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Stroke Discourses and Remedies in Urban and Rural Tanzania

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October 2008

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CONTENTS

TABLE OF CONTENTS I

LIST OF TABLES IV

LIST OF FIGURES IV

ABSTRACT V

ACKNOWLEDGEMENTS VI

ABBREVIATIONS VIII

1 CHAPTER ONE: INTRODUCTION 1

1.1 BACKGROUND TO THIS STUDY 1
1.1.1 Tanzania Stroke Incidence Project 2
1.1.2 Initial small scale study 3
1.1.3 Current study 4
1.2 AIMS OF THE STUDY AND RESEARCH QUESTIONS 5
1.2.1 Aims 5
1.2.2 Research questions 6
1.3 STROKE AS A MEDICAL AND SOCIAL CONDITION 7
1.3.1 Stroke as a cardiovascular disease 8
1.3.2 Trend of CVD in developing countries 9
1.3.3 Factors associated with the rise of CVD in developing countries 12
1.3.4 Social representations of stroke 14
1.4 OUTLINE OF THE THESIS 15
1.5 CONCLUSIONS 17

2 CHAPTER TWO: LITERATURE REVIEW 19

2.1 INTRODUCTION 19
2.2 THE STUDY OF STROKE 20
2.2.1 Social studies on stroke worldwide 20
2.2.2 Stroke studies in developing countries 21
2.2.3 Stroke studies in sub-Sahara Africa 22
2.3 BUILDING ON PREVIOUS STUDIES OF ILLNESS IN TANZANIA 24
2.4 MODELS FOR STUDYING TREATMENT-SEEKING BEHAVIOURS 33
2.4.1 The Sociobehavioural Model (SBM) 34
2.4.2 Kroeger's health choice model 34
2.4.3 Young and Garro's treatment decision model 35
2.4.4 Limitations of treatment-seeking models and approach in this study 36
2.5 REQUISITES FOR SUCCESSFUL HEALTH INTERVENTIONS 37
2.6 OVERVIEW OF ANTHROPOLOGICAL THEORIES OF ILLNESS 40
2.6.1 'Civilized' vs 'primitive' medical systems 40
2.6.2 Ethnomedicine 42
2.6.3 Ecological theory 43
2.6.4 Cultural interpretative theory 45
2.6.5 Critical medical anthropology 46
2.7 MY THEORETICAL APPROACH 49
2.8 CONCLUSIONS 50

3 CHAPTER THREE: THEORETICAL FRAMEWORK 53

3.1 INTRODUCTION 53
3.1.1 An overview of the framework 55

3.1.2 Power 57
3.1.3 Ideology 59
3.2 A TOOLBOX FROM FOUCAULT 62
3.2.1 Discourse 62
3.2.2 Power and knowledge 65
3.2.3 Some limitations of Foucault's approach 66
3.3 BOURDIEU'S CONCEPTUAL TOOLBOX 68
3.3.1 Habitus 70
3.3.2 Strategy and strategizing 73
3.3.3 Symbolic power 75
3.3.4 Some limitations of Bourdieu's approach 78
3.4 CONCLUSIONS 79

4 CHAPTER FOUR: METHODOLOGY 82

4.1 INTRODUCTION 82
4.2 STUDY SITES 83
4.2.1 General description of Hai district 84
4.2.1.1 Historical background of the Chagga 87
4.2.1.2 Modern healthcare provision in Hai 89
4.2.2 General description of Temeke district 91
4.2.2.1 Historical background of the Swahili of Dar-es-Salaam 95
4.2.2.2 Modern healthcare provision in Dar-es-Salaam 96
4.3 DATA COLLECTION 99
4.3.1 Ethnographic fieldwork 99
4.3.2 Focus Group Discussions (FGDs) 100
4.3.3 In-depth interviews 101
4.3.4 Key informant interviews 103
4.3.5 Vignette technique 103
4.3.6 Case studies 104
4.3.7 Other forms of data 105
4.4 DATA ANALYSIS 105
4.4.1 Practical data processing 105
4.4.2 Theoretical approach to data analysis 106
4.4.3 Reflexivity 109
4.5 ETHICAL CONSIDERATIONS 112
4.6 CONCLUSIONS 113

5 CHAPTER FIVE: STROKE DISCOURSES AND THE EXPERIENCES OF SUFFERERS AND CARERS. 115

5.1 INTRODUCTION 115
5.2 CONTEXTUALISING FINDINGS 116
5.3 TERMS FOR STROKE 118
5.4 STROKE DISCOURSES 120
5.4.1 Biomedical discourse 120
5.4.2 Lay biomedical discourse 122
5.4.3 Religious informed discourse 123
5.4.4 Supernatural beliefs informed discourse 127
5.4.5 Cultural beliefs informed discourse 129
5.4.6 Discussion of discourses 131
5.5 EXPERIENCES OF SUFFERERS AND THEIR CARERS 133
5.5.1 Experiences of stroke sufferers 135
5.5.2 Experiences of carers 138
5.6 CONCLUSIONS 142

6 CHAPTER SIX: TREATMENT PATTERNS, DECISION-MAKING PROCESSES AND THE BIOMEDICAL TREATMENT OF STROKE 144

6.1 INTRODUCTION 144
6.2 DECISION-MAKING ON WHAT REMEDIAL COURSE TO PURSUE 145
6.3 GENERAL PATTERNS OF STROKE REMEDIES PURSUED 148
6.4 BIOMEDICAL TREATMENT 153
6.4.1 Health facility based treatment 153
6.4.2 Home based biomedical treatment 159
6.5 DISCUSSION 159
6.6 CONCLUSIONS 163

7 CHAPTER SEVEN: TRADITIONAL AND FAITH HEALING OF STROKE . 166

7.1 INTRODUCTION 166
7.2 TRADITIONAL REMEDIES 167
7.2.1 Problematising terminology: traditional medicine and traditional healing 167
7.2.2 Healer administered traditional treatment 168
7.2.3 Typology of traditional healers 169
7.2.4 Traditional medicines for stroke 178
7.2.5 Self administered traditional treatment 183
7.2.6 Discussion of traditional remedies 187
7.3 FAITH BASED HEALING 190
7.3.1 Characteristics of faith based healing 190
7.3.2 Discussion of faith based healing 195
7.4 CONCLUSIONS 198

8 CHAPTER EIGHT: OPPORTUNITIES FOR INTERVENTIONS 202

8.1 INTRODUCTION 202
8.2 AN OVERVIEW OF STROKE INTERVENTIONS 203
8.2.1 Stroke knowledge and awareness interventions worldwide 203
8.2.2 Stroke treatment interventions worldwide 204
8.2.3 Relevant stroke treatment interventions or components for developing countries 206
8.3 POTENTIAL INTERVENTIONS GROUNDED IN THIS STUDY 210
8.3.1 Community-targeted and based interventions to raise stroke knowledge and awareness 210
8.3.2 Community based interventions on treatment of stroke 217
8.4 DISCUSSION 220
8.5 INTEGRATED COMMUNITY BASED INTERVENTIONS 223
8.6 CONCLUSIONS 226

9 CHAPTER NINE: CONCLUSIONS AND POLICY RECOMMENDATIONS . 228

9.1 SUMMARY OF CONTRIBUTION 228
9.2 SUMMARY OF FINDINGS IN RELATION TO STUDY OBJECTIVES 230
9.3 POLICY RECOMMENDATIONS 234
9.4 CONCLUDING REMARKS 237

GLOSSARY 238

BIBLIOGRAPHY 240

APPENDICES 252

LIST OF TABLES

Table 1: Top five causes of death in Hai: July 2004 to June 2005 10
Table 2: Explanatory variables of health care choice 35
Table 3: Chiefdoms in Hai division in 1961 88
Table 4: TSIP findings on the first type of help sought for stroke 153
Table 5: Typology of healers providing stroke remedies in Temeke and Hai 173

LIST OF FIGURES

Figure 1: Stages in the epidemiologic transition 11
Figure 2: Theoretical framework 57
Figure 3: Illustration of the Habitus 73
Figure 4: Factors in play in strategizing 74
Figure 5: A maize and banana farm in Nkwarungo village, Machame 86
Figure 6: Mfooni village shopping centre, Machame 87
Figure 7: A tarmac road passing between a banana farm and water tank in Machame 89
Figure 8: Main mtaa (street) of Saba-saba area, Temeke 92
Figure 9: Saba-saba along Kilwa road 93
Figure 10: Boys playing football near the TAZARA railway line in Saba-saba 94
Figure 11: High density housing in Saba-saba 95
Figure 12: A woman clothed in Khanga common among women in Saba-saba 96
Figure 13: Maps showing location of the two research sites 98
Figure 14: Nkwarungo Lutheran church 126
Figure 15: Kalali mosque 126
Figure 16: Mfooni Lutheran church 127
Figure 17: Flow of stroke remedy seeking processes 148
Figure 18: Container and capsules of Indian cholesterol lowering medicine 185
Figure 19: Common theoretical viewpoints of traditional and faith healer 201
Figure 20: Proposed interventions 209
Figure 21: Media attractive power in Sabasaba 212
Figure 22: Factors which influence stroke treatment options 233

Abstract

While stroke is an emerging health problem in sub-Sahara Africa, there are no detailed studies on its representations and treatment in rural and urban communities. This is the first anthropological study contrasting different representations of stroke in two sites in sub-Saharan Africa. It draws on data collected during one year of qualitative research fieldwork in rural (Hai) and urban (Dar-es-Salaam) Tanzania, using a mix of qualitative methods such as extensive ethnographic fieldwork and case studies.

Using a power relations framework crafted from concepts developed by Foucault and Bourdieu, I analyse the way stroke is constructed and negotiated in the two sites. Stroke discourses and practices are products largely of the interplay of social, cultural, historical and economic processes. I examine these interactions at the individual, family, and community levels. My findings show that although there are several competing discourses about stroke in each site, one tends to become dominant. A given discourse acquires a dominant position by virtue of being associated with a stronger power base rooted in local and regional processes. Different stroke discourses lead to the pursuit of different remedies which range from hospital to a variety of traditional and faith-based healing. Social negotiations characterise the selection of treatment, and people commonly combine several options to obtain care.

I outline potential community based stroke interventions to improve knowledge, awareness and treatment about stroke, such as working with community members who hold symbolic power. I make four health policy recommendations. I emphasize the need for developing health programmes informed by contextual dynamics. Raising awareness is an important first step in implementing such programmes. I highlight the need to learn from successful interventions, such as the effectiveness of interactive and appropriate health messages delivered through popular mass media. Finally, to address resource shortage, I recommend integrated healthcare for several related illnesses such as stroke, diabetes and hypertension.

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Abbreviations

AHA	-American Heart Association
AIDS	- Acquired Immuno Deficiency Syndrome
AMMP	-Adult Mortality and Morbidity Project
ARVs	- Anti Retro Virals
BP	-Blood Pressure; sometimes used to refer to hypertension
CDI	-Community Directed Intervention
CHAWATIATA	-Chama cha Waganga wa Tiba za Asili Tanzania: Association of traditional healers in Tanzania
CHMT	-Council Health Management Team
CMA	-Critical Medical Anthropology
CT Scan	- Computerised Tomography Scan
CVD	-Cardiovascular Disease
Dar	-Dar-es-Salaam
DMO	-District Medical Officer
DOTS	-Directly Observed Treatment of Tuberculosis Short course
DSCO	-District Sports and Culture Officer
DSS	-Demographic Surveillance Site
ECG	-Echocardiogram
FGDs	- Focus Group Discussions
HAART	-Highly Active Anti Retroviral Treatment
HIV	- Human Immunodeficiency Virus
ITNs	-Insecticide Treated Nets
KCMC	- Kilimanjaro Christian Medical Centre
MUHAS	-Muhimbili University of Health and Allied Sciences
SASPI	-Southern Africa Stroke Prevention Initiative
SBM	-Sociobehavioural Model
SSA	-sub-Saharan Africa
TAZARA	-Tanzania Zambia Railway Authority
TDR	-Special Programme for Research and Training in Tropical

	Diseases
TB	-Tuberculosis
TSIP	- Tanzania Stroke Incidence Project
WHO	-World Health Organisation

1 Chapter One: Introduction

This chapter provides both an introduction to my study and an outline of my thesis. As such, it is a brief chapter outlining the aims and substance of the thesis. I provide the background to my study outlining its genesis and progression. I show how this study was conceived from issues arising from carrying out an epidemiological study of stroke in my two research sites. In addition, I briefly describe findings from an initial small scale study I carried out on causation beliefs and treatment-seeking for stroke before commencing the current study. I demonstrate how the current study benefited in its design and the way it was carried out from experiences and findings from the initial study.

I then state my study aims including the research questions which largely guided my fieldwork. I contextualise the study of stroke by providing two perspectives of stroke both as a medical and social condition. I also give an overview of the trend and issues associated with the rise of CVD in developing countries. I delineate the structure of the thesis by briefly describing what is addressed under each chapter. Lastly, I conclude the chapter by summarising the main points covered and introduce the next chapter.

1.1 Background to this study

This medical anthropological study sets out to examine the complex social, cultural, historical and economic factors and processes which characterise how people make sense of, and treat stroke in a rural and urban Tanzanian setting. It is designed to explore in detail the interplay of the dynamics of contextual factors, complex belief systems and social processes responsible for the production and perpetuation of stroke discourses[1] and subsequent treatment-seeking practices in the study areas. In addition, it utilises findings to explore and propose ways of initiating appropriate stroke interventions. This study

[1] In my study I use the term 'discourse' as defined by Foucault to mean the way stroke is consciously or unconsciously constituted and made explicit through the way it is imagined and talked about and its related practices. I elaborate the concept further in chapter three.

draws entirely on qualitative methods and specifically in-depth interviews, key informant interviews, case studies and focus group discussions undertaken within a broader ethnographic inquiry.

1.1.1 Tanzania Stroke Incidence Project

The initial thoughts for this study came from experiences of carrying out an epidemiological study of stroke incidence in Tanzania (the Tanzanian Stroke Incidence Project: TSIP). The TSIP is the first major epidemiological study of stroke to be undertaken in sub-Saharan Africa (SSA). While available data suggest that stroke is an emerging problem in SSA, there had hitherto been no population-based stroke incidence studies published and little is known of morbidity and mortality of stroke in sub-Saharan Africa (Connor et al. 2007, Walker et al. 2000b).

The TSIP was a prospective, three year study, operating in two study populations within Tanzania: Dar-es-Salaam (an urban centre) and Hai (a rural location). It was designed as a prospective study with 'hot pursuit' of cases in two large, well-defined, relatively stable populations in which there is an accurate and regularly updated measurement of the denominator populations. Data were collected for three complete years between 2003 and 2006. When someone was suspected of having suffered a stroke, one of the TSIP enumerators informed the TSIP supervisor who would then, if stroke was diagnosed, arrange transport and admission to hospital (Kilimanjaro Christian Medical Centre for the Hai district and Muhimbili University Hospital for the Dar-es-Salaam project area), and also inform the research doctor. The research doctor coordinated the investigations which involved carrying out a number of tests on the patient, including an echocardiogram (ECG), Computerised Tomography (CT scan) head scan and blood tests. The doctor would also arrange for a follow-up appointment once the individual had left hospital with their carer. Routine medical management of the patients was carried out by the respective hospital medical teams. All individuals were followed up at one month and six months to assess recovery and any deaths were immediately reported to the research doctor. The project met the costs of transport to hospital, hospital stay, investigations,

hospital treatment and also one year of treatment for chronic problems identified, such as hypertension.

In its first two years, the TSIP had been proceeding well in the Hai district where only two people refused to participate out of over a hundred stroke sufferers identified. However, in Dar-es-Salaam there were initial difficulties with patient recruitment as individuals appeared to be much more reluctant to go to hospital. From preliminary discussion with stroke sufferers, their families and traditional healers, it became apparent that there are complex belief systems surrounding stroke, which profoundly affect treatment-seeking behaviour. It was at that stage that I was contacted by the TSIP and I conducted a small qualitative preliminary study on perceptions and treatment-seeking for stroke in Dar-es-salaam and Hai prior to commencing my PhD studies in Durham.

1.1.2 Initial small scale study

In my initial, small scale study (Mshana et al. 2008), data were collected through semi-structured interviews in September 2004 in Dar-es-Salaam and March 2005 in Hai. A total of 80 semi-structured interviews (40 in each site) were conducted with 20 stroke patients, 20 of their friends or relatives, 10 traditional healers, and 30 other local residents.

This initial study was very descriptive in nature seeking to get a broad picture of what is taking place in terms of local understandings and treatment-seeking patterns for stroke. Its findings were therefore interpreted as explanatory models (Kleinman 1980) for stroke. Key findings from this work showed that in Dar-es-Salaam stroke is widely believed to emanate from supernatural causes (demons and witchcraft), while in Hai, explanations drew mostly on 'natural' causes (hypertension, fatty foods, stress). These findings are explained in part by historical and cultural differences between the two areas, and in part as ways of coping with the stresses of modernity and globalisation in urban settings. These different beliefs and explanatory models fed into treatment-seeking behaviours. The first option for stroke treatment in Hai was hospital treatment, while in Dar-es-Salaam-- where hospital avoidance was related to a belief in demons-- it was traditional

healers. In both sites, multiple treatment options (serially or simultaneously) were the norm. Interviews clearly showed that beliefs outweighed other factors, such as cost and distance (potential major obstacles), in shaping effective treatment. Findings from the initial study also clearly indicated that the beliefs and causal attributions were not static, nor were they framed within a single explanatory paradigm. They were multi-faceted, constructed and negotiated through lay people's interactions with healers, doctors, relatives and significant others. This also shaped treatment-seeking decisions as an interactive, dynamic process.

Insights from this preliminary research were instrumental to the way the current study was designed. Specifically I realized that conducting long term ethnographic fieldwork work would enable me to conduct a detailed, thorough analysis and interpretation of stroke discourses in the two research sites. It would also enable me to engage anthropological theory as I carried out fieldwork in order to make a more rigorous investigation and interpretation of the stroke discourses. In addition, I realized that I needed to conduct repeated interviews with my respondents especially the stroke sufferers and their carers in order to build better rapport and cross check the information they gave me during interviews. The good rapport and opportunity to cross check information obtained during interviews lead to getting richer narrations about my respondent's experiences and construction of stroke. I also realized that if I could follow-up a few case studies of stroke sufferers and their families over a period of time, I would get a better understanding of stroke discourses. The case studies would also provide a more nuanced picture of my findings. I therefore took into account all these issues when designing the current study as detailed in the next section.

1.1.3 Current study

This current study sought to investigate in detail the complex interplay of the many factors and belief systems reported in the initial study and literature. Following the grounded theory approach (Glaser and Strauss 1967), findings from the initial study and literature review were taken as data in order to compare with what emerges from my detailed fieldwork of the current study (Glaser 1998). Data comparability and inductive

fieldwork is a key aspect of the grounded theory approach guiding the collection, analysis and development of theory (Glaser 1998). In Chapters 3 and 4, I provide a detailed account of how I utilised a modified version of grounded theory in carrying out my fieldwork and developing theory. Therefore my PhD study goes further than the initial study by critically engaging anthropological theory all the way through the collection and analysis of data. Furthermore, it has a firm empirical grounding as it builds on repeated interviews with stroke sufferers and their carers, key informants and other members of the study communities. It therefore benefits from a wider range of qualitative data collection methods. In addition to interviews I conducted focus group discussions and a long term ethnographic inquiry whereby I lived in the study areas for several months. All these methods enabled me to conduct a much more thorough and context-informed analysis.

Thus this study engages with wider theory. Importantly also, it makes a contribution to the health policy arena by specifically exploring and proposing ways of designing community based stroke interventions.

1.2 Aims of the study and research questions

1.2.1 Aims

This study aimed to:

1 Investigate local understandings and beliefs in relation to causes and appropriate treatment of stroke.
2 Investigate experiences of stroke sufferers and care providers and examine how these experiences shape their perceptions and reaction to the illness.
3 Investigate individual and social factors affecting representations and decision-making in relation to the treatment of stroke.
4 Investigate the range of traditional, medicalized and other avenues for stroke treatment, and the relationships between them.
5 Investigate ways of initiating relevant strategies to promote belief or behaviour change where appropriate, as well as promote health services for stroke sufferers.

1.2.2 Research questions

In carrying out my research, I devised a series of research questions to guide my fieldwork. These research questions helped to explore the way I investigated matters related to my research in a flexible way. In other words, the research questions did not rigidly guide my fieldwork but provided stimulant starting points for pursuing my research aims. Following are the research questions:

1. How do people in Tanzania understand the causes and nature of stroke, and what are the relationships between such beliefs and health-seeking behaviours?
    - What are the salient beliefs about stroke and its causes?
    - How do such beliefs translate into health-seeking behaviour?
    - What factors mediate the relationship between beliefs and practice in the context of stroke?
    - Why are people in a rural area (Hai) apparently much more willing to seek western style medical help following stroke than those in the urban area in Dar-es-Salaam?
2. What are the lived experiences of stroke sufferers and their carers, and how do these experiences change their worldviews in relation to life and illness in general, and stroke in particular?
    - How do stroke sufferers make sense of, and cope with, their condition?
3. What are the key socio-cultural processes that impact on people's decision-making for stroke treatment, both at the household level and the community level?
    - What impact do different forms of power relations have on such decision-making?
    - What are the social support mechanisms available for stroke sufferers at household and community level, and how do stroke sufferers vary in their ability to access and mobilise these support systems effectively?
4. What are the characteristics and nature of the treatment of stroke available in the two sites?

- What is the nature of treatment provided through biomedical services, and by traditional/faith healers? For example, what is the composition of medicines given and diagnostic paradigms employed? How do traditional and faith healers vary in the treatments they offer?
- How do interactions with treatment providers (both modern and traditional / faith healers), and power relations between patients and healers, shape and transform beliefs about stroke and the processes of treatment decision-making?
- Is there a role for traditional/faith healers and modern healthcare providers to work together in offering stroke treatment? (For example, traditional or faith healers may have an important role in helping people to make sense of, or comes to terms with, a condition which is not easily curable.)
- How does the experience of treating patients influence the ways in which the healers themselves understand and treat stroke?

5. How do other contextual factors (e.g. cost, distance of health facilities, transport, public health interventions etc.) affect both beliefs and treatment-seeking behaviour for stroke? How do interactions between beliefs, other contextual factors, and past experience of treatment-seeking feed into and shape people's responses to stroke?
6. What kinds of interventions might be appropriate to improve outcomes for stroke sufferers?

1.3 Stroke as a medical and social condition

In this study, I examine stroke as both a biomedical and social condition. I engage the interplay of these two perspectives and their associated discourses. However, since this is a medial anthropological study, I am primarily interested in exploring the social construction of stroke through examining in detail the social processes of the way its discourse is produced and sustained. In the next two sections I provided an overview of stroke as a both a biomedical and social condition.

1.3.1 Stroke as a cardiovascular disease

From the biomedical perspective, stroke falls under the broad category of cardiovascular diseases (diseases affecting the blood circulation system). As the blood circulation system is complex, there are scores of CVDs. These include coronary heart disease (disease of the blood vessels supplying the heart muscle) and rheumatic heart disease (damage to heart muscle and heart valves) just to mention but a few.

In a simple biomedical definition, stroke is caused by the disruption of the blood supply to the brain due to either blockage (ischaemic stroke) or rupture of a blood vessel (haemorrhagic stroke) (Walker 2004). This disruption leads to brain cells being deprived of oxygen and nutrients which could lead to damage or death of brain tissue. Clinically stroke is defined as 'rapidly developing clinical signs of focal (or global) disturbance of cerebral function with symptoms lasting 24 hours or longer or leading to death with no apparent cause other than that of vascular origin' (WHO MONICA Project 1988). Stroke is also commonly known as cerebrovascular accident (CVA).

Major symptoms of a stroke can be grouped under four broad categories (Walker 2004). First is the sudden numbness, weakness or paralysis on one side of the body with signs such as a drooping arm, leg, eyelid or dribbling mouth. Second is sudden slurred speech or difficulty finding words or understanding speech. Third is the sudden blurring, disturbance or loss of vision, especially in one eye. Fourth is dizziness, confusion, unsteadiness and/or severe headache. Medical treatment of stroke involves preventing subsequent (secondary) strokes and managing the resulting disability (e.g. physiotherapy) and preventing recurrence by, for example, managing hypertension (high blood pressure). While carrying out my fieldwork, I realized that stroke is commonly confused with hypertension and other heart diseases. This confusion is common among lay people and has also been reported by a study exploring knowledge and perceptions of stroke among adults in Nigeria (Ayanniyi, Akande, and Mustafa 2006). In this study, more than half of the participants thought the heart was injured when a stroke occurred and the majority associated it with hypertension. Similar confusion of stroke with heart attacks and the apparent lack of knowledge about it have also been reported from studies conducted in

developed countries (Drummond, Lincoln, and Juby 1996, Wellwood, Dennis, and Warlow 1994). Although hypertension is the biggest single risk factor for stroke, clinically it is a different condition.

1.3.2 Trend of CVD in developing countries

It is predicted that CVD will become a major cause of mortality and morbidity in developing countries therefore becoming a major public health problem (Reddy and Yusuf 1998). If the current demographic trends continue, it is estimated that by the year 2025, 90% of the global CVD burden will occur in low and middle income countries (Hackam and Anand 2003). Indeed there is evidence from the areas where I conducted my research that CVDs are one of the top five causes of mortality among certain age groups. For example a recent mortality census conducted in Hai district shows that cardiovascular diseases are among the five top causes of mortality from ages 35 upward, becoming the main cause for the age group of 60 years and above: table 1.

	Males			Females		
Age group (years)	Cause of death	%	No	Cause of death	%	No
0-4	-Acute respiratory infections	22.4	26	-Acute respiratory infections	23.8	29
	-Still birth	21.6	25	-Still birth	22.1	27
	-Acute Febrile Illness	14.7	17	-Acute Febrile Illness	19.7	24
	-Prematurity and/or low birth	10.3	12	-Prematurity and/or low birth	10.7	13
	-Birth injury and/or asphyxia	6.0	7	-Undetermined	5.7	7
5-14	-Tuberculosis/AIDS	40.0	12	-Tuberculosis/AIDS	29.4	5
	-Unintentional Injuries	26.7	8	-Acute Febrile Illness	23.5	4
	-Acute Febrile Illness	6.7	2	-Unintentional Injuries	17.7	3
	-Intentional Injuries	6.7	2	-Acute abdominal conditions	5.9	1
	-Undetermined	6.7	2	-Acute respiratory infections	5.9	1
15-34	-Tuberculosis/AIDS	30.3	36	-Tuberculosis	57.9	62
	-Unintentional Injuries	15.1	18	-Acute Febrile Illness	8.4	9
	-Intentional Injuries	13.5	16	-Cardiovascular Disorders	5.6	6
	-Acute Febrile Illness	12.6	15	-Undetermined	4.7	5
	-Central nervous system	4.2	5	-Neoplasms	3.7	4
35-59	-Tuberculosis/AIDS	34.8	100	-Tuberculosis/AIDS	52.2	108
	-Unintentional Injuries	11.2	32	-Acute Febrile Illness	10.1	21
	-Acute Febrile Illness	10.8	31	-Cardiovascular Disorders	7.3	15
	-Cardiovascular Disorders	8.7	25	-Neoplasms	7.3	15
	-Intentional Injuries	7.0	20	-Undetermined	3.9	8
60+	-Cardiovascular Disorders	21.0	64	-Cardiovascular Disorders	22.5	58
	-Acute respiratory infections	14.4	44	-Undetermined	15.5	40
	-Neoplasms	13.4	41	-Acute respiratory infections	13.6	35
	-Acute Febrile Illness	8.9	27	-Neoplasms	11.6	30
	-Undetermined	8.9	27	-Acute Febrile Illness	11.2	29

Table 1: Top five causes of death in Hai: July 2004 to June 2005

Source: National Sentinel Surveillance System Report for Hai District (Hai District CHMT 2006).

The epidemiological transition model (Omran 1971) proposes that over time, CVDs will become a public health problem in developing countries, overtaking infectious diseases. This model demonstrated that with industrialization, the major causes of death and disability in the developed countries have shifted from the prominence of nutritional

deficiencies and infectious diseases to those classified as degenerative such as CVD, cancer and diabetes. To date five stages have been identified in the epidemiological transition process as illustrated in figure 1.

STAGE 1
Age of pestilence and famine [rheumatic heart disease, infections, and nutritional cardiomypathies] e.g. SSA, rural India, South America

↓

STAGE 2
Age of recent pandemics [as in stage 1 plus hypertensive heart disease and hemorrhagic stroke] e.g. China

↓

STAGE 3
Age of degenerative and man made diseases [all forms of stroke, ischemic heart disease at young ages, increasing obesity and diabetes] e.g. urban India, former socialist countries

↓

STAGE 4
Age of delayed degenerative diseases [stroke and ischemic disease at old age] e.g. Western Europe, North America, Australia and New Zealand

↓

STAGE 5
Age of health regression and social upheaval [re-emergence of death from rheumatic heart disease, infections, increased alcoholism, violence and increasing ischemic heart disease in the young] e.g. Russia

Figure 1: Stages in the epidemiologic transition

Stages 1-3 were identified by Omran (1971), stage 4 by Verbrugge (1984) and stage 5 by Yusuf et al (2001). Despite the threat from an upsurge of CVD and modeling predictions, there has been little public health response in the developing countries (Reddy and Yusuf 1998).

1.3.3 Factors associated with the rise of CVD in developing countries

There are several factors associated with the rise of CVD and have been matters of concern in developing countries. Reddy and Yusuf (1998) summarize them as follows:

a) Early age of CVD deaths in developing countries: it has been observed that deaths from CVD occur at an early age in the developing world compared to the developed world. For example the proportion of CVD deaths below the age of 70 deaths was 26.5% in the developed world compared to 46.7% in the developing world (Murray and Lopez 1994). This may be due to lack of proper diagnosis and appropriate treatment.

b) Lifestyle changes: lifestyle changes accompanying industrialization and urbanization in the developing countries could contribute to the rise of CVD. For example, lifestyle changes leading to less physical activity could lead to increase in body weight and blood pressure which are risk factors for CVD. Lifestyle changes and pressures of urbanization could also lead to increased stress levels.

c) Nutrition transition: a review by Drewnowski and Popin (1997) showed that the global availability of cheap vegetable oils and fats has resulted in the increase of fat consumption in low income countries. For example, in China, the proportion of upper-income persons who were consuming a relatively high fat diet (>30% of daily energy intake) increased from 22.8% to 66.6% between 1989 and 1993.

d) Potential effect of impaired fetal nutrition: there has been an association between birth size and CVD in later life (Barker 1995). If proven to have a causal link, the 'fetal origin hypothesis' could mean that CVD will become more common in the developing world where poor maternal nutrition continues to be a major public health problem. It is

postulated that poor maternal nutrition leads to impaired fetal growth, resulting in low birth weight, short birth length and small head circumference. These influences 'program' the fetus to develop adaptive metabolic and physiological responses that facilitate survival but may later lead to increased glucose intolerance, hypertension and dsylipidemia in adult life (Barker 1995).

e) Tobacco trends: there is a rising tobacco consumption pattern in many developing countries. Cigarette producing companies are expanding and marketing aggressively in developing countries especially after the enactment of tougher anti-smoking and advertising laws in Western Europe. For example, in SSA smoking is higher among the urban, less educated and lower socio-economic status workers (Bovet et al. 2002, Pampel 2008). In Tanzania, the Tanzania cigarette company (TCC) is often publicly praised by government officials as a success privatization story for increased productivity and efficiency without critically reflecting of what this means with regards to public health.

Other studies have reported additional factors associated with the rise of CVD in developing countries as summarized below:

f) Socio-economic status: in western societies, CVD has been shown to be patterned by socio-economic position (Kaplan and Keil 1993). It is documented that people in the lowest socioeconomic strata, whether defined by income, education, or occupation are consistently at a greater risk of CVD (Kaplan and Keil 1993, Veazie et al. 2005). Socioeconomic status is also a factor in determining CVD survival (Tonne et al. 2005). Since the majority of poor people in the world live in the developing countries, the fact that low socio-economic status is related to higher CVD prevalence could spell a looming epidemic in waiting in such countries.

g) HIV/AIDS and stroke: HIV/AIDS is a major epidemic in SSA. Several hospital-based studies in SSA have reported on HIV positive individuals who also get strokes although no association between the two has been established (Mochan, Modi, and Modi 2003, Patel et al. 2005, Tipping et al. 2007). These studies had various design constraints

including a small sample size. There has been calls for community based, well designed case control studies to clarify the impact of HIV and its therapy on the nature and management of stroke (Connor 2007).

On the other hand, there have been conflicting reports on the association of HIV/AIDS therapy and stroke. For example, the introduction of protease inhibitors and nucleoside reverse-transcriptase inhibitors for the management of HIV infection has been associated with an increased risk of CVD (Grinspoon and Carr 2005, Stein 2005). Some studies have found that HIV infected adults receiving Highly Active Anti Retroviral Treatment (HAART) are at an increased risk of CVD due to metabolic complications such as dyslipidemia, insulin resistance and altered fat distribution (Friis-Moller et al. 2003). However other studies have refuted this observation (Bozzette et al. 2003). If the association between HAART and CVD is clearly established, this will be unfortunate news for SSA, where the highest proportion of HIV infection worldwide is found. Currently many countries in the region are rolling out nation wide anti-retroviral treatment (ART) programmes. In a few years time, we are bound to see many HIV positive people in SSA move to HAART as a result of drug resistance or treatment failure. If the causal link between HAART and CVD is established this could imply a potential upsurge of CVD in SSA.

1.3.4 Social representations of stroke

To my knowledge, there are only three published social studies on stroke in SSA that have reported that lay people often emphasize the social aspects of stroke. For example residents of a rural part of Limpompo province in South Africa make a distinction between stroke as a natural condition *xistroku* (a Shangaam term derived from the English medical term stroke) and stroke as a social condition *xifulana* (Hundt, Stuttaford, and Ngoma 2004). *Xistroku* is believed to be treatable in hospital while *xifulana* is believed to be caused by human agency and best treated by traditional healers. *Xifulana* is said to be caused by jealousy, hatred and poverty and transmitted by the victim stepping over a witchcraft 'trap' intended to harm them.

Another stroke study conducted among the South African Indian Muslim society reported that in addition to the medical perspective, stroke was largely framed as an illness resulting from the will of God (Bham and Ross 2005). Healers in this study said stroke results from the imbalance between hot and cold in the body. Other social causes of stroke mentioned in this study were curses from other people and evil spirits known as *jinn*.

My initial study also showed that lay people in Hai and Dar-es-Salaam defined stroke differently (Mshana et al. 2008). The Swahili word for stroke is *kiharusi*. This specific noun has no other meaning in Swahili. It was the main term for stroke in Dar-es-Salaam, though in Hai, stroke is more commonly referred in Swahili as *paralaizi* (derived from English paralysis) or *presha* (derived from English pressure), due to people associating stroke with partial body paralysis and hypertension. As already pointed out in an earlier section, in Dar-es-Salaam stroke is widely believed to be a social condition emanating from supernatural causes (demons and witchcraft), while in Hai, it is mostly defined as a natural condition caused by hypertension, fatty foods and stress. I will discuss the social construction of stroke in more detail when I present and discuss my findings in later chapters.

1.4 Outline of the thesis

I have contexualised my study of stroke by showing the importance of conducting such studies owing to the threatening trend of CVD in developing countries. I have briefly discussed factors which are attributed to the current raising and predicted further rise of CVD in the future in developing countries. I have presented how stroke is both a medical and social condition and stated that my study primarily investigated the social aspects of the illness.

In chapter two, I review literature on stroke studies by first providing an overview of social studies of stroke worldwide. I also demonstrate how there is paucity of published

stroke studies in the developing countries. Thereafter, I review epidemiologic and social studies of stroke in sub-Sahara Africa. I then situate my own study by providing an overview of social studies of illness conducted in Tanzania and present four selected studies to highlight relevant issues to my study. In the same chapter, I review three models developed to study treatment-seeking behaviours and in the course outlining their strengths and weaknesses. The three models are: the sociobehavioural model; Kroeger's health choice model; and Young and Garro's treatment-seeking model.Thereafter I discuss main anthropological theories of illness and state how my theoretical framework fits within the broader body of theories. I then briefly outline my own theoretical framework which I elaborately present in the following chapter.

In chapter three I start by discussing in detail how my theoretical framework evolved through the grounded theory approach. I then situate my theoretical framework through engaging in a general discussion of concepts of power and ideology which are closely linked to my framework. I then present my theoretical framework I developed using concepts by Foucault and Bourdieu as 'tool boxes'. I explain in detail how I have developed my framework using Foucault's concepts of discourse and power/knowledge and Bourdieu's concepts of habitus, strategy and strategizing and symbolic power. In setting out my theoretical framework, I give examples of how it relates to findings from my study.

In chapter four I describe my two study sites i.e. Hai and Temeke districts. I provide the socio-demographics of the populations including the geographical, historical, economic and health services background of the two areas. After that, I discuss my five qualitative data collection methods which are: ethnographic fieldwork, in-depth interviews, key informant interviews, key studies and focus group discussions. Additionally I discuss the practical and theoretical approaches to my analysis of the data. Lastly, I discuss how I dealt with ethical issues prior to and while carrying out my study.

I devote chapter five to presenting findings on the way stroke is constructed and its various discourses in my two research sites. I illustrate how the various social and power

relations processes and practices relate to the discourses. In the same chapter, I present the experiences of stroke sufferers and their careers and how these experiences shape their discourses and representations of stroke.

In chapter six I describe and analyse the general treatment-seeking patterns and decision-making processes for stroke. I also present and analyse findings on the biomedical treatment of stroke in the two research sites and the way they relate to the different discourses. Along the same lines, in chapter seven I present findings on traditional and faith based remedies for stroke in the two research sites.

In chapter eight, I explore and present potential community-based stroke interventions derived from my findings and analysis. The proposed interventions derive from my overview of stroke interventions in other parts of the world and my findings. I propose appropriate and feasible interventions which could be implemented in the two research sites or any other areas with similar settings. In chapter nine I conclude my thesis by summarizing my main findings and arguments and make appropriate policy recommendations.

1.5 Conclusions

In this chapter I have provided an introduction to my study by tracing its origin through the experiences of carrying out the TSIP and my initial study. I have discussed the various issues which I carefully considered when designing my study. In this chapter I have clearly stated my study aims and research questions which guided my data collection. I have also engaged the research problem my study addresses through generally discussing the threat of CVD in developing countries including Tanzania. In addition, I offered the two perspectives of stroke both as a medical and social condition and emphasized that my study primarily investigated the social aspects of the illness.

I now turn to review selected and relevant literature related to the study of stroke. I provide an overview of epidemiologic and social studies of stroke worldwide and in sub-Sahara Africa. I then situate my study in the Tanzanian context by providing an overview of social studies of illness conducted in Tanzania. I review three models developed to study treatment-seeking behaviours, engage the main anthropological theories of illness and state how my theoretical framework is situated within the broader body of theory.

2 Chapter Two: Literature Review

2.1 Introduction

This chapter aims to provide a review of the literature related to my study. In the first section I review literature on the study of stroke. I begin by providing an overview of social studies on stroke conducted in different parts of the world. I report the major themes covered and highlight some of the findings. I then provide a general overview of stroke studies in developing countries. Thereafter, I narrow and focus my review to stroke studies conducted in sub-Sahara Africa. I cover what has been done through epidemiologic and social studies.

In the second section of the chapter, I present the main themes covered by illness studies conducted in Tanzania. I then present and comment on four selected anthropological studies in Tanzania. Since I did not find any published social studies from stroke in Tanzania,[2] I have selected the four studies for several reasons. Two studies were conducted in Dar-es-Salaam which was one on my research sites. One of them covered the problem of high blood pressure which is one of the major risk factors for stroke. The second study covers cultural beliefs related to childhood malaria in Temeke district (the same district where I conducted my study). Since I did not find any relevant published anthropological studies conducted in Hai, I picked the two other studies conducted in rural Tanzanian areas which share similar characteristics with Hai. As in Hai, these areas are predominantly Christian with a long history of operation of missionary hospitals. Among them, one was conducted in Arusha region which borders Hai district to the North.

In the third section I review three treatment-seeking models which have often been utilized in studying treatment-seeking behaviours in different parts of the world. The models are: the sociobehavioural model; Kroeger's health choice model; and Young and

[2] I am aware of only one published study, that being my own initial work (Mshana et al 2008).

Garro's treatment-seeking model. I highlight the usefulness and limitations of the models. In section four, I provide a brief overview of the key lessons and features of successful health interventions drawn from different parts of the world. The section provides a background to chapter eight which proposes community based stroke interventions grounded in my findings.

In section five, I review five major anthropological theory approaches in the study of health and illness. I provide an overview of the initial approach of 'civilized' as contrasted to the 'primitive' medical systems, ethnomedicine, ecological, cultural interpretative and critical medical anthropology theoretical approaches. In section six, I briefly outline my theoretical approach which makes use of a critical perspective to analyse stroke discourses using concepts from Foucault and Bourdieu. Finally, I conclude the chapter by summarizing the main points covered and introduce the next chapter.

2.2 The Study of stroke

2.2.1 Social studies on stroke worldwide

Social studies on stroke in other parts of the world have explored a range of issues related to the physical, social, biomedical aspects of stroke. Studies have also been conducted on the provision of services to sufferers in hospitals and home settings. An anthropological study on the experiences for stroke sufferers in the United States found that the illness had transformed the sufferer's worldview in many different ways (Kaufman 1988). In this study, stroke sufferers reported that the illness had transformed their body image. This was after realizing how the physical limitations caused by the illness made them dependent on other people's help with simple things they had taken for granted, such as moving their limbs. In addition their suffering experience had made them realise the limitations of biomedical treatment e.g. physiotherapy, despite having hopes for full recovery initially. A study in Sweden (Bendz 2000) reported that for stroke sufferers, the main impact of the illness was the disruption of their physical bodily function such as decreased strength. Sufferers in this study also talked of decreased cognitive abilities such as loss of memory and concentration.

Other studies have focused on communication between stroke sufferers and the care providers. For example Miller et al (1999) found that among Asian communities in the UK, stroke sufferers found it easier to talk about their illness to their spouses rather than nurses and doctors. Other work has highlighted the rehabilitation benefits of better communication between health providers, stroke sufferers and their relatives (Anderson and Marlett 2004). Another body of literature has reported on community members' understanding of stroke risk factors. For example, a quantitative study in the USA (Reeves, Hogan, and Raffertu 2002) and a qualitative study in Australia (Yoon and Byles 2002) found that respondents commonly mentioned stress, diet, high blood pressure, age, physical inactivity and smoking as the risk factors for stroke.

In a comprehensive review of qualitative studies of stroke worldwide McKevitt et al (2004) highlighted major areas covered. They found that qualitative studies have explored issues of care and rehabilitation therapies and ways of improving them. For example, several studies have solicited views on the provision of services by multidisciplinary stroke units (comprising doctors, specialist nurses, physiotherapists, speech therapists and members of other relevant professions) with the aim of determining the usefulness of the different components of the units. Other studies have explored the experience and information needs of stroke sufferers and their carers such as interpretation of stroke symptoms. Both sufferers and carers reported a range of effects to their lives such as lifestyle changes, emotional and social loss. Loss of productivity was commonly reported by young sufferers. Coping mechanisms for sufferers include working through their tasks slowly and spiritual practices such as prayer. Sufferers expressed feelings of uncertainty of recovery. The review found that other studies have focused on exploring best ways of providing rehabilitation services such as physiotherapy. Qualitative studies also explored the issue of communication between professionals and sufferers and ways of improving community services.

2.2.2 Stroke studies in developing countries

There is a severe lack of good quality stroke epidemiological data from the developing

countries due to scarcity of population based stroke incidence studies (Feigin 2005). A recent population based incidence study in Chile showed that stroke outcomes and incidence in the mainly Hispanic-Mestizo population were similar to other populations in the developed countries, though the proportion of intracerebral haemorrhage was slightly higher (Lavados et al. 2005). Despite the paucity of incidence studies, it is estimated that two thirds of stroke deaths world-wide occur in the developing countries (World Health Organisation 2005).

2.2.3 Stroke studies in sub-Sahara Africa

There is a paucity of data on stroke in sub-Saharan Africa (SSA). There has been no published population based incidence study on stroke in SSA. I am aware of only one completed population based stroke incidence study in SSA, the TSIP. Likewise, there are few community based stroke prevalence studies in SSA. Danesi, Okubadejo and Ojini (2007) conducted a door to door stroke study in an area with a population of 750,000 in urban Lagos, Nigeria. They found the crude prevalence rate of 1.14 per 1,000. They hypothesized that lower prevalence rates could be due to lower incidence or higher mortality in developing countries. The SASPI team (2004) found that in South Africa, the stroke prevalence rate from 734 individuals visited and 103 identified cases (adjusted for non-response) was 290 per 100,000 (population of 60,000). Walker et al (2000a) found that the prevalence rate for rural Hai district in Tanzania was 73 per 100,000 (population of 148,135).

Most studies on stroke in SSA are hospital based. For example, Garbusinski et al (2005) conducted a hospital based study in the Gambia. It followed up 148 stroke patients admitted at the hospital aged above 15 years. Most of the patients (93%) were Muslims. The patients were followed up at home for up to 1 year after discharge. The study found that hypertension and smoking were the most prevalent risk factors. It also found that stroke affected the social function of survivors such as income generating activities, reduced their ability to attend social gatherings, pray at Mosques and church and going to the market. The return to normal social life among survivals was rare.

Fatoye et al (2006) conducted a cross-sectional study to examine emotional symptoms and quality of life among primary caregivers of stroke patients at a Nigerian hospital. They found that care giving imposed a high emotional burden on the carers. Care givers also showed symptoms for anxiety and depression. The same group (Fatoye et al. 2007) conducted a study investigating cognitive impairment and quality of life among 109 stroke survivors and the same number of controls. Unsurprisingly, more stroke survivals than controls reported cognitive deficits and lower quality of life. Karaye et al (2007) conducted a hospital based study to examine cardiovascular risk factors in Nigeria. They found that cardiovascular risk factors of hypertension and dyslipidaemia were most common among stroke patients.

Local beliefs and understandings surrounding stroke in sub-Saharan Africa are equally poorly understood as a result of few published studies. Ayanniyi et al (2006) conducted a cross-sectional descriptive study to investigate knowledge and perception of stroke among adults in Osogbo, Nigeria. They selected 900 study participants aged between 18-80 years through multi stage sampling. More than half (54%) of study participants said the heart was affected during a stroke. The majority (83%) knew that stroke is preventable. Stroke survivals were perceived less likely to return to the pre-stroke quality of social life. Participants mentioned hypertension, stress and old age as common risk factors.

Hundt et al (2004) investigated lay conceptualizations of stroke-like symptoms and impact on health seeking behaviour, as part of a prevalence study in a rural population of South Africa. They reported that stroke-like symptoms were considered both a physical and social condition. Plural healing using clinical and social means (visiting doctors, healers, prophets and churches) were common. As this was a cross-sectional study, information on treatment-seeking at the time of stroke affliction relied on recall from some years previously, and the sample might have under-represented those with severe strokes who did not survive in the longer term. Bham and Ross (2005) appraised cultural beliefs and practices of South African Indian Muslims, concluding that faith and religion featured strongly with regards to stroke aetiology. In this second study, both traditional

and western medicines were used for treating stroke, though western healthcare treatment was regarded as culturally inappropriate. Only caregivers and traditional healers were interviewed in this study and not stroke patients themselves.

There is therefore lack of community-based epidemiologic and social stroke studies in Africa. For any success of stroke interventions in SSA, the social aspects of the illness need to be investigated further in order to facilitate the design of appropriate and context relevant interventions.

2.3 Building on previous studies of illness in Tanzania

In Tanzania, studies report that access to health care is influenced by a variety of factors. For example, research has shown that health seeking in the country is influenced by cultural knowledge and interpretation of illness symptoms (Comoro et al. 2003, Kamat 2006, Plummer et al. 2006). In this context supernatural illness causation beliefs are common, often, for example, citing jealousy motivated witchcraft (Plummer et al. 2006). Other factors determining health seeking in the country are structural and gender constraints (Green 2000, Kamat 2006) trust in providers (Tibandebage and Mackintosh 2005) and economic aspects especially the ability to pay user fees in public facilities (Mubyazi et al. 2006, Muela, Mushi, and Ribera 2000).

In this section, I explore selected ethnographic research studies on the perceptions of illness and treatment-seeking carried out in Tanzania. I have selected four papers to focus on and highlight the common patterns in the way ethnographic studies of illness have been conducted. In addition, I present some findings from the studies. All four are anthropological studies examining illness discourses of interest to my study.

The studies report on various factors which influence illness discourses in Tanzania. They highlight issues such as cultural framing of illness, including typology and healing paradigms; beliefs about causation and appropriate treatment; the role of religious and

witchcraft beliefs; economic issues such as costs; multiplicity of healing options-plural healing serially or simultaneously; historical factors such as the provisions of health services by missionary hospital; the changing nature of health institutions; the interplay of biomedical and local illness discourses; and gender issues in access to health.

Two studies were conducted in Temeke and Ilala district in Dar-es-Salaam. Temeke is one of my research sites therefore the two studies provide a good background to my research in that area. And as already stated, since I did not find any published relevant anthropological illness studies conducted in Hai district, I selected the other two conducted in rural predominantly Christian areas of Tanzania. And as already pointed out, similar to Hai, the two areas (Mbulu and Ulanga) have a long history of Christian missionary health service provision.

a) Study on Cultural Interpretations of an Emerging Health Problem of Blood Pressure in Dar-es-Salaam, Tanzania (Strahl 2003)

This study was conducted in Ilala district in Tanzania. The fieldwork was carried out between May 2000 and April 2001. It employed an interpretive approach in examining how people experienced and interpreted high blood pressure (BP). In particular, it examined illness as a representation or embodiment of social suffering. The author reports that among the Swahili of Dar-es-Salaam, traditional concepts of illness coexist with biomedical practice. Therefore local understanding of illness is embedded in medical pluralism and must therefore be studied from its context. The majority of people in the study area are Muslims.

In this study, a rapid ethnographic pre-study was conducted at the beginning to assess locally meaningful illness conceptions and behaviour. Thereafter focus group discussions (FGDs) were conducted with members of the community to assess knowledge of BP and from the FGDs participants and eleven members were selected for follow up interviews. The FGDs and interviews were used to devise semi-structured interview guides for subsequent interviews. The interview schedule contained open and closed questions on patterns of distress, perceive causes and treatment-seeking behaviour of BP.

30 interviews were conducted with hypertensive people obtained through a local clinic established in 1996 offering free service and drugs to people diagnosed as hypertensive. In addition, 30 interviews were conducted with non hypertensive people in Ilala.

The study found that BP was well known and discussed in Ilala. The local concepts of BP incorporated some biomedical aspects such as that it is chronic and incurable and could cause stroke and death. The illness was closely related to the heart e.g. too much or too little blood circulating in the body. The Swahili words *moyo* (heart) and *roho* (spirit) were commonly used in the discourse of its effect. Thoughts (*mawazo*) were commonly cited as a cause of BP due to stress of the changing nature of life in Dar-es-Salaam. The local discourse also incorporated mass media health messages such as the reducing risk factors through weight loss, low fat, oil and salt intake. The study reported that in Ilala, BP is generally viewed as a health problem best treated by biomedicine through drugs and regular check up. There were plenty of stories circulating in the study area about people who fell suddenly, became paralysed and/or died unexpectedly without any preceding signs of illness. This is very similar to the way stroke was described by my study participants and I have reason to believe that some of those stories were narrations about stroke episodes. It is interesting that despite all these puzzling accounts, the biomedical paradigm was almost always elicited to explain BP. But one has to note that this study mainly obtained its participants from a network starting at a clinic offering hypertension treatment services. It is likely that the BP sufferers and their controls had already a favourable view of biomedical services through this exposure. Another weakness of the study is that it did not interviews traditional and faith healers to explore other BP discourses which could be operational in Ilala.

b) Study on the Cultural Knowledge and Micropolitics of Therapy Seeking for Childhood Febrile Illness in Temeke, Dar-es-Salaam (Kamat 2006)

This study was conducted in a Temeke village of Mdafu. It explored the complexities of treatment-seeking for childhood malaria. Fieldwork was conducted between May 2000 and September 2001. The village has 5,500 residents. 95% are Muslims and 40% Zaramo. In the village, there are three privately owned pharmacies offering a range of

over the counter medication. Four traditional healers reside and practice in village. Of the four healers, only one practices full time. There are also nine traditional birth attendants though they are rarely consulted. Health care is, in this case, pluralistic, involving Swahili medicine, biomedicine and pharmaceuticals.

The study draws from qualitative methods conducted within a wider ethnographic inquiry. Participant observation was conducted at the local public clinic. During observation, informal conversations with more than 150 mothers and caretakers were carried out. Additionally, ethnographic interviews with 45 mothers who had come to clinic with child under 5 were conducted. Ethnographic interviews comprised of life histories and illness narratives.

The author argues that in Temeke the issue of user fees is not the primary reason why mothers delay seeking treatment for childhood malaria at the public health facility. User fees were collected at the public health facility though children were rarely refused treatment if their parents or guardians were unable to pay. Contrary to emphasis in literature on the role of user fees in determining health seeking, this study demonstrates that cultural meanings of the illness, structural disadvantages affecting women's access to resources, contingent circumstances and poor communication between health care providers and caregivers at the government health were more influential.

On average, the delay in bringing children to the clinic was between 48 hours and a week. From the interviews, mothers said that the main reason for the delay was that they thought it was an ordinary fever (*homa ya kawaida*). In local illness framing, *homa ya kawaida* is not treated unless it develops into high fever (*homa kali*) or *degedege*. *Degedege* is commonly believed to be caused by a coastal spirit that takes the form of a bird. The bird is believed to cast its shadow on vulnerable children at night resulting to the child developing convulsions or dying. This belief about *degedege* is common in coastal Tanzania and has been reported by other studies (e.g.Comoro et al. 2003). Kamat found that most mothers gained knowledge of *degedege* through second hand hear say.

