

A PILOT STUDY INTO THE FUNCTIONING OF FAMILIES WITH A MEMBER
WHO IS A HOSPICE PATIENT TO DETERMINE WHETHER HOSPICE
FAMILIES REQUIRE FAMILY THERAPY

ALISON EVANS

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Department of Psychology,
Rhodes University, Grahamstown.

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C O N T E N T S

Abstract.....	1
CHAPTER 1	
Overview.....	2
CHAPTER 2	
Perspectives on Death and Dying.....	5
CHAPTER 3	
The Hospice Approach.....	12
CHAPTER 4	
Dealing with Terminal Illness - The Family as Focus.....	17
CHAPTER 5	
Family Therapy in the Context of Terminal Illness.....	30
CHAPTER 6	
Methodology.....	37
CHAPTER 7	
Results.....	45
CHAPTER 8	
Discussion and Conclusions.....	51
REFERENCES.....	65
APPENDIX	
Family Assessment Device.....	69

ABSTRACT

The aim of this pilot study, which was carried out under the auspices of the Grahamstown Hospice, is to evaluate the functioning of families with a terminally ill member, in order to establish whether these families require family therapy. The Family Assessment Device (FAD), based on the McMaster Model of Family Functioning, was used. Data from 20 families was analysed and the extent to which these families constitute a clinical sample is highlighted. In terms of the dimension of General Functioning, 15 families emerged as functioning at a problematic level. Communication emerged as the most dysfunctional of the seven dimensions of the FAD, with 17 families functioning at a problematic level. As a result of these findings it is argued that family therapy should be incorporated into the range of services offered by hospices. Limitations of this study and directions for future research are also discussed.

CHAPTER 1

OVERVIEW

The aim of this exploratory study is to investigate the functioning of families where one member is a hospice patient. Although there has been a prolific increase in interest in the field of thanatology in the last few decades as measured by research output, specialist journals and ongoing projects, the focus has tended to be on the individual patient. Very few studies have concurrently assessed both patient and family members (Northouse, 1984). Thus it is contended that this study - with its focus on the family as a whole - constitutes a valuable contribution in a highly neglected yet crucial area of research.

Hospices deal on an in-patient or domiciliary basis with people who are terminally ill - helping them and their families to cope with the implications of living while dying. Help offered addresses needs on physical, emotional, psychological and spiritual levels.

Writers in the field of hospice work are quite explicit in their acknowledgement that caring for a terminally ill patient involves caring for the family in this difficult transition period (Kübler-Ross, 1970; Lamerton, 1980). For there is no doubt that terminal illness impacts on family functioning in crucial ways that often have implications for the quality of the dying process.

However, hospice concern for the family tends to focus specifically on helping individual family members handle this difficult stage of life. This can include support on an emotional level in coming to terms with the impending death as well as practical help in dealing with the day to day demands of intensive home nursing (Buckingham, 1983).

However, the contention of this study is that the care and support offered to the family often needs to be greatly extended to include family therapy where the focus of attention is family functioning per se rather than family

interactions around the dying member. It will be argued that the family as a whole should be seen as the patient rather than the individual who happens to be dying. In this way death can be integrated in a more holistic fashion into the life-history of the family.

At a theoretical level the family is viewed from a systems perspective and it is maintained that the traditional hospice approach of considering the needs of each individual family member in relation to the dying patient is insufficient - it is crucially important to look at the system as a whole.

The project - which forms part of a body of on-going research into various aspects of hospice functioning in South Africa - has been carried out under the auspices of the Grahamstown Hospice Association. In addition to the families interviewed in Grahamstown, several families in Cape Town and Port Elizabeth were also interviewed. In this way an adequate body of data was obtained to be statistically significant.

In the study twenty hospice families are visited and interviewed using the Family Assessment Device (FAD) which is based on the McMaster Model of Family Functioning. The results are analysed statistically and clearly indicate that the hospice families assessed constitute a clinical sample.

As it is not the intention to demonstrate a causal link between illness and family dysfunction, a control group has not been incorporated into the design. It will be argued that all families have problems in functioning at various stages in the family life-cycle and it might well be that family therapy could be useful at various times in the history of any one family, whether there is a terminal illness in the family or not.

The contention is that families with a dying member are likely to be functioning at a pathological level which although not necessarily caused by the impending death may possibly be exacerbated by it. It is argued that this poor level of functioning often impedes the dying process in terms of the hospice ethic. These patterns of malfunction in hospice families need to be assessed, and should be addressed by means of family therapy if the

hospice ethic of helping the dying person and his or her family is to be truly fulfilled.

