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THE BRITISH HOSPICE MOVEMENT - A CRITIQUE OF THE RESOURCE
MOBILIZATION PERSPECTIVE

by

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- 1 -



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ABSTRACT

The purpose of this study is to investigate the domestic Hospice Movement. Alone, a psychological perspective is inadequate for an understanding of the forces involved in the initiation of hospice enterprises. A sociological approach is necessary to provide a complementary balance and to reveal the mutual influence of social and individual factors. A Resource Mobilization perspective (McCarthy and Zald, 1977), is adopted for this purpose.

The scope of the study is confined to the genesis and initial development of hospice projects. Interviews with, and questionnaires completed by, individuals involved with the Martin House Childrens' Hospice project, provided information regarding factual, resource mobilizing aspects of their involvement, together with subjective accounts of their activities within the Movement.

The history and development of the Movement are outlined briefly. A background to the field of collective behaviour and social movements provides an introduction to an outline of Resource Mobilization theories.

A survey of societal attitudes to death, and dying, both past and present, together with some cross-cultural references, challenges the notion that western society is characterised by a, "denial of death," and suggests that it is better described as,

"death transforming."

Hospice philosophy and individual attitudes to death are also considered, as a prelude to appraising both the benefits and the deficiencies of the use of a Resource Mobilization perspective in studying the Hospice Movement.

The future of the Movement is discussed, with particular reference to the question of integration into the National Health Service. In order to achieve a greater understanding of the Movement, past, present and future, it is felt that any approach should stress the dynamic interaction between participating individuals and the wider issues of both intra- and extra-Movement resource mobilization.

Finally, AIDS is considered in relation to the Hospice Movement. This is seen to represent potentially the biggest challenge to the terminal care services.

CONTENTS

	PAGE NO.
ACKNOWLEDGEMENTS	2
ABSTRACT	3 - 4
CONTENTS	5 - 6
CHAPTER ONE: THE HISTORY AND DEVELOPMENT OF THE HOSPICE MOVEMENT	7 - 15
CHAPTER TWO: OVERVIEW OF COLLECTIVE BEHAVIOUR AND SOCIAL MOVEMENTS	16 - 22
OUTLINE OF A RESOURCE MOBILIZATION PERSPECTIVE	23 - 37
CHAPTER THREE: SOCIETAL ATTITUDES TO DEATH	38 - 62
CHAPTER FOUR: HOSPICE PHILOSOPHY AND INDIVIDUAL ATTITUDES TO DEATH	63 - 87
CHAPTER FIVE: RESOURCE MOBILIZATION AND HOSPICE PROJECTS: APPLICATIONS	88 - 108
CHAPTER SIX: RESOURCE MOBILIZATION AND HOSPICE PROJECTS: DEFICIENCIES	109 - 127

CHAPTER SEVEN: CONCLUSIONS - FUTURE OF THE HOSPICE MOVEMENT	128 - 139
CONCLUSIONS	140 - 162
APPENDIX ONE: THE CHALLENGE OF AIDS	163 - 172
APPENDIX TWO: QUESTIONNAIRE	173 - 174
BIBLIOGRAPHY	175 - 187

CHAPTER ONE

THE HISTORY AND DEVELOPMENT OF THE HOSPICE MOVEMENT

The hospice movement has been described as, "a microcosm of human physical and spiritual development throughout the centuries," (Hillier, 1983 p.321). The provision of rest and peace for both worldly travellers and pilgrims was fundamental to the notion of hospice. Such aims represent human beings as both physical and spiritual in nature, in the way that they were regarded by many modern hospices.

Known hospice origins can be traced from Roman times and the work of Fabiola, in the reign of Emperor Julian the Apostate. As a Roman matron and disciple of St. Jerome, Fabiola and her associates provided food and rest to travellers, helped the sick and cared for dying pilgrims. In Matthew 25:35 the text describes the construction of shelters for the poor, "I was a stranger (xenos) and ye took me in," (Manning, 1984, p.34). This demonstrates the foundation of the spirit underlying these early shelters. They were places where believers could exercise their Christian duties. Thus all three states of man, resting, active and dying, were cared for together, unlike the modern practice of assistance from an array of specialists in both sickness and health. The approach of this Roman hospice has characterized hospices ever since, in the sense of catering for the physical and spiritual welfare of its beneficiaries, although at different times and in different places the emphasis on either of the two

elements has varied. Talbot, a researcher of early hospices (in Manning, 1984, p.34) says,

"Note that there is no still care of dying as such, though one can imagine that a wounded pilgrim or one vowed to a pilgrimage who was too old for it, might die along the way, in the care of a hospice if he or she were very lucky. In general, the idea of a hospice had nothing to do with death the idea being to give the pilgrims shelter and help them on their way. Helping towards the shrine had nothing to do with helping them towards heaven."

Nevertheless, care of the sick and dying became an inevitable responsibility as time went on. This involved, "unconditional acceptance and concern for one's fellow man regardless of wealth, religion and age," (Manning, 1984, p.35).

The movement can be followed through Europe and beyond, for example the magnificent hospice of Turmanin in Syria, in A.D. 475; from the eleventh century Knights Hospitallers of the order of St. John of Jerusalem, who in their devotion referred to their patients as, "Our Lords the Sick," to the multitude of monastery-based hospices of the Middle Ages. Increasingly such places acted more for resting travellers and less as havens for the sick and dying. Even this practice ceased with the dissolution of the British monasteries, by Henry VIII.

From about the fifteenth century, prototypes of the modern hospice started appearing in Europe. An early example named

Hospice de Beaune was established in 1443 in the French region of Burgundy. Early in the seventeenth century a young French priest, St. Vincent de Paul established the Sisters for Charity in Paris and opened several houses for the care of orphans, the poor, sick and dying. From France the concept of hospice spread to Prussia, Ireland, England and Australia.

The Prussian Baron von Stein visited these Roman Catholic Sisters a century later and was inspired enough to encourage a young Protestant pastor, Fliedner, to found Kaiserwerth, the first Protestant hospice, also staffed by nuns. It is interesting to note that nuns from both these programmes accompanied Florence Nightingale to the Crimea, where it might be said that the notions of compassion and competence, of the profession nurse, began.

In the middle of the nineteenth century, Mary Aikenhead founded the Irish Sisters of Charity consisting of nuns who had experienced the ordeal of the Crimean War. They founded Our Lady's Hospice for the care of the dying at Harold Cross in Dublin. An acute need for such a place existed due to the horrors of the Irish potato famine, together with the establishment of the English Poor Law. The resulting privations and indignities occurred at a time when the attitude of many English people was that illness and pain were punishments for sin. Also, hospitals in England were selecting outpatients for research and teaching and actively advocating the disposal of the chronically and terminally ill to other, even less sympathetic institutions.

Five of the Irish Sisters of Charity founded St. Joseph's Convent in London's East End, in 1900, and started to visit the homes of the sick. Two years later they opened St. Joseph's Hospice with thirty beds for the dying poor. Only two other hospices existed in London at that time; the Hostel of God, run by Anglican Sisters and St. Luke's House for the Dying Poor, founded in 1894 by Dr. Howard Barnett and managed by a Methodist committee.

A cursory glance at the situation in the United States of America, shows a parallel development, with the initiatives being taken by religiously motivated individuals. After watching a friend die of cancer, the daughter of Nathaniel Hawthorn founded an order of Dominican nuns, devoted to terminal care. The first hospice appeared in New York in 1899, and the expansion of the Servants of Relief for incurable cancer produced six more in the U.S.A.

Half a century later, in England, Cicely Saunders began work at St. Joseph's Hospice, which she continued for seven years, developing techniques for control of pain together with total care for dying patients, methods which lie at the heart of modern hospices worldwide. Due also to the lack of priority given to spiritual care in the existing, inadequate facilities for the terminally ill, Saunders a qualified nurse, social worker and doctor, as well as Christian, developed the idea of a place which would be an oecumenical religious and medical establishment, providing the best care for the dying and giving opportunities for teaching and research in all related fields.

Two developments in the 1950's gave impetus to the full flowering of the Hospice Movement. Firstly a survey by the Marie Curie Foundation against malignant diseases, emphasised the need for more hospices. Secondly, the results of the conversations between Cicely Saunders and David Tasma, a Polish refugee who died in 1948 in the Archway Hospital in Highgate. Shirley du Boulay in her biography, "Cicely Saunders" (1984) says that Tasma, "more than any other single person, was to be the catalyst and inspiration of her work," (p.54).

In 1964, Saunders opened a building fund and in 1967 St. Christopher's Hospice opened in Sydenham, London. From the beginning, St. Christopher's has become the model most often referred to in the blossoming modern Hospice Movement.

Looking at the development of the British Hospice Movement, it can be seen that St. Christopher's Hospice resulted from years of evolution and careful, determined planning. Its impact has been significant both in the numbers of dying patients helped as well as the education of numerous health staff.

Since the opening of St. Christopher's, services for the terminally ill have expanded in four main areas. Facilities for the dying in private foundations, nursing homes and non-National Health Service Hospices have increased. Continuing care units set up by the National Society for Cancer Relief and maintained by the National Health Service have been developed. Home care teams,

cooperating with family doctors and district nurses, social workers and chaplains have combined to form hospital support teams. Their role is to advise on terminal care on acute hospital wards. None of these groups aim to replace all other help to become the sole caregivers for the dying patient, rather they represented attempts to share the burden of such work, by operating with the existing services to a greater or lesser extent. An important consequence of the emergence of these groups has been the rising standard of terminal care for patients with whom they have never been in direct contact. This effect demonstrates the importance of communication and education within and between groups whose purpose it is to care for the dying.

Examples of the private foundations caring for the terminally ill, even before the opening of St. Christopher's, includes the Marie Curie Foundation providing homes for all manner of cancer patients, and the Sue Ryder Foundation, the majority of whose beds were occupied by the chronic sick. In the five years between 1975 and 1980 there was a dramatic increase in all types of terminal services, especially those financed by the National Health Service (Ford, 1979).

The increasing concern with terminal care has posed problems for the government, especially one in which the role of the National Health Service is constantly under scrutiny and review. There has been a growth of public awareness and support for the idea of hospices, but as services were developed differently in different parts of the country, those areas poorly served have experienced increasing pressures to alleviate this imbalance.

Lunt and Hillier, in an article in the British Medical Journal in 1981, showed the situation in the fourteen Regional Health Authorities in Britain, with Scotland and Wales counted separately, in January 1980, indicating major discrepancies in the available services throughout the different regions of Britain. Perhaps unsurprisingly the North of England which includes areas of dense industrial population, fares much worse than the Thames Region (including London) or the South. Thus there is public pressure in the North to provide equivalent services to those existing in the more affluent southern regions.

A government review of available services, "The Report of the Working Group on Terminal Care of the Standing Sub-Committee on Cancer," chaired by Eric Wilkes(1980), warned against rash planning of hospices and continuing care units which cannot be adequately financed. The report emphasized the need, "To encourage the dissemination of the principles of terminal care throughout the health service and to develop an integrated system of care with emphasis on coordination between the primary care sector, (the G.P., nurse, and associated team), the hospital sector and the hospice movement," (p.11). Existing units were encouraged to undertake day care, high quality research, teaching, and to look for finance towards voluntary funding.

The policy advocated was already being pursued by the National Society for Cancer Relief, which acknowledged that the capital and maintenance costs of specialized units would be very high, and there would be difficulty finding enough staff if large

numbers of new hospices were to be opened. An added constraint upon expansion was the fact that for the first time since its creation in 1947, the National Health Service had reduced its spending, therefore raising the quality of care of the dying had to be achieved as inexpensively as possible. As a result the Society supported the development of home care teams, operating from the existing continuing care units. Such teams typically work under the directorship of a doctor and included nurses, physiotherapists, occupational therapists, social workers and sometimes chaplains. Working closely with primary care gives the team visits patients' homes individually to offer support to both the patients and their families. Provided that there are sufficient resources and support, people often prefer to die at home, amidst familiar people and surroundings, (Corr and Corr, 1983.) Such an interdisciplinary approach caters for the patients' and families' needs, where they feel most at ease, in the home. This alleviates some of the pressures on hospital beds.

The National Health Service also funds hospital support teams which act in much the same way as the home care teams, except that they operate in hospitals, seeing patients when requested by other specialists. Such teams often enhance the prospects of earlier discharge and continue to support the patients in their homes. There are now about eighteen Hospital based Support teams in the U.K., the first being established in St. Thomas' Hospital, London, in 1977.

The present numbers of hospices and hospice projects is most

easily discovered from using the "1987 Directory of Hospice Services, in the U.K. and the Republic of Ireland." The Directory is compiled by the Hospice Information Service, which was initiated by St. Christopher's Hospice in 1977. It "provides an information exchange and communication network for the Hospice Movement throughout the United Kingdom," (1987 Directory of Hospice services, p.1). The 1987 Directory includes details of over one hundred in-patient units and over one hundred and seventy home care services, of which more than one hundred are based in the community, separate from existing units. A significant role has been played by Cancer Relief in the development of both home care and in-patient facilities through the establishment of their MacMillan Units, now operating within the NHS, and the MacMillan Home Care Nursing Services. The total also includes eleven Marie Curie Memorial Foundation Homes and seven Sue Ryder Foundation Homes. Despite some statutory funding for the costs of patient care in independent hospices, nearly all rely on local fund raising and community interest for capital and the vast majority of their running costs. The 'Help the Hospices' charity, "is currently endeavouring to reach sources of funds not so far available to them and to add a more general voice to the local endeavours, many of which have to struggle for adequate local support," (Dame Cicely Saunders, 1987 p.1).

Finally, the 1987 Directory includes the details of over forty planned hospice units and home care teams, which are due for completion within the next two years.

CHAPTER TWO

OVERVIEW OF COLLECTIVE BEHAVIOUR AND SOCIAL MOVEMENTS

In order to locate the resource mobilization perspective in a meaningful context, it is necessary briefly to survey the field of collective behaviour and social movements, identifying the major trends together with the competing conceptualizations and explanations of these phenomena (collective behaviour and social movements). Against this background resource mobilization approaches are contrasted with preceding and alternative perspectives.

The actions of the crowd have been the concern of scholars since the early Crusades. More recently, a by-product of the activities of the sans-culottes, in the French Revolution, was the development of crowd psychology (Bruce Mazlish, "The French Revolution in Comparative Perspective." *Political Science Quarterly*, 85, June, 1979). Observations of the behaviour of Parisian mobs in the late nineteenth century, led to the development of a notion of crowd or mob psychology. From such origins arose the theory that crowds are composed of, "normal, moral, law-abiding citizens whose 'thin veneer of civilization' is stripped away temporarily," (Mazlish, 1970, p.255, in Turner and Killian, 1972).

The vaguer conception of the public has intrigued the

layman, and although he lacks a clear conception of what constitutes the public, it is believed to be important in terms of both public opinion relative to the individual and the sources of change in public opinion.

The crowd, the public, along with fads and crazes constitute the field of collective behaviour. The sociologist, who tends to be concerned with the study of consistencies in group life, made more predictable by relatively stable social structure and existing norms, must ask questions about the psychological and social forces involved in situations where conventional behaviour ceases to occur. Questions are asked about the interaction between individuals within collectivities, the influences upon norms, as well as enquiring into the social organisation of collective behaviour.

Collectivities, composed as they are of individuals, provoke questions concerning the characteristics of those involved, including age, education, socioeconomic status and how these are related to the resulting behaviour.

Such is the sphere of collective behaviour, which although studied previously was not introduced and given sociological currency until Park and Burgess (1921) used the term. This represented an elaboration of Park's (1904) efforts to, "delineate the crowd and public as distinctive social forms," (Turner, 1981, p.2). Their contribution was particularly significant as they introduced a field of enquiry, devoid of judgemental and psychiatric concepts, whilst employing

sociological terms. This contrasts with the work of LeBon, "The Psychology of Crowds" (1895), Trotter, "Instincts of the Herd in Peace and War" (1917), and others (Tarde, 1890; Sighele, 1901) which is set against a backcloth of fears about the crowd's alleged threat to societal stability.

Turner (1981) outlines several themes that characterize most of the work in the Park and Burgess tradition. Firstly, social movement is viewed as a sociological phenomenon and a form of collective behaviour. This contrasts interest in movements incidental to the study of broader social processes or even psychological orientations. It involves carefully attending to principles and processes connecting social movements to other forms such as crowds and publics.

Secondly social movements are seen as examples of purposive collaboration, promoting or resisting change as a result of institutional structures failing to satisfy the collaborators' requirements. Thirdly, important topics for investigation have included the forms and causes of change during movement careers, (for example, Edwards 1927; Hopper, 1950). As part of this theme, collective behaviourists regard goal evolution and change to be a product of modified, "collective definition among movement adherents and public opinion," (Turner, 1981, p.5). An example of this is the evolution of the American temperance movement goal from temperance to prohibition.

A fourth theme is the relationship between movement practice and success, and its interaction with existing institutional

structures, the community, alternative movements and interest groups, via publics.

Fifthly, work in this tradition has assumed that human beings, both in and outside movements, are heterogenous and social. Movements are said to attract members or adherents with diverse characters, motives and perceptions.

A final theme, stemming from the link between collective behaviour and symbolic interactionism (Blumer, 1946, 1957; see below) is that, "social movements are viewed as instrumentalities in the continuous construction and reconstruction of collective and individual views of reality. Altered ways of viewing are often more important products of social movements than any specific organizational or political accomplishment," (Turner 1981, p.6). As shall be shown, this approach is very much at odds with the resource mobilization perspective, which neglects to consider several of the factors central to the collective behaviour tradition, outlined above.

Mention must be made of the 'group mind' issue, that is whether the group exists as more than the sum of individual responses. Different emphases suggest either individualistic or group type descriptions although the nature of any conclusions will tend to reflect the purpose of the study in question. Generally though, the collective behaviour approach recognizes the role of the individual, whether it be in terms of his contribution to a movement goal or in an assessment of the consistency of behaviour in and out of the movement. Again, this

tends to be a neglected area in subsequent resource mobilization perspectives.

A brief overview of the chronological progression within the sphere of collective behaviour will add clarity and impose some order on the approaches to social movements, and will thus enable the resource mobilization perspective to be more clearly fixed within this scheme.

Following LeBon's work on crowd psychology at the turn of the century, together with Park and Burgess' early study of collective behaviour the emphasis has shifted towards an, "interest in the dynamics of relatively unscheduled social events either for their own sake or for the sake of their contribution to healthy protest and change," (Beckford, 1985, p.3,).

European unease regarding popular involvement in politics was 'Americanized' and produced synthetic theories about 'normal' societies functioning according to shared values. From this emerged the need to explain any deviations from the American norm. The term 'structural functionalism' subsumes these efforts to account for unscheduled, uninstitutionalized social events. The most famous theorization of collective behaviour being the normal response to structural strain is N.J. Smelser's "Theory of Collective Behaviour," (1962). This theory was used in Zurcher and Kirkpatrick's case study, "Citizens for Decency: Antipornography Crusades as Status Defence," (1976).

Symbolic interactionism (Blumer, 1946, 1957, 1969) offered an alternative to structural functionalism, along with relative deprivation theory. Blumer spanned the gap between the founding American sociologists and post World War Two theorists. This interest was more in the symbolic forms through which collective behaviour was mediated than in its structural determinants. Significant developments of this theory include R. Turner and L. Killian's "Collective Behaviour" (1957) and McPhail and Miller's notion of 'the assembling process.'

Relative deprivation theorists (Aberle, 1962; Glock, 1964) attempted to clarify the relationship of collective behaviour outbreaks to specific conditions of perceived deprivation or frustration, thus improving on the work of, for example, Neil Smelser. Such a perspective was readily adopted in the, "post war enthusiasm for the statistical analysis of aggregate data on such things as income distribution, rates of social mobility and status inconsistency," (Beckford, 1985). Relative deprivation theory was used more in relation to social movements than to collective behaviour.

Post war studies tending to reduce the meaning of moral reform and protest to a reaction to perceived status inconsistencies, such as Gusfield's "Symbolic Crusade: Status Politics and the American Temperance Movement" (1963) together with the work of Zurcher and Kirkpatrick (1976) mentioned earlier, are still immersed in theoretical controversy: controversy which provides a vantage point from which to view many widely held assumptions regarding social movement

participation (Beckford, 1985).

OUTLINE OF A RESOURCE MOBILIZATION PERSPECTIVE

As has been seen, the emphasis on structural strain (Neil Smelser's "Theory of Collective Behaviour," 1962), generalized belief and deprivation have largely ignored ongoing problems and strategic dilemmas of social movements. McCarthy and Zald in their "R.M. and social movements : a partial theory," (American Journal of Sociology, 1977) refer to a social movement (S.M.) as a set of beliefs and opinions existing in a population which represent certain preferences for changing some elements of the social structure and /or reward distribution in society.

The Hearts and Minds Approach

The motivational model of which the above are examples or the "hearts and minds" approach has traditionally been used by sociologists as a broadly based dispositional theoretical background, as a means of studying social movements. The dominant emphasis is on the psychological states of those who are attracted and participate. It assumes a three stage sequence of social movement affiliation (Bromley & Shupe, 1979).

- i) Predisposing conditions; needs and motives of individuals,
- ii) An exposure to the new beliefs which appeal to those predispositions, and

iii) Resulting behaviour as a committed member of the group.

Such an approach posits the question why do individuals join and implies, according to Bromley and Shupe (1979) from their study of the "Moonies in America," that the movements arise by providing coping mechanisms for individuals. From this, it is stated, are produced the tendencies, firstly to develop a social pathology perspective (Hine, 1970) viewing such a psychological approach as an almost sufficient explanation, and secondly, to ignore, to a great extent, an examination of social movements from an organizational perspective.

It is taken for granted, by such motivational models, that social movement organizations constitute structure through which discontent is reflected and expressed. The various assumptions regarding functioning tend to ignore or distort organizational dynamics.

Thus, four main criticisms can be made of a "hearts and minds" approach.

- 1) Consistent motives, on the parts of the actors, are assumed.
- 2) It assumed high levels of discontent, resulting in a pathology orientation.
- 3) There is little emphasis on how social change is achieved and organized.
- 4) There is a de-emphasis on the interaction between the movement and society.

Some studies have demonstrated no support for a relationship between deprivation and the outbreak of movement phenomena and a willingness to participate in collective action (Snyder & Tilly, 1972). Also Marx (1970) showed no support for the expectation of generalized belief prior to outbreaks of collective behaviour or initial movement involvement. Tilly (1973) stated that such psychological approaches exclude the processes by which persons or institutions outside collectivities become involved.

The Nuts and Bolts Approach

"The 1970's saw a reaction against the grand theories of normative functionalism and relative deprivation. Instead emphasis shifted to the 'nuts and bolts' of social movement organizations. The overriding preoccupation was with the means by which human and other resources could be mobilized in pursuit of a movement's goals," (Beckford, 1985). McCarthy and Zald (1977) stated that they wanted to shift, "from a strong assumption about the centrality of deprivation and grievances to a weak one," (p.1215) possibly making them a secondary component in social movement generation.

This resource mobilization (RM) perspective "facilitates an organizational analysis of social movements," (Bromley and Shupe, 1979, p.19). McCarthy and Zald, two of the main proponents of this approach based their work on that of Daniel Moynihan. It was first formulated in a piece in, "Public Interest" (1965, called, "The Professionalization of Reform" (D.P. Moynihan) and

expanded in his 1968 work, "Maximum Feasible Misunderstanding". John McCarthy and Mayer Zald in their, "The Trend of Social Movements in America: Professionalization and Resource Mobilization," (1973) developed, extended and supported Moynihan. Their approach was narrower than alternative resource mobilization theories where protest was seen as growing from the ongoing political process and being part of it (Oberschall, Tilly & Gamson) and applied to the 1960's, although its generality was asserted. Politics was seen to play a minor role (more as a limit than an engine); rather it was an economic theory, indifferent to ideology and with very little or no dependence on grievances.

R.M. deals in general terms with the dynamics and tactics of social movement growth, decline and change. It emphasises societal support and constraint of social movement phenomena in relation to various resources, links of social movements to other groups, dependence on third parties for success, and tactics used by the authorities to control or incorporate movements. R.M. depends more on politics, sociology and economics than social psychological theories.