In Mdafu village, if symptoms of fever are perceived as severe, the child is taken to hospital. Home and hospital treatment was pursued either serially or simultaneously. At the clinic, doctors and nurses did not clearly communicate the diagnosis was given to mothers or caregivers by doctors or nurses. For example, instead of being told that their child had malaria, they were told they had *homa* or *homa kali.* When seeking treatment for their children, women dealt with logistical and economic problems such as lack of ability to pay for proper and complete treatment due to poverty and failure to get care of the other siblings while away from home.

An apparent weakness of the study is that it was mainly carried out in a single health facility in one village. In addition, interviewed mothers were selected from the clinic and not the wider community. Furthermore, the use of traditional medicine treatment was not explored as a possible delay for hospital treatment.

c) Cross-Cultural Healing in East African Ethnography (Rekdal 1999)

This paper highlights cross-cultural therapy amongst the Iraqw people of northern Tanzania. The research was carried out in southern Mbulu area in Arusha region, just north of Kilimanjaro. Fieldwork was conducted between several time periods from September 1989 to May 1990, October 1993 to October 1994, and June to August 1995. Mbulu is predominantly Christian with a long history of Missionary hospitals operated by the Roman Catholic and Lutheran churches.

The study reports that a prominent feature of health-seeking behaviour among the Iraqw of northern Tanzania is a tendency to seek out healers from other ethnic groups. Traditional healers of the Iraqw are not members of the ethnic group nor are they 'traditional'. Most of them come from other ethnic groups such as the Sukuma, Ihanzu, coastal Swahili and Somalis. Most could not even speak Iraqw. The author says this is contrary to the way the African traditional healer is often presented in literature as people who share the locality, social network and cultures of the people they treat.

The main reason for this trend is the underlying perception that the origin of the most powerful medicine is located outside Iraqw culture. Common were stories of how particularly important Iraqw clans were founded by powerful healers coming from neighbouring ethnic groups. This was also framed in the belief expressed through Iraqw sayings such as 'it is your neighbour who will kill you'. Distant healers were often seen as neutral of local social conflict since most healers mainly employ divination in telling the cause of an illness. The ambiguity of the cultural distance and the power of the unknown stranger seemed to reinforce the preference for foreign healers. The author argues that though many ethnographies of health seeking behaviours in east Africa report findings of similar nature, they do not prioritize it in their description and analysis of the nature of local treatment.

The author further argues that there are three reasons for the neglect. First is due to historical factors related to the pre colonial and colonial European image of Africa being comprised of 'separate' tribes with limited contact with each other mainly through conflict and warfare. He says this was done for the purpose of enabling effective colonisation either through the policy of divide and rule or with the aim of establishing administrative structure on societies which were not organised around chiefdoms. The second reason is due to the dominance of the structural functionalist tradition in early anthropological studies in Africa. These studies were concerned with studying the internal structure of the ethnic groups. Traditional healing was studied as part of the study community's culture and therefore cross-cultural therapeutic practices were considered irrelevant in analysis. Thirdly is that recent anthropological studies have tended to overlook cross-cultural therapeutic feature in an effort to re-construct and image of the 'witch doctor' and utilise the African traditional healer in their critic of western society and biomedicine.

Although this study offers a good insight into traditional medicine in an African setting, it does so in a general way. It would have been much stronger and more comprehensive if the author had selected a few illnesses as case studies and studied more closely traditional treatments offered by the different kinds of healers.

d) Study on the Institutional Determinants of Health Seeking Behaviour in Southern Tanzania (Green 2000)

The paper is based on doctoral fieldwork carried out in Ulanga district, Morogoro between 1989 and 1991. Further research data was gathered during a month long informal visit in 1995. A further six weeks of fieldwork was conducted in 1996. During this period, focus group discussions (FGDs) were conducted with health service users together with formal interviews with health staff and officials in villages in the district. In total 300 individuals participated in either the FGDs or interviews. In addition, repeat interviews were done with selected case studies. Additional data was gathered in 1999 when the author was involved as an advisor in a joint donor appraisal of the government's programme of work. Key informant interviews were also carried out.

The author conducted an anthropological analysis of healing strategies employed by rural men and women when ill. The majority of people in Ulanga are Catholic Christians and are engaged in maize and rice farming. There is one district hospital and one large mission hospital which is far from the district centre. There is also a network of village based government and mission clinics. Generally public health facilities are in poor condition, understaffed and in short supply of drugs. Private health facilities are perceived as better. Distance and cost were sometimes barriers to people seeking treatment.

The study found that local therapies and biomedicine were viewed as complementary strategies aimed at dealing with different aspects of disease causation. The author argued that people in rural areas were not abandoning their faith in 'modern' medicine but sought alternative access to hospital medicines through an expanding sector of private practitioners. They also sought complementary services from local healers and voluntary organisations.

In this study it was reported that people waited for a few days to see if their health improved before purchasing drugs over the counter. If the condition did not improve they

visited a local dispensary for injection and if still unwell visited a hospital for specific diagnosis. In the study area, people differentiated between the cause of disease and its physical manifestations. For example if a sickness was perceived as originating from outside a victim's body in their social relationship with other people or spirits they were usually treated by local healers. The physical symptoms of sickness were treated with 'modern' medicine. The first type of treatment sought varied from sufferer to sufferer and case to case. Mixed treatment of local and modern medicine was used in cases whereby the illness was long term or not responding to treatment. Switching of healers and biomedical practitioners was common until recovery, or inability to sustain costs cut it short. Seeking treatment could also stop after despair to the incurability of the illness.

The study reported that mental illnesses and cancer were considered as incurable by specialists in both local and 'modern' sectors. Usually, treatment of these was sought to relieve suffering. Women's infertility was strongly associated with witchcraft and attacks by spirits making it largely in the domain of local healers. The power of local medicines depends on the abilities of the person empowered to create them and the materials from which they are prepared.

The study reported the presence of many local healers distributed in villages across the district. The healers maintained social relations with their clients through living with them in their residences and eating together. There are three categories of healers in Ulanga. First are 'spirit mediums' whose power to heal and make medicines comes from external sources in form of spirits. They relay on divination for diagnosis. Their treatment involves oral and topical medicines made from wild plants and trees. The second group of healers are those practicing Islamic medicine. They derive their knowledge and healing power from God through the Koran. They are a minority group of local healers in mainly Catholic Ulanga. The third group are herbalists. Their knowledge is based on learning and practise and their treatment usually addresses symptoms and causes.

In Ulanga, all forms of treatment entail some form of payment. While the biomedical services take cash payments, local healers take other forms of payment such as chicken.

The author argues that cost alone was not the criteria for selecting a health facility. Perceived quality of service and the social context of its delivery were equally important. Individual adults usually made treatment decisions themselves. Social and labour obligations caused delay for women to seek treatment.

This was a stronger study than the previous three as it combined a variety of methods collected over a period of time. Additionally it managed to interview the same respondents in different occasions therefore avoiding the weakness of deriving findings from one-off interviews. However like the previous study, it studied treatment-seeking of a variety of illnesses in a very general sense. Its holistic approach may mean that it could not study in detail factors determining treatment-seeking for the specific illnesses as these may be different. In addition, later fieldwork data were collected when the author was employed as a donor advisor to a group of donor supporting health care in the area. In a way, this role could have influenced his approach and interpretation of data.

Relevance and lessons from the four studies

The four studies demonstrated that plural healing is a common feature of health seeking in urban and rural Tanzania. They also reported that the way an illness is framed locally often determined the nature of treatment sought. For example the study on childhood malaria in Dar-es-Salaam showed that the local framing of childhood malaria determined whether hospital treatment was sought early or delayed. The ability to pay for health services was not the only factor considered when people made healthcare decisions. Local discourses (for example the 'supernatural' causation theories), individual and structural constraints, the state of health services and the nature of the communication between service providers and seekers were sometimes prioritised when determining the treatment course.

The studies also demonstrated the readiness of local illness discourses to adapt from either public health messages or healing practices and paradigms from 'outside' the communities. For example, the local notion of BP in Dar incorporated notions adopted from health messages delivered through the mass media such as radio and television.

Additionally, the cross-cultural nature of traditional healing in Mbulu where the Iraqw embraced healers from other communities further demonstrated the adaptive nature of local illness discourses. Redkal's problematisation of the definition and composition of traditional healing is very useful. He highlighted the cross culture nature of healing practices which is sometimes underplayed in many studies conducted in Africa.

The two studies conducted in Dar-es-Salaam did not explore traditional treatments and this could have lead to the omission of an important viewpoint having acknowledged the pluralistic nature of treatment-seeking in the study areas. Conducting longer ethnographic fieldwork facilitating the opportunity to conduct repeated interviews with the same respondents to clarify and get more information adds to the validity and strengths of findings. The extra depth of findings and analysis by Redkal and Green demonstrate the benefit of such long term ethnographic fieldwork.

2.4 Models for studying treatment-seeking behaviours

Over the years a variety of models have been developed to study treatment-seeking behaviours. These models were developed to help predict or account for healthcare seeking in different communities. The formation and analytical approach of most of these models employed quantitative variables and methodology largely ignoring qualitative methods. The quantitative nature of the models (mostly developed and spearheaded by medical sociologists) has often prioritised demographic and socio-economic determinants of healthcare choice. While having the strength of dealing with large population samples and therefore having a wider scope of generalization of findings, they often lack the depth and richness obtained through qualitative studies. Studies employing qualitative methods have often produced rich information detailing the health seeking choices taken by individuals or groups of people and the underlying factors. Qualitative studies of treatment-seeking behaviours (spearheaded by social anthropologists) have sought to understand the contextual, social and cultural meanings related to illness and suffering and have found these to be primary in explaining remedy seeking endeavours. In the

following section I briefly review three commonly utilised models for studying treatment-seeking behaviours weighing their strengths and weaknesses.

2.4.1 The Sociobehavioural Model (SBM)

The SBM was developed to predict use of treatment resources with a representative sample of households. The model provides a framework that unifies a variety of models (Cummings, Becker, and Maile 1980) and describes health care use as a function of 'predisposing', 'enabling', and 'need' factors. Predisposing factors are demographic and attitudinal factors that exist prior to the onset of illness that may influence health care use. Enabling factors are factors that facilitate access to health care such as the availability of services or financial resources to purchase services. Need factors reflect people's perceived need for services and the severity of the illness episode, as measured by indices such as the number of symptoms or the number of disability days. Studies employing the SBM usually use large representative samples or national data and the results aim to provide policy makers with general patterns of healthcare use and access (Weller, Ruebush, and Klein 1997). Though widely used, the SBM has its limitations. Firstly, its utility for predicting a wider variety of health care choices is unclear. It is pointed out that studies using the SBM rarely include information on alternative sources of treatment and self treatment (Weller, Ruebush, and Klein 1997). This omission compromises the generalisability of findings and is unable to account for healthcare choices within the broader context (Weller, Ruebush, and Klein 1997). Secondly the SBM does not describe adequately the treatment-seeking processes (Mechanic 1979).

2.4.2 Kroeger's health choice model

Kroeger (1983) summarised research which used quantitative approaches in studying choice of healthcare. He organised the variables from these studies into three categories: characteristics of the subject (predisposing factors), characteristics of the disorder and their perception and characteristics of the services (enabling factors). Stoner (1985:42) elaborates Kroeger's variable categories by saying:

> **characteristics of the subject** refer to features of individual health seekers which correlate with the differential use of health care resources...**characteristics of the**

> **disorder and their perception** refer to person's beliefs regarding the nature or etiology of the illness for which help is sought...**characteristics of the service (enabling factors)** refer to those features of the health care delivery system that promote or discourage the use of various resources within the community.

Kroeger summarises the variables in the following table.

Characteristics of the subject	Characteristics of the disorder and their perception	Characteristics of the service (enabling factors)
-age -sex -socioeconomic level -occupation -ethnic group -marital status -household size -formal education -degree of cultural adaptation -assets (land, livestock, cash) -interaction with family, neighbours, community -innovators	-chronic/acute -severe/trivial -etiological model (natural, supernatural) -expected benefits of treatment (modern, traditional) -psychosomatic/somatic	-accessibility -appeal (opinions, attitudes toward traditional and modern healers) -acceptability, quality, communication -costs

Table 2: Explanatory variables of health care choice
Source: Kroger (1983:149)

Kroeger's categorisation of the variables has enabled a systematic approach to the collection and analysis of health seeking behaviours. It provides a simplified and useful way of approaching such studies. However, since these variables may mean different things to individuals or groups of individuals, they have potential of being misrepresented in course of data collection and analysis. In addition, some of the variables may not be totally separated from other in the way they are operationalised by people. For example, socioeconomic factors may be inextricably intertwined with other variables such as formal education and assets. Hence separating these into distinct variables may be problematic.

2.4.3 Young and Garro's treatment decision model

Young and Garro (1994), also see Young (1980) developed a treatment choice model based on their work in rural Tarascan village in Mexico. This model incorporated provisions for local meanings of illness. It presupposed that there is a 'link between

cultural knowledge (beliefs) and purposive action' (Young 1980:106). Young (1981:5) argued that a common culture provides community members with 'shared standards or rules for solving problems and selecting particular courses of action'. He outlined four factors which are considered for making treatment choices in Tarascan. These are gravity of the illness, knowledge of a home remedy, faith in the effectiveness of a remedy and accessibility (cost and transport). Young tested the model on 323 illness episodes and found that it accounted for 91% of the choices made. Though this model incorporated cultural interpretations of illnesses and actions, it does not provide for intracultural variation as this may be important in the way illness is framed within a particular community. In addition, it does not acknowledge that meaning is socially constructed and may have underlying interests of certain groups in society (Keesing 1987).

2.4.4 Limitations of treatment-seeking models and approach in this study

As an example of most health seeking models designed to cut across a wide range of populations, the three models demonstrate several weaknesses. Stoner (1985) points out that the definition of the variables used in such models is difficult. For example variables such as the household income may vary by season or year. Size of household may also be very difficult to determine given the differences of household definitions across cultures. Such variables are usually superficially defined and applied. He also argues that the quantitative analyses conducted usually derive causality through statistical calculations underplaying the role of individuals to make independent choices outside of statistical logic. In his words, such models 'infer causality from statistical correlation, and imply that determining factors are consciously assessed and considered in the process of health care decision-making' (Stoner 1985:44). In most cases individuals do not consciously evaluate all options before making healthcare decisions.

Following Comaroff (1983), Stoner (1985:44) adds that the isolation of factors in decision-making 'decontextualize a process that is intimately related to the natural and cultural environment of the illness'. And as already highlighted in the previous section, these models overlook the intracultural variation in how problems involving illness are framed and subsequent remedial courses.

In addition, such models have a problem of taking illness discourses at face value. The factors in models are taken at one point in time. There is no account of the social, cultural, historical and economic processes responsible for production of the factors. This study used qualitative methods to study treatment-seeking behaviour for stroke and therefore overcame the weaknesses of most models of testing pre-conceived categories of 'determinants' of treatment-seeking. In the present study, treatment-seeking behaviour for stroke was studied as embedded in the cultural, social, economic and political context in the study areas. An exploratory approach was employed seeking to understand treatment-seeking for stroke from both 'emic' and 'etic' views.

2.5 Requisites for successful health interventions

It is acknowledged that initiating and sustaining health behaviour change interventions with a health impact is difficult (Panter-Brick et al. 2006). Nevertheless, there are documented cases of successful health interventions which managed to achieve impact from different parts of the world. A recent review of health interventions from different part of the world demonstrates that health interventions can achieve sustainable and cost effective health impact (Levine 2004). The review presents seventeen selected cases of interventions such as the prevention of river blindness in sub-Saharan Africa, the control of trachoma in Morocco, almost elimination of measles in southern African countries and the reduction of infant deaths due to diarrhea in Egypt. The cases were selected using the following criteria: they had to be large scale with a nationwide coverage or larger; they had to have a major positive impact on health; the improvement had to be attributable to the health intervention; they had to produce sustainable impact for at least 5 years; and they had to be cost-effective.

Context sensitive interventions which address specific risky behaviours (such as risky sex) rather than aiming at a general behaviour (stop sex) have shown to have a higher chance of success in achieving a health impact. For example, in Levine's review, a

condom programme targeting commercial sex workers Thailand was able to reduce HIV incidence by 80% between 1991 and 2001 (averting 200,000 new cases) (Levine 2004). Therefore specific interventions targeting a particular group (sex workers) that are core to transmission of HIV in the early stages of an epidemic (when infection is still confined to core groups) prove to be successful. On the other hand, for mature and generalised epidemics (already spread to the general population) the approach should be different by developing community targeting interventions. In another example, a national campaign in Egypt increased the awareness and use of rehydration therapy thus reducing infant deaths from diarrhea by 82% between 1982 and 1989 (Gomaa et al. 1988, Levine 2004). The intervention in Egypt demonstrates that an intervention to increase community awareness of a health problem delivered through the right communication means (in this case television) and combined with practical solutions to supplies can achieve a health impact. In the Gambia, clear awareness of the need to combat malaria and mosquitoes led to success in behaviour change in a bed net repair intervention (Panter-Brick et al. 2006).

Therefore health messages composed in local languages and delivered through culturally relevant vehicles such as songs are likely to be embraced by the community and facilitate health behaviour change (Panter-Brick et al. 2006). Communication via wide reaching and entertaining mass media programme (using local languages) should therefore be used to deliver health messages in target communities. Interactive stroke awareness interventions whereby there is exchange of information between implementers and target groups have shown to be more successful than one way communication from implementers to target groups (Smith et al. 2008).

The seventeen cases of successful health interventions presented in Levine's review show that 6 factors are key to success. These are: political leadership and champions; technological innovation; expert consensus around the approach; effective use of information by management; strong management on the ground; and adequate and sustained funding. The same review provides six important lessons for health interventions:

i) Major health interventions can work even in the poorest of countries

ii) Governments can get the job done as the public sector was central to the delivery of services on a large scale

iii) Effective use of technology (such as a new drug) combined with effective management and affordability

iv) Partnership and collaboration between the different players around a common purpose is crucial

v) Health impact is attributable to specific efforts rather than broad economic and social improvements

vi) Successful programmes come in many shapes in terms of approaches.

The guidelines provided by the American Heart Association (AHA) outlines seven factors which influence health promotion in a population (Veazie et al. 2005). These are:

i) The presence of other interventions

ii) Quality of implementation

iii) Strength of community support and involvement

iv) Leadership and trust surrounding the initiative

v) Cultural competence and relevance of the intervention

vi) Social cohesion

vii) Political, social and economic support.

Community involvement and sector-wide approaches are central for the success of any health promotion efforts. This realisation is entranched in historical health promotion declarations by the WHO and partner organisations over the years (WHO 1978, WHO 1986, WHO 1997). For example, the Alma Ata declaration stipulates that social and economic sectors must be involved in attainment of good health at the primary community level (WHO 1978). It also affirms the right and duty of communities to participate in planning and implementing their health care. Moreover it underlines that health interventions should be based on socially acceptable methods derived from research.

The Ottawa charter calls for empowerment of communities through supporting their ownership and control of their health (WHO 1986). It calls for facilitation of community members to prepare for, and cope with, chronic illnesses. On its part, the Jakarta declaration underlines that chronic illnesses pose new health problems worldwide and calls for harnessing social and cultural resources in promoting community health (WHO 1997).

The interventions I propose in chapter eight largely focus on aspects corresponding to the aims of my study. I also take into consideration the lessons put forward from the review of successful interventions in other parts of the world and WHO recommendations on community involvement. Evidence from research studies shows that stroke is preventable and can be successfully managed. Therefore the interventions I propose in my thesis are based on the premise that developing successful interventions against stroke and other CVDs is possible even in rural areas of least developed countries. Such interventions should be targeted and theory based (Fishbein 2000). In addition they must be informed by a detailed understanding of the social dynamics and healthcare delivery systems. They must aim to utilise the available resources (human, equipment and funding). By building on a detailed understanding the discourses about stroke, social dynamics, and practicalities of stroke treatment my proposed interventions are compelling and likely to succeed.

2.6 Overview of anthropological theories of illness

Theorizing in illness studies within anthropology became more consolidated as medical anthropology developed as a distinct sub-discipline. In the following section, I provide an overview of medical anthropological theory. I trace its development and review the current main theoretical approaches within the field of medical anthropology.

2.6.1 'Civilized' vs 'primitive' medical systems

The study of how 'other' (non-western) societies explain and treat illnesses has a long history within anthropology. Though originally undertaken as part of the larger studies of

culture, early anthropological work formed an early body of work on how these societies explained and reacted to illness. Perhaps the most influential early theoretical framework for studying illness among 'other' societies resulted from the work of Rivers in the 1920s (Rivers 1924, Rivers 1926). Rivers outlined what to him were the differences between 'civilized' and 'primitive' medical systems. According to him, medicine in the west was based upon objective and rational science whereas the 'primitive' medical systems are founded upon ideas of magic and religion. He argued that from the 'primitive's' viewpoint, illness was seen to be caused by sorcery and actions of the spirit world. In this respect, prevention of illness was a matter of respecting taboos and religion rules and cure obtained through ritual and magic. Evans-Pritchard also reported that the Azande of Sudan made sense of and explained illness within a framework of misfortune and witchcraft (Evans-Pritchard 1937).

This view was 'confirmed' and perpetuated through a variety of anthropological work conducted on non western medical systems for many years. It was later challenged and refuted through other anthropological work. For example, Dunn (1968) adopted a 'systems' theory in order to make the comparison between the different medical systems around the world fairer. Within the 'systems' approach, magico-religious explanations of health and illness were seen as rational and inevitable given they were embedded and articulated within a cultural worldview based on religious and magic beliefs (Rogers 1991). The view that there are different bases and forms of rationalities has of recent been further explored. Shweder (1986) talks of 'divergent rationalities' by saying that rationality should be understood as a diverse concept and differently constituted around the world. It has been further argued that rationality should not solely be taken as an abstraction of reasoning but 'as it is variably constituted given the political-economic, social, and cultural contexts in which it is produced' (Hunt and Mattingly 1998). Rationality is therefore diverse and its processes are not universal (Shweder 1986). As Shweder (1986:191) says:

> theories, doctrines and concepts often classified by outside observers as symbolic, delusional, ideological, supernatural or religious, not only are viewed as

> reasonable, natural and object to the insider, but are also sufficiently explained by reference to processes legitimately classified as rational.

The medical systems approach continues to be employed in illness studies among nonwestern societies. Ethnomedicine is another approach which has commonly been employed in studying non western societies especially in Africa. In the following section I discuss this approach in detail.

2.6.2 Ethnomedicine

The ethnomedical approach postulates that each society has a medical system that provides a framework for understanding disease causation, ways of diagnosis and how they should be treated. Fabrega (1975:969) defines ethnomedicine as 'the study of how members of different cultures think about disease and organize themselves toward medical treatment and the social organisation of treatment itself'. Fabrega is unhappy with the way anthropologists have handled ethnomedicine and says that they tend to regard ethnomedicine as one of those domains of culture that has been neglected or handled indirectly by researchers. Nichter (1992:ix) defines ethnomedicine broadly explaining that it entails

> a study of the full range and distribution of health related experience, discourse, knowledge, and practice among different strata of a population; the situated meaning the aforementioned has for peoples at a given historical juncture; transformations in popular health culture and medical systems concordant with social change; and the social relations of health related ideas, behaviours, and practices.

Within the ethnomedical framework, the social aspects of 'disease' are given primacy. Fabrega argues that 'disease' among 'non-literates' is directly tied to the social behaviour of the person and to his ability to function and has heavy social implications. He argues that societies define disease in an adaptive way in order to make sense and rationalize treatment. He says;

> all non literate groups have articulated beliefs and explanations about disease. Rather than viewing these beliefs as naive and superstitious, they must be seen as adaptive and 'designed' to resolve the crisis and uncertainty surrounding disease

> by explaining the causes of disease and rationalizing treatment. In addition they also pattern the expectations of the sick person and of those around him, resulting in a host of altruistic behaviours (1975:970)

Comaroff (1983) pointed out two problems in studying health, illness and healing. The first one is what he calls 'analytical involution' which is the decontextualisation of healing systems and illness as a discreet domain of empirical inquiry. Health systems and illness constructs only take meaning if they are studied and interpreted within the context that they are produced (Comaroff 1983, Nichter 1992). The second theoretical problem is associated with the objectification of culture and its analytical concepts (Comaroff 1983). This, he cautioned, could lead to the underestimation of intracultural variations and resistance.

The ethnomedicine approach has been criticised for assuming that each society has a more or less discrete medical system which can be discovered and compared with other systems. It has been pointed out that this approach does not offer an explanation for why individuals within the same medical system would deviate and act differently. Some researchers lament that they failed to discover any medical systems in the societies they studied. For example after studying how the Wimbum of Cameroon understand and handle kwashiorkor, Pool (1994) concluded that the Wimbum do not have a medical system as such, but are confronted with a wide ranging complex of illnesses and other misfortunes for which all the different kinds of healers, traditional and biomedical should, between them, have a cure. Despite the shortcomings, the ethnomedical approach has been widely used in social medical studies. For example, the approach has been used in studies of illness causal beliefs and treatment-seeking behaviour for various ethnic groups in Africa such as the Kenyan Luo and Maasai (Sindiga 1995a, Sindiga 1995b, Sindiga 1995c). Despite its weaknesses, this approach is useful as it recognises that illnesses should be studied and interpreted within their wider social and economic context.

2.6.3 Ecological theory

This approach emphasizes the study of health and disease within a wider environmental context (Decosas 2002). The medical ecological approach builds upon the acceptance of

the concept of adaptation (Baer, Singer, and Susser 1997:21). The concept is defined as denoting behavioural or biological changes at either the individual or group level that support survival in a given environment. McElroy and Townsend (2004) say that medical ecology seeks to address questions that reflect a system of relationships among health, community and environment. They give further details about the premises on which the ecological model is based with regards to health and disease:

- There is no single cause of disease. A disease can be caused by a chain of factors related to the ecosystem imbalances
- Health and disease develop within a set of physical, biological and cultural subsystems that continually affect one another
- Environment is not merely the physical habitat, the soil, air, water and terrain which we live and work but also the culturally constructed environments, streets etc. People create and live within social and psychological environments and their perception of their physical habitat and roles is influenced by social values and world view.

Social ecology[3] includes both social, economic and physical settings within a context (Grzywacz and Fuqua 2000, Panter-Brick et al. 2006). Stokols (1992:7) says it gives 'greater attention to the social, institutional, and cultural contexts of people-environment relations than did earlier versions of human ecology, which were more closely oriented to biological process and the geographic environment'. The social ecological approach thus heeds to the call for a model that recognizes that health is determined by a wide range of biological and social factors (Krieger 1994, Levin and Browner 2005). For example, Grzywacz and Fuqua (2000) link socioeconomic status, family, work and school in their social ecological model for improving health.

(Whiteley 1999) as quoted by (Decosas 2002:4) lists six principles of social ecological analysis. These are:

- Identifying a phenomenon as a social problem

[3]'Social Ecology' is also a political movement led by Murray Bookchin. I am not talking about that movement but the theoretical framework of the same name.

- View the problem from multiple levels and methods of analysis
- Utilise and apply diverse theoretical perspectives
- Recognise human-environment interactions as dynamic and active processes
- Consider the social, historical, cultural and institutional contexts of people-environment relations
- Understand people's lives in an everyday sense.

The original ecological approach has been criticized for making other factors e.g. culture subordinate or just a response to natural factors (a form of environmental determinism). Good (1994:45) argues that the ecological approaches usually take disease as a natural object whereby it is viewed as an object separate from human consciousness. In turn, 'medical systems are seen as utilitarian social responses to intrusive conditions'. He continues to argue that in such an approach, 'culture is absorbed into nature, and cultural analysis consists of demonstrating its adaptive efficacy' (Good 1994:46). He concludes that in such understanding a full appreciation of the human cultural and symbolic construction of the world they inhabit is lacking.

2.6.4 Cultural interpretative theory

The interpretative approach has a long presence in anthropology and was recently elevated through the work of Geertz. He famously asserted that 'culture is a web of significance' which we have ourselves spun (Geertz 1973). He therefore argued that interpretation in the search for meaning is the primary undertaking in cultural analysis. Good (1994) observed the emergence of the cultural interpretative or meaning centred approach in medical anthropology was a direct reaction to the dominance of the ecological perspective on health issues. He argues that interpretative anthropologists have placed the relation of culture and illness at the centre of analytic interest. Kleinman (1988) defined illness as 'how the sick person and the members of the family or wider social network perceive, live with, and respond to symptoms and disability'. Good (1994) added that the more fundamental claim from the meaning centred tradition has been that disease is not an entity but an explanatory model. To meaning centred anthropologists, disease belongs to culture, in particular to the specialised culture of medicine. And

culture is not only a means of representing disease or illness, but is essential to its very constitution (Good and Good 1981, Kleinman 1980). Good (1994) argued that complex human phenomenon are framed as 'disease', and by this means become the object of medical practices.

Baer, Singer and Susser (1997) say that from the cultural perspective, disease is knowable by both sufferers and healers alike, only through a set of interpretive activities. These activities involve an interaction of biology, social practices, and culturally constituted frames of meaning, and result in the construction of 'clinical realities'. Baer, Singer and Susser (1997:25) pointed out that the primary shortcoming of the cultural interpretative approach has been 'its inattention to the role of asymmetrical power relations in the construction of the clinical reality and social utility of such construction for maintaining social dominance'. They argued that 'the role of political economy (e.g., class relations) in shaping the formative activities through which illness is constituted, made the object of knowledge, and embedded in experience, for example, is largely ignored' by cultural interpreters. Keesing (1987:161) argues that,

> cultures do not simply constitute webs of significance, systems of meaning that orient humans to one another and their world. They constitute ideologies, disguising human political and economic realities as cultures are webs of mystification as well as significance.

From his research he found that cultural meaning is not a collective phenomena as widely believed but is constituted and interpreted by 'experts' in any generation in a continuous process (Keesing 1987). He argues that cultural knowledge should be viewed as 'distributed and controlled' (Keesing 1987:161). He insists that knowledge is not only a key to cultural meaning, but also to power (Keesing 1987:165).

2.6.5 Critical medical anthropology

In the 1980s, another theoretical paradigm commonly known as critical medical anthropology (CMA) emerged. The approach was consolidated and its profile elevated through the work of Merril Singer and others (Baer 1997, Baer, Singer, and Johnsen 1986, Pelto 1988, Singer 1989, Singer 1990, Singer 1995, Singer, Baer, and Lazarus

1990, Singer, Davison, and Gerdes 1988). The theoretical approach emerged to question and challenge the dominance of the ecological and cultural interpretive approaches within medical anthropology. It also sought to discontinue the perceived medicalization of medical anthropology (Singer 1989, Singer 1990). Its proponents claimed that the other approaches were narrow as they ignored the wider political and economic aspects of health. In Singer's words, other approaches 'suffer the narrowness of vision that earned anthropology its reputation as a discipline shackled to microscopic understanding' (1990:179).

Drawing from a Marxist and neo-Marxist perspective, CMA calls for a closer examination of the social and material relations (such as class) determining health and illness. Friedrich Engels and Rudolf Virchow are often cited as pioneers of this perspective (Baer, Singer, and Susser 1997). Engels (Engels 1969[1845]), observed first hand the conditions of the working class in his position as a middle level manager in his father's textile mill in Manchester. He maintained that disease in the textile workers was rooted in the organisation of capitalist production and the social environment in which they lived as a result of their meagre wages. Virchow argued that the material condition of people's daily life at work, at home, and in the larger society constituted significant factors contributing to their disease and ailments. He made these conclusions after studying typhus, cholera and tuberculosis epidemics in Germany (Baer, Singer, and Susser 1997).

For Baer, Singer and Susser (1997:27) the critical approach understands health issues within the context of the encompassing political and economic forces including 'forces of institutional, national and global scale that pattern human relationships, shape social behaviours, condition collective experiences, reorder local ecologies and situate cultural meanings'. For them, CMA primarily seeks to understand the social origin of disease. It seeks to identify the political, economic, social structural and environmental conditions in all societies that contribute to illness. For example, Farmer (1996) argues that women face elevated risk of HIV infection and bear the burden of AIDS more than any other social group in society due to social structure which has rendered them powerless. In

most cases, social inequality confines women at the bottom of society where they bear the brunt of disease. He argues that 'in many settings HIV risks are enhanced not so much by poverty in and of itself, but by inequality' (Farmer 1996:37).

Therefore, CMA proposes that 'true' changes to health provision cannot be achieved without addressing wider political economic issues such as the business nature of health provision spearheaded by the role of pharmaceutical companies on global and national health forums. Recently global warming and its threat to global health (such as falling food and fresh water supplies and their resulting consequences) has been pointed out as resulting from the contradictions of the world capitalist system obsessed with the urge to guide the interests of the global corporation (Baer 2008). Within the critical perspectives of health and illness, power relations and struggles are taken as central in defining and prioritising illness within a society. Class differences determine whether an illness is labeled as such and whether people of different class backgrounds access the care and treatment available.

As pointed out in the previous section, critical medical anthropologists have often criticized those employing the cultural interpretive approaches in medical anthropological studies of cultural determinism. They are quick to point out that meaning is socially constructed and embedded in social, economic and ideological interests (Keesing 1987, Singer 1989). Keesing (1987) argues that even among classless societies cultural ideologies empower and benefit some to the expense of others. Apart from his critique of Geertz's famous interpretive assertion that cultures are 'webs of significance' by adding that they are also 'webs of mystification', he argues that when we talk of culture as a system of meanings, we need to ask ourselves 'who creates and define cultural meanings, and to what ends' (Keesing 1987:161).

Ironically, in criticizing cultural and medical approaches as establishing some forms of determinism, CMA is criticized for replacing the former with political and economic determinism. CMA calls for an interpretation of health and illness through the framework of the broader political and economic factors without giving due recognition to micro

factors such as the cultural, religious and biological aspects of health. The approach has also been criticized for overriding the role of subjects in health issues through its preoccupation of structure. Good (1994:61) says it 'authorizes the perspective of the observer over against the claims of those we study'. It also faces criticism for ignoring the subjective aspect of illness as examined through phenomenological studies.

2.7 My theoretical approach

My theoretical approach sought to study stroke discourses and treatment-seeking behaviours within a broad social, cultural, economic and historical context. Through employing this broad approach, my theoretical framework is similar to the critical approach. Nevertheless, I do not employ a typical CMA approach as I equally examine the social, cultural, economic and historical factors to establish their role in the production and perpetuation of stroke discourses in my two research sites. I do not prioritise political and economic factors in my analysis as championed by CMA. In my view this could lead to an imposed and therefore a biased analysis. Moreover, this study departs from CMA per se in that it does not take the position that the macro level factors entirely determine the micro level in shaping health and illness issues. In my theoretical approach, both macro and micro level factors shaping health and illness are equally examined and appropriately acknowledged.

My theoretical framework is also different from the CMA tradition in that it is not entirely class based. In addition to the socio-economic aspects, I also examine other aspects of community life such as religion and cultural beliefs shaping stroke discourses. I treat these diverse aspects equally during the analysis to determine how they pan out in the production and perpetuation of stroke discourses. In other words, I did not go to the field with a pre-conceived notion of which one among these aspects are primary (as probably a typical CMA researcher would do), but rather sought to examine them in the field and through data analysis.

In the next chapter, I craft my theoretical framework from the works of Foucault and Bourdieu. I use several of their concepts as a 'tool box' to enable me to undertake my study. I place power relations analysis at the core of my framework in line with Foucault's notion of power that, he argues, is in every aspect of community life. By placing the analysis of power relations at the core on my theoretical framework, I employ a critical perspective. In my theoretical approach I take Foucault's view point that the production of knowledge in closely related to power. Therefore I closely examine the interplay of power and knowledge in the production and perpetuation of stroke discourses. I also examine the wider social, cultural, historical and economic factors that are responsible to the production and perpetuation of the stroke discourses in my two research sites. At the micro level, I examine the particular practices related to stroke by the individuals, families and entire community. In this regard, I utilise Bourdieu's concepts of habitus, symbolic power, and strategy and strategizing.

2.8 Conclusions

In this chapter, I have reviewed a select background literature for my study. From the review, the paucity of detailed ethnographic studies of stroke in sub-Sahara Africa is apparent. I have demonstrated the approach often taken in ethnographic illness studies through presenting and discussing four case studies from Tanzania. I have highlighted finding themes from the studies and with the benefit of hindsight pointed out ways they could have been better approached. I have also underlined the limitations of only employing quantitative methods in the studying treatment-seeking behaviours through a review of the three treatment-seeking models. In the process, I have demonstrated the added value of qualitative studies in studying illness discourses. Furthermore, I have provided an overview of the important features and lessons from successful health interventions which can be harnessed in the design of community based stroke interventions.

I have also presented an overview of anthropological approaches in studying health and illness demonstrating the strengths and weaknesses of each approach. I have traced the origin and development of anthropological studies on illness. I have argued that though the ethnomedical approach has been useful in health systems comparative studies, it has failed to sufficiently account for intracultural variations. Additionally the approach has in a way entrenched the dichotomy of 'traditional' versus 'modern' health systems which is somehow misleading. It has been argued that there is always aspects of traditional and modern elements in any society including those in developed countries (Latour 1993). Thus the dichotomy of 'traditional' versus 'modern' may itself be a product of modernisation (Latour 1993). My study found that within a community one illness discourse may become dominant over others. Therefore in some communities one may find the biomedical discourse dominant while in another it may be others such as culture or religion. However, this is not to say that other discourses cannot exist alongside and time and again challenge the dominant one.

The interpretive meaning approach is useful though it falls short of conducting a much deeper analysis of the cultural meanings of health and illness. It does not adequately acknowledge that meanings are created and perpetuated by particular, powerful agents. In this approach it is always assumed that the cultural meanings are a 'common good' of the entire community or group. On the other hand, the ecological perspective is useful in that it calls for an examination of the wider social arena in the analysis of health and illness. Its wide analytical framework takes into account the social, cultural, historical and economic factors of health undertaken within a broader sphere of the examination of human-environment interactions. Its call for multidisplinarity is particularly useful. However, it also fails to recognize that among the community groups, there are particular individuals or groups of people who have more power to influence illness discourses. This is mainly from the reason that they draw their symbolic power either through their education, professional accreditations or positions in society such as being religious leaders. It generally underplays the role of power relations in the equation of examining the historical, cultural, social and economic factors responsible for the production of illness discourses.

Multilevel power analysis is important in studying the production and perpetuation of illness discourses. In this regard the critical perspective takes into account the power relations bit which is missing in the other approaches. The shortfall of the mainstream critical approaches has been their tendency to base power analysis entirely on class. The prioritisation of structures over subjects is another weakness of the approach. It is from this background that I develop my theoretical framework which takes the critical view point of assigning power relations analysis a central role. However, I do not base my analysis entirely on class but look for other bases of power in the broad community such as in cultural and religious cosmologies and institutions. I also give equal weight to agency and structure within my analysis as my data suggest that these are all important in the production and perpetuation of stroke discourses.

I devote the next chapter to developing and discussing my theoretical approach utilising concepts generated by Foucault and Bourdieu.

3 Chapter Three: Theoretical Framework

3.1 Introduction

This chapter aims to outline the theoretical framework which engaged my research process, in particular data collection and analysis. My theoretical framework evolved through a process utilising a slightly modified version of the grounded theory approach (Glaser and Strauss 1967). In this approach, it is the data which largely guides theorizing. Glaser (1998:3) defines grounded theory as the 'systematic generation of theory from data acquired by a rigorous research method'. Clarifying a common misunderstanding among its critics and users, he emphasizes the 'emergence' of theory from data and not necessarily 'invention'. He says, 'grounded theory is the discovery of what is there and emerges. It is NOT invented' (Glaser 1998:4). On her part, Charmaz (2006:2) highlights another important aspect of the approach which is its systematic yet flexible characteristic, 'grounded theory methods consists of systematic, yet flexible guidelines for collecting and analyzing qualitative data to construct theories 'grounded' in the data themselves'.

In the grounded theory approach, data collection and analysis goes hand in hand. It is essentially an inductive method (Glaser 1998) whereby data are examined to capture emerging theoretical concepts. Thereafter hypotheses are formulated and data examined again to test them. The cross examination between data and theory continues until 'theoretical saturation' is achieved (Bryman 2004). Theoretical saturation implies that there is no further need to review or collect more data to examine how well they fit with the developed concepts. Grounded theory underscore the 'modifiability' of theory through being informed by the data (Charmaz 2006). Charmaz (2006:pp 3-4) accentuate the point when she says:

> We build levels of abstraction directly from the data and, subsequently, gather additional data to check and refine our emerging analytic categories. Our work culminates in a 'grounded theory', or an abstract theoretical understanding of the studied experience.

The grounded theory approach discourages reading substantive literature prior to fieldwork. The idea is to keep the researcher as free minded as possible in order to be able to capture the emerging concepts without preconceived conceptual categories (Glaser 1998). This view led to some of the critics of the approach to interpret it to mean that grounded theory assumes that researchers go to the field with absolute objectivity free of 'contamination' from existing literature and theory (Charmaz 2006). For example, Bulmer (1979) questions whether it is possible for researchers to postpone their awareness of other theory and literature until at a later stage of analysis. In answer to the criticism and partly in recognition of existing professional, grant application and PhD processes which require that the researcher engages some literature prior to fieldwork, Glaser (1998) recommended that such literature should be treated as data and used for comparison. He (1998:68) recommends that one should read in areas that:

(i) Will not pre-conceptually, contaminate the emerging theory

(ii) Will keep up theoretical sensitivity, learning of theoretical codes and knowledge of the usage of social theory.

In essence, the grounded theory approach recommends that a researcher should read theoretical literature with a conscious intention of taking note of what exists and aim to use it to compare with what will come from the field. In no circumstances should the pre-fieldwork literature be allowed to determine what would come from the field. In line with this perspective, and as evident through my overview of the broader anthropology of illness theoretical literature in the previous chapter, I treated the literature as data which I compared with theoretical concepts which emerged from the field. Throughout my research undertaking, the 'literature data' was 'constantly corrected, put into perspective and proportioned in relevance by constant comparative method'(Glaser 1998:72).

Therefore in my case, I set out for the field (first in August 2006) after reviewing a range of anthropological theories of illness such as explanatory models, social ecology and critical perspectives. The data generated in the first stage of fieldwork allowed me to focus on particular areas of theory which seemed the most appropriate for my research,

that is, the critical perspective paying particular attention to socio-historical factors and power relations. After the initial stage of my research, I briefly left the field and took time in Durham (April to May 2007) to refine further my theoretical focus through preliminary data analysis and additional review of relevant literature. Thereafter (end of May 2007), I returned to the field until October 2007 to test whether the critical theoretical framework developed from the first period of empirical work was borne out by the remainder of fieldwork and refined it accordingly.

In the following two sub-sections, I provide an overview of my framework which makes use of Foucault's concepts of discourse and power/knowledge and Bourdieu's concepts of habitus, strategy and strategizing, and symbolic power. I begin by situating my framework within the broader critical anthropological theory through a brief discussion of the concepts of power and ideology. In addition, I discuss how I have utilised the framework to carry out a macro and micro level analysis.

In sections three and four I expand the discussion of Foucault's and Bourdieu's concepts consecutively and state some of the limitations of their theoretical positions. I also illustrate the relevance of their selected concepts by giving examples from my data. In the final section I conclude the chapter by restating the main points covered and introduce the following chapter.

3.1.1 An overview of the framework

My framework draws primarily on different aspects of the works of Michel Foucault and Pierre Bourdieu. I employ selected relevant concepts from each of them to enable me to make sense of my data and undertake a thorough analysis.

Both Foucault and Bourdieu encouraged researchers to employ their concepts to facilitate analytical endeavours. Specifically, Bourdieu encouraged researchers to develop and utilise his concepts as 'tool boxes' (Bourdieu and Wacquant 1992). On his part, Foucault was open to a varied interpretation and application of his ideas in order to achieve one of his fundamental goals i.e. to provide a critical alternative to the dominant analytic

frameworks. He was also happy for people to utilise his ideas as 'tools' in whatever ways they saw fit in order to carry out a critical analysis.

> I would like my books to be a kind of tool-box which others can rummage through to find a tool which they can use however; they wish in their own area...I would like the little volume that I want to write on disciplinary systems to be useful to an educator, a warden, a magistrate, a conscientious objector. I don't write for an audience, I write for users, not readers.
> (Foucault 1974:523-524) as cited in (Stevenson and Cutcliffe 2006)].

In my framework, Foucault's concepts of knowledge/power and discourse facilitate a macro level analysis factoring in different historical processes responsible for producing the illness discourses (and within it stroke discourses) in my two research sites. Furthermore, the macro level analysis is employed in order to analyse in detail the current stroke discourses and practices operating in, and as contrasted between, the two sites.

On the other hand, Bourdieu's concepts of habitus, strategizing and symbolic power facilitate a micro level analysis of the specific practices related to the perception and treatment-seeking for stroke in the two sites. The different practices in relation to stroke are analysed and interpreted using these three concepts which make up part of his broader theory of practice. I illustrate my framework in the following diagram.

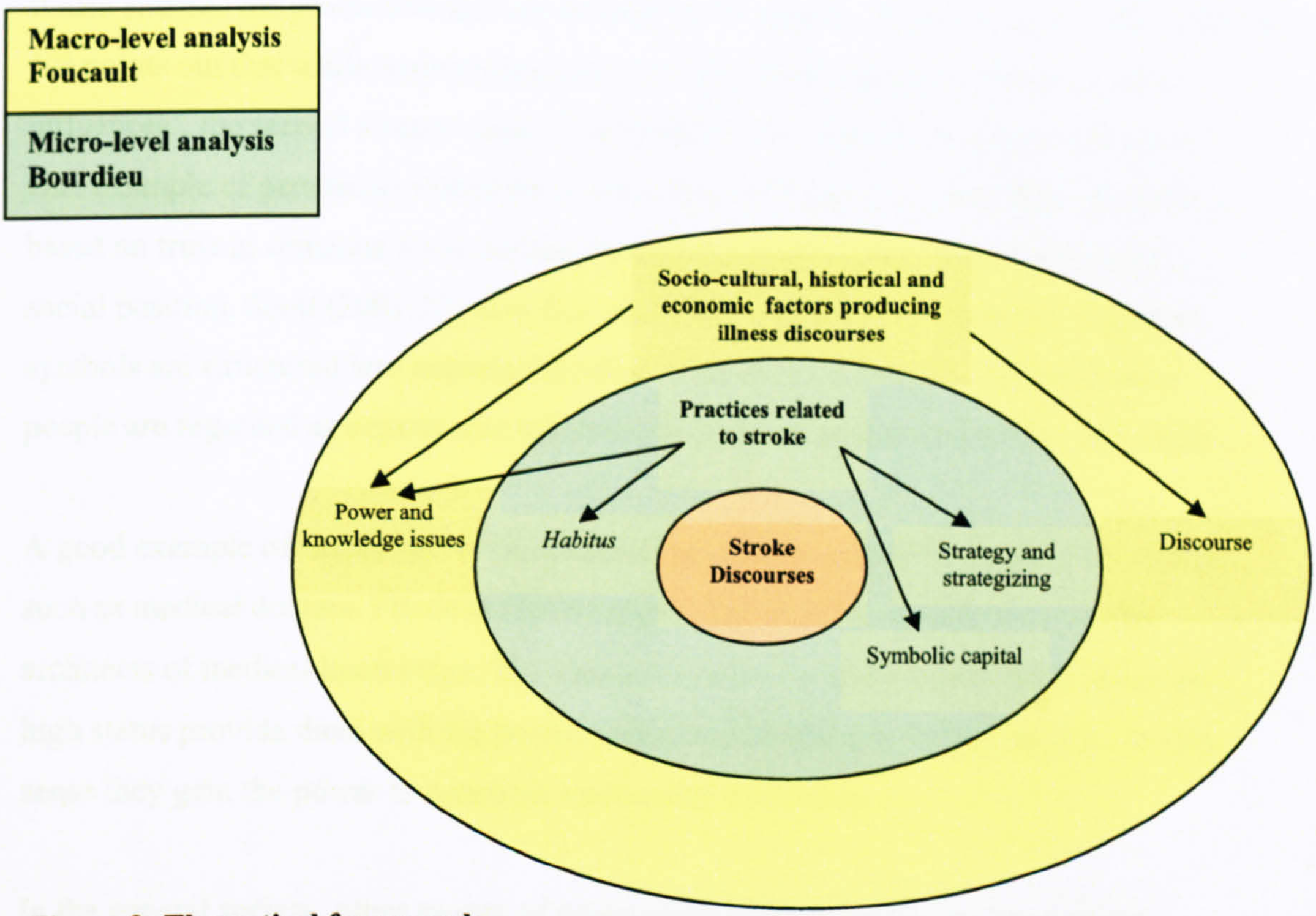


Figure 2: Theoretical framework

3.1.2 Power

Bourdieu and Foucault place power relations analysis at the centre of their theoretical concepts. Broadly defined, power is the production of causal effect (Scott 2001:1). From a social perspective, it is 'a form of causation that has its effects in and through social relations' (Isaac 1992:2). Therefore when exercising power, agents have an intention of producing particular outcomes. Scott (2001:2) says social power is 'an agent's intentional use of causal power to affect the conduct of other participants in the social relations that connect them together'. Though there are many forms of power, within my framework I am primarily interested in its social aspects.

Bourdieu and Foucault have sometimes been classified as writers belonging to the 'second stream' of power research which focuses on researching the strategies and

techniques of power (Scott 2001). Generally this group views power as diffused widely in society rather than just being concentrated in organisations or institutions (Scott 2001:2). It also stresses the productive and not the repressive aspects of power. Scott (2001:pp 9 & 12) points out that while mainstream power research highlighted 'corrective causal influences', the second stream research emphasized the 'persuasive causal influence'. One example of persuasive influence is the notion of 'expertise'. This type of power is based on trust in someone's specialised knowledge or skill rather than their specific social position. Scott (2001:22) says that expertise comes into being when 'cognitive symbols are structured into organised bodies of knowledge in terms of which some people are regarded as experts and others defer to their superior knowledge and skills'.

A good example of 'expertise' is the authority granted people with medical knowledge such as medical doctors. Friedson (1986) argues that doctors and shamans are the architects of medical knowledge. Their assumed superior skills, expert knowledge and high status provide them with the power to dispense healing or withholding it. In this sense they gain the power to construct knowledge for others.

In the general society, other groups of people with what is viewed as 'specialised knowledge' may also exercise power due to their expertise. For example, while doing my fieldwork I came across an illustration of how the notion of expertise is incorporated in the local illness discourses. In Dar-es-Salaam, traditional healers are commonly referred to in Swahili terms '*fundi*' and '*mtaalamu*' which means expert or someone with technical knowledge. Medical doctors and other health practitioners were also often accorded the same expert status.

Since Bourdieu and Foucault see power as a fundamental and diffuse aspect of society's social relations, they assert that any meaningful attempt to analyse the way society works must give due recognition to the centrality of power relations. Coming from the same angle, I acknowledge that the production of stroke discourses is a result of complex and dynamic social interactions. I therefore place power relations analysis at the core of my research on the way stroke is perceived and treated in the two sites. I define power

following Bourdieu and Foucault who argued that it is present in all aspects of social life. I examine the way power is involved in framing and treating stroke. Within this framework, stroke perceptions and treatment-seeking behaviours are taken as products of the various social-cultural, historical and economic processes.

Findings from my research clearly indicate that for any meaningful analysis of the way illness discourses are produced and the way people act in response to illness, one must analyse the power relations operating at different levels of society. This includes the relationships between individuals, within and between families, different groups (such as religious, professional and social groups) and at the broader community in general. In addition, one needs to look into the power relations underpinning the different forms of illness discourses, their origin and power bases, how and why they are acquired and passed on, who possess them, how they operate including how opposing forms of knowledge and discourses pan out at these different levels. The same analytical viewpoint guided my endeavour of exploring ways of initiating community based stroke interventions in similar settings.

3.1.3 Ideology

The concept of ideology is important when one examines how social interaction and inherent power relations lead to the production and perpetuation of social representations of phenomenon or experience. In this section I review the various definitions of ideology in order to provide a background to my discussion of the theoretical concepts I utilise from Foucault and Bourdieu. The definitions I review shed light on similar matters related to the emergence, embodiment and perpetuation of illness representations (or discourses).

Eagleton (2007) offers a comprehensive overview of different definitions of ideology. He outlines sixteen definitions of the concept pointing their strengths and weaknesses (Eagleton 2007:1-2). However, I find six of his definitions of ideology as more relevant to my research (Eagleton 2007:28-31). He defines ideology primarily as the 'the general material process of production of ideas, beliefs and values in social life' (Eagleton

2007:28). He argues that this definition is neutral both politically and epistemologically. The definition is also close to the broader meaning of culture as it talks about the way individuals 'live their social practices' (Eagleton 2007:28).

In his second more specific definition he says it is 'ideas and beliefs (whether true or false) which symbolize the conditions and life experiences of a specific socially significant group or class' (Eagleton 2007:29). This definition makes a difference between ideas and beliefs. However, he cautions that it is important to make a distinction between 'ordinary' ideas (say held by children) and other ideas with 'social significance'. To him, this definition is close to the concept of 'world view' though world view encompasses more fundamental matters e.g. life and death.

The remaining four definitions talk of ideology as being concern with the promotion and legitimization of interests. For example, he defines ideology as the 'promotion and legitimation of the interests of such social groups in the face of opposing interests' (Eagleton 2007:29). With regard to stroke discourses, one may for example talk about specific discourses promoting and legitimizing interests different groups in the social structure such as medical doctors, healers, religious leaders. He argues that within this definition, ideology is taken as a 'discursive field in which self promoting social power conflict and collide over questions central to the reproduction of social power as a whole' (Eagleton 2007:29).

The fourth definition also talks about promotion of interest but in this case it is the broader 'sectoral interests'. It is the 'promotion and legitimation of sectoral interests confined to the activities of a dominant social power' (Eagleton 2007:29). Fifth, he defines it as 'ideas and beliefs which help to legitimate the interests of a ruling group or class specifically by distortion and dissimulation' (Eagleton 2007:30) and lastly as 'false or deceptive beliefs... arising not from the interests of a dominant class but from the material structure of society as a whole' (Eagleton 2007:30). This group of definitions talk of ideology in functional terms mainly for the maintenance of the status quo of certain social groups.

