. (2002). *Cultural competence in health care: Emerging frameworks and practical approaches*. The Commonwealth Fund.
4. *The American Heritage? New Dictionary of Cultural Literacy*. (2005). Third Edition. Boston: Houghton Mifflin Company.
5. Shiu-Thronton, S. (2003). Addressing cultural competency in research: Integrating a community-based participatory research approach. *Alcohol Clinical Research*, 27(8), 1361-1364.
6. Crampton, P., Dowell, A., Parkin, C., & Thompson, C. (2003). Combating effects of racism through a cultural immersion medical education program. *Academic Medicine*, 78(6), 595-598.
7. Cook, C.T., Kosoko-Lasaki, O., & O'Brien, R. (2005) Satisfaction with and perceived cultural competency of healthcare providers: The minority experience. *Journal of the National Medical Association*, 97(8), 1078-1087
8. Office of Minority Health. (2002). Teaching cultural competence in health care: A review of current concepts, policies and practices. Washington D.C.: U. S. Department of Health and Human Services. Contract Number: 282 - 98 - 0029.
9. U.S. Department of Health and Human Services. (2001). Mental health: Culture, race, and ethnicity-A supplement to Mental health: A report of the Surgeon General. Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Service.
10. O'Brien, R.L., Kosoko-Lasaki, O., Cook, C. T., Kissell, J, Peak, F., & Williams, E. H. (2006). Self-assessment of cultural attitudes and competence of clinical investigators to enhance recruitment and participation of minority populations in research. *Journal of the National Medical Association*, 98(5), 674-682.

11. Kellogg Community Health Scholars Program, 2001.
12. Jones L., & Wells K. (2007). Strategies for academic and clinician engagement in community-participatory partnered research. *Journal of the American Medical Association*, 297(4), 407-410.
13. U.S. Department of Health and Human Services. (2001). *HHS fact sheet: Reshaping the health of minority communities and underserved populations*. Accessed 11 May 2010.
14. U.S. Department of Health and Human Services. (2010). *Human Subjects Protection and Inclusion of Women, Minorities, and Children Guidelines for Review of NIH Grant Applications*. p. 1. Retrieved 11 May 2010.
15. U.S. Department of Health and Human Services. (1994). NIH Guidelines on inclusion of women and minorities as subjects in clinical research. NIH Guide, 23 (11).
16. The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. (1979). *The Belmont Report: Ethical principles and guidelines for the protection of human subjects of research*. Retrieved 11 May 2010 from Office for Human Research Protections.
17. Shore, N., Wong, K., Seifer, S., Grignon, J., & Gamble, V. (2008). Introduction to special issue: Advancing the ethics of community based participatory research. *Journal of Empirical Research on Human Research Ethics*, 3(2),1-4
18. Skloot, R. (2010). *The immortal life of Henrietta Lacks*. New York: Random House, Inc.
19. Jones, J. (1992). *Bad blood: The Tuskegee Syphilis experiment, new and expanded edition*. New York: Free Press.
20. Washington, H. (2008). *Medical apartheid: The dark history of medical experimentation on Black Americans from colonial times to the present*. New York: Doubleday.
21. Byrd, M., & Clayton, L. (2001). *An American health dilemma: Race, medicine, and health care in the United States 1900-2000*. New York: Routledge.
22. Guidry, J., & Decuir A. (1997). Cultural sensitivity training module for health providers to increase cultural competence in working with African-Americans. *Abstr Book Assoc Health Serv Res Meet*. 1997; 14: 65.
23. Weisman, J. S., Betancourt, J., Campbell, E. G., Park, E. R., Kim, M., Clarridge, B. . . & Miana, A.W. (2005) Resident physicians' preparedness to provide cross-cultural care. *Journal of the American Medical Association*, 294(9), 1058-1067
24. Day, J. C. (1996). *Population projections of the United States by age, sex, race, and Hispanic origin: 1995 to 2050*. U.S. Bureau of the Census, Current Population Reports, 25-1130.
25. U.S. Department of Health and Human Services. (2001). *NIH policy and guidelines on the inclusion of women and minorities as subjects in clinical research - Amended*, October 2001. Retrieved 11 May 2010.
26. Corbie-Smith, G., Ammerman, A. S., Katz, M. L., St. George, D. M., Blumenthal, C., Washington, C. . . & Switzer, B. (2003). Trust, benefit, satisfaction, and burden: a randomized controlled trial to reduce cancer risk through African-American churches. *Journal of General Internal Medicine*, 18(7), 531-41.
27. Thomas, S. B., & Quinn, S. C. (1991). The Tuskegee Syphilis Study, 1932 to 1972: Implications for HIV education and AIDS risk education programs in the black community. *American Journal of Public Health*, 81(11), 1498-505.

28. Shelton, D. (2008). Establishing the public's trust through community-based participatory research: a case example to improve health care for a rural Hispanic community. *Annual Review of Nursing Research*, 26, 237-59.
29. Moreno, G., Rodriguez, M. A., Lopez, G. A., Bholat, M.A., & Dowling, P. T. (2009). Eight years of building community partnerships and trust: The UCLA family medicine community-based participatory research experience. *Academic Medicine*, 84(10), 1426-33.
30. Christopher, S., Watts, V., McCormick, A. K., & Young, S. (2008). Building and maintaining trust in a community-based participatory research partnership. *American Journal Public Health*, 98(8), 1398-406.