One of the main emphases in the R.M. perspective is the possibility that if vital resources (e.g. money, visibility) can be generated without discontents in large numbers, such discontents, that is individuals with particular grievances, may not be necessary. Further, there would be very different organizational implications if the ideological and financial supporters were separate, (and each group relating differently to

the presumed beneficiaries) than when the assumed discontents are the sole or primary resource base. It is possible to question the extent to which the actions and policies, of a social movement, follow the vested interests of elites, (those commanding a large resource pool), organizational interests per se or interests of presumed beneficiaries.

Thus, it would appear, as Freeman (1979) stated, there isn't a simple linear relationship between ideology and strategy, as often is assumed, rather there is a dynamic one; it may be seen as something of a chicken and egg problem.

Turner and Killian (1972) are less hesitant stating their assumption, "... that there is always enough discontent in any society to supply the grass-roots support for a movement if the movement is effectively organized and has at its disposal the power and resources of some established elite group,"(p.251). Despite appearing somewhat cynical, this assumption lies behind much of the work performed using the R.M. perspective.

In order to work with the R.M. perspective it is necessary to describe the language used in the labelling of various of the components involved, both internally and externally, in this view of social movements.

McCarthy and Zald (1977) describe the structures associated with social movements. A Social Movement Organization (SMO) is a complex or formal organization which identifies its goals with the preferences of a SM and attempts implementation of these

goals.

All SMO's that have as their goal the attainment of the broadest preferences of a particular social movement, constitute a Social Movement Industry (SMI). These have been called the organizational analogue of a SM.

SMS are never fully mobilized and are typically represented by more than one SMO. Thus it is possible to account for the rise and fall of SMIs in a way that is not wholly dependent on the size of an SM, or the intensity of preferences within it.

Finally, a Social Movement Sector (SMS) consists of all SMIs in a society, irrespective to which SM they are orientated.

McCarthy and Zald (1977) made a series of hypothesis relating to these organizational levels.

1) "As the amount of discretionary resources of mass and elite publics increases, the absolute and relative amount of resources available to SMSs increases," (p.1224).

2) "The greater the absolute amount of resources available to the SMS, the greater the likelihood that new SMIs and SMOs will develop to compete for these resources," (p.1225).

3) "Older established SMOs are more likely than newer SMOs to persist throughout the cycle of SMI growth and decline," (p.1233).

4) "The more competitive an SMI (a function of the number and size of the existing SMOs", the more likely it is that new

SMOs will offer narrow goals and strategies," (p.1234). (In the struggle for survival you specialize" Durkheim).

5) "The larger the income flow to an SMO, the more likely the cadre and staff are professional and the larger are these groups," (p.1234).

6) "The larger the SMS and the larger the specific SMIs, the more likely it is that SM careers will develop," (p.1235).

Looking more closely at the SMO level, it can be seen that one of the main concerns is with potentially mobilizable resources. These can be divided roughly into tangible and intangible resources.

Tangible resources, for example, money, space, means of publicizing existence and ideas, are interchangeable up to a point. It can be a mistake to judge the affluence of a movement by monetary contributions alone. For example, when a new movement emerges from an old one, the old may provide cooptable communication systems and networks and very valuable resources which would be expensive or unattainable if the older movement did not exist.

People are generally characterised as intangible resources, and there is heavy reliance on people in SMs, as they represent a higher proportion of SMS resources than do tangible resources. They are harder to convert into political pressure, let alone social change, especially as they are not particularly liquid, yet for many activities they are more valuable. Three main categories of resource contributed by people are;

a) Specialized resources, possessed by a few (although these few can be adequate.) These include expertise, access to other resource networks, access to relevant decision makers, and status. b) Time. c) Commitment - in this context meaning a willingness to take risks and/or entertain inconvenience.

Three major sources of mobilizable resources, are labelled in McCarthy and Zald's RM Literature as the Beneficiary Constituency, the Conscience Constituency, and Nonconstituency Institutions.

Beneficiary constituents are potential beneficiaries of a movement who supply resources.

Conscience constituents are sympathizers providing resources but who are not part of the 'beneficiary base.'

Nonconstituency institutions are available independent of the movement's existence and can be potentially coopted by it (e.g. laws). One has the theoretical 'right' to the resources of this, that is, access is institutionalized.

Thus it can be seen that resources are needed to mobilize resources, and these may not be abundantly available. The density of the resources affects the cost of mobilization. There may be a coappearance of movements as resources generated by one movement can be used for cognate works, for example, organizing or publicizing skills are transferable, across movements.

It is the constituents of an SMO who provide it with resources, such as legitimacy, money, facilities and labour, in order for it to achieve its target goals. 'Adherents' to a movement are individuals or organizations who believe in its goals, (but who do not mobilize resources for the movements.) On one level, it is the task of resource mobilization to convert adherents into constituents, to maintain constituent involvement or to convert non-adherents into adherents. Such non-adherents would tend to be what Turner (1970) called the, 'bystander public', that is neutral individuals, completely uninvolved with the SM. Together with the aforementioned categories of individual, 'opponents' control very limited resource pools, for which there is competition. 'Elites' control larger resource pools and are therefore crucial to some aspects of resource mobilization by an SMO. McCarthy and Zald (1977) made several hypotheses regarding these constituencies in relation to social movement organization.

1) "Regardless of the resources available to potential beneficiary adherents, the larger the amount of resource available to conscience adherents the more likely is the development of SMOs and SMIs that respond to preferences for change," (p.1225).

2) "The more an SMO is dependent upon isolated constituents, the less stable will be the flow of resources to the SMO," (p.1228).

3) "An SMO which attempts to link both conscience and beneficiary constituents to the organization through federated

chapter structures, and hence solidarity incentives, is likely to have high levels of tension and conflict," (p.1231).

4) "The more an SMO is funded by isolated constituents, the more likely that beneficiary constituent workers are recruited for strategic purposes rather than for organizational work" (p.1235), (eg. mentally handicapped children collecting money in the street, or miners' funds collectors).

5) "The more an SMO is made up of workers with discretionary time at their disposal, the more readily it can develop transitory teams," (p.1236).

Predictably there are various constraints on the use of resources, often depending upon their source. It is important to acknowledge the existence of a constraining 'filter' between a resource and SMOs. Such a filter can totally redirect the resources of a movement. SMOs deal with filtered resources, not the raw product.

Discussing mobilization and tactics in contemporary movements, in particular the Feminist Movement, Jo Freeman (1979) suggests that pre-movement experiences and preferences, and personal situations, as constraints, shape tactical choice and may also affect the kind of resources readily at hand in the daily round of the constituents, producing a tactical opportunity for one movement organization not available to another. Thus some constraints in one situation could facilitate resource mobilization for others in another context.

Oberschall (1973) says that risk-reward or cost-incentive

considerations are central to an understanding of mobilization. At each stage the cost-reward balance for members and leaders is crucial to any explanation. It is not hard to imagine such considerations producing constraints on resource mobilization.

McCarthy and Zald (1974) mentioned five categories of constraint:

- 1) Values (Turner, 1970)
- 2) Past Experiences
- 3) Reference Groups
- 4) Expectations
- 5) Relations with Target groups (Turner, 1970)

Turning to the SMO structure, there are various factors which will influence strategic options. Whether it is; inclusive/exclusive, centralized/decentralized, isolated/interacting with the social system, will all affect the efficiency and manner of resource use. Leadership and the decision making structure is a key strategic concern and will influence the extent to which resources are directed towards group maintenance needs or goal attainment.

A less common model in the literature, although possibly more common in reality, is the model of a decentralized, segmented, reticulate movement with no real centre, or at best a simple division of labour (Gerlach and Hine, 1970).

Problems tend to arise when a movement attempts to pursue

strategies for which their structures are inappropriate; hence, structure and internal organization is seen to both facilitate and to constrain resource mobilization.

Zald and Ash (1966) claim that the most viable movement is one with several organizations that can play different roles and pursue different strategic possibilities. Thus the growth, development and demise of a movement is not the same as that of the individual organizations within it.

Arguably one of the main strengths of the RM perspective is its emphasis on the external influences on movement strategy and activity. Such external factors include both other SMOs, in a network of cooperating-competing organizations, and the authorities and agents of social control. Relating more specifically to the larger society, this provides the infrastructure used by SMIs. Aspects utilized include the communication media, levels of affluence, degree of access to institutional centres, pre-existing networks and occupational structure, etc.

By use of the media a movement can potentially activate reference publics and elites who control resources. This can produce a response from the authorities, depending upon the extent to which the relevant resources are of interest to those authorities.

In societies where movement success in mobilizing resources and affecting the authorities depends to some extent on arousing

constituencies through the media, "issue attention" cycles (Downs, 1972) become the predictor of movement and organization success. More competition from alternative issues increases the likelihood that movements' allocation of resources is towards maintaining audiences and movements have a diminishing ability to sustain continued support.

Harvey Molotch in, "Media and Movements" (1979) discusses the extent to which the media can shape a movement. From a class perspective he sees the media in the hands of a ruling, though not unified, elite. The resulting agenda and images of movement activity is shaped less by the actors than by the media's judgement of, "newsworthiness." This represents a complex mixture of political and social values and competitive desires to reach and hold audiences.

The control of movements is, or can be, significantly dependent upon regime structure. From the support of liberty in totalitarian regimes to the fostering of 'War on Poverty' in the Johnson administration in the USA, Gamson's "Power and Discontent" (1968) brought the relations of the authorities and partisans to the centre stage. Tilly (1978) supporting this approach says that structure and the response of a regime and its institutions, are central to social movement life in society.

As Schattschneider (1960) stated, institutional responses to SMS are not often impartial, thus sometimes an SMOs success is due to its ingenuity to effect pressure, creating new avenues for action, and/or substituting abundant resources for sparse ones.

An intimate knowledge of the workings of the political system may negate the need for some of the above.

A sometimes neglected facet of external influence on a movement is the potential benefit of having a solid opposition, that is the unity of the group can be enhanced by such an opposition. It is the perceived, not real opposition which is important for a viable, active organization, although no simple relationship exists.

SOMs expectations regarding external factors, eg. the attitudes of potential target groups and the response of the bystander public will provide a base for SOM plans. Such expectations are derived from pre-movement experiences and from cognate groups. When action is initiated direct feedback is very relevant to future actions although McCarthy and Zald suggest that there is often repetition of successful actions without reference to the reasons for the original success.

Thus it seems that SOMs' potential for RM is affected by authorities and agents of social control. Choices of the SOMs are also constrained by factors such as the pre-existing organization of various segments of the SM, size and diversity of the SMI of which it is a part and the competitive position of the SMS (Zald and McCarthy, 1974). Other external factors include war, broad economic trends, natural disasters, etc.

The RM model outlined here emphasises the interaction between resource availability, the pre-existing organization of

relevant structures and entrepreneurial attempts to meet relevant demands.

At this stage the application of the RM perspective to the modern Hospice Movement is introduced.

Resource Mobilization provides a useful way of looking at the setting up of hospice projects. Yet it is pertinent to go beyond it, revealing other necessary factors and discovering the possible implications of such an organizational emphasis, which might be seen to detract from the original concepts and philosophy of hospice.

Work in the USA on their hospice movement has shown a grave concern among some that the imperatives of financial shortage is producing a change of emphasis toward economic rationalization, bureaucratization and professionalization, and away from the human, spiritual, religious concerns of the founding members and their philosophy, (Abel,1986; Paradis,1984).

Is this trend evident in our domestic hospice programs? How far are volunteers still an important/vital part of such projects? Such questions relate to the wider issues involved in the possible divergence between a relatively impersonal preoccupation with the mobilization of resources and the beliefs of movement members concerning the nature of death and the quality of dying and the necessity for action to ensure what they regard as a better way of dying.

CHAPTER THREE

SOCIETAL ATTITUDES TO DEATH

The current tendency in literature concerning changing attitudes to death appears to show an unquestioning acceptance of the notion of the modern 'denial of death.' (DeSpelder and Strickland, 1983). Much of the work quoted originated from the work of the French social historian, Philippe Aries (Western Attitudes towards Death: From the Middle Ages to the Present, 1974). His formulation of forbidden death being the last stage in a sequence of changing attitudes to death in Western Society, has provided an easily acceptable account of what Aries, and others (F. Borkenan, The Concept of Death, in Death and Identity ed. R. Fulton, 1965, p.42) see as the essential denial of death.

It does not seem unreasonable to wonder whether in fact authors in this area, armed with the neat concept of a death denying society, suffer from some form of confirmatory bias in their subsequent appraisal of death in the western world. A description of our society, a society which provides a multitude of often contradictory indicators as to its attitudes to death, defies a single, simple descriptive label, nevermind an explanation. We do not face death in a single form; death manifests itself in old aged senility, the end of agonizing illness, sudden unexpected heart attack, death of a child,

accidents, murder, suicide, war, to name but a few of the almost limitless possibilities. It might be said that there are as many different ways of death as there are ways of life.

To investigate and clarify any existing patterns in our attitudes to death, it is valuable to look at some of the literature pertaining both to western society's historical treatment of death, and to the attitudes toward death in diverse cultural situations. The latter might be important, not only for straightforward comparative purposes, but because, whether we like it or not, English society is not culturally homogenous. We are not free from alien influence, and certain sections of what might be called the 'normal' indigenious English, those with liberal or 'left wing' attitudes towards assimilation and incorporation of immigrant cultures, would stress that this process of becoming more cosmopolitan, a multicultural society, is not a move away from 'the' English attitude, rather it is a development or modification of an essentially negotiable English attitude.

Much of the existing literature on death has come out of America, and concerns the changes in that society. Although possibly not wholly generalizable, the trends noted do appear to be of relevance to the processes which have occured in England.

Accepting that death is an inevitable aspect of existence and that one's death and attitudes towards it must in some respects reflect one's life, then it becomes obvious that attitudes to death have varied due to differences in life styles

throughout history. The perceptions of pre-industrial man presumably differed from those of industrial man. The only evidence we have of early man is in the form of physical artifacts, together possibly with vaguely comparable primitive societies still in existence. Thus ascertaining their attitudes to death is necessarily somewhat speculative and our view of their attitudes may reveal as much of our way of thinking as it does of the hopes, fears and beliefs of earlier men.

Early man is said to have viewed death not as a "permanent termination of existence," (Manning, 1984, p.19), rather as a tangible transition from one stage to another. Van Gennep, the Belgian anthropologist coined the phrase, 'rites de passage,' which is much used to describe this progression from stage to stage; birth, puberty, marriage and death were ritualized in the life of early man, each representing the passing from one mode of existence to another. Thus there was a belief in some form of life after death. Malinowski saw the essential significance of religion in the courage it provided for men to face not only the world, but also, particularly, the inevitability of death.

Thus in some sense, early man is thought to have regarded life as purposive, ordered and even controlled. Many cultures, according to Beattie(1964), included in their world view a notion of intentionality, which applied equally in death as in life. This can be contrasted with modern Western law, which distinguishes between intentional death, for example murder and suicide, and unintended or accidental death. The idea of an ordered universe, imbued with intention, characterized the

medieval cosmological conception of man set in his place in the world, fitting into the eternal structure, over which God presided.

That, "primitive man saw death as an intrinsic component of life," might well be true, but to say that he, "thought very little about his individual demise," Manning, 1984, p.19) is not so obvious. To all outward appearances an old woman of the Siriono, a semi-nomadic Bolivian Forest tribe, left to die of hunger as she has outgrown her usefulness (Hohnberg in "Old Age" de Beauvoir, 1972) might be as questioning regarding death as an aged relative dumped in a modern English Old Peoples' Home. Both can physically surrender to their fate, accept it, to all intents and purposes, but to suggest that it neither preoccupies nor concerns them, is to go beyond the evidence, in a manner that denies to the more primitive, the capacity for reflection about their existence. So while some form of anthropological observation might be legitimate, caution is needed in the formulation of the psychological states of historical primitives. What can be said, though, is that there was an almost universal belief in some form of continued existence, after death. From the Egyptians to the great Eastern religions, this is the case.

Turning more specifically to the Western tradition, the most widely cited views are those of Aries (1976). A brief survey of the chronological scheme he presents, demonstrates neatly how he sees the 'death denying' society coming about.

Aries' notion of "Tamed Death" extends from the sixth to the

nineteenth century, and can be divided into three distinct periods. The first of these periods is the early Middle Ages, during which death was accepted as a part of human existence. This was generally consistent with the belief of a natural and divine law binding the universe, with death being part of this overall design. Church teaching led to a hope in the after life. The sense of a collective destiny is subsumed by Aries under the descriptive slogan, "All people die." During this phase of western development, death is seen as a ritual organized by the dying person and presided over by him, knowing its protocol. Dying and death are public ceremonies and there is a simplicity with which the rituals are performed. Reminiscent of this is Solzhenitsyn's passage in "Cancer Ward." Yefrern remembered the old folk, "took death calmly ... and they departed easily, as if they were just moving into a new house," (A. Solzhenitsyn, Cancer Ward, N.Y. 1969, pp. 96-97). There was at this time a co-existence of the living and the dead. Cemeteries, which afforded asylum and refuge, in the church and churchyard, were still public places.

Aries second Tamed Death stage is known as, "One's Own Death." The new phenomenon was the introduction of individuality to the individual's death. In support of this change, which occurred around the twelfth century, Aries gives four pieces of evidence. The portrayal of the Last Judgement at the end of the world involves the Book of Life, Liber Vitae, now as an individual account book or balance sheet, rather than the previous conception of it, "as a cosmic book, the formidable census of the universe," (Aries, 1976, p.32). This judgement was

displaced to the end of each life, to the precise moment of death. Macabre themes were prevalent together with an interest in portrayals of physical decomposition. Finally, a return to funeral inscriptions and personalization of tombs, indicates the ascendance of the importance of the individual in death.

By the fourteenth and fifteenth centuries there was an increasingly close relationship between death and the biography of each individual life. Possibly it is from here that the idea of one's life flashing before one's eyes at the moment of death, originates. It was believed that a man's attitude at that moment would provide his biography with its concluding meaning. Therefore by the end of the Middle Ages, death had dramatic significance together with an emotional burden which it previously lacked. Thus, the role played by the dying man was strengthened. "Death became the occurrence when man was most able to reach an awareness of himself," (Aries, 1974, p.46).

La Mort de Toi, "Thy Death", is said by Aries to constitute the final stage of "Tamed Death." From the beginning of the eighteenth century there was much more concern, evidently, with the death of others. The Romantic era saw death exalted and dramatized. Mahler, Dickinson and Shelley described death as the Ultimate Lover, "the pinnacle of perfection and beauty," (Manning, 1984, p.20) the transformation of the flawed, imperfect physical into a sublime spiritual existence. The idea of romantic death was seen in the works of Lamartine, the Bronte Sisters and Mark Twain. Increasingly, it seems, passionate expressions of sorrow and grief accompanied bereavement compared

with the early Middle Ages; "mourning was unfurled with an uncustomary degree of ostentation," (Aries, 1974, p.67). There appeared to be a new intolerance with the separation involved in death. The memorialization of death was linked to the appeal of "beautiful death," involving the heroic and mysterious. "The sad beauty of death elicited feelings of melancholy, tinged with optimism that there would be an eventual reunion of the family in a Heavenly home," (DeSpelder and Strickland, 1983, p.57).

Together with an increase in the visibility of mourning came a secularization of the legal aspects of death. The will was transformed from the religious testament containing pious clauses into a document for the distribution of the deceased's worldly fortune. Vovelle's thesis (*Piété baroque et déchristianisation*, Paris, 1973) is that this was a sign of the de-Christianization of society, whereas Aries (1974) claims that it represents a new trust and closeness in families - powers were delegated to surviving members which were formerly jealously exercised.

Whether this change heralded the first rumblings of a secular break with traditional beliefs, the idea of a corporate salvation lived on. Yet, by way of an apparent contradiction "by our modern view, 18th century preparation for death is a highly individual matter, a lonely preparation for the lonliest journey," (McManners, *Death and the Enlightenment*, 1981, p.64). Such diverse reports of the nature of death suggests that caution is needed in attempting to generalize about the attitudes to death of a variety of cultures over many score years. The problems evident in generalizing about contemporary attitudes to

death apply to earlier periods, when the records of everyday attitudes are less than satisfactory.

Sometime during the second half of the nineteenth century, Ariès perceives a dramatic change from "Tamed Death," to "Forbidden Death." The antecedents of this can be seen in the increasing concern for the death of others. This trend developed to the extent that it was felt necessary to spare the dying and to hide them from their condition. Possibly the challenge to orthodox Christian beliefs, seen to come from science and the, "general unsettling of minds," caused to some extent by the popularization of Darwinian theory prompted some to question the assumption of an afterlife and hence a more worldly preoccupation involved a fear of death. Related to this might have been the revulsion increasingly felt towards the ugliness of decay and dying, for this was hardly in keeping with the spirit of progress and development, not only of the individual, in terms of a notion of evolution, but also in terms of the social Darwinism of Herbert Spencer together with a colonizing, expansionist zeal - the creation of an empire upon which the sun never set.

Such a general synopsis might appear to be a neat, rounded explanation for certain attitudes, but like much of the work done, it ignores, due to lack of information, the views, whatever they may have been, of the vast majority of the population. The only relevant census from this period, the Church Survey of 1851, showed that even then, only half the population attended Church. The new urban industrial working class, living in squalor and extreme deprivation, were an untapped resource; their attitudes

were not recorded. Did the privations of city life drastically change the working man's view of death compared with the slog of a rural life at the mercy of the weather, poverty and what was, to all intents and purposes a feudal system? Aries has described the romantic era and the glorification of the idealized death - who is he describing? "Disease was rampant and unchecked; smallpox, typhus, typhoid, and dysentery made death common place," (Plumb, 1950, p.12) These are hardly conducive to a glamorous death. Plumb continues to quote a contemporary description from 1721, of the parish disposal of paupers' corpses in Manchester;

"They dig in the churchyards, or other annexed burial places, large holes or pits in which they put many of the bodies of those whose friends are not able to pay for better graves; and then those pits or holes (called the Poor's Holes), once opened, are not covered till filled with such dead bodies... How noisome the stench is that arise from these holes so stowed with dead bodies, especially in sultry seasons and after rain, one may appeal to all who approach them," (quoted in England in the 18th Century (1714-1815), T.H. Plumb, 1950, p. 12-13).

This is about as romantic as the fact that at the same time only about three children in four, born in London, survived, and it is likely that the infant mortality rate was higher in the new industrial northern towns. Plumb writes, "In the midst of death, the people sought palliatives and found them in drink, gambling and violence," (Plumb, 1950, p.13). This is a far cry from a relative handful of poets and associated literati, waxing lyrical about the beauty of death.

It is hard to avoid the conclusion that such depictions of attitudes to death, given now, to represent 'an age' are at their very best, a gross misrepresentation of what was happening - death has been retrospectively sanitized. Being less charitable, such versions of contemporary attitudes constitute a false, though well-established, historical stance, based not only in ignorance, but also it might be suspected, in an attempt, for whatever reason, to present the past as some sort of Golden Age, the halcyon days of a natural order in which man's position was somehow comprehensible and honourable.

Thus although it seems reasonable to question the validity of certain widely cited generalizations regarding attitudes to death, one change that is much less disputable is the shift from death in and with the family to death removed from the home into the care of 'professionals', clergymen, doctors, and undertakers. Aries claims that the, "brutal revolution in traditional ideas and feelings," (1974, p.85) occurred first in the USA and moved to England and into industrialized Europe. Patterns of death in nineteenth century America were very much rooted in the family and the home, where death often occurred. The family washed and prepared the body and either they or a local carpenter made the coffin, which was set in the parlour of the home, for friends and relatives to view the body and to partake in the rituals of mourning. Children as well as adults were involved. A simple ceremony at the local cemetery, with several verses from the Bible read by the local parson was followed by the grave being filled in by the family. "Each person learned about death

firsthand. From caring for the dying family member through disposition of the corpse, death was within the realm of the family." (DeSpelder and Strickland, 1983, p.6-7). Such practice is echoed in D.H. Lawrence's depiction of death in a northern English mining community in the early part of the twentieth century, in his short story, "Odour of Chrysanthemums" (1911). As might be expected this direct experience with death was the norm throughout earlier European history. In eighteenth century France, "death was at the centre of life as the graveyard was at the centre of the village," (McManners, 1981, p.76). This author gives some idea of the scale of experienced death in eighteenth century France. The national averages concerning infant mortality showed around a quarter of babies born in the early years of the century, died in their first year and another quarter before they were eight. Of one thousand people only two hundred would reach the age of fifty years and only one hundred would reach the Biblically allotted span of seventy years, an age which is about equal to the average age of death in many Western European countries today. A man who had reached fifty would probably have seen his parents die, buried half his children and probably his wife, together with numerous uncles, aunts, cousins, nephews, nieces, and friends.