In this broad range of definitions, we see that ideology is closely related to promotion and legitimization of ideas, beliefs, practices and interests of different social groups within a society. In this regard, stroke discourses in my two research sites contain some of the characteristics of ideology discussed. As such, they may be examined on the kind of interests they represent and how they maintain (or attempt to maintain) the status quo of certain social groups or institutions whether biomedical, traditional or religious. This will become evident after I have presented my findings in later chapters.

The concept of discourse is closely related to the broader Marxist theory of ideology. Marx's theory of ideology may be taken as part of his broader theory of alienation (Eagleton 2007). Its central argument is that humans submit to power, products and processes of their own activity after those phenomena assume autonomous existence after escaping the control of human subjects (Eagleton 2007). Within this outlook, material conditions are given primacy. For example, Marx and Engels argue in *The German Ideology* that human practice 'is a product of conscious direction which was produced by material conditions' (Eagleton 2007:73). They argue that although extant material conditions are primary, people do not recognize this due to mystification.

In a way, Bourdieu takes a similar position when he talks of misrecognition. To him, though the habitus guides human practice, people are not aware of it as they take things for granted as natural. As we will see later in this chapter, he refers to this misrecognition as the *doxic* experience. For his part, Foucault also argues that subjects often fail to recognise the production and existence of discourse.

It has been pointed out that Bourdieu's theory of practice draws on Marx's *Theses on Feuerbach* (Jenkins 2002). There is a striking similarity with, for example, what Marx wrote when he said:

> All social life is essentially practical. All the mysteries which lead theory towards mystification find their rational solution in human practice and in the comprehension of this practice.

(Marx pp. 84 as cited by Bottomore & Rubel 1963).

In Marxist theory, ideology is associated with dominant political power located within institutions. It was in disagreement with this view that Foucault came up with his concept of discourse (Eagleton 2007). And as we have already seen, Foucault argued that power is present in every aspect of social life and, rather than being possessed, is exercised.

3.2 A toolbox from Foucault

I have to confess from the outset that crafting a theoretical framework using Foucault's theoretical concepts is not an easy task. He has often been described as an obscure and difficult writer (Guedon 1977). This comment is partly due to a frustration emanating from an expectation of most of his readers hoping to identify a clear and coherent theme within his work. For example, several commentators, including Freundlied (1994), point out that Foucault often revised his ideas over time and therefore appears contradictory. Foucault himself was not apologetic and often dismissed such complaints.

The 'open ended' manner of Foucault's ideas could in a way be seen as a product of his life long endeavour of challenging 'established' analytical frameworks and ways of thinking (to use his words 'dominant discourses'). One could argue that the fact that his work is perceived as difficult to 'pigeon hole' (Stevenson and Cutcliffe 2006) is in a way an achievement of his challenge of 'entrenched' analytical mindsets. His wide appeal partly explains why Foucault's work has been applied across a broad range of disciplines from philosophy, psychology, anthropology and medicine. It is with this note that I further discus two of Foucault's key concepts that have helped me develop my argument.

3.2.1 Discourse

Discourse consists of 'a set of common assumptions that, although rarely consciously recognized, provides the basis for conscious knowledge' (Foucault 1972:49). In his later work, (Foucault 2002:54) he expands on the concept by saying that discourses are 'practices which systematically form the objects of which they speak'. Individuals

appropriate and apply discourses by using their conscious and unconscious mind (McHoul and Grace 1993). From this viewpoint, assumptions and representations about stroke may be examined as discourses manifested through practices and speech.

Following this perspective, my research examines how stroke is described and discussed through the interviews I conduct (sayables) and ethnographic observations (appearances). In Foucauldian terms, that is to say I partly applied an archaeological analysis. This involves examining the relationship between the visible (appearances) and the sayable (statements) (Stevenson and Cutcliffe 2006).

According to Foucault, a typical archaeological analysis provides a descriptive picture (the way things are). It does not attempt to offer an interpretation as this, according to Foucault, is a futile exercise. Foucault argues that interpretation has no end as 'there is nothing primary to interpret' (Stevenson and Cutcliffe 2006). To him, text should be read as text and the aim of archaeology should primarily be to examine how these different texts relate to each other in the production of a discourse. It strives to 'describe statements in the field of discourse and the relations of which they are capable' (Foucault 2002).

In discourse analysis, the term 'discursive formation' is used. The French linguist Michel Pecheux is often credited with coining the term. A discursive formation is related to the (unwritten) rules which govern what people say from particular social positions (Eagleton 2007). It is 'a set of rules which determine what can be said and must be said from a certain position within social life' (Eagleton 2007). However, these expressions only make sense if examined within the context in which they are produced. Their meanings 'change significance as they are transported' from the discursive formations within which they occur (Eagleton 2007).

It is important to point out that within my framework, I do not treat stroke discourse as value free. Rather, I examine them as emerging from a socio-historical context. It is therefore imperative to examine discourses within such an understanding. Employing a

discourse analysis was very useful in contrasting findings from my two sites given the importance of their distinct historical and cultural backgrounds. It enabled me to contrast stroke discourses in the two sites as informed by different historical, economic, social and cultural backgrounds.

In examining stroke discourses in my two research sites, I found that there were several competing discourses including the biomedical, religious and cultural. This interaction among the different discourses involves power relations. As within a Foucauldian analytical framework, there is a close relationship between discourse and power: 'discourses are not merely effects or end-products of power; rather, power relations are seen to be immersed in discourses' (McHoul and Grace 1993:52).

Within the power interplay of the multiple discourses, there emerges a dominant discourse. A discourse becomes dominant because it has a strong power base. This base could take a number of forms or a combination of several - such as religious, cultural and education systems. Manias and Street (2000) point out that discourses become dominant because they 'have an established institutional basis, such as in the law, in medicine, or in the organisation of the family and work'.

Dominant discourses may also be considered as 'regimes of truth' that determine what counts as important, relevant and 'true' knowledge (Foucault 1980:131). However, regimes of truth cannot be understood in absolute terms as existing outside the knowledge and power relations of discourses but, rather, they must be understood in relational terms (Foucault 1980). In the following section, I expound the interconnectedness between discourse, power and knowledge.

Before proceeding further, it is important to note that the dominant discourse does not occupy this position permanently. Its position is constantly challenged (and may even be replaced) by other discourses. As an example, in rural Hai the dominant discourse is that stroke is a 'natural' biomedical condition requiring a biomedical intervention. On the other side, in urban Dar the dominant discourse is that stroke is a supernatural condition

requiring supernatural intervention. These dominant discourses are constantly challenged by other discourses as we will see in later chapters.

3.2.2 Power and knowledge

As already pointed out, in a sharp departure from the Liberal and Marxist models, Foucault argued that power arises from every interaction in society. Power is 'everywhere; not because it embraces everything, but because it comes from everywhere'(Armstrong 1985). In the Marxist definition, power is secondary to the economic while in the Liberal view it is secondary to social position (Armstrong 1985). Foucault did not entirely disagree with the Marxist and liberal definitions, but saw that as presenting only one form of power (Scott 2001). He argued that power must not be analysed in the traditional 'juridico-discursive' way, but as:

> Something which circulates, or rather as something which only functions in the form of a chain. It is never localised here of there, never in anybody's hands, never appropriated as a commodity or piece of wealth. Power is employed and exercised through a net-like organisation. And not only do individuals circulate between its threads, they are always in the position of simultaneously undergoing or exercising this power. They are not only its inert or consenting target; they are always also the elements of its articulation. In other words, individuals are the vehicles of power, not its points of application (Foucault 1980:98).

From this perspective, power can therefore not be possessed, but exercised. In addition it does not flow from a centralised source but it is multidirectional. It does not operate only from the 'top down' but also from the 'bottom up'. Foucault challenged the prevailing Marxist view that power is primarily unidirectional and repressive by arguing that it is also productive (Manias and Street 2000). For him, power has the ability to produce things or reality: 'it traverses and produces things, it induces pleasure, forms of knowledge, produces discourse' (Foucault 1980:119). Here Foucault is driving the point that discourse is indeed a product of power.

Foucault saw a close link between power and knowledge because power is needed for the production of knowledge and knowledge is required for the exercise of power – each is

implicated in the other (Cheek and Porter 1997). To him, power and knowledge is one thing. Power cannot be 'seen' but becomes visible through its effects. Armstrong (1985) says 'its manifestations can be observed at the local level where it produces its immediate effects in terms of creating new objects to social perception and thereby knowledge of them'. Through this argument, knowledge about the different representations of stroke were engaged and analysed as products of power.

Foucault recommends that power analysis should begin with the examination of the minimal interactions in society then proceed 'upwards'. By employing this 'bottom up' analysis of power relations I was able to examine the stroke discourses manifested through the talk and other kinds of interaction between individuals and within families and different groups. In strictly Foucauldian terms, I may say I conducted a genealogy. This is a way of examining how a particular practice is developed or brought into being (Stevenson and Cutcliffe 2006). Cheek and Porter (1997) say Foucault's genealogy is 'a technique used to expose the way in which power enables discourse to emerge, be replaced or developed and changed over time'. He says it is 'a form of history which can account for the constitution of knowledge, discourses, domains of objects e.t.c.' [sic] (Foucault 1980:117). Discourse may therefore also be seen as a product of power relations fronted as knowledge.

3.2.3 Some limitations of Foucault's approach

Foucault's position that power is everywhere in society has been criticised as an oversimplification and undermining the role of power in bringing about social change (Eagleton 2007). He did not acknowledge that though there are many forms of power they have varied significance. For example, while it might be true that power is exercised when two boys fight for a ball, it is false to equate it to a resistance movement fighting to replace a government (Eagleton 2007).

Foucault talks of resistance as to him without resistance there are no power relations (Foucault 1980, Foucault 2002). Therefore his analysis offers a possibility of change

through resistance on the part of individuals. An example may be through subjects' questioning of forms of knowledge presented to them as expert opinions.

Additionally, Foucault is criticised for his inability within his analysis to give agency the central place it deserves. He is often labelled as overly deterministic by making individuals subject to structure. For him, as a result of existing power relations, individuals are confined into operating their agency only within the existing discourses.

This may not be a necessarily wrong premise as my research has demonstrated it is possible that agency could mostly be exercised between the various stroke discourses prevailing in the two sites. The way individuals construct stroke could shift over time between the various discourses such as the biomedicaly and religiously informed discourses. In my research I obtained no evidence of individuals charting entirely new discourses, like not seeking any remedy for stroke. A common strand of the various discourses is that when someone gets a stroke they must 'do something'. This meant seeking a remedy either through the biomedical (hospital), cultural/local (traditional medicine) or faith based (prayer). Not doing something was therefore not an option.

In addition, I argue that the applied orientation of health related research, strives for interventions to address particular health problems. Therefore, when a person talks of instituting interventions, they are in a way talking about curtailing agency through veering towards charted discourses (in this case produced in the name of interventions). The success of the majority of health interventions depends on their ability to exercise some form of constraint over agency. The prerequisite for any successful intervention probably lies in the ability to minimise those who employ unrestricted agency. In most cases, when we talk of health interventions, we probably mean promoting a particular discourse. My research suggests that within the 'effective health intervention' discourse, Foucault's view that agency only operates within structural boundaries may not be entirely counter productive. Nevertheless I recognize the need in other instances to provide a version of agency that is independent and entirely in the domain of individuals,

even if it may mean that certain categories of individuals are eventually classified as outcasts or social misfits.

3.3 Bourdieu's conceptual toolbox

My framework also utilises Bourdieu's concepts of habitus, strategizing, and symbolic power. Bourdieu's broader theory of practice is embedded within human practice. He believes that a researcher should be able to develop theory through careful observation and analysis of human practice. To Bourdieu, when we engage in a practice, we reveal conceptual schemes apparent through practice. He argues that practice, practical knowledge, and the network of practical relations, through habitus, is a product of the history of economic and symbolic exchanges 'and reproduces that history through structuring structures in agent's mental dispositions' (Bourdieu 1977). He points out that in practices, agents satisfy vital symbolic and material interests. Bourdieu develops his theory through attending to the interconnections of practice and economic interest within the habitus, and in that way attempts to thread the gap between social structure and agency, objectivity and subjectivity (Jenkins 2002).

According to Bourdieu, social sciences alternate between two 'irreconcilable' perspectives, objectivism and subjectivism. He cites Durkheim as an example of one of the proponents of objectivism through his concept of social facts. Durkheim (1970:250 as cited by Bourdieu 1989) argued that 'social life must be explained, not by the conception of those who participate in it, but by deep causes which lie outside of consciousness'. On the other hand, he cites Schutz's work as primarily engaged with subjectivism through ethnomethodology when he argued that humans should be seen as active participants in a social world which they have interpreted through their sense of reality. He contends that:

> the observational field of the social scientist-social reality-has a specific meaning and relevance structure for the human beings living, acting, and thinking within it. By a series of common-sense constructs, they have pre-selected and pre-interpreted this world which they experience as the reality of their daily life...the thought objects constructed by the social scientist in order to grasp this social

> reality have to be founded upon the thought objects constructed by the common-sense thinking of men, living their daily life within their social world (Schutz, 1962:59 as cited by Bourdieu 1989).

Bourdieu's concept of 'practical sense' within his broader theory of practice seems to draw from Shutz's idea of 'common sense constructs' grounded in the individual's sense of reality (Bourdieu 1989).

It is interesting that Bourdieu sees himself in a mission to bridge objectivism and subjectivism through the theory he develops. His ambition becomes evident when he says, 'notions such as habitus (or system of dispositions), practical sense, and strategy are tied to the effort to get away from objectivism without falling into subjectivism' (Lamaison and Bourdieu 1986:111-112). One wonders how he aims to achieve this given his admission that the two approaches are 'irreconcilable'. Nevertheless, he attempts to reconcile the two positions through offering his own version of structuralism (though he always refused to be categorized as a structuralist) which he calls 'constructivist structuralism' or 'structuralist constructivism' (Bourdieu 1989). In explaining what he means by 'structuralism' he says:

> there exist, within the social world itself and not only within symbolic systems (language, myths, etc.), objective structures independent of the consciousness and will of agents, which are capable of guiding and constraining their practices or their representations (Bourdieu 1989:14).

And by 'constructivism' he means:

> there is a twofold social genesis, on the one hand of the schemes of perception, thought, and action which are constitutive of what I call habitus, and on the other hand of social structures, and particularly of what I call fields and of groups, notably those we ordinarily call social classes (Bourdieu 1989:14).

And his notion of constructivism leads to my discussion of his concept of *habitus*.

3.3.1 Habitus

Habitus is a central concept in Bourdieu's theory. In his words, habitus consists of

> systems of durable, transposable dispositions, structured structures predisposed to function as structuring structures, that is, as principles of the generation and structuring of practices and representations (Bourdieu 1977:72).

Bourdieu (1977) talks of three aspects of dispositions. First, they are the result of an organizing action and a set of outcomes as approximating to structure; second, a way of being or a habitual state; and thirdly, a tendency, propensity or inclination (Jenkins 2002).

He says a habitus produces practices and representations which are available for classification but which are objectively differentiated. However, they are immediately perceived as such only by those agents who possess the code, the classificatory schemes necessary to understand their social meaning (Bourdieu 1977). Habitus thus implies 'a sense of one's place' and a 'sense of the place of others'.

Objectification of structure and human relations is a central process of creating and maintaining the habitus to appear as a natural phenomenon. He points out how the 'established order' achieves misrecognition of the habitus as a natural and taken for granted occurrence when he says:

> every established order tends to produce (to very different degrees and with very different means) the naturalization of its own arbitrariness...of all the mechanisms tending to produce this effect, the most important and the best concealed is undoubtedly the dialectic of the objective chances and the agent's aspirations, out of which arises the sense of limits, commonly called the sense of reality, i.e. the correspondence between the objective classes and the internalized classes, social structures and mental structures, which is the basis of the most ineradicable adherence to the established order (Bourdieu 1977:164).

The habitus operates either with or without the consciousness of individuals. Individuals don't deliberately draw from it when they act. As it were, action just happens. Bourdieu says that it is this 'thoughtlessness' that makes the habitus particularly powerful.

The habitus is acquired and embodied through the process of socialization during the early years of a person's life:

> habitus as the social inscribed in the body of the biological individual, makes it possible to produce the infinite acts that are inscribed in the game, in the form of possibilities and objective requirements (Lamaison and Bourdieu 1986:113).

The socialization into the habitus is based on an individual's position within the social structure. This structure may be based on different social groups or identities such as religious groupings (Collins 2002). And even though it is embodied, the habitus remains a social phenomenon related to social position of both the 'socialiser' and 'socialised'. Bourdieu makes this point by arguing that it is, 'a system of schemes of perception and appreciation of practices, cognitive and evaluative structures which are acquired through the lasting experience of a social position' (Bourdieu 1989:19).

Here Bourdieu seems to suggest that the habitus is class based since it is socially acquired through one's position in the social structure. He argues that once the habitus is acquired through one's social position, it influences their practices for the rest of their lives. This may be pointed out as a weakness of the habitus as it does not provide for social change (King 2000). It does not account for social mobility and religious converts. What becomes of people who were brought up in a particular social class and later move to another class through achievement? What about those who were socialized under a particular religious orientation e.g. Roman Catholic or Muslims and convert to say Pentecostalism later in adulthood? In short, there is an unhelpful rigidity in Bourdieu's depiction of the habitus.

In a way, Bourdieu attempted to address the issue of change through insisting that the habitus must always be seen in relation to the 'field'. He says it is 'a system of predispositions acquired through a relationship to a certain field' (Bourdieu 1990:90). He defines the field as 'historically constituted areas of activity with their specific institutions and their own laws of functioning' (Bourdieu 1990:87). The field is a social arena in which 'struggles and manoeuvres take place over specific resources or stakes

and access to them' (Jenkins 2002:84). Stakes are 'cultural goods (life-style), housing, intellectual distinction (education), employment, land, power (politics), social class, prestige' (Jenkins 2002:84).

Positions in the field and dispositions constituting the habitus can and, in many cases, do change.The same habitus can therefore produce different practices depending on what is happening in the field (Jenkins 2002). In addition, it is not fixed neither through time to an individual nor between generations (Mahar, Harker, and Wilkes 1990). Hence others have argued that the habitus could be seen as a mediating and not a determining construct (Mahar, Harker, and Wilkes 1990). An important point to note is that the field is structured internally in terms of power relations (Jenkins 2002).

Since the operation within the habitus is neither conscious nor unconscious, therefore taking it as a natural occurrence is what he calls the 'doxic' experience. Bourdieu argues that people operate within this doxic experience until it is challenged through a crisis giving rise to mutually related orthodoxy and heterodoxy. However crisis *per se* does not necessarily lead to the emergence of an alternative view: 'Crisis is a necessary condition for a questioning of doxa but is not in itself a sufficient condition for the production of a critical discourse' (Bourdieu 1977:169).The orthodox tries to re-establish the position of the doxa while heterodoxy offers other challenging alternative views, he argues that 'an orthodox or heterodox belief imply awareness and recognition of the possibility of different or antagonistic beliefs' (Bourdieu 1977:164). Bourdieu elaborates his concept in the following diagram.

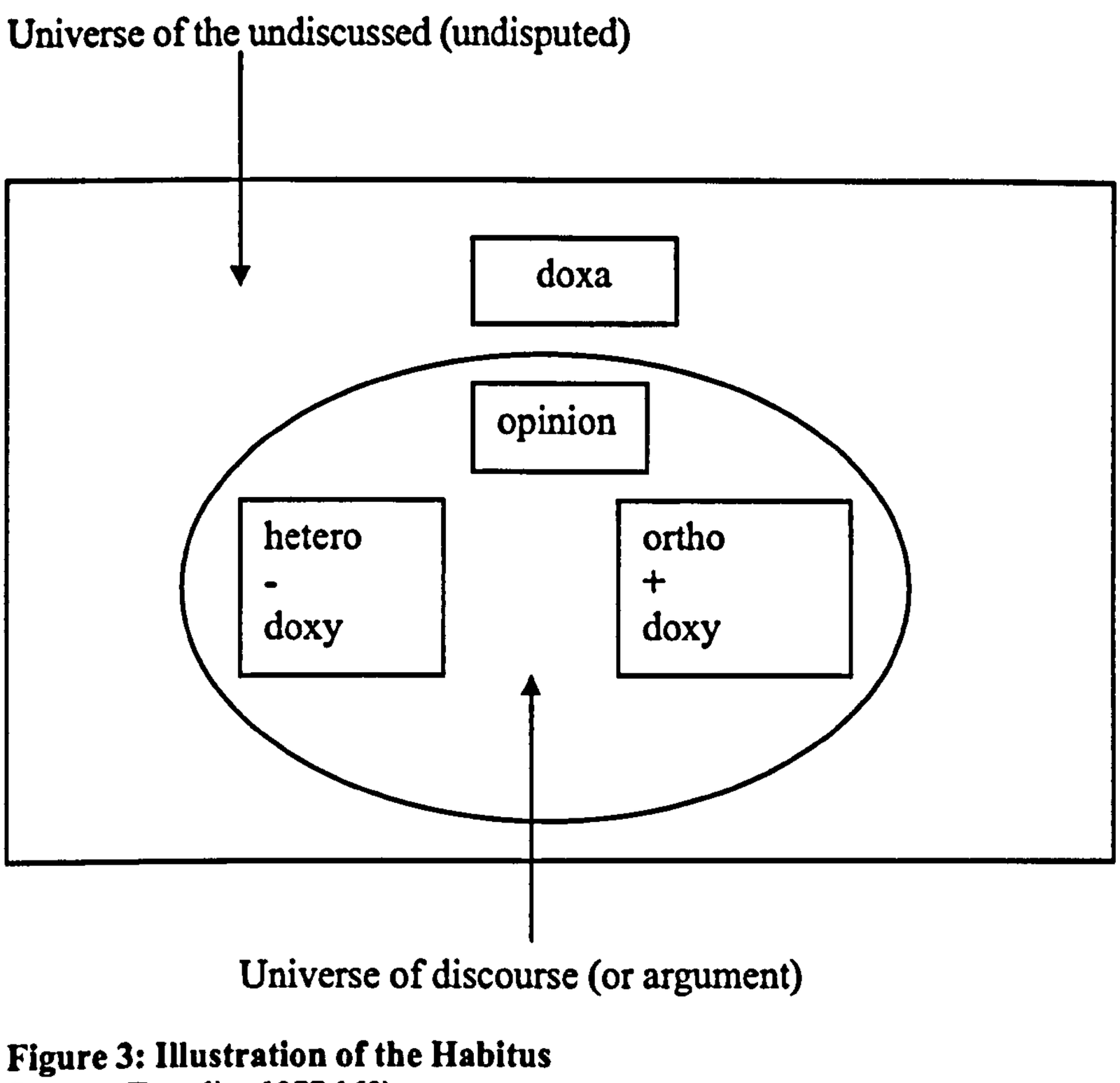


Figure 3: Illustration of the Habitus
Source: (Bourdieu 1977:168).

In his later works, Bourdieu seemed to suggest that the habitus is not the only thing guiding practice but only one of them. He pointed that the 'habitus is one principle of production of practices among others and although it is undoubtedly more frequently in play than any other' (Bourdieu 1990:108).

Therefore I interpret representations of stroke and their related practices in Dar and Hai by employing the concept of habitus. The different representations and practices emanate from complex social relations and processes involving conscious and unconscious endeavors leading to the different ways stroke is conceived, classified, interpreted and acted upon.

3.3.2 Strategy and strategizing

In his opposition to the proposal that human practice is a result of entirely rational action, Bourdieu emphasized his notion of logical practice. For him, practice is not entirely a conscious or unconscious enterprise but rather it is guided by what he calls 'practical sense'.

And therefore he argues that strategy should be taken as a product of unconscious and not conscious nor rational calculation. It is 'a product of practical sense, of a particular social game' (Lamaison and Bourdieu 1986:112).

This practical sense is acquired primarily through socialization. Bourdieu's practical logic has several characteristics. First, people take themselves and their social world for granted as they do not think about it. Secondly, practical logic is characterized by fluidity and indeterminacy as it is not entirely based on rules (Jenkins 2002). However, this is not to say that Bourdieu entirely rejects rules (whether transmitted orally, in written form or formed into coherent systems), but sees them operating within the habitus in the production of practice (Lamaison and Bourdieu 1986).

Bourdieu elaborated his concept of strategizing through an analysis which shows a complex interplay of various factors in honour, kinship and inheritance among Kabylia and Bearn societies. These factors are summarized in the following model.

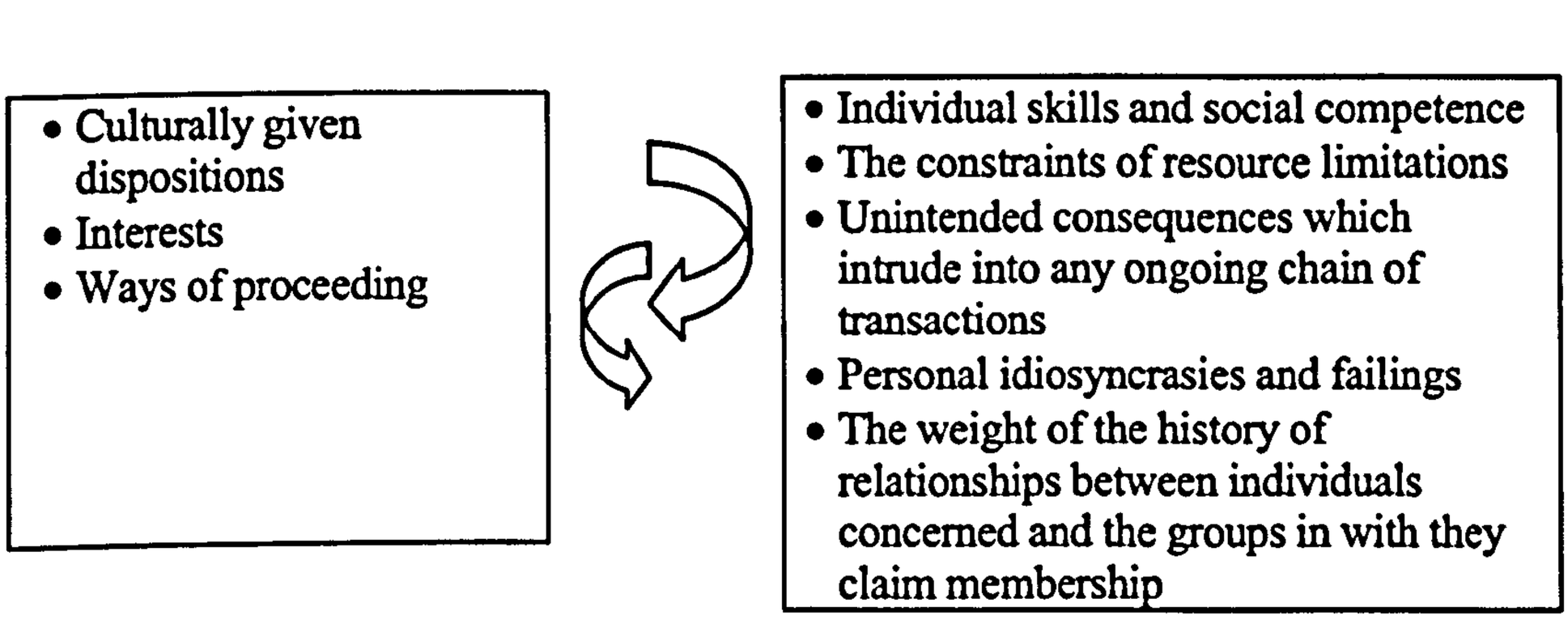


Figure 4: Factors in play in strategizing
Source: Based on (Jenkins 2002:72).

Jenkins (2002) points out that through this model, Bourdieu makes two important points. First, that social interaction is a mixture of freedom and constraint, and secondly, practice is a product of an ongoing process of learning beginning from childhood. Additionally, this model sees practice as a product of the encounter between the habitus and its dispositions

(left box) and the constraints, demands and opportunities of the social field (right box). This is therefore another way possibility of change is accommodated within Bourdieu's theory.

Bourdieu cautions that within logical practice, there must be a balance between logic and practice. He says too much logic may be counter-productive to practice. Giving an example of rituals and myth, he says 'too much logic would often be incompatible with practice or even in conflict with practical ends' (Lamaison and Bourdieu 1986:114). Jenkins (2002: pp. 69 & 71) summarises Bourdieu's conception of practice under three features:

i) Practice is located in time and space.
ii) Practice is not consciously or not wholly consciously organised and orchestrated.
iii) Although it is mostly achieved without conscious deliberation, it is not without purpose.

The concept of strategizing is useful when analyzing stroke treatment-seeking behaviours. For example, treatment-seeking can be seen as a negotiation between freedom and constraint with the habitus on one hand and the field on the other. In line with Bourdieu's model, I take into account the way factors such as individual skills, the constraints of resource limitations, relationships between individuals and groups to which they claim membership (e.g. religious groups) determine treatment-seeking within the broader sphere of practical sense. In addition, switching between different stroke treatment options (i.e. biomedical, traditional or faith) may seem illogical and indeterminate to an outsider. But when interpreted within a framework of 'practical sense', this fluidity may be taken as a strategy in dealing with stroke.

3.3.3 Symbolic power

The third of Bourdieu's concepts that I employ is that of symbolic power. In a close definition to Foucault's description of discourse, Bourdieu defines symbolic power as 'the ability to constitute visions' (Bourdieu 1989:23). He says it is the ability to make things in words, 'the power to impose upon other minds a vision, old or new' (Bourdieu 1989:23). From this definition, two things characterize symbolic power. First, it entails

the ability to create 'reality' by means of words, and secondly it is the ability to impose that 'reality' on others. Therefore in relation to stroke one would need to examine two things. First, we ought to examine the way the different stroke discourses are constituted. Secondly we should investigate how a discourse is thereafter 'imposed' on others as a 'true' construct of stroke.

Bourdieu (1989) further elaborates that symbolic power rests on two other things. First, it has to be based on possession of symbolic capital. He defined symbolic capital as the 'accumulation of a capital of honour and prestige' (Bourdieu 1977:179). According to him, symbolic capital is accumulated over time and can readily be converted into economic capital. Bourdieu argues that symbolic capital is 'nothing other than economic and cultural capital when it is known and recognized' (Bourdieu 1989:21). Therefore to him, symbolic capital is 'a credit' and 'it is the power granted to those who have obtained sufficient recognition to be in a position to impose recognition' (Bourdieu 1989:23). Therefore within a particular community, the holders of symbolic power could be people such as opinion leaders, experts and doctors.

Secondly he talks of 'symbolic efficacy' which depends on the degree to which the proposed vision is founded in reality. To him, in order for a reality to be successfully imposed on others, it should as much as possible correspond to what is actually 'taking place' as apparent to subjects. This closeness to reality does not only refer to physical reality, but also includes social, religious or cultural 'realities' which are already entrenched in a community. For example, if within a religious cosmology supernatural beings are already assigned position, when an illness is constructed by the holders of symbolic power as being caused by demons, it readily 'makes sense' to the people within that religious group.

It is important to note that the realities constructed should also be fronted as 'legitimate'. When further elaborating his idea of symbolic power, Bourdieu (1989) talked about 'symbolic struggles'. According to him, symbolic struggle is the 'power to produce and

to impose the legitimate vision of the world' (Bourdieu 1989:20). Therefore, one may also talk about the 'legitimate' constructs of stroke in terms of its cause and treatment.

Bourdieu says symbolic struggles may take place on two sides: the objective and subjective. On the objective side it entails fronting and exhibiting particular representations. He says, 'one may act by actions of representation, individual or collective, meant to display and to throw into relief certain realities' (Bourdieu 1989:20). On the collective form of objective symbolic struggles, he gives an example of demonstrations whose goal is to exhibit a group, its size, its strength, its cohesiveness, to make it exist visibly (Champagne 1984 as cited by Bourdieu 1989).

The manipulation of image is vital in order to successfully entrench a 'legitimate reality'. Therefore strategies of representations become important in the endeavor. He points out 'all the strategies of representation of self that are designed to manipulate one's self image' (Bourdieu 1989:20). Bourdieu also recognizes that agents act in an attempt to change the social constructs and it related structure. He argues that 'one may act by trying to transform categories of perception and appreciation of the social world, the cognitive and evaluative structures through which is constructed' (Bourdieu 1989:20).

Therefore in the symbolic struggle for the production of 'reality', symbolic capital becomes very important and agents make use of it:

> in the symbolic struggle, for the production of common sense or, more precisely, for the monopoly over legitimate naming, agents put into action the symbolic capital that they have acquired in previous struggles and which may be juridically guaranteed (Bourdieu 1989:21)

By mentioning 'juridically' guaranteeing, Bourdieu brings forward another aspect of symbolic capital. That it is 'officially' guaranteed and sanctioned for example through the education system. He says this happens through the 'recognition of education credentials as proof knowledge of expertise' or when 'someone is granted a title, a socially

recognized qualification' (Bourdieu 1989:21). At this point the holder of the title is 'freed from symbolic struggle' as their expert perspective is sanctioned by the state.

This is an interesting point in relation to stroke discourse as medical doctors and other health professionals are usually perceived as 'experts' by the majority of community members given their recognized and officially sanctioned qualifications. On the other hand, faith and traditional healers struggle to legitimize their views since they don't possess officially sanctioned qualifications. They therefore depend on 'socially recognized' qualifications legitimized through social position and interactions through their followers or people who consult them. My findings show that traditional healers struggle more as they often suffer from the effects of a negative perspective of their practice such as its association with witchcraft. When I talked to them, they were often keen to show me a government certificate in recognition of their practice. They also expressed a desire to collaborate with biomedical doctors in an effort to have their perspectives 'approved' by those endowed with symbolic capital (hence legitimized).

Bourdieu argues that symbolic struggle is a continuous process even though there is always an attempt by officials to impose an 'official view' expressed through official discourse. He says:

> in the struggle for the production and imposition of the legitimate vision of the social world, the holders of bureaucratic authority never establish an absolute monopoly, even when they add the authority of science to their bureaucratic authority (Bourdieu 1989:22).

3.3.4 Some limitations of Bourdieu's approach

A common criticism directed against Bourdieu is that his analysis is entirely class based. For him, classification is 'at the heart of social order and organisation' (Jenkins 2002). He sees classification as important in social construction done either by individuals or collective entities:

> Systems of classification which reproduce, in their own specific logic, the objective classes, i.e. the divisions by sex, age, or position in the relations of production, make their specific contribution to the reproduction of the power

> relations of which they are a product, by securing the misrecognition, and hence the recognition, of the arbitrariness on which they are based (Bourdieu 1977).

In consideration of this criticism, my analysis of stroke related practices was not entirely based on class. As already stated earlier, I carried out my analysis of stroke discourses by examining the broad social, cultural, religious and economic dynamics.

Though he was dismissive of such criticism, Bourdieu is also accused of subtle utilisation of structural and functional approaches in a kind of academic 'recycling' whereby old ideas are given new character addressing current challenges. Many people (including myself) would see no problem in this kind of endeavour only if sources were explicitly acknowledged. Aware of this criticism, Bourdieu argued that the writings he has drawn from, had encouraged him to express his thoughts rather being mere larceny.

Bourdieu never laid claim that his analytical viewpoint was the only 'correct' one. In other words he did not claim 'expertise' on subject areas or ethnographies of the people he studied (such as the Kabyle) but was at pains to point out that his research analysis only presented one of the many possible stories (Jenkins 2002). Additionally, he ventured to examine his methodology (his practices) and acknowledge that his work should be read as a product of the way he conducted his research. This reflexive attitude is his strength, given that it is rare in many ethnographic accounts. Bourdieu is often credited for his strive to ground his theory on empirical fieldwork (Jenkins 2002).

3.4 Conclusions

In this chapter I have presented my theoretical framework which depends on concepts from Bourdieu and Foucault as toolboxes. Foucault's concepts of discourse and the interplay of power/knowledge are adopted to facilitate the identification and examination of the emergence and existence of the multiple stroke discourses. Bourdieu's concepts of habitus, symbolic power, strategy and strategizing are employed to examine specific practices leading to the production and perpetuation of the discourses.

Bourdieu and Foucault are often criticised for changing positions in their conceptual frameworks. This should not be a major concern as it is widely acknowledged (and expected) that theories must be flexible and adaptive to the ever changing context. In addition, the two theorists are sometimes labelled as 'theorists of suspicion' due to their standpoint of not taking for granted what takes place. They are also criticised, for giving little recognition to subjects and prioritising social structure over agency. This criticism seems to stem from our human quest for the ideal of us having total freedom. Therefore the proposition that social structure may shape our actions most of the time seems frightening. But following Bourdieu, one may argue that probably these fears are themselves a result of the capitalist habitus whereby individual freedom is cherished as the corner stone of what it is to be human.

My theoretical framework proposes that the production and perpetuation of stroke discourses and treatment is a product of both conscious and unconscious endeavours of agents and social processes shaped by the systematic social, cultural, historical and economic factors. At the core of all these processes are power relations issues. Therefore the analysis of the various factors in play in the production and perpetuation of the way stroke is perceived and treated must involve the analysis of the power relations in its midst. This analysis starts at the individual level and works its way up to the wider community. The interaction of the different stroke discourses in the research sites and how decisions for seeking treatment are made is also examined. In addition, as a 'product' of this analysis, ways of initiating promising community-based stroke interventions is offered.

In the next chapter I describe the methodology I used to collect and analyse my data. I offer a detailed account of how I investigated stroke discourses through a thorough examination and analysis of the context of their production i.e. social-cultural and historical processes and the specific practices related to stroke. Later in my empirical chapters, I further make the connection between my theoretical framework and findings.

In addition, later on in the concluding chapter, I revisit my theoretical framework and make more explicit links with my findings.

4 Chapter Four: Methodology

4.1 Introduction

This chapter aims to describe the methodology of my research. Specifically, I describe my two research sites and discuss how I went about collecting and analysing my data. In the first section, I depict in detail my two research sites in rural and urban Tanzania. I present the socio demographics of the two populations and the historical, social and economic characteristics of the areas. I also provide background information on the development and the current status of biomedical health services in the two sites.

In the second section, I discuss meticulously the five methods I used to collect data. The methods are ethnographic fieldwork, in-depth interviews and key informant interviews (incorporating the vignette technique), focus group discussions and case studies. Moreover, I discuss how I compare my treatment-seeking behaviours data with that from the Tanzania Stroke Incidence Project (TSIP) interviews with stroke sufferers. I did this in order to get a sense of how common are the treatment-seeking options and patterns I found out through my qualitative research.

In the third section, I discuss the way I approached data analysis both practically and theoretically. I discuss how I was able to conduct a power relations analysis of stroke discourses using the suitable theoretical positions of Foucault and Bourdieu.
In section four, I reflect on my role as a Tanzanian researcher undertaking fieldwork at home. I also describe how I obtained ethical clearance to carry out my study from the appropriate bodies. I discuss how I dealt with the different ethical issues in the course of undertaking my research. Lastly, I conclude the chapter by summarising the main points covered and introduce the next chapter.

4.2 Study sites

I carried out my study in two sites: one in an urban setting (Temeke district of Dar-es-Salaam region) while the other is in a rural setting (Hai district of Kilimanjaro region). The two were part of the three sites where the Tanzanian Adult Morbidity and Mortality Project (AMMP) was set up in the late 1980s. In the course of its operation over a ten year period, the AMMP set up demographic surveillance sites (DSS) in each of the three sites: urban Dar-es-Salaam and rural Morogoro and Hai. The DSS were primarily established to determine the causes and trends of mortality and morbidity in Tanzania (Kitange et al. 1996).

The Tanzania Stroke Incidence Project (TSIP) was carried out in the Dar-es-Salaam and Hai study populations of AMMP. This was mainly due the fact that at the time of its inception, there were only two hospitals in Tanzania which were equipped to carry out Computerised Tomography head scans: one of the hospitals was in Dar-es-Salaam (Muhimbili) and the other was in Moshi Kilimanjaro (KCMC) near Hai site. CT scans are necessary tests in order to make valid medical stroke diagnosis. As specified in my introduction chapter, my initial research link with the TSIP and the value of identifying and following up clearly diagnosed stroke cases made me also pick Temeke and Hai as my research sites.

While the selection of the two sites provided an opportunity to examine rural and urban differences related to stroke discourses, there are clearly confounding factors operating. The two sites have different geographical features leading to differing social and economic activities. In addition they have distinct histories, social and cultural backgrounds thus making a direct comparison unattainable. However, by conducting my study in two sites I had a good opportunity of contrasting stroke discourses in an urban and rural setting through taking into account their differences. Indeed the two sites offer a good opportunity to demonstrate how such differences could lead to the production and perpetuation of differing illness discourses generally and stroke discourses in particular. In the following section I describe my two sites in detail.

4.2.1 General description of Hai district

Hai district is located in Kilimanjaro region in northern Tanzania. According to the 2002 national census, the district had a population of 258,935 people (127,127 males and 131,808 females). The largest ethnic group is the Chagga (75%) followed by the Maasai (12%), Pare (10%) and other ethnic groups making the remaining (3%) (Indepth Network 2002). The district has two main physical features: the mountainous terrain towards the famous Mount Kilimanjaro and the flat lowlands plains on the leeward part of the mountain. The fertile mountainous terrain has a high population density as the majority of the population is settled in the area. The main highway from Arusha town (tourist centre and headquarters of the East African community) to Moshi town and Dar-es-Salaam city passes through the district's administrative town of Bomang'ombe. The AMMP area in Hai comprises eight wards which are: Machame East, Machame South, Machame North, Machame West, Machame Uroki, Masama East, Masama West and Masama South. On average, a ward comprises five to six villages.

The district has two rainfall seasons. The long rains start from February to June and the short rains start from October to January. The lowlands (e.g. Bomang'ombe, Mtakuja and Rundugai areas) receive less rain than the highlands as the only substantial rain period is during the long rains period. Agriculture is the main economic activity in Hai. Due to the climatic conditions, people residing in the lowlands produce seasonal crops such as maize, beans, cassava, sorghum, groundnuts and sunflower. In some parts of the lowlands, people irrigate their farms using water from nearby rivers via furrows. In addition to farming, animal keeping is another common economic activity (especially among the Maasai) in the flat terrain area due to its landscape and grass vegetation. Animals kept include cattle, sheep, goats, and domestic fowl such as chicken and ducks.

The highlands towards the mountain receive more rain and are composed of fertile volcanic soil. This area is mostly populated by the Chagga ethnic group. Historical accounts as far back as the 18th century (1880) document that bananas, all kinds of yams,

beans, eleusine and maize were cultivated in Chagga land (Stahl 1965). Even at present, the highlands are characterised by the cultivation of bananas mixed with coffee, beans and maize. Due to recent rainfall shortages due to climate change, residents in the highlands also water their banana and coffee farms by tapping nearby rivers via furrows. Of recent, medium scale commercial flower farming for export has been started near Machame area.

Owing to the hilly terrain and shortage of grazing fields on the highlands most Chagga families have traditionally kept a few cattle indoors opting to fetch grass for feeding them. The grass is usually cut ether using sickles and machetes and tied in long bundles which are carried on the head. Fetching grass is therefore one of the main daily activities of women and children though generally the ownership of cattle is the realm of males. Residents in the highlands also keep goats, sheep, chickens and ducks. Many highland residents either own or hire farms (from people with big land or public land owned communally by the village cooperative societies) in the lowland plains where they cultivate maize and beans for food. I conducted my ethnographic fieldwork mainly in Machame area located in the highlands. When I began my fieldwork in August 2006, residents of Machame were harvesting maize and beans cultivated in farms on the lower plains.



Figure 5: A maize and banana farm in Nkwarungo village, Machame

In general, the highlands of Hai are more developed than the lower lands due to the influence of the missionary settlers who built churches, schools and health facilities. In addition, superior revenue from coffee in the past years enabled residents of the highlands to build more permanent structures than their counterparts in the lowlands. As one travels between the highlands and the lowlands one would notice that there are more iron sheet and cement block houses in the highlands than the lowlands where mud and grass thatched houses are common. At present though, coffee revenues have reduced due to fluctuations in the world market and the collapse of farmers' cooperative unions.



Figure 6: Mfooni village shopping centre, Machame

4.2.1.1 Historical background of the Chagga

The Chagga are a patrilineal Bantu speaking group. The earliest documented account of Kilimanjaro area and the Chagga was by a German missionary and explorer named Rebmann (Stahl 1965). He is credited as the first European to visit Chagga land after he walked from the Kenyan coast. In his first journey to Kilimanjaro Rebmann was accompanied by a experienced Swahili caravan leader known as Bwana Kheri who had visited Chagga land several times before (Stahl 1965).

It is acknowledged that the origin and history of the Chagga is complex (Setel 1996, Stahl 1965). The Chagga have often been described as an absorbing community since there has been accounts of people of other areas such as Taita and Kamba hills in the North (Kenya) Usambara hills in the East and Unyamwezi (South) coming and settling among the Chagga during the long distance trade era (Stahl 1965). Chagga history is also complex due to a high number of chiefdoms which existed before the British colonial administration streamlined them into fewer. A rough estimate puts the number of chiefdoms in Chagga land in early 19th century to be not less than 100 (Stahl 1965). Each unit had its own ruler (*Mangi*) though the number was reduced to around 50 by the last decade of the 19th century through absorption (Stahl 1965). By 1899 the number had

been reduced to 37 and to 15 by 1961 (Stahl 1965). Chiefdoms were abolished soon after Tanganyika gained independence in 1961 in a bid by the first Tanganyika government to forge national unity and reduce ethinic division. At the time the chiefdoms were abolished, Hai had six chiefdoms.

Chiefdom	Mangi in 1961	Number of tax payers
Siha (Kibong'oto)	John Gideon	3,082
Masama	Charles Shangali	5,271
Machame	Gilead Shangali	7,923
Kibosho	Alex Ngulisho	7,493
Uru	Sabhas Kisarike	6,049
Moshi	Tom Salema	4,299

Table 3: Chiefdoms in Hai division in 1961
Source: Stahl (1965)

In recent years various socio-economic dynamics have brought changes in Kilimanjaro region. For example, population increase has led to the decline of available fertile land for growth of traditional crops such as bananas and coffee. On the fertile highlands, a family owns between 1/4 and 1/8 of an acre which is only enough to build a house and grow some bananas and beans. These changes have also had an impact to the traditional ways of life of the Chagga such as the *kihamba* (Chagga term for farm) system whereby each family depended on its family farm for subsistence. In the past, the *kihamba* system assured the dominance of male members of the community over economic resources resulting in subsequent social power. Since land ownership is dwindling due to division to sons and their families, the economic power of men at the household level has reduced. In the past coffee and cows belonged to the husband while bananas, beans and chicken belonged to the wives. But currently, many families depend on selling bananas for subsistence. Bananas have therefore transformed from a food crop to a cash crop fetching between T Shillings 3,000 and 5,000 per batch.[4] During the dry periods when bananas become scare they can fetch up to T Shillings 8,000. At current there is talk of bananas belonging to both spouses. In addition, women's economic power has increased as they are the ones going to look for casual labour at the maize and horticulture farms. They are

[4] At the time I conducted my fieldwork 1 UK pound was equivalent to between 2,400 and 2,500 Tanzanian Shillings

paid about Tanzanian shillings 2,000 per day which they use to support their families. Men do not prefer doing casual labour because they regard it demeaning and also because their wives get money to sustain them anyway.



Figure 7: A tarmac road passing between a banana farm and water tank in Machame

Such changes have led to the migration of Chagga adults and youth to other parts of the region and country seeking economic opportunity (Setel 1996). In a way, the in and out migration of the Chagga has facilitated adoption of new lifestyles and cultural exchange such as the use of traditional medicine from other peoples and parts of the country.

4.2.1.2 Modern healthcare provision in Hai

Though considered rural, Hai has a well developed road, education and medical infrastructure compared to other rural areas in Tanzania. There are 19 public (government) health clinics (*zahanati*) and many more private ones located within the district. There are also 3 public health centres (*vituo vya afya*) located in Nkwansira, Kisiki and Masama villages. A health centre is a larger health facility than a clinic as it offers in patient services and operates a laboratory for investigations. Therefore a health centre has a larger number of staff than a clinic. On average a clinic would have 3-6 members of staff while a health centre would have between 10-15 members of staff.

In addition to the clinics and health centres, there are 4 hospitals in Hai. These are Kibong'oto hospital, Kibong'oto national TB hospital, a new Hai district hospital (all public) and Machame hospital (private). Kibong'oto national TB hospital was established in 1922[5] specifically to provide tuberculosis treatment services. Within the compound of Kibong'oto national TB hospital another independent hospital Kibong'oto district hospital is located. It was established in 1952[6] and until recently it was the designated district hospital for Hai. Within a period of the past several years a new district hospital has been built at the district headquarters town of Bomang'ombe. Machame hospital is a 220 bed hospital privately owned by the Lutheran church. It was established more than 100 years ago by German Lutheran missionaries.

There has been a long presence of modern biomedical services in Hai dating back to the late 1800s. A case in hand is Machame hospital and its network of clinics established by German Lutheran missionaries in the late 1880s (Lutheran Church Northern Diocese of Tanzania 1993).[7] The establishment of Machame hospital can be traced back to 1893 when German Lutheran church missionaries treated sores and skin problems under a tree within the present hospital premises. The hospital underwent transformation into a major hospital since that time. Even during the first and second world wars, the hospital continued to function by providing services to the local population. After the First World War the German staff were temporarily not allowed to stay in Tanganyika and for five years between 1920-1925 the first African employed at the hospital (Mr Gideon Mkony) managed the hospital. Between 1957 and 1962 the hospital was expanded to 120 beds. Between 1963 and 1968 the hospital was expanded to its current capacity of 220 beds. During the same time a clinical officer training college was built within the hospital.

To date Machame hospital has an extensive network of dispensaries in the following surrounding areas:

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[5] Personal communication by Hai district medical officer.
[6] Same source as in footnote 1.
[7] I obtained the history of Machame hospital from an official document I was kindly offered by the hospital's management. The document was written during the celebration of 100 years of the hospital in 1993.

i) Masama dispensary-16 bed built in 1917 under a German missionary Rev Gutmann.

ii) Lyamungo dispensary-built in 1957. Closed by government in 1970 because government had build own dispensary nearby. Re-opened by church in 1978.

iii) Lemira dispensary- established in 1971.

iv) Nomenti dispensary- established in 1987.

v) N'guni dispensary- established in 1987.

vi) Lukani dispensary-established in 1988.

From this account it is evident that the provision of biomedical health services has a long history in Hai.

4.2.2 General description of Temeke district

Temeke district is located in Dar-es-Salaam region, the commercial capital of Tanzania situated on the shores of the Indian Ocean. Temeke in located in the southwestern part of Dar-es-Salaam city. According to the 2002 national census, the district had a population of 768, 451 people (387,364 males and 381,087 females). The population in Temeke is of mixed ethnicity from other parts of Tanzania though originally occupied by the Zaramo ethnic group. 70% of residents in the Dar-es-Salaam AMMP project area are Moslems while Christians make the remaining 30% (Indepth Network 2002). The AMMP area in Dar-es-Salaam covered 4 wards namely Mtoni, Chang'ombe, Keko and Ilala. Compared to the other two district of Dar-es-Salaam (Ilala and Kinondoni), Temeke is considered to be of a lower socio-economic status due to its poor transport infrastructure, housing and social services such as water, electricity and health. The main economic activities in Temeke are commerce, including all forms of trading, both large and small-scale, formal employment in the government or private sectors, and fishing.



Figure 8: Main mtaa (street) of Saba-saba area, Temeke

I specifically conducted my ethnographic fieldwork in the Saba-saba area of Mtoni ward. The area has acquired its name from the nearby 'Saba-saba' ground which holds the annual international trade exhibition. The area sprawls outwards alongside a busy main highway (Kilwa road) running from the city centre to the south. The road is always busy, with big lorries and lots of mini town buses (known in Swahili as '*dala dala*') rushing past. One can see faces pressed up against windows, and people standing up, crammed into the minibuses and using every available space. Bordering the road are stores selling maize, general goods and hair salons, food stalls and bars. Dust is often in the air, and at times the floor appears to merge into a rubbish dump, and then returns to sand.



Figure 9: Saba-saba along Kilwa road

The eastern part of Saba-saba stretches across a railway track (commonly known as TAZARA) running from the city station and docks to southern Tanzania and Zambia. Residents often use the railway line as a foot path to walk along from one place to another. The majority of households in Saba-saba do not have running water. Their residents have to buy water for domestic use from people who have running water in their homes and have decided to do the business of selling it. A 20 litre bucket of water is sold for between 10 and 20 shillings. In figure nine, one can see two girls carrying water buckets on their heads along Kilwa road. .



Figure 10: Boys playing football near the TAZARA railway line in Saba-saba

As one walks down the main street (in Swahili *mtaa*) of Saba-saba, they are met with an urban bustle of life and colour, as market stalls, street sellers and stands with colourful, painted advertisements line the sides of the *mtaa*. People and vehicles of all ages cross paths, and greet each other. As one walks around, poverty literally surrounds you in the maze of streets and houses that are found in this area. Population density is extremely high evident through closely built houses. In some places one has to negotiate the footpaths between narrow alleys passing between closely built walls and windows. Along these footpaths, one cannot walk far without stumbling upon a group of children, women or men going about their daily tasks.



Figure 11: High density housing in Saba-saba

4.2.2.1 Historical background of the Swahili of Dar-es-Salaam

As already stated, the population of Temeke is typical of urban Tanzanian populations comprising several multi ethnic groups. Though the original ethnic resident group is the Zaramo (a Bantu speaking group) the area is also populated by other Bantu speaking groups which settled there long before the recent immigration of other groups for employment, education and business purposes. The long settled ethnic groups in Temeke are the Matumbi, Mafia and Ndengereko. It is difficult to pinpoint the exact time of immigration of these other groups but they probably moved and settled in the area hundreds of years ago in pursuit of trade and fishing. These long settled ethnic groups are generally referred to as the Swahili (people of the coast) by other recently immigrant ethnic groups and those in the hinterland.