In terms of the nature of the terminal illness most hospice patients have some form of cancer and the majority of patients involved in this study are cancer sufferers - some in remission and some not. However, hospice does not restrict its services according to diagnosis and therefore having cancer has not been made a prerequisite of being included in this project. In actual fact the terminally ill members of the families in the study are almost exclusively cancer sufferers (sixteen out of twenty patients). Because of the prevalence of cancer in hospice patients, literature focusing exclusively on cancer and its impact has been considered highly relevant to this study.

The meaning of "terminally-ill" also needs to be clarified.

When a hospice becomes involved with a family the assumption is that the ill person in the family is terminally ill. However, the definition of "terminally-ill" is broader in some contexts than in others. Although within the orbit of generally accepted hospice philosophy it tends to mean that the ill person is likely to die within the next few months, the reality of at least the Grahamstown Hospice is that supportive help is being given to families where the ill person has a much more generous prognosis and may even in one or two cases live for years. The crucial factor is considered to be that the illness in all cases impacts on family members in different ways. In addition, the normal course of the illness is that the patient will die from it. In the study families with a terminally-ill member are referred to as "terminally-ill" families as a form of shorthand. This is not intended to be an evaluation of the family in any other sense.

In this project the fields of clinical thanatology and family therapy have been joined in a way that hopefully will be enriching to both and lead to further research. Much more research needs to be carried out in this area and in the discussion section consideration will be given to issues such as what can be done in the light of these particular findings, what the shortcomings of the project are, and where the thrust of future research should be directed.

CHAPTER 2

PERSPECTIVES ON DEATH AND DYING

The on-going thrust of work in the field of clinical thanatology is to open up and explore perspectives on death. This will ultimately help both the dying individual as well as family and friends to experience this particular stage of life in a less destructive and more integrated and holistic way.

Much of what we bring to this stage of life in terms of our own emotional expectations stems from the viewpoints current in contemporary society. Attitudes to death have undergone changes through the ages in the same way that a multiplicity of social, sexual and political attitudes have changed. In order to assess any aspect of the experience of dying in a meaningful way it is thus important to contextualise death within the contemporary meanings of our society. For it is these meanings which inform the phenomenological world of the dying person and his or her family.

Until recently there were very few studies on the psychology of death and dying. The first publication to reach a wide audience was Herman Feifel's study The meaning of death in 1959. Since then studies in this area have proliferated and the field of clinical thanatology has become firmly established.

Historical Perspectives

In the Middle Ages in Europe death was seen as a door offering temporal human-kind the possibility of immortality (Feifel, 1977). However, religious beliefs have waned and the secular view of death has in part stripped away our support systems. Feifel (ibid) talks about the ways in which our capacity to integrate personal death has been undercut.

Implicated are factors such as the current predominance of the nuclear family and the dismantling of rooted neighbourhood and kinship groups, as

well as the fragmentation engendered by the burgeoning age of technology. The emotional and institutional supports which previously helped to cushion the impact of death are absent and the rituals which served as markers to legitimize death as part of life's experience are to a large extent no longer with us.

Elliot (1972) introduces the concept of public death as opposed to private death. Death through the ages has been a private affair, a matter between a man and his gods. However, in the nineteenth century some health workers decided that an untimely death was now to be a matter between a man and society. So it was that death became public, a matter of concern for us all. Infant mortality and endemic disease thus became matters of social responsibility and millions of lives were deliberately protected from nature. Modern medicine played a large part in this scenario for with its advent death came to be seen as the end of life rather than as an enemy threatening to interrupt its course. Society thus became dedicated to the preservation and care of life.

And yet, as Elliot (*ibid*) so lucidly points out, as much as we are concerned with saving lives, so we are also intent upon destroying them. He describes this age as the most violent period in history and estimates that there have already been one hundred million man-made deaths this century. Paradoxically our age is characterized by its vast effort in saving human life and yet huge vigour in destroying it.

This point is also made by Illich (1976, p.206) who says, "Curiously, death became the enemy to be defeated at precisely the moment at which megadeath came upon the scene".

Schneidman (1976, p.87) reflects this same paradox, referring to the huge efforts and resources invested in creating what he describes as "megadeath capability" at the same time that we are directing scientific and medical efforts to save individual lives and extend life expectancy.

Later in the same work (p.322) he refers to what he calls the oxymoronic climate of our century which is illustrated by "the massive destruction of our

fellow humans and the concomitant movement toward the more humanitarian treatment of the dying individual...". Caught between these two extremes it has become extremely difficult to experience death as a natural phenomenon in a holistic context. This has resulted in a degree of alienation which has led to silence and suffering on a grander scale than ever before.