Referring back to the issue of modern western denial of death, it appears that in the place of this over-generalized, over-simplified misleading description of the modern attitude to death, various component factors, making up various contemporary attitudes to death, can be identified. Among these, there are several influences, lessening our familiarity with death.

In North America, where the so called "brutal revolution" (Aries, 1974, p.85) in attitudes to death occurred, a brief look at the life expectancy and mortality rates demonstrates why death has become less immediate in modern life. Since 1900, the average life expectancy has increased from forty seven to seventy three years. The differences between white and black expectancy has been significantly reduced and death in childhood is only about a tenth as likely as it was at the turn of the century. The factors involved in this decreased mortality rate include better care of mother and babies during and after pregnancy, together with a drastic reduction in the prevalence of whooping cough, diphtheria and polio.

Geographical mobility together with the changed composition of families has lessened first hand experience of death. The modern nuclear family is distanced from those members closest to death, the old, relative to the extended family of the earlier years of the century. Family and friends no longer necessarily remain in close proximity throughout their life times. Changes in educational availability and employment necessitate moving home. In this way families are often separated and first hand experience of family deaths is much less common than it once was. It might even be suggested that such separations constitute, "litte deaths" (Manning, 1984, p.23), which may lessen the impact of the death of a family member or friend.

Increasingly both the old and young, have as goals the attainment of some form of independent living, a home of one's

own. Housing developments sometimes reflect this desire, and estates are marketed in such a way as to appeal to young first time buyers, or a secluded little close may be aimed at attracting those of retirement age, to a peaceful little dwelling of their own (Eastbourne, Bournemouth, etc.) Thus there is reduced contact among generations. A possibly more ominous trend contributing to familial disintegration, is the success of nursing homes and old peoples' homes in luring many of the elderly, or their families, to see these institutions as an easy alternative. Many of these are run solely on commercial profit-making grounds, and the impression gained of some is that they represent unofficial, long-term 'hospices.' Even those old people who have lived most of their lives close to their families often end up through illness and infirmity, in hospital which is, "followed by death in an institutional setting," (DeSpelders and Strickland, 1983, p.13).

Thus death has, on the whole, been displaced from the home. Institutionalization of death and care of the dying has made everyday dying less visible. By the middle years of this century statistics from the U.S.A. showed that the proportion of deaths in institutions appeared to be rising by over one percent per annum. (M. Lerner, in "The Dying Patient, Ed. O.G. Brim, 1970). Still taking the U.S.A. as indicative of Western European trends, DeSpelder and Strickland (1983) state that, "most urban deaths, as many as ninety percent, now occur in institutional settings." Less than one hundred years ago most westerners died in their own homes, even in the cities around three quarters of deaths occurred in the home.

Related to this type of dying is what Knutson (1972) calls the shift in the patterns of mortality and morbidity, from acute infectious diseases to chronic disorders and slow patterns of dying. Heart disease and malignant neoplasms (cancer) accounted for 37.8% and 20.6% of all American deaths in 1978, (U.S. National Center for Health Statistics). As the course of such diseases is charted and increasingly accurate prognosis made, the treatment and care of patients has moved to the locations where relevant techniques of cure and delay are situated. Despite cut backs in Britain, in NHS funding, hospitals still offer many more resources for such conditions than can be found in an individual's home. Even those individuals who survive heart disease and cancer, tend only to live on into older age, where their lives become isolated from the younger portions of society, and thus their deaths tend to be invisible.

Illness, aging and dying have become institutionalized, "partly in response to the sheer numbers of patients requiring medical care and partly as a reflection of a social context which promoted health as a reflection of the good life," (Manning, 1984, p.21). Aries would claim that much of the concern surrounding dying lies with the ease with which the survivors can make the event tolerable. As the initiative, according to his progression, has shifted from the dying person, to the family, and finally on to 'professionals', there is a need to avoid, "the embarrassingly graceless dying," (Aries, 1974, p.90) which invariably involved too strong an emotion. Such emotions must be withheld in public. It should be added that it is only the

intensely negative emotions of grief that are frowned upon, hence a solitary and almost shameful mourning is the only recourse - this is likened, by Gorer (1965) to a form of masturbation. Nevertheless, people may be expected to cry at funerals. This suggests that such generalizations are of limited usefulness.

Inevitably the question must be asked, why has this aversion to the public face of dying and bereavement, as experienced by the ordinary person, occurred? Aries (1974) talks of, "an new sentiment characteristic of modernity,"(p.87). This relates to a form of hedonism, the urge towards undisturbed happiness which allows no place for strong, unbearable emotion and the ugliness of dying amidst a happy life. It is possible that compared with the vast majority of history when life was hard, and it is not difficult to imagine that death could be seen as some sort of release, life is now, for many, significantly easier, and possibly there is a reluctance to 'let go' of what one has. The increasingly secular nature of society together with a materialism (Lamerton, 1981), in the widest sense, appear related to this phenomenon. By materialism is meant not only the consumerism of a world of widely available material goods but also the emphasis on body image, what might be called the cult of the body. We live in a young, fitness and beauty oriented society. The preoccupation with the maintenance of youthful, exciting life, necessitating a concern with immediate, worldly affairs can easily be seen to promote a reluctance, if not positive aversion to the inevitable processes of decay, degeneration and eventually death. But examples can be seen from much earlier societies where the emphasis was upon youth and

vigour. Jokes were made in ancient Greek society of those older men who frequented the gymnasias to watch and to envy their youthful counterparts exercising in a way of which they were no longer capable, (Carlton, 1987). And yet then, as now, such a system of values must be regarded as essentially flawed; it demonstrated a wholly unrealistic approach to life, an unhealthy clamouring to make permanent that which is necessarily transitory. Thus it is that Gorer (The Pornography of Death, 1955) refers to an interdiction, forbidding death, the causes of which include the need for happiness, the moral duty and social obligation to contribute to the collective happiness, in order to avoid boredom and sadness. To show sadness is to sin against happiness and by threatening pleasure society risks losing its raison d'etre.

This shift in emphasis in our society could be described as a symptom of what Sorokin calls the 'sensate' phase in societal development, or rather decline. This is the phase of complaisance and settling back to enjoy that which was attained during the 'ideational' phase of enterprise, industry and innovation, a time of progress and achievement. (P. Sorokin, 'Cultural and Social Dynamics, 1937). Whether or not this model is entirely applicable is uncertain, but it provides an interesting tool for potentially revealing speculation.

Together with this hedonistic materialism is another process which can be identified, and might well be considered to be inextricably linked with more general themes of institutionalization and preoccupation with worldly concerns.

This process involves the technologization and medicalization of death. With the advent of increasingly complex technology designed to prolong life has come the unwillingness to treat death as an acceptable and tolerable part of medical life, (Lamerton, 1981). Biomedical science includes the use of computers in, for example, physiological monitoring and also diagnostic and therapeutic procedures, imaging systems such as the, "computerized axial tomographic," scanners which enable every section of the human body to be visually probed, together with countless other applications, including the most directly relevant, 'life-support machines.' "Coupled with the ethical maxim that whatever can be done should be done to keep an individual alive," (DeSpelder and Strickland, 1983, p.18) these technological advances have not only lessened direct contact with death, outside a highly specialized institutional setting, but they often seem concerned solely to preserve what might be called biological life, heedless of whether perhaps the time has come for an individual to die. Death has been turned over to specialists, who, up until the point of death often attempt all they can to preserve life, at all costs, often only prolonging dying.

Within the majority of medical institutions, there would appear to be an ethos of, 'death as failure.' Medicine is almost always viewed as life-extending, it is cure-oriented, without adequate concepts, let alone facilities, for those embarrassing failures who do not conform. The Medical Model, as described by Baldwin (1985), places high value on the concept of the, "integrity of the organism," in relation to its total functioning

and adjustment. Death and dying does not readily fit into such a scheme. The socially acceptable, "sick role" identified by Talcott Parsons in the 1950s is not accompanied by an equally well defined, "dying role." "If the dying person does not exhibit this cheerful will to live, friends and family (together with the attendant specialists) may feel angry or rejected," (DeSpelder and Strickland, 1983, p.125). Thus for both patient and medical institution alike, death poses more problems that may be necessary.

But to regard the attitude of, 'death as failure' as simply part of the modern, secular, materialistic 'death denying' culture, if that is what it is, is to ignore the examples of other cultures, which illustrate clearly the connection between death and failure, in vastly different social contexts.

Within the Thonga, Bantu settled in arid country on the East African coast, the aged are little respected, have no economic resources and inspire almost no affection. The collective neglect of the elderly and dying is directly related to their failure to cope with worldly demands. Simmons, in his, "The Role of the Aged in Primitive Society," (1945), claimed that out of thirty nine tribes studied regarding neglect and abandonment of the old, it was usual in eighteen, and not only among the nomadic. Yet, even though death is viewed as a failure to meet the demand of everyday, communal life, it is still seen as inevitable, and rather than being villified, the dying are sometimes treated very well, on this, their last journey. The Hottentot possess a respect for their old with their valuable

knowledge and advice, and most importantly as they preside over the rites de passage within the group. Yet, before 1900, the old would be neglected once the loss of their faculties rendered them useless. Their sons would ask for permission to get rid of them, which was always granted. The sons would provide a feast for the village and everyone would say goodbye to the elderly person before they were removed to a remote hut and left to die of hunger or to be killed by wild beasts, (S. de Beauvoir, "Old Age" 1972).

If it is the case that, "In all societies... the issue of death throws into relief the most important cultural values by which people live their lives and evaluate their experiences," (Huntingdon and Metcalf, 1979, p.2, quoted in Garland, "The Greek Way of Death" 1985, p.xi), then the character of western societies in general cannot easily be categorized as, "death denying" as death is treated openly and widely in a number of diverse forms. It is misleading and incorrect to suggest that we deny death; rather the presentation of death in everyday life should be regarded and used in an assessment of societal attitudes to death.

The language used about death, although in certain circumstances, euphemistic, does not necessarily involve a denial of death. DeSpelder and Strickland (1983) provide a list of over sixty euphemisms used about death. Yet amongst these supposedly "mild, indirect or vague expressions," terms such as, "annihilated," and "liquidated," seem to be a long way from, "resting in peace," and "on the other side." Such a diversity in

terms suggests that rather than there being one common attitude of denial there are various attitudes to death which are manifested differently in different situations. It would seem understandable that Amy Vanderbilt's advice that words such as "death", "died", or "killed" should be avoided in letters of condolences ("Amy Vanderbilt's Complete Book of Etiquette, 1959) where the bereaved recipients will invariably be faced with a shocking and saddening major life event, compared with a soldier referring to the death of another in battle, as his friend having been, "wasted." The use of language to ease the pain of death does not readily support the notion of a prevailing attitude of denial, rather it often seems to reflect the context of usage, the attitude towards the deceased, previous socialization, including religious teaching, and the extent of the user's vocabulary, among other things.

Death-related humour and the response to it are as varied as the types of death known to that society. From a mild black comedy which may be almost universally enjoyed, to a modern 'alternative' comedian's treatment of death, which to many may appear to be in very bad taste, death is acknowledged. Whether or not the humour reveals or reflects some underlying anxieties about death, and represents a form of coping mechanism for either the individual or a collectivity, it would appear that the most that can be concluded from this is that death is a perennial concern, which invades even those areas of life in which it may seem most incongruous.

Due to the large scale removal of death from our firsthand

experiences, media sources provide us with a vicarious experience of death. Such coverage of death reveals certain patterns and priorities in our treatment of death.

As often as not, newspaper, radio and television headlines pertain directly or indirectly to death. From great natural disasters, such as an earthquake in Mexico, to the rampage of a crazed gunman in an otherwise sleepy rural town, the deaths involved tend not to be of an everyday nature, and understandably so. Mass death, spectacular death, unusual or inexplicable death and death of the famous, are all totally newsworthy. Thomas, in "The Last Dance", (1983) describes how unrepresentative such media coverage is. The deaths of around fifty million people annually is not particularly newsworthy - firstly it is not practical to report in depth each individual death and secondly it would be virtually meaningless to read of these deaths, for the vast majority of people. The priorities in our own press, for example, are clearly demonstrated in a comparison of the daily obituary columns, an alphabetical listing of vital statistics, "as uniform as a row of tiny grave plots (Kastenbaum, "Death, Society and Human Experience," 1981, p.93) with the banner headlines accompanying the death of the famous.

Although the media may mould and reflect attitudes to death, there is sometimes disharmony between the presentation and the audience response. For example an Ontario newspaper showed a picture of a distraught mother at the moment of learning of her daughter's fatal injuries. An outraged public described the picture as "a blatant example of morbid ludicrousness," and, "the

highest order of poor taste and insensitivity," ("News Photographer, 36:3, March, 1981, p.22). It might be, as has been suggested, that the onlooker can "ascribe emotions to the grief-stricken that are not really present," (Huffman, "Putting Grief in Perspective," 1981), but the media's insistent emphasis on the dramatic raises issues of its ethical integrity (Huffman, 1981). These occurrences indicate that attitudes pertaining to what is acceptable in death vary and thus the attempt to encapsulate societies' death-responses in a single slogan is necessarily limited in its potential usefulness.

The media's selectivity is not its only contribution to the everyday presentation of death. Michael Arlen (1976) noted its, "detached and caption like quality," resulting in, "snippets of information," about reported deaths, ("The Cold, Bright Charms of Immortality" from *The View from Highway 1*, 1976, p.34-68). News of mass death from starvation in Ethiopia might be interposed between coverage of a royal visit to the Bahamas and the closing novelty item about a skateboarding duck.

Increasingly, though, there are occasions, most notably involving the death of a particularly prominent individual, for example Martin Luther King, Jr., when the media reflects the, "myriad expressions of grief, incomprehension, and deep human response," (Arlen, 1976, p.50) presenting both the private and public faces of death and bereavement. It might be said that in these cases the media plays a central role in what is essentially, a "national rite de passage," (DeSpelder and Strickland, 1983, p.23).

Moving from the news to entertainment provided through the media, which increasingly involves home viewing of recent film releases on video, death is far from uncommon as an integral part of entertainment. A glance through the television magazines shows that in any one week there may be several programs which include death in some form. The vast majority of deaths portrayed may not realistically reflect the experiences of the population, few people are shot by police in an attempted bank robbery or are blown up as their car hurtles off a cliff into the sea, but this merely suggests that rather than our society denying death, for the purposes of entertainment, it transforms it. The transformation often involves depicting death in a form which is remote from daily death in our hospitals. This distancing of death might be regarded as a depersonalization of the image of death and thus a means of portraying an entertaining often exciting death in an easily copable way. And although death may be somewhat glamorized and spectacularized this does not preclude the expression of emotion, both on screen or stage, or in the response of the audience. The same arguments may be made about the portrayal of sex in the media. Often the sex portrayed is not of an everyday nature, from the proverbial amorous milkman seducing the vicar's wife, in any tabloid, to James Bond's repeated conquests of exotic foreign spies, the image of sex is presumably not representative of the experiences of the vast majority of the population. But this does not imply that, as a society, we forbid or deny sex, just as we do not, as a society, forbid or deny death. The term, "the permissive society," could equally include the manifestations of death as

well as sex, with which we are presented. Possibly there is a case for a retransformation of both of these, into something more than their current status in much popular film and literature which presents them as casually offered 'cheap thrills.' The problem with this, for the purveyors of packaged sex and death, is that the mundane everyday reality is not as commercially viable.

In conclusion, it appears that it is inaccurate to describe our society, simply, as death denying. The formulation of grand historical theories about western attitudes to death has been shown to be problematic, especially with regard to a lack of representativeness among those who presumably held such attitudes to death. What can be clearly seen is that in the twentieth century, western man has become increasingly distanced from firsthand experience of death. The factors in this decreasing familiarity with death include changing life expectancies and mortality rates, geographical mobility together with changing family structures. Death has become increasingly institutionalized; from dying through to burial, 'professionals' have replaced family and friends in those roles and functions closest to death. The medicalization of death and dying, with the advent of advanced life-prolonging technology and an ethos of 'death as failure' have also contributed to the decreasing visibility of death in everyday life.

Societal indicators of current attitudes to death, including language, humour, the news, media and entertainment seem to indicate not a denial of death, but rather a trivialization and

transformation of death. Visible death tends to be unrepresentative of common experience, it is violent, inexplicable, spectacular, glamorous, or the death of the famous. These packaged portrayals of death seem to be related to the materialistic hedonism of modern western society, where the mundane lives and deaths of everyman are transformed and dramatized, thus distancing them from reality and presenting few awkward questions regarding the individual's imminent demise.

Paz claimed that, "a society that denies death ends by denying life," (Octorio Paz, "The Labryinth of Solitude: Life and Thought in Mexico," 1961 ,p.60). An amended version may be more apt for modern western society; "A society that transforms death, ends by transforming life."

CHAPTER FOUR

HOSPICE PHILOSOPHY AND INDIVIDUAL ATTITUDES TO DEATH

'Hospice Philosophy' can be understood on two levels. The first is philosophy as practice, that is those activities which make up a stereotypical hospice institution, which give it its peculiar character and distinguish it from other methods of terminal care. These hospice practices range from pain control and alleviation, to an emphasis on communication, caring as opposed to curing, education, and bereavement counselling. The second level on which 'hospice philosophy' can be understood is in terms of the complex of attitudes and beliefs which underlies the hospice practices. Although the emphasis appears to be upon increasing the level of personal autonomy in death, the hospice concept goes beyond this, and often involves a prescription for the type of death and dying which is favoured. In their own terms, "they offer a 'good death' to anyone willing to reach out and ask for it," (Manning, 1984, p.32).

This chapter will include a relatively brief account of the hospice philosophy as practice, but will concentrate upon the more fundamental beliefs which have moulded the form of hospice practice.

The proliferation in hospice institutions over a relatively short period, has been explained by Corless (1985) in terms of,

"the intrinsic appeal of providing care when, 'nothing more can be done'," (Corless, 'Nursing Clinics of North America, Vo. 20, June, 1985, p.282). Implicit within this is the apparent contradiction that by doing less for the patient, doing less is actually doing more. In contrast with intensive technology, hospice practice offers intensive care.

Dame (Dr.) Cicily Saunders at St. Christopher's Hospice, London, set out to identify the priorities in terminal care, which she felt were neglected in hospitals. As in the existing facilities for the dying, the judgement and knowledge of doctors were invaluable for the alleviation of symptoms and the control of chronic pain. The hospice priority of the alleviation of pain, vomiting, constipation and breathlessness, was recognized within the context of imminent death and accompanied by an attempt to cater for the emotional, psychological and spiritual aspects of the patient. It is only by a release from the unpleasantness of their physical condition that patients can begin to make the most of the time left to them. The emphasis is upon removing the physical distractions inherent in dying so as to enable the patient to achieve some form of existence satisfactory to him. Thus the priority is, "effective and holistic pain control," (Manning, 1984, p.47). The emphasis on holistic care is particularly pertinent to any comparison between hospital and hospice care. The proponents of hospice care stress that human life is more than, "a breathing lung and beating heart," (Rossman, P. "Hospice: Creating New Models for the Terminally Ill." Fawcett Columbine, N.Y., 1977, p.30). Thus a variety of professionals are needed in a hospice; nurses,

chaplains, social workers, dieticians and even occupational therapists. These specialists constitute part of the health-care team, the establishment and maintenance of which is another hospice priority. The patient and his family represent the other essential element of the health care team. The emphasis within this structure is upon an unhindered flow of information and involvement. The emotional investment runs directly counter to many orthodox hospital systems where doctors and nurses are encouraged or even instructed, not to become involved with the patient. "Involvement is the very essence of hospice care; without it only a hollow shell remains," (Manning, 1984, p.47).

Another priority enunciated in various hospice literature is subsumed under such notions as involvement, and is rather nebulously identified as regarding the patient as a 'human being.' Although vague, the hospice emphases make this practical consideration very clear. An attempt is made to acknowledge and help with the patient's inevitable anxiety, fear and confusion in a constructive and humane way. Communication is vital in this situation, and among other things, serves to guard against medical abandonment, as often seems to happen on acute hospital wards when it is felt that nothing more can be done to cure the patient. The hospice situation is designed so that it is up to the patient how much communication occurs, and the nature of the interaction is determined by the patient.

Dr. Kubler-Ross (1977) outlined five reasons for giving the patient a choice about how much communication occurs regarding knowledge of their condition:

1) It is the patient's right to come to terms, both spiritually and emotionally with his own death.

2) The object in question, that is the patient's body and its condition, is the patient's property.

3) Successful doctor/patient relationships are founded upon trust; this will only be preserved if a patient knows that the truth is accessible.

4) Only the patient knows what worldly obligations, arrangements need to be considered, in the event of their death.

5) Honesty allows the family to behave sincerely, without pretence, with the patient.

If a patient chooses to hear the truth of his condition and to face up to it with the help of family and other terminal caregivers, this is what Glaser (1965) calls, 'open awareness.' This is contrasted with, firstly, 'closed awareness,' where doctor and family know, but the patient doesn't, the former colluding in deceiving the patient. Secondly, 'suspected awareness' describes the situation where family and doctor know, and the patient suspects. This involves much anxiety, associated with a lack of trust and confidence. Finally, Glazer describes, 'mutual pretence,' where all parties know the truth, but pretend not to. A case can be made, in this instance, that the patient can achieve a certain dignity, yet it is felt important that

motives should be questioned before adopting this mechanism of coping via false communication.

A fourth priority concerns the architectural character of the hospice building, with as much effort as possible being made to provide a homely environment, or how the hospice authorities perceive a home environment to be. It is not difficult to see the inadequacies of drab, impersonal hospital rooms, and any change in this is likely to be an improvement. Rather than privacy, hospitals seem to offer isolation. The hospice alternative provides open, spacious and bright areas; not claustrophobic or oppressive rather encouraging outward spiritual expansion and expression. Here, there is a discernable continuity from Medieval hospices where the emphasis was upon feeling the warmth of a homely environment, rather than an uneasy stranger or outsider.

A new trend in this area of hospice care, is the move towards easing the pressure on the family for relatively short periods of possibly a few days or until a specific problem has been solved, thus enabling home care for the patient for as long as possible, as this is seen as the ideal environment, if at all possible. Generally, hospices intend to supplement rather than to duplicate existing facilities.

The development of daycare facilities allow both the family and the patient to be weaned onto the hospice system and provides some respite and distraction for those concerned in home care. If the patient eventually reaches the point where hospice

in-patient care is the best alternative, then he will have spent as much time as possible in the familiar and hopefully supportive environment of his home whilst having built up a trusting, cooperative relationship with the hospice staff.

The training and education of medical staff in the management of terminal disease and an analysis of their own attitudes towards death, in relation to their hospice function, represent a fifth priority. Organized programmes exist and include lectures, seminars and workshops together with a range of relevant literature and study facilities, but it is felt that still more are needed.

The final priority which clearly illustrates the holistic emphasis of hospice care involves the continued contact and concern with the family of a former patient. The family are regarded as a vital element in the care team and as such, deserving of follow-up bereavement counselling. This is not generally difficult to arrange, as unlike hospitals, the family are actively involved from the moment the patient is in any way associated with the hospice. Thus the hospice cares for the whole family as the death is seen as their death as well as the death of the patient.