Swahili is an identity referring to the East African coast population of a mixture of Arabic and Bantu groups (Caplan 1997, Wynne-Jones 2007). The interaction between East African coast Bantu groups and Arabs goes back to well before the colonial period. (The) Swahili is therefore a general label of people residing from Southern Somalia

through the Kenyan and Tanzanian coast to the northern part of Mozambique (Giles 1995, Wynne-Jones 2007). People residing in islands along the east African coast such as Zanzibar and Mafia are also characterized as the Swahili.

Swahili identity has been constructed in a variety of ways through research by scholars from various disciplines such as history, archaeology, anthropology and political science by emphasizing aspects of interest to them (Caplan 1997, Wynne-Jones 2007). For example the Arabic or Bantu origins of the identity may be emphasized depending on the nature and aim of a study (Wynne-Jones 2007). Swahili language is a product of a combination of Bantu dialects and Arabic and Portuguese. It is interesting to note that none of my informants self identified as Swahili but always identified themselves by their 'original' ethnic groups such as Zaramo, Ndengereko and Mafia.



Figure 12: A woman clothed in Khanga common among women in Saba-saba

4.2.2.2 Modern healthcare provision in Dar-es-Salaam

There are 113 health facilities in Temeke (of which 23 are public). The facilities are scattered around the district and are also utilised by people who come from outside the

district. In the course of looking for better services, some residents of Temeke also utilise health facilities located in either Ilala or Kinondoni districts.

Officially, the district is served by Temeke district hospital, a 150 bed public health facility. The hospital is usually overwhelmed by the large number of people who seek services. Common are stories of patients queuing for hours as they wait to be served by the overstretched medical staff. It is common practice for severe and complicated cases at the hospital to be referred to Muhimbili national referral hospital (located in Ilala district) for further management.

Historically, most public hospitals in Dar-es-Salaam were built during the colonial period to cater primarily for colonial government employees. An example of such health institutions are Muhimbili national referral hospital and Ocean road hospital. Muhimbili hospital was built by the British colonial government in the 1950s. It was initially named after Princess Margaret (Queen Elizabeth II's late sister) who had visited the colony during that time. Most public hospitals and clinics/dispensaries in Dar-es-Salaam were built after independence either through government or private funds or contributions by residents.

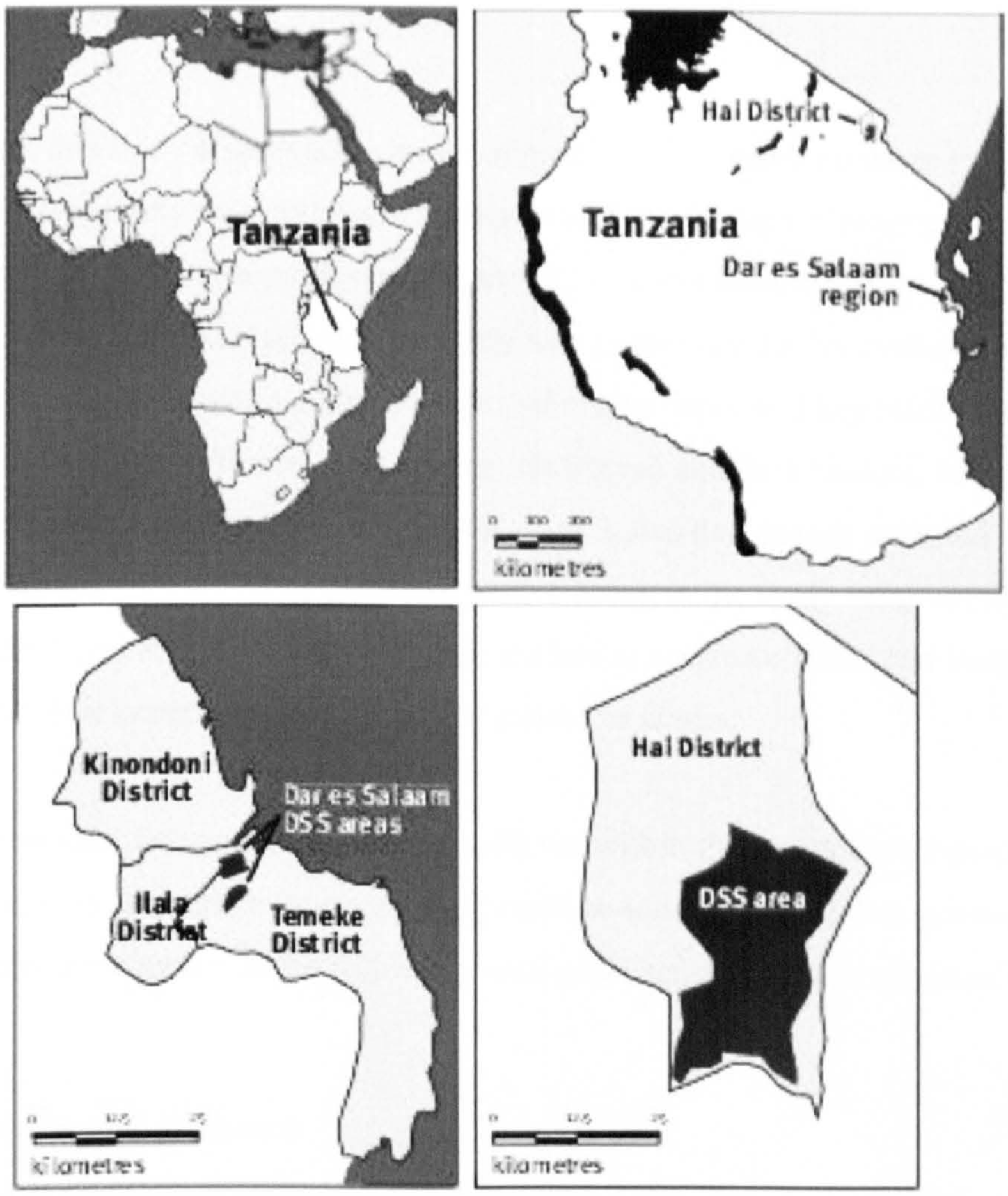


Figure 13: Maps showing location of the two research sites [8]

The top left frame shows the location of Tanzania in Africa. The top right frame shows the location of Dar and Hai in Tanzania. The bottom frames show the AMMP DSS sites in Dar and Hai. I conducted my fieldwork in Saba-saba area of Temeke district and Machame area of Hai district which are located in the former AMMP DSS sites.

[8] **Source:** Indepth Network (2002). Population and Health in Developing Countries. Ottawa: IDRC.

4.3 Data collection

As indicated, this study employed a variety of qualitative research methods in data collection. The primary data collection method was done through ethnographic fieldwork. I lived in each of the two research sites for periods of about six months. In addition, during my stay in Dar and Hai I collected data using other qualitative methods namely; focus group discussions with young and older adults, in-depth and key informant interviews with stroke sufferers, their careers, traditional and faith healers, health workers in public and private facilities and religious leaders. I also had chance informal interviews and conversations with different groups of people living in the study communities. In addition I identified and followed up 20 case studies of stroke sufferers and their families documenting their experiences and practices related to stroke.

All these other qualitative methods were conducted within the broader ethnographic inquiry in order to facilitate a thorough interpretation and analysis of data grounded within the broader context. In the following section I discuss my data collection methods in detail.

4.3.1 Ethnographic fieldwork

This method is also known as participant observation in the broader social science literature (Bernard 1995). It is the main research method used in social anthropology. During ethnographic fieldwork, a researcher spends an extended period of time living along with the community under study in order to gain as complete as possible an understanding of the study topic. Data obtained through ethnographic fieldwork may also supplement and validate information obtained through other methods (Sanjek 1990).

In addition to providing a broader context, ethnographic fieldwork tends to produce more valid data as it does not depend entirely of self reporting (Bernard 1995). It enables a researcher to observe what is happening in the field in relation to their subject of interest. It is acknowledged that reported data has some validity limitations as respondents tend to provide the researcher with 'edited' or 'sanitised' accounts of what is taking place

(Bernard 1995, Bryman 2004). This may be for various reasons such as protecting the status quo of the individual or their communities. Thus prolonged ethnographic fieldwork provides a researcher with an opportunity to get a better sense of what is going on as they engage in daily activities of communities. Ethnographic fieldwork also provides a researcher with the opportunity to cross check the validity of data they are collecting through talking with other people in the community (Bernard 1995).

I commenced my ethnographic fieldwork in August 2006 by living in Hai for four months. In December 2006 I moved to Dar where I also lived for a period of 4 months. In May 2007, I came to Durham for six weeks of preliminary analysis and further reading before going back to Dar and Hai to complete my fieldwork. While carrying out my ethnographic fieldwork I lived in rented accommodation in Machame area in Hai and Saba-saba area in Dar-es-Salaam. I went about my fieldwork daily and documenting observations and conversations in an ethnographic diary.

I decided to live in Machame because it is centrally located between the highland villages towards Kilimanjaro Mountain and the lower leeward side. Saba-saba in Dar-es-Salaam is also centrally located for one to be able to easily access other parts of Temeke. In course of my fieldwork, I participated in life activities in the village/*mtaa* like all other members such as attending ceremonies, public meetings and other social gatherings. I traveled around my study sites by walking short distances and using public transport when traveling between long distances.

4.3.2 Focus Group Discussions (FGDs)

FGDs are a widely utilised qualitative research method especially when exploring understandings and attitudes at the wider community level (Bloor 2001, Fern 2001, Morgan 1997). The method enables a researcher to investigate an issue of interest while at the same time observing the group dynamics and consensus reaching on the topic under investigation. The use of FGDs was particularly useful in my study as it enabled me to explore how stroke is perceived in terms of priority health needs, how it is generally understood in the two communities and reacted upon. FGDs also provided an

opportunity to explore power differences between local people and decision-makers, as well as the degree of consensus on specific topics of inquiry.

I conducted 6 FGDs in each site with participants of two main age groups. The first group was of younger males and females of less than 45 years of age. The second group comprised of older male and female adults aged more than 45 years. Each FGDs was same sex and facilitated by a same sex researcher (either myself or my two male and female research assistants in each site). The FGDs comprised 6 -12 members. The discussions were conducted in Swahili (the widely spoken nation language) and were voice recorded.

These were participatory FGDs using free listing and mapping to stimulate and guide discussions. The purpose of conducting free lists was to isolate and define relevant illness categories from the community's point of view. Free listing questions simply ask the respondents to list as many items as they can think of in a particular category, for example, talk about stroke in general and categories of stroke as conceived in their community. It is the best way to ensure that the concepts and the domain are culturally relevant. In addition, free listing was used to explore how people term different illnesses including stroke. I also explored ideas about 'different' types of strokes and how they are perceived in terms of importance and seeking treatment. Participants were also requested to discuss the type of service available whether 'modern' or 'traditional' and how they are accessed.

4.3.3 In-depth interviews

I conducted in-depth interviews using semi-structured guides (SSI). The interviews explored a broad range of issues related to stroke discourses from the history of health seeking to current practices. The interviews also explored personal experiences of stroke, the experience of caring and support of stroke sufferers, perceptions on cause and risks, treatment and coping with stroke. By interviewing individuals about their own experiences, one can move from a normative view (expressed for instance during FGDs) to the practice of individuals, through their narratives. In-depth interviews allow for

maximum flexibility of coverage and can capture the richness of the themes emerging from the respondents' talk (Drever 1995).

Specifically, I conducted the following number of interviews: repeated interviews with 20 stroke sufferers and 20 carers. In addition I conducted 20 one-off interviews with stroke sufferers and 20 one-off interviews with their carers. I also conducted 10 repeated interviews with traditional healers, 4 interviews with faith healers and 8 interviews with health workers/doctors. Therefore in total I conducted in-depth interviews with 102 individuals.

Following is the range of issues explored during interviews with each group.
Stroke sufferers: these were interviewed to enable them talk about their experience, for example, how and when their stroke(s) happened, how they make sense of it (e.g. why it happened to them) and what they did afterwards. Stroke sufferers were requested to reflect on how the illness has transformed their lives and world view. This reflection included both physical and non physical aspects of their lives.

Carers (relatives and close friends of sufferers): these were interviewed on how they understand stroke, and how they take care of the stroke sufferers. They were also interviewed on how caring for a stroke patients has transformed their families and their own world view. During the interviews, questions about treatment for stroke sufferers were asked and how these decisions are negotiated and made within their families and wider community.
Service providers (medical professionals in modern healthcare settings, traditional and faith healers): these were interviewed on their understanding of stroke in terms of cause, risks and treatment. They were also asked how they diagnose and treat stroke. For traditional and faith healers, interviews solicited exact details on how they treat stroke, for example, what materials they use to prepare the medicine and how they are utilised. Interviews also solicited explanations of any beliefs systems (e.g. cultural or religious) which are applied in diagnosis and treatment of stroke.

4.3.4 Key informant interviews

Key informant interviews are usually conducted with informants who are purposively selected because of their knowledge of the researched topic (Bernard 1995). It is a method used to obtain more detailed and information and clarify points of conflicts from data obtained through other methods. Key informant interviews are best suited when conducted within an ethnographic enquiry as the researcher has the time to know members of the studied community and therefore be able to gauge which members hold suitable information with regard to their research topic.

I conducted interviews with purposively selected key informants in order to get detailed information on stroke discourses. I interviewed 20 key informants (10 in each sites). These were mostly older adults (most above 60 years) with knowledge about the history of the study sites. They were also selected because they had rich information about illness discourses and the range of stroke treatment. I also used my interviews with the key informants to crosscheck and clarify information I had obtained through the other methods.

4.3.5 Vignette technique

Vignettes are stories generated from a range of sources including previous research findings (Hughes 1998). Miles and Huberman (1994: 81) define them as 'a focused description of a series of events taken to be representative, typical, or emblematic' in a research topic or field. Vignettes are useful when a researcher aims to clarify what is happening by theorising and 'formulating core issues' (Miles and Huberman 1994). They make reference to important points in the study of perceptions, attitudes and beliefs (Hughes 1998). Respondents are asked to respond to these stories and the situation they represent in a third party scenario. They therefore provide a researcher with an opportunity to get the views of study participants on the data gathered and theorising from its preliminary analysis (Miles and Huberman 1994).

In 40 in-depth with stroke sufferers, carers and key informant interviews, I employed the vignette technique in order to get more information of stroke discourses and examine

relate to each other. The technique was useful in understanding the reasons and process through which choice between the different treatment options is done. I developed two sets of vignettes stories appropriate for each of my two sites after gathering data from the first set of interviews. I also used the technique to allow people to talk about their practices or representations of stroke in a third party scenario in order to make them freer to talk and express their opinions without the fear of how they would be perceived. The vignettes were administered at the end of the interviews in order to avoid biasing the participants.

4.3.6 Case studies

Case studies are an appropriate research method when a researcher aims to examine the contextual aspects of the topic under study (Yin 2003). The method enables a researcher to study the phenomenon of interest within the context of its occurrence and specifically, 'when the phenomenon under study is not readily distinguishable from its context' through complex interactions (Yin 2003:4). Though the case study is a method on its own merit, it is useful in providing comparative and illuminating data when multiple data collection methods are employed. In my study, I have used them to provide material which complements that collected through the other methods and specifically in order to provide vivid illustrations on the life of families with stroke sufferers. I utilise multiple case studies representing the different characteristics and circumstances of families such as their different religious backgrounds, socioeconomic status and different family structures and size. I selected the cases after undertaking several weeks of ethnographic fieldwork and the first round of interviews.

I closely followed up 20 case studies (10 in each site) of stroke sufferers and their carer families over a period of six months. I visited and interviewed stroke sufferers and family members on several occasions. I selected the case studies in order to follow-up how the sufferers and their families deal with issues related to stroke. I also used the case studies to examine practical aspects of how they dealt with stroke. The method provides real case scenarios of what happens when people grapple with stroke in the two research sites.

4.3.7 Other forms of data

When I present findings regarding treatment-seeking behaviours for stroke in chapter six, I include comparative treatment-seeking data from the TSIP survey questionnaire. I have presented this data in order to demonstrate the representativeness and strength of my qualitative findings. These data have not been published anywhere and its availability adds to the strength of my findings as the TSIP data draws from a wider sample of stroke sufferers. I also use pictures I took during my fieldwork for illustrations. The pictures I use were carefully selected to avoid recognition of people in them and compromise anonymity.

4.4 Data analysis

4.4.1 Practical data processing

Data analysis comprised two main stages. The first stage of analysis occurred while I was carrying out my fieldwork. This is in line with the grounded theory approach whereby there is simultaneous data collection and analysis. This repetitive interplay between data collection and analysis is what Bryman (2004:399) terms 'iterative' process. I examined the data I collected as I went along and wrote analytic notes on what was emerging. During fieldwork, I also coded my field notes using the 'open coding' approach (Strauss and Corbin 1990). This coding approached is defined as 'the process of breaking down, examining, comparing, conceptualizing and categorizing data' (Strauss and Corbin 1990:61). In addition, I listened to the audio tapes of interviews and FGDs and categorised emerging patterns using the same approach. I engaged my preliminary findings from the field through cross checking data from different methods and sources. I also clarified issues which were still not clear through engaging the research participants and further observation.

I conducted the second stage of analysis after I left the field and came back to the UK. This entailed transcribing all voice recorded FGDs and about two thirds of the interviews. I translated one third of the Swahili transcripts into English in order to give access to my data to my non Swahili speaking supervisors. I selected interviews for transcription on

two criteria: first, I selected interviews which went particularly well in which respondents provided rich information and illustrations on emerging concepts. Secondly, I selected interviews which were difficult to interpret whereby respondents either produced disjointed accounts or very different information from the majority others. I used the same two criteria to select the one third of FGDs and interview transcripts for translation into English in order to facilitate input from my supervisors.

In addition, I open coded some of the transcripts (one third) using NVIVO (QSR International Pty, Sydney, Australia) software to cross check if the same conceptual categories (as the ones from the field coding) were maintained. Thereafter I re-read the transcripts and re-listened to the recording to cross check the emerging concepts from the preliminary analysis in the field and test hypotheses I had formulated from the data (Bryman 2004). As already indicated, in both stages of analysis, I derived theoretical concepts from ethnographic notes and FGDs and interview transcripts by coding the data into emerging categories. Subsequently, I undertook a close examination and inductive testing of the theoretical concepts to establish their relationships. The concepts were constantly refined by engaging data already collected and following new data.

In both stages of coding, I made sure that the contextual value of the data was not lost as this is cited as the main shortcoming of text coding (Bryman 2004). In addition, in the course of coding and retrieving the data, I made sure I kept touch with the 'narrative flow' of the data. This was particularly important as I conducted a 'narrative' analysis of the accounts of some research participants in order to get their interpretation of the accounts. Bryman points out that with narrative analysis 'the focus shifts from "what actually happened" to "how do people make sense of what happened"' (Bryman 2004:412). This is important in order to get an emic view of the topic of investigation, even though researchers are cautioned to treat the narratives critically (Bryman 2004).

4.4.2 Theoretical approach to data analysis

As discussed in the previous chapter, my approach of making use of a grounded theory analysis led to the 'emergence' of the power relations theory from my data (Glaser 1998).

Subsequently I refined my analysis and later data collection stages by engaging a power relations theoretical framework employing the relevant theoretical positions of Foucault and Bourdieu discussed in the previous chapter. This mainly involved the examination of data obtained from the different groups of respondents and their social positions within their communities. In addition, I examined the personal experiences of the respondents in relation to stroke and their interpretation of it. Besides, I examined the link between the various stroke discourses and their base institutions.

Foucault argues that discourses should not be treated as 'group of signs' but 'practices that systematically form the objects of which they speak'(Foucault 2002:54). Though he acknowledges that discourses are composed of signs, but they do more by using the signs 'to designate things'(Foucault 2002:54). The observation, documentation, gathering of statements from interviews and analysis of practices related to stroke enabled me to analyse the 'objects' formulated which were the different representations and ways stroke is constructed and treated.

In my analysis of text data, I utilised aspects of Foucault's discursive analytical approach. He described the way to conduct a discursive analysis by saying:

> We must grasp the statement in the exact specificity of its occurrence: determine its conditions of existence, fix at least its limits, establish its correlations with other statements that may be connected with it, and show what other forms of statement it excludes.(Foucault 2002:30).

The data from the five methodologies I employed produced views and experiences about stroke which may also be termed as 'statements'. In examining the power relations aspects of the statements, I employed Foucault's suggestion of a three way process (Foucault 2002:55). He says three tasks should be undertaken when conducting such an analysis beginning with the question, who is speaking? Further questions would be:

> Who is accorded to use that sort of language?... Who is qualified to do so?... What is the status of the individuals who-alone-have the right, sanctioned by law or

> tradition, juridically defined or spontaneously accepted, to proffer such a discourse? (Foucault 2002:55)

Here we see Foucault talking about something similar to Bourdieu's concept of symbolic power. As pointed out in the previous chapter, symbolic power entails the official recognition either through law or recognized qualifications or legitimate position of views or statements by certain people.

Through their symbolic power, such views carry more weight than others. These views acquire certain credibility and are more likely to be taken as 'facts' as they are given by people regarded as experts. Picking an example of medical statements, Foucault (2002:56) says :

> medical statements cannot come from anybody; their value, efficacy, even their therapeutic powers, and, generally speaking, their existence as medical statements cannot be disassociated from the statutory defined person who has the right to make them, and to claim from them the power to overcome suffering and death.

According to Foucault, the second task in examining the power relations of statements involves the examination of the institutional base of a discourse. He argues that 'we must also describe the institutional sites from which the doctor makes his discourse, and from which this discourse derives its legitimate source and the point of application'(Foucault 2002:56). Therefore in my analysis, I examined the institutional bases of the different data texts, statements and discourses whether being a biomedical, cultural or religious base.

The third task is to examine the position of the subject in relation to the discourse (Foucault 2002:57-58). In Foucault's words 'the positions of the subject are defined by the situation that it is possible for him to occupy in relation to the various domains or groups of objects'. For example he points out that one might ask, is he or she a questioning, listening, seeing or observatory subject? And here the criticism which is leveled against Foucault comes in. He is clearly assigning the subject a position which he is conditioned by the discourse that is listening, questioning or observing. He or she is in

a way a reacting subject and not composer or central participant of discourse as social interaction theory would suggest. Taking into consideration such shortcomings and the view of social interaction theory (Charmaz 2006) that individuals are not passive but rather active participants in social life, my analysis treated subjects as active participants in the discourse therefore central in constituting and perpetuating it.

I also employed Bourdieu's concept of field during my analysis. In this regard, stroke is taken to be constructed in relation to the person's habitus and conditions in the field (social structure). This could either be due to their religious or cultural beliefs, their education level and professional status, if they are medical doctors and practitioners, healers (traditional or faith), religious leaders, community leaders, role in family (father, mother, child), of ordinary community members. These positions interact with their habitus in an ongoing process.

In this analytical approach it is assumed that in the production and perpetuation of stroke discourses, people unconsciously (or consciously) move between fields, and this leads to repositioning of their habitus. The examination of individual's positions in the field is similar to the discursive analysis presented by Foucault.

4.4.3 Reflexivity

It is important for a researcher to try to be aware of, and factor in, some of the things which might influence the kind of data they gather. This is a significant exercise as it enables one to realise and acknowledge the possible strengths and weakness of their data. Reflexivity is therefore an important concept in carrying out social research in general and ethnographic fieldwork in particular. It has been pointed out that 'concepts of reflexivity range from self-reference to self-awareness to the constitute circularity of accounts or texts' (Bourdieu and Wacquant 1992:37). In particular, Bourdieu is known for his preoccupation with reflexivity as he insists on 'a self analysis of the sociologist as a cultural producer' (Bourdieu and Wacquant 1992:36). In carrying out my research I followed Berger's view that reflexivity entails 'self-awareness and reflection' which is

valuable for researchers to locate their position and role in carrying out research and producing the research findings (Berger 1981, Berger 1991).

Being a Tanzanian carrying out ethnographic research in my country I engaged in an ongoing process of being aware of my different roles as 'the ethnographer-as-member-of society and ethnographer-as-analyst' (Bourdieu and Wacquant 1992:37). Despite the effort in self reflection I realise that the ideal of becoming 'the utterly detached observer' (Berger 1981:222) is not always achieved especially if the Tanzanian habitus was unconsciously guiding some of my ways of carrying out fieldwork and interpretation of data. Nevertheless the self reflection exercise helps one to check some bias in carrying out research. Bourdieu argues that there are three sources of bias when carrying out social research. The first source of bias may arise due to 'the *social* origins and coordinates (such as class, gender, ethnicity etc.)' (Bourdieu and Wacquant 1992:39). This source of bias is linked to the social structure. It is therefore plausible that despite my efforts to reduce the social desirability bias, my research participants and other members of the study communities still perceived me as a privileged, educated, urban, male Tanzanian researcher.

In addition, since I always seemed interested to talk about stroke and illness in general, some of my respondents and informants used to address me as 'doctor'. Though on several occasions I told them that I was not a doctor, some would still refer to me as 'doctor' when we met again on different occasions. This made me wonder whether their perception was due to the fact that I always seemed interested in talking about illness whenever we met. Or was it due to my association to TSIP and the similar things we were both enquiring about? I tried to address this perception through clarifying verbally that I was not a doctor. I also decided to talk about other general things such as the weather and sports when I met my respondents. I hope that this helped in clarifying my role as a researcher though I will probably never be able to know for be sure to what extent my conscious endeavour changed their perception of me.

The second source of bias that Bourdieu highlights is linked to the 'position that the analyst occupies, not in the broader social structure, but in the microcosm of the *academic* field, that is, in the objective space of possible intellectual positions offered to him or her at a given moment, and, beyond, in the field of power' (Bourdieu and Wacquant 1992:39). Here, Bourdieu brings out the point that the way one is ushered and natured into a research career or training may have a long lasting effect on the way they interpret any social phenomenon they study. This viewpoint is similar to what the grounded theory approach is uncomfortable with when it refutes the deductive approach to theorising of findings arguing that it imposes a certain preconceived theoretical stance on the data (Glaser 1998). My inductive approach to data analysis ensured that I avoided imposing any preconceived theoretical views on the data.

It is important to point out that being a Lutheran Christian, I sometimes found myself in a dilemma through some of the information I obtained during my fieldwork and the circumstances I had to go through to obtain them such as visiting and listening to different types of faith and traditional healers. It is always assumed that researchers would 'remove' their person's hat and 'put on' the objective researcher hat when carrying out fieldwork. Then after completing fieldwork they would 'remove' their researcher hat and 'put back' their person's hat. In practice it probably does not happen in the seemingly easy way as portrayed. We probably always move between our different roles as researchers and self even while carrying out fieldwork.

Thirdly, Bourdieu talks of 'the *intellectualist* bias which entices us to construe the world as a *spectacle*, as a set of significations to be interpreted rather than concrete problems to be solved practically' (Bourdieu and Wacquant 1992:39). Therefore rather than researchers treating things they study as something they do not want to 'tamper with', they must acknowledge that their research might as well already have interfered with what is happening in the field. In this last point Bourdieu underlines his view that social research should have an applied value rather than it only be done for academic purpose's sake and not be put off by fear of 'contaminating' the field. This is what he terms 'epistemic reflexivity'.

In highlighting these points of reflection, I echo what Bourdieu said about his research. He resisted claiming 'expertise' on subject areas or ethnographies of the people he studied and was at pains to point out that his research findings only presented one of the many possible stories (Jenkins 2002). Additionally, he ventured to examine his methodology (his practices) and acknowledge that his work should be read as a product of they way he conducted his research. It is with reflexive note that I will embark in presenting my findings in the following chapters.

4.5 Ethical considerations

Ethical approval for the study was obtained from the Tanzanian Medical Research Coordination Committee and the ethics committee of the department of anthropology of Durham University. In conducting my fieldwork, I took into consideration ethical interests and obligations to my research participants, communities, national and professional bodies as recommended by the Association of Social Anthropologists of the UK and the Commonwealth (Association of Social Anthropologists of the UK and the Commonwealth 1999).

In particular, prior to commencing my ethnographic research I informed and obtained permission from the relevant national, district and village/*mtaa* authorities. I made sure I introduced my research to people I interacted with in the two research sites. For FGDs and interview respondents, I introduced the study through an information sheet read to them which clearly indicated that participation in the study was voluntary and that participants could withdraw from the study at any time without giving reasons. I left a copy of the information sheet with my contact details to each participant in case they wished to contact me in the future for matters related to my research. Informed oral or written/thumbprint consent was requested from those willing to participate in my study. Confidentiality and anonymity was assured and ensured in the information gathered from

the study participants by, for example, using codes instead of names when writing ethnographic notes.

4.6 Conclusions

In this chapter I have presented my research methodology by describing my two research sites by detailing their geographic and socio-economic characteristics. I have showed how the different historical, social and economic processes facilitated shaping their current form. In addition I have discussed at length the historical development of biomedical health service provision in the two areas. This will help put into context my findings of the current stroke discourses and demonstrate how they are informed by such processes.

I have also discussed the five qualitative methods I employed in collecting data namely, ethnographic fieldwork, in-depth and key informant interviews, focus group discussions and case studies. I have detailed how I utilised the methods and stating how each adds value to my findings. I have also presented how I approached data analysis practically and theoretically. I have pointed out that a portion of recorded data were transcribed and translated from Swahili to English. The transcripts and field notes were then analysed using an inductive approach. My theoretical approach to data analysis sought to examine the power relations underlying the production and perpetuation of stroke discourses. For example, I pointed out how I utilised Foucault's concept of discursive analyis and Bourdieu's concept of symbolic power to examine the social production of stroke discourses. The power bases of the different stroke discourses and the social groupings and positions of their agents were closely examined. The interchange of the various discourses within the health and social fields were also closely scrutinized.

In a later section of this chapter I reflected on my dilemmas in carrying out my fieldwork and present how I dealt with them. I examined how my social position in the 'research field' (my two research sites) could have impacted the kind of data I gathered.

Specifically I discuss how I dealt with my fieldwork interactions and experiences and how these could have resulted in the nature of data I gathered. I have also briefly discussed the ethical considerations I undertook in carrying out my research.

In the following chapter, I present my findings on the stroke discourses in Dar and Hai together with the experiences of sufferers and their carers.

5 Chapter Five: Stroke Discourses and the Experiences of Sufferers and Carers.

5.1 Introduction

This chapter presents and analyses findings on the various stroke discourses in Hai and Dar. As stated in chapter 3, my definition of discourse follows Foucault's contention that they are 'a set of common assumptions that, although rarely consciously recognized, provides the basis for conscious knowledge' (Foucault 1972:49). Therefore I present the different representations or assumptions about stroke I found during my fieldwork. I had gathered these discourses either explicitly or implicitly from the study participants and my ethnographic observations. In Dar and Hai, the various discourses are evident through the way stroke is talked about and the various practices related to it. Through observation and examination of the practices related to stroke I came up with the several categories of discourses I present. Foucault explains how practices reveal the underlying assumptions and knowledge about something when he says that discourses are 'practices which systematically form the objects of which they speak'(Foucault 2002:54). From this viewpoint, assumptions and representations of stroke were examined as discourses manifested through practices and speech.

My research revealed five prevailing categories of stroke discourses in Hai and Dar-es-Salaam. The first category is the *biomedical discourse* which is common among health workers. Second is the *lay biomedical discourse* which is mostly common among ordinary members of the community in Hai, and less common in Dar. The same discourse is also common among the least qualified health workers. Third is the *supernatural beliefs informed discourse* which is the most common in Dar and least common in Hai. Fourth is the *religious informed discourse* which is relatively common in both Dar and Hai. And lastly but not least is the *cultural informed discourse* which is the least common in the two sites. In presenting these discourses I describe and discuss the exact nature of each discourse and how they are presented, who perpetuates them and the underlying

reasons and dynamics. I also examine their power bases at the different levels of the community. Nonetheless, it is important to point out that the discourses I present are not clear cut categories of the different representations of stroke in the two research sites. As it will become evident, they sometimes overlap.

In the second part of this chapter I present and analyse the experiences of stroke sufferers and carers. I examine these experiences through a perspective utilising aspects of the phenomenological and social features of chronic illnesses viewpoints. These experiences are important in order to put into context the various discourses presented in the first part of the chapter. Even more important, they underscore the point that despite the academic endeavour of my study, it also gives voice to the sufferers and their carers and portrays them as 'real people' struggling to come to terms and cope with the illness.

In last section of the chapter I summarise the main points covered and introduce the next chapter.

5.2 Contextualising findings

Before proceeding further, I must underline two points in order to put into perspective the findings I present. First, I must point out that the awareness and knowledge of stroke in the two sites is very low and more so when compared to other more prominent illnesses such as malaria, AIDS and hypertension. This is an unsurprising finding given its comparatively low prevalence reflected in negligible coverage in the official, local and media discussions of health problems in the country. The groups of people who had a better level of awareness and knowledge of the condition were the sufferers themselves, their carers, their relatives who had contact with them since they got the affliction, and other members of the community who had encountered an episode of stroke during their daily activities or heard about it during informal conversations. The majority of the FGDs participants and other research participants from the general public either had never heard of the illness or had vague notions. The majority of health workers had some knowledge about the illness though some confused it with a heart attack (*ugonjwa wa moyo*).

Traditional healers and faith healers who had handled cases of stroke had knowledge of the illness. Research participants in all FGDs strongly expressed the view that stroke awareness and knowledge is very low among people in their areas. To underline the magnitude of the low awareness and knowledge, all research participants advised that as one key undertaking of any stroke intervention in their areas, people should be educated about the condition (*ni lazima watu waelemishwe kuhusu huu ugonjwa*).

Secondly, there was divided opinion from my research participants on the perceived prevalence of the illness. Though most of the research participants had the opinion that stroke is on the rise in their areas, when I asked them to give specific numbers of people they know who have been afflicted by the illness many could not. This was different when I asked them to name a number of people who had malaria in their area whereby they easily provided estimate numbers. The key informants I interviewed also had differing opinions on whether stroke is more prevalent currently compared to the past years. Out of the twenty key informants I interviewed on several occasions, eighteen thought that stroke was more prevalent in the past, while the remaining thought it is more prevalent now. The research participants, who thought that stroke was more prevalent in the past, said that in those days they used to hear about many cases of strokes compared to now. They argued that in those days the number of strokes cases were just as prevalent as tuberculosis (TB) which at that time killed a lot of people. The two key informants had the opinion that strokes are more prevalent now because they hear about many people who either have been afflicted by it or die from it. For example one key informant pointed out to me that about two weeks prior to our meeting, two people had died of stroke in their *mtaa* (street).

The two points highlight the fact that awareness of and knowledge about stroke is low. The second point highlights that though there is general perception of the 'upcoming' problem of stroke, research participants found it difficult to substantiate this view compared to other more prevalent illnesses such as malaria. The two points highlight the fact that there was disagreement among study participants on various views and demonstrate my endeavor as a researcher to establish what was really going on. In other

words I demonstrate that I subjected the various accounts of my research participants to a critical thorough appraisal (Bryman 2004).

5.3 Terms for stroke

I will begin my presentation and analysis of the various discourses in Dar and Hai, by introducing the terms used to refer to stroke. The Swahili word for stroke *kiharusi* is more recognized in Dar than in Hai. This may be due to the fact that Swahili is more widely spoken and understood in coastal Dar than Hai where Chagga and other ethnic languages such as Maasai and Pare are commonly used especially among the older generation. Therefore in Dar the term *kiharusi* is most often used to refer to stroke. On the other hand, in Hai stroke is more commonly referred to as *paralaizi* (paralysis) or *presha* (pressure), due to people associating stroke with partial body paralysis and hypertension. The two Swahili terms used in Hai have been derived from English and closely resembles the biomedical terms for stroke. They are therefore a clear example of how a local discourse internalises other discourses by means of the terminology (Strahl 2003). Close contact with the biomedical illness model though health facilities or informal conversations results in such assimilation. It is an indication that in Hai the foundation of stroke discourses is rooted within the biomedical paradigm and its institutions (health facilities). On the other hand in Dar, the common use of the Swahili noun is indicative of the weak position of the biomedical model and the strength of the locally oriented discourses rooted in local language.

The noun *kiharusi* has no other specific meaning in Swahili. Even in Dar where it is commonly used, there is no general consensus on the meaning of the Swahili term for stroke. From my research, I gathered that the term might have been derived from the Swahili term for wedding-- *harusi* for the reason that stroke sufferers spend most of their time indoors. Only two of my key informants (both residing in Dar) could provide an explanation of the origin of the word *kiharusi*. The remaining key informants said they

did not know why the illness is called *kiharusi* but thought the term refers to the paralysis caused by the illness (though the Swahili word for paralysis is *kupooza*).

The two informants who explained the origin of *kiharusi* held the opinion that the word is derived from another Swahili word *harusi* which means wedding. They argued that the illness was given the name because people who get it are usually kept indoors because of physical disability (they cannot walk) but more importantly as a requirement for traditional remedy treatment. One informant said that the term *kiharusi* means '*ugonjwa wa kukaa ndani*' (an illness which requires one to stay indoors). Common among the Swahili and other coastal ethnic groups is a cultural practice of keeping indoors a bride-to-be (*mwali*) for several weeks prior to marriage. During that time she is provided with nice food (such as rice and chicken) and her skin treated using local herbs and coconut concoctions to make it soft and lighter. The bride-to-be is kept indoors to keep her away from the sun and nourish her so that when she comes out on her wedding days she looks beautiful. Another reason for keeping a bride-to-be indoors is to 'protect her' against men who might want to have sex with her or elope with her before the wedding day.

My two key informants concluded that because stroke sufferers are expected to stay indoors for long periods of time, the illness was given the name *kiharusi* meaning 'something similar to a wedding' -- *ki-harusi*. This practice is upheld strongly in Dar especially when an episode of stroke is believed to be caused by a *jini* (demon—sometimes pronounced with Arabic connotation as *jinn*) and traditional medicine used. In such cases the treatment requires that the sufferer does not meet people who are 'unclean' while on treatment, for example, people who have had sex and not taken a bath. During treatment the person puts on clothes of a specific colour which help make the *jini* leave (preferably black—known is Swahili as *Kaniki*). The sufferer is kept in a room with no or low lighting. During treatment it is only the traditional healer and few close relatives such as spouses or children who are allowed to visit the sufferer as it is believed that if they are allowed to go out they might meet the person who had caused the illness; who would see that their mission had succeed. The practice of keeping people who are undertaking traditional therapy away from the general public for fear of interference (or

contamination) on treatment has been documented by other ethnographic studies in Tanzania (Kamat 2008, Rekdal 1999). The preference for traditional healers residing or coming from outside the areas of residence of sufferers partly explains the phenomena (Kamat 2008, Rekdal 1999). I expound this issue in detail in chapter seven when I discuss traditional remedies for stroke.

5.4 Stroke discourses

5.4.1 Biomedical discourse

The biomedical discourse was commonly expressed by the health workers in the two sites. This discourse embodies the medical definition of stroke provided in chapter 1.The health workers who expressed this discourse consist of clinicians, nurses and doctors working in the private and public primary health facilities and hospitals. For example, a male clinical officer in Hai said:

> *Many strokes are caused by hypertension ...although there are so many causes of stroke I think that is the main reason that causes stroke...hypertension...and that cause is difficult to solve. I [also] think there is rupture of some blood vessels and old age...many patients we attend are aged...I am not sure about stress, but [I am sure of] hypertension.*

Another clinical officer at a private health facility in Dar said:

> *It is an illness which is very complex...it is a condition which happens and make some of the body parts paralyse...and when some of the body parts paralyse, it shows that this person has stroke...for example, someone might paralyse one side of the body, a leg... an arm paralyses...and for some of them, the mouth twists...things which show that the person has had a stroke...others cannot talk...others cannot walk...all those things.*

Then the same respondent continues later in the interview saying:

> *Hypertension is caused by so many things...like smoking, taking alcohol...and taking lots of meat causes people to gain so much weight and have big bodies also causes hypertension...including other causes such as inheritance...there are other people if something dramatic happens their hearts are strained and they get such problems.*

The health workers said they acquired the discourse through their professional training courses or through interaction with colleagues. Here we seen a feature of what Bourdieu terms 'symbolic capital' which has been 'juridicially guaranteed'. As indicated when expounding his concept of symbolic capital in chapter 3, he argues that such symbolic capital is sanctioned through the education credentials provided by the education system which acquire 'socially recognized qualification' (Bourdieu 1989:21).

In Hai and Dar, the biomedical discourse is communicated during encounters between the health workers and members of the community in the health facilities or informally when talking about stroke outside health facilities. Its power base are the health workers themselves operating within the health institutions such as community based primary health facilities and hospitals. In the process of being communicated to stoke sufferers, their carers or other people in the community, it displays the expertise and knowledge authority of the health workers. It embodies the ability of the health workers to construct knowledge for others (Friedson 1986) as it is taken as expert opinion. As Foucault (2002:56) noted :

> medical statements cannot come from anybody; their value, efficacy, even their therapeutic powers, and, generally speaking, their existence as medical statements cannot be disassociated from the statutory defined person who has the right to make them, and to claim from them the power to overcome suffering and death.

Compared to other discourses prevailing in the two sites (in quantitative terms--how it is often expressed) the biomedical discourse is the least prevalent discourse expressed by my study participants. Nevertheless it is the most powerful discourse in Hai since it is reinforced by the lay biomedical discourse and to a lesser extent by the religious informed discourse. Even in Dar where it is less popular compared to the supernatural belief informed discourse, it is powerful when expressed since it is rooted in the health workers and health facilities power bases and has official recognition. Though it seeks to assert it official status, the discourse in challenged by other discourses existing in the two sites as discussed in the following sections.

5.4.2 Lay biomedical discourse

The lay biomedical stroke discourse is the most common discourse in Hai and the second most common discourse in Dar. It is fundamentally derived from the biomedical discourse. It can thus be termed as a local expression (or extension) of the biomedical discourse. It embodies local terms expressed through Swahili-tised English terms such as *paralaizi* (paralysis) and *presha* (pressure). It can be described as a crude expression of the biomedical discourse embodying local terms and portraying the extent to which the local community has embraced the biomedical illness paradigm. The lay biomedical discourse reinforces the 'expert' position of the biomedical discourse (Bourdieu 1989, Foucault 1980, Friedson 1986). It underpins the power of the health workers who express it with accuracy and authority.

Through examining the terms it uses to refer to stroke, I realised that the lay biomedical discourse confuses hypertension (which is also referred in Swahili as *presha*) and stroke. Many research participants thought that stroke is similar to *presha* and that there is no distinction between the two. For example most research participants expressing this discourse had the view that *presha* causes stroke because almost all of the people they knew who had a stroke had a history of *presha*. For example, a female key informant in Dar expressed this confusion when she said:

> *Others say it is because of the heart...they were checked and found that their heart beat had gone up...until they got a stroke on one side...there are others you just hear that they had a headache then you hear that aah, they have paralysed ...now I don't understand how the headache or increase in their heartbeat causes the paralysis or whether there are other viruses which enter into one side and cause that...I have no idea.*

The majority of research participants who expressed the lay biomedical discourse also had the view that stress due to life hardships causes stroke. They mentioned the hardships causing stress related stroke as lack of money to pay school fees for their children, buy clothes and home items such as soap, salt, cooking oil, meat and cooking vegetables.

When I asked my research participants who expressed this discourse what were their sources of their information for stroke, I often got different answers from different groups of people. Stroke sufferers and their carers said their main sources of information were the doctors and nurses who attended them. Other research participants said that they had heard about stroke from other people in their village who had a sufferer in their family. Others said they had heard about it through their interactions with TSIP project enumerators. Few others said they heard about it on radio, though when I asked them the details of what they heard most of them could not tell. It is important to point out that the operation of TSIP in the study areas might have increased the knowledge about stroke and introduce the biomedical discourse to the stroke sufferers and their carers. Hence, it must be acknowledged that it is possible the popularity of the lay biomedical discourse among the stroke sufferers and their carers is partly due to their interaction with the TSIP and the health service they obtained through the project.

While carrying out my research, I noted that the relationship between medical professionals (such as clinicians and doctors) and patients is very didactic. Doctors are taken (and take themselves) to possess the ultimate knowledge of stroke and how to treat or prevent it. Their word is often taken as a fact by their patients, relatives and other community members. People are therefore reluctant to ask important questions they might have about the condition or their course of treatment. They see this as equivalent to questioning the ability of the doctors and fear that they might offend them leading to getting poor service. In other words, through expressing the biomedical discourse, the doctors and clinicians possess and exercise power over how stroke is framed.

5.4.3 Religious informed discourse

The religious informed stroke discourse upholds either a Christian or Islamic outlook depending on the religious position of the one expressing it. From my conversations and interviews with Christian church leaders and Imams of mosques, it became apparent that both Christian and Islamic paradigms recognise that illness (such as stroke) is part of the human being's struggle in life. Therefore humans should expect to become ill at one point in their lives. However, the religious informed discourse asserts that since God is in

control of everything, he has the ability to either protect people from illness or cure any type of illness. In Hai the Christian religious discourse dominates while in Dar it is the Islamic based discourse which dominates.

A pastor in Machame provided an explanation of his faith when he said:

> *We were born and just found hospitals [operating]...and we were just going to hospital...I don't know who started hospitals for us and when...[but] after the word of God was brought and we read his word, and believed in the word of God... the service of praying for ill people started...after we received the word of God that it cures...Jesus cures...for our faith that service started at that time and God was seen as truly curing eeh, and even now we continue and people get cured.*

Later on during the interview, the same pastor further explains:

> *It is not humans who cure...No...it is God, and because it is God who does that after we have prayed and believe that God has done it...then it is God's work to set them free [cure].*

My Moslem key informants told me that in Islam, humans are supposed to believe absolutely in the ability of God to deal with all matters and not to rely on fellow humans. This is termed *shirki* (depending more on the ability of human than Allah) and is forbidden among the Islamic interpretations of my research participants. Therefore, depending totally on the ability of medical doctors or traditional healers may in some cases be interpreted as *shirki*. The term is commonly used to refer to visits to traditional healers who engage in divination to tell cause of illness or date of death (*ushirikina*). An Imam in Hai explained this view by saying:

> *We forbid **shirki** [that is] going for divination, we do not forbid finding medicine for treatment...we do not ostracise any person for going to find medicine, we ostracise people who go for divination or who go to engage in **ushirikina** that is going and be told to offer a goat or a lamb or chicken, we do not allow those things.*

The Christian paradigm which is more common in Hai expresses the belief that illness is the work of the devil. Some research participants held the view that is it a product of sin, therefore necessitating people who have sinned to come back to God to experience his healing and protective power from illness.

In rural Machame (Hai), the symbolic power base of mainstream religion (both Christian and Islam even though more noticeably in the former) is visibly demonstrated by the huge church and mosque buildings scattered around the area. The huge buildings symbolise ownership of enormous resources and having many followers who had facilitated their construction. The huge buildings also convey the message that the religious establishments have many followers who fill these big buildings in days of worship (even though they are rarely ever full at these times).

The symbolic power of the religious establishment in Hai is also demonstrated in the manner that Fridays and Sundays are recognised and enforced as official resting days. This is more marked on Sundays when there is reduction of work activities and travel, closure of most shops, and very few public transport vehicles going to Moshi town. On these days one would witness groups of people streaming to, or coming from church or mosque. The sanctity of the days of worship is upheld by the different groups in the community, even those which belong to other religious groups (such as Moslems resting on Sundays). For example, a male traditional healer in Machame told me that he usually does not see or treat people on Fridays and Sundays as he rests on those days.

Following are pictures of churches and a mosque in Machame demonstrating their symbolic power base.

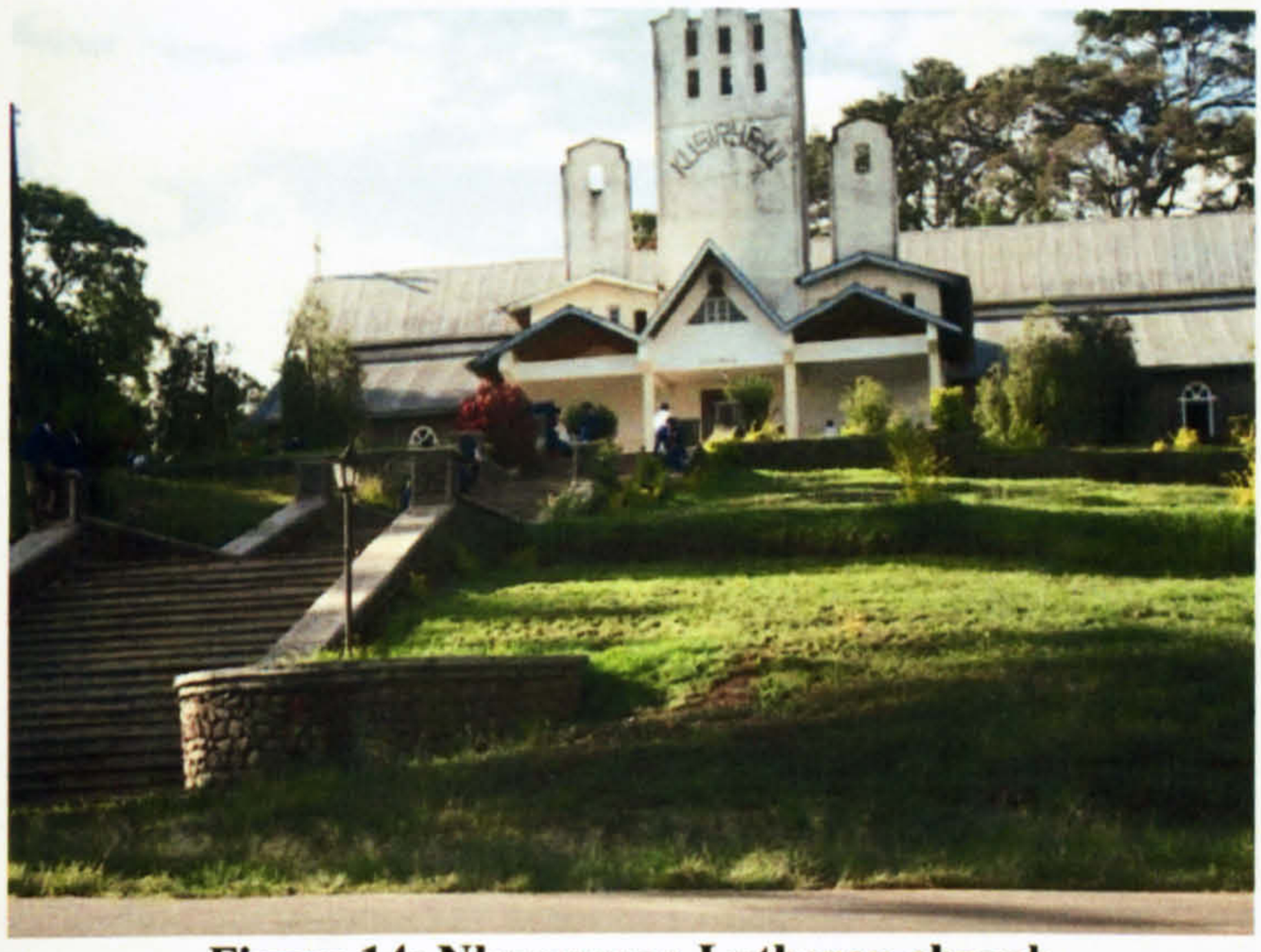


Figure 14: Nkwarungo Lutheran church

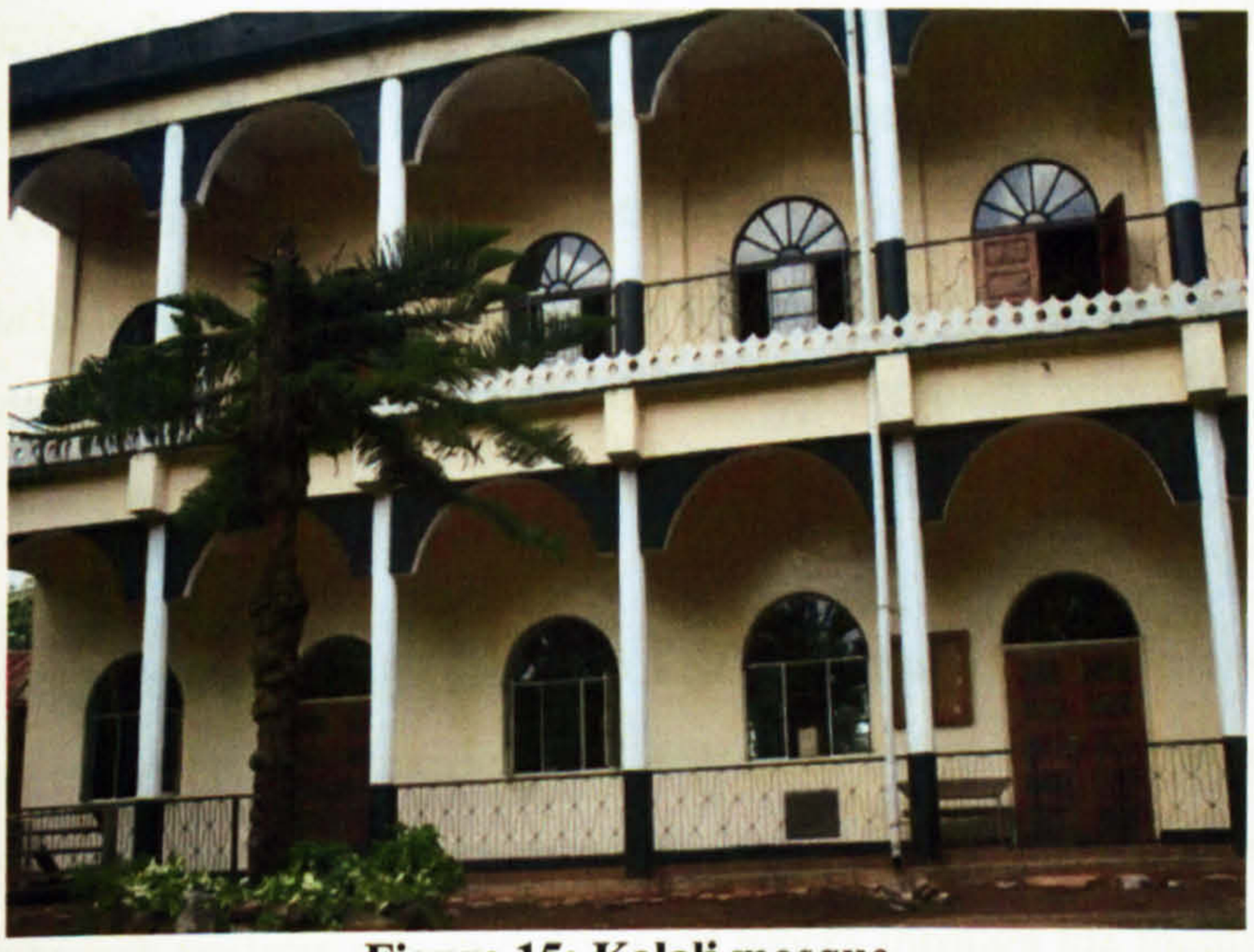


Figure 15: Kalali mosque



Figure 16: Mfooni Lutheran church

In relation to stroke, the Christian and Islamic perspectives express a similar discourse which is that stroke is caused by supernatural beings in the form of either demons or *jinns*. The two viewpoints part company in the way they represent the demons or *jinns* (in terms of their origin and intentions) and ways of dealing with (removing) them through prayer. I discuss in detail the common and different viewpoints when I present the traditional and faith based remedies for stroke, in chapter 7.