The Effects of Modern Medicine on Attitudes and Practices Towards Dying

Medical advances have had many implications for death and dying. The time between the onset of illness and actual death has been lengthened, often dramatically. The locus of dying has changed from the home to institutions and the saving of life has become the paramount goal of the health professional (Feifel, 1977).

Within the modern medical model, traditional approaches to health care emphasise cure and the prolongation of life. As Buckingham (1983, p.x) says, "such care is restrictive and insensitive to the needs of the terminal patient and the families who have accepted the reality of death and wish to focus on the quality of the life remaining".

Death is regarded not as a natural event but as a technological failure. Society tends to ignore the dying in its desire to deny the inevitability of death (ibid).

Thus death is no longer accepted as a matter of course but is rather something to be expunged. Talk about death is taboo in our time in much the same way that sex was for the Victorians. Death is treated with suspicion and as a failure. Society has become responsible for preventing the death of each one of us and treatment has become essential whether it is effective or not. Ironically, as Illich (1976) points out, the encounter with the doctor is as inevitable as the eventual encounter with death.

Extending our perception of death, Illich (ibid, p.208) says, "Our new image of death also befits the industrial ethos. We are consumers of medical care

and the doctor rather than the patient now struggles with death. War on death is total. The medicalization of death has led to health care becoming what Illich calls a "monolithic world religion".

Traditionally the person best protected from death is the condemned man who is not given the chance to commit suicide. But as Illich (ibid, p.210) points out the person best protected from dying nowadays is the sick person in a critical condition. "Society, acting through the medical system, decides when and after what indignities and mutilations he shall die."

As Elliot (1972) points out, the manner in which people die reflects more than any other fact the values of a particular society. Death is no longer an isolated personal event and we are caught in the matrix of our own phenomenological world.

The Isolation of the Dying

Societal, familial, and intrapsychic processes are all involved in promoting the isolation of the dying (Herz, 1980). In keeping with the massive denial of death in our society we have created what Herz (ibid, p.223) describes as "death specialists" such as hospitals, morticians, funeral directors to deal with all aspects of dying. Thus death is handled by others outside the immediate family and this has led to the family becoming distanced from the dying person.

In similar vein Kastenbaum (1977) refers to what he calls the death-system in our society. This has many faces and forms a subtle undercurrent infiltrating many aspects of life - for example there is the undertaker, the insurance salesperson, the florist, the canner of petfood, the minister of war and so on.

He also mentions the strong investment we have in the preservation of life and the medical attitude of death as failure. He gives the example of a false-bottomed stretcher being used to transport the dead in hospitals.

Kastenbaum (ibid, p.86) says that a society "whose health-care establishment goes out of its way to devise a cloak of invisibility around the dead tells us something about fundamental attitudes toward the meaning of human life".

Winder (1978) suggests that death and dying are surrounded by a conspiracy of silence. Dying is treated with suspicion and a so-called good death occurs without notice and preparation.

In addition attitudes to cancer are relevant to this particular study because the majority of hospice patients are cancer sufferers. Sontag (1979) discusses the negative societal reaction to cancer. She points out that we frequently regard physical illness as a metaphor based on punitive or sentimental fantasies and that cancer is especially encumbered by the trappings of this metaphor.

She discusses the way in which cancer is seen to result from the repression of emotion and leads to feeling of shame. Those with cancer are shunned by relatives and friends and felt to be morally if not literally contagious. She suggests that we collude in a conspiracy of silence about cancer which informs the psychosocial world of the cancer patient and makes them feel shunned. This has important implications for hospice families.

Winder (1978) makes a similar point, referring to society's tendency to view cancer as something obscene and offensive. This attitude and the myths surrounding cancer lead to the cancer patient experiencing a sense of isolation and abandonment. Garfield (in Feifel, 1977) also refers to the barbaric isolation of the terminally ill and suggests that we must stop relating to dying people as lepers.

Kalish (in Feifel, 1977) refers to the difficulty we have in talking about death because of the death taboo - in some way we feel that if death is not mentioned the person cannot die. Sadly what almost seems like the apotheosis of this taboo is seen in the attitude of the medical profession. For not only is death viewed as failure but the erstwhile compassionate physician changes his behaviour the closer the patient comes to death, for

example visits to the bedside become briefer and contact less (Geyman, 1983).

Hackett (1976) refers to the incredible negligence shown by doctors for the process of dying. They attempt to excuse their negligence by accepting as fact many myths about the dying patient