The hospice perspective on death and dying manifested itself in organizational characteristics. Abel (1986) describes how early hospice movement leaders shared certain attitudes with those behind alternative institutions of the 1960's and 1970's. These priorities included "nostalgia for simple, old fashioned

ways, dissatisfaction with bureaucratic and authoritarian institutions, faith in the power of nature, a determination to avoid domination by experts and a desire to improve the quality of personal relationships," (Abel, 1986, p.71). Obviously experts were necessary to the movement, but hospices, by giving equal status to the work of diverse professionals avoided automatic dominance by those traditionally viewed as superior in normal medical situations. Thus physicians in the hospice environment were treated as team members, with no entitlement to any positions of leadership, (Rossman, P., "Hospice: Creating New Models for the Terminally Ill: Fawcett Columbine, N.Y., 1977). A sense of 'community' and team spirit was encouraged, and was seen as a way of limiting orthodox power relationships.

In line with 1960's counter-institutions some hospice activists attempted to span the gap between the expert and non-expert. Hence the centrality of concern for human relationships, with an emphasis upon caring and intimacy, negated the automatic assertion of professional superiority as some hospice leaders suggested, professional codes of conduct did not always facilitate an air of close, feeling support, but rather tended to elevate and to isolate them from those they were supposed to help. Rossman (1977) suggested that a postman knowing a patient's name, or a cleaner talking normally to a patient was at least as valuable as a professional caregiver. Thus, continuing in this vein, many hospice programmes rely very heavily upon non-professional volunteers.

Reform movements of the 1960's and early 1970's were

generally concerned with the rights of social service consumers and attempted to bring professionals closer to the clients in the case of the hospice movement. In order to achieve this proximity between what were regarded as simply two or more individuals, the accessibility to complete, accurate information, for the patient, was stressed, and physicians who neglected to communicate honestly with patients were the object of hospice supporters' criticism.

Behind this emphasis upon honest communication lay the fundamental notion of individual choice, a notion which is of paramount importance in the Hospice Movement. The dying patient is encouraged to, or at least assisted in, retaining a sense of autonomy and individual mastery over his life. To this end hospice staff have been encouraged to become genuine listeners, (Cox, 1980) and to regard the terminally ill patient as a, "giver as well as receiver," (Buckingham, 1983, p.67).

The idea of personal choice also included a rejection of regimentation in care giving. Patients' differences were respected so that they could choose which clothes they wore, when they wanted to do things, including have their meals and possibly most importantly there were no restrictions on visiting hours, (Abel, 1986). Although various hospices have different practices, these organizational characteristics, in spirit, at least, appear to be pretty well universal.

The core concern of hospice care to maintain in the patients a feeling that they have preserved their independence and

retained control over that life which is left to them, cannot be stressed too heavily. The length and quality of living, not to mention life itself, is too often beyond the control of the individual experiencing it, for reasons which could be abolished in a different kind of environment. Yet the helplessness arises not only from environmental factors nor even just the realization of diminishing capacity, "but also from the community's response to that loss ... If individuals are evaluated by society's standard of role fulfillment, then those no longer able to function according to expectations are subject to self-doubt and, to varying degrees, to societal disdain," (Corless 1985, p.282). When lack of role fulfillment is involuntary, as is obviously the case with the terminally ill, then dispensation from normal role obligations is given by society. Talcott Parsons (1951) elucidated the various roles accompanying illness, subsumed under the title of "the sick role." Although a sick role may enable certain freedoms for a patient, such as less work and responsibility, there are two potential problems with this for the dying patient. Firstly there are certain actions which are prescribed but also actions which are proscribed, such that perhaps for the sake of those around the terminally ill individual, as much as for him, his actions are constrained, his freedom of choice is diminished if he conforms to role expectations. Thus, for example it might be regarded as tasteless for a dying person to display publicly a complaining, even cowardly approach to death. Thus in this sense role adherence can be seen to be both liberating and confining. A second problem for a dying person in terms of a dying role, is that, in Western society, at least, there does not seem to be "a

clear consensus regarding care of the dying and the role of the dying patient," (DeSpelder and Strickland, 1983, p.125). In an atmosphere of such uncertainty, it might be difficult for a person to die in a peaceful or dignified manner. Hospice caregivers attempt to alleviate such problems by a, "recognition of the value of human life in having meaning for the person," (Corless, 1985, p.283).

A Good Death

A survey of the hospice perspective, its aims and priorities would be incomplete without mention of the notion of a "good death." There is no single definition of the, "good death" and in this respect hospices cannot be treated as homogenous. Nevertheless pervading the literature and practice of specialized terminal care is the belief in an ideal way to die. This ideal might be seen as variable for different individuals, with an emphasis on personal expression, yet behind the individual differences lies a wish to, "die well." One aspect of this is encapsulated in the twenty third Psalm;

"Yea, though I walk through the valley of the shadow of death, I will fear no evil, for thou art with me; thy rod and thy staff comfort me."

Although these sentiments represent an intrinsic part of the Judaeo-Christian tradition, they seem also to have found a place of importance in an increasingly secular society. It is somehow felt better to die at peace with oneself, unafraid, or at least

not overtly so, of one's imminent death rather than to make a fuss or express fear. Such a death is seen as dignified. The wish to retain or attain dignity whilst dying, is not exclusive to a Christian or any other religious doctrine, yet the Christian notion of a "good death" appears to be prevalent both in secular British society as well as within the British Hospice Movement, where the efforts made, outlined above, are, in part at least, aimed at providing the possibility of what might be considered to be a, "good death."

Possibly dying well is as much for the benefit of those present, as for the dying person. An exemplary death provides a good model to those witnessing it, of how to die, and also possibly enables them to cope with the death much more easily, with less anxiety, than if the dying process involved screams of agony and fear, together with desperate appeals for a chance to continue living.

Thus, although not explicitly stressed, in the hospice literature, the notion of a 'good' or 'exemplary' death does seem to be an important component of hospice philosophy. The ideals espoused in various works as being those underlying the Hospice Movement (see, for example, Manning, 1984) that is, representing some sort of hospice philosophy, also include a strong emphasis upon the need to restore, to the dying individual, a certain amount of autonomy. The sphere of the self-determination is said to be the type of death which the individual wished to experience, or rather the manner in which the individual wishes to approach dying.

Yet is it reasonable to advocate, as appears to be the case in some parts of the Hospice Movement, a certain type of death, that is a 'good' death, whilst proclaiming that the individual is given freedom to die in a way chosen by the individual, apparently unconstrained by situational norms?

There appears to be a certain contradiction or at least confusion in the literature pertaining to hospice philosophy. It is interesting to consider, briefly, Martin Heidegger's view of what constitutes an individual who genuinely faces up to the responsibility inherent in a life involving choice, that is an individual who is, "authentic." In Heidegger's "Being and Time," (1927) he explains the notion of, "authentic." He states that through anxiety man encounters nothingness and becomes aware of his finitude and the necessity of death; but through resolution, man, who moves in time from the past to the future, through the present, appraises himself, chooses with the whole of his being, and thereby achieves authentic existence. Authenticity also involves a "living towards death" as the ultimate possibility. If the Hospice Movement makes death just another role, it is certainly antithetical to the Hospice Movement. Using Heidegger's term, can an individual be authentic if he allows himself to be led along the hospice path, as described in academic hospice literature, (for example, Abel, 1986), towards that satisfactory, acceptable and copeable-with death, prescribed by the institution which directs him at the end? It is perhaps worth referring, briefly, to what could be called an existential perspective.

The notion of choice is fundamental to the existential approach. It is misleading to refer to 'the' existential approach rather, the common ground between a whole variety of thinkers is their interest in human freedom (Warnock, 1970). General though this may be, it is valuable to introduce an existential perspective in relation to the question of choice in dying.

Often, due to the beliefs of certain existentialist philosophers, such as Bataille, Sartre, Camus, Jaspers and Heidegger who were atheists, existentialism is seen as synonymous with atheism. "To Heidegger, man's life is a journey in the form of a parabola from void to void. Man is afflicted with a sense of nothingness," (Rayner Heppenstall, 1945, p.57). Yet others could be described to a greater or lesser extent, as Christians; Berdyaev, Dostoevski, Unanmumo, Maritain, Chestov, Marcel and Kierkegaard. Soren Kierkegaard (1813-1855), the Danish philosopher, in his work on existential metaphysics, "Either/Or," outlined how he saw choice as the only means of overcoming despair, thus enabling man to transcend what he called the, "aesthetical" and "ethical" modes of existence and to reach the ultimate, "religious " stage of existence. But it should be said, within this scheme, that "to choose Christianity is to choose suffering," (Croxall, 1948, p.36).

Although the details vary enormously within existential literature, the pervasive emphasis upon the need, as an individual, to choose, appears to be close to the sort of

opportunity for choice attributed to hospice philosophy and practice (Abel, 1986; Corless, 1985, Manning, 1984). It is the coincidence of the advocacy of individual choice and the encouragement towards some sort of prescribed "good" death, which suggests some confusion or uncertainty in the literature. If the hospice approach actually reflected a broadly existential perspective, it would appear quite probable that traditional societal views expressing a need to conform to a particular kind of dying, would be subordinated to individual choice.

Alleviation of pain, clean surroundings and good food combined with ease of access for family and friends, would appear to most to be conducive to peace, harmony and relaxation of mind and body. But there is something less tangible, in the literature, an air of acceptance, possibly an implication that this step, that is, death, is too easy, easier than it is or possibly should be. That is not to suggest that dying should be accompanied by agony and terror. Rather the possibility exists that in this, "community of the dying," which after all is what the hospice is, individuals may be lulled by the accepting ambience and submission to imminent death, perhaps subliminally, into an unnatural, even unhealthy, capitulation. Such a surrender, if it exists, is not as overt as the physical sedation of some hospitalized terminally ill patients, producing a semi-comatose state, but may, in its own way, be just as worthy of questioning and enquiry.

Fear of Death and Dying

Possibly the main purpose served by the tranquil hospice atmosphere is to combat what might generally be considered to be the major psychological concomitant of death and dying, fear.

Fear is not necessarily a bad thing. It can be seen to have biological value and could be regarded as a constituent of the survival instinct, vital for individual existence, (Hinton, 1967). Even so, despite certain age variations regarding attitudes to death, indicated by among others, Middleton, 1936; Feifel, 1956 and Swenson, 1957, fear of death and dying is widespread; whether it be the fear of pain, indignity at the last, the unknown when human life ceases, it is not uncommon to find individuals who are afraid to die. From prisoners on death row to poets such as John Betjeman (Birkenhead, 1958) and the celebrated lexicographer, author and critic, Samuel Johnson, death is accompanied by fear. It might even be added that at one point Jesus Christ expressed fear, although at another, submission and acceptance.

Despite the apparently prevalent fear of death, recent literature provides conflicting views on both the universality of such fear, together with its possible causes. Manning (1984) claims that the notion of ceasing to exist lies at the root of a fear of death and dying and that the orientation of modern western life, education in particular, is towards 'knowledge' as opposed to self-awareness. From this preoccupation with knowing, she suggests that, "We fear the unknown," (Manning,

1984, p.23). In this bland form, such a statement needs to be qualified, and such an explanation has been attacked by Cassell (1978). He claims that there are many things that we do not know, yet are unafraid of, such as, the meaning of antimatter or the dark side of the moon before the advent of space travel. The fact that unknown death has a qualitatively different meaning from the unknown antimatter suggests that it is meaning which is important. Such meaning, suggests Cassell indicates an individual contribution to our own concept of death, something from, "within ourselves," (Cassell, 1978, p.171). One element of a personally constructed fear of death may involve the fear of losing control (Manning, 1984). At this point it is important to acknowledge the distinction between the fear of death and the fear of dying. It is not uncommon to hear, "It is not so much death I am afraid of, as dying." Dying is a much more comprehensible process, one which we can learn about from experience and hence realistically anticipate. This might involve the fear of pain and not being able to cope with the physical details of dying, together with being afraid of the reactions of others, their sadness and possibly their future. Although it would appear possible to anticipate a host of potential fears involved with dying, "William Ostler, the great physician, one wrote that he could hardly remember a dying patient who was afraid of death. That, too, has been my experience. In a recent study on the dying by Avery Weisman the same finding emerged," (Cassell, 1978, p.171-172). The same author also notes that paradoxically it is those closest to death and perhaps more aware of the facts of dying, that is, the aged, who tend to fear death and dying less than younger people. In

spite of the inevitable exceptions, it might be postulated that after a certain length of life (varying between individuals), depending possibly on its content, there comes a time, almost like any other stage of maturation, when an individual is ready for death. This could involve a sense of fulfillment and of having had, "a good innings." Such findings in the older generations suggest that dying need not be accompanied by fear and anxiety, yet this must be qualified by noting that situational factors, including familial relations and welfare could greatly influence an individual's experience of, and attitude towards, dying.

Nevertheless, fear of death and dying does exist, and it is interesting to turn to the work of Elizabeth Kubler-Ross (1977), a section called, "On the Fear of Death," for both a brief outline of her views on the fear of death, together with a possible prognosis. Death, claims Kubler-Ross, is feared due to its unfamiliarity. Death has always been distasteful and to the unconscious part of self, "death is never possible to regard in ourselves," (Kubler-Ross, 1977, p.2). To the unconscious we can only be killed, we cannot simply die. Therefore death is associated with a bad and frightening act. Kubler-Ross continues by suggesting that from the death of a loved one can come an increased fear of one's own death. Connected to this is Cassell's contention "that we, the living, remote from our own deaths but standing at the bedside of the dying, have confused our own fear of death with their fear of dying and in that confusion have denied our dying patients a means to remain in control of their own deaths," (Cassell, 1978, p.174). A

combination of guilt, shame and grief, experienced due to the death of another, is felt to contribute to an increased fear of our own mortality.

Kubler-Ross offers suggestions as to the alleviation of such fears and ways of coping and dealing with death and dying, based upon over twenty years in this field, culminating in international recognition as one of the foremost authorities. "If a patient is allowed to terminate his life in the familiar and beloved environment, less adjustment is required of him," (Kubler-Ross, 1977, p.7). She espouses the involvement of children, in the dying process, so as to provide gradual preparation for them, helping them to view death as a part of life. The stress upon a familiar environment is continued as she says that, "The days are gone when a man was allowed to die in peace and dignity in his own home," (Ibid, p.7). Death is seen as increasingly more gruesome, lonely, mechanical and dehumanized. This results, as said before, in a lack of autonomy in illness. "He may cry out for rest, peace, dignity, but he will get infusions, transfusions, a heart machine, or a trachostomy," (Ibid, p.8). Kubler-Ross questions whether the reason for the mechanical, impersonal approach is our, (the presumably healthy living), own defensiveness. Are we avoiding reminders of our own mortality? The efforts to prolong life at all costs ignore any notion of normal biological maturation which involves, inevitably, a time to die. A case must be made for the proposal that sometimes an individual is truly ready to die, physically, mentally and spiritually, and for such individuals such willingness to die should be respected. In part, this is

what the Hospice Movement advocates.

Anger in Death and Dying

Death and the manner of dying are, ultimately, personal issues. Some will feel that they are prepared and accepting of death and may perform well in the role of the 'good' death. Yet, for those who feel that their time is not yet nigh, it should be their prerogative to fight against their situation, to be angry. In much of the literature on hospice, possibly stemming from the influential work of Kubler-Ross and her outline of the stages of dying (On Death and Dying, E. Kubler-Ross, 1977) anger is seen as a frequent, though not particularly desirable, part of dying; a part which it is best to overcome, to have done with. It seems very possible that the major aversion towards this facet of dying comes from those surrounding the dying patient. Obviously it is not pleasant to experience another's anger and even bitterness, especially that of a close friend or relation.

In Kubler-Ross' scheme, 'anger' represents stage two, following 'denial' and preceding 'bargaining', 'depression' and finally 'acceptance'. It is acknowledged that not every patient experiences or demonstrates each stage, nor necessarily in this order, but the impression is that a "successful" death is one in which the patient had reached the stage of acceptance and contemplates death calmly and peacefully. A fine example of such a death comes in Plato's, "The Last Days of Socrates," in which Socrates, condemned to die acknowledges and accepts his

forthcoming death with inspirational calm, an example to all those present; "I should only make myself ridiculous in my own eyes if I clung to life and hugged it when it had no more to offer... I am told that one should make one's end in a tranquil frame of mind," (Plato, Penguin classics, 1969, p.181).

But in others, this type of death would be out of character. In its place a constructive, striving anger is sometimes the most appropriate way for an individual to respond. Jory Graham, in her work, "In The Company of Others. Understanding The Human Needs of Cancer Patients," (1982) discusses the concept of 'anger as freedom,' as an assertion of our continuing existence in the face of perceived annihilation. "Healthy anger gives us vitality. It is a glorious sign that we're far from dead... Healthy anger gives us purpose, challenges us to make new decisions, encourages old ideas," (Graham, 1982, p.26). The sentiments underlying this attitude to death and dying are eloquently and vividly expressed by Dylan Thomas (1952, p.116);

"Do not go gentle into that good night,
Rage, rage against the dying of the light."

Religious Faith in Death and Dying

Despite the increasingly secular nature of western society, (Gorer, 1955) religious faith is still a potent force for many facing death and such faith may make both the fearful and angry response, to death, redundant. "Many faiths assert that man does

not wholly die and they help the faithful by preparing them for the end of their mortal existence," (Hinton, 1967, p.13).

The view of some sort of afterlife appears to have been held since prehistoric times. Neanderthal findings at La Chapelle-aux-Saints, in France, suggest a belief that the dead had needs and that their existence did not end with the cessation of human life. From the Vikings to the ancient Egyptians, whose extensive arrangements for life after death were shown in the excavation of the pyramids, various forms of religious faith have enabled man to approach death with the feeling that death is not a final end, rather some sort of transition.

In some contemporary religious faiths the nature of a continued existence is not necessarily desirable and depends upon the conduct and content of worldly existence. Within the Buddhist religion the peaceful end of worldly desire, nirvana, can only be approached through a life of patience, abstinence, humility and morality; until this state is attained, "there is condemnation to an endless cycle of craving, existence, birth, old age, death, ignorance, and again, craving," (Hinton, 1967, p.37).

Within mainstream Christianity, ignoring the predeterminationist views of, for example, the Calvinists, a good life is felt to qualify one for heaven. It would seem that a belief in hell, as an alternative destination for those who sin, is decreasingly regarded as believable, (Gorer, 1955).

Nevertheless, it appears that ~~in~~ spite of a relative decrease in religious beliefs, in absolute terms, there are still millions of people in this country, for whom religious belief is an important part of their lives and deaths. As previously stated, related to such beliefs are notions of a 'good' death, one in which worldly affairs are concluded and subordinated to a calm anticipation of the end of worldly existence and the commencement of eternal spiritual life.

Thus, when considering individual attitudes to death, religious beliefs constitute one of the few sources of certainty to some of those contemplating death. Such peoples' attitudes and behaviour whilst dying, will presumably be influenced by what they regard the end result of dying to be. To others, whilst holding religious convictions, death may still be regarded with terror. For John Betjeman, as with Dr. Johnson, such fears were, "a malaise of the soul against which his religious beliefs, strongly held, appear to offer no adequate shield," (Birkenhead, 1958, p.17). Religious beliefs represent a potent, but by no means universal, source of comfort for those facing death.

To summarize, this chapter has outlined most of the major components involved in hospice philosophy and individual attitudes to death. a distinction has been made between hospice practice and hospice philosophy, although the latter term often includes the former, as the practical application of hospice philosophy.

The priorities identified in hospice care cover many of the

elements which produce anxiety in both those who are terminally ill, and their close friends and family. The hospice aims to provide holistic, humanitarian care including specific attempts at pain alleviation, honest communication, conducive physical surroundings, together with training and education facilities for terminal caregivers and bereavement counselling for the families.

Hospice organization has been related to that of various counter or alternative institutions of the 1960's and early 1970's. The hospice movement has been described as having an affinity with the egalitarian atmosphere of such institutions, in which traditional operating distinctions are transcended (Abel, 1986).

Highly emphasized within much of the hospice literature is the desire to provide the dying individual with the opportunity to choose, to demonstrate personal autonomy throughout dying. Such individual freedom is seen to be constrained by both the environment and by societal role expectations. Included in these expectations is the pressure to die a 'good death,' or as DeSpelder and Strickland (1983) prefer, an "appropriate" death. Many of the existing views regarding the notion of dying well appear to reflect similar ideas inherent in the Judeo-Christian tradition. To a certain extent, conformity to these notions can be discerned within the aims of the Hospice Movement, as described in academic hospice literature (Abel, 1986; Corless, 1985; Manning, 1984). In some of the same literature, an almost existential quality regarding hospice care, is espoused. Although the goal of increasing individual power and choice is

laudible, the loose use of the term, "freedom" must be rectified and qualified. The notion of freedom in dying is something of a misnomer. It would perhaps be more accurate to talk of varying degrees of unfreedom. After all, how free can a dying person be, even ignoring the often attendant physical and mental limitations caused by the terminal condition?

Some of the major factors influencing and reflecting the individual's attitude to death, fear, anger and belief or faith, have been covered briefly in order to indicate the type of problems experienced by hospice caregivers, together with the strength brought by some patients, to their own situation.

Hospices advocate an acceptance of the course of nature. "They attributed much of the agony of the dying to unnecessary medical interventions and sought to dispense with heroic and other life-sustaining techniques. Viewing death as a natural event rather than a technological failure, they did not hide the dying," (Abel, 1986, p. 73). De Boulay (1984) in her biography of Cicely Saunders, quoted a widely travelled doctor who said that existing care of the dying, that is non-hospice care, was more primitive in Blackpool than in India, Nigeria, New Guinea or Queensland.

Whatever the theoretical debates about individual freedom or the meaning of death, the striking feature of hospice practice is that they just get on and do it. In practice there appears often to be, as observed by a group of social work students in St. Joseph's in 1960 where Cicely Saunders worked with terminal

patients, a marked lack of narrow-mindedness which might so easily be present in a place run by a particular order. Agnostics, atheists and non-thinkers were all helped to accept death in the most suitable way for them as individuals. The oft repeated phrase, "Oh, He's himself," summed up this attitude. The nuns would much rather a patient died complaining, though still fully themselves, "than drugged into some pseudo-saintly calm," (De Boulay, 1984, p.72).

It is this application of theory in daily practice which seems to encapsulate the essence of hospice philosophy. They deal with the individual human being with all the myriad of variations this necessarily involves. It is the person who counts.

At this point the question must be posed, 'How does the hospice philosophy get put into practice?' The answer, in part, is provided by the use of a resource mobilization perspective. However useful this approach proves to be, it needs to be supplemented by psychological data. Thus, the next two chapters consider the uses and the deficiencies, respectively, of resource mobilization, as an approach to studying a hospice project.

CHAPTER FIVE

RESOURCE MOBILIZATION AND HOSPICE PROJECTS: APPLICATIONS

The intention of this chapter is to combine the theoretical perspective of Resource Mobilization with the process of hospice project development, in order to demonstrate the usefulness of such an approach, in describing movement activities. A case study of the Martin House Childrens' Hospice project provides an illustration of the ways in which Resource Mobilization language can be applied to the actual experience of project genesis and development. This will involve a summary of project antecedents and developments together with a more thorough examination of the internal and external dynamics involved in the progression of the hospice project. Internal factors include consideration of tangible and intangible resources, together with structure, leadership and organizational constraints, while external factors include a whole array of potential constraining and facilitating influences.

The information on project activity has been gleaned from hospice literature, such as newsletters and pamphlets, together with questionnaire responses and interviews with project members.

Martin House Childrens' Hospice was opened to families, for the first time, in August, 1987. This represented the culmination of a project, to start a hospice for children in the

North of England, which had started over three and a half years earlier, in February, 1984.

The first childrens' hospice in Western Europe, Helen House, was opened in Oxford in November, 1982. Helen House grew from the work of Mother Frances Dominica, Superior General of the Anglican Society of All Saints, who is also a Registered Sick Children's Nurse, and provided an example and stimulus for the creation of the Martin House project. Initially much of the motivation and encouragement for a northern childrens' hospice came from Helen House and its supporters. The Helen House News (No. 7 February, 1984) heralded the plans for Martin House. It reported, "several medical consultants, two clergy, the Reverend Dennis Walker and the Reverend Richard Seed, both known to our Community for a number of years, and the Prioress and several Sisters of the Order of the Holy Paraclete, are among those on the Planning Committee," (Mother Frances, H.H.N. February, 1984). Mother Frances encouraged support for the new project even though this could mean Helen House support being, "diverted to the north."