In some instances the religious informed stroke discourses reinforce the biomedical discourse. None of the research participants expressed a directly contradictory view between the religious informed stroke discourse and the biomedical discourse. Some of my Christian research participants said that God works through the medical drugs and treatment procedures. The Moslem informants also expressed a belief that, God willing (*Inshallah*), the drugs and procedures lead to relief.

5.4.4 Supernatural beliefs informed discourse

The supernatural beliefs informed discourse is most prominent in Dar and less common in Hai. The discourse represents stroke as a result of demons and *jinns* and witchcraft and appropriately treated using traditional remedies.[9] Swahili terms such as *upepo mbaya* (literarily meaning bad wind), *mdudu* (insect) and *mnyama* (animal) are used to refer to

[9] This discourse is detailed in Mshana et al 2008.

the demons causing stroke. Social conflict (such as jealous of property, work promotion) is the main cause for witchcraft induced stroke. This discourse is reinforced by traditional healers who associate the cause of stroke with human agency through sending the demons to attack others.[10] In these cases, people should first seek treatment for removing the demon. A female key informant in Dar said:

> *In the past and even now people say that when somebody falls [and loose conscious] in the toilet they say it is a **jini**...a **jini** has attacked them that is why they have fallen down...in the past when you fall down the only explanation is that you have a **jini**...and the treatment in the past is similar to now, because when somebody has paralysed they do not have strength...they do not have any sense in their body...they [relatives] take the person inside his/her house and look for someone [healer] to administer treatment...they buy the medicine...the person is massaged intensively...massaged until they can sit up...that's when they are taken outside their house ...but as people say it [stroke] comes back three times...for the first two God willing you get relief...either you could only be affected on one arm or leg...but if it comes back the third time you are gone [die].*

In Dar, the belief that most strokes happen in toilets was often expressed. It resonates with local interpretations of Islamic teaching incorporating aspects of traditional and religious beliefs with demons assigned to specific locations. People are taught to utter a special prayer when entering and leaving toilets in order to avoid being attacked by such demons. In rural Hai, witchcraft causing stroke was the least expressed discourse. A few research participants (mostly traditional healers) said that stroke was caused by witchcraft. Traditional healers in both sites perpetuate beliefs that stroke is caused by witchcraft and related demons, with appraisal of causes through divination and possession. All study respondents who reported visiting a traditional healer were told this by those healers.

Giles (1995) provides an illuminating glimpse in the supernatural beliefs along the east African Swahili coast. She argues that despite declining, spirit beliefs are still prominent among the Swahili of the east African coast. Among the Swahili, possession spirits are

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[10] Chapter 7 provides a detailed account and discussion of the role of traditional healers in perpetuating this discourse.

represented as an independent form of creation distinct from the ancestral spirits common among other African ethnic groups. Diagnosis and treatment of such spirits requires the services of traditional ritual specialists. Spiritual beliefs are regarded as part of the Swahili culture which is a blend of indigenous African and Arabic cultural practices (Wynne-Jones 2007). As such they are a popular discourse of illness causation and treatment among the Swahili (Beckerleg 1994) and the Eastern African coast in general (West 2006).

5.4.5 Cultural beliefs informed discourse

The cultural beliefs informed discourse is the least common and is dwindling among the range of stroke discourses in the two sites. Many informants I talked to had the opinion that traditional practices in treating illness have declined over the years. For example, a male key informant in Hai said:

> *In the past when people got ill, they had their healers/doctors...even those with broken bones had healers who treated them very well...for example there were traditional medicines which were very effective in treating...for example there is one old man at Nkuu area who could treat broken bones...they could mend a broken leg...they first put it in its proper position, then puncture the skin using a knife and take some herbal leaves and squeeze its fluid on the open wound so that the medicine gets into the body...then they would find an animal's hide, put on top of it and tie...the medicine were very effective in curing people very quickly and better than these modern medicines...there are many people here in Nkuu who were given these medicines.*

The cultural beliefs discourse was given by seven research participants, and among them, only two gave first person accounts of participating in practices based on the discourse. The discourse builds on local cultural explanations of illness. It frames stroke as an illness resulting from either not appeasing the ancestral spirits or culturally framed supernatural causation. For the former, treatment involves giving ritual offering to ancestors while for the latter it entails the use of traditional medicine.

Three research participants in Hai held the view that stroke happens when an individual fails to do certain things which their ancestors want (such as periodical traditional rituals). Their ancestors therefore decide to punish them by letting a stroke afflict them. If

the sufferer and their relatives suspect their ancestors to be the cause, they organise a ritual ceremony wherein they slaughter a goat and pour its blood on the burial place of an ancestor. During the ceremony, local brew (*mbege*) is also poured on the same spot. Thereafter, all the people who had participated in the ritual eat and drink the remnants of the offerings at the same location. Such practices are shunned however by the Christian religious discourse as sinful. Islamic discourse expressed by the Imams also shunned the practice though not as strongly as their Christian counterparts. For example, a male informant in Hai said:

> *This issue of offering...Mm, it is done at night not during the day...I think it is because people do not want to be seen during the day as some are Christians...it will be known in their church...known by other church members...the ones who engage in ancestral offering are the ones who consult traditional healers ...therefore they must follow their advise on the cause of their illness...there is a link between the ones who give ancestral offerings and traditional healers ...the healers are the ones who tell you to go and slaughter a goat...slaughter for a certain grandfather or mother any who has passed away who was not happy with something... you are told to slaughter for them ...but now these practices are vanishing...in the past the old people would go and ask for the cause of illness...I have someone who is very ill I need help...and some of it was effective ...they slaughter [a goat] and the ill person who could not even eat gets better...they slaughter at four in the evening and by nine at night the ill person starts eating food...the next day the ill person returns home...but in the past many people had goats but now only a few have... and those traditions are disappearing.*

The cultural explanation of illness as caused by angry ancestors is reported among other cultures in Africa such as the Maasai (Sindiga 1995b) and Luo (Sindiga 1995a, Sindiga 1995c). For example among the Luo of Kenya, AIDS is expressed through a discourse detailing it as a cultural curse known as *chira* (Sindiga 1995c).

In Dar, another version of the cultural beliefs informed discourses of stroke was expressed. It is based on comparison with a form of severe childhood malaria called *degedege* (which causes convulsion). The perceived similarity between *degedege* and stroke was expressed by a female key informant who said that even children could get stroke. When I probed further, I discovered that she was actually talking about *degedege* and she acknowledged that the two illnesses are very similar in terms of their cause and treatment. Another female research participant said that stroke and *degedege* are very

similar --like twins. The research participants said that in the past many people thought *degedege* was caused by witchcraft or supernatural means and parents would never take their children to hospital because they believed that if they were injected they would die. Other social studies conducted in Dar and coastal Tanzania found a similar cultural discourse framing *degedege* as caused by the shadow of an evil bird and injections are believed to be fatal (Comoro et al. 2003, Kamat 2006). These studies indicate that traditional remedies (inhaled or taken orally) are regarded as the most appropriate treatment rather than biomedical treatment.

Another female research participant showed me her grandson who had *degedege* in the past and had nearly passed away because his mother had delayed taking him to hospital due to fear of injections. But later, when they brought the boy to his grandmother, she took him to hospital where he was treated. She said that the boy got better after five days of treatment composing of a blood transfusion, oral dehydration salts and several injections. The participant said that her first hand experience of having a grandchild who had *degedege* and who recovered after hospital treatment had changed her previous views about the illness. This is evidence of the possibility of change of discourse due to experience or what Bourdieu calls a challenge to an established discourse (orthodoxy) through a crisis leading to a new discourse --heterodoxy (Bourdieu 1977).

5.4.6 Discussion of discourses

In Hai, stroke is largely framed within the biomedical discourse. On the other hand, in Dar, stroke is mainly framed within Muslim and local oriented discourse explaining its cause in term of supernatural causes (*jinns*, demons and witchcraft). A Foucauldian analysis (Foucault 1972, 1980, 2002) interprets that in Hai there has been a long term historical interaction between Christian missionaries, medical establishments (hospitals) and education system producing the health workers. The visits and settlement of European missionaries went hand in hand with the establishment of religious, health and educational institutions. In the course of these processes, a biomedical illness framework was introduced and entrenched. This biomedical paradigm was sustained and perpetuated through the establishment of hospitals, a health education system and churches and

conveying consistent messages such as that illness is caused by natural factors such as micro-organisms and should be treated in established health facilities, by trained personnel. This went on simultaneously with promoting the Christian religious paradigm that illnesses were also caused by the sinful nature of humans and that in order to get cured from illness people should stop and repent their sins. Hand in hand with entrenching the biomedical and religious paradigms, the 'indigenous' or cultural paradigm which among other things explained illness cause as supernatural and treated using traditional medicine was eroded. This happened in various ways including patients being told that it is sinful to visit traditional healers or perform offering rituals to ancestors in an attempt to appease illness.

On the other hand, Temeke in Dar has a very different history. Generally, the Tanzanian Indian ocean coast has a history of co-existence of Muslim and African traditional systems known otherwise as a 'Swahili' culture (Giles 1995, Wynne-Jones 2007). The transition observed in Hai, is not as established in Temeke because there is a strong presence of Muslim knowledge extended through *madrassa* schools. Muslim cosmology recognises the existence of *jinns* which parallels traditional notions of *spirits* and therefore is more tolerable to African traditional cultural practices (Giles 1995). For example as it will become clear in chapter 7, many traditional healers in Dar combine Koran verses and African traditional medicine for stroke treatment. During my fieldwork I came across several Islamic sheikhs who are also traditional healers but never a Christian priest practising traditional medicine.

In addition to the co-existence and tolerance of the Islamic and traditional illness paradigms, there have been very weak links between 'structures of authority' and the people of Temeke ever since the colonial era. If one takes the biomedical establishment as one extension of the government through healthcare provision policy, it can be said that in Temeke, there has been weak links between the establishment and the people as there has been no strong historical presence of government, missionary medical or educational establishments. My key research participants talked about how they went through the Islamic *madrassa* schools as these were the only ones accessible to them

during the colonial times in the 50s. The 'modern' education system was not established in Temeke and therefore had no strong 'foothold'. There were very few hospitals built, and those few, such as Muhimbili Referral Hospital and Ocean Road Hospital were built by the colonial government to mainly cater for government employees. In Temeke it is evident that historically there has been a big gap between the predominantly Muslim community and 'representatives of power'. This can be attributed to the historical disconnection between Muslim communities with the colonial government and the post independence government. Even at present, one can literally 'observe' the weak relation between the structures of authority and people in Temeke as characterized by poor health and educational infrastructure.

We can fully draw on Bourdieu's (1977) concepts of orthodoxy and heterodoxy when examining the different stroke discourses in Hai and Dar. An orthodox discourse is what is commonly accepted, in this case, as the dominant discourse in each site. Bourdieu would argue that in any community there are competing statements or paradigms. But in some communities because of the linkage between different structures of power such as schools, churches and government, the dominant paradigm is able to put its feet more firmly on the ground and push aside other heterodoxic statements. In Temeke there has been more room for heterodox statements and the orthodoxy (biomedical) is less powerful than Muslim and traditional discourses. While in Hai, school, churches and medical establishments are very influential, in Temeke, communities themselves have perpetuated their ideas much more strongly through social networks, *madrassa* or linkage between *madrassa* and traditional healers as gate keepers of the dominant discourse.

5.5 Experiences of sufferers and their carers

In examining and interpreting the experiences of stroke sufferers and their carers, I make use of the phenomenological approach. From the grounded theory analysis I undertook, concepts of meaning and experience emerged strongly as ways in which the stroke sufferers and their carers make sense of stroke. I therefore make use of the approach to

respect and voice their interpretations and experiences of dealing with stroke. Furthermore, the approach makes it possible to appreciate an insider's view of what it entails to be a stroke sufferer or caring for someone with stroke within that context.

In health related research, the phenomenological approach has mainly been used to explore the illness perspectives and experiences of sufferers. More recently, phenomenological studies have been broadened and framed to explore issues related to the 'native's point of view, with meaning, subjectivity, or consciousness' taken as matters constituting the 'phenomenon' under investigation (Kaufman 1988). Phenomenological studies have been useful in understanding the way illness experiences have made sufferers (re)examine and alter their 'self' (Kaufman 1988).

On their part, studies on the social aspects of chronic illnesses also enquire the meaning and consequences of an illness to sufferers and their carers (Pierret 2003). It has been showed that making sense of illness and suffering is an important endeavour for sufferers of chronic illnesses. For example, Nettleton (2006) reports that people with medically unexplained symptoms (MUS) struggle to ascertain their source of suffering. And when they fail to locate the source, they express shame and guilt which negatively affects their sense of self and social identity.

Chronic illnesses make a sufferer engage in a significant self-reflection exercise which may lead to a change of the 'self' (Charmaz 1983, Pierret 2003). Sufferers convey a sense of 'loss of self' as certain 'taken for granted' body images and functions are altered (Charmaz 1983). In most cases, the alteration of the 'self' resulting from suffering from a chronic illness leads to sufferers living a restricted, isolated, life feeling they are disgraced and posing a burden to their families (Charmaz 1983). Moreover, their experiences of interaction with healthcare providers may also lead to one's examination and sometimes reconstitution of the self (Nettleton 2006). Studies on the sociology of chronic illness highlight the complex changes in the doctor (or health practitioner) and patient relationships (Amstrong 2002, May 2006, Nettleton 2006). The changing landscape in the medical management of chronic illnesses and healthcare mean that the

role of sufferers in the management of their conditions has increased. As self management has become increasingly common, it is even more important to understand and document the lived experiences of the sufferers (May 2005).

It is argued that recent developments in healthcare provision has led to patients changing from just being passive and receptive of medical care to being active and engaging (Amstrong 2002, May 2006). May (2006:15) talks about 're-engineered patients' who are:

- Actively engaged in the decision making process
- Experts with knowledge and skills for managing their conditions
- Resourceful in making use of the knowledge they have and relate it to service provision
- Prudent in the sense that they are willing not to rely heavily on the services of formal care.

Chronic illnesses may also lead to a series of other outcomes such as loss of productive function, financial difficulties, family strain and stigma (Charmaz 1983). Within the power relations framework I employ, I interprete the struggle of the sufferers to regain control of their physical bodies and social lives as their power struggle to assert their control over the two aspects--physical body and social life. In Scott's perspective, it is their ability to produce the causal effect of their choice (Scott 2001) which involves how they want to get on with their physical and social lives. Stroke affliction introduces a challenge on how they achieve that intention. On the other hand, their carers struggle to free the people they care for from the illness and also regain control of their own social life which has been altered by the demands of caring. It is from that viewpoint that I present the next section.

5.5.1 Experiences of stroke sufferers

My study shows that the experiences of the sufferers vary with the degree of physical disability they have experienced. The degree of physical disability determines how other aspects of their lives are affected. Unsurprisingly, those with minimum disability were

able to continue with their lives with a higher degree of normalcy than the ones who had suffered severe disability (such as those who need help to move and with severe cognitive impairment). Whenever I visited sufferers with severe disability I found them either seated inside their houses in the living room, or sometimes seated outside their house in the sun (more common in Hai where it is much colder) or under a tree or house shed if sunny. Seeing them in such circumstances created an impression of loneliness and isolation. A 82 year old female stroke sufferer in Dar-es-Salaam said:

> *My body is like I told you...in some days I would wake up like now and you find me talking....there are other times aahh! I can not even talk, I become very tired until I cannot even lift my mouth, I become tired...I become very tired.*

Out of the forty stroke sufferers I interviewed (half of whom I followed closely during my fieldwork) only one had no obvious sign of physical disability. The woman from Hai went about her daily chores as normal, and whenever I went to visit her at her home, I found her working in her banana and beans *shamba* (small farm) next to her home. Nine sufferers had medium disability in that though they were not in full control of their limbs (one had a problem with one eye); they could go about their activities in moderation. The ones with moderate disability complained of getting headaches if they worked continuously for long periods of time. The remaining thirty participants had disabilities which prevented them from going about their personal and other activities without some form of assistance. Some of the sufferers were in very poor condition. For example, while carrying out my fieldwork, five of the sufferers I had interviewed earlier in my research passed away. Later conversations with their relatives suggest that they might have suffered a secondary stroke. Stroke studies in Africa have documented high case fatality either due to delayed or unsustained treatment of risk factors for stroke such as hypertension (Connor et al. 2007, Walker et al. 2003).

Stroke sufferers I interviewed often talked about how the illness had affected them physically and psychologically. Most talked of the things (especially chores) they can no longer do since they had their stroke. They also complained about their inability to participate in social activities. For example a 76 years female stroke sufferer in Hai said:

I used to go to church [but now] how would I go...how should I walk?...I can't walk...the last time I went to church was the year I became ill... [since then] I have failed...eeh, totally, I just stay inside...now I can't even walk to the road, I can't, even going to the farm I can't...I stay just here.

The sufferers also reported experiences of 'psychological tantrum' when they wanted to do something and their body would not allow them to. All of them showed optimism that they would 'recover' and return to their pre-stroke condition though most had suffered different forms of disability for several years. Most of them 'measured' their recovery through talking about the things they could not do in the past which they could now do such as washing clothes, sweeping their houses and compounds, or walking to church. They also talked of their ongoing struggle with the illness and how it had made them physically powerless, and expressed optimism of one day getting back in 'control' of their bodies and do the things they desired (see also Kleinman 1988).

The economic effect of stroke is a major theme which recurred when sufferer's talked about the effects of the illness. All of them were very concerned that they could no longer provide for their families or contribute to their income. They also expressed disappointment that the illness has made them dependants to their spouses and children as they could not earn an income through activities such as farming and business. Some of the families of the sufferers were large with between ten to almost twenty members therefore providing a challenge for those looking after them.

When recalling how they had turned into physical and economic dependants, the sufferers became very sad. Two female sufferers wept while they were narrating their stories in an ultimate demonstration of the sadness the affliction had brought to their lives. Their tears also demonstrate their feeling of powerlessness towards the disabling state caused by the illness. A few participants (four) were employed workers before they had stroke, so they were benefiting from a small amount of pension from their employed work. However, the fact that they had to stop work due to the illness is disheartening for them.

The diminishing quality of life among stroke sufferers is documented by other studies conducted in Nigeria (Ayanniyi, Akande, and Mustafa 2006, Fatoye et al. 2007) and elsewhere in the world (McKevitt et al. 2004). The two studies from Nigeria report the physical and social deterioration of the lives of stroke sufferers as the main effects. A combination of physical and cognitive loss has also been reported by other studies (Bendz 2000). Despite the range of reported effects on the lives of sufferers, my study shows that they continue to show optimism that they could restore their physical lives with the help of service providers (medical doctors, traditional and faith healers). With time, some of them accept their altered body image and social lives after 'coming to terms' with the reality of the limitations the illnesses has imposed on their body after enduring the disabilities from stroke for several years (most between 3 to 5 years).

The continued treatment stroke sufferers receive, keeps their hope alive that one day they may recover from the illness and claim the control of their physical and social lives once more. Even if they don't recover, the experience of prolonged treatment and management of the condition may make the sufferers develop a better understanding of the illness and how to handle it. For example studies on long term sufferers of diabetes in western countries have shown that some of them become 'expert patients' possessing rich knowledge about how to handle their condition after years of treatment (Standing and Chowdhury 2008, Van Damme, Kober, and Kegels 2008).

5.5.2 Experiences of carers

My findings show that stroke sufferers are primarily cared for by their spouses (wife or husband) and children. If the sons are adults and have wives and live with their parents the wives care for a suffering parent in turns (cooking, feeding, bathing and taking them to the toilet). If the family can afford to, they may hire a helper to care for their patient (male or female, depending on sex of patient). One family in Hai had a male employee taking care of a male stroke sufferer as his wife had passed away and his sons lived away from the village. In Dar, only one female sufferer had an employed carer as she did not have relatives living with her. She is a retired worker therefore could afford to pay for her carer from her pension money.

From their study, Fatoye et al (2006) report that care giving impose an emotional burden on care givers. Care givers interviewed in their study showed symptoms of anxiety and depression. The same effects are reported by a review of studies on the impact of stroke on care givers (Low, Payne , and Roderick 1999). My qualitative study did not employ the necessary research tools for measuring depression and anxiety. I therefore based my assessment on my observations and narratives of research participants. All the carers I talked to recounted the challenges of taking care of the physical needs of the sufferers. These include dressing, feeding, bathing and taking them to the toilet. Carers also talked about how their family and general view of life has been changed by the stroke episode, especially when the afflicted was the main provider of the house. For example a 43 year old female in Dar-es-Salaam taking care of her husband said:

> *[Caring] changes one's view of life because this is something you never expected...then it happens abruptly, it changes things...until things go back to normal it takes time...for example we were dependent on dad [husband] on his various activities...but now it has changed...I have to take over...life has changed...because he was a head of the house, but now he is sat down...things have to change...even the children feel down because the one we depended on is now unable...though we were also producing something, but now things have become uncertain.*

Carers of sufferers whose condition has improved, were quick to point how the treatment they have received (either using modern or traditional medicine) has helped. They also showed optimism that the condition of the sufferers would improve further. Some of the carers were realistic in their view that this may not mean getting back to the pre-stroke state. They usually talked about *kupata nafuu* (getting relief, gradual improvement). Most carers also talked about how taking care of the sufferers has affected them economically through loss of opportunity to make income. For those undertaking biomedical treatment, they often narrated the high costs for drugs and transport to hospital when seeking treatment. For example, a 68 year old female carer in Dar-es-Salaam said:

> *I think about life, that is difficult, like now I have an ill person [husband] as he is...he does not have a job, I have to trouble myself so that we get something to eat with the children, I trouble myself so that children go to school...I trouble*

myself...I pay [school] fees for children, their father is there sitting as you can see...who will do those things if not me...that is when I get confused, if I have no money I must think what to do so that I get money to survive with my children and the ill person...he needs soap for washing his clothes, he needs to eat in the afternoon and evening...he needs a good place to sleep.

The following two case studies highlight further some of the experiences I discussed. Since I had first visited the two families when I was doing my initial study in 2005, I was able to discuss with them how their condition has been since then.

Case 1: Mr and Mrs JN-stroke sufferer and spouse

Mr JN is 73 years old who lives in Narumu village in Hai. He had his stroke in 2004. During my visits, I usually found him seated outside near one of the houses within the compound. When I visited him for the first time, I found a man chatting with the respondent. I later learned that the man is a neighbour and friend of the respondent. In later days, I learned that the man is actually a brother in law of the respondent as his son has married a daughter of Mr JN. Mrs JN is 71 years old. During my first visit I found her put out beans in the sun to dry. The couple live with their granddaughter called RN (child of their late daughter). RN is in primary school (standard 7). All family members are Catholics.

When I first visited him, Mr JN said he has stopped taking 'modern' medicine for controlling his hypertension because he has run out of supply since sometime last year (could not remember the exact time). Since then he has not taken anything for his illness as he has no money to buy them from drug shops. He said his neighbour (who I found him with) had gone to the village health centre for more medicine, but he was told they were out of stock.

Mr JN's family is very poor. This is evident through the quality of their two houses in their compound. Both have been built using tree poles, mud and are roofed using iron sheets. In addition, every time I visited the family, Mrs JN kept on lamenting about how difficult life is. She said that since her husband had the stroke, he had not been able to engage in any productive activity such as farming hence becoming totally dependent on her. And since she can not leave him unattended and go to farm, they have become poorer. She can only farm at their small *shamba* near their house which is about three quarters of an acre. The *shamba* is mostly covered by bananas and a few coffee trees. In one section of the plot there are maize and beans. During one of my visits, I had finished my interview with Mr N and he went inside one of the houses to rest. His wife immediately followed him inside and she came out after a short while. She then told me that she had gone inside to help Mr JN change his trousers as presently he cannot dress himself. In our several conversations, Mr JN made it clear that had it not been his caring wife, he would have been dead a long time ago.

The case of Mr and Mrs JN demonstrates how an old couple in rural Hai struggles to cope with the different aspects of the effects of stroke in their lives. Mr JN is totally dependant on his wife for physical assistance and economic support. He is no longer

taking any anti-hypertensives as he cannot afford to buy them from local shops. On her part, Mrs JN narrates the burden of taking care of her ailing husband and the resulting inability to engage in meaningful income generating activities. Amidst their struggle with illness and increasing poverty, Mr and Mrs JN have to take care of their grand daughter without social support from their relatives, but only from a friendly neighbour.

Case 2: Mrs AMS--stroke sufferer

Mrs AS is a 52 year old Moslem stroke sufferer. She lives in Masama village in Hai with her 57 years old husband (Mr S) who takes care of her. The sufferer's family is poor and depends on farming. There are 2 houses within their compound (of about 30 square metres). The houses are built using tree poles and mud and are roofed using iron sheets. At the backyard, bananas and tomatoes are planted on a small portion of land. The farmed land is about 15 to 30 square metres.

The couple have 4 children who live in Dar-es-Salaam and Arusha. They used to live with their son in the village, but unfortunately he passed away in June 2006. He had a history of poor health and could not speak. Mrs S told me that their son was admitted at KCMC hospital for 6 months. She said that during the six months her son was admitted at hospital, her husband used to go to KCMC daily. He used a bus fare of 3,000/- shillings every day (approximately 90,000 shillings every month = 540,000/- shillings for 6 months) to visit and care for his son. The sufferer said caring for their ill son had been a big economic burden to them, and on top of that, it made them unable to take care of their farm.

When I visited her during my PhD fieldwork, I found the sufferer in a better physical shape than I saw her in 2005. At that time she could barely walk and she spent most of her time lying down on a mat outside their house. This time I found her seated on a chair inside their house. She said her condition has improved and she can do some light household chores such as sweeping the compound, washing her light clothes and dishes. She also said that she can walk without any assistance. For example, she can walk from her house to the main road (about 100 metres). She does it twice daily (mornings and evenings) as a way of exercising.

Mrs AMS said though she feels better, she has not been using any 'modern' medicine since I last saw her in 2005. Instead she uses only garlic and cucumber when she does not feel well. She usually chews one piece of garlic; and if available, eats one cucumber. She believes these are effective for lowering hypertension.

The case of Mrs AMS demonstrates how a female Muslim woman in rural Hai copes with the affliction of stroke over a period of years. She is totally dependent on her husband for support as their children live away. Their survival is largely dependent on farming a small piece of land. She narrates the case of her son who passed away after

being hoptalised for several months to demonstrate how prolonged illness siphons family resources. Over a period of three years, Mrs AMS gradually improves from the physical disability caused by stroke. Though not clearly linked with any specific treatment she received, she attributes her improvement to foods stuffs she believes have medicinal value to control her hypertension.

5.6 Conclusions

In this chapter, I have presented and discussed the five categories of stroke discourses in Hai and Dar. I have described their nature, who expresses them and their power base in the community. I have also engaged with comparative literature and made analytical interpretation using my theoretical framework. I have discussed and analysed the different terms used for stroke in the two research sites. I have contextualised my findings by discussing the awareness and knowledge about stroke. I have also highlighted that I analysed the differing opinions of my research participants by seeking clarification from them, cross checking their accounts through other participants and comparing data from the different methods I employed.

I have also presented the experiences of the stroke sufferers and their carers. Stroke sufferers expressed how the illness had affected them physically, socially and psychologically. Most showed optimism that they would 'recover' and return to their pre-stroke condition though most have suffered different forms of disabilities for years. In addition they expressed a desire to get back in control of their bodies and lives. All expressed disappointment that the illness has led to social isolation and made them dependants on their spouses and children as they could no longer earn an income. Their carers (especially women) talked of the challenges of taking care of the different needs of the sufferers. They also lament the social and economic costs of caring.

Within the study sites, experiences and understandings of stroke varied dramatically in form and depth between individuals. Whilst some adopted a western, biomedical

perspective and expressed a discourse linking stroke to hypertension, or an interruption to blood flow to the brain, others framed stroke as caused by *jinns* or demons. The existence of such diverse and apparently contradictory understandings of stroke in a population which supposedly share culture and lifestyle is demonstrative of the dynamism of cultural beliefs. Indeed, the fact that such differences exist suggests that people's perceptions of the causes of disease are not static, and can be changed and developed under the influence of contextual factors.

In the next chapter I present and discuss the treatment-seeking patterns and decision-making processes for stroke. I also present findings relating to the biomedical treatment of stroke.

6 Chapter Six: Treatment patterns, decision-making processes and the biomedical treatment of stroke

6.1 Introduction

This chapter presents and analyses findings relating to the general patterns and the decision-making processes for the treatment of stroke in Dar and Hai. It also presents findings on the biomedical treatment of stroke in the two sites. In the following section, I set this and the following chapter (traditional and faith based healing of stroke) in context by first describing and analysing the decision-making process from the time the affliction occurs to a person to the time it is treated. In the course of so doing, I discuss the characteristics and highlight the dynamic and complex nature of the treatment decision-making process.

In section three, I describe and discuss the stroke treatment patterns in the two sites. I depict the kinds of remedies sought as first option during episodes of stroke. In addition, I describe the subsequent kinds of remedies sought for the same episode of stroke after the first treatment option has been utilised. Thereafter, I compare my findings on the general pattern of the nature of treatment sought when someone suffers a first time stroke with those of TSIP which are drawn from a larger sample of the same populations.

In section four I present findings on the biomedical treatment of stroke in the two sites. I describe and discuss the two main types of biomedical stroke services utilised in Dar-es-Salaam and Hai which are, health facility based services and home based treatment. In section five, I discuss findings presented in this chapter by engaging appropriate literature addressing some of the characteristics of stroke treatment-seeking behaviours in the research sites. Lastly, I conclude this chapter by summarising the key findings and introducing the next chapter.

6.2 Decision-making on what remedial course to pursue

Stroke is an affliction the onset of which happens very rapidly with little if any fore warning signs (Walker 2004). There is usually no slow progression of symptoms requiring a carefully thought through remedial plan. For secondary strokes (stroke happening after the first one) there is at least a history of the affliction therefore the dramatic suddenness of the occurrence is less traumatic.

As a result of the circumstances of its occurrence, the immediate decision on what remedy to be pursue after a person has had a stroke is in most cases made under circumstances of panic, anxiety, pressure and urgency. In some cases of first time strokes, the sufferers are not in a position to make or participate in the decision on what to do immediately after an episode as many would be unconscious. Many of my research participants who had witnessed a person suffering a stroke attack told me that even after regaining consciousness, most sufferers had experienced some kind of cognitive and physical impairment which made them unable to participate meaningfully in such decision-making. It is only after some hours or days of treatment (or probably a natural recovery of the brain) that they are able to comprehend what has happened to them and make their wishes on what remedial course to pursue known to those looking after them. Many stroke sufferers I interviewed told me that they could not remember precise details of what happened when, and immediately after, they had their strokes and had to rely on the accounts of their relatives and other people who were present at such moments.

Therefore, for most first stroke cases, it is either the immediate family (spouse and adult children) or relatives living near the person who has suffered a stroke who decide on what remedial course to take. Information about the occurrence is later sent to other relatives or adult children who live away. Generally it takes several hours or a few days before they arrive at the household of the sufferer. At that stage such family members would also be involved in the process of decision-making which in most cases meant either concurring with the remedial course already taken or recommending a different option. My findings show that at that stage, the decision-making process becomes

consultative and debated especially if there are differences of opinion on the kind of remedies preferred by the family members or friends.

My findings show that in most cases it is the immediate family of the sufferer who decide what remedial course to take. In most cases the immediate family would comprise the spouse and adult children of the sufferer. Other siblings of the sufferer or their spouse could also be consulted especially if they live nearby and later came to see the sufferer. This decision-making scenario is more common in rural Hai as it was likely that such close relatives would either be living near the sufferer's homestead or in the same village. In urban Temeke, it is mostly the neighbours in good social relations with the family or members of their social network such as people who attend the same mosque, church, fellow workers, entrepreneurs who are involved in the decision-making process.

The economic position of the sufferer and immediate family members of the sufferer determine whether they would have much power to influence decision-making on what treatment option to pursue. If the family is poor and depend on other people for financial support, it is likely that they would not be in a position to enforce their view on what remedy to pursue especially if it differs from the relatives or social network members who support them financially. On the other hand, if the family of the sufferer is able and financially independent, they are likely to make the decision they want on their own or in consultation with the people close to them. In addition to economic ability, the family of sufferers who have adult working children or educated (secondary or college education) children are also likely to make their own decisions about treatment without much undue influence from either relatives or social network members. Therefore, the process of deciding which remedial course to pursue for a stroke episode is a social process involving circumstantial and negotiated power dynamics. People who are likely to influence the type of the first and subsequent remedial courses tend to be the ones holding some kind of symbolic capital through their position within the family and community at large reinforced by economic, education or other kinds of socially respected attributes.

The changing nature of the economic landscape giving more access to cash for women mean that women are more involved and influential in treatment decision-making within households. This is explicit in the example about the economic changes in Hai provided in Chapter 1 whereby the decline of coffee as a cash crop and the rise of banana and casual labour as main sources of income mean that women have more access to cash. Women in Dar also engage in small entrepreneurial activities such as selling rice buns to support their families. The wives of stroke sufferers are therefore more involved in treatment-seeking decisions at the household levels as they are now also providers. Employed women with guaranteed income may have a bigger say in such matters. This is a good development given the documented evidence of the limitations women face on decision-making related to heath due to their inaccessibility of resources (Green 2000, Kamat 2006).

My findings show that the decision-making process from the time a stroke happens to someone to the point a remedy (or remedies) is sought involves four stages. The first stage is characterised by the sudden affliction of stroke on someone. This unexpected event may happen at any time and location. My research participants talked about the different times of the day they had their stroke ranging from morning, afternoon, late evenings and late at night while asleep. The location where stroke happens also ranges from work places, in commuter buses, social gatherings, walking pathways or in their home while doing different chores, relaxing with families or while asleep at night.

In the second stage, following the commotion of the unexpected occurrence of stroke, people within the vicinity of the sufferer 'make sense' of the stroke in various ways. They interpret what has happened either through the framework of their habitus (acquired through the socialisation process), their prior knowledge of stroke, their prior experience of seeing a person who had a stroke or drawing from the various discourses they know or have heard regarding the condition.

Thereafter, in the third stage, a process of decision-making regarding what to do commences. This process can itself be divided into four steps. The first step, taken

immediately after the affliction has struck, involves people who are present at the place where the stroke had occurred. These could either be fellow workers, entrepreneurs, commuters, other onlookers and so on. Secondly, and depending on the location where the sufferer had the stroke, the immediate family of the victim is notified. The notification is done either by sending someone or through a mobile phone call to the immediate family members of the afflicted person. Thereafter the third step of decision-making ensues, mainly involving the immediate family, relatives or members of the social network of the sufferer. Later on, the fourth step of decision-making also commences involving the wider network of relatives and members of the immediate family's social network in a more complex process. The process involves power dynamics and the evaluation of the efficacy of the different remedies proposed and their financial implications.

The fourth stage of the decision making course of action begins with the pursuit of the treatment option selected and other subsequent options. The described decision-making process is elaborated in the following diagram:

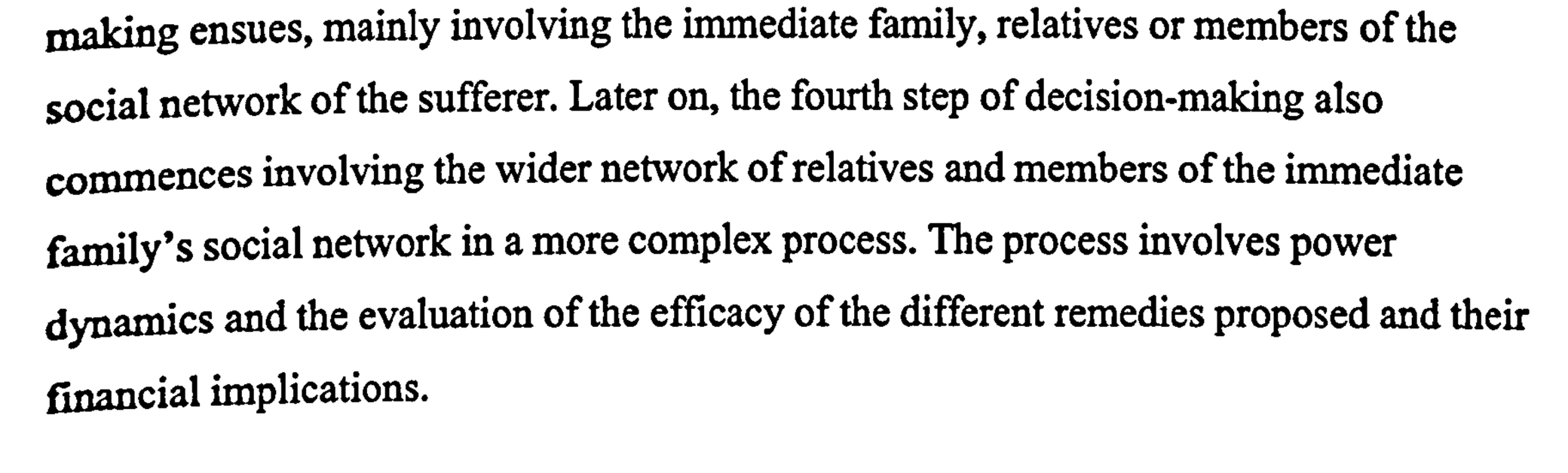


Figure 17: Flow of stroke remedy seeking processes

6.3 General patterns of stroke remedies pursued

During my entire time of fieldwork, I did not encounter any case of someone who suffered a stroke and did not pursue some kind of remedy. When a stroke afflicted someone, a remedy is always sought.

The remedies sought for stroke in Dar-es-Salaam and Hai can be grouped under four general categories. These are, using traditional remedies, consulting faith healers for healing prayers, seeking biomedical treatment services, or combining biomedical treatment with either traditional or faith healing. Though some stroke sufferers seek the service of faith healers after trying out traditional remedies, I did not encounter any case of a stroke sufferer who simultaneously combined traditional and Christian faith healing. The two categories of remedies are generally perceived as incompatible. All of the Christian faith healers I interviewed actively discourage the people they pray for from consulting traditional healers. However, the separation between traditional healing and faith healing is more marked among Christian faith healers. Among some categories of traditional healers, there is common utilisation of Islamic interpretations and cosmology. These differences and complexities will become more apparent when I present each of the stroke remedies utilised in urban Dar-es-Salaam and rural Hai in a later section of this chapter (biomedical treatment), and the next chapter (traditional healing and faith healing).

There are three reasons for the combination of different forms of stroke remedy. The first is due to lack of improvement when using a particular treatment option. After either being treated in hospital or using traditional medicine for a prolonged time without improvement, some sufferers decide to combine different types of treatment. The second reason is due to a desire to maximize chances of recovery by increasing the 'power' of the treatment through combining two types of remedy. Thirdly, it is due to the pressure of relatives and members of the social network of the sufferers. Plural healing practices are a common feature of treatment-seeking in Africa (Aikins 2005, Beckerleg 1994, Hundt, Stuttaford, and Ngoma 2004, Kamat 2008). Belief that illness is caused by either natural or supernatural reasons, pursuit of efficacious treatment, unsustainable costs of care and social pressure are the major reasons for the practice (Beckerleg 1994, Comoro et al. 2003, Hundt, Stuttaford, and Ngoma 2004, Kamat 2006, Kamat 2008).

The general patterns for the kind of treatment sought for the first episode of stroke differed between the two sites. In Hai, health facility based treatment is mostly preferred and utilised as the first treatment option by the majority of stroke sufferers. In Dar-es-Salaam, most first time strokes are treated using traditional medicine administered by different types of traditional healers. These patterns are similar to the nature of the dominant discourse in each site as presented in Chapter 5- the biomedical and lay biomedical discourse in Hai and local and religious discourse in Dar. Subsequent forms of remedy utilised also differ between Dar and Hai. In Dar the second likely remedy to be used is health facility based treatment closely followed by faith healing. In Hai it is traditional healing, closely followed by faith healing. However these remedial options are not always sought serially as some sufferers switch between different forms of remedies and within one category of remedy back and forth a phenomenon which has been described in other literature on treatment-seeking in Africa as 'healer shopping' (Aikins 2005). Also as already pointed out, the combination of remedies is common.

Case illustration 3: Mama AC (stroke sufferer)

The following narrative of Mama AC, captures some of the findings presented in the two previous sections on decision-making and patterns of treatment-seeking. Mama AC is a 54 years old resident of Saba-saba area in Temeke who suffered a stroke in 2004. She was married, but separated from her husband after the couple failed to have a child. In her endeavour to get a child, she used hospital and traditional treatment but was not able to conceive. Her husband then decided to leave her and find another woman who could give him children. Mama AC was an army officer of the rank of Major with the Tanzanian Army. She retired in 2006 partly due to ill health caused by her stroke. She complains of dementia and can only walk short distances. She lives with a house maid who takes care of her and a child left to her by the daughter of her younger sister who had passed away during labour. The child has lived with her since the age of two and she took charge of her education until she completed secondary school and a college course in hotel management. In her conversations she describes her as her own daughter. Apart from earning a salary as an army officer, Mama AC also engaged in the business of decorating halls for ceremonies and providing catering services. From the business she earned

between Tanzanian shillings 100,000 and 200,000 per event. However, since she had her stroke, she has not been able to continue with the business. In the following excerpt of an interview with Mama AC, she narrates her experience of suffering a stroke and the subsequent events.

Excerpts from interview with Mama AC

When I came back I was very angry why he [husband] is following me! What have I done … now when I was thinking I had the stroke while seated here on the couch…Just here I found out I … like my right side was shaking, I also found out my right leg was already… my hand and my mouth had gone aside…I told my children to go and tell their aunt [my young sister] of Keko, tell her I am sick, my young sister living at Keko.

They went and told her, when she came she told me that I had a stroke…she said we have to find a traditional healer to treat your stroke….I told them similar to the way I believe and what happened to me … that my brain was affected because of [high blood] pressure so I know this is pressure, so I have to go to the hospital and not any traditional healer. My sister then said you have been walking in the sun, I think you have been hit by the wind [*upepo*] or the *jinn* has struck you, so my sister let us start with the traditional healer then we will go to the hospital…It was a very difficult day and I delayed to go to the hospital, so I had to sleep, that was Friday. I slept…until Saturday morning we were still arguing…she was asking that I give her money so that she fetches a traditional healer, and I told her I won't give her money may be I should give them money to take a taxi and go to the hospital. As a result Saturday was when I agreed with my young sister and we took a taxi and went to the hospital, now it was not Temeke or may be Mikocheni, we went to a private doctor known as Dr M who is near Temeke hospital.

We went there and when they took some tests and the way I could not walk, they told me that my nerves have been affected and I have stroke…the [blood] pressure was 200/160… They gave me an injection to reduce the pain and other injections, which they said it will just take a short time in that side which was paining me, I had terrible pains and it will stop, and I rested there for three hours…the pains were the same. After six hours they gave me another [injection] I was discharged to go home, but the pain was the same.

When I came back here … I found out there is a woman who had come with traditional medicine, and I [at that time] had already taken an injection and the medicines. So they took coconut oil and mixed with those herbal medicines and started to massage me…they were massaging my whole body…they started with the side which was paralysed. At night I went to the hospital for an injection, I had told them [relatives] that you might continue with your treatment but I must also continue with hospital treatment…They said do what you believe so let us take you to the hospital, but we do not want you to take an injection because this is stroke, and it does not need an injection…I said as long as I have started an injection and it has not affected me, so try to understand me that this is pressure and I know the cause…so they told me you are adamant, you go… So I went and fortunately my young sister did not leave me, we went together and my elder sister remained here with other women, who came to see me…our relatives. I took a taxi with my young sister and went…I took an injection and came back, they started to massage me again, so my right side skin was badly affected because of intense massaging…they massaged with a lot of energy and those medicines had big particles...and coconut oil but if that medicine was at least

smooth it would have been okay, but it had big particles…so the skin was peeled off…because of the energy they used and the heat of the oil and that friction of the particles…When I complained of pain, they said that is the way it was supposed to be done.

I had a belief that this illness was caused by veins which were affected, and because we have been educated several times by health people that a person who has BP has to live like this so that this will not happen…Ee, so when it happened to me it was not new in my ears because that is what I have been hearing every day, people who have pressure and people who have stroke understand that it is because of pressure, so I have seen them…So I understood what happened to me…Ee, but many said that you are bewitched with stroke… there is a *jinn* which they call it crippled *jinn*…Now that crippled *jinn*, when it is sent to you must be crippled even if you were walking…if it attacks on one side, that side will be affected, but when it attacks straight on, you become crippled you will not walk. When I came here they told me that my sister decided to come with the traditional healer, and told him that our patient is so stubborn let us go and talk to her…So he came with the books and read the names of the *jinns* and started to explain to me, I listened but I had to stick to my ground. He told me that he is able to remove the *jinn*… eeh so I must use medicines for massage, you inhale the vapour you take the vapour in a container then you drop those medicines to be burnt, and with that fire while you have been covered by a bed sheet…Now you have to stay there and get inside you … they say that smoke makes the wind of a *jinn* to be removed…eventually I refused and told them to stop massaging me or using other traditional medicine…my younger sister said if that is the case I am going back to my home and continue with my work and you will continue with yours…Because it was not the first time in my life for somebody to abandon me, I agreed with her and I gave her the fare to return to her home.

The case of Mama AC elaborates the social and economic dynamics facing people who suffer a stroke. It shows how she links her stroke with her history of hypertension and stress from conflicts with her husband from whom she had separated. For her, these past experiences of illness and stress which led to close contact with biomedical services provide a framework for interpreting the cause of her stroke and the appropriate way to treat it. On the other hand her young sister and other relatives draw from the dominant discourse in Dar believing that the stroke is caused by *jinn* (demon). The fear for the detrimental effect of injections for stroke sufferers is also made explicit. The ensuing negotiation process on what treatment to take makes Mama AC delay to start treatment until the next day after her stroke. Her determination that she is taken to hospital combined with her economic ability to pay for her transport and treatment ensures that her wish is eventually granted. However, to find a compromise with the views of her relatives and ensure their social support, she combines hospital with traditional treatment. In her narrative, the relatives solicit the view of the traditional healer to try to convince her that stroke is caused by *jinn*. After the combination of both hospital and traditional treatment fails to achieve the expected relief, Mama AC is left alone to continue with her

struggle with the affliction after her sister blames her for stubbornness after refusing traditional medicine treatment from the beginning.

My findings on the general patterns of remedies sought for stroke in Dar-es-Salaam and Hai are very similar to those from the TSIP quantitative questionnaire affirming that this pattern is shared by both sites. The TSIP questionnaire was administered to all new stroke cases in a larger sample of the same population as mine. From a sample of 177 stroke sufferers, the nature of remedy sought for first strokes follow a similar line with mine, that is, traditional remedies being utilised most in Dar-es-Salaam and biomedical remedies being utilised most in Hai. This is illustrated in the following table:

Treatment option	Dar	Hai
Hospital	18	55
Traditional healer	23	0
Private doctor	7	3
Dispensary	9	31
Health centre	0	7
Inpatient	0	1
Relatives	3	15
Village health worker	0	5
Total	60	117

Table 4: TSIP findings on the first type of help sought for stroke[11]

In the following section, I present in detail, and discuss, the characteristics of biomedical treatment of stroke in Dar-es-Salaam and Hai.

6.4 Biomedical treatment

6.4.1 Health facility based treatment

The majority of people in Hai seek biomedical treatment (rather than other) for stroke. In the course of my fieldwork I realised that this is true not only for stroke, but also for other illnesses. In Hai, health facility based treatment of stroke typical starts at a nearby private or public clinic or dispensary. After assessment by the health workers at the clinic, the

[11] Unpublished data obtained from the TSIP principal investigator and statistician.

sufferer is referred to a bigger health facility for further diagnosis and management. In some cases first treatment is sought directly from a bigger health facility such as a health centre or hospital if it is located near the sufferer's home. In Machame, the bigger health facilities utilised by stroke sufferers are Machame Hospital (popularly known as Nkwarungo), Kibosho Hospital (for residents of Narumu area) or Kibong'oto Hospital. If the condition of the sufferer improves after treatment, they are discharged from hospital and return to their homes. On the other hand if their condition does not improve, they are referred to either Mawenzi regional hospital, or KCMC, the tertiary referral (consultant) hospital in Moshi town, for further treatment.

Several of my research participants (stroke sufferers or their carers) narrated that some of the local private hospitals are reluctant to give referrals to KCMC even if the condition of the sufferer does not improve after days or weeks of treatment. Research participants say that the reluctance is due to the fear of staff and the administrators of the hospitals of losing income if they keep on referring stroke cases to other hospitals. Some relatives of stroke sufferers narrate how they resort to threatening the doctors refusing to refer their afflicted relatives to KCMC that they would not pay their hospital bills if their wish is not granted. They say that it is only after giving such threats that the referral is finally given. On the other hand though, some of the medical staff in these hospitals told me that they saw no reason for referring every stroke case to the other hospitals because they felt they have the ability to manage successfully the cases at their facilities.

In most cases, the person afflicted by stroke is taken to the health facility using a hired car (either private or commercial). The small public transport buses popularly known in Machame through their Swahili name *haisi* (derived from English of Japanese brand name Hiace) are also hired for the purpose. Depending on the distance to the facility or time of the day (it is generally more expensive to hire a vehicle at night than daytime), hiring a vehicle for taking someone to hospital costs between 5,000 - 50,000 shillings. Some sufferers are carried to the facility using local hand carriers made using a piece of cloth and two rods known in Swahili as *Machela*.

Similarly, in Temeke district, biomedical treatment for stroke is sought at a nearby public or private facility. At the private and public clinics, initial assessment and diagnosis is undertaken. If stroke is suspected or the condition considered too complicated to be handled at the facility, the patient is referred to Temeke district hospital. Some of the sufferers are taken directly to Temeke district hospital if they live near the hospital or if their relatives can afford the transport costs. At Temeke, a stroke patient is treated for several days or even weeks and if their condition improves they are discharged. If the condition does not improve, they are then referred to Muhimbili for further management.

In Temeke, transport to a health facility is done either through a hired private or public vehicle. Most of my research participants in Temeke utilised taxis to travel to health facilities for treatment. As in Hai, depending on the distance to the health facility, a taxi costs between 2,000 - 10,000 shillings. Amongst the stroke sufferers I interviewed, only one has a private car which was used to go to hospital for treatment.

Many of my research participants complained of poor services at public health facilities. They said that, in comparison, private health facilities offered better services though were correspondingly more expensive. For example, most of my research participants who had been treated at Temeke hospital complained of the long waiting time before they were able see a doctor. They also complained of poor and inadequate facilities such as beds.

On the other hand, the health workers I interviewed in Hai and Temeke complained of the high number of patients they attend each day. These complaints mostly come from health workers working in public health facilities. They attended many patients in a working environment characterised by inadequate facilities and medication. For example they complained about lack of X-ray facilities in their facilities. Health workers in public health facilities also complained of poor supply of the drugs they need to manage stroke such as anti hypertensives.

Most of the smaller health facilities in Temeke and Dar are managed by either clinical officers or nurses. A few qualified medical doctors are found at the bigger hospitals such

as Kibongo'to and Machame in Hai and Temeke district hospital in Dar-es-Salaam. Most of the qualified doctors available to stroke sufferers are based at the two referral hospitals in my sites, which are KCMC and Muhimbili. Even at these referral hospitals, there are virtually no specialist neurologists. Through my research I learned that there is no specialist neurologist at KCMC which is a referral hospital for the whole northern region of Tanzania. The hospital utilises, intermittently, the service of a European neurologist from a nearby private hospital (Marangu). There are two neurologists at Muhimbili who serve all national neurological cases referred to the hospital.

Through my interviews with the health workers at the smaller health facilities, I discovered that some of them were unclear between a heart attack and a stroke which are clinically two different conditions. This lack of clear knowledge of the difference between stroke and a heart attack could lead to slow and inaccurate diagnosis and therefore delayed treatment. In both sites and in all types of facilities, nurses are usually the cadre of health workers available at the facilities most of the time and are the ones who take blood pressure measurements and give advice to home based stroke sufferers.

The consultation fee at public health facilities costs 1,000 shillings. Stroke management drugs are often not available in public health facilities and people have to buy them from small local drug shops or larger pharmacies. Bigger private hospitals such as Machame have a more reliable stock of medicines though they are regarded as expensive by most research participants. In Tanzania, there is a public 'health insurance' programme (*bima ya afya*). The programme operates through the public health facilities and hospitals. Each family pays 10,000 shillings per annum and all family members become eligible for treatment (consultation and drugs) for the whole year. Research participants say that only few families could afford, or are willing, to pay for health insurance. Many prefer to gamble and only pay when a family member becomes ill requiring health facility treatment.