The Martin House Appeal was launched on February 2nd, 1984 even though a site had not been found. Martin House's own newsletter (No.2 April, 1985) reported the first meeting of the leaders of the Friends Groups, Governors and other voluntary workers. The presence of Mother Frances, who spoke at the meeting, reinforced the appreciation of the debt owed by Martin House to the example of Helen House, which as the then Chairman of the Martin House Project, Revd. Richard Seed said, "has paved

the way and...we are building up a brother and sister relationship with them," (Richard Seed, M.H.N. April, 1985)

By February, 1986, Helen House News (No. 11 February, 1986) was able to inform its readers that the Martin House Project had completed the purchase of the hospice site, in Boston Spa, near Wetherby, North Yorkshire, and that building was to start in the spring.

In their own Newsletter (MHN No. 4 March, 1986) Martin House announced that Leeds City Council had finally granted detailed planning permission. Earlier Project plans were rejected by the Leeds Labour Council due to what was felt by Project members to be the Council's hostile reaction (uninformed as it was) to what it regarded as some form of private health care facility. Building was forecast to begin in June, 1986, "with April and May seeing Tenders offered and Contracts signed," (MHN, March, 1986).

Also at this stage, the appeal aims were clarified. Using the example of Helen House, whose annual running costs then ran at £210,000, which were not quite covered by the £2 million in their endowment fund, the Martin House Project anticipated slightly greater running costs. Hence the Governors raised the appeal to £3.5 million. The estimated costs per annum were at least £230,000; this it was hoped would come out of endowment income. Thus about £1 million to build and £2.5 million to be in the endowment fund was to be the new target.

Two new Governors together with an Appeals Consultant were welcomed publicly to the Martin House team in the same Newsletter, and information was given regarding the new site of the Martin House office, the third in six months.

In May, 1986, the Lord Mayor of Leeds dug the first sod from the six-acre site in Boston Spa. Building started on June 30th, 1986, and the company who won the £935,000 contract, although a national company, had a large area office, thus local people were involved in the construction. (MHN No. 5 July, 1986)

The same Newsletter introduced the newly appointed Head Nurse together with the new Vice Chairman, chosen by the Governors.

Helen House News (September, 1986) covered the Martin House foundation stone laying, and more detail of the same event was given of this ceremony, on September 16th, in Martin House's own December Newsletter (MHN No. 6 December, 1986). This included a feature on the opening of Martin House's first charity shop, in Leeds, on Nov. 21st, 1986, together with the appointment of a general handyman/gardener.

The final Martin House News (No. 7 July, 1987) prior to opening, timetabled the Open Days which preceded the hospice becoming fully functional, and detailed the forthcoming dedication of the Chapel and Sisters' House on 27th July. The project reported its only major internal setback, the former administrator had to be dismissed following investigation of

Martin House accounts. In the same Newsletter the new Administrator was introduced along with the office teams which continued to work in the completed hospice. Some details were also given of the staff, "We have a large number of Registered Sick Children's Nurses, some Registered General Nurses, a physiotherapist, two teachers, a social worker, several nursery nurses and psychology graduate," (MHN No. 7 July, 1987). At this stage the chairman stood down to devote himself to the work of chaplain to the hospice and vicar of the parish, to be replaced by the Vice Chairman. The readers were also presented with a brief breakdown of the financial state of the project, which in just over three years had raised £2.5 million.

This outline represents a superficial chronology of the major events through the process of project development, as presented publicly through the hospice project's own newsletter, together with that of Martin House's 'sister' hospice, Helen House.

In order to examine the Martin House project more closely, in the light of a Resource Mobilization perspective it is necessary to locate it within the field of social movement theorizing. According to McCarthy and Zald's "Resource Mobilization and social movements: a partial theory," (1977) the Martin House project would fall into the category of a, social movement organization. That is, Martin House represents a formal organization which identifies its goals with the preferences of a social movement, in this case the Hospice Movement, and attempts to implement these goals. Martin House together with all other

hospices and hospice projects constitute a social movement industry. These ventures can be regarded as the organizational analogue of the social movement.

Many of the general hypotheses outlined earlier (see chapter on R.M. Perspective) would be supported by the general levels of relative affluence experienced in the post-1970's recession society which can be seen to exist in Britain today. The proliferation of charities, anything up to four thousand new charities every year, would tend to support the McCarthy and Zald hypothesis regarding the relationship between resource availability and SMI/SMO incidence. This indicates a continuing expansion of the Social Movement Sector (SMS).

Martin House represents a good example of specialization within an SMI. Although it is not claimed that the project team decided to start a childrens' hospice so as to win the struggle for survival, by specializing, (Durkheim) by being only the second childrens' hospice, and the only one in northern Britain, Martin House clearly attains a competitive advantage over other hospice projects (SMOs) within the SMI, by presenting to its potential adherents, at once narrow and especially poignant goals.

Together with specialization, professionalization is one of the major features of an SMO with a large income, as specified by McCarthy and Zald (1977). Martin House is no exception to this. Within ten months of the appeal being launched, an administrator had been appointed to take charge of establishing Martin House

Hospice. "This job is to co-ordinate voluntary workers, publicity and fund-raising until the target of £3.5 million is reached and run the non-medical side of the hospice when it is built," (M.H.N. No.4 March, 1986). The first administrator was dismissed before the completion of the building, and convicted of fraud. He was replaced by the former chairman of the Leeds Western Health Authority.

Martin House developed its own selection and appointments procedure, during the appeal stage, and one year before the hospice became operational they appointed a Head Nurse, after two days of interviews. During this year, her function was to recruit her nursing team, a task jointly undertaken with the local G.P., the Hon. Medical Officer to Martin House together with the chairman of the governors, and to train them. The Head Nurse was also responsible for establishing contact with, "other medics, G.P.'s, consultants, Nurses etc. to spread the news of Martin House as well as making some home visits," (MHN, No.5 July, 1986).

Other professional staff ranged from a general handyman and gardener to an appeals consultant, who came, "with the expertise of co-ordinating large scale fund-raising events and planned programmes for giving information to groups - such groups as Rotaries and Round Tables," (M.H.N. No.4 March, 1986). The increased paperwork also necessitated employing two part-time clerks, who between them covered a forty hour week, together with a girl on a Youth Training Scheme taken on for several months.

The main concerns of a resource mobilization perspective, in terms of an individual SMO, such as Martin House, include, by definition, an emphasis upon potentially mobilizable resources, both tangible and intangible.

To a certain extent, tangible resources, for example, money, space, and publicity of existence and ideas, are interchangeable. In the case of Martin House, as with most other SMOs, these various forms of tangible resource mobilization overlap. Money was raised through established systems of organized giving, such as covenants and bankers order, together with straightforward one-off donations. Martin House goods were made available using an order form accompanying their newsletters. Such goods ranged from notelets and pens, to teatowels and T-shirts. As the project developed the range of goods offered in this way increased.

Discrete fundraising events comprised a highly visible element of the resource mobilization process as displayed in Martin House literature. Events included, 'Family Fun Day' at Castle Howard, North Yorkshire, involving entertainments, stalls, side-shows and raffles, sponsored annual Great Yorkshire Bike Ride, from Wetherby to Scarborough, raising about £14,000, and sponsored parachute jumping. Some events provided funds for several charities, such as the Great Yorkshire Bike Ride, and a Gala Evening at the Sadlers Wells Opera House, In London, in which the Royal Ballet prepared a special childrens' evening.

Another money raising strategy was to use existing

organizations and events; turning their attention to Martin House. General Motors and the Football Association donated a new car, for a raffle. An England football player presented it to the Martin House administrator, adding publicity to the fund raising effort. Similarly, two local league football managers added their support to the project; both able to utilize their own organizations and connections for the aid of Martin House. The London Marathon was also used by twenty one runners sponsored for Martin House. The project was even offered a special discount rate for a holiday house in a small Spanish town. Eight percent of all bookings were given to the appeal.

Publicity was combined with financial gain in both the Martin House Christmas card venture, in which a competition was held for designing, with publicly presented prizes, the cards being sold, and in the appeal's connection with the Yorkshire Post newspaper. Martin House News (No.2 April, 1985) thanked the staff of the Yorkshire Post, for all the valuable time and space given to communicating what Martin House is and also for raising almost £100,000 through its readers," (MHN No. 2 April, 1985).

On a national scale, Martin House received publicity and funds when the Editor of the Sunday Telegraph, Peregrine Worsthorne, opened an exhibition of oils, pastels and drawings by Jocelyn Galsworthy, in Belgravia, London in 1986 asking everyone to support Martin House and the work it is doing. A percentage of proceeds from sales and commission resulting from the exhibition were donated to the project, together with almost £1,000 in direct donations.

H.M. forces overseas made big efforts to raise funds for Martin House, as did several commercial enterprises. North British Trust Hotels, from Oban, presented a cheque for £20,000 to the celebrity, Jimmy Saville, who gives as much support as he can to the project. The Leeds based supermarket group, ASDA, gave £10,000 and Marks and Spencers from Blackburn contributed £2,000 to the appeal.

The project team arranged for an office to be established in Boston Spa, from which to co-ordinate their activities. A High Street location reflects their attempts to be in the public eye, thus attracting patronage from organizations who also benefit from publicity. The Trustees Savings Bank donated a mobile information centre/shop. The caravan, painted in Martin House colours, together with TSB logos, was used at venues such as the Great Yorkshire Show; the publicity benefiting both parties concerned. Similarly, Appleyards (Yorkshire) Ltd., a garage group, loaned a car to Martin House. This was invaluable in the task of drumming up support and awareness of the project. Again, not surprisingly, the car featured prominent advertising for the loaning company.

About ten months before the opening of the hospice, Martin House's first charity shop opened on a busy through route in Headingley, Leeds. "The stock is good-as-new clothes and bric a brac, toys and craft goods together with the ever increasing Martin House range," (MHN No. 6 December, 1985). The shop hours are 9.30 am to 5.00 pm, Monday to Saturday. Goods bought either

in Boston Spa, from the office shop, the charity shop in Leeds or by mail order, could be paid for by cash, cheque, Visa Card or Access, and Barclaycard numbers could be quoted over the telephone, facilitating easier purchase.

The aforementioned resources were all to a large extent centrally controlled from the Martin House centre in Boston Spa. The various Friends Groups, of which there are around thirty, comprising of an average of four or five people, with some significantly higher, were and are, responsible for a significant amount of project resource mobilization and represent visible extensions of the Martin House project, beyond the local area in which it is based and subsequently well known and supported.

Aside from personal communication, the tangible resources of the loaned car, the caravan, the office and shop, media coverage, particularly the intimate connections with the Yorkshire Post newspaper, facilitated rapid, up to date and relatively extensive publicity for the project. This, was, in turn, converted into tangible resource acquisition, namely, money.

People are the major form of intangible resource. From the Martin House Project voluntary helpers completed questionnaires. The questionnaire (see Appendix II) was completed by 25 Martin House constituents. Four of these were interviewed, whilst the rest (21) received and returned postal questionnaires. The response rate for postal questionnaires was 100%. Apart from the four who were interviewed who all belonged to the same Friends Group, all the others were selected at random from the Martin

House contact list of Friends Groups.

The questions fall into two main categories, within which are several subgroups. The first section pertains to factual information about personal details plus project activity. The second enquires as to more subjective areas such as attitudes to death, perceptions of others' attitudes, and religious belief, together with personal experiences. The aim of the questionnaire is not to generalize regarding causal relationships between belief and activity, but rather to emphasize those components involved in movement membership, without suggesting that these influences are different or peculiar to the Hospice Movement. Thus, for the purposes of this study, a control group is not needed.

Differences are identified within the respondents and between various groups of questions. The responses demonstrate, as much as anything, how the respondents present themselves, without explaining why they behave as they do. The questionnaire responses reported in this chapter pertain to factual resource mobilization topics. The following chapter deals with the more subjective areas of enquiry, from the questionnaire, including attitudes to death, dying and terminal care, that is, what might be described as the more psychological aspects of hospice involvement.

None of those surveyed could be described as beneficiary constituents, that is, potential beneficiaries of a movement who supply resources, although indirectly some might be regarded as

such if they eventually used the hospice either themselves (all respondents said that they would consider using a hospice) or benefited through a member of their family using Martin House.

The best term to describe the voluntary workers, is conscience constituents, that is, they are sympathizers providing resources but who are not part of the 'beneficiary base.'

As suggested by the Resource Mobilization Perspective, it is the task of a movement's resource mobilization to convert adherents, those who believe in movement goals but do not mobilize resources, into constituents, and to convert non-adherents or the, "bystander public," (Turner, 1970), into adherents. One hundred percent of those questioned, from the Martin House Project, indicated that they had brought people into the project who were previously unconnected with it.

Of those questioned, from Martin House, the contributions made included specialized resources, time and commitment. (68%) contributed financially; (88%) contributed in terms of labour, which sometimes involved using their own facilities, for example holding a coffee morning at home, for the appeal; and (16%) contributed specialist knowledge. Among those in the last category, the form of knowledge included medical experience and fundraising techniques.

In the case of Martin House and the wider Hospice Movement, the notion of 'opponents' is not especially relevant to resource mobilization except in terms of competition from other SMOs vying

for the patronage of both the bystander public, adherents and 'elites' controlling larger resource pools.

Such elites included local and national businesses such as Frigidaire and British Telecom, both providing equipment, government funded organizations such as the Manpower Services Commission, which provided landscaping through the Community Rural Aid, together with the Youth Training Scheme which provided an administrative assistant. As a charity, the project could take advantage of nonconstituency institutions such as the exemption from rates, refuse clearance and enviromental health workers who would service the hospice Jacuzzi, used for physiotherapy.

Possibly surprisingly, the National Health Service, which the hospice was intended to supplement, did not figure directly among relevant target elites. There was no direct financial link from the NHS, although the District Health Authority was actively involved in an official adminstrative capacity, monitoring and sanctioning developments. Indirectly the NHS provided all the medical staff appointed by the Martin House Governors, as all had NHS experience. All the professionals recruited were from the Local Authority. Besides health professionals, these included teachers and social workers.

McCarthy and Zald (1977) made certain hypotheses regarding the constituencies of SMOs (see chapter outline R.M.). It



certainly appears to be the case, in the Martin House Project, that it is provided with resources by organized groups of conscience constituents e.g. the various Friends Groups, as opposed to resources being made available due to potential beneficiary adherents. This, though, is not to say that the Martin House SMO arose in response to potentially available resources among conscience adherents.

Martin House constituents do not seem to be isolated, although they are, to some extent, widely geographically distributed, hence the flow of resources does not seem to have been hindered. Neither have the constituents, both conscience and potential beneficiary, been organized into federated chapter structures as a means of achieving solidarity, avoiding the resulting tension predicted by Zald and McCarthy (1977). (44%) of respondents had experienced some form of organized contact with potential beneficiaries of Martin House, while (48%) had no experience of organized contact with people who will be using Martin House. The formal contact which did occur between these groups, who are not incidentally, identified as discrete groups outside this study, was in the form of open days, speaking visits involving parents of ill children, and did not involve the formation of the kind of structures described by McCarthy and Zald (1977). Due to the exclusive nature of the hospice, being just for children, their parents are regarded as beneficiaries, as for the most part, it would not make much sense to regard the children in terms of, for example, chapter membership.

Indirectly, and with qualifications, beneficiary constituent

workers are recruited for strategic purposes. The family of some ill children were prominent in the laying of the Martin House foundation stone, a public ceremony, but this would appear to be more involvement of already closely involved families for internal group purposes rather than the strategic public use of potential beneficiaries. (MHN No. 6 December, 1986). Potential beneficiaries are featured regularly in Martin House newsletters and one element of this coverage could be interpreted as the strategic use of beneficiaries. The families of ill children are not simply recruited in a strategic capacity, if at all, rather they are involved, as are many other conscience constituents in organizational work. There does not seem to be a clear relationship between the relative isolation of constituents and strategic use of potential beneficiary constituents.

Dealing with the last of McCarthy and Zald's hypotheses relating to constituents, it would appear that at least (40%) of those questioned had discretionary time; (28%) housewives and (12%) retired, and their involvement as heads of Friends Groups suggests that discretionary time can be used in the formation of what might be described as, "transitory teams," (McCarthy and Zald, 1977, p.1237).

Turning to the Social Movement Organization structure of Martin House, (M.H.), there appears to be a marked lack of centralized control over the wider elements of the project, such as the Friends Groups, and much of the ad hoc fundraising organized by loosely affiliated constituents. In this sense the SMO is relatively inclusive regarding participation in resource

mobilization and this lack of exclusivity is reflected in the interaction with relevant elements of the existing social system, such as the local council, churches, the National Health Service, British Telecom and various local firms and businesses.

Of the leaders and spokesmen of the Martin House Friends' Groups questioned, only about one third, (32%) felt that project activities were determined by a controlling body. Thus any direction from the Martin House committee of Governors was not intrusive or overt from the point of view of the Friend's Groups. Although contact between the disparate groups and M.H. was encouraged by the central group of the Martin House Appeal based in Boston Spa, it was left to the relatively autonomous groups to arrange visits and most of the fundraising activities. The responsibility of Friends' Groups for their own actions enabled the emphasis of the central project group to be on goal attainment, that is establishing a working and relatively secure hospice, rather than on group maintenance.

Consideration of factors external to the Social Movement or in this case the Social Movement Organization, is possibly one of the main strengths of the Resource Mobilization Perspective. External factors include both other SMOs, in the network of cooperating-competing organizations, together with the authorities. Martin House, not suprisingly, has intimate contacts with Helen House, the only other childrens' hospice. In terms of organizational procedure and example, together with sharing adherents and constituents and more intangible resources such as encouragement and emotional support, Martin House and

Helen House can be seen as cooperating SMOs, although in some sense they may compete for similar resources.

Martin House is affiliated to the Association of Hospice Administrators, although is not particularly active in this national association. From the Martin House administrator it appears that there is no overt competition for resources with other northern hospices, although it was felt that in the inevitable search for support, Martin House, as a childrens' hospice was, "on the winning side," (Robin Wood, M.H. Administrator, personal communication) due to its "sentimental appeal."

The authorities and agents of social control were only influential on a local level. Throughout the project the District Health Authority monitored the progress of Martin House so as to register the hospice - a prerequisite for the hospice to become operational.

The only major obstacle to project success presented by the authorities, in this case, Leeds City Council, was the initial refusal to grant planning permission for the hospice building. The Martin House team felt that the Council misunderstood the project and wrongly assumed that the hospice represented some form of private medicine, something to which the Labour Council was ideologically opposed.

Turning to the activation of the public and various elites, who control desired resources, outside agents were used for

project publicity. Various personalities and celebrities were visibly associated with Martin House. These ranged from the Duchess of Kent, already linked to Helen House, to the Disc Jockey, Jimmy Saville, famous for his charity fundraising efforts, international footballers, the Lord Mayor of Leeds and Mother Frances, the founder of Helen House, well known in hospice circles.

The regional newspaper, the Yorkshire Post adopted the project and became involved to such an extent that the Medical Correspondent of the paper is Chairman of the Board of Governors of Martin House. The Yorkshire Post regularly featured the hospice project, raising awareness, support and money.

Television also covered the project. Yorkshire television showed an hour long documentary on Martin House while other local stations featured news items on the project, particularly at Christmas. The hospice project team did not appear to make strenuous efforts to gain media coverage, but this may have been partly due to the motivation of the Yorkshire Post editorial team to take the initiative regarding regular and frequent coverage of the project. The paper's adoption of the project negated the need for the Martin House SMO to allocate resources towards maintaining audiences, as the, "issue attention" (Downs, 1972) of the paper's readership was seemingly continuous.

The project made its own efforts for publicity through the publication of an appeal folder including a brochure about the project background and aims, together with information about how

help could be given to Martin House. These were distributed through existing project and social networks, which were often one and the same. The project team laboriously searched through the available lists of trusts to find suitable bodies to approach with the Martin House Appeal information.

As outlined earlier, local firms and branches of national companies became involved in broadcasting the existence of the appeal by the donation of a car, an information caravan together with public presentations of money to the appeal.

In this way, use was made of established networks external to the Martin House Appeal and to the wider Hospice Movement. Resources were mobilized by commercial groups utilizing their own connections which existed totally independently of the hospice appeal. An example of this is the appointment to the governors, early in 1986, of the Chairman of Fridgidaire, who donated most of the electrical appliances and represented Northern businessmen.

The use of existing facilities extended from business support from interested companies, the credit arrangement facilities provided by Barclaycard and Access, to the spiritual support of the Sisters of the Order of the Holy Paraclete.

Methods of resource mobilization adopted by Martin House, together with the kind of support the appeal attracted, reflect its public image of a relatively local and uncontroversial social movement organization. Hence the violent reactions of the

authorities or opposition groups to some social movements, included as important external influences on movement success, in much resource mobilization literature (see, for example Bromley and Shupe, 1979), are not readily applicable to either the British Hospice Movement or Martin House, as a constituent SMO.

A final external factor said to influence resource mobilization is the level of affluence in the SMO's context. The immediate area around Martin House appears as rural and relatively affluent, with, if anything, a middle class population, although the sphere of interest of the project includes the nearby urban centre of somewhat run-down Leeds, with a cross-section of ethno-socio-economic status individuals. Although hard to quantify, the impression gained of many of those involved in the project is of reasonably comfortable, although by no means necessarily rich, upper-working class and middle class individuals. It can be said, with reasonable confidence, that the levels of affluence amongst the target groups within the broad context of the Martin House Appeal, were sufficient to not be an obvious hinderance to resource mobilization.

The Martin House Project provides a useful example of many of the main aspects of resource mobilization as outlined by proponents of the Resource Mobilization Perspective (McCarthy and Zald, 1974). Martin House demonstrates the interaction between resource availability, the preexisting organization of relevant structures and the entrepreneurial attempts to establish a viable service.

CHAPTER SIX

RESOURCE MOBILIZATION AND HOSPICE PROJECTS: DEFICIENCIES

The Resource Mobilization perspective can be seen to be useful as a description of the process of social movement organization (SMO) development, providing useful terms and structures with which to organize a view of project activities. Yet this approach is limited in its scope due to a neglect of equally important and complementary factors influencing the form of SMO activity.

This chapter intends to indicate various areas of deficiency in the Resource Mobilization approach by suggesting the relevance of factors which it ignores or minimizes. Such influences upon social movement genesis include, necessarily, the nature of the movement and the attendant beliefs or ideology. The work on attitudes to death, both societal and individual, covered in earlier chapters, is pertinent to project adherence and activity. Social grouping, based upon extra-movement beliefs, such as religion and politics, is seen to be important, as are individuals' experiences pertaining to death and care for the dying. Individual involvement in SMOs is considered in relation to psychological approaches to personality, motivation and various aspects of moral behaviour such as altruism, religiosity and moral ideology.

The Hospice Movement provides a good example of a social

movement in which SMO success is as dependent upon qualitative factors such as belief and experience, as upon quantitative resource mobilization. By asking what the Hospice Movement is, what attitudes it represents and encourages, it is possible to go beyond a purely, "nuts and bolts" approach to social movements. To summarize what has already been stated regarding the nature of the Hospice Movement, in its societal context, the Movement has been described as being in alignment with various of the counter-institutions of the 1960's and early 1970's (Abel, 1986). As such, it was believed to share the values of these alternative organizations, values which emphasized egalitarianism, where traditional operating distinctions were replaced and the primacy of the individual human being was asserted.

Through honest communication it was intended, as we have seen, to restore to the individual a certain autonomy, a say in his own death, thereby enabling a semblance of dignity for the dying person. The view of the human being was one of an active, decision-making individual, right up until death, "a giver as well as receiver," (Buckingham, 1983, p.67).

Hospice aimed to facilitate various qualitative aspects to dying. Within the holistic, humanitarian hospice approach, specific attempts were made to alleviate pain, communicate openly with patient and family in conducive surroundings, cater for the bereaved and to pass on the lessons learned through training and education for other terminal care-givers.

Just as the Hospice Movement is in favour of certain things,

so it opposes certain existing attitudes and practices. The Hospice Movement is seen to stand against the notion of death as failure, either medical or personal, rather seeing death as a natural event. It also opposes superfluous medical interventions whose only function is to prolong dying in the face of imminent death.

Adherence to Hospice Movement beliefs, referred to earlier, can be reasonably seen to be a likely, even necessary, component of involvement in a hospice project as there are limited tangible benefits to be accrued from project membership, beyond the satisfaction of being involved in what is felt to be a 'good' cause, aiming to do the 'right' things. Much of the early work, setting up a project is mundane and repetitive, demanding time, sometimes money and most often labour - 88% of those questioned from the Martin House Project, contributed labour. The work is neither glamorous nor financially rewarding for the individual. Nevertheless, mixing with like-minded people, working for a common cause, prompted 88% of respondents to feel that their ideas regarding hospice had been reinforced, with 12% whose views were unaltered by project involvement. This suggests that the underlying philosophy of hospice and associated attitudes are of importance to constituents and that it is not merely the incidental social interaction which is rewarding.

Hospice constituents from the Martin House Project were asked directly about their perceptions of societal attitudes toward death together with their own. Although by no means unanimous in their attitudes and appraisals, the respondents

displayed views which generally concurred with the conclusions drawn about societal attitudes to death in an earlier chapter, for example 52% felt that suffering and death are increasingly institutionalized, that is, removed from the public gaze and catered for by specialists. 24% were unsure. 52% also felt that the prevailing attitudes encountered in daily life tended to involve the denial or ignoring of death, 12% felt that there was an attitude of openness towards death, while 36% felt that neither was particularly evident, although comments were added that death was trivialized by media coverage.

Of those who expressed a firm view (N=16) 87.5% claimed that their own attitude towards death was one of acceptance and openness, whilst the remaining 12.5% said they preferred to ignore death.

Despite just over half the respondents feeling that prevailing societal attitudes to death involved a denial or ignoring of death as opposed to the contention made earlier that societal attitudes were better described as death transforming, an interesting observation is that nearly two thirds of those questioned had strong attitudes towards death, with nearly ninety percent of these describing their own attitude to death as, one of openness and acceptance. It may be considered that such views are not wholly founded in ignorance or inexperience of dying, for even aside from personal experiences of death, 80% of the respondents had visited a hospice, and hence could be presumed to have some experience of death and dying.

It appears that those questioned hold reasonably strong views upon death and attitudes towards it, but more impressive in terms of consensus of opinion within the group questioned were the attitudes of constituents towards terminal care facilities. 96% felt that existing facilities for terminal care, excluding hospice care, were inadequate, with 4% unsure. When asked if they felt that hospice provided the answer, 76% were affirmative, with the remaining 24% either unsure or feeling that hospice provided a partial answer. 100% said that they would consider using a hospice, surely an indication of strong belief in the cause for which they worked. Although such views may not be atypical they indicate certain shared concerns among members of the hospice project.

Possibly the increased certainty regarding questions about terminal care relative to the more diverse responses to other question topics, resulted, in part, from the closeness of care to their every day activities. This can be contrasted with the relatively abstract nature of how they perceive societal attitudes to death. The impression from some interviews was that terminal care was something the constituents felt something about, whereas more nebulous issues pertaining to death and dying had to be thought about at greater length, before attitudes could be articulated. Rather than concluding that this implies some sort of denial of death, it might be simply that the deeper philosophical aspects of death are not an everyday topic for thought and discussion, although when confronted with such issues, the constituents readily considered and expressed their views.

Adherence to, and membership of, a social movement organization, and hence a social movement, can be seen to depend upon shared beliefs at a different level from that of attitudes directly concerning death and care of the dying. Social grouping, pre-dating S.M.O. involvement, based upon extra-movement beliefs are seen to be important.

It has already been indicated, from questionnaire responses, that personal contacts accounted for 68% of initial involvement in the Martin House project. 96% of those questioned reported that their introductions of new people into the project were based on existing social connections. 76% of respondents said they met socially with other members of the project group. These figures alone do not necessarily indicate extra-movement attitudinal affinity, simply an existing social network. The use of such networks in the mobilization of resources is included in the Resource Mobilization perspective, but the attitudinal, even ideological component of such networks appears not to be considered as a significant factor, and is duly under-emphasized.

In terms of resource mobilization, a possibly important factor influencing behaviour is political belief. Although rather general and stereotyped, it might be thought that, depending upon the issue, those with a Conservative orientation might be more inclined to take the initiative without expecting government help, believing in personal enterprise as a means of achieving a desired goal. Comments added to the questionnaire tended to support this notion of a general correlation between

political affiliation, 44% were Conservative Party voters (this represents around 60% of those who reported political affiliation) and advocacy of personal initiative in S.M.O. activities. Only 8% felt that it was solely the duty of the government to provide money for the Hospice Movement. Nearly one quarter (24%) felt that it was solely the duty of individuals, whilst 68% felt that both the government and individuals should contribute to such causes.

The impressions of an orthodoxly right-wing core of conscience constituents was further reinforced by the presence of a significant majority (80%) claiming allegiance to and membership of the Church of England. The remaining 20% comprised 8% Catholic, 8% Methodist and 4% Jewish.

Through interviews with several members of one of the Martin House Friends Groups (Leeming Bar), the closeknit, Church-going, Conservative character of many of the S.M.O. constituents was brought into sharp focus. Here an established Church of England social network was clearly evident. In voting Conservative many of the Martin House constituents were by no means unusual, especially those in the Leeming Bar Friends Group, whose parliamentary constituency returned a Conservative Cabinet Minister at the last election. These Martin House Friends numbered among the 84% who reported that their religious views had made them more positive towards death, dying and care of the dying. Interviews indicated that the notion of a 'good death', as described earlier, was prevalent and important to those involved in the Martin House Project. Qualificaitons were made

however, both in interview and on the questionnaire, about the qualitative aspects peculiar to childrens' death. This was stressed as an important factor by many respondents and was cited as a reason for particularly specialized and dedicated care. Alongside the notion of a 'good' Christian death for children, it was felt that distraction and occupying of sick children was especially important, together with added support and comfort for the parents of terminally ill children.

Respondents who had experienced the death of a child known to them seemed particularly committed to efforts being made to establish an exclusively childrens' hospice. This may not appear to be especially remarkable as it might well be expected that such experiences would influence attitudes towards care of the dying, but this is exactly the issue. Past experiences should not be casually included as simply a possible constraint on resource mobilization (McCarthy and Zald, 1977), rather it should be suitably emphasized as a significant motivating force influencing, both quantitatively and qualitatively, S.M.O. adherence.

76% of respondents claimed that close experiences with death had influenced their beliefs regarding death, dying and/or care of the dying. This 76% comprises 52% who cite close personal connection with death, and 24% whose experiences include those gained through their work in a medical context. This 24% is almost the same 24% who are, or have been, occupied in some form of health or medical occupation. Others experiencing death through their occupation are clergymen, together with their

spouses.

Although not all those who reported attitudinal changes as a result of experience of death clarified what these changes involved, those who elucidated the nature of experiential influence were strongly in favour of hospice care as an alternative to existing inadequate facilities for terminal care, as cited above. Experiences with death seem to have been largely unsatisfactory in the sense of impersonal medical service, long, drawn-out illness accompanied by severe pain for both the dying and their relatives, and exclusion of family and friends resulting in isolation of the dying.

Thus, past experiences, both bad and good, in the sense of unpleasant memories of non-hospice death together with good impressions of hospices from both visits and personal contacts, are perceived as important factors in the motivations of individuals who chose to become actively involved in a social movement, where the major discernable rewards appear to be in the form of satisfaction with the knowledge of active involvement in a needy and worthwhile cause. Such individuals are aptly named, conscience constituents.

A further point, suggested during an interview with the leader of the Aylesbury Hospice Appeal, a project to establish a ten bed adult hospice within the grounds of the local hospital, serving the Aylesbury area, in Buckinghamshire, worthy of investigation in future work is what might be termed a, "loss" or "void" hypothesis. It was evidently apparent through

coordination of the Aylesbury Appeal that a notable number of constituents had experienced some form of significant loss in their lives, creating a void, which involvement in the hospice project might help to fill. The losses involved included several constituents who had lost husbands, those who lost other close family members, and those who had recently lost a full time job, be it through retirement or otherwise. One such lady had verbalized this to the Appeal Leader suggesting that she really would not know what to do with herself once the Appeal finished. Some comments made by respondents from the Martin House Appeal indicated that involvement in such a project was a good method of spending one's retirement.

It would appear that an evaluation of significant life events among social movement constituents might reasonably be expected to reveal other important motivating factors towards S.M.O. adherence and activity. This again, supports the contention that it is inadequate to characterize social movement membership as a mechanistic, impersonal process, in which individual belief, experience and social context, together with personal needs are relegated to a position of relatively minor importance. An appreciation of the interaction of a certain set of psychological preoccupations with the mechanics of movement development is necessary in order to reveal how psychological components come to be influential. Taking a psychological approach only fails to show why, for example some people who share relevant beliefs with constituents might not become drawn into movement activities. Physical opportunity and ability coincidental with appropriate and conducive psychological

predispositions are necessary prerequisites of movement involvement.

Thus, it is being suggested that two broad sets of conditions, that is, those related to the individual, and those of the wider Resource Mobilization perspective, are more or less sufficient for providing an overall appraisal of Hospice Movement involvement and activity.

To suggest that Resource Mobilization literature does not include reference to, so-called psychological factors would be unfair and incorrect. But the form in which these are presented does not appear to do them justice, qualitatively or quantitatively. For McCarthy and Zald (1977) they represent constraints upon the use of resources. The five categories of constraint, of which these form a part are; values (Turner, 1970), past experiences, reference groups, expectations and relations with target groups (Turner, 1970). Such constraints are depicted as forming a constraining 'filter', between the resources and the S.M.O., one which can drastically alter the raw resource before it becomes available to the S.M.O.

Psychological factors which are described as constraints appear to be transformed from a human concern, relevant to actual, acting individuals, into an almost economic, practical consideration, devoid of personal meaning beyond its effect upon the mobilization of resources for an S.M.O. An illustration of this is provided by the work of Oberschall (1973) in which he claims that risk-reward or cost-incentive considerations are

central to an understanding of mobilization. As stated above, (R.M. Outline), at each stage the cost-reward balance for members and leaders is crucial to any explanation. The cost-reward balance for constituents may well be crucial, but those psychological components underlying an individual's decision, regarding costs and benefits, are of significant importance in providing a deeper understanding of motivations, thus in this sense going beyond a simple economically-oriented evaluation of resource attainability.

Results from the survey of Martin House constituents indicates how particular attitudes, rather than representing constraints upon mobilization, act to facilitate the attainment of resources, namely, money. 64% said that there were no methods of fundraising which they considered to be unacceptable on either personal or moral grounds. 28% said they did object to certain fundraising methods, including gambling and tobacco and alcohol related money, whilst 8% did not know what they thought. 64% did not know of any firm or agencies from whom they would find it difficult or unacceptable to receive contributions. 24% did envisage certain firms being problematic as contributors, for roughly similar reasons as in the previous category. 12% were unsure.

From these results it is not hard to imagine the potential potency of psychological factors, for a social movement organization, and hence a social movement, in a constraining, facilitating or transforming capacity.

Motivation

Individual involvement in S.M.O.s has been considered in broadly psychological terms, but is useful to look closer at some relevant work in mainstream psychology, by outlining some approaches to motivation together with various aspects of moral behaviour, especially altruism. A study of such areas is felt to be especially pertinent to a complementary psychological perspective when examining social movements in the context of resource mobilization.

Motivated or 'goal-directed' behaviour is generally regarded by psychologists in terms of a series of processes which start, steer, sustains and eventually stops a certain behaviour (Taylor and Sluckin, 1982). Necessarily, motivation is a huge topic, but its scope can be limited in a study of S.M.O. involvement to various aspects within a social context. Adler (1870-1937) suggested that a mature person develops, "social interest" (1939) - a comprehension that co-operation with others for mutual benefits within society is a good strategy. Thus there must be a reconciliation between self-interest and social co-operation. At one level, S.M.O. involvement would appear to require some form of, "social interest."

Work on values and self-identity (Maslow; 1968, 1973) particularly self-evaluation, suggests that motivation to achieve certain higher order needs, such as those involved in the establishing of a better system of care for other people, is related to the attainment of various lower order, "deficiency

needs," ranging from food and warmth to self-respect and status within society. The concern of conscience constituents for an external cause is one indication of what Maslow (1973) refers to as a, "self-actualized" individual. Much of Maslow's work requires clarification to be of use in evaluation of individuals adhering to a social movement, but the concepts involved, which include an individual's use of value-judgement and self-appraisal to guide behaviour, are of potentially significant importance in an understanding of individual activity in the context of social movements.

To some psychologists, "the acquisition of personal values and the application of value-judgements in relation to self-concepts is a central concern," (Taylor and Sluckin, 1982, p.583). Inherent in this aspect of personality, and of significance for movement involvement, is a facet of moral psychology, namely, altruism.

Communal living demands that occasionally the individual put the interests of others first. Social acceptance depends upon acknowledgement, by the individual, of obligations to the group, which may take precedence over his own interests. Religions, "have urged that a disinterested concern for the welfare of others is one of the highest ideals that men can pursue," (Wright, 1971, p.126). Both society and religions may recognize and approve of such behaviour and the latter, "promise such benefits as the peace of mind of a clear conscience in this world and rich rewards in the next," (Wright, 1971, p.126).

Altruism might be measured in terms of the various costs of an action to the individual. Yet Wright (1971) adopts, as a working hypothesis, the proposition that altruistic tendencies are encouraged or minimized according to whether their consequences are satisfying to the individual or not. Such rewarding results may not be obvious as their nature may be subtle or obscure.

Respondents from Martin House indicated that much of their behaviour was motivated by belief in the hospice cause but factors such as social interaction, alleviation of boredom, and in-group conformity may well be involved in movement adherence. The notion of altruism as social conformity, that is, altruistic behaviour constrained and directed by the norms of the group to which the individual belongs, together with his social role, suggests that the influence of others upon a person's behaviour will be relevant to an understanding of both social movement recruitment and ongoing activity. The coincidence of constituents from existing social grouping further suggests social conformity as a factor in their involvement. Related to this may be a sense of social responsibility. Berkowitz and Danials (1963) demonstrated that people feel under some sort of obligation to help those who are dependent upon them. Subsequent studies have shown that the level of this tendency depends upon an individual's social class and background, upon his attitude to those who are dependent and upon whether he has himself been helped recently (Goranson and Berkowitz, 1966; Berkowitz and Friedman, 1967; and Greenglass, 1969).

Work has been done-- of the effect of altruistic example (Bryan and Text, 1967) showing that exposure to another's altruism significantly increased altruism in those who had observed the altruistic behaviour. Rosenhan and White (1967) demonstrated that charitable giving in children was greatly increased by experiencing model giving, inspite of it being implied that others would not be aware of if they gave or not. Horstein, Fisch and Holmes, (1968) also showed that if a model is obviously pleased with his own altruism, the observer is more likely to imitate him. Again, altruistic example among members of a social group involved in rewarding social movment activity may well provide impetus for others within the group, experiencing the effects of the altruism in others, be it in the form of contentment, activity, motivation or enhanced social interaction, to become actively involved in a S.M.O. Martin House figures support this pattern of existing networks mobilizing to help the hospice project. 96% of respondents brought people into the project, that is converted bystander public into adherents and adherents into constituents, through existing social connections. Presumably those with whom people mix socially tend to be potentially influential and able to suggest new behaviours to their peers. If enough individuals within a group are seen to adhere to a certain cause, this may be established as a group norm and subsequently social role and status are to some extent determined by behaviour in relation to the cause, in this case a hospice S.M.O.

Of the potential correlates of altruism, age, intelligence and sex-difference, only the last seems to show results of

relevance to social movement activity, mainly because evidence for age and intelligence is slender, to say the least. The contention that females are more socially responsible than males, (Wright, 1971) suggests that they would display stronger altruistic tendencies. Societal pressures still tend to prepare females for a more nurturant and self-sacrificing, other-oriented role and still provide more time for females to devote themselves to others in this capacity. 80% of Martin House constituents interviewed or questioned, selected randomly from a contact list were female. Krebs (1970) conducted a thorough review of the data on altruism and found that out of seventeen studies, no sex differences were found in eleven of them. Those reporting sex differences did tend to favour females. Of particular interest, from those studies conducted, is the finding that women report engaging in more charitable activity (London and Bower, 1968).

Finally, work has been conducted on religion as a correlate of altruism. There is no firm evidence that altruism accompanies reported Christian belief. Friedrichs (1960) found a negligible tendency for reported charitable action to go with belief in God, though it was unrelated to church attendance. Cline and Richards (1965) found no evidence of a stronger "good Samaritan" attitude in believers than in non-believers.

It is possible that the social context of religion is more important, to many individuals, than faith itself. Drawing a distinction between such individuals for whom religion answers needs for social status, respectability and unity with others, and those who don't seem to require psychological supports from

religion yet attempt to live their lives according to the teaching to which they are committed, may provide a method for approaching social movement adherence. Replacing religion with movement involvement in the above distinction may prove enlightening as to the composition and motivations of those involved in a given social movement or S.M.O.

It has been suggested that various psychological factors play a significant role in the behaviour of individuals in relation to social movements. People develop various ideologies, "and some of their activities are closely related to the 'constructions' derived from the principles involved in the ideology," (Taylor and Sluckin, 1982, p.585), in this case relevant beliefs involve personal attitudes to death together with perceived societal attitudes and practices. Social grouping, be it guided by politics, religion, or even geographic proximity, influences behaviour through pressures to conform and the existence of established norms and shared values. Nevertheless it is not being suggested that movement involvement is necessarily the result of group pressure. To some the establishment of better facilities for the terminally ill represents a vocation, a prime example being Dame Cicely Saunders who founded St. Christopher's Hospice in London. There is also a place for what might be called disinterested, problem-centred altruism. Some altruistic action on the part of hospice constituents, possibly those who have experience of death in other medical service situations such as hospitals act out of a dispassionate assessment of the situation, because logic demands a certain solution to the problem. To such people a

consideration of their actions as being selfless is irrelevant. "Their attention is wholly focused upon the realization of a general value (that is not a self-orientated one) such as the increase of health ... in a community, the efficient and humane running of an institution," (Wright, 1971, p.151).

Past experiences can be seen to provide strong motivational forces towards improvement of terminal care. Many of the voluntary comments added to questionnaires emphasized the emotional impact of experiencing the painful death of a close relative, especially children, and the strengthening effect of a strong Christian belief. Many respondents cited these two factors as central to their attitudes regarding terminal care and their motivations towards movement involvement.

The Resource Mobilization Perspective proposes the utilization of existing networks in S.M.O. activity as a significant factor in S.M.O. success, but it is impossible to gain an appreciation of what such networks involve without a deeper evaluation of the psychological factors, both individual and social, at work in the field of potential and actual movement activity.

Social Movements do not automatically arise in society. They result, in part, from the purposive actions of people, both individually and in groups. Motivations for these actions are myriad and complex. An appropriate consideration of such driving forces, that is, a human perspective, is a vital component in an understanding, partial or otherwise, of social movements.

CHAPTER SEVEN

CONCLUSIONS - FUTURE OF THE HOSPICE MOVEMENT

Despite its growth and success, the Hospice Movement in England faces changes which would drastically alter hospice care as it has been for the last two decades and even end the Hospice Movement as an observably discrete form of terminal care. The debate within terminal care is whether or not the Hospice Movement should be integrated into the medical mainstream, or remain as a more or less independent movement, maintaining its own philosophies and practices which distinguish it from the larger more impersonal N.H.S.

This debate, in some ways, parallels the distinctions made in this study between the competing emphases for looking at the Movement. A Resource Mobilization perspective places major importance upon organizational and financial considerations, the "nuts and bolts" of movement working. The alternative, complementary approach, proposed here, aims to supplement the impersonal, purely functional Resource Mobilization approach with a psychological perspective, intended to promote individual beliefs and attitudes, inherent in the movement, to a position consistent with their undoubted influence.

Somewhat analgous to the Resource Mobilization emphasis is the urge towards movement integration into the mainstream of

health care. The pressures for integration are inextricably linked with the variety of funding resources, together with legitimation and status enhancement and a move towards hospice bureaucratization and professionalization.

Opposed to this trend are the so-called hospice fundamentalists who feel that an organizational and materialistic emphasis, in hospice projects, could herald the subsequent neglect of the human, spiritual and religious concerns of the founding members of the movement. It is this qualitative aspect of the concept of hospice which is seen to be under threat from an integrated system of terminal care, in which increasing store is laid by operational efficiency and value for money. These are the very aspects of the existing health care system which the Hospice Movement aimed to abolish in its treatment of the dying.

The integration debate represents a thorny problem for the Hospice Movement, with both sides having legitimate claims to have the interests of the terminally ill at heart. The integrationists claim that effective terminal care is not feasible outside the relative resource security of the mainstream National Health Service, and the fundamentalists feel that the very qualities of care peculiar to hospice and vital to satisfactory treatment of the dying are doomed in a huge resource-oriented, cost-effective bureaucracy.

The Hospice Movement in North America provides a magnified forum in which to observe much the same battle. Already in the U.S.A., legislation has been passed pertaining to hospice funding

and more assessment has been made in academic and medical journals, of the results and implications. Thus it would appear useful to consider the North American pattern, as portrayed in published papers, as an indicator of the possible consequences of integration for the Hospice Movement in England.

"Many of the initial hospice programs in the United States developed outside hospitals... Hospitals were generally not interested in the care of the dying and in some instances were actively hostile to the idea of special care of the dying," (Torrens, 1985, in, Cunningham, 1985, p.124). In hospice programmes, "much of the leadership and motivational force comes from nonprofessionals and from the general public," (Torrens, 1985, in, Cunningham, 1985, p.124). The results of this, according to Cunningham (1985) are both good, due to the subsequent innovation and change, and bad, because of the antipathy felt by some hospice workers towards hospitals and doctors which colours hospice attitudes towards established aspects of health care.

Nevertheless, there have been various pressures on hospice programmes, to accommodate the existing health care system. Kanter (1972) suggested that the inability of utopian societies to remain self-sufficient meant that the boundaries separating them from the surrounding society tended to dissolve. They gradually lose their distinctiveness as products and personnel are exchanged. Hospices are no exception to this pattern, (Abel, 1986). Commentators have discussed the dangers to social movements of relying on external sources of funding. McAdam

(1982) claimed, "The establishment of external support linkages threatens to tame the movement by encouraging insurgents to pursue only those goals acceptable to external sponsors," (p.97).

The success and growth of hospice programs relies upon the ability of its members to persuade other individuals and institutions (elites) to provide resources such as money, legal entitlements and public support (Levy, 1982). Some home-care programmes depend upon community hospitals and nursing homes for in-patient care and many in-patient facilities supplement their services through home health agency contracts (Buckingham and Lupu, 1982). Often community-based hospice programmes are actually coordinating those services provided by pre-existing local agencies. Another reason for hospice acceptance of the medical community is that hospices are dependent upon hospital discharge planners and private physicians for referrals.

Thus, integration is the major strategy used by hospice programs to gain organizational stability. "The archetypal integrated program attracts support from members of the medical and business community and is bureaucratic in structure, relying on a paid staff for patient services. It does not rely primarily on volunteer and community support and places a high emphasis on building a stable economic base through use of third-party funding," (Paradis, 1984, p.387-388). Before outlining the form of this 'third-part funding,' it is worth noting that the emphasis upon fiscal security and integration mirrors the pattern of movement growth and development described by a Resource Mobilization perspective and involves the attendant neglect of

ideological motivations underpinning the hospice philosophy which are of comparable importance to movement direction and success.