Some research participants said that they prefer going to private clinics rather than public ones because in private clinics one could negotiate to pay their bill in instalments. This is

possible since the private clinics are based within their localities and the workers known by them personally. Most of the research participants who utilise hospital treatment for stroke talked about the costs associated with looking after someone who has been admitted to hospital. They describe the problems they had with the high cost of fare for going to visit and deliver food to their patient. In most health facilities in Tanzania, food for the in-patients is prepared at home. The quality and type of food offered at health facilities is not regarded as adequate.

Scepticism about the effectiveness of hospital treatment of stroke is common in Dar-es-Salaam. For example one research participant talked about a neighbour who had a stroke and was taken to hospital but later died. Another said, *'nobody comes out of hospital better, they are all sick'*. The disdain surrounding hospital treatment of stroke in Dar-es-Salaam is reinforced by misinformation spread by some traditional healers. Some traditional healers reportedly tell the people they treat that hospital treatment could not treat stroke cases caused by supernatural means. The fact that hospital treatment does not guarantee a return to pre-stroke physical and mental state reinforces such views.

The following case illustration demonstrates some of the discussed characteristics of health facility use for stroke treatment in the two research sites.

Case 4: Mrs PN - Stroke sufferer

Mrs PN is a 36 year old woman who had a stroke in 2003. Her 42 year old husband (Mr N) does business selling second hand clothes in various markets in the Hai district. He usually buys the clothes at Kiborloni market in Moshi town. He then sells the clothes at different markets in different villages every day as each village has a specific market day. He rests only on Sundays. Mr N is a Lutheran church leader leading 24 households in his *mtaa* (street). He is a leader together with two other people and they visit all the 24 households in their *mtaa* once in every week. During the visits, they pray together with the household members and use the occasion to remind them about different church projects taking place in their area. The main purpose of their visits is to strengthen the church members spiritually.

Mrs PN says that her condition has generally improved since she had the stroke. She is currently able to do household chores such as fetching water, cooking and washing clothes. Mr N said she could only do the chores in moderation because sometimes she gets headaches. When she gets a headache, she stops doing the tasks and takes a bed rest. When she gets the headaches, their three children help her with household tasks. Their first born daughter has finished primary school and

joined a nearby tailoring college. Their second born daughter is in standard 5 and their last born son (7 years) is also in primary school. Mrs PN decided to stop having more children after she had her stroke. She had an operation to close her fallopian tubes.

She said since she had her stroke she has only been using biomedical treatment. She narrated that when she had her stroke, she was taken to the community dispensary in the village where she stayed from 11.00 am to late evening. The health workers at the dispensary had told her husband that she should stay at the clinic so that they could observe her condition, but by evening, her condition had worsened and she lost consciousness. Her husband then transferred her to Machame hospital where she underwent treatment for 11 days. Despite being treated at Machame hospital for the 11 days her condition did not improve. Her husband then asked the doctor attending her to write a referral letter so that he could take her to KCMC. The doctor refused to write the letter saying they should continue treating her at Machame hospital. But her husband was adamant and insisted that he wanted to take his wife to KCMC and that if they refuse to give her the referral letter he would take her there without their approval and won't pay the medical bill. The doctor then agreed to write the letter and she was transferred to KCMC. She was admitted at KCMC for 8 days and her condition improved after treatment. On the 8th day she started walking with the aid of walking sticks. After being discharged from KCMC she started going to Lambo public clinic (near her home in Machame) for checking her blood pressure and treatment of other illnesses. She said before her stroke she had never gone to Lambo clinic as she only used to go to a nearby private community dispensary instead.

Mrs PN said that since she had her stroke she has been having attacks similar to epileptic fits (at least 3 times a month). When she uses drugs from the hospital the frequency of fits reduces. In one of my visits, she said that two days prior to my visit she had felt unwell and went to Lambo clinic for treatment. They checked her blood pressure and it was normal. She was diagnosed with typhoid fever and given medication. She showed me that exercise book she uses for hospital records and it showed on that day her blood pressure was 120/75 and weight was 50 kg. She said she has lost a lot of weight since the time she had the stroke. At the time she had her stroke her weight was 80 kg. She said even the dresses she wears currently would not fit her then because she used to be very big. She said when she had the stroke people had to struggle to carry her to hospital because of her weight.

Whenever I visited the family, Mr N often said that since his wife had her stroke in 2003 he has faced many problems. He said he is thankful to God that she can now walk by herself and do chores because she could not do anything after her stroke. They had to turn her in bed, bring her urinating utensils on bed and help her in many other ways as she was incapacitated.

This case study presents some of the features of biomedical treatment of stroke discussed earlier. Mrs PN commenced treatment at a nearby primary facility and thereafter at a bigger private hospital. Treatment at the larger private facility did not lead to improvement and after a struggle between the husband and medical staff she was referred to KCMC. Mrs PN attributes her improvement to the treatment she received at KCMC. After her discharge from KCMC, she continued treatment at a primary facility based in

her community. The support she received from her husband and children helped her cope with the illness as she made every effort to live the life she had preceding her stroke.

6.4.2 Home based biomedical treatment

After treatment at a health facility, stroke sufferers continue to be cared for and treated at home. For most stroke sufferers utilising biomedical remedies, this is a common scenario since stroke is an affliction from which recovery is not achieved in a short time (Tilling et al. 2001). Prolonged home based care is therefore an important aspect of the biomedical treatment of stroke.

In Dar and Hai home based care focuses on management of pain through the administration of pain killers, hypertension management and aspirin. It involves either daily administered anti hypertensive drugs and/or aspirin either obtained in a nearby clinic or bought from a nearby shop. Home based treatment is sporadic depending on the condition of the sufferer or the ability to purchase the required drugs. For example, drugs may only be bought, or a visit by a health worker from a nearby clinic organised, if the sufferer complained of pain or if their condition deteriorated.

If caring is prolonged to years, the carers show signs of caring 'fatigue' and the sufferer's complaints are taken as 'normal'. Some of my research participants told me at times they had to make hard choices between buying food and other essentials for the family and buying drugs for treating a condition with a minute chance of cure. At such stage, other remedies such as faith or self administered traditional medicine are likely to be utilised as they are either free, bought through flexible payments schemes, or demand less effort in procurement and administration for the carers.

6.5 Discussion

Decision-making for stroke in Dar and Hai is characterized by the often complex interaction of different factors in the field, for instance, the circumstances under which a stroke has occurred, the prior knowledge or information on stroke, the prevailing discourses, ability to

pay for initial and subsequent treatment intertwine in a complex social process. The decision-making process for the first and subsequent treatment options is characterized by negotiation, compromise and conflict of the discourses about the cause and appropriate treatment of stroke. Family and social relations together with the circumstantial environment in which a stroke occurs entail the dynamic and complex treatment decisions and treatment-seeking process. The social dynamic nature of treatment-seeking is a common feature in Tanzania (Comoro et al. 2003, Green 2000, Kamat 2006). A recent review of qualitative and quantitative studies from different parts of the world found that younger and better educated patients and women prefer more involvement in medical decision making (Say, Murtagh, and Thomson 2006). The review also found that the experience of illness and medical care, the nature of interaction with medical professionals, the nature of the decision to make, the health condition of the patients and knowledge they have about their condition determine their involvement in the decision-making process.

In Dar and Hai people make sense of stroke when it happens by drawing (consciously or unconsciously) on their habitus in order to explain what could have happened (Bourdieu 1977). The habitus is a product of socialization within a particular social, religious or cultural worldview. As in the example of Mama AC and her relatives, they also draw on the prevailing discourses and especially on the dominant one within the particular community. In a case of differing or contested discourses (as in the case of Mama AC), other people with persuasive power, and taken as experts (Friedson 1986, Scott 2001), are brought in to reinforce a particular discourse. Mama AC's relatives brought a traditional healer to convince her that her stroke was caused by a *jinn* and therefore required traditional treatment. In this case the healer displays his role of constructing knowledge for others (Friedson 1986) and hence their reference as *fundi* (expert). Mama AC resisted being converted into another discourse by sticking to the knowledge she obtained through her interaction with biomedical service providers. Since she was economically independent, she was able to resist the social pressure to embrace the discourse fronted by her relatives and traditional healer. A compromise is reached with the combination of both traditional and biomedical treatment.

Hospital treatment of stroke in Dar and Hai is sought from both public and private health facilities. Public facilities are mostly preferred because they are perceived as cheaper than private. Pluralistic medical systems are common in sub-Saharan Africa with a mix of public and private sectors (Bloom and Standing 2008, Van Damme, Kober, and Kegels 2008). In Dar, the fear of injections (reinforced by the dominant discourse in the site) is the main reason for avoidance of hospital treatment. This is related to the belief that stroke is caused by demons who would get a way of sucking the sufferer's blood if injected. This discourse is also reported in South Africa where stroke is framed as a social and physical condition (Hundt, Stuttaford, and Ngoma 2004). It is interesting that a similar discourse is present in two far apart places in Africa, and may suggest some wider, over-arching discourse. This may be an indication of how biomedical treatment is received with sceptism and resistance expressed through such discourse in those contexts. Since injections represent the common symbol of biomedical treatment (West 2006), its rejection represents resistance to the whole paradigm.

The economic ability of the family of the afflicted person determines their bargaining power for treatment of their relative. This is an important feature of the decision-making dynamics as ability to pay for services is an important aspect of treatment-seeking in Tanzania (Mubyazi et al. 2006, Muela, Mushi, and Ribera 2000). Recent changes in the socio-economic arena, whereby women have access to resources and therefore economic power, mean that they are now more influential in the decision-making process for ill family members. This is an important development as it ensures that the decision-making process is more participatory offering women the ability to enforce their views through exercising their newly acquired power (Foucault 2002, Scott 2001).

The concept of strategizing (Lamaison and Bourdieu 1986) becomes relevant when analysing stroke treatment-seeking behaviours in Dar and Hai. For example, treatment-seeking can be seen as a negotiation between freedom and constraint with the habitus on one hand and the field on the other. The interactive process takes into account factors such as individual skills, the constraints of resource limitations, relationships between individuals and groups to which they claim membership (e.g. religious groups) in determining

treatment-seeking (Jenkins 2002). Also, although switching between different stroke treatment options (i.e. biomedical, traditional or faith) may seem illogical and indeterminate to an outsider, when interpreted within a framework of 'practical sense', this fluidity takes the form of a strategy for dealing with stroke (Lamaison and Bourdieu 1986).

Problems within the healthcare system may be seen as constraints in the field which produce different treatment-seeking practices. As in other parts of Africa, biomedical stroke treatment follows the trend of general hospital care (Connor et al. 2007, Danesi, Okubadejo, and Ojini 2007, Fatoye et al. 2007, Garbusinski et al. 2005). Stroke sufferers are managed within the general wards. There is an acute shortage of specialist neurologists in Tanzania and they are based in major referral hospitals. The lack of qualified medical doctors in the health facilities based in the communities mean that stroke sufferers experienced delayed diagnosis and treatment.With the documented elaborate process before a sufferer arrives at such health facilities, it is likely that stroke diagnosis and care may be delayed exposing the sufferers to the danger of a secondary stroke.

The lack of human resource and shortages of supply is a common feature of the health care system in Africa (Bloom and Standing 2008, Connor et al. 2007, Ebrahim and Smith 2001, WHO/TDR 2008). The lack of adequate diagnostic facilities and low morale of the overburdened health workers mean that the quality of services available to the stroke sufferers is affected. The lack of other rehabilitative treatment such as physiotherapy and speech therapy mean that the sufferer's chances of recovery or gaining back lost function is less (Langhorne and Dennis 1998, Stroke Unit Trialist's Collaboration 2007, Tilling et al. 2001). The lack of observable improvement in physical recovery of stroke sufferers makes proponents of other discourse sceptical of the benefit of hospital treatment. Although a few of the health centres (such as Kisiki in Machame) and hospitals have designated equipped units for physiotherapy, the lack of qualified staff combined with the general understaffing of health workers lead to the underutilisation of such units.

Historical development of biomedical services in the two sites has had an impact on the way biomedical treatment is utilized. In Hai where there is a long historical presence of biomedical services (as illustrated in Chapter 4 where I presented the state of health facilities in Dar and Hai) leads to its dominance. This resonates with Foucault's view that discourses are also products of historical processes (Foucault 2002).

Since most stroke sufferers eventually end getting home based care after health facility treatment, there is need to strengthen the caring skills and knowledge of home care providers. The technical and logistical ability of primary health facility staff, who are, in most cases the ones supporting home care, should be improved by providing training for proper post stroke management. In Chapter 8 I discuss in detail the potential interventions for improving facility and home based care for stroke sufferers.

6.6 Conclusions

Treatment-seeking patterns for stroke in Dar and Hai correspond closely with the pattern of the popularity of the discourses in each site. The pursuit of relief from the outcomes of stroke affliction by the sufferers, their relatives and members of social network means that all available options may be pursued albeit in a different order by different individuals and groups. The perceived efficacy of a particular treatment or remedy option, social pressure from relatives and members of social networks, the enforcement of particular discourses by the creators of knowledge in a community, the economic ability to initiate and sustain a particular treatment option determine what remedial course is pursued. Plural healing practices (either serially or simultaneously) and healer shopping are employed in seeking treatment of stroke in the two parts of Tanzania. As in the cases of other illnesses such as diabetes (Aikins 2005), child malaria (Comoro et al. 2003, Kamat 2006) and other various illnesses (Beckerleg 1994, Green 2000), the onset of stroke demonstrates the complexity of treatment-seeking in the African context which should be treated seriously by any health intervention effort.

The decision-making process for the nature of the remedial course to pursue in the event of a stroke is socially dynamic and interactive. It involves conditions in the field, the habitus of stroke sufferers, relatives and people within their social network. The people involved in the decision-making also draw from the knowledge and information about stroke they had previously obtained though social interaction with other community members or service providers.

My findings indicate that the economic position of a family influences the nature and quality of treatment and care available to stroke sufferers. This is determined by the economic ability of the sufferers, their immediate families, and the extended families. For example, people or families with resources are able to access services from private facilities which offer better services than public ones. However, I should mention that the extended family and its traditional functions in Hai and Temeke are not as strong as they used to be. My research participants say that the nature and frequency of support from relatives has diminished compared to the past. Therefore, the burden of caring for stroke sufferers is largely shouldered by their close family comprising of spouses and children.

Biomedical treatment for stroke in Dar and Hai is either obtained through health facilities or administered at home after discharge from hospital. Hospital treatment mostly commenced at the small clinics located within the communities. Most of these facilities are poorly equipped and under staffed. They are also characterised by erratic drug supplies. The situation is worse in public facilities compared to private. Relatively better service is available at the bigger hospitals though these also suffered from lack of specialist doctors familiar with stroke. The quality and nature of the process for obtaining treatment through the biomedical services in Hai and Dar-es-Salaam mean that stroke sufferers are likely to delay getting appropriate diagnosis and treatment therefore reducing their chances of survival and increasing their risk of getting a recurrent stroke. Home based biomedical services are utilised by most stroke sufferers in the longer term. This is done either through the support of staff from the smaller health facilities within the communities or self administration by over the counter drugs bought at drugs shops in the village or *mtaa*.

In the next chapter I present findings on the traditional and faith based treatment of stroke in Dar and Hai.

7 Chapter Seven: Traditional and Faith Healing of Stroke

7.1 Introduction

This chapter presents and analyses findings on the range of traditional and faith based remedies for stroke in Dar and Hai. It builds on the previous chapter which presented findings on the decision-making process and patterns for treatment of stroke in the two sites, followed by the presentation of findings on the biomedical treatment of stroke.

In section two of this chapter, I present the range of traditional remedies utilised for the treatment of stroke in both sites. I start by problematising the use of the terms traditional medicine and traditional healing. I briefly highlight some aspects which make the two terms problematic in their use and clarify how I employ them in my study. I then describe and discuss in detail the typology of traditional healers offering the different kinds of stroke remedies. Furthermore, I describe the exact nature of treatment they provide. In the same section I also present findings on the traditional remedies self administered by either the stroke sufferers or their carers.

In section three, I present the nature of faith based healing available to stroke sufferers in the two sites. I describe the characteristics of Christian faith healing which is predominant in the two sites. Within each of the sections two to three, I discuss my findings and engage relevant literature. I also interpret my findings by connecting with my theoretical framework. In the last section of the chapter I conclude by summarising the key points covered and introduce the following chapter.

7.2 Traditional remedies

7.2.1 Problematising terminology: traditional medicine and traditional healing

The use of the term traditional medicine amongst researchers in Africa has been problematised (West and Luedke 2006). In some health related research it is used to refer to indigenous medicines or healing paradigms of particular ethnic groups (Sindiga 1995a, Sindiga 1995b, Sindiga 1995c). This perspective ignores the fact that the exchange of healing remedies and paradigms between different African ethnic groups and other societies outside Africa (such as Europe) has been documented since the early nineteenth century (Rekdal 1999). Recent research in South Eastern Africa has demonstrated that traditional healers in the area employ paradigms and medicines which may not be indigenous to a particular ethnic group or community. For example, West (2006) found out that healers in Mozambique invoke healing spirits from Tanzania whom they categorise as 'Arab spirits' or *jinns*. His research also shows that some healers from Mozambique travel to Tanzania to practise healing. Feierman (2006) calls this exchange and spread of healing practices and remedies 'profusion of practices'.

Cross-cultural healing means that ethnic groups embrace medicines and healers from other ethnic groups (Rekdal 1999). Indeed my research has demonstrated that cross-cultural and cross-geographical healing paradigms and medicines are a common feature traditional healing in Dar and Hai using medicines obtained from other countries such as Arabic countries, India and China. Therefore in my thesis I use the term traditional medicine to refer to indigenous and non indigenous medicines (both coming from other parts of Tanzania and outside the country) as contrasted to biomedical western type medicine.

Likewise, the term traditional healer is problematic (Kamat 2008). Though within health research it is often used to refer to indigenous healers, again the evidence from my research and South East Africa (Feierman 2006, West 2006) shows that the so called 'traditional healers' employ cross geographical border medicines and paradigms either obtained by virtue of their belonging to other ethnic groups outside the areas they

operate, training they obtain outside their communities or countries or embracing 'new' paradigms and medicines which are more efficacious or appealing to their clients. Therefore in my thesis I use the terms 'traditional healing' and 'traditional healers' to refer to the broad range of healing practices ranging from local (in the sense of originating from within the communities in the research sites), cross-cultural remedies (originating from other communities living outside the study communities) and cross-border remedies (coming from outside Tanzania). My findings on the cross-cultural and cross-border nature of traditional healing in Dar-es-Salaam and Hai demonstrate the ways in which these healers are engaged in an ongoing modification of their practice through learning and adapting new remedies.

7.2.2 Healer administered traditional treatment

In Tanzania, traditional healers have formed organisations to facilitate the coordination of their practices, protect their interests as a group and generally to enable them 'speak in one voice'. Most of these organisations are legally registered as associations and used as advocacy tools for raising the profile of their activities to the general public and therefore legitimising their practice. For example in Hai, the District Sports and Cultural Officer (DSCO) is aware of one such organisation operating in his district. The Swahili name of the organisation is *Chama cha Waganga wa Tiba za Asili Tanzania* (CHAWATIATA) that is, the organisation for traditional healers in Tanzania. The organisation has a written constitution and is headed by a district chairman assisted by a secretary. The Hai DSCO has the impression that not many traditional healers in the district are members of the CHAWATIATA because of the high annual fees. However he is not aware of the exact amount of the annual membership fee for the organisation.

In Tanzania, there is a requirement that at the district level of government all traditional healers operating within its boundaries be registered and given permits by the DSCO. This arrangement demonstrates that at the district level, traditional healing is perceived as a cultural issue therefore appropriately handled by the culture office and not the office of the District Medical Officer (DMO). The DMOs deals with all health related issues in the district. However, at the national level there is a different arrangement whereby

traditional healing is handled by two ministries, the ministry of health and social services and the ministry of sports and culture. In practice though, it has been difficult to implement the policy of registering all traditional healers operating within a particular district. In Hai many traditional healers are mobile and based in remote rural villages, therefore they do not see the need to take the trouble to be registered. Since most do not consider themselves formal healers, it is difficult to ascertain their number. The same scenario prevails in Dar where traditional healers prefer to operate independently out of the official circles.

In Hai, most traditional healers are based in Boman'gombe town and the lower lands villages of Rundugai and Mtakuja. There are fewer traditional healers in the upper lands of Machame, Masama, Sanya and Lyamungo. The Hai DSCO estimates that there are about fifteen traditional healers in Machame area. As a result of these complexities, I could not obtain an accurate record of the number of the registered healers operating in Temeke and Hai. The Hai DSCO estimates that there are about 40 traditional healers in the whole district while the DSCO for Temeke has the opinion that there are over a hundred in his district.

7.2.3 Typology of traditional healers

Traditional healers in Tanzania are described as a very heterogeneous group not having much in common in terms of demographic characteristics such as religion and level of education (Gessler et al. 1995). They also comprise various categories ranging from herbalists, ritualists to spirit healers (Gessler et al. 1995, Green 2000, Rekdal 1999). Some practice specialised healing of specific illnesses or conditions such as fertility and broken bones (Green 2000, Kamat 2008).

There are several types of traditional healers providing remedies for stroke in Temeke and Hai. I have come about these categories after examining the nature of treatment offered by the different groups of healers in the two sites. Therefore my typology of healers engaged in treating stroke in Dar and Hai is not based on labels that the healers themselves necessarily characterise their practices, but I use them for the purpose of

analysis and clarity of presentation. Traditional healers in Hai and Dar are referred using several Swahili terms such as '*waganga wa kienyeji*' [local doctors], '*wagaga wa jadi*' [traditional doctors], and euphemisms such as '*fundi*' and '*mtaalam*' [both meaning expert]. The use of the term *mtaalam* in reference to traditional healers has also been documented by another ethnographic study conducted in a village near Dar-es-Salaam (Kamat 2008). In rare cases traditional healers are referred using the formal Swahili term '*waganga wa tiba za asili*' [traditional remedies doctors]. *Waganga* (sing. *mganga*) may be literally translated to mean doctor and is used to refer to both traditional and medical doctors. The Swahili word *mganga* has its origin in the Bantu word *nganga* which is used in many Bantu speaking groups to refer to healers (Feierman 2006).

In Hai, there are three types of traditional healers dealing with stroke. These are healers who only utilise herbal remedies, those who use divination together with local or foreign medicine (Arabic and Indian) and those who use spirits together with local or foreign medicine. Herbalists are the minority and diagnose illnesses by studying the symptoms and listening to the narration of the sufferers. They try to disassociate themselves from witchcraft and divination. For the second group of healers, divination (*kupiga ramli*) is usually the first thing which a healer undertakes when consulted. It involves finding out the cause of the illness. During the process of divination, a healer writes on a blackboard in order to work out the cause of the affliction. Other items such as small gourds may also be used during divination. After divination, the sufferer is told who had caused their illness and given medicines to cure their affliction and protect further 'attacks'.

The third group of healers invoke spirits to predict the course of illness and the appropriate treatment. Such healers say that it is the spirits who posses the knowledge about traditional medicine and only speak through them. A female healer says when in a state of possession she speaks about the exact things needed to be done as part of the treatment such as offering sacrifices to ancestors. While still in the state of possession, she also mentions the specific types of medicine to be prepared for curing the ailment. When not possessed by the spirits, the healers are not able to tell a cause of neither the

illness nor its appropriate treatment. They are not able to remember anything they say while possessed.

There are very few traditional healers in Machame area where I conducted the bulk of my ethnographic fieldwork. The majority of the healers operating in Machame have immigrated from other parts of Tanzania and especially from the neighbouring Tanga region. I only came across two Chagga traditional healers who operate in the area. All of the established healers in Machame belong to the Sambaa ethnic group which originates from Tanga. My findings show that there are two main reasons for the few numbers of traditional healers in Machame. The first reason is due to the cultural practices of the Chagga who did not have a strong cadre of healers within their traditional cultural setup. Several of my key informants told me that traditionally the Chagga did not have established healers among themselves. Healers in Chagga land have always come from outside their community from either their Pare or Sambaa neighbours. Some Chagga started practising traditional healing after travelling out and living among other people outside their community where they learned such practices.

The second and most common explanation I got from my research participants was that the reason for the few numbers of healers in Machame is due to the long historical presence of Christianity which discourages all forms of traditional healing. A traditional healer narrated how the Christian church establishment has been fighting traditional healing practices in Machame. He told me that some residents of Machame have been waging a 'war' against them (*tunapigwa vita*). Public officials such as village leaders spearhead the 'war' after being pressurised by the church establishment to evict the healers. The reason for the eviction push is that traditional healers are perceived to be engaged in some form of witchcraft. The healer continued his narration by giving his own experience of how the village officials harassed him when he immigrated into the area but failed to achieve their goal due to his resilience. He argued with them that he had done nothing wrong since traditional healing is legal in Tanzania with established procedures for one who wants to practise it. And since he showed them his permit from the DSCO, they found no ground to enforce their plot.

The narration provides good evidence of how traditional healing is perceived in Hai. It also shows how the Christian establishment in the area is capable of exerting pressure on local government officials to root out practices which contravene their views. The same healer had the opinion that traditional healers are less powerful than the religious organisations which have been against their practice for many years. Since religious organisations have many followers, they are able to mobilise them to boycott their services and hence force them to move from their area. Traditional healers in Machame try to cope with such economic 'sanctions' by 'outsourcing' their services to people who live outside the area in order to maintain their income by. All traditional healers I interviewed usually travel outside of Machame to treat people.

Several research participants in Machame talked about residents fearing being seen visiting traditional healers as it leads to them being ex-communicated from the church. Residents who are associated with consulting traditional healers may be refused church services such as baptism of their children and Holy Communion. As a result, some residents of Machame opt to visit the healers secretly at night as they fear being seen if they do so in daytime.

On the other hand, there are many traditional healers operating in the Saba-saba area of Dar where I undertook my ethnographic fieldwork. The healers in Dar experience wider freedom of practice than their counterparts in Hai due to the cosmopolitan nature of the population. The majority of the healers in Saba-saba come from the wider coastal area in Dar and other neighbouring areas. In addition, some of the healers come from nearby Islands in the Indian Ocean such as Pemba, Unguja and Mafia.

There are three categories of traditional healers dealing with stroke in Temeke. There are those healing through engaging spirits together with using medicine, those healing using certain interpretations of Islamic cosmology and the knowledge of the Koran only, and those who combine certain interpretations of the Koran, Islamic cosmology and local medicine and medicine from other parts of the world. Traditional healers buy the

imported medicines from shops specialized in selling it. The imported traditional medicine comes mainly from India and the Arab gulf countries such as Oman. The three groups of healers operate individually as there is no formal contact between them.

The following table summarises the different types of traditional healers operating in Dar and Hai.

Type of healer	How become healers	Nature of healing
Herbalists	Through inheritance, selection and practical learning	Utilise herbs only from natural vegetation
Spirit plus medicine healers	Spontaneous selection by spirits or *jinns* or through family line	Invoke spirits who tell cause of illness and appropriate remedy. Also use herbal and/or animal products
Diviners plus medicine healers	Either inheritance through family line or learning from established healers	Divination plus herbal and/or animal products
Islamic interpretations plus medicine healers	Either inheritance through family line or learning from established healers	Application of specific interpretations of the Koran plus herbal and/or animal products
Koran based healers	Through learning involving attending Islamic schools and colleges	Apply only received interpretations of the Koran and Islamic cosmology

Table 5: Typology of healers providing stroke remedies in Temeke and Hai

The following three cases illustrate the kinds of traditional healers operating in Dar and Hai.

Case 5: Mr EK - The Herbalist

Mr MK is a Pare male herbalist in his 50s who treats people at his home in Rundugai village in Hai district. He also self identified as a Roman Catholic. His homestead is composed of one large house which is built using stones and mud and roofed using iron sheets. At the front of the house there is an old tractor which seems to have been broken down for a long time. Whenever I visited EK we chatted in a room located at the back of his house which he uses as a consulting room. There are three chairs and a table in the room. In the same room there are several paper boxes and nylon bags stuffed with dried roots and tree barks of different kinds.

EK said he started practicing healing after a strange supernatural being appeared to him several times some years back. The supernatural being looked like a human being but was not entirely human. It took him into bushes and forests within the vicinity of his village and outside the area and showed him the different medicinal plants. During that time he lived in the forests and caves. After mastering the knowledge about medicinal herbs he returned to his village and started treating people with different types of illnesses.

EK self indentifies as a herbalist treating people using herbs only. He does not treat people who say they have been bewitched. When he gets such people he usually tells them to consult other healers who deal with such matters. He makes diagnosis of illness after carefully listening to the sufferer's description of their symptoms. Thereafter he prepares the appropriate medicine using herbs. He also uses coconut oil as a remedy for various illnesses.

EK treats a range of illnesses from stroke, cancers, broken bones, abdominal ulcers and male impotency. However his speciality is female infertility. He showed me several notebooks in which he keeps records of women he had treated for fertility problems. He also showed me a book of names of children who have been born after he had cured their mothers of infertility. He usually requests his clients to come back to report to him if they get children of which some return and some don't. He is quite organised by keeping records of clients he has treated. He said his charges range from a few hundred shillings to thousands. For example if a woman has a child after his treatment they pay him 20,000 shillings.

EK said that the people he treats come from different parts of the country. Some of them come from neighbouring countries such as Kenya and Uganda. He says that many researchers within Tanzania and others coming from outside the country visit him to learn about how he treats people. BM himself has been treated in hospital on several occasions. He suffers from an allergy after diagnosis at KCMC.

In the case presented, Mr EK self identifies as a herbalist and Christian. He was initiated into herbal treatment by a strange supernatural being and underwent training in the bush. He distances himself from witchcraft and talks of the ways in which he diagnoses illnesses by listening to the explanation of the sufferers. He keeps records of successful cases he treats, though this provides a biased picture as unsuccessful treatments are not recorded. His clients come not only from his village but also from other parts of the country and East Africa which is indicative of outsourcing practices for traditional medicine.

Case 6: Mama D- Spirit and medicine healer

Mama D is a female traditional healer in her 50s operating in Saba-saba area of Dar-es-Salaam. She has separated with her husband whom they had two children together. She has been practicing traditional healing for over 10 years. She has a house which she built using income

obtained through healing charges. The house is built using cement blocks and roofed using iron sheets. She uses a room on the front left side of the house for consulting and treating. There is a mat in the room which she uses to sit on when talking to her clients and there are two wooden chairs for people who consult her. In the room there are many items she uses for healing such as large red and black pieces of clothes, wooden and plastic containers with powder like materials. There are also several beads and small gourds.

Mama D became a healer after becoming ill for some time. She was then taken to a traditional healer who treated her and discovered that she had *jinns* who demanded that they stay in her body and she becomes a traditional healer. That was the condition for her to get better. She agreed to become a healer and went to another healer who taught her how to heal people using the *jinns* known as *maruhani*. She stayed with her teacher for two years receiving instruction through observing what her teacher did when treated people of different ailments. After the two years, she set up her own place and started treating people.

When an ill person comes to her, she invokes the *maruhani* who then narrate the cause of the illness and instructs how to treat it. They specify the medicines to give the sufferer and where to get it. When she is possessed by the *maruhani*, she is not conscious of what they say. She therefore needs an assistant who interprets what they had said. The interpreter is called '*mkaramani*'. She then fetches the materials for preparing the medicine either from shops or bushes and forests located outside Dar-es-Salaam such as Kisarawe and Bagamoyo.

Mama D has treated only two stroke sufferers to date. One lives in Dar, and the other one lives in her home village (a relative). She said both sufferers got some relief after her treatment although they did not return to their pre-stroke condition. Her treatment for stroke entail orally taken medicines and massaging three times a day (morning, afternoon and evening). The massaging material is made by mixing certain types of medicines with coconut oil or castrol oil. She says stroke is caused by a *jinn* also known as *mdudu*. The *mdudu* is usually a product of 'human's poison' '*sumu ya kibinadamu*'. God did not create the *mdudu* but humans did. Humans create the *wadudu* (pl) in order to harm other people who they don't like out of envy. But one can obtain 'protection' from such people and *wadudu*. She said she usually offers the protection to her customers in case they requested.

Mama D narrated that during treatment, stroke sufferers are usually kept indoors for two reasons. First is due to the fact that they cannot walk due to their physical inability. Secondly is that the healer does not allow them to go outside until a time they are satisfied that the medicine has worked '*dawa imemkolea*'. In addition, the treatment requires that the sufferer not meet people who are 'unclean'. Such people are those who have had sexual intercourse and not taken a bath, or those who have gone to the toilet and not washed themselves properly. If such people come into contact with the sufferer they would cause treatment failure. Therefore during treatment, a sufferer is advised to be attended only by very close relatives such as spouses and children and the traditional healer. A stroke sufferer may therefore stay indoors- out of people's site- for the whole duration of their treatment. During this time, they are not allowed to receive hospital treatment for fear of being injected- which will give the *mdudu* a passage to suck their blood and die after two days. The sufferer can only be allowed to go to hospital after the healer is satisfied that their medicine has worked.

Mama D says that although *jinns* can treat many types of illnesses, they also have limits as there are certain types of *jinns* who cannot treat certain types of illnesses. So, if someone is utilising the *jinns* who do not have the ability to treat that particular illness, the treatment will fail.
She is skeptical whether traditional healers can work together. She is concerned that some of the

traditional healers are selfish, and when they participate in research projects with other healers, they keep all the fame and money for themselves. She provides an example of a project she was involved in the past which dealt with HIV/AIDS research with a focus on traditional medicine. The department of traditional medicine of the Muhimbili University of Health and Allied Sciences (MUHAS) conducted the study. As part of the study, healers in the area were identified, and encouraged to bring their medicine to MUHAS for analysis and trials on AIDS sufferers. All healers participating in the study were supposed to be paid. However, one healer who was coordinating the link between the healers and MUHAS decided to tell the people conducting the study that he is the only expert healer dealing with AIDS and the rest are bogus. He therefore disconnected other healers from the project and took only his medicine for tests and subsequently paid money. He used the money to start business projects, but all of them collapsed after some time. He also used some of the money to buy a car, but it later had an accident after running over his child at his home. She said due to the bad things he did to the other healers, God repaid him though having all these misfortunes.

The case of Mama D demonstrates that women are also engaged in traditional healing. Even though she has separated with her husband, she manages to build a good house from her income obtained from healing. Her own illness experience and treatment by a healer leads to her becoming a healer. The transformation of patients to healers has been reported as a common way through which healers enter into the practice in Africa (Gessler et al. 1995, Reis 2000). Mama D expresses a discourse detailing stroke as caused by humans through their creation of *mdudu* or *jinns*. She narrates how such attacks are treated and in the process explains the hazard of injections to people with stroke. In her narrative, it is the spirits who have the knowledge on treatment and only use her as a medium for treating people- she is a conduit, as it were, for the power of the spirits. She explains failure to treat other forms of illnesses to the inability of *jinns*. She is skeptical on the potential for collaboration between traditional healers.

Case 7: Mr OK –Koran based healer

Mr OK is a male traditional healer in his 40s who uses only Islamic cosmological and knowledge of the Koran to heal people. He is well educated compared to other traditional healers I encountered during my fieldwork. He was a Christian and had attended the Catholic seminary at Kigamboni in Dar-es-Salaam for several years before converting to Islam. He also trained as a technician at the Dar-es-Salaam technical college and obtained a full technician qualification. In addition, he holds a diploma in materials management. After converting into Islam, OK went to University in Turkey where he studied the Koran and Islam for several years and afterwards went to Jeddah in Saudi Arabia for 3 years for further Koran and Islamic studies.

In healing, he employs a type of Islamic interpretation called '*falakia*'. He defines this version of Islamic healing as one trying to understand how the office of God works in relation to the world

and use that knowledge to cure people of different ailments. It involves studying and understanding how God organizes his work through the different beings he created. He says that the office of God is well organised with specific tasks assigned to specific angels and their workers. He gives examples of angels and their tasks as –*Akidu* who together with his/her workers (who number in trillions) is charged with the task of recording all things which happen in the world. Another angel is *Rakibu* and his/her many workers who have the task of recording all good deeds of people so that they would be judged fairly on judgment day.

He narrates a complex astrological account of how the universe is organised and how the planets, moon and sun operate. To him this knowledge is important in order to understand what to ask from the angels depending on the time they are serving this world. He says angels and *jinns* serve the world on specific days and times. Therefore if one wants to request them for anything, they must know what date and time they operate and put a request at that particular moment. The key is to know the communication codes and how to reach these angels and *jinns* and they will do whatever one asks them for (including healing people). He acknowledges that some people could misuse such knowledge to cause harm to other people as the angels and their workers will do whatever the person in touch with them asks them to. He says humans who misuse this power will be punished on judgment day. He points out that Christians are mistaken by saying that *Lusiferi* (Lucifer) was an angel of God before he turned against him and was cursed and thrown away from heaven. He says according to Islamic teaching, *lusiferi* is a *jinn* as it does not ascribe to the view that angels can disobey God since they are not created with free will. It is only *jinns* and human who were created with free will and could therefore choose whether to obey or disobey God.

His interpretation of Islam categorises two types of *jinns*, good *jinns* and bad *jinns*. The bad *jinns* are followers of their leader lusiferi who was cursed by God. Cursed *jinns* consist of 21 tribes (*makabila* 21). He argues that there are some healers who use these cursed *jinns* to harm or cure people. He particularly had very negative views about healers who use *maruhani* (spirits) for healing. To him, such healers use the cursed jinns instead of the good *jinns* (*majini watukufu*). He asks why once the *maruhani* posses a healer, the healer cannot understand what they are saying until another person interprets it?

OK says that *jinns* can kill any disease causing organism including viruses. Therefore they can cure any illness and that is why he uses them in his healing practice. It is only humans who get ill and not angels and *jinns*. The only two things angels and jinns cannot do are: preventing someone from dying and protecting someone from getting old. Mr K says he has the ability to call *jinns* and use them for any purpose. He could ask them to take him to Zanzibar, and they would take him there immediately. He could not tell how many stroke sufferers he has treated. He says stroke is also called '*buruda*' meaning cold (derived from Arabic).

OK is ready to collaborate with any research programme to demonstrate how his practice of *falakia* cures people. He says if a programme for treating stroke sufferers is set up in Saba-saba area, he is ready to be given a room within a health facility where he will treat people using his knowledge, and people evaluate his success.

Mr OK employs his version of Islamic knowledge and interpretation for healing. His previous background as a Christian enables him to compare the cosmological outlooks of

the two paradigms and challenge the Christian outlook. His educational background enables him to articulate clearly his viewpoint and also to point out 'flaws' in the practice of other healers who, he explains, use wrong *jinns*. He attributes his healing ability to God through his creations (angels and *jinns*). He is positive about the possibility of collaborating with a community based programme for treatment of stroke as he sees it as an opportunity to demonstrate the ability of *falakia* and secure his status as an expert in society.

7.2.4 Traditional medicines for stroke

Traditional healers in Dar and Hai prepare medicine using leaves, barks or roots of natural plants. The healers fetch the ingredients either from nearby or distant bushes and forests. Some of them buy the plant ingredients from shops or other people selling traditional medicine as some of the plants have become scarce due to human activity of clearing forests and climate change. Some of the medicines are prepared using animal products such as pigeon blood, and lion fat.

There is a wide range of traditional remedies for stroke administered by healers. They range from burnt substances which sufferers are made to inhale, topical, and orally taken medicines. Other types of medicines include those used for massaging. Massaging is done in order to restore the physical function of the affected body parts. Massaging done by the traditional healers may have some beneficial value as it involves stimulating the muscles of the paralyzed part of body. Some healers say that they also exercise the body parts of the sufferers during the massaging sessions. However some healers complain that massaging is very laborious as it needs to be done at least three times a day (morning, afternoon and evening). If limited by time, a healer may opt to massage a sufferer just twice a day instead (morning and evening).

The various traditional healers I interviewed had varied experience of treating stroke sufferers. Some had more experience of treating stroke sufferers because they have a good reputation of successful treatment. For example, one traditional healer in Saba-saba says he has treated more then 30 stroke sufferers while another has not treated one for the

past five years. A traditional healer in Machame reports that he treated five stroke patients since he started practising traditional medicine. Out of the five, two had recovered fully (suggesting they had regained their pre-stroke state). The other three had not recovered fully and had stopped utilising his services. It is therefore essential to realize that the validity of a healer's accounts (as well as the range of their experiences) varied from one to another.

A traditional healer in Dar-es-Salaam, famous for his success in treating stroke, commences treatment by a process he calls, in Swahili, '*kufusha*'. This is the process of exorcizing the *jinn/mdudu* and it involves making the sufferer inhale smoke and vapour from a combination of several medicinal plants. The combination of the plants used for this purpose is called '*nyungu*'. The second stage of treatment involves taking oral medicine prepared using plants and roots obtained locally from forests or bought from shops selling traditional medicine. Some of the plants he uses for stroke treatment at this stage are *Mfalsida*, *Mmavimavi*, *Mwinga jinni*, *Mwinamia maji*, *Kabir shamsi*, and *Mpesi*.[12] Some of these plants have a strong aroma typical being the *mmavimavi* plant which has a pungent smell. In the second stage of treatment he also uses verses from the Koran and *dua* (prayer). The third stage entails massaging the patient until they regain sensation and movement of limbs. The healer prepares the material for massaging by mixing several items such as coconut oil, sunflower oil, castor oil, cloves, paraffin, lemons and other medicines such as *Kamni asweda*, *Kamni asiadi*, *Halititi*, *Hamdadi*, *Kachiri*, *Kibiriti upele*, *Kashkash maua*, and *Ali njinji*.

As in the example of case 2 (Mama D), some healers require the people they treat to stay indoors for the whole period of treatment. This is done in order to prevent them from coming into contact with people who caused their ailment and might decide to interfere with the treatment by making further witchcraft attacks. They could also come into contact with 'unclean' people who would make the treatment ineffective[13].

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[12] Refer to the glossary in the appendices for the meaning of these terms.
[13] This is a very similar notion to 'contamination' in biomedical treatment.

Traditional healers offer flexible payment modes and are therefore considered affordable and fair by users of their services. For example, most of them prefer their clients to pay them in full after getting cured. The initial money they demand is only for covering the costs of preparing medicine. These costs include fare to the forests where the medicinal plants are found and the cost of buying from shops some of the materials they use for preparing the medicine.

All the traditional healers I interviewed were optimistic with the idea of collaborating with biomedical interventions about stroke treatment. They wanted their work to be evaluated and given the respect they thought it deserved once shown to be effective. They were ready to be given a few stroke sufferers to try their medicines. Some, though, were skeptical about whether they could achieve cooperation among themselves due to the selfishness of some of them who might want to benefit financially.

The following two cases further illustrate the types of traditional healers operating in Dar and Hai and the nature of the remedies they employ for treating stroke.

Case 8: Mr BM - Diviner also using medicine

Mr BM is a Sambaa traditional healer based in Narumu village in Machame. He immigrated in Machame from Kiborloni fourteen years ago. His brother is still practicing traditional medicine in Kiborloni. He became a healer after inheriting the practice from his father who was also a traditional healer using *maruhani* (spirits). He described *maruhani* as a form of spirit dancing whereby drums are beaten in a specific rhythm to invoke the spirits. After being possessed, a healer is able to tell the cause of illnesses and appropriate treatment.

BM had been married to several wives over the past years and has several children. At present he does not have a wife as he had divorced his previous one who was a drunkard. Since he keeps *jinns* (*nafuga majini*) for traditional healing, he had to divorce his drunkard wife as *jinns* do not like alcohol. BM engages in different types of treatment practices among them divination. During divination he tries to ascertain the ancestral origin of the patient. He says there are 12 broad clans of people in the world. Six clans are the source for good health and six are the source of illness. After knowing the clan of the patient through divination, he is able to tell the cause of their illness and subsequently its appropriate treatment. There are two types of illnesses he treats: those which are due to natural causes and those due to *jinns*. As part of his treatment he makes sure the *jinn* releases the sufferer. He says that illnesses caused by jinns must be treated using traditional medicine as such illnesses are not compatible with some aspects of hospital treatment. For example, *degedege* (severe child malaria) must be treated using traditional medicine. If a child with degedege is injected, they may die.

BM mainly treats psychiatric cases and had treated nine cases since moving to Machame. He also treats female infertility, epilepsy and paralysis. He narrated how he had treated a female stroke sufferer who got the illness while living in another part of Tanzania (Morogoro). When the woman was brought to her she could not walk. But after treating her, she recovered fully and returned to Morogoro to continue with her job. According to BM, her illness was caused by work related jealousy and she had been bewitched by her fellow worker.

BM obtains his medicines from forests around Kilimanjaro such as Himo area. He purchases some of his medicines from Mombasa store in Moshi. He says all types of medicines for stroke, *jinns* and degedege are available at Mombasa store. Mombasa store shop operators usually give them instructions on how to mix the medicines. He administers some of his medicine by making incisions (*chanjo*) on the sufferer's skin and applies medicine. Through such a method the medicine goes directly into the blood stream of the sick. Other methods he employs are topical application (*kupaka*), inhalation of burnt leaves (*kufusha majani*), and bathing (*kuoga*). He keeps pictures of people he has cured which he proudly showed me.

BM does not have a fixed cost for his services. He charges between 500 and 1000 shillings for the cost of preparing the medicine (*gharama ya dawa*). The cost for his labour varies but may go up to 10,000 shillings. Some of the people he treats opt to pay him in kind such as giving him a bag of sugar. The brother of the female stroke sufferer he healed paid him 20,000 shillings.

The case of Mr BM is an example of a Sambaa healer who emigrated to Machame from Kiboroloni (near Moshi town), manifesting the cross-cultural nature of traditional healing in the area. He narrates how traditional healing is a family practice and which he inherited from his father. He elaborates how he engages in divination in order to ascertain the family origin of his clients and tell the cause of illness. He is particularly enthusiastic about one case of stroke he treated and keeps a photograph to show to people visiting him. The photo is proof of the efficacy of his treatment, though he does not talk of unsuccessful cases. In terms of payment of fees Mr BM is both flexible and considerate, allowing both payments by installment, and in kind.

Case 9: Mr AF - Islamic interpretation plus medicine

Mr AF (famously known as sheikh A) is a male traditional healer in Saba-saba, Dar-es-Salaam who originally came from Pemba Island in Zanzibar. He practices traditional healing by combining knowledge and verses from the Koran and traditional medicine knowledge he obtained from his father who was a traditional healer. He says traditional healing is their family's tradition as his grandfather, father and siblings all practice(d) traditional healing. Apart from learning healing from his relatives, he attended lessons from healing teachers in parts of Pemba called

Wambaa and Msuka. He says Msuka is regarded as the headquarters of the expertise on *jinns*. He narrates that in Msuka there are people there who have the ability to call a *jinn* like they call a small child. And if a *jinn* disobeys they are threatened with burning. In Msuka there are experts who can just point a finger to a *jinn* and it catches fire. He also trained on healing in Lamu (Mombasa). He says there is a difference between knowing the Koran and knowing how to heal people as one can study the Koran well and yet know nothing about healing.

AF is famous for treating strokes in the Saba-saba area and says he has treated 37 stroke sufferers. Out of the 37, he failed to cure only seven because the illness had become chronic. Some among the seven sufferers have since died. He claims that the remaining 30 sufferers have recovered fully. He gives an example of a TSIP enrolled stroke sufferer he had previously treated. I had interviewed the stroke sufferer who said that he initially refused to be taken to hospital when approached by TSIP community enumerators. At that time he was still receiving treatment from AF. After AF was satisfied that the treatment was sufficient, he allowed him to go to hospital. The stroke sufferer later passed away after suffering a secondary stroke. When I asked him why the man suffered another stroke and passed away if he had fully recovered; he said that the man had not take his advice to get 'protection' from him to prevent another stroke. He says the man had two wives and they were always competing on whom among them he should spend most of his time with. On the day he had his second stroke, the man had gone to visit his other wife in Mbagala area. His other wife who lives in Saba-saba was not happy and therefore decided to 'do what she knew' implying that she used supernatural means to cause his stroke.

At the time I conducted my fieldwork in Dar-es-Salaam, AF was treating four stroke sufferers. He had been requested to treat another four sufferers but declined. He says that he does not like to treat many stroke sufferers concurrently as the treatment is very time consuming. It involves massaging the sufferer at least three times a day. He therefore fears that if he takes lots of stroke sufferers at once, he won't get the time to do other things. He narrates that from his experience, stroke is a much bigger problem in Dar than in Zanzibar. He gets lots of stroke sufferers because he has a good reputation of successfully treating stroke cases.

AF says there are more than 41 different types of medicines for stroke. He gave me a long list of names for the medicines. Some have Arabic and Indian names. He said some of the medicines he collects from Kisarawe forest and others he buys from shops selling traditional medicine. Some of the medicine sold in the shops comes from Arabia (Arabic countries) and as far as India. He buys the different ingredients from the shops and he mixes them to make the medicine he wants. He showed me some of the medicines for stroke during my visits to his place. AF is certain that stroke is caused by *mdudu* (*jinn*). There are two types of *wadudu*: one created by God and the other created by man. The one created by God likes to stay in dirty places such as toilets and places where rubbish is thrown. This type of *mdudu* also likes to stay where donkeys are. When I asked him why the *mdudu* likes to stay near donkeys, he could not offer a specific reason but thought it was just the way they are created. If someone is attacked by such an *mdudu*, they are treated first by smearing dirty things on their body such as rubbish and urine. After the smear, the *mdudu* usually releases the person and thereafter they can be treated using traditional medicine.

The second type of the *mdudu* causing stroke is usually made by humans. He showed me an old book with Arabic writings and drawing of the *mdudu* who is formed (*kutengenezwa*) and sent to cause a stroke to someone. He said he can recite the Arabic verses and form the *mdudu* and put it on a road where when the intended person passes by, it attacks them. He said in most cases, humans create stroke due to work related jealousy. For example if someone gets promoted, the other workers become angry and may decide to visit a healer who then creates a *mdudu* to harm the person promoted. The *mdudu* would make a stroke happen to the one promoted so that they

fail to work and the other workers get promoted instead. He says injections are fatal for people who have been attacked by a *jinn* because once you bleed such a person, the *jinn* will get a way of sucking the person's blood and kill them. He obtained the books with information on healing from his father, and some he gets from people he treats (as gifts). He was given one of the books by a person who used to work in the Tanzanian embassy in Oman whom he had helped get promoted.

AF is very keen to get acknowledgement on his ability to treat stroke sufferers by doctors in hospitals such as Muhimbili. He says he would like to be given a few stroke sufferers to treat and afterwards have his work evaluated by doctors. He is sure people will be amazed by his ability and may decide to refer more stroke sufferers to him. Likewise, he said that he is ready to advise the sufferers he treats to go to hospital after finishing his course of treatment.

The case of AF, a Pemba healer operating in Dar, provides another example of cross-cultural healing for stroke. He traced his healing heritage to his family and Pemba origin where there is expertise on dealing with *jinns*. The fact that he was also trained in Kenya is demonstrative of cross-border healing practices. He made a distinction between knowledge of the Koran and healing. His reputation for successful treatment of stroke means he gets many clients. AF locates the cause of stroke within a discourse which explains it as caused by *mdudu* (*jinn*) created either by God or man. The creation of the harmful man made *mdudu* is due to social and work-related conflicts. The line between him as a healer or harm causing person becomes hazy after he admits having the ability to create *mdudu*. He echoes the discourse that injections are fatal to stroke sufferers. He blames the failure of treatment (indicated by the recurrence of stroke) on the disregard of his advice by his clients. AF is keen for his expertise in treating stroke to be formally recognized and yearns for approval by those endowed with the recognised status of expertise granted to medical doctors (through symbolic power).

7.2.5 Self administered traditional treatment

In addition to the specialised traditional medicine remedies administered by the healers, some stroke sufferers self administer the traditional remedies. These remedies are grouped under three categories. The first category comprises of medicines obtained from the traditional healers after completing the main part of treatment. Thereafter self administered treatment is done at the homes of the sufferers and their carers. These medicines are prepared by the healers, and the sufferer and their carers given instructions

on how to use them. Some of the medicines are put into bathing water of the sufferers or used for massaging the impaired body parts. Other types of medicines (mostly in powder form) are taken orally or inhaled.

The second category of self-administered traditional remedies result from the knowledge about the remedies passed from older generations of parents, relatives or friends. Some of this knowledge is obtained in the course of social interactions and conversations about stroke. These kinds of remedies include what I term 'first aid' remedies. My research participants spoke about certain things one is supposed to do immediately after a person is afflicted by stroke. Such practices included the smearing of the person affected with either urine or faeces, and slapping back into place the affected part of the face with a sandal. Other such self-administered treatment involves consuming certain food stuffs which are believed to have some medicinal value on stroke. Such food stuffs include cucumbers and garlic which are believed to have medicinal effect on stroke and other illnesses such as stomach ailment or renal complications.

The third category is the self-administered traditional medicines bought from shops selling traditional medicine. In such cases relatives or friends of a sufferer go to the shop and describe to the shop attendant the symptoms affecting their relative or friend. The shop attendant listens to the description of symptoms and gives them the appropriate medicine. All traditional shop attendants have knowledge about the type of illnesses that the medicines they sell treat – in this sense they are like pharmacists within the biomedical system. They can be categorised as 'quasi' traditional healers. The traditional shop attendants give instructions on how to administer the medicine. In some cases they tell the person purchasing the medicine the cause of the illness especially if they show interest in knowing.

During my fieldwork, I was able to visit these shops and purchase a variety of traditional remedies for stroke. Some of the medicines (such as lion fat and coconut oil, often mixed with a black powder made from ground seeds of specific plants such as sunflower) are prepared for massaging purposes. Some of the medicine in powder form is supposed to

be taken orally by either putting it in the sufferer's tea or porridge. The medicines sold in the shops are either made from ingredients obtained locally or imported from India, China and Arabic countries.