Returning to third-party funding, which has become a significant bone of contention within the Hospice Movement, it can be seen that hurried legislation has produced many dilemmas for hospices. "In 1982... Congress passed legislation enabling certified hospices to receive medicare reimbursement. What emerged is a reimbursement program that differs substantially from the movement that spawned it," (Greer and Mor, 1985, p.5). The Tax Equity and Fiscal Responsibility Act (TEFRA) of 1982 is regarded as a mixed blessing, (Abel, 1986). On the one hand it officially approves the Hospice Movement, provides various reimbursement and sets certain defining standards for hospice care. But, on the other hand, the Movement has been distorted by the conditions laid down to those organizations receiving payment under the Medicare benefit. One example is that, "hospitalization cannot exceed 20 percent of aggregate patient days and that hospices must assume financial responsibility for the cost of inpatient stays," (Abel, 1986, p.79). This encourages home-care at the expense of inpatient care, which may sometimes be more appropriate. The home-care emphasis also discriminates against hospices located in inner-city areas where a high proportion of the population live alone, (Abel, 1986).

Irrespective of incurred expense, hospices are reimbursed on the basis of daily rates for four categories of care, also a \$6,500 cap per patient has been fixed, and is applied annually on an aggregate basis. Significant numbers of hospice

administrators claim that this rate is insufficient to provide quality care. When the cost of a patient's care exceeds the cap the hospice cannot discharge them, and rightly so. But this regulation encourages hospices to consider predicted length of survival and need for expensive services in admitting, (Owen-Still, 1984). Thus it appears that legislation and the increasing role of large insurance companies in hospice care, (Cummings, 1985) have produced an overriding preoccupation with the quantitative rather than the qualitative aspects of terminal care.

In contrast with the integrated programmes, the non-integrated hospices relies heavily on volunteers and community members for patient services and financial aid, and strongly emphasizes community education and involvement, "rather than the development of third-party funding mechanisms," (Paradis, 1984, p.388).

Overall results suggest that as hospices become increasingly integrated they lose some of the idealism upon which they were founded, and have changed their organizational structures together with the pattern of their patient care. Conclusions as to the general benefits or otherwise, for terminal care vary. Paradis (1984) claims that there is no evidence to suppose that integration into the medical mainstream has adversely affected the quality of patient care or patient satisfaction with hospice services. Abel (1986) has more reservations. Referring to the Medicare hospice reimbursement scheme she suggests that, "Though creation of this benefit may have been facilitated by increased

support for hospice ideals, the government views hospices primarily as a way to save money. Paradoxically, as hospices have grown in popularity, the critical force of the movement has been blunted," (Abel, 1986, p.71).

Despite governmental and legislative differences between England and the U.S.A., not to mention differences within the respective Hospice Movements, the integration debate on both sides of the Atlantic displays certain fundamental similarities. In order to assess the integration debate in England it is necessary to survey the domestic situation. The 1987 Directory of Hospice Services in the U.K. and the Republic of Ireland includes over one hundred in-patient units in the specified areas. In spite of some statutory funding for the costs of patient care, in some of the independent hospices, they all depend upon local fundraising and community interest for capital and most or all of their running costs, (Saunders, 1987). The vast majority of independent hospices are established as charities and run on a voluntary basis. Individual patients are not charged and medical need determines eligibility. Capital funding for local independent hospices comes from three main sources; local appeals; grants from charitable trusts and corporate funders; and, sometimes, contributions from the District Health Authority. The National Society for Cancer Relief, a registered charity, provides most of the money for the N.H.S. units, with the District Authorities making minor contributions. Sue Ryder and Marie Curie Homes are almost totally financed by the agencies who administer them.

Regarding revenue funding, the N.H.S. is an important contributor to the running costs of nearly all its own continuing care and other hospice services. A study undertaken in 1983, following the Third National conference on Hospice Finance and Administration in April, 1983, of N.H.S. support throughout all, the then, seventy seven hospice inpatient units showed that the N.H.S. support was 43.8%, (Hill and Oliver, 1984). The N.H.S. financial support is largely channelled through payment for contractual beds for N.H.S.-referred patients. Most District Authority support has come through payment for actual beds contracted at a particular time, although an example of a Health Authority agreeing to finance all running costs on completion of building is the Aylesbury Vale Hospice Project. Alternative sources of finance for independent hospices include covenanted income, trust grants, industrial and commercial corporate funders, together with individual contributions. Support groups and local Friends Groups provide further continuing support.

In January, 1987, the National Association of Health Authorities (NAHA) launched "Care For The Dying", its guidelines for Health Authorities planning the provision of terminal care. Mr. Anthony Newton, M.P., Minister for Health, spoke at the launch in London. He emphasized the need for planning in any effective and comprehensive improvements and said that the Government wanted the N.H.S. to take greater responsibility for such planning and developing of terminal care, (Cancer Relief News, Spring 1987). The subsequent Department of Health circular stressed the importance of collaboration with the voluntary sector and other statutory agencies. The Health Circular

included, in this emphasis upon collaboration, the need to come to financial arrangements with those voluntary organizations providing services deemed an essential part of the Health Authority's plan for terminal care. Also mentioned were previous circulars which outlined various legislation pertaining to guidance on contractual arrangements for treatment of N.H.S. patients in external establishments (S.23, 1977 N.H.S. Act) and to powers to assist voluntary bodies by making available to them, land, buildings, vehicles, medical supplies and special equipment, (Health Circular HC (87) 4, DHSS, Health Services Development - Terminal Care. Feb., 1987).

Whilst the authorities seem to wish for increased integration, the Hospice Movement, although not wholly united on these issues, has moved towards coordination of hospice activities. "The charity, Help the Hospices, is currently endeavouring to reach sources of funds not so far available to them and to add a more general voice to the local endeavours," (Saunders, 1987, p.1). There is general agreement that the Movement would benefit from a central organization, but doubts exist about the wisdom of reinforcing the separation from the mainstream of health care, "when its future viability rests very much on its working closely with the N.H.S. and developing an integrated system of care between hospice, home and hospital," (St. Christopher's Study Report, p.26). It appears to be hospice administrators rather than the medical personnel who feel the need for a coordinating body. The Hospice Information Centre based at St. Christopher's Hospice, Sydenham, in operation since 1983, represents a central educational facility for the Movement.

Yet the ubiquitous problem of financial security remains for many projects.

The increasing interdependence between hospice projects and the N.H.S. does not necessarily provide much comfort for those who advocate integration. Resource shortages in the Public Sector and increased, continuous pressure from the government for public enterprises to provide value for money, to hone down their activities so as to rationalize all their operations means that even areas of long established importance, which does not include specialized terminal care, are under threat. Thus the future of certain hospices is very precarious. During a period of economic constraints, the District Authorities are likely to support only those hospice facilities which most usefully complement their own terminal care services and plans.

Scepticism regarding integration comes not only from factions within the established health profession. Some of this reticence about terminal care, "may stem partly from the fact that until recently, any doctor opting for hospice work was entering a field with no recognized career structure," (Wertheimer, A., the Guardian, Feb., 3rd, 1988). Yet this scepticism is not nearly so vociferous as the opposition to integration from certain "fundamentalists" within the Hospice Movement. They claim to stand for the concept of hospice in its unadulterated form. They fear the heavy hand of bureaucracy stifling the independent and innovatory spirit of the Hospice Movement, "diluting its character and endangering not only the immediate welfare of existing patients, but also its long term

influence," (Taylor, 1983, p.39).

Nevertheless, the bulk of opinion within the Hospice Movement is in favour of closer ties with the N.H.S. and integration into the medical mainstream. In the words of Cicely Saunders, "We moved out of the N.H.S. in order for principles and practice to move back in," (in *The Hospice Movement in Britain: its role and its future.* Taylor, 1983, p.30). Thus the hospice model is seen not as an end in itself but rather as a catalyst to widespread change within the existing system. Among some of the Hospice Movement adherents there is a fear of indiscriminate mushrooming of hospice projects, founded upon local sentiment rather than a synoptic appraisal of the national terminal care needs, and this danger has worrying implications for future financial viability and quality of hospice provision. According to Taylor (1983) this has reinforced the tendency to adopt a pragmatic view of its role amongst the Hospice Movement's leading supporters. This echoes the sentiments of the Wilkes Report on terminal care (1980).

There are some obvious benefits to be gained from closer contacts with the N.H.S., in both the short and the long term, regarding the dissemination of new thinking and practice, coordination of facilities and potential financial support. It is regarding this last aspect that caution must be taken. The pre-eminence of economic considerations in the public sector, especially in education and the health service, is widely felt to be inappropriate as the major consideration. Some areas are beyond simple cost analyses, their profits cannot be measured in

purely financial terms and serious thought must precede any headlong rush into any arrangement where rationalization and profitability are of paramount importance. The Hospice Movement is a prime candidate for integration, yet it is also potentially susceptible to distortion and reduction, if economic considerations continue to prevail over those of medical and human importance.

Thus, in conclusion, as suggested before, the Resource Mobilization perspective must be supplemented and complemented by broader psychological considerations. This somewhat parallels the proposition that a Health Service integrated with the Hospice Movement needs to retain the holistic, qualitative approach that the concept of hospice, represents, if it is not to squander over two decades worth of dedicated personal initiative and effort in the field of terminal care.

CONCLUSIONS

The scope of this study, which aims to evaluate the usefulness of a Resource Mobilization Perspective upon Social Movements to the domestic Hospice Movement, has been limited to the early stages of Movement development, namely the genesis of hospice projects. Much work has been done on established hospices (e.g. Parkes, 1979), and the people who work in them (e.g. Lamerton, 1980). This study aims to assess the influences on project creation and individual involvement, together with a description of the organizational factors involved in the establishment of a hospice project.

Assessment was made on the basis of existing literature together with interview and questionnaire responses of those actively involved in a hospice project. The case study of a hospice project concerns Martin House Childrens' Hopsice. The use of a relatively specialized project, aiming to provide terminal care exclusively for children, is useful in that it bears many of the hallmarks of the wider Hospice Movement, in addition to those factors which illustrate the heterogeneity of the constituent parts of the Hospice Movement. Such specialized projects, whilst perhaps at an advantage in terms of resource mobilization also reveal the importance of an array of individual motivational factors, which may or may not be qualitatively distinct from those involved in other elements of the Hospice Movement.

Tracing the historical development of the Hospice Movement a continuity in approach can be discerned. Even from the earliest known examples of hospice, the holistic approach to care of the individual is evident. The early caregivers were truly, 'general practitioners'. Invariably the motivations behind the hospice incentives were religious, from the Roman matron and disciple of St. Jerome, Fabiola, the eleventh century Knights Hospitallers of the Order of St. John of Jerusalem to the monastery-based hospices of the Middle Ages. Christian orders, both Catholic and Protestant, perpetuated the notion of hospice from the seventeenth century onwards, through the work of the Sisters of Charity in Paris, Fliedner in Kaiserwerth, Mary Aikenhead's Irish Sisters of Charity in Dublin and later St. Joseph's Hospice in London in 1902.

These projects provided respite for those bereaft of home and family support, often the very poor, in their final days. The emphasis was upon the spiritual aspects of care, together with any physical care possible. Dame Cicely Saunders, who established the first modern hospice, St. Christopher's in 1967, encapsulates the complex of influences which can be seen at work in the modern Hospice Movement. Saunders is a qualified nurse, social worker and doctor, as well as a Christian, (de Boulay, 1984).

The Movement tends not only to concentrate upon direct care of the dying, but also upon teaching and training those involved. It is felt that the dissemination of knowledge throughout the

various constituents will lead to better standards of terminal care, both in and out of the Hospice Movement. This represents the utilization of personal and organizational networks in the development of the Movement.

It is just such an organizational perspective that is the concern of the Resource Mobilization approach. Resource Mobilization can be seen as a reaction against the previous motivational models, such as that of Smelser (1962), that is, dispositional theoretical approaches towards explanation of social movements, relying heavily on social psychology. Such models owe much to the origins of enquiry into the field of collective behaviour, with the work of Le Bon on the crowd (1895) and subsequent notions of the public. Yet despite its deemphasis upon for example collective behaviour notions of the public, such things can be seen to be important in the assessment of a social movement. In this case, the public is relevant in so far as societal attitudes influence the success of a movement in mobilizing resources, from fundraising to recruitment.

Resource Mobilization redresses the imbalance inherent in a purely 'hearts and minds' approach to social movements, with an emphasis upon how social change is achieved and organized, and upon the interaction between the movement and society. Nevertheless, it is inadequate to approach the study of a social movements without a consideration of the potential discontent underlying the activity of movement adherents. An explanation either neglecting or taking for granted a 'free-floating' mobilizable, "grass-roots support," (Turner and Killian, 1972,

p.254,) is necessarily incomplete, as for one thing, it neglects the dynamic relationship between ideology and strategy (Freeman, 1979).

The language of Resource Mobilization does though provide a set of useful terms with which to label various elements of the resource mobilization process and organization. The terms used are helpful in ordering social movement experience and thus represent an aid to clarity.

The evolution of the Hospice Movement supports Zald and Ash's (1966) claim that movement viability is enhanced by the possession of several organizations playing a variety of roles and pursuing different strategic possibilities. Within the domestic hospice scene there are various diverging emphases, specific cancer hospices, childrens' hospices, home care teams, hospital support teams, wholly independent free-standing hospices, NHS supported units and fully-integrated NHS hospice facilities.

Although the Resource Mobilization Perspective can be seen to provide a useful structure on which to hang various descriptive details pertaining to individual movements, it must be noted that the Hospice Movement is by no means typical of the types of movement often cited in social movement literature. Although dealing with a fundamental, inescapable aspect of life, the Hospice Movement is a relatively uncontentious movement. It is neither potentially revolutionary, nor violent and its relations with the authorities do not involve the type of

conflict involved in, for example, the anti-Vietnam War movement, the Civil Rights Movement in the U.S.A., or the Moonies (Bromley and Shupe, 1979), in various countries. Opposition to hospice activities, is not, on the whole, organized or readily apparent. Despite these obvious differences, the Hospice Movement is seen to be amenable to certain aspects of social movement theory.

Many of the operational processes described in the Resource Mobilization literature were observed in the Martin House Childrens' Hospice Project. Relations between Hospice Movement S.M.O.'s were seen to be close and supportive, especially in the case of childrens' hospices as only one, Helen House preceded Martin House. The benefits derived from Helen House were not only by means of direct support and experience, but the sensitization of the public, to such causes, by the prototype Helen House Hospice, appears to have contributed to both the scale and speed of response to Martin House.

Martin House represents a specialized S.M.O. within the wider social movement, a quality providing an increased strategic impact and supporting Resource Mobilization patterns. Combined with specialization, Martin House, along with the rest of the Hospice Movement, displayed the expected characteristics of both professionalization and bureaucratization, which brought with them certain invaluable experience and efficiency, mainly through the skills acquired by employees in their previous occupations.

The successful mobilization of both tangible and intangible resources was achieved thorough utilization of a wide variety of

internal and external means. Established systems of organized giving, such as covenants and standing orders, were exploited and the project produced its own Newsletters both for and by constituents; this represented an effective and reinforcing communication network, a formalized version of the regular social interaction between constituents, adherents and non-adherents, so vital to the mobilization of tangible and intangible resources.

The project was seen to coopt commercial enterprises, quite independent of any connections with terminal care, for the purposes of project benefit. In this way, Martin House demonstrated overt business strategies and attitudes, which may appear to be far removed from the philosophy of the Hospice Movement. The shared advertising of garages and banks, with hospice projects, for mutual financial gain, demonstrates commercial expedience on the part of both parties. To some this seemingly unlikely collusion may appear to be a case of questionable profit-motivated means being justified by ideologically loftier ends. Invariably though, this appeared not to be a problem for those constituents involved, who, much of the time, were free from centralized project directives, and left to their own devices to raise as much money as possible for their hospice project.

Although not overt, it would appear that when an S.M.O. benefits from a variety of discrete resource mobilizing sources, for example local Friends Groups, they may well develop a sense of amicable rivalry and competition, with regard to amounts raised. Subtle encouragement for such Stackhanovite tendencies

could well be seen to enhance mobilization levels, per group.

The relative autonomy of the Martin House constituents indicated that the central appeal body could concentrate on goal attainment rather than upon group maintenance. This suggests that at the core of the project at least, the major motivation is to achieve the Hospice goal, rather than to provide a means of social interaction for the constituents.

The Resource Mobilization Perspective emphasized S.M.O. dealings with external groups and external influences. Martin House displayed involvement with various outside bodies and elites, together with utilization of non-constituency institutions, such as charitable status legislation. Project dealings were political, with the local City Council, medical and professional, with the District Health Authority and other hospice projects, together with resource-oriented activities. Publicity represents a major requirement for S.M.O. success and hence involvement with outside agencies. Celebrities, newspapers, television, local companies all provided a means of widening the Martin House network and increasing awareness which may eventually be transformed into tangible benefit. The levels of local affluence represent an important contextual factor in the potential success of the Martin House project. This would appear generally to be the case with hospice projects, not simply due to financial support from the local population, but also hospice sites seem to display a rather tranquil, refined air. Necessarily, such peaceful seclusion, especially if in an urban environment, comes at a price. The siting of a hospice can thus

influence the type of support it receives. The spacious, countrified nature of Martin House's landscaped site represents an impressive and worthwhile goal and it is not hard to imagine the impression such an image leaves upon potential contributors attending the Martin House Open Days. Possibly visiting adherents and constituents evaluate the hospice setting, in part, by imagining how conducive it is to a peaceful, unhindered death. If this is the case, then the sites chosen by various hospices are likely to encourage support. Even those in urban environments, such as the prototypical modern hospice of St. Christopher's, in Sydenham, often achieve a surprising tranquility, creating their own peaceful oasis amidst everyday city life.

In order to achieve a more complete assessment of the Hospice Movement it is necessary to look beyond the individual S.M.O.'s and the present movement, to observe the modern Hospice Movement as the result of a revival of earlier practice. This resurgence of hospice can be understood within the context of several antecedent factors, as outlined by Sharma and Langston (1985). These are; (a) perpetual power struggle between the secular and religious influences, in Medieval times, resulting in reduced resource support for existing hospices, (b) increasing popularity of the doctrines of the protestant Ethic, Social Darwinism and Laissez Faire, (c) decline in feudal values and weakening of traditional systems of support for the extended family, neighbourhood and other local structures, (d) increasing every day influence of urban materialistic values, (e) transformation of death in its daily presentation and (f)

inappropriate treatment of the terminally ill in hospitals and nursing homes.

Care must be taken when referring to societal attitudes to death, not least because of the cultural heterogeneity inherent in modern Western societies. Grand surveys of historical attitudes have also proved problematic, for example the scheme of Aries (1974) with its attendant problems of evidence, interpretation and generalization.

However, there has been a shift towards a greatly reduced familiarity with everyday death, over the past century. This has been accompanied by an emphasis upon youth, beauty and health, procrastination regarding acceptance of the inevitable move to middle and old age. Thus the artificial prolongation of youthfulness has been partnered by the inappropriate prologation of life. The institutionalization of death, reducing its visibility from increasingly secular society, involved the professionalization, medicalization and technologization of death and dying. With the invasion of such processes into the death of men, it is easy to see the image of a resource mobilization approach to death, in society, at the expense of the essentially personal, human and often religious experience of individuals.

Technical and medical progress contributed to the attitude, within the health services, of death as failure, thus any transformation, or denial as it is commonly described, of death, is a transformation of failure. The notion of death distorting society, one which clamours for worldly success and in which

decreasing faculties and physical degeneration are unacceptable, readily conjures up images of ominous, hedonistic, "Brave New Worlds," yet death as failure, either as a product or symptom, can be seen in a wide variety of cultures (de Beauvoir, 1972).

Increasingly, experience of death in modern Western society is vicarious; death encountered in this way is trivialized and transformed, we see death of the famous, violent, unusual, mysterious and mass death. The death of everyman, institutionalized and isolated, is not evident, perhaps because it is the death of everyman, because this is what is feared, it is ugly and does not help to bolster hopes and ambitions, nor support the comfortable, sanitized world we might wish to inhabit.

The Hospice Movement, can, in part, be seen to be a reaction against such societal attitudes, against the rejection of, and disengagement from, the dying although the nature of specific units created exclusively to cater for a 'community of the dying,' might be interpreted as a modified form of a societal wish to isolate the dying and to spare the unconnected healthy and living from this reminder of our common fate. Hospice practice advocates 'intensive care,' with the emphasis upon care. On the physical side, this very much involves the alleviation of pain and the various unpleasant physical constraints. This is regarded as beneficial in itself but also because it is necessary if the individual is to play an active part in his situation. In order to achieve this, hospice staff cover a wide range of specialisms, both medical and psychological or spiritual. One of

the distinctive characteristics of this health care team is the emphasis upon involvement with the patients, a quality which tends to be discouraged in more traditional medical settings, where the stress seems to be upon institutional requirements more than on the individual. Hospices tend to allow privacy as opposed to isolation, and the role of involvement extends to the friends and family of the patient, who are regarded as an integral part of the whole dying process - both to give help and to receive it. The family are also regarded as performing a vital function in communication with the dying person, the amount and style of which is up to the individual. Unconstrained communication is regarded as an essential element in the attainment of individual autonomy for the dying. The qualitative aspects of hospice care are a means to this end. The stresses within hospice care aim to be upon the fundamental beliefs about treatment of the dying rather than upon the compromising details of organization and resource mobilization, though whether these priorities manage to survive the increasing pressures upon the Movement, remains to be seen.

However, if hospice care is to restore, to the individual, some form of personal mastery in the terminal situation, ideology and philosophical underpinnings must be manifested in some type of operational structure. Early proponents of the hospice ideal had a significant interest in the organizational aspects of terminal care, which they felt to be imperative if the care of the dying was to escape from the bureaucratized, authoritarian grasp of traditional health care, and to become established within the more conducive context of an egalitarian, more

communal environment, (Abel, 1986).-- Thus there was a concern with the professional staff relationships as well as the problems of the dying person.

Role ambiguity is seen to be inherent both in traditional care givers and terminal patients. The ill-defined dying role can be regarded as at once liberating and confining, as well as confusing due to the lack of consensus regarding what this should involve, (see DeSpelder and Strickland, 1983). Many of the hospices, guided as they are by various forms of Christian belief tend to advocate the notion of a 'good death,' that is a dignified acceptance of one's fate, combined often with some kind of spiritual peace and anticipation of continued existence in a better place. Thus while physical constraints are removed, certain subtle behavioural expectations are evident in some hospice practices, creating the impression of a confusion between personal freedom, to the extent to which this is feasible, and prescription of a certain type of institutionally defined death.

Nevertheless, the holistic hospice approach does seem to combat the fear of death (see Kubler-Ross, 1977), through its palliative care. Despite the desirability of a calm end, the actual practice of hospice reveals an acceptance of individual needs and styles, including anger. Although seen by some as a stage to be transcended, if possible, (Kubler-Ross, 1977) by others, anger is regarded as potentially freeing, in the face of what can understandably be regarded as a terrifying experience, (see Graham, "anger as freedom," 1982, p.15).

For many individuals, facing the prospect of death, comfort can be found in the adoption of a world-view, an, "affirmative collective ideology," (Becker, 1973, p.202). In this way an individual can escape from isolation, "to become part of such a larger and higher wholeness as religion has always represented,"(p.202), (see Rank's Kierkegaardian conclusions regarding neurosis, from which this is adapted - Rank, O. "Modern Education: A Critique of Its Fundamental Ideas," Agathon Press, 1968).

In the absence of a traditional world-view, religion takes on a very personal meaning. Such a lonely leap into faith, as prescribed by Kierkegaard, may just as well provide the strength needed to face death, as does more orthodox religion, although this is disputed by Becker (1973) who suggests that, "In order for something to seem true to man, it has to be visibly supported in some way - lived, external, compelling," (Becker, 1973, p.199). Perhaps this aspect of the hospice, "community of the dying," with its attendant value and belief systems, and provision for religious reinforcement, supplies many of the beneficiaries with their tranquility in the face of death. Such belonging may provide a coping mechanism in the presence of the fearful realization that we die alone and that ultimately we cannot really share the experience with even the closest of friends.

Thus hospice can be seen to be as much a prescription for a way to live, as it is for a way to die. Life and death are regarded as inherent aspects of a continuous existence. The

holistic all-embracing attitude, often regarded as a reflection of the counter-culture roots of much of the modern Hospice Movement (see Abel, 1986) is an important indicator of the major role played by, what might generally be termed, psychological motivating factors, in Movement initiative and involvement. There are intrinsic rewards for adherents and constituents, founded upon their beliefs about the need for hospice facilities. Such beliefs include personal views on death together with appraisals of societal attitudes to death and dying. Movement members, due to their activities, can be regarded as being in a position to hold views on death which are based upon more than mere speculation.

Amongst constituents, interviewed and questioned, dissatisfaction with existing terminal care service was universal, with the majority feeling that hospice care provided the best alternative, so much so that all the respondents claimed that they would consider using a hospice.

Many of the views expressed appeared to be based upon the practical considerations of terminal care, as much as upon more abstract philosophical deliberation. Constituents demonstrated very similar behavioural patterns which, again, were not overtly explained in terms of values or beliefs resulting from intellectual enquiry, but rather they seemed to consider their affiliation to interconnecting social, religious and political groups in a fairly down to earth, almost mundane manner, the impression created being that participation in these networks was the result of implicit beliefs, lived, rather than examined.

A significant factor cited regarding project involvement, and representing possibly the most tangible of the various motivating influences, was the close experience of death of another, especially in the case of Martin House, the death of a child. The latter was persistently reported as qualitatively different and more harrowing than other categories of experienced death.

It was observed that both good and bad experiences of death and dying, provided strong motivations for adherence to hospice work. Together with this, religious, in particular, Christian belief was described as central to much of the Movement activity studied. An interesting and potentially revealing suggestion from the organizer of an adult hospice appeal (Aylesbury Vale Hospice Appeal) indicated that with the motivations provided by religious belief and personal experience of death, the life events of a potential adherent or constituent are influential in movement involvement. The "loss" or "void" hypothesis suggests that the recent loss of a major aspect of an individual's life, be it a family member, partner or job, creating a gap in their life, is seen to be correlated with SMO involvement. This would suggest that such constituents are potentially cooptable by a variety of movement organizations, and are not peculiar to the hospice movement. The social movement activities of such individuals represent an area for future research.

Academic psychology is of particular relevance to the assessment of the range of constraining and facilitating

influences upon Hospice-Movement activity. Among those areas of suggested pertinence are notions of altruism, conformity, religious belief, manifested in both personal and social actions, along with the needs of individuals, at different levels of existence, (see Maslow, 1968, 1973). Included in such needs may be a requirement to belong. Becker (1973) suggests that certain people, "need the conviction of numbers in order to strengthen and externalize something that otherwise remains very private and personal... To see others like oneself is to believe in oneself," (Becker, 1973, p.200). For some movement members, belonging may represent a means of transcending their individual existence, it may provide a means by which they can achieve, otherwise unattainable, worth and esteem.

If the psychological elements involved in an integrated assessment of the Hospice Movement were to be studied in more depth, in future research, a useful approach would include extensive interviewing in order to elucidate a, social representations perspective, (see, for example, Farr and Moscovici, 1984, and, Herzlich, 1973).

Undoubtedly, there exist volumes of research in psychology, of relevance to S.M.O. and wider social movement involvement, of which the above are simply indicators. The intention is to demonstrate the need to consider the contribution of such disciplines if more complete appraisal and comprehension is to be achieved, of a movement which in its short and dynamic history has developed in leaps and bounds, and which presently finds itself in a crucial state of transition.

The rapidity and complexity of Hospice Movement progress illustrates the need to encompass a broad range of approaches in a consideration of not only its past and present, but also its future. Alone, psychological perspectives, or a Resource Mobilization approach have limited predictive power. This results, in part, from the failure of either to account adequately for the potential guiding forces, both internal and external, behind the movement. Together with an appraisal of organizational and structural aspects of the Hospice Movement, the importance must be stressed, of the internal dynamics of the movement, including the ideology, and the perceived obligations of participants, both to others and to themselves.

There is a dynamic interaction between Resource Mobilization and the psychological aspects involved. It is not sufficient simply to attempt to characterize their respective contributions in terms of a straightforward dichotomy of the 'how' and the 'why' of the Hospice Movement. Resource Mobilization influences can be seen to influence attitudes, just as various beliefs can be seen to influence resource mobilization. For example, the structure and organization of various communication networks, including social, commercial, political and religious connections, can be observed to facilitate the dissemination of information and beliefs regarding hospices and hospice ideology, which have subsequently motivated previously unconnected individuals, that is, members of the bystander public, to become adherents and constituents. Thus, there are mutual influences, suggesting that a model of the Hospice Movement, and quite

probably a variety of other social movements, should display this reciprocal flow of influences and the interaction between that which is personal and individual and that which is impersonal, for example economic, legal, political, and organizational considerations.

It is through a wider approach that it might be possible to elucidate the direction of the Hospice Movement and to gain a better understanding of its present condition and position.

Ironically the success of the Movement and its ideas has begun to raise problems and to produce strains and there is concern about, "the possible indiscriminate, sometimes emotional, proliferation of independent hospice-type units and the implications which this has for future staffing requirements, revenue costs and N.H.S. planning," (information literature from St. Christopher's Study Centre).

The need for some kind of central policy on hospice development, possibly even centralized administration of enterprises, is particularly acute if the current political trend towards privatization continues. Cancer News (1987) reported the call, from a conference on children's hospices, for a halt to the proliferation of hospices for children. " Prof. Eric Wilkes, Co-Chairman of Help the Hospices, has written to the Minister of State for Health, Mr. Anthony Newton MP, calling on him to use the influence of his department and the health authorities to resist further developments in this area... Children with grave diseases are best cared for at home and the hospital and

community services should embrace the philosophy of care demonstrated at Helen House," (Cancer News, 1987, p.3). This move by a central hospice body indicates the mobilization of external elites in order to coopt various non-constituency institutions to impose a specific direction and control upon S.M.O. activities.

Increasingly there are moves amongst the members involved in national Hospice Movement policy to provide more home care and cooperate with the N.H.S. in the de-emphasis upon in-patient care, where at all possible. In part, this is due to the government imposed need for "rationalization" in all areas of the public sector. With the inevitable capitulation of philosophically motivated Hospice Movement exclusivity, in the face of bare economic requirements, the Movement heads for integration with a threatened public enterprise, the N.H.S., whose present status is precarious.

Irrespective of the state of the N.H.S., for those who value the continuance of the Hospice Movement, there is reason for caution and anxiety. The Movement's progress is rapidly making itself unnecessary, at least in its present semi-independent form. For many involved in the Movement, the attitude is reflected in what might be termed, "the teacher idiom." This is that if the teacher performs its function properly, the teacher becomes redundant. The Hospice Movement's integration into the mainstream and the proliferation of its ideas within existing services, sound the death knell of its independent existence. This is not necessarily unfortunate, if the medical establishment

truly learns from the example of the Movement, although the creation of a hospice atmosphere, conducive to the expression of the essential components of hospice, will be less easy to achieve in existing terminal units, connected and imbued as they are, with the traditions of their parent structures and institutions. In spite of this it might be hoped that within the prevailing political climate of private enterprise and individual initiative combined with the tightening of public sector belts, there will still be room for motivated, vocationally-oriented hospice supporters to influence practice.

A potential benefit of the incorporation of hospice philosophy into the N.H.S. is that the values espoused for care of the dying will be, "applied to a wider segment of medicine, dealing not just with terminal illness but also with chronic complaints," (Manning, 1984, p.165) and beyond. The holistic, humanized approach to health care would be especially welcomed in the treatment of the elderly in society. Presently, ageist attitudes reflected in societal neglect and institutionalized isolation for a large proportion of what is a rapidly growing segment of the population, must be combated if all responsibility for the parents of the present generations is not to be effectively abdicated. The old deserve the type of treatment advocated by the Hospice Movement, not because they are dying but because they are still very much alive.

"The principles of hospice care... may be seen as a distillation of the best in medical practice - and therefore have significance beyond the field of terminal care," (information

provided by St. Christopher's Study_Centre, 1987). Implicit in this approach is the acceptance by health service professionals of greater responsibility for, "the general well being of the patient and not just the treatment of symptoms of physical or mental illness," (Ibid).

Until such integration and extension of ideals is achieved, the Hospice Movement must be cautious, as, "they are often seen as elite and selfish units, unsure of their own motives, opposed to all forms of traditional medicine, at war with bureaucrats, social planners and the conventional medical establishment," (Manning, 1984, p.166). She continues to quote Torrens, who suggests that the new challenge for the Movement, rather than being simply the fight for existence and identity, is to match their identity to the requirements of community and culture, to move onto new projects and into previously unconquered areas and so provide, "a catalyst for future developments," (Torrens, in Manning, 1984, p.167).

It would seem that these aspirations will only be achieved through an emphasis upon the type of factors described in a Resource Mobilization approach. To survive in what is, in effect, a commercial environment, the Movement needs to consider its economic viability, especially if it is to continue to embrace the health service mainstream. Contrary to what has been described as the counter-culture origins of much hospice ideology, the Hospice Movement, integrated or otherwise, only represents one institution replacing or supplementing another, a qualitative change in the care offered, rather than a rejection

of institutions per se. The institutional nature of the Hospice Movement is reflected in what appears to be a strong conservative element among its adherents, although this is not to suggest that the Movement is homogenous, either in its composition or orientation.

The variations within the Hospice Movement only go to highlight the inadequacies of Resource Mobilization used in isolation and the inflexibility of adopting it as a sole perspective. Alone this approach is no more useful than the use of an exclusively psychological perspective.

This study attempts to do to such limited views of the Hospice Movement, what the Hospice Movement attempts to do to traditional terminal care facilities; that is to identify those areas of strength and weakness, in order to supplement the latter as necessary. In both cases this involves the imposition of a human perspective within the context of a dynamically functioning society, from which the object of scrutiny takes on fresh colour and is thus imbued with new meaning.

Whilst future research into terminal care in general, and hospice-type care in particular, could proceed in a variety of directions, the major claim for attention must lie with the horrifying impact of AIDS, not only in our culture, but worldwide. The inadequacies of terminal care facilities and the ambivalence of many otherwise motivated hospice adherents, not to mention widespread antipathy towards anything, actually or perceived to be, connected with AIDS, represents a huge area of

enquiry. It should be hoped that such enquiry will reveal certain truths surrounding the disease, uncover those areas of falsehood and rectify the attendant misconceptions and misinterpretations. In this way it might be hoped to devise and implement means of equipping terminal care services with effective, efficient and humane methods of providing for AIDS patients.

APPENDIX ONE - THE CHALLENGE OF AIDS

Terminal care services face potentially their most challenging problem with the arrival of a new disease in our society. When that disease is one which kills significant numbers of people, of those infected, without our real understanding why, and its spread seems to be through minority groups, to the rest of the population, the reactions are qualitatively and quantitatively different from anything that has faced society for many decades.

AIDS, Acquired Immune Deficiency Syndrome, resulting from HIV infection (Human Immunodeficiency Virus) is a disease surrounded by ferocious antagonism towards those known or suspected to be infected, and about which there is misinformation and lack of caring both within the statutory services and in society at large.

The spread of AIDS in the USA and increasingly in the UK has been described as "a very political epidemic," (Altman, 1986, p.57). It has been suggested that the determinants of health and illness are usually considered as biological and that the science of medicine is capable of producing "an unchallengeable and autonomous body of knowledge which is not tainted by wider social and economic considerations," (Doyal, 1979, p.12). Yet the response to AIDS is imbued with notions of morality and individual responsibility; a trend which appeared to pre-date the emergence of AIDS. "The issue of 'personal responsibility' seems

to be re-emerging within medicine itself," (Zola, 1978, p.84. See also Butler, 1927, p.88).

Together with the view that individual transgressions are responsible for illness is the tradition of regarding epidemics as the consequence of social collapse and degeneracy. "Both the Moral Majority, who are recycling medieval language to explain AIDS, and those ultra-leftists who attribute AIDS to some sort of conspiracy, have a clearly political analysis of the epidemic it is clear that the way in which AIDS has been perceived, conceptualized, imagined, researched and financed makes this the most political of diseases," (Altman, 1986, P.63).

The onset of AIDS resulted in disputes about the mobilization of resources for both research and the care of victims as well as over scientific theories. Much of the controversy and politicization of the disease, in the western world, results from AIDS being very specific in the groups which it has infected, Haitians, haemophiliacs, intravenous drug-users and above all, male homosexuals.

Since the media took up discussion of the illness in 1981 (in the USA) the public reaction has varied from panics regarding its spread, through for example blood transfusions, to regarding it as an affliction of "the other", something affecting those already earmarked for misfortune. Gradually, with the spread of the virus into the heterosexual population, this attitude has started to change.

The link in the public imagination between AIDS and the presence of homosexuals occurred when some of the religious, moral and cultural arguments against homosexuality seemed to be disintegrating and "allowed for some very nasty scape-goating," (Altman, 1986, p.106). For the 'religious right' in the USA, AIDS provided a Heaven sent (quite literally) opportunity to condemn homosexuality. "Might we be witnessing, in fact, in the form of a modern communicable disorder, a fulfillment of St. Paul's pronouncement: 'the due penalty of their error?'" (Southern Medical Journal, Feb. 1984.)

Epidemiologically, the spread of AIDS was, in part, due to the increased opportunities for rapid and multiple homosexual encounters existing in the large urban centres of the developed world. The equation of AIDS with homosexual males included a belief that the blame for the spread of the disease lay with homosexuals and that others who caught AIDS were 'innocent victims'. Such a view was reinforced by the staunch fundamentalist traditions which supported notions of Divine retribution through disease and subsequently influenced the attitudes of those who might otherwise have pledged support for a potentially catastrophic epidemic. "What I see," said Ronald Godwin of the Moral Majority, "is a commitment to spend our tax dollars on research to allow these diseased homosexuals to go back to their perverted practices without any standards of accountability," (in Brandt, 1985, p.180).

Such was, and to some extent is, the social context of AIDS. The disease is projected to spread rapidly through the UK which

seems to be following American patterns of infection. The projected figures for the UK in 1990 are 20,000 AIDS cases, 10,000 AIDS deaths, and 2,000,000 estimated carriers / infected with the AIDS virus, (statistics available from the world health organisation, the Communicable Disease Surveillance Centre, London, and the US Centre for disease control, Atlanta.)

This clearly represents a situation far beyond the capacity of existing medical and terminal care services. "We are planning for 10,000 people with AIDS in London in 1990, of which maybe a half will have died. Most are going to die at home because the hospitals won't be able to take them, and the hospice movement isn't so far admitting people with AIDS because they don't fit their criteria," (Christopher Spence, Director of London Lighthouse, Observer, Dec. 13, 1987.)

The London Lighthouse is so far the only organisation attempting the present and future care of AIDS sufferers both at home and in their 25-bed unit. Whilst the government has given £10 million to the Haemophiliac Society, which represents 6% of the AIDS sufferers in the UK, the Lighthouse is only asking for £1.2 million although they are working with 28% of the country's AIDS victims.

In the words of its information leaflet, "London Lighthouse is a registered charity set up to provide a range of services for people affected by HIV infection, ARC (AIDS Related Complex) and AIDS. The Lighthouse intends to offer its services within a familiar and welcoming environment, enabling those who are

terminally ill to live and die well, and those who are infected to improve the quality of their lives in order to take responsibility for their own health and to fight the infection. The services that Lighthouse offers to the community are aimed at bringing together the various information, support, training and residential services in order to combat at every stage the isolation that it is essential to overcome in dealing with this disease."

The Lighthouse includes home support services, a housing programme, a range of health programmes drawing on the work carried out in the successful treatment of cancer and other chronic diseases, as well as work in the USA on people with AIDS, to assist HIV carriers to stay well, and a residential unit, which appears to espouse the notions inherent in the Hospice Movement.

This AIDS centre can be seen as an extension of the holistic hospice approach, as the emphasis is not simply upon dying well, but also living well. "The whole focus of the project is health. Dying is a perfectly healthy thing to do," (Spence, Observer, Dec. 1987.) Thus the centre is not simply an AIDS hospice, rather care of those terminally ill with the disease is incorporated into a much broader structure, one which makes no artificial and divisive distinctions between individuals who are at different stages of life and who all need some sort of support.

Unfortunately, the perceptions of the disease and of its

victims, as depicted in the media, has had real social and political consequences. Thus the London Lighthouse has met with vociferous opposition from, among others, local residents in Notting Hill. The Sunday Times (28 Sept. 1986) suggested that the local reaction to the London Lighthouse could happen all over England. The approach of papers such as 'The Sun' and 'The News of the World' have exploited peoples' fears about AIDS and "opponents of the scheme are now indulging in an orgy of homophobic propaganda," (Time, Aug/Sept 1986).

At a meeting called by the Lighthouse project so that local people could hear what the centre would involve, from people experienced in working with AIDS patients, and in an attempt to allay fears about possible risks to the community, a specialist doctor was frequently heckled by a minority of the four hundred people present. Much of the abuse was in the form of anti-homosexual slogans and quasi-religious objections, (City Limits, Aug. 1986).

Houses in the staunchly Conservative borough of Kensington and Chelsea received anonymous leaflets urging them to "write and object today," (Observer, July 1987), and residents belonging to the North Kensington Community Concern, representing around 2,000 local objectors threatened a rates and rent strike if the go-ahead was given, by the local council, to the development. A boycott of the local swimming pool was also threatened, (Kensington and Chelsea times, Aug. 1986).

The London Standard (Sept. 1986) quoted residents

complaining that "this place is being treated as a dumping ground. We have a drink rehabilitation centre just around the corner and also a drug treatment centre." The fears of one parent were said to be typical of many; "I'm afraid of so many homosexuals being nearby. Some of the kids are just too friendly and I think they could be in danger," (The London Standard, Sept. 1986).

Nevertheless, with the careful work of their Media Resources and Literature Promotions group, the Lighthouse used the publicity to achieve a, "fantastic groundswell of goodwill," (Observer, Dec. 1987). Letters to various papers indicated the work of the Lighthouse and rounded on some of the opposition who fought the centre so as to preserve the value of their property. "As for the Yuppies, North Kensington will be a better place without them. They have forced up already high property prices in the area to a level that locals can't possibly afford," (Resident Response, Sept. 1986).

It may be speculated that reticence on the part of the government to help such projects is in part due to a clash of ideologies with those people involved in the projects, irrespective of their individual AIDS status. The advent of AIDS hysteria has seen the mobilization of powerful social movements from diverse backgrounds. The Gay Movement is necessarily inextricably linked with the epidemic, and despite continuing perceptions of AIDS as "the gay plague," (The Sun, Dec. 1984) it is in these very communities, felt to be most prolific, that the spread is seen to be halted or at least slowing down. Their

internal communication networks have been used successfully in places such as San Francisco, with the dissemination of acquired knowledge pertaining to healthy living and safe sex.

Of five workers interviewed from the London Lighthouse, all identified themselves as Labour voters, as opposed to the significantly Conservative character of the Martin House hospice project, religious affiliation and orthodoxy was notable in its absence, especially Church Of England, and the projects to which members had belonged apart from the Lighthouse reflected a strong AIDS bias, together with certain homosexual and left-wing radical movement activities, as opposed to a background within the established Hospice Movement. In keeping with such trends is the expression of the Lighthouse members of their aversion to certain methods of fund-raising on both moral and personal grounds. The impression gained of those involved is of a highly motivated close-knit group, unified by a strong ideology and by the opposition of an array of established groups both in the form of active opposition by certain religiously and politically - motivated groups together with the reluctance of various statutory bodies and institutional elites to provide support. Among these elites, ironically, is the established Hospice Movement. This, in part, is seen by those involved with AIDS patients, especially in independent projects such as Lighthouse, to be due to the social perspective of the disease casting a shadow which those concerned find difficult to avoid, "and where relationships not perceived as wholesome by society are then not regarded as having emotional validity. The practical consequences of this has been that hospices have refused to

accept AIDS patients who instead have had to face death in circumstances which are less than the best our society can provide, while grief is having to be faced in private and alone, and often with an overwhelming sense of guilt," (London Lighthouse leaflet, 1986).

Within a few NHS establishments, provision is being made by an enlightened few. At St. Stephen's Hospital, Fulham, "the circles of support only start with the doctors, counsellors and nurses. Behind them stand the social workers, the charitable organisations such as the Terence Higgins Trust and Body Positive, the DHSS and housing and social services departments in local authorities," (Observer, Dec. 1986.) These different levels of support are vital as the impact of AIDS has been seen to have catastrophic effects on all areas of life. The nurses at St. Stephen's have attempted to circumvent the NHS economies to make the AIDS ward as homely as possible, and outside contact together with active patient contribution is encouraged. These bastions, beleaguered amidst hostility and shortages, provide a shining example of care which transcends the purely medical facilities which have pushed back the frontiers of science at the expense of a rounded consideration of those whom it is intended to benefit. The Buddy system, run by the Terence Higgins Trust, represents the need for people to provide a non-medical, non-professional approach to those who are dying. Buddies are unpaid volunteers who according to one PWA (person with AIDS) "is like a friend, sister, mother, father and brother rolled into one," (article by Philippa Braidwood, Observer, 1987).

These initiatives only serve to exemplify the requirements for terminal care, especially in the light of what might prove to be the biggest killer disease of the century. Not only is AIDS seemingly inevitably lethal, but "In our particular culture, you can't pick three more taboo subjects than sexuality, the fear of disease - and death. AIDS raises the lid on all of them," (AIDS Counsellor, St. Stephen's Hospital, Fulham.) AIDS represents a vast challenge, one in which the hospice approach is of potential relevance. But it is questionable whether the realities of the disease will be met by the existing Hospice Movement, integrated or not. Even apart from its increasing links with mainstream health services, the Movement displays certain entrenched views characteristic of some of its component political and religious groups. If the Hospice Movement is not to be seen to abdicate its avowed responsibilities and to revert to a system of effective terminal care for only a privileged section of the population, then it must accept its duty to confront the needs of the potentially awesome numbers of dying AIDS victims. It is commonly felt that while deaths are still mainly concentrated among a number of high risk groups, by the 1990's every person in the country will know or have known someone with AIDS.

In this situation there is no room for prejudice in terminal care.

Name (Mr, Mrs, Miss)

Occupation

Education (School/College)

Political Affiliation (type i.e. party member of voter)

Religion/Denomination

1. Have you ever been to a hospice ? If so, which ?
2. Which other projects have you been involved with before this one ?
3. Did you become involved with this project after learning of it from;
Newspapers Television/Radio Personal Contacts
Job Application Church Other
4. On average, how many hours per week do you spend on project work ?
5. Do you contribute to the project in the form of ;
Money Labour Specialist knowledge
6. (i) Have you brought people into the project who were previously
unconnected with it ?
(ii) Were these through existing social connections ?
7. (i) Do you meet socially with other members of the project group ?
(ii) If yes, on average, how many times per week ?
8. Have you had any organised contact with people who will be using the hospice
9. (i) Are project activities determined by a controlling body ?
(ii) If so, is there a good working relationship between the controlling
body and the appeal volunteers ?
10. Do you feel that it is the duty of individuals to contribute to hospice
projects or should it be the role of government to provide money for such
causes ?
11. (i) Are there methods of fundraising which you would consider to be
unacceptable on either personal or moral grounds ?

(ii) Are there any firms or agencies from whom you would find it difficult
or unacceptable to receive contributions ?

(iii) Have you experienced any obstacles to fundraising/promotion due to the opinions of the people approached for support ?

If so, what were they ?

12. Since your involvement in this project have your ideas regarding hospice value been reinforced reduced unaltered ?
13. Have your religious views made you more positive towards death, dying and care of the dying ?
14. Do you feel that suffering and death are increasingly institutionalized i.e. removed from the public gaze and catered for by specialists ?
15. Do you feel that prevailing attitudes encountered in daily life tend to involve the denial and ignoring of death openness towards death
neither particularly ?
16. Do you share any of these views ? If so, which ?
17. Do you think that the existing facilities for terminal care are adequate ?
If not, do you feel that hospice care provides the answer ?
18. Would you consider using a hospice ?
19. Have any close experiences with death influenced your beliefs re. death, dying, and/or care of the dying ?
If so, please elaborate.
20. Please feel free to add any other comments or information.

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