During one of my visits to a traditional medicine shop in Moshi town (Mombasa store), I purchased traditional medicines used for treating stroke. The shop attendant explained that they sold two types of stroke medicines. One is in capsule form and the other in powder form. The one in powder form is prepared by the shop operators locally and is sold for 5,000 shillings. The powder is mixed with either sunflower oil and applied on the affected area (paralysed part) twice in a day (morning and evening). The one in capsule form is imported from India and is sold for 8,000 shillings. The capsules are sold in a plastic container with instructions in English. The patient is to take two capsules per day, one in the morning and another in the evening. When I read the instructions on the container, I discovered that the capsules are described as cholesterol regulators. They are therefore probably more effective in reducing the risk for secondary stroke rather than 'treating' the primary episode. Following is a picture of the capsules and their container:



Figure 18: Container and capsules of Indian cholesterol lowering medicine sold at Mombasa store in Moshi

In the following case illustration, a female stroke sufferer narrates the range of self administered traditional remedies she uses in her quest for relief.

Case 10: Mrs LK, Usari village, Machame

Mrs LK is a 45 years old woman living in Usari village in Machame. She suffered a stroke in 2003 but has since recovered her physical function as she does her chores as normal. Mama LK's husband works in an animal hide processing plant in Moshi town where he cuts, dries and puts colour on animal hides. I never met Mr K as he was always away when I visited the family. He lives in rented accommodation in Moshi town and comes to Machame only once per week (mostly on weekends).

Mr and Mrs K have 12 children. She narrates that when she had her last child, health workers at the hospital she delivered advised her to stop having more children as it had become risky for her health. She and her husband heeded to their advice and she had the operation two weeks after giving birth to her last borne. Since most of the time her husband is away from home, her older children are the ones who take care of her when ill.

Mrs LK says that since she had her stroke in 2003 she has utilised different types of treatment. At first she utilised medicines she obtained from hospital but stopped after she ran out of stock. The anti-hypertensive drugs she used to take finished about a year ago. After that, she embarked on using herbs she picked from the surrounding area. She prepared the herbal potion by boiling leaves of a plant known in Swahili as *tambazi* and drinking the concoction. Though she used the potion for a prolonged time, she never got any better. She had previously used the *tambazi* concoction for treating abdominal pains way before she had stroke. She learned about the medicinal value of *tambazi* from her parents while still a child.

At present she is using Chinese medicine for treating her hypertension. Her husband bought the medicine in Moshi. She says the medication is helping her a lot as since she started using it, she feels much better. In one of my visits to her home she showed me three types of Chinese medicine she uses for treating her hypertension. The first is in pill form (small white pills) which she keeps in a plastic bottle. I could not read the Chinese writings on the container. The second type of medication is in fluid form and is also kept in a plastic container. She mixes it with honey before taking it. The third type of medication is Chinese tea which she uses to help her cut weight. The tea leaves are kept in sachets in a paper packet. She puts one tea sachet in a cup of warm water and takes it twice daily (in the morning and evening). The instructions on the tea paper packet are written in English. The tea goes by the brand 'golden tea' and indicated that it was manufactured in China. According to the instructions on the label, the daily recommended dose is taking it three times daily.

The case of Mrs LK demonstrates how a rural woman struggles to cope with the post effects of stroke despite having a large family to look after and an absent husband. She is a regular user of hospital services but switches to self administered traditional medicine after running out of stock. Her use of Chinese medicine demonstrates her willingness to take up cross-border medication in her effort to get better.

7.2.6 Discussion of traditional remedies

The use of traditional remedies for stroke is more common in Dar-es-Salaam than Hai. Healer and self administered traditional remedies characterise the use of traditional medicine in the two sites. These include oral and topical administered medicines and others used for massaging the affected body parts. The medicines are prepared using local and imported vegetation and animal products. Massaging concoctions are prepared using clove, castor, sunflower and coconut oil. My research shows that among the five groups of healers, only two groups are regularly engaged in treating stroke sufferers as they provide recent narrations of treating stroke sufferers and are more knowledgeable of the exact remedies for stroke. These two groups are the diviners who also use medicine and Islamic interpretation healers who also use medicine. From my ethnographic fieldwork it is clear that there is a more open and publicly accepted utilisation of traditional medicine for treating illnesses in Dar-es-Salaam. This results from the dominance of the discourse combining local and Islamic cosmological outlook of illness in the site. On the other hand, the long establishment of particular forms of Christianity which discourage its followers from using services of traditional healers, early and intense exposure to biomedical health services from the missionary and colonial times has contributed to its low utilisation in Hai.

Most traditional healers in Dar and Hai attribute their steer into the practice to family connections. This is either through family inheritance or spontaneous choice by ancestral spirits. Hence the likelihood of becoming a healer partly results from socialisation into the 'healing habitus' which the healers describe as a 'family tradition'. The healing habitus is affirmed through years of training received from other healers or institutions (such as Islamic colleges). Therefore the likelihood of someone who has been socialized into a healing habitus becoming a healer later in life is greater than someone who has no such background. My research also demonstrates that healing practice involves both males and females. The female healers (like in the case of Mama D) ensure that they use their income for taking care of their families especially children. In addition, the existence of female healers provides an opportunity for stroke interventions to seek and

ensure that the involvement of women (in this case female healers) in community health interventions is enhanced.

Traditional healing for stroke is also used in South Africa (Bham and Ross 2005, Hundt, Stuttaford, and Ngoma 2004). Its utilisation is informed by local discourses ascertaining its appropriateness to the context and people using it, and perceived effectiveness. In Dar and Hai the psychological benefits of treatment by traditional healers through the greater attention available for the individual from the healers should not be underestimated. Furthermore, the massage and exercises performed by the healers provide somatic benefits to the sufferers. The cost and perceived ineffectiveness of biomedical treatment of stroke makes traditional remedies more appealing. One example of the appropriateness of traditional medicine is the nature and flexibility of its payment mechanisms. Muela et al (2000) report that people in Tanzania prefer services of traditional healers because they are perceived as cheaper (than biomedical services) as payments are made in installments rather than upfront and in lump sum. Some healers avoid mentioning the exact cost of their therapy and prefer to hint through mentioning the amount other healers charge or other clients pay though in the end they accept whatever amount their clients offer them (Kamat 2008). In addition, traditional healers accept payment in kind rather than cash which may be more convenient for residents of rural and urban areas where obtaining readily available cash is difficult (Baltussen and Ye 2006, Muela, Mushi, and Ribera 2000, Stekelenburg et al. 2005). The fact that traditional healers offer flexible payment modalities and are closer to the community mean that they are better poised to provide affordable service for first time strokes and long term care for those ending up at home.

Cross-cultural traditional healing is commonly practiced in Dar-es-Salaam and Hai. Sambaa healers are prominent in predominantly Chagga Hai and Pemba healers prevail in Dar-es-Salaam. Cross-cultural healing results from either the absence of strong local healers or the pursuit of more powerful remedies found in outside communities (Rekdal 1999). From his research near Dar-es-Salaam, Kamat (2008) argues that people do not consult their local healers because of their perceived ineffectiveness of their therapy. Giles (1995) reports that Pemba is famous throughout the coastal Swahili areas for its

powerful spirits and witches. It is also identified as the original homeland of one of the most important types of spirits in the possession cult cosmology. Therefore Pemba healers in Dar (as in the case of AF) are regarded as experts in dealing with *jinns* including those causing stroke. Spirit healing is commonly practised by the Swahili along the East African coast (Giles 1995, West 2006). Giles (1995) argues that spirit possession has a long history along the East Africa coast and is rooted in Swahili cultural tradition and in similar with Swahili culture, it draws from both Middle Eastern (Arab) and indigenous African spirit beliefs.

Cross-border traditional remedies for stroke are common in Dar-es-Salaam and Hai through healer or self-administered remedies bought from traditional medicine shops. Cross-border healing practice is a result of the in-migration of healers who received their training outside Tanzania. Some of the Koran healers had prolonged training in Arabic countries (such as Saudi Arabia and Egypt) therefore bringing back different healing paradigms. This is also true of other healers who reported receiving their training in neighbouring countries, for instance in Mombasa, Kenya. Similar to cross-cultural healing, cross-border healing is utilised for the desire of more powerful and effective remedy. Cross-cultural and cross-border healing practices for stroke may also be interpreted as a form of outsourcing for better services and/or for more clients. Healers outsource for better treatment regimes and clients. Their adoption of healing practices and medicines from elsewhere is an attempt to meet the expectations of their clients and community at large in an ever changing therapy setting concurrent with the social, political and economic dynamic environment (Kamat 2008).

On the other hand desperate clients pursue, within their budget, healing at any locality without regard to territorial or cultural boundaries. Kamat (2008) and Rekdal (1999) argue that the desire for being discreet about their illness and therapy and therefore preventing possible 'interference' of treatment from neighbours or other people who might have caused the illness leads to sufferers pursuing healers outside their places of domicile. Additionally they point out that distant healers are attractive because of the perceived power of 'unknown' or 'stranger' and their neutrality in relation to social

conflict which had resulted into the ailment . The phenomenon of cross-cultural and cross-border healing may be interpreted as a significant part of strategy and strategizing for the treatment of stroke (Jenkins 2002, Lamaison and Bourdieu 1986). It is guided by the habitus on one hand (discourses about the cause of stroke and appropriate treatment) and conditions in the field (lack of healers, lack of powerful, effective remedies and their availability in other ethnic groups or areas).

7.3 Faith based healing

7.3.1 Characteristics of faith based healing

Faith healing for stroke in Dar and Hai is predominantly Christian. Though the population in Temeke is mostly Moslem, Christian faith healers dominate. There are no Islamic faith healers based in Machame and Saba-saba. One research participant in Saba-saba talked about visiting an Islamic faith healer living in another part of Dar called Kimara.

There are three types of faith based healing utilised by stroke sufferers in the two sites. The first type involves prayers offered at the home of the sufferer or in hospital. This type of healing is generally carried out at the home of the sufferers by either their family members or members of their religious group. Healing prayers are usually a part of the social support offered to stroke sufferers and their families through membership of church groups. It is done as part of the home based care for stroke sufferers confined in their homes due to impairment. The support groups offering prayer and moral support are mostly organised either formally or informally by members of the established churches. For example in Machame, the Lutheran church has established prayer group networks which compose of church members living in the same *mtaa* (street). The prayer network groups have leaders for each *mtaa* who are responsible for visiting their members and providing them spiritual support through Bible studies and prayer sessions.

The second type of faith healing involves prayers conducted at the homes of specialised faith healers. These faith healers are widely known in their communities and have a

reputation of successfully healing people suffering from a variety of ailments. Word about them is usually spread through the testimonies of those whom they had healed or social networks. During my fieldwork there were three (two male and one female) established Christian faith healers based in Machame. In the Saba-saba area of Dar-es-Salaam, there were five (one female and four males) famous Christian based healers. People with illnesses of all kinds are taken to the homes of the specialist healers to be prayed for. Faith healers attract people from within their communities and distant places. Some of these healers establish their own churches after attracting many followers.

The third type of faith healer is one that conducts healing prayers at public religious meetings. These meetings are seasonal and organised by established preachers coming from outside of the study areas. They would either come from other parts of Dar-es-Salaam or other towns in the country. Such meetings attract large crowds of people often of different religious backgrounds. Praying for ill people is usually done after the preacher has delivered their sermon. During the prayer session, attendees are asked to repent their sins and receive healing miracles. In all such meetings some of the healed people are requested to give testimony about the history of their illness and how they were healed. Some of my stroke afflicted research participants said that they attended such meetings and after such prayers they felt better and that their condition improved.

The second and third types of Christian faith healing are becoming very popular in Tanzania and other parts of Africa where it is most often called 'Pentecostal healing' (Adogame 2007). In predominantly Christian Hai, faith healing enjoys more legitimacy as it does not contradict the mainstream churches' point of view regarding the cause and appropriate handling of illness. Christian faith healing does not directly contradict the biomedical view point either. For example, some of my research participants said that the faith healers pray for the biomedical drugs used by the sufferers to work effectively. Other research participants believe that God works through the biomedical drugs by making them powerful.

The Christian faith healers I interviewed explained that the important thing about faith healing is that it deals with both the soul and the body of a sufferer. Healing of the soul requires the sufferer to repent their sins to God and thereafter praying for their continued healing. Once the sufferer has repented their sins and forgiven then healing becomes possible. A male faith healer in Mfooni village in Machame said:

> *Definitely they [sufferers] will have two types of diseases...that of the soul and that of the body...ee, therefore you have first to bring them closer...to God...to their creator. Then after that you can bring that body...to their creator...because they have refused...and if you renounce God, definitely those diseases will come after you...because you have renounced your creator...definitely they will come after you. Now when you go back to your creator, who created you, and you repent before him, he will forgive you, he will also cure the soul...and the body.*

Specialised Christian faith healers pray for people of all religions though a precondition for such prayers is that the sufferer must repent and come back to God. This in most cases requires being born again and accepting Jesus into their lives. Healing of this type is done by the healer praying for the sufferer and God healing them through the power of the Holy Spirit. During the healing sessions, specialized faith healers preached their interpretation of Christianity by citing verses from the bible. Some of the faith healers hold the view that illness is a direct result of going against the will of God and choosing to follow the devil instead. They believe that God did not create illness for humans but that it was the devil who brought illness through disobedience to God. In their preaching, Christian faith healers discouraged their followers from visiting traditional healers as their practice is viewed as engaging in some form of witchcraft and evil-doing.

The specialised faith healers I interviewed said that they had prayed for people who had been afflicted by stroke and they got healed. For example, one male Christian faith healer in Saba-saba claims to have healed eight stroke sufferers in the past year. He reported that most of the ill people who come to him do so as the last option after failing to get cured in hospital or after unsuccessful visits to traditional healers. As part of the healing process, faith healers exorcise the demons that had caused the illness. These demons are taken as agents of the devil sent to torture humans. Some healers acknowledge that

healing does not happen instantly as some of the stroke sufferers have deformations which require time to heal. One specialised Christian faith healer in Saba-saba remarked that as part of the healing process, she sometimes massaged stroke sufferers using olive oil that she has prayed for. She also recommends nutritional diets to facilitate recovery and general good health.

On one occasion, I visited a female faith healer in Machame and found about 50 people at her home. They were waiting outside a mud house specially designated as a healing house. Inside the house, the faith healer was praying to a group of people. The people waiting outside entered the 'consulting room' in turns (on a first come first served basis). The people I found at the healer's compound waited with their relatives, were suffering from various illnesses. The faith healer later said that people come to her from areas around Machame and distant towns such as Arusha. Likewise, some residents of Machame and Saba-saba sought healing prayers from prominent faith healers who live outside their areas.

Faith healers place their source of healing in God who has given them the healing 'talent' (the Swahili term is *Karama*). Therefore they do not charge for their service as they say they did not pay anything to acquire the ability. But in most cases during the healing prayer sessions offerings are given by people attending the session. The money collected as offering is usually used to fund the activities of the healers including taking care of their daily needs. Also, in some cases, healed people gave money to the healers as a thanks giving offering to God for their healing.

All faith healers were positive about the potential for collaboration with biomedical stroke research projects. They recommended educating community members via mass media and via youth and women groups as part of the process. The following case illustrates some of the discussed features of faith healing of stroke.

Case 11: Mama T- Christian faith healer

Mama T is a female Christian faith healer in her 50s who operates her own church in the Saba-saba area (famously known as *kwa mama T*). She has converted her residential house into a church building. At first she used one room in her house for worshiping and praying for people, but she later decided to use the whole house for the purpose. There are two houses within her church compound. The main house is used as a church and there is another smaller house on the left side of the entrance gate to the compound. The main house has a small room on the right front side which she uses as an office. Before the office, there is a waiting room for visitors or church members with wooden benches and plastic chairs. The rest of the house comprises of one large room with wooden benches which is used for prayer and worship by the church members. Mama T and her family live in a house next to the church compound (with a separate gate).

Mama T says she was called into service by God and given the task of preaching to people. As part of her work, she also prays for people who have problems including all kinds of illnesses. She narrates that when she was first called into service, she was taken in spirit into the spiritual world and after coming back, she was given the task. She works by the power of the Holy Spirit who instructs her what to teach. Mama T says that the devil is the source of all human suffering including illness. It is therefore essential for one to return to God before experiencing his healing power, '*Ugonjwa ni wa shetani, Mungu hakuumbia mtu maumivu*' –'Illness belongs to the devil, God did not create pain for humans'. She also believes that illnesses are a form of demons '*ugonjwa ni pepo*'-implying that demons are the source of illness.

People of all faiths and denominations consult her. She says people have many problems (including illnesses) regardless of their beliefs therefore they come to her for solutions. She affirms that many stroke sufferers come to her for prayers. Most of them had already sought help from traditional healers but failed to get any relief. At that stage, the sufferers decide to come to God because the traditional healers have failed. God then heals them through the power of the Holy Spirit after she prays for them. She describes her task as '*kukemea*'-to rebuke -and gives an example of how Jesus rebuked the devil in the desert. She also gives an example of God's healing power as told in the Bible in the book of Mathew where Jesus cured a paralyzed man. She refers to another story in the Bible whereby the disciples of Jesus failed to exorcise demons from a boy until Jesus did it. Jesus then told his disciples that they had failed to rid the boy of demons because of their little faith. Mama T concludes that faith is the source of all healing.

When she receives stroke sufferers, Mama T takes olive oil and prays for it and apply it on the sufferer's body. After a few days of the treatment, the sufferer gets relief. Interestingly, Mama T acknowledges that not all stroke sufferers get instant relief as some have experienced limb deformation due to the stroke. She says 'you find someone's arm is bent and shrinks due to having the stroke for a long time, therefore they may need massaging and time before they get relief'. She says the Bible acknowledges that there are some plants which have medicinal value, therefore she uses some plant products such as olive oil as part of the treatment. She also gives advice on nutrition such as encouraging people to eat pawpaws, carrots as that may speed up their recovery and prevent future illnesses. She holds the view that all plants were created by God, therefore there should not be people who discourage others from using them.

Mama T has the opinion that any intervention aiming to work against stroke should make 'educating people' one of its key strategies. The education should target the risk factors for stroke and how it should be treated. She advises that such messages should be delivered through theatre groups as many people like such things. In addition she advises that such intervention

programmes should work with youth and women groups in order to get their messages through. She is convinced that it is possible to change people's attitudes because people working on HIV/AIDS programmes have succeeded to change people's attitudes despite the pervasive stigma existing initially.

The case of Mama T portrays a female Christian healer who has managed to establish her status in the community as a very successful and effective healer. In the process she established her own church with many followers. She sees herself as a facilitator of healing by connecting people and God through faith. For her, faith is the key to healing. She referred to the biblical (Matthew 17: 16-20) example of the disciples who fail to exorcise a demon until Jesus intervenes as an example of what happens when faith fails. She locates the source of healing in God through the power of the Holy Spirit. In healing stroke, she combines physical healing (applying olive oil and nutritional advice) and healing of the spirit (bringing people of all faith to God).

7.3.2 Discussion of faith based healing

Specialised faith healing for stroke in Dar and Hai is Christian oriented. Islamic faith healers did not operate within my study areas during the period of my fieldwork. Faith healing for stroke addresses the physical and spiritual aspects of the condition. This approach is typical of the Christian Cartesian viewpoint that humans are composed of two parts-- the physical body and soul. Therefore before healing the physical body, healers commence with healing the soul through the repentance of sin and coming back to God, the creator. This is an essential precondition for Christian faith healing held more strongly by the new generation of Pentecostal churches in Africa which emphasize spiritualism (Adogame 2007, Agadjanian 2005). In so doing, God is acknowledged as the source of all healing power through the Holy Spirit.

Within the Christian healing paradigm employed in Dar and Hai, to consult traditional healers is sinful as they are agents of the devil. The perception that traditional healers engage in some form of witchcraft is the main framework informing such a viewpoint which is also reported by other studies conducted in the African context (Agadjanian 2005, Teuton, Dowrick, and Bentall 2007, West and Luedke 2006). On the other hand,

biomedical treatment is non-antagonistic to the faith healers because they believe that God works though the biomedical drugs thereby making them stronger and increasing their efficacy (Teuton, Dowrick, and Bentall 2007).

Faith healing may be interpreted as a practical embodiment of religion in dealing with illness—'religion…is lived and felt and practiced' (Csordas 2004:182). The various forms of religion are in one way or another concerned with health and healing, and both religion and medicine address matters of death and life (Csordas 1987). Religious faith healing may also be interpreted as a way of drawing on the religious habitus for people who have experienced an overtly religious upbringing. Religious identity expressed in whatever way (whether in a conscious or unconscious, coherent or incoherent manner) (Collins 2002) is consolidated as a resource for coping with an illness crisis. Religious solidarity and appeal is facilitated through social support and the belief that since God is in control, there is room for optimism (Adogame 2007). Giaquinto et al (2007: 994) argue that a religious community is a 'shelter where prevention, promotion and mutual collaboration fosters coping strategies against negative life events'. And it is widely held that religious participation has some health benefit especially if linked to a group of worshipers as it may enhance better communication and habits such as abstinence from smoking and alcohol, and discourage risky sexual behaviour (Agadjanian 2005, Fitchett et al. 1999, Giaquinto, Spiridigliozzi, and Caracciolo 2007).

On the other hand, religious practice may have elements of negative coping which results into negative effect especially when sufferers think (or are made to believe) that they have been abandoned by God or are receiving a punishment for their sins (Fitchett et al. 1999). Some religious interpretations of illness may become counter productive as some sufferers may abandon treatment believing that they have been cured through faith healing (Agadjanian 2005). For example in Uganda, 1.2% of patients receiving anti retro viral treatment for HIV/AIDS through a national programme abandoned treatment believing that they had been cured after being prayed for by religious healers (Wanyama et al. 2007).

The link between religion and health has been a subject of several research studies. But to begin with, such studies face problems of how to define and measure religion and religiosity. The dilemma is whether to classify religiosity only from reports of attendance to public worship and participation or also include private devotional activities (Ellison and Levin 1998, Giaquinto, Spiridigliozzi, and Caracciolo 2007). Despite the problems inherent with the unit of measurement for religiosity, some studies suggest that religious practice has health benefit. As already stated, it is argued that religion may have a protective effect on health through dietary restrictions (which may result in avoidance of food associated with risk of particular illnesses) , and prohibiting smoking and alcohol (Fitchett et al. 1999, Giaquinto, Spiridigliozzi, and Caracciolo 2007). Nevertheless the effect of such restrictions is only achieved by those who adherence to them which is a difficult behavioural issue to underpin.

Ellison and Levin (1998) conducted a comprehensive review of such studies and give three ways in which prayer or religious commitment may have health benefit. These are: (i) receiving social and emotional support, (ii) enhancing personal efficacy and (iii) acquiring coping strategies that emphasize positive cognitive beliefs and emotions. However, other studies have shown no benefit of religious activity on health. For example, Fitchett et al (1999) found out that religion did not facilitate better recovery or adjustment for 96 inpatients of different medical conditions including stroke in a rehabilitation centre. Nevertheless the study found that religion was a source of consolation for some patients.

In Dar and Hai, self or family prayer is commonly practised by stroke sufferers, their families and members of their religious groups. Prayer as a form of spiritual practice assists sufferers in coping after a stroke. It is a specific self-care strategy that some sufferers use after stroke (Robinson-Smith 2002). Giaquinto et al (2007) found that prayer was the most common form of religious coping among a group of 132 stroke inpatients at a rehabilitation centre. In her study of how prayer is used to cope with stroke, Robinson-Smith (2002) found that it made sufferers connect to God and linking back to early family life. For stroke sufferers who embraced prayer as a coping strategy,

prayer and religious beliefs had played an important part in their childhood. In other words, there was a religious habitus which guided they way in which they dealt with stroke. For religious converts, it may mean that since they are faced with a crisis (stroke affliction), their doxa or world view has been challenged therefore calling for their representations of stroke and illness (orthodoxy) be replaced by a 'new' heterodoxy (in this case religious oriented representations of stroke) (Bourdieu 1977). From my findings, self and family prayer is not regarded by the general public in Dar and Hai as a formal way of faith healing as contrasted to faith healing offered by specialised faith healers and at religious public meetings.

Psychologically speaking, there are three main types of coping with a crisis of the self (Faull and Hills 2006). *Inertia* coping requires someone to do nothing when faced with a challenge to the self in the belief that the challenge will resolve itself. *Action coping* involves doing something to address the challenge itself and regain pre-trauma identity. *Transformation coping* allows retention of well being through acknowledging and accepting disability as an opportunity for a new identity. Acute care aims to restore function to previous levels of health, while chronic care seeks to enable the individual to healthily cope with permanent loss of function (Faull and Hills 2006). Therefore religion may well be beneficial to stroke sufferers by enabling them to come to terms with the affliction, accept and live positively with any resulting disabilities, and face the future with hope rather than dread. Indeed, it is argued that one important function of religious healing is the generation of hope to sufferers of illnesses (Adogame 2007, Nwoye 2002).

7.4 Conclusions

In this chapter I have presented and discussed the range of traditional and faith based remedies for stroke used in Dar and Hai. Traditional remedies are either administered by the healers or self administered by the stroke sufferers themselves or their carers. Traditional healing comprises of aspects of spirit healing, Islamic knowledge and cosmological healing, divination and different types of medicines. Traditional remedies

comprise of locally obtained medicines or imported from countries such as India, China, and Arabic states. It also includes cross-cultural and cross-border healing practices in the pursuit of efficacious remedies by the healers and sufferers. Cross-cultural healing makes use of healers from other ethnic groups outside the study sites such as the Sambaa healers in Hai and the Pemba healers in Temeke. It also comprises of outsourcing of cross-border remedies obtained either through local shops selling traditional medicine or training of healers outside the country.

The main form of faith healing is through Christian healing prayers conducted by specialised preachers. Most of the faith healers emphasize Christian ministry through their healing practices. Islamic based specialist prayer healing is rare and accessed outside the study areas. Christian faith healers discourage their clients from consulting traditional healers whom they perceive as agents of evil. Stroke sufferers in my study sites outsource traditional and faith healing services from outside the study area. This is done by either visiting healers who live outside the area or bringing traditional healers to treat them at their homes. Likewise, traditional healers from the study sites travel to other parts of Dar-es-Salaam and Kilimanjaro to treat stroke sufferers.

Findings presented in this chapter show that it is easier to initiate collaboration between biomedical health workers such doctors and either traditional or faith healers than it is between traditional and faith healers. Both traditional and faith healers express willingness to participate in biomedical and officially initiated stroke treatment programmes. However, they are very skeptical with a suggestion of cooperation between them. The conflicting relationship between traditional healers and faith healers has been documented by a research study on Psychosis in Uganda (Teuton, Dowrick, and Bentall 2007). Even among traditional healers some of them question the ability and competence of other healers. These issues demonstrate that the initiation of collaboration between the different types of traditional healers is not as easy as sometimes portrayed in literature.

My findings further indicate that there are common theoretical viewpoints in the way both traditional healers employing aspects of Islamic knowledge and cosmology, and

Christian faith healers frame and treat stroke. The first common ground is the affirmation by both that the source for all healing power is God. Therefore in order for their treatment to have the desired effect, God must work through them and assent to what they do. However, God's healing power is operationalised differently by the Christian faith healers and the Islamic oriented traditional healers. For the Christian healers, God's healing power operates through the Holy Spirit and requires a sufferer to 'repent their sins' and come back to God as a precondition. On the other hand, for the Muslim healers, God's power is operationalised through acknowledging that he is the source of all things and working through the beings he created such as angels and *jinns*. This may also entail offering prayers known as '*dua*'.

The second common ground is that both faith and traditional healers attribute stroke cause to supernatural beings either in the form of demons or *jinns*. Therefore an important first step for faith healing or traditional medicine treatment entails the exorcizing of such beings. However, the two remedial paradigms part ways on explaining what these beings are. For Christian faith healers, demons are 'agents' of the devil and torture people who sin against God. They are therefore evil beings which work against the plan of God to have people follow his way and live a life free of illness. On the other hand, Islamic cosmology recognizes the existence of 'good' and 'bad' *jinns*. To some traditional healers, 'good' *jinns* can be used to treat people of different ailments including stroke. The 'bad' *jinns* are either the followers of the devil (*lusiferi*) or 'made' and sent by human beings to cause harm to other humans including causing illness. This observation is elaborated in the following diagram.

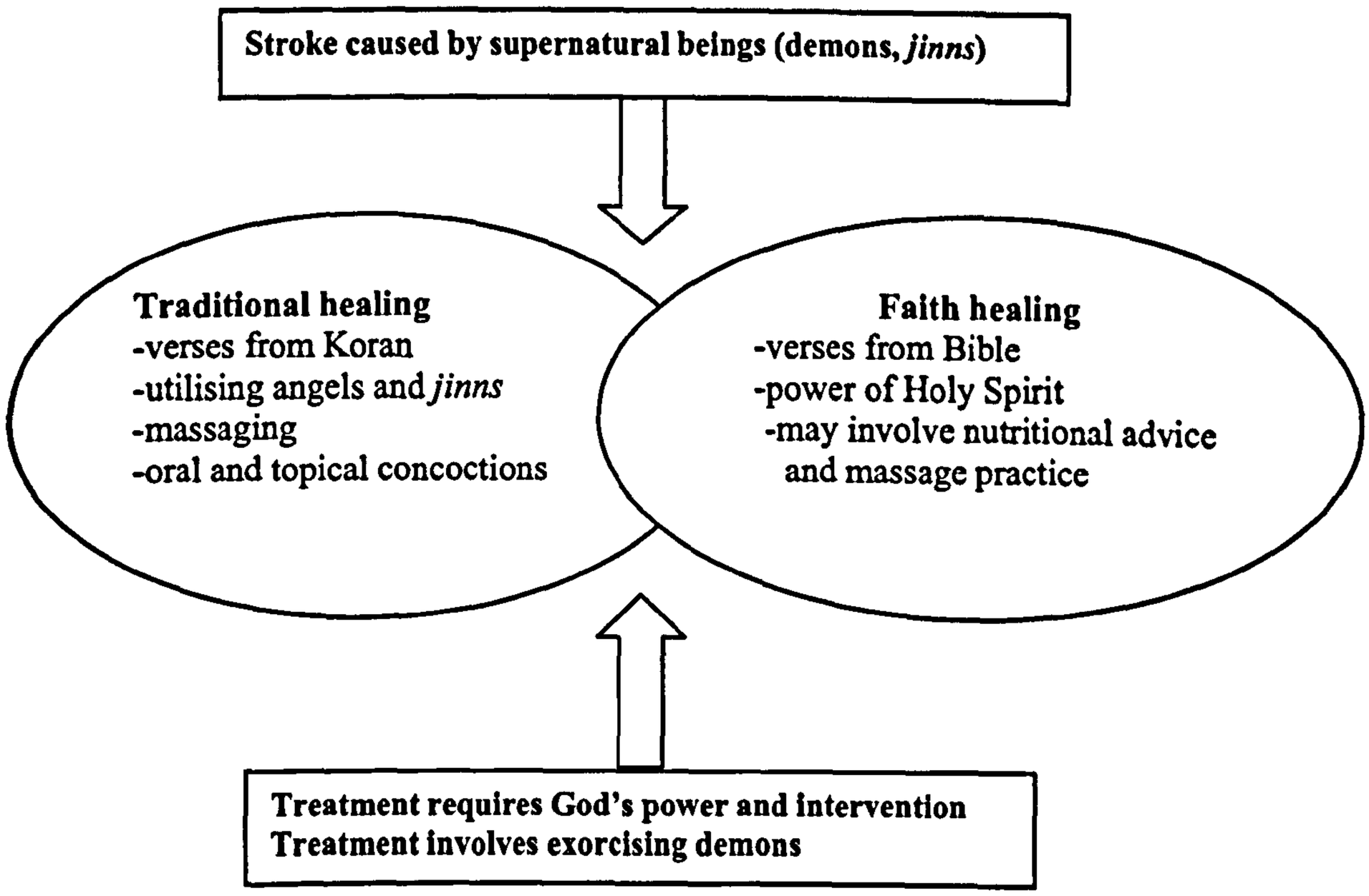


Figure 19: Common theoretical viewpoints of traditional and faith healer

There is therefore potential for theoretical informed interventions to employ these common grounds to bring together the traditional and faith healers within stroke interventions. This could be achieved by pointing out to both groups (of traditional healers and faith healers) that since all agree that the source of all healing is God, and that demons or *jinns* cause stroke, it would be better to reframe their discourse antagonising each other's work and explore a common way of addressing the needs of the sufferers and their families.

In the next chapter I explore a range of possible stroke interventions and go on to propose specific interventions, based on my research findings.

8 Chapter Eight: Opportunities for Interventions

8.1 Introduction

This chapter reviews how different kinds of community targeted and based interventions for stroke could be developed and implemented. The ideas are based on my findings presented in the last three chapters and from a review of interventions worldwide. They are therefore applicable to the two research sites and other areas with similar characteristics. In the following two sections I present the range of stroke awareness and treatment interventions which have been developed and implemented in different parts of the world. Most of these interventions have been designed, implemented and evaluated in developed countries. I review them to highlight what has already been done and contrast to what could realistically be done in a developing country context such as Tanzania.

In sections four and five I present my ideas on how community targeted and based awareness and treatment interventions could be approached and implemented in Dar-es-Salaam and Hai. Thereafter, I discuss the interventions by connecting with my theoretical framework developed in chapter 3. Since the proposed approaches and interventions are based on findings from my detailed ethnographic study, they take into account contextual factors and therefore have a greater chance of success if implemented in similar settings. It is argued that an important component for success in community based programmes is taking into consideration what is known and transforming it into effective and sustainable interventions (Veazie et al. 2005). Therefore in addition to my own findings, I review selected community interventions which have been implemented in Africa and draw from some of their experiences. I conclude the chapter by restating the main points covered and introducing the next chapter.

8.2 An overview of stroke interventions

8.2.1 Stroke knowledge and awareness interventions worldwide

In some developed countries there has been long term implementation of stroke knowledge and awareness interventions. Such interventions have primarily aimed to raise the knowledge and awareness of risk factors for cardiovascular disease generally and stroke in particular (Ebrahim and Smith 2001). The interventions provide information through a range of means such as in written, audio or visual form (Ebrahim and Smith 2001, Smith et al. 2008, Veazie et al. 2005). The existing public health interventions on knowledge and awareness of stroke and other cardiovascular illnesses are dominated by a biomedical outlook often addressing the biological risk factors (Veazie et al. 2005). These are done either directly or indirectly through the promotion of healthy diets and lifestyles. Healthy diets are framed in terms of high fruit and vegetable intake and reduction of chemically processed foods often high in salt and sugar. The promotion of physical activity and reduction of alcohol intake, foods high in carbohydrates and smoking is also promoted through such public health campaigns. For example, in the UK healthy diets campaigns are delivered primarily through the mass media, food stores and health services. In some cases they involve school campaigns and leaflets distributed in various places such as hospitals.

Despite the intensive implementation of knowledge and awareness interventions, there has been little or mixed evidence of benefits. For example, a qualitative study in Australia showed that knowledge of stroke is still limited among the general public (Yoon and Byles 2002). A survey conducted in the UK showed that 25% of stroke sufferers could not differentiate a stroke from a heart attack (Wellwood, Dennis, and Warlow 1994). In another study the same proportion of stroke sufferers (25%) were not aware that stroke is caused by damage in the brain (Drummond, Lincoln, and Juby 1996). It has also been pointed out that stroke sufferers and their families based within the community feel they are not given enough information about stroke to help them cope with life after hospital (Stroke Association 2006).

One possible reason for the lack of sufficient knowledge about stroke despite these efforts could be due to the ineffectiveness of the strategies used. In pursuit of the hypothesis, Smith et al (2008) conducted a meta analysis of intervention studies providing information to stroke sufferers and their carers. They assessed the effectiveness of different information provision strategies in improving outcomes for stroke sufferers and carers. The interventions were in the form of written information such as booklets and leaflets, lectures with opportunity to ask questions, interactive workbooks, phone calls and face to face meetings. They reviewed 17 randomised controlled trials (involving 1773 stroke sufferers and 1058 carers) which showed that the interventions significantly improved knowledge of stroke among the sufferers and carers. They also had some effect on one aspect of patient satisfaction and depression scores. However there was no significant effect reported on number of cases of anxiety or depression in sufferers nor carer's mood or satisfaction. This meta-analysis concluded that information provided in an interactive way (offering repeated opportunity to ask questions) was more effective in improving the mood of stroke sufferers.

On the other hand (see chapter 2), there is a lack of clear and focused stroke awareness interventions in developing countries. In sub-Saharan Africa, knowledge of stroke is still very low and confusion mars the discourse on its causes and physiology (Ayanniyi, Akande, and Mustafa 2006, Hundt, Stuttaford, and Ngoma 2004, Mshana et al. 2008). Furthermore, in most countries in sub-Sahara Africa, health interventions are driven (understandably) by the focus (in terms of resource allocation and priority) on addressing the main infectious illnesses such as malaria, AIDS and diarrhoea (Ebrahim and Smeeth 2005, Kumaranayake and Watts 2001). However, since CVD including stroke are coming up as a new wave of epidemics (Bovet et al. 2002), there is a need to put in place and promote interventions aiming to raise the awareness and knowledge on such illnesses.

8.2.2 Stroke treatment interventions worldwide

Worldwide, stroke treatment interventions have primarily functioned to provide services through the existing hospital systems or extended community services. The 'gold standard' recommendation is to provide treatment within specialised stroke units. The

other forms of treatment services include treatment provided in general wards and mobile stroke units (Stroke Unit Trialist's Collaboration 2007). These interventions aim to cut the time between when someone suffers a stroke to the time they get proper diagnosis and treatment.

Stroke units operate in *specialised wards* with multidisciplinary teams consisting of specialist doctors, nurses, physiotherapists and speech therapists. This multidisciplinary nature of stroke units aims to ensure that the wide range of treatment needed by the sufferers is met in order to facilitate speedy recovery. Studies that have examined the pattern of recovery after a stroke suggest that it is likely to occur within the first six months after stroke (Tilling et al. 2001).

It has been demonstrated that organised stroke unit care is more effective than other forms of care including mixed ward care. A recent review of 31 randomised control trials (6,936 participants) compared stroke unit care with general wards (Stroke Unit Trialist's Collaboration 2007). Only one out of the 31 trials was conducted in sub-Sahara Africa (Cape Town in South Africa). The meta-analysis showed that more organised care was consistently associated with three improved outcomes for stroke sufferers namely; surviving their stroke, being independent (not requiring assistance for transfer, mobility, dressing, feeding or toileting) and living at home. The same meta-analysis compared stroke unit care with general wards among 31 randomised controlled trials (5,592 participants). This study showed that treatment in specialised stroke units reduced deaths and dependency at one year post stroke follow-up.

Several explanations are given as to why stroke units improve patient's outcomes. These include better diagnostic procedures, better nursing care, early mobilisation, the prevention of complications, and more effective rehabilitation procedures (Langhorne and Dennis 1998). A range of studies have also been conducted to assess the benefits of treatment after a sufferer has left hospital. A recent review conducted a meta-analysis to assess the effects of therapy-based rehabilitation services targeting stroke sufferers living in the community within one year of their stroke or discharge from hospital (Outpatient

Service Trialists 2003). The services assessed were physiotherapy and occupational therapy, the object of which was to improve task oriented behaviour such as walking and dressing. 14 randomised controlled trials (1617 stroke sufferers) were reviewed and showed that the therapy appeared to improve independence in personal activities of daily living. However, the degree of benefit achieved was uncertain.

The benefit of long term therapy for stroke sufferers *living in the community* has also been assessed. Aziz et al (2008) reviewed studies on therapy-based rehabilitation services for stroke patients living at home more than one year after stroke. They conducted a meta-analysis of five randomised controlled trials (487 stroke sufferers). They found inconclusive evidence of benefit of such therapy as it was unclear whether such therapy could improve recovery. From their review, they concluded that though home-based therapy is widely accepted as part of stroke management, there is a paucity of trials examining its benefits.

The body of evidence presented in this section shows that specialised stroke treatment undertaken by stroke units offers the best chance for survival and recovery. The best chance of recovery appears to be within the first six months after a stroke. Rehabilitation services after a sufferer has left hospital appear to have some benefit though it is hard to pinpoint the exact nature and extent of benefit. Therefore, for long term stroke sufferers based in the community rehabilitation and offering some form of chronic care seems the most appropriate service.

8.2.3 Relevant stroke treatment interventions or components for developing countries

In sub-Saharan Africa, hospital stroke case fatality is very high (Connor et al. 2007). Late presentation in hospital may result from treatment-seeking behaviours preferring traditional or faith based healing (Bham and Ross 2005, Hundt, Stuttaford, and Ngoma 2004, Mshana et al. 2008). While the stroke unit's approach is effective and widely utilised in developed countries, it is not a feasible option in most of the developing countries. The health care delivery systems in the later suffer from acute staff and facility shortages making the establishment of such units difficult and unsustainable.

As demonstrated in my findings on biomedical health service provision for stroke sufferers in Dar-es-Salaam and Hai, the health delivery system is marred with problems of staff and facility shortages. Additionally, for the majority poor, issues of costs and accessibility may prevent uptake of such services even if established. For example, the local government chairman for Saba-saba area in Dar-es-Salaam pointed out to me that although the area has over 23,000 residents, it has no government health facility to serve the population. People had to travel to Temeke district hospital for treatment requiring that they pay for transport to get to the hospital. Though Temeke district council has shown willingness to build a health facility in the area, the problem has been acquiring the land to build the facility. The council wants residents of Saba-saba to provide the land for the council to build the health centre. Purchasing the land would cost several millions of shillings which the poor people in the area cannot afford. Such an example demonstrates how, in a developing country context such as Tanzania, the setting up or improvement of appropriate stroke services in health facilities may only be considered as a long term goal requiring expensive structural development.

In the short and medium term, community-targeted and based interventions are the most feasible option as they do not require immediate and heavy investment in infrastructure and human resource. I am therefore primarily recommending short term and medium-term community approaches and interventions for stroke in Dar-es-Salaam and Hai. In the following sections, I explore and propose community-targeted and community-based stroke interventions. By community-targeted interventions I refer to interventions which although may be based outside a community, but they target it as its end point. An example would be a radio programme which is aired from a radio station based outside a community but carrying a specific message for that particular community. By community-based interventions, I refer to interventions which are largely based and operated from within a particular community.

The interventions I propose are grounded in a theoretical framework recognising that power relations are crucial in facilitating or hindering any activity targeting society. I

have taken into account the fact that in any community it is likely there will be multiple stroke discourses and related practices. Therefore, my proposed interventions take into consideration the institutional or social power bases as made clear through my fieldwork. This is in addition to the other contextual issues such as infrastructure and education levels which are very important for the success of any such interventions. Figure 20 illustrates the interventions I propose.

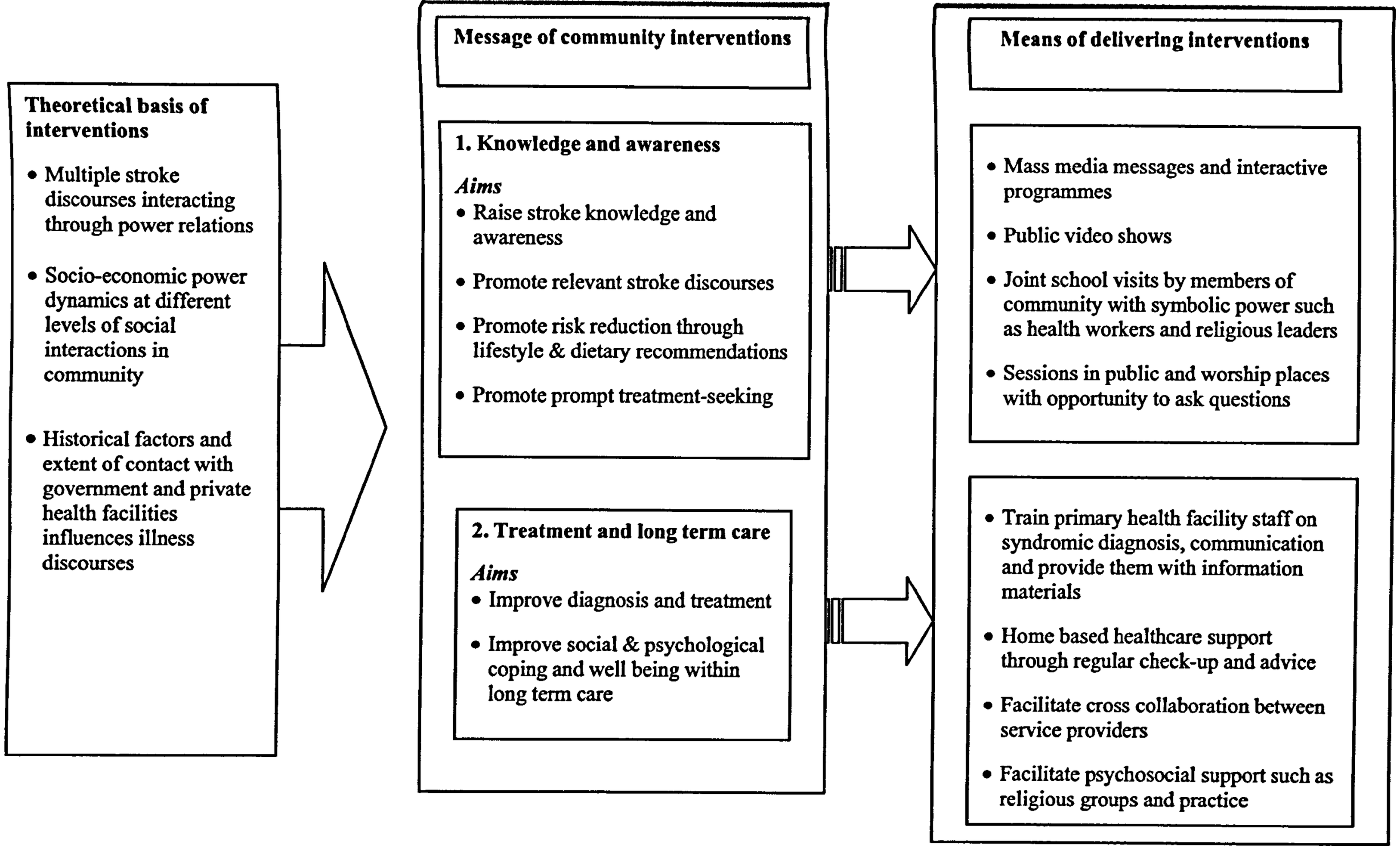


Figure 20: Proposed interventions

8.3 Potential interventions grounded in this study

8.3.1 Community-targeted and based interventions to raise stroke knowledge and awareness

From my fieldwork in Dar-es-Salaam and Hai, the lack of information and awareness of stroke among the majority of the community members was apparent. From a public health perspective, most people did not have the knowledge and information of what stroke is, its risk factors and treatment. The majority of the people with whom I had conversations about stroke were not entirely sure of what stroke was and in many occasions asked me to explain to them its causes and treatment. This lack of knowledge becomes more troubling when exhibited by people who are engaged in treating it. Several of the traditional, faith and health workers did not articulate their understanding of the illness very well (notwithstanding the different paradigms they employ). For example, in chapter five I pointed out how some health workers were confused about the etiology of stroke. Another such example is of a traditional healer in Hai who at the end of our interview asked me to explain to him the causes and treatment for stroke. He then went ahead and took notes of my admittedly largely biomedical based explanation and said he would keep them for future reference. In addition (as demonstrated in chapter 5) there is confusion between stroke and hypertension (*presha*) as they are usually taken to mean the same thing. Although hypertension is a risk factor for stroke, it is a different medical condition.

It is therefore imperative for any community-based stroke intervention to commence with a strong awareness and knowledge component. This is essential particularly for the 'new' epidemics in the developing countries such as stroke. This view is upheld by several of my older research participants who had the opinion that stroke was not as prevalent in the past.

The community targeted and based interventions would thus address the lack of knowledge and awareness about stroke and aim to influence the discourse about stroke by

clarifying some of the misconceptions. In addition, it is important to point out to community members that the prevalence of stroke is likely to rise. The community-targeted and community-based stroke knowledge and awareness interventions should thus aim to:

a) Raise stroke knowledge and general awareness in the community

Such interventions would target community members of school-going age and adults. They should involve the mass media such as radio and TV stations. The majority of my research participants favoured this mode of knowledge delivery. They were confident that using the mass media would ensure that a wide audience is reached. It is estimated that 58% of households in Tanzania own a radio (Tanzania National Bureau of Statistics 2005). During my fieldwork I noted that many people listened to the radio once in a day or at least weekly. This was particularly true for those who use commuter buses which tune to FM stations playing music and occasional news bulletins. The popularity and power of radio programmes combining music and news bulletins become vivid when one walks along the main street in Saba-saba. Music is usually played loud in the shops, bars and food stalls in a bid to attract customers.

Therefore radio programmes containing short messages, discussions and music may well be a good way of delivering information about stroke. The messages would be delivered in Swahili which is a widely spoken national language. In rural Hai, messages in Chagga could also be considered. In her study of High Blood pressure (BP) in Dar-es-Salaam, Strahl (2003) found that the framing of BP contained messages obtained from public health programmes delivered through the mass media. This shows that local illness discourses may be influenced and mirror other discourses obtained through the mass media. Therefore mass media such as radio may be a potential and effective strategy although it is true that poor households are unlikely to have radio or TV. In many cases, families would have a radio but would not have money to buy batteries. However it is common in Dar-es-Salaam and Hai for people to listen to radio or watch TV in their neighbours' and friends' homes, or while in commuter buses. Therefore people who do not own radios could still be reached through such means.

In Saba-saba there are people who do business of showing films and football matches in large communal-like rooms known as video halls. People pay 100 shillings to watch a movie or football match. These video halls are popularly attended by adult men and young men and children. These could be potentially useful avenues for showing stroke awareness video tapes although the presence of women in the audience should be facilitated. For example, such shows could be made available to women gatherings or done at times and days convenient for women when they are not engaged with household chores. However, if the poorest members of the communities are to be reached, the use of the media should be just one component of a broader strategy.



Figure 21: Media attractive power in Sabasaba

The picture was taken in the main street in Saba-saba area showing a series of shops on one side of the road such as hair saloons, tailoring shops, video library and food kiosks. The different shops were playing loud music from tapes and FM stations. The group of children seen is watching a video tape from a TV in the video library. This is demonstrative of the attractiveness of TV and video media for people who might not have TVs in their homes.

Another way of reaching the public is by organising school visits by the people with symbolic power capital in the communities to promote knowledge and awareness of stroke. Messages delivered by such people have the power to prompt action. People with such powers include religious leaders and health workers. At the same time there could be facilitation of delivery of messages in places of worship and practice, public gatherings such as market places and schools through interactive oral communication. Many of my research participants had the opinion that there should also be public meetings for educating people about the illness. Others said they were willing to be involved in raising stroke awareness so long as they received appropriate training from the Ministry of Health or from some other qualified agency. The willingness of community members is a good indicator that if facilitated they become an important ingredient of an intervention (WHO/TDR 2008).

A way of initiating dialogue between the community, researchers and policy makers could also be the mass media. Such measures could entail organizing radio programmes which enable contact between the communities, policy makers in the ministry of health and researchers through organizing discussion groups held within the study areas. These discussions could be recorded and later aired through radio programmes to the wider community. During the discussions, researchers would present their findings and representatives of the different groups in the communities and policy makers would be given the opportunity to discuss them. Through the discussions members of the communities would make their wishes known to the policy makers. On the other hand, the policy makers would be encouraged to explain in simple terms the policy process and what may be achievable from the findings. This kind of approach would stimulate the interaction between study communities and policy makers and should ensure that there is a power balance between the organizers and communities.

A common way of providing health information has been the use of flyers (Smith et al. 2008). However my research shows that flyers are a problematic way of delivering messages within the context of my study sites due to logistical difficulties of distribution. There is also concern regarding the accessibility of the information to the majority poor

most of whom (especially the older generation) may be unable to read. For example, in Hai there is a flyer in circulation about hypertension which has been prepared by the DMOs office (using own budget funds). The DMO informed me that the flyer was produced through the 2004/2005 district budget and has been distributed to all health facilities in the district. Health facility workers are supposed to use the flyer to disseminate information about hypertension and how to manage it. The aim is that the flyer should reach all hypertension patients, stroke sufferers and any other patients who visit the health facilities and show an interest in learning about the illnesses. The flyer is written in Swahili and has sections on what is hypertension, risk factors, prevention, outcomes and treatment. The leaflet mentions that untreated hypertension may lead to stroke, liver damage and heart and eye problems. Nevertheless, none of my research participants had ever seen the leaflet. In fact it was not available in the public dispensaries and health centres I visited. This indicates that its distribution may not be as widespread as reported by the district health authorities.

b) Promote relevant stroke discourses

Any community based intervention should commence with some preliminary work to identify the range of stroke discourses and identify their sources of power, such as institutions, individuals, opinion leader, household members, religious leaders, networks of power. Such work could be conducted through rapid assessment methods such as participatory discussion groups and interviews with key research participants. Thereafter, the interventions should work with the groups of people who exercise power at all levels of society to influence stroke discourses to desired outcomes. For example, they would target the power bases of the various stroke discourses in order to promote the appropriate discourses. Such interventions ought to be tailored to target the different positions occupied by community members within the social structure.

Such interventions could also be done through school visits or information giving in places of worship and public meetings. At the core, the interventions would aim to work with the holders of symbolic power, like religious leaders, medical professionals, respected traditional and faith healers, to address the different stroke discourses and

promote the desired information. Almost all religious clerics I talked to were very enthusiastic about the prospect of taking part in such a strategy and some even asked me to give them information sheets that they could read to their followers after prayer sessions. It is possible, of course, that they also see such a strategy as an opportunity to enhance their social positions (through the reinforcement of their symbolic power) within the wider community.

c) Promote reduction of risk behaviours relating to lifestyles and diet

Risk reduction should also be addressed by the mass media strategies outlined in (a). They would employ the same power relations strategies outlined in (b). The messages would target lifestyle changes addressing issues such as healthy food intake, reduction of smoking, physical activity and stress management. Additionally these messages would be delivered by the community based group leaders through oral communication in mosques, churches and other places of worship, places of practice for health workers, faith and traditional healers, public gathering places such as markets and weekly school visits (in joint teams). The community leaders should be encouraged to hold the public meetings and school visits as frequently as possible and provide attendees with the opportunity to ask questions as this has been proven to be an effective strategy for stroke interventions elsewhere (Smith et al. 2008).

It must be acknowledged that implementing such interventions would pose numerous challenges as they would require behavioural changes (such as food and activity cultures). In addition, there could be practical challenges such as the facilitating of movement of the community implementers. Moreover, the evaluation of such interventions may be difficult especially in a rural setting. In one such example a community- based intervention was implemented with the aim of reducing salt intake and thereby to reduce blood pressure in Ghanaians (Cappuccio et al. 2006). The intervention aimed to assess the feasibility of salt reduction as a way of reducing BP in twelve rural and semi-rural villages in the Ashanti region of Ghana. The intervention consisted of a health education programme through public meetings which were done daily during the first week of the study and once weekly thereafter. Sessions were held in communal

places such as churches, churchyards, schools and community centers. The sessions last for approximately one hour. The intervention achieved salt reduction with a small reduction in the population systolic BP (2.12 mmHg at 3 months and 1.34 mmHg at 6 months--both statistically significant). Nevertheless the programme was beset by a series of practical difficulties such as logistical arrangements and communication leading to different turnouts for the sessions.

d) Promote prompt seeking of stroke treatment

Promotion of positive health seeking (prompt and effective treatment-seeking) could also be done through public health messages. These could outline the importance of early diagnosis, treatment/management and availability of health services and encouraging cross reference between faith and traditional healers on one hand and biomedical services on the other. The same means of communication, including radio broadcasts and oral communication at schools and public places should be employed. It must be noted that cross reference may not be easy to initiate and sustain as it requires the different service providers to value and trust each other and be good at provision of care.

These interventions would aim to raise stroke knowledge and awareness in the targeted communities. This is the first step in the reduction of the incidence of stroke in the longer term. Some of my research participants were very optimistic that people could change their views about stroke through an intensive awareness campaign and gave examples of how people have changed their views about TB. They said that this has been the case because people in the community have seen the improvement of TB services and the benefit of treatment. They reported that in the past people used mostly traditional treatment for TB but case fatality was high. However, after a combination of an intensive campaign to raise TB awareness in the community and the government making sure TB drugs are available free in government hospitals, many people came forward for treatment. These observations must be treated with caution as they are based on perception rather than systematic evidence. Nevertheless they underscore the point that communities acknowledge the benefit of health awareness campaigns and are willing to participate when facilitated. It must be acknowledged that for stroke this may be harder to

achieve given the limitation of aspects of treatment on recovery of physical function which may be an important indicator to the community of the effectiveness of the treatment promoted.

8.3.2 Community based interventions on treatment of stroke

From my findings, it is apparent that treatment for stroke sufferers is at best patchy and at worst non-existent. Provision ranges from biomedical treatment to faith and traditional healing. In this section I propose two categories of community based interventions for stroke sufferers. These interventions would aim to:

a) Improve stroke treatment services for sufferers

As pointed out in Chapter 6, hospital treatment services for people afflicted by stroke in Hai and Dar-es-Salaam are poor. They are characterised by delay in diagnosis, misdiagnosis and late referral to major hospitals capable of properly diagnosing and handling stroke cases. There is a paucity of diagnostic facilities such as CT scan and x-ray machines. Rarely do stroke sufferers get physiotherapy services. Even when they are aware of the service, they may not be able to sustain the transport costs to physiotherapy units at Muhimbili or KCMC, given that public transport would in many cases not be an option. Other rehabilitative services such as speech therapy are non-existent. The situation is further worsened by the shortage of staff in public health facilities leading to high doctor-patient ratios and low staff morale.

Therefore we can classify the feasible interventions to improve treatment services in this context into one of two groups. The set of interventions should aim to make sure that there is a prompt and proper diagnosis at the primary facilities and a speedy referral to the major hospitals. This will be achieved by providing basic stroke diagnosis training (such as syndromic diagnosis) to the nurses and clinical officers who provide the first service to stroke sufferers. Such training together with simple reading materials would improve the diagnostic capability at the community based primary facilities. The training should emphasize the importance of quick referral to maximize chance of survival by preventing a secondary stroke. The treatment of hypertension which is the biggest risk factor for

stroke should also be underlined. As a successful example, a community development programme in Bangladesh (Bangladesh Rural Advancement Committee-BRAC) successfully trained community health workers in four weeks to provide health service on selected illnesses such as anaemia, cough, diarrhoea and pepctic ulcers (Standing and Chowdhury 2008). Though the community health workers had basic education, they provided equal service as those trained in formal colleges. The BRAC health workers were selected from the communities they were based hence had a good understanding of the context.

Cross collaboration between traditional, faith and biomedical services should be facilitated in order to make possible speedy diagnosis and treatment. Traditional and faith healers should also be trained to identify the basic symptoms of stroke and encouraged to refer cases immediately to hospital. For traditional healers, the fear of income loss and loss of their authority may make them reluctant to embrace the idea of cross reference. These fears should be addressed within such interventions. The recognition of the practice by faith and traditional healers by the biomedical service providers could function as a boost to their symbolic power through collaborating with those endowed with it by the governing authorities (Foucault 2002). I am suggesting that traditional and faith healers be incorporated into the formal health-care system.

This approach of 'recognising' the practice of traditional and faith healers could be very useful in chronic care for long term stroke sufferers as it could achieve psychological satisfaction to the patients and their relatives. This could in turn lead to reduction of conflict between family members as we have previously demonstrated some relatives may want to see traditional or faith healers first while others might want the patient to be taken to hospital straight away. On the other hand, traditional and faith healers will not resist to refer stroke sufferers who seek treatment from them due to fears of losing income as they will still get the opportunity to 'treat' the patients afterwards.

In any intervention strategy, serious consideration must also be given to ways in which the improvement of communication between service providers and sufferers can be

facilitated. Some research participants proposed that health workers be trained to communicate more effectively with sufferers, such as telling them clearly what they are suffering from. Many sufferers leave hospital without a clear message of what has afflicted them because of lack of information from health workers. Facilitation of better communication is a crucial aspect to ensure better services to stroke sufferers (Anderson and Marlett 2004).

The second set of interventions should address the long term needs for care and support. This would also potentially involve health workers at the primary facilities located within the communities. Training and support of simple BP measuring machines could be provided. The aim would be to prevent recurrent strokes and other medical complications. These workers are more likely to have formed a rapport with community members having established some form of social relationship with them. Therefore they are best positioned to provide such support given their familiarity of the conditions and social and economic dynamics at the community level.

b) Improve the psycho-social well being of stroke sufferers and their carers

Despite the high case fatality for stroke in Africa, it is likely that many stroke sufferers will end up getting long term care at home. In an earlier section, I pointed out the limitations of biomedical stroke treatment generally and more specifically in a developing country context such as Tanzania. Therefore, for many surviving stroke sufferers, regaining full physical function is unlikely; most are likely to end up at home where continued care and coping is necessary. *Transformative coping* which allows the retention of a sense of wellbeing even with a disability seems the most appropriate for stroke sufferers (Faull and Hills 2006). In this regard, spiritual and religious support may be crucial as it may offer some form of chronic healthcare which enables an individual to healthily cope with permanent loss of function. These religious practices may either be practiced by the sufferers themselves or supported by family, religious network members and formal religious healers.

Interventions should encourage social networking and support for stroke sufferers and their carers. They could be modelled along the lines of existing social support groups such as the *mtaa* based church groups or good neighbourhood groups. Such groups could reduce the social isolation of sufferers and their carers. They would also provide spiritual support which is important for sufferers of chronic illness. The knowledge and awareness interventions should also encourage community social support of sufferers and their families. Religious leaders and faith healers could also play a vital role in providing social support for home based stroke sufferers. It is acknowledged that prayer and religious commitment may be helpful in providing social and emotional support beneficial to health (Ellison and Levin 1998). Religious beliefs have been shown to offer stroke sufferers some sort of protection from emotional distress (Giaquinto, Spiridigliozzi, and Caracciolo 2007). Spiritual and religious practices have also been shown to be helpful in making sufferers cope with stroke affliction (Ellison and Levin 1998, Giaquinto, Spiridigliozzi, and Caracciolo 2007, Robinson-Smith 2002) and in South Africa they are considered the most cultural appropriate form of coping with stroke (Bham and Ross 2005).

Traditional healers may also offer some form of psychological support for stroke sufferers who are still at the stage of action coping which aims for regain of control and retaining of the pre-stroke physical and mental state. As demonstrated in Chapter 7, through continued treatment, traditional healers offer some hope that recovery is possible and make stroke sufferers and their carers face the future with hope rather than dread.

8.4 Discussion

The interventions I propose in this chapter are based on a thorough analysis of the stroke discourses and treatment seeking behaviours in the two research sites. In proposing the interventions, I have carefully taken into consideration the complex power and socio-economic relations within the two research sites. Rather than introducing totally new dynamics and discourses, my approach aims to put up the stroke interventions on the

foundation of existing socio-economic dynamics and power relations. Consequently, the approach facilitates a smooth integration of the interventions into the community social landscape and health care system and avoid unnecessary resistance to particular discourses such as the resistance the biomedical stroke discourse encountered in Dar-es-Salaam (Mshana et al. 2008). Thus, the identification of the power bases of the various illness discourses (such as social or religious institutions, opinion leaders, particular religious interpretations) is important initial work for any intervention and such information should be used in the design and promotion of the appropriate discourses.

The approach I use in proposing these interventions is thus different from the three treatment seeking models discussed in chapter 2. The three models (the Sociobehavioural Model, Kroeger's health choice model and Young and Garro's treatment decision model) ignore the theoretical viewpoint that health discourses and related variables (including demographic variables) have social, historical and economic attributes. These attributes are not static as they embody the socio-economic changes taking place in the communities and society at large. As pointed out in chapter 2, the standardised definitions of the variables are problematic as they do not sufficiently take into account the contextual and intracultural variations. In contrast to my proposed interventions, the three models tend to 'decontextulise' (Stoner 1985) an interactive process of how illness discourses and treatment seeking behaviours evolve. By ignoring the socio-economic and historical context which leads to the emergence of varying illness discourses and treatment seeking patterns as in the case of Temeke and Hai, the models are bound to impose superficial units of analysis which may lead to design of 'context blind' interventions.

Following Foucault, the interventions I propose assume a close relationship between power and knowledge. As outlined in chapter 3, Foucault argues that there is a close link between power and knowledge because power is needed in the production of knowledge and knowledge is required for the exercise of power (Cheek and Porter 1997, Foucault 1980). Therefore for the first set of interventions (knowledge and awareness interventions), knowledge about stroke will blend with the symbolic power of the

different stake holders (such as biomedical health workers, traditional and faith healers) in promoting awareness of the risk factors for stroke and what do to when encountering the affliction. My research has demonstrated that these groups of people have significant influence in perpetuating the active stroke discourses within their areas through their symbolic capital which is their 'accumulation of a capital of honour and prestige' (Bourdieu 1977:179).

The introduction of the short and medium term interventions at the community level is bound to introduce new power dynamics in addition to the ones already existing. As such, the introduction of community based programmes may threaten the social position and the nature and extent of power exercised by those with symbolic power. If not part of the interventions, the holders of symbolic power may feel threatened and become resistant. Despite resistance being an integral part of power dynamics (Foucault 1980, Scott 2001), it is important for the success of any intervention to minimise social resistance especially from those whose opinion would carry extra weight when uttered from a particular social position. As Foucault (2002) argues, it matters 'who' is speaking and from 'what' social position, as the same discourse uttered from the different social positions could have differing effect. The interventions I propose are therefore designed not to necessarily create new and antagonistic sources of power but build on what already exists. Nevertheless, I must point out that the aim would not be to perpetuate the status quo of the holders of symbolic power, but to engage them and the wider community in addressing the problem of stroke.

The joint sessions by the different stake holders in public places or schools would have valuable symbolic significance since they would draw on their symbolic role as 'formulators of knowledge' (Bourdieu 1989). These different groups have vested interests in safeguarding their social interests and status (Eagleton 2007). In addition, since symbolically they represent opposing discourses prevailing in the community (such as in the case of Dar-es-Salaam where the traditional healers represent the supernatural beliefs informed discourse and Imams represent the religious informed discourse) their coming together in public and fronting a non-antagonistic discourse would have great

significance in reconfiguring the positions of the varying stroke discourses in the wider community. As pointed out in chapter 3, Bourdieu's argues that symbolic power is the 'ability to constitute visions' and 'the power to impose upon other minds a vision, old and new' (Bourdieu 1989:23). Hence the joint visits would carry more weight and positive impact than if only conducted by researchers or health programmes officials. On the other side, if not properly engaged, the symbolic leaders could have a detrimental effect when they utter opposing discourses to a health intervention. As an example from Northern Nigeria demonstrates, a group of Imams opposed child polio vaccination on religious grounds resulting into community resistance of the programme (Raufu 2002).

Messages in local language(s) addressing prevailing local stroke discourses and providing information about treatment services will connect with the members of the community as they will be perceived as addressing 'real' situations in their communities. The use of popular mass media and such messages would have 'symbolic efficacy' which Bourdieu argues depends on the degree to which the proposed 'vision' is founded in reality (Bourdieu 1989). As I pointed out in chapter 2, it has been demonstrated that in some instances local illness discourses assimilate or mirror other discourses obtained by community members through the mass media (Strahl 2003).

Facilitating health workers to exercise power over stroke through support of prompt and proper diagnosis at the primary facility and speedy referral to major hospitals will empower health workers and the health system in general in addressing the problem. In addition, spiritual and religious support is crucial for the long term care of stroke sufferers and their carers as it enhances a sense of still being in control of the situation and provide them with a sense of power and control over the illness.

8.5 Integrated community based interventions

In this chapter I have proposed a series of community targeted and based interventions. I have based these proposals upon an overview of the different practices around the world

and from my research findings informed by my theoretical framework. Nonetheless, I must acknowledge that setting up community-based interventions will be challenging due to the practical requirements. In addition, the evaluation of such interventions is (usually) difficult and at times provide mixed messages as to their benefit (Ebrahim and Smith 2001). For example, a comprehensive study in Finland (North Karelia Study), building upon the support of local community leaders and the general public, provided a comprehensive intervention package involving the mass media, workplaces, primary care, hospital, schools and local communities. It addressed multiple risk factors for cardiovascular health interventions such as smoking, cholesterol reduction and blood pressure. The intervention was evaluated over a period of 10 years and found no demonstrable differences in risk factors between the intervention and control areas. Some community based interventions addressing cardiovascular risk factors have reported some success (Bovet et al. 2002, Cappuccio et al. 2006). However, the extent and duration of such effects is not known since most are evaluated within a short period of time.

Despite the gloomy picture coming from the evaluation of some community-based interventions, learning from successful interventions addressing other illnesses is extremely useful in order to make possible the design of effective and appropriate interventions. For example, it has been demonstrated that it is possible to set up and implement community based health interventions in rural and urban Africa (Cappuccio et al. 2006, WHO/TDR 2008). The ability to set up and implement interventions in such settings is encouraging despite the difficulties. Among the many challenges are poor infrastructure, shortcomings within the health systems such as shortage of supply and reluctance of health workers to allow community implementers to handle drug administration(WHO/TDR 2008). Other constraints, such as social acceptability of the interventions, have been shown to improve over the time of implementation especially when there is demonstrable benefit (WHO/TDR 2008).

The most challenging aspect of setting up any interventions, and community-based interventions in particular, is funding. The issue of sustainability of such interventions must also be addressed. In most cases community based efforts usually fail through lack

of funding -- even in developed countries (Veazie et al. 2005). Community based stroke programmes may be difficult to sell in a country such as Tanzania still struggling to contain infectious epidemics such as HIV/AIDS and malaria. Therefore, creative interventions addressing the issue of funding and sustainability are needed. The interventions I propose build on using the available human resource within the community and health service delivery. They only require investment in training at the beginning (capital investment) and sustained needs based training. They are built on the theoretical premise that recognition and reinforcement of social and symbolic power will be the prime motivators of the implementers of the interventions. In this way they are appropriately equipped to be sustainable as they rely on existing social dynamics for momentum.

Implementation of integrated health interventions is another good way of dealing with lack of funding for setting up and implementing community based interventions in resource poor settings. At present there are numerous AIDS care and support programmes being setup in many parts of Tanzania. With the availability of cheap generic ARVs, AIDS is increasingly transforming from a fatal to a chronic illness needing long term care. Therefore the exploration of a combination of programmes addressing chronic care for AIDS and chronic illnesses such as stroke, diabetes and hypertension may be the most cost- effective, serving to ease the burden across the dilapidated rural health care systems (Ebrahim and Smeeth 2005). Such intervention may be the only feasible way of ensuring long term care for sufferers of chronic illnesses especially in remote rural parts of Africa. The interventions I have proposed could therefore be implemented as part of a larger integrated community based care and support intervention package for chronic illnesses such as HIV/AIDS, stroke and diabetes.

Indeed the implementation of integrated community health programmes is not new and has been shown to be both feasible and effective in African settings. For example WHO/TDR have completed evaluating a community directed intervention (CDI) for five health problems in Africa (WHO/TDR 2008). The intervention involved the community in implementing five interventions which are: Vitamin A supplementation, distribution of

insecticide treated nets (ITNs), directly observed treatment of tuberculosis short course (DOTS), home management of malaria and distribution of Ivermectin for Onchoceriasis treatment. The intervention was conceived after the success of the community-directed treatment of Onchoceriasis which covered approximately 60 million people in different African countries. The multicountry study was conducted in Cameroon, Nigeria and Uganda and was evaluated within three years using quantitative and qualitative methods. The trial showed that four community-directed interventions were more effective than the standard approaches delivered through the health delivery systems of the three countries. Twice as many children with fever received antimalaria treatment, possession and utilization of ITNS was two times higher in intervention areas, vitamin A coverage was significantly higher in intervention areas and ivermectin distribution was boosted by an additional 10%. Only DOTS for TB did not show any significant difference between the intervention and comparison communities. The CDI approach was more cost effective than conventional delivery systems. Intrinsic incentives, such as recognition, status, knowledge, and skills gain were more powerful motivators to the community implementers than material incentives. Through training and support, the community implementers effectively delivered the five interventions despite the lack of supplies of drugs and nets.

8.6 Conclusions

From this review of stroke interventions, it is clear that the establishment of effective stroke units in a developing country, such as Tanzania, is unrealistic in the short term. The most relevant and compelling interventions are those which are relatively inexpensive, aiming to improve care within the existing health delivery system. This could be achieved through the improvement of stroke awareness and knowledge, diagnosis and treatment through training of health staff, and ready availability of drug supplies. Such interventions need to be based on a detailed understanding of the social context, the utilization of an appropriate theoretical grounding and evidence from other studies in similar context on what works.

In the short and medium term, community-based initiatives to hasten referral and treatment should be pursued through the training of simple stroke diagnostic techniques to primary facility staff, encouragement of quick referral to better staffed and equipped hospitals, and encouragement of cross reference between traditional and faith healers and biomedical services. This could be combined with efforts to support more effective outreach services of primary facility staff who are largely responsible for hypertension management in primary care. On the other hand, faith and traditional healers may offer psycho-social support and hope to long term sufferers based in the community.

Integrated community based interventions are feasible in a resource constraint country such as Tanzania. A combined community based intervention programme addressing several chronic illnesses such as stroke and AIDS may be a long term solution to funding and sustainability issues currently limiting healthcare provision in Africa and other developing countries. In the next chapter, I conclude my thesis by summarizing the key points and by suggesting key policy recommendations.

9 Chapter Nine: Conclusions and Policy Recommendations

9.1 Summary of contribution

This is the first anthropological study to theorise the social aspects of stroke in sub-Saharan Africa. By contrasting findings from two sites, my study uniquely demonstrates that historical and socio-economic factors are an important component of the way illness discourses develop and are perpetuated. Through studying the contextual dynamics of stroke in Tanzania, this thesis underscores the complex interactions that underlie stroke discourses and treatment-seeking behaviours. It deploys a range of qualitative methods to provide a robust and grounded evaluation of stroke representations requiring careful attention in the design of interventions. This thesis makes the following new contributions to existing body of theory and literature on stroke discourses and the general study of the social aspects of illness in Africa:

Centrality of historical and socio-economic processes in production of stroke discourses

After contrasting my findings from two sites, I argue that health related discourses should be studied as products of ongoing socio-economic processes, both explicit and inexplicit. I demonstrate that the historical and socio-economic processes which characterise the two research sites have resulted in the production of the particular stroke discourses prevailing in these areas. The community's interaction with foreigners and their health related discourses (for example Christian missionaries in Hai as well as Arab traders along the Indian Ocean coast in Dar-es-Salaam) set in motion a variety of transformations in the framing of illness and its treatment.

My analysis challenges the positions of other theoretical perspectives employed in studying illness discourses. For example, ecological approaches tend to study the social context as it exists at one point in time, without taking into critical consideration the historical and economic factors which gave rise to that context. I also question those

approaches which prioritise the study of 'local' meanings relating to health in general and stroke in particular. These perspectives do not give due recognition to the fact that the meaning of health-related social phenomena are produced and sustained by interested parties in society. This process is achieved through the dynamic of power relations which, if not carefully examined, might seem 'natural' in their occurrence (Bourdieu 1977). Failure to acknowledge the re-constitution and modification of illness discourses, due to the interchange of treating and healing practices (for example through cross-cultural and cross-border healing practices), leads to be readily labeled as 'indigenous' or 'cultural' practices. I therefore affirm that the study of illness discourses should not base itself on snapshots of context or meanings as they appear at one point in time. Instead, such studies should acknowledge that context and the creation of meaning is the product of past and ongoing historical and socio-economic processes which need careful consideration.

Social power relations produce dominant stroke discourses

My inductive analysis demonstrates that underlying subtle power relations, in the course of social interaction and institutional struggle for dominance, play a central role in constituting the different stroke representations or discourses. These power dynamics are also the reason why some discourses gain ascendancy over others. I show that through socialisation and socio-economic interactions, social structures largely determine the way stroke is represented. These structures also facilitate the embodiment of power in the production and perpetuation of stroke discourses through concepts of knowledge and expertise. Socialisation into the medical profession or traditional healing through training and learned practice produces 'experts' who are at the forefront of creating and imposing onto others particular representations of stroke. These representations are fronted as knowledge about stroke; they are embodied by the sufferers, their carers and members of the community. I have explored this process by employing Bourdieu's notion of the interplay of habitus, symbolic power and conditions in the field characterised by practical logic of individuals. The concept of habitus was particularly useful in exploring the embodiment of stroke related practices in the two communities.

Addition to existing literature on stroke

In the literature review, I demonstrate that there is paucity of studies that address the social aspects of stroke in sub-Saharan Africa (SSA). To my knowledge there are two published studies (apart from the one on my initial work), on the subject from SSA (Bham and Ross 2005, and Hundt, Stuttaford, and Ngoma 2004). Both studies were conducted in South Africa and reported on medical and social perceptions of stroke without detailing how they pan out in the communities and implications on healthcare delivery. In this thesis I evaluate the relative importance of competing stroke discourses in urban and rural areas and, in addition, explore practical ways of addressing the problems facing healthcare agencies that are responsible for the delivery of services to stroke sufferers. Thus my study makes a valuable contribution to both the academic and applied aspects of the literature.

9.2 Summary of findings in relation to study objectives

In this section, I recall my objectives and how I address them.

a) Investigate local understandings and beliefs in relation to stroke

In addressing my first objective, I show that the nature and timing of external contacts through religious, social or economic interactions, leading to the exchange of healing and health-related practices, establishes a foundation for the emergence of particular illness discourses. In rural Hai, the early contact with Christian missionaries who established and promoted biomedical health institutions led to the early entrenchment of the biomedical discourse through the establishment of health facilities. There is dominance of particular forms of Christianity which actively support the biomedical-oriented discourses and discourage others. This has resulted in the former gaining institutional reinforcement and therefore accruing advantages over other discourses. The development of the health infrastructure over the years and exposure to modern lifestyles and employment and education-seeking endeavours outside the district continues to perpetuate the dominance of the biomedical discourse in Hai. Close contact with public health officials who

communicate specific representations of stroke further reinforces the dominant biomedical oriented discourse.

On the other hand in urban Dar, the early contact between local ethnic groups and Arab traders led to the emergence of Swahili culture along the east African coast (Caplan 1997, Wynne-Jones 2007). The culture and world outlook blends local ethnic and foreign illness discourses. This is exemplified by the spiritual practices along the Swahili coast which contain the co-existence of Arabic and local African spirit beliefs (Giles 1995). The early dominance and current strong presence of the Islamic education system (through *madrassa* schools) and low level contact with the biomedical institutions in the past means that the locally oriented discourses about illness dominate. The belief systems predominant in Dar provide a strong power base for two discourses, supernatural beliefs informed discourse and the religious informed discourse, resulting in difficulty for the biomedical discourse to break ground. My study also demonstrates that, in both sites, those regarded as experts are engaged in a process of defining, embracing, reinforcing or fronting their preferred discourse to other community members.

b) Investigate experiences of stroke sufferers and care providers

To address my second objective, I demonstrate the way in which stroke sufferers grapple with regaining control of their physical bodies and social lives. Depending on the extent of the disability from stroke, they experience varying degrees of dependence in their lives. Those with minor disabilities, live a life close to normality, though they are constantly 'reminded' of their physical incapability (such as experiencing headaches after prolonged work). Those with severe disabilities are more dependent (in all aspects; physical and economic) on their carers. Stroke sufferers and their carers are engaged in an ongoing struggle to get 'back in charge' of their lives by fully engaging in social and income generating activities in order to provide for their families and live a fulfilling life. Both groups perceive stroke as an interruption in their lives and are determined to overcome it by pursuing the treatment options of their choice.

c) Investigate individual and social factors affecting decision-making

I have demonstrated that decision-making in relation to stroke is complex. It starts immediately from the time stroke afflicts someone and continues throughout the treatment. It is based on several factors such as the prevailing discourses, social dynamics and power interactions at the family and community levels, together with the evaluation of the costs of the remedial courses undertaken. The economic ability of individuals or families is an important element in the dynamic and ever-changing landscape of illness discourse and treatment-seeking. Changes in the economic landscape, making cash more accessible to women in the household, lead to changes in the social dynamics and health-related decision-making, whereby male dominance is challenged. My study further demonstrates that the treatment decision-making process for stroke involves many individuals such as those present at the time when a stroke happens, members of the immediate and extended family, and members of their social networks.

d) Investigate the range of traditional, medicalized and other avenues for stroke treatment

In addressing my fourth objective, my study shows that in both Hai and Dar stroke is treated through four main categories of treatment. These include facility based or home based biomedical treatment, self or healer administered traditional and faith based remedies, and a combination of either biomedical and traditional healing or biomedical and faith healing. I demonstrate clearly that these categories are not separate entities in that there is a degree of interaction between them. For an individual, carer or member of the sufferer's social network to pursue and be satisfied with a particular treatment option, their level of belief on the credibility of the treatment needs to be high. Such belief is influenced by several factors as illustrated in figure 22:

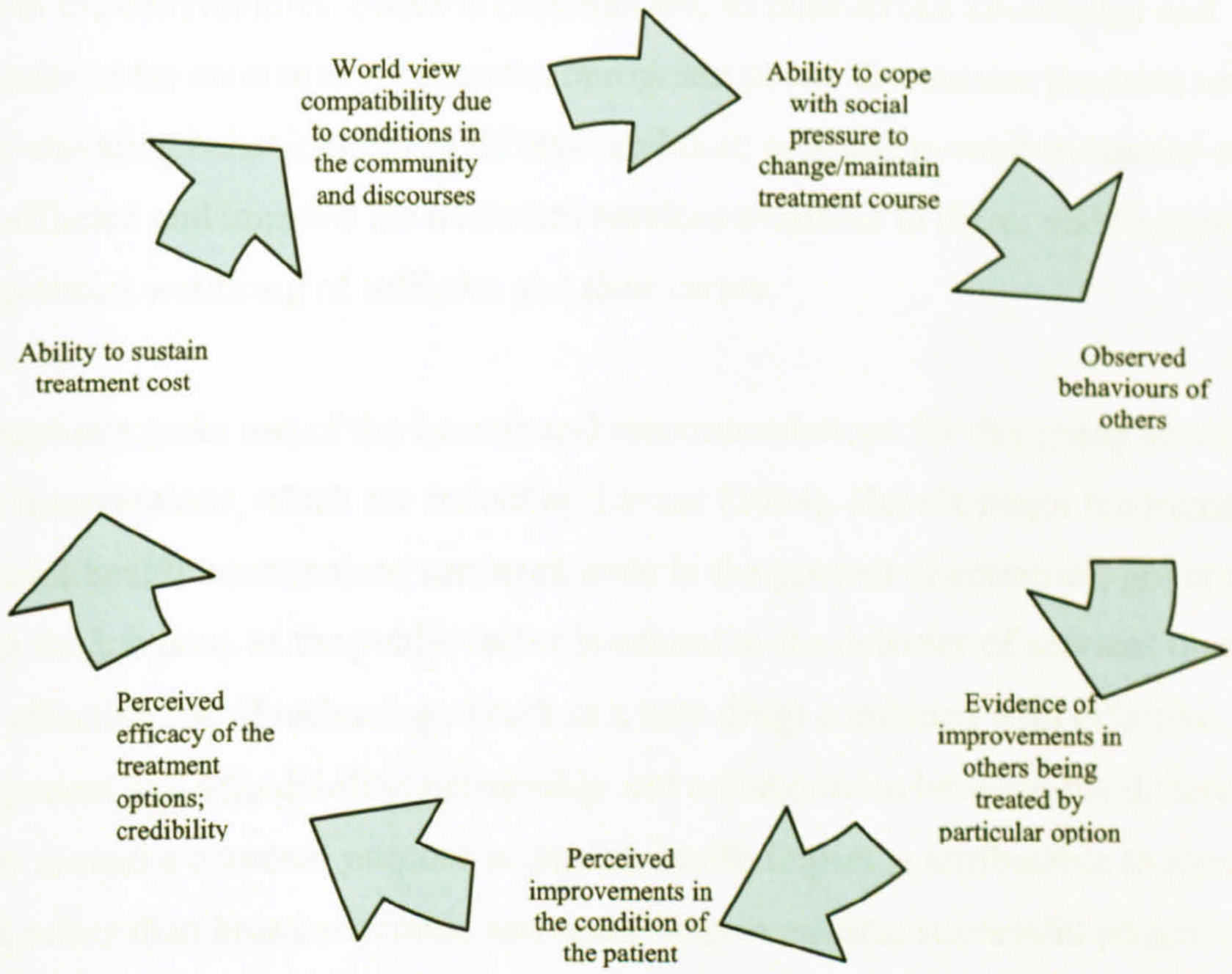


Figure 22: Factors which influence stroke treatment options

I also examine the compatibility or incompatibility of the various treatment options and explore ways of promoting tighter collaboration across them. I demonstrate how traditional healers address new challenges they face, such as demands for effective treatment from their clients, by adapting new forms of treatment from other cultures and countries.

e) Explore ways of promoting relevant strategies to promote appropriate change

The interventions I propose are based on the premise that developing successful interventions against stroke is possible, even as Levine (2004) argued, in least developed countries. My suggested interventions are grounded in theory emerging from a detailed understanding of the social dynamics and healthcare delivery systems. They provide for the utilization of the available resources (human, medical equipment and funding) and proven, effective ways of delivering health messages utilizing available mass media. The interventions I propose aim to address the problem of stroke by addressing health-related

issues in the communities. Specific concerns are: to raise stroke knowledge and awareness in the community; promote appropriate stroke discourses; promote reduction of risk-elevating behaviours from lifestyle and diet; promote prompt treatment-seeking by those afflicted and improve the treatment services available to them; and improve the psycho-social wellbeing of sufferers and their carers.

My proposals make use of the lessons and recommendations for designing successful health interventions, which are set out by Levine (2004). Her six major recommendations are: major health interventions can work even in the poorest of countries; governments can get the job done as the public sector is central to the delivery of services on a large scale; effective use of technology (such as a new drug) combined with effective management and affordability; partnership and collaboration between the different players around a common purpose is crucial; health impact is attributable to specific efforts rather than broad economic and social improvements; successful programmes come in many shapes in terms of approaches. My specific proposals are to: hold mass media interactive programmes to raise awareness of stroke; organize joint school visits by community members with symbolic power such as health workers and religious leaders to hold interactive sessions on stroke with pupils; arrange joint sessions in public and places of worship; train health facility workers on syndromic diagnosis of stroke and provide them with simple medical equipment such as blood pressure measuring machines; provide home-based support for stroke sufferers through regular check-up and support by health workers; and facilitate collaboration between the different groups of service providers.

9.3 Policy recommendations

As outlined in chapters one, two and eight, health policy making is usually based on evidence from quantitative studies with large representative samples. However, findings from systematic qualitative studies can be especially useful as they offer an in-depth and contextually informed understanding of the topic of study as well as paying particular

attention to detail and contextual complexity. They can demonstrate the ways in which a 'few' people with symbolic power could influence illness discourses, and if their influence is negative, this has downbeat implications for health interventions. For example, the dominant discourse in Dar is that stroke is caused by demons, *jinns* or witchcraft and the perceived fatality of injections; this means that any intervention aiming to steer the community towards hospital treatment must address that discourse. Since such a discourse is rooted in the local social power bases and has an upper hand over other discourses, ignoring it or dismissing it as a mere misconception is bound to be counter productive. Intervention designed for implementation in such a context must be grounded on theoretical and practical ways of engaging the discourse.

Drawing on my empirical findings, I make four main policy recommendations:

i) ***Careful attention to context***

I underline a well known assertion that policy making should continue to heed to the call to implement interventions which are informed on what is happening on the ground (WHO/TDR 2008). Qualitative studies provide insights into community dynamics, which shape the course of treatment seeking for stroke. The wealth of information derived from interviewing stroke sufferers, their carers, religious leaders, and following-up families of stroke sufferers provides information that is highly relevant to policy makers.

ii) ***Raise awareness***

My study has shown that there is very low awareness of stroke as even health workers are not clear about the etiology of stroke. Therefore, raising awareness and knowledge of non-communicable illnesses such as stroke is an important first step for implementing successful health interventions. For example, a study conducted in Gambia (Panter-Brick et al. 2006) and a review of malaria interventions in Africa (Williams and Jones 2004), have shown that pre-existing high awareness of malaria in the population led to high uptake of proposed malaria interventions. If population awareness is low, it could lead to the rejection of interventions due to opposing discourses. Such an example was recently reported from Nigeria where child polio

immunization was rejected in a northern part of the country due to opposing discourses spearheaded by Islamic religious leaders that the vaccine was deliberately contaminated with HIV and meant to make people infertile (Raufu 2002).

iii) Use key lessons for success

Policy making must continue to harness lessons from effective intervention studies. For example one key lesson relevant to stroke and other non-communicable diseases in Tanzania is the benefit of using interactive health messages in local languages and popular mass media. For example, in Egypt child diarrhea and mortality was reduced significantly through television messages in the local language, which targeted mothers of children (Gomaa et al. 1988).

iv) Address resource needs

There is urgent need to find solutions for shortage of resources for implementing health interventions in developing countries (Ebrahim and Smeeth 2005, WHO/TDR 2008). Implementation of integrated interventions addressing more than one health condition (e.g. linking stroke, diabetes and hypertension) must be considered as the way forward as they make better use of the meagre human resources available within the healthcare systems of these countries. In carrying out the policy recommendations, there is a need to ensure that all levels of the health system are taken on board; from the national level to the lowest unit in the community (Standing and Chowdhury 2008).

In Tanzania, and probably in comparable 'developing countries', investment in health and other supporting infrastructure must continue to be prioritised in order to address structural shortcomings, such as those revealed in my study. One notable example is that for rural Tanzanian standards, Hai is unique for having a total of 75 health facilities (of which 25 are public). The long presence and relatively better accessibility of these health facilities through a developed road network (together with other factors) has had a positive impact on treatment-seeking behaviours of the

residents in comparison to an urban area like Temeke in Dar. In the long run, a planned and extensive network of facilities will generally help lower the costs of access to healthcare - costs which are a major burden to the majority poor population in Africa (Muela, Mushi, and Ribera 2000).

9.4 Concluding remarks

This study argues that historical, social and economic power relations play a central role in the production and perpetuation of illness discourses. These processes function at different levels of society, through the multitude of interactions taking place at individual, community and institutional levels. Religious, medical and educational systems together with biomedically trained health workers, and faith and traditional healers are constantly engaged in framing and reframing illness in their capacity as experts. Prioritising a detailed understanding of local, regional, national and international power relations as well as these various socio-cultural systems helps facilitate the design of interventions with a better chance of success.

I recognise the existing tension between health researchers who may propose theoretical recommendations which policy makers find hard to implement. Health policy makers are faced with practical dilemmas of how to implement effective interventions within a context of meagre human resources and shortage of medical equipment. By studying stroke discourse and treatment within a community context, my study offers practical suggestions informed by a detailed understanding of the context on how stroke prevention and services may be improved in a developing country context such as Tanzania.

Glossary

Alinjinji	– Medicine reportedly originating from the Arabic gulf countries and sold in traditional medicine shops. It is in black power form
Halititi	-Medicine made from drying and grinding the black seeds of the *Halititi* plant which grows in the Arabic gulf countries. The medicine is sold in traditional medicine shops
Hamdadi	-A local Tanzanian plant believed to have medicinal value common among the east African coast
Jini	- Also pronounced with Arabic connotation as *jinn*: means demons, supernatural beings.
Kabir Shamsi	-Medicine in black power form reportedly originating from the Arabic gulf countries and sold in traditional medicine shops
Kachiri	-Local Tanzanian brown plant producing flowers which are dried up and grinded to be used as medicine
Kamni asiadi	-Medicine in dried bark form originating from India and sold in traditional medicine shops
Kamni asweda	- Medicine in green brownish powder form. Reportedly originating from India and sold in traditional medicine shops
Kashkash maua	-Plant producing red flowers which are dried and grinded to be used as medicine. Reportedly imported from Arabic gulf countries and sold in traditional medicine shops
Kibiriti upele	-Local Tanzanian shrub which has bark with nudges. Its barks are dried and grinded to be used as medicine
Kufusha	-Make one inhale smoke or vapour from a combination of medicine
Mfalsida	-Local Tanzanian plant with medicinal value which is dried, grinded and inhaled
Mmavimavi	-Literally means 'like feaces'. A local Tanzanian shrub with a strong feaces-like smell, which is dried and applied on the body of the stroke sufferer to make the demon leave

Mpesi	-Also known as *mpepe*. A local Tanzanian plant believed to have medicinal value
Mwinamia maji	-Literally means 'bending on water'. A local Tanzanian plant which grows near water sources such as rivers
Mwinga jinni	-Literally means 'the chaser of jinn'. A tree which roots are used to prepare medicine for chasing a demon causing stroke. The roots are dried and used in the process of *kufusha*

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Appendices

Appendix 1

Stroke vignette for Hai

Masawe and Joyce live in Nkuu area in Hai. Masawe is 65 years old and Joyce is 55 years old. They have been married for 30 years and they are devoted Christians. Masawe sells bananas at Kwasadala market and Joyce is a housewife. They have four children together - two daughters and two sons. Both daughters are married and live with their husbands in other parts of Kilimanjaro region. One son lives in Moshi and he works at the sugar factory as a driver. The other son lives in Arusha where he works with the railway company.

Six months ago, Masawe had stroke while selling bananas at the market place. He had the stroke in the morning as he was arranging his bananas for the day's business.
WHAT DO YOU THINK HAPPENED AFTERWARDS? WHY?

Fellow traders took Masawe to his home after his stroke using a hired car. Joyce (his wife) called her four children and told them about what had happened to their father. She also informed their neighbours and relatives. The three children living in Kilimanjaro region arrived at their parent's home within two hours after receiving the news. One of Masawe's brother, Joyce and one of her daughters wanted Masawe to be taken to hospital for treatment but his son who works at the sugar factory and his other sister wanted a traditional healer to be called to treat him at home,.
WHAT DO YOU THINK REALISTICALLY HAPPENED IN THIS SITUATION? WHY?

Masawe was taken to hospital for treatment and after receiving treatment for two weeks he got relief. One day his friend John visited him to see how he was doing. John told Masawe he had a relative who also had a stroke last year and was taken to a traditional healer where he received treatment and was much better. John advised Masawe to go to the traditional healer for treatment. The next day after John's visit, Masawe's other friend Mosha also came to see him. Mosha told him he had a neighbour who had a stroke nine months ago and was taken to someone in another part of Hai who prayed for people with various illnesses to get healed. Mosha said his neighbour got much better after being prayed for and he advised Masawe to visit the person so that he is also prayed for.
WHAT DO YOU THINK ALI SHOULD REALISTICALLY DO IN THIS SITUATION? WHY?

Before Masawe made a decision what to do next, he told his wife Joyce about what his friends John and Mosha had advised him. His wife discouraged Masawe from going to the traditional healer since it is against their Christian faith. She instead agreed that he should visit the person who prays for people to pray for him. Next, Masawe consulted his

son who works in Arusha, and had the opinion that his father should only go to hospital for treatment. He told his father that cost would not be an issue, as he would fully pay for his treatment.

WHAT DO YOU THINK ALI SHOULD REALISTICALLY DO IN THIS SITUATION? WHY?

Appendix 2

Stroke Vignette for Dar-es-Salaam

Ali and Asha live in Magomeni area in Dar-es-Salaam. Ali is 65 years old and Asha is 55 years old. They have been married for 30 years and they are devoted Muslims. Ali sells coconuts at Magomeni market and Asha is a housewife. They have four children together - two daughters and two sons. Both daughters are married and live with their husbands in other parts of Dar-es-Salaam. One son lives in Dar-es-Salaam and he works at the port as a driver. The other son lives in Morogoro where he works with the railway company.

Six months ago, Ali had stroke while selling coconuts at the market place. He had the stroke in the morning as he was arranging his coconuts for the day's business.
WHAT DO YOU THINK HAPPENED AFTERWARDS? WHY?

Fellow traders took Ali to his home after his stroke using a taxi. Asha (his wife) called her four children and told them about what had happened to their father. She also informed their neighbours and relatives. The three children living in Dar arrived at their parent's home within two hours after receiving the news. Ali's brother, Asha and one of her daughters wanted a traditional healer to be called to treat Ali at home, but his son who works at the port and his other sister wanted to take him to hospital for treatment.
WHAT DO YOU THINK REALISTICALLY HAPPENED IN THIS SITUATION? WHY?

A traditional healer eventually treated Ali at home for two weeks and he got some relief. One day his friend Bushiri visited him to see how he was doing. Bushiri told Ali he had a relative who also had a stroke last year and was taken to hospital where he received treatment and was much better. Bushiri advised Ali to go for treatment at hospital. The next day after Bushiri's visit, Ali's other friend Mohamed also came to see him. Mohamed told him he had a neighbour who had a stroke nine months ago and was taken to someone in another part of Dar-es-Salaam who prayed for people with various illnesses to get healed. Mohamed said his neighbour got much better after being prayed for and he advised Ali to visit the person so that he is also prayed for.
WHAT DO YOU THINK ALI SHOULD REALISTICALLY DO IN THIS SITUATION? WHY?

Before Ali made a decision what to do next, he told his wife Asha about what his friends Bushiri and Mohamed had advised him. His wife discouraged Ali from going to hospital since they cannot afford to pay for his treatment as he stopped selling coconuts in the market after he had the stroke. She also said that from what she knows stroke is caused by demons and injections are fatal. She was also against the idea of Ali going to prayers since the prayer was Christian given that they are Muslims. Next, Ali consulted his son who works at the port, and had the opinion that his father should go to hospital for treatment. He told his father that cost would not be an issue, as he would fully pay for his treatment.

WHAT DO YOU THINK ALI SHOULD REALISTICALLY DO IN THIS SITUATION? WHY?

Appendix 3

Study on perceptions and treatment seeking for stroke in urban and rural Tanzania.

Focus Groups Discussions guide.

A. Free Listing

Supplies for free listing exercise
Marker pens, flipchart, note cards.

Questions for free listing

- **List all illnesses and associated symptoms in your community [can use symbols to represent illnesses] [Assuming that stroke will be mentioned, if not prompt].**
- **Which of these illnesses will people seek treatment for? Why?**
- **Lets now talk more about stroke**
  - How do people understand stroke in your community
  - Why do people in your community understand stroke in the way you have explained?
  - What are the different types of strokes and their causes?
  - What makes them different? Probe whether it is causes or symptoms.
  - Explore the source of information on stroke for people in the community and how this influences their understanding of stroke.

- **How do people get stroke?**
  - Explore perceived risk factors
  - Explore prevention issues

B. Mapping

Supplies for mapping exercise
Flipchart, marker pens.

Participants will then be asked to draw a map of their village/*mtaa*. In course of mapping and discussions, we will use flip charts and maker pens of different colours to represent different treatment options. The colours may be used to represent the following:
Green=Hospital
Blue=traditional medicine
Yellow =faith healing
More marker pen colours will be used as more treatment options are identified.
Different colours will also be used to write factors determining and the reasons for a course of treatment.

Guiding questions for mapping exercise

1. Where do people go for treatment of any illnesses (general)?

2. Where do people go for stroke treatment?

3. We will now rank the places people go for treatment by:
-Most utilised
-Friendliness and trust of providers
-Cost
-Distance

4. How do people decide to go there for treatment?
Explore
-Intra household decisions
-Social networks
-Location of services
-Number and nature of service providers
-Facilitating infrastructure e.g. roads

5. Do they just use one treatment option or several?

-Why
-How

6. When and why do people seek treatment for stroke?

-Levels of impairment (perceived and actual; physical and non physical)
-Burden of the disease on patients and family life (perceived and actual; physical and non physical)

7. What can be done to help people with stroke?

-Explore possible interventions at all levels

End

Thank participants for their time and valuable contributions.

Appendix 4

Muongozo wa usaili kwa wagonjwa wa Kiharusi

1 Personal information

1.1 Je, una umri gani?

1.2 Je, umeoa/olewa?

1.3 Unaweza kunieleza kiwango cha elimu yako?

1.4 Je, wewe ni dini gani?

1.5 Unaweza kunieleza historia fupi ya ushiriki wako kwenye dini yako? **Uliza:** Uliingia vipi na lini?

1.6 Je, wewe ni kabila gani?

1.7 Unafanya shughuli gani kujipatia kipato? **Uliza:** Kama ana shughuli zaidi ya moja.

2 Bodily practices

2.1 Je, mwili wako/mwili wa binadamu unafanyaje kazi? **Uliza:** Aeleze kwa kina. **Mfano:** Mfumo wa damu, suala la mwili na roho na kadhalika?

2.2 Je, mtu mwenye mwili ulio kamili anatakiwa aweje? **Uliza:** Aeleze kwa kina kila kitu anachokitaja.

2.3 Je, mtu mwenye mwili usio kamili anakuwaje? **Uliza:** Aeleze kwa kina kila kitu anachokitaja.

2.4 Je, mtu akuugua, ni nini kinatokea katika mwili wake? **Uliza:** Aeleze kwa kina.

2.5 Je, mtu akiugua ugonjwa wa kiharusi (stroke), nini kinatokea katika mwili wake? **Uliza:** Aeleze kwa kina kila kitu anachokitaja.

3 Illness history

3.1 Je, ni kwa muda gani umekuwa ukiugua ugonjwa wa kiharusi?

3.2 Je unaweza kunielezea jinsi ugonjwa huu ulivyokuanza? **Uliza:** Lini, Kwa vipi, Wapi, Kwa nini?

3.3 Je, ulijisikiaje ulipoanza kuonesha dalili za ugonjwa wa Kiharusi? **Uliza:** Kwa namna walivyojisikia katika vipindi tofauti vya muda, na kama hisia hizo zilikuwa wakati wote wa kupata dalili taratibu au kama hisia hizo zilibadilika na muda.

3.4 Je, unaweza kunielezea kwa kina namna ulivyotibiwa baada ya kupata ugonjwa huu wa kiharusi? **Uliza:** Aeleze kama amekwenda hostpitali, kuombewa au kwa waganga wa asili/kienyeji.

3.5 Je, ni nani aligharamia/anagharamia matibabu yako ya ugonjwa wa kiharusi? **Uliza:** Aeleze kwa kina.

3.6 Je, ni kwa jinsi gani mambo yamebadilika tokea upate ugonjwa wa kiharusi? **Uliza:** Mabadiliko ya mtizamo wa maisha, mabadiliko ya kimwili na yasiyo ya kimwili.

4 Historical issues and treatment paradigms power relations

4.1 Je, zamani mababu na bibi zetu waliokuwa wanaishi eneo hili walikuwa wakifanya nini wanapougua? **Uliza:** Aeleze kwa kina.

4.2 Je, huduma ya watu kwenda hospitalini wanapougua ilianzaje katika eneo hili? **Uliza:** Ilianza lini? Nani alianzisha?

4.3 Je, huduma ya watu kuombewa kidini ili wapone magonjwa ilianzaje katika eneo hili? **Uliza:** Ilianza lini? Nani alianzisha?

4.4 Watu wengi wakiugua katika eneo hili wanapata matibabu gani? **Uliza:** Hoptitali, kiasili/waganga wa jadi, kuombewa?

4.5 Je, kwa nini wanakwenda katika hiyo njia uliyotaja, na sio hizo nyingine mbili zilizosalia? **Uliza:** Aeleze kwa kina.

4.6 Je, kama mtu ni mkristo au muislamu anaweza kwenda kwa mganga wa jadi kwa ajili ya matibabu? **Uliza:** Aeleze kwa kina kwa nini haruhusiwi au anaruhusiwa na dini yake?

4.7 Je, kama mtu ni mkristo au muislamu anaweza kwenda kuombewa ili apone ugonjwa wake? **Uliza:** Aeleze kwa kina kwa nini haruhusiwi au anaruhusiwa na dini yake?

5 Household decision making and property ownership

5.1 Ni nani anamiliki mali katika mji? **Uliza:** Ni baba au mama? Au watoto? **Uliza:** Aeleze kwa kina.

5.2 Ni nani anafanya maamuzi katika nyumba? **Uliza:** Ni baba au mama? Au watoto? Ki vipi? Kwa nini?

5.3 Ni nani anafanya maamuzi mgonjwa atibiweje iwapo atatokea katika mji? **Uliza:** Ni baba au mama? Au watoto? Ki vipi, Kwa nini?

Appendix 5

Muongozo wa usaili kwa wahudumu wa wagonjwa wa kiharusi.

1 Personal information

1.1 Je, una umri gani?

1.2 Je, umeoa/olewa?

1.3 Unaweza kunieleza kiwango cha elimu yako?

1.4 Je, wewe ni dini gani?

1.5 Unaweza kunieleza historia fupi ya ushiriki wako kwenye dini yako? **Uliza:** Uliingia vipi na lini?

1.6 Je, wewe ni kabila gani?

1.7 Unafanya shughuli gani kujipatia kipato? **Uliza:** Kama ana shughuli zaidi ya moja.

2 Bodily practices

2.1 Je, mwili wako/mwili wa binadamu unafanyaje kazi? **Uliza:** Aeleze kwa kina. **Mfano:** Mfumo wa damu, suala la mwili na roho na kadhalika?

2.2 Je, mtu mwenye mwili ulio kamili anatakiwa aweje? **Uliza:** Aeleze kwa kina kila kitu anachokitaja.

2.3 Je, mtu mwenye mwili usio kamili anakuwaje? **Uliza:** Aeleze kwa kina kila kitu anachokitaja.

2.4 Je, mtu akuugua, ni nini kinatokea katika mwili wake? **Uliza:** Aeleze kwa kina.

2.5 Je, mtu akiugua ugonjwa wa kiharusi (stroke), nini kinatokea katika mwili wake? **Uliza:** Aeleze kwa kina kila kitu anachokitaja.

3 The dynamics of care

3.1 Je, ni nani katika familia yenu ambaye anamhudumia mgonjwa huyu? **Uliza:** kazi hiyo walipewa na familia? Ni jinsi gani ilivyoamuliwa?

3.2 Je, unaweza kunieleza kwa kina huduma unazompatia mgonjwa? **Uliza:** Nani analipa gharama? Kwa nini?

3.3 Je, unaweza kunielezea uzoefu wako wa kumhudumia mgonjwa? **Uliza:** Je, zoefu huu wa kumhudumia mgonjwa umebadili vipi mtizamowako wa maisha? Kivipi?

4 Historical issues and treatment paradigms power relations

4.1 Je, zamani mababu na bibi zetu waliokuwa wanaishi eneo hili walikuwa wakifanya nini wanapougua? **Uliza:** Aeleze kwa kina.

4.2 Je, huduma ya watu kwenda hospitalini wanapougua ilianzaje katika eneo hili? **Uliza:** Ilianza lini? Nani alianzisha?

4.3 Je, huduma ya watu kuombewa kidini ili wapone magonjwa ilianzaje katika eneo hili? **Uliza:** Ilianza lini? Nani alianzisha?

4.4 Watu wengi wakiugua katika eneo hili wanapata matibabu gani? **Uliza:** Hoptitali, kiasili/waganga wa jadi, kuombewa?

4.5 Je, kwa nini wanakwenda katika hiyo njia uliyotaja, na sio hizo nyingine mbili zilizosalia? **Uliza:** Aeleze kwa kina.

4.6 Je, kama mtu ni mkristo au muislamu anaweza kwenda kwa mganga wa jadi kwa ajili ya matibabu? **Uliza:** Aeleze kwa kina kwa nini haruhusiwi au anaruhusiwa na dini yake?

4.7 Je, kama mtu ni mkristo au muislamu anaweza kwenda kuombewa ili apone ugonjwa wake? **Uliza:** Aeleze kwa kina kwa nini haruhusiwi au anaruhusiwa na dini yake?

5. Household decision making and property ownership

5.1 Ni nani anamiliki mali katika mji? **Uliza:** Ni baba au mama? Au watoto? **Uliza:** Aeleze kwa kina.

5.2 Ni nani anafanya maamuzi katika nyumba? **Uliza:** Ni baba au mama? Au watoto? Ki vipi? Kwa nini?

5.3 Ni nani anafanya maamuzi mgonjwa atibiweje iwapo atatokea katika mji? **Uliza:** Ni baba au mama? Au watoto? Ki vipi, Kwa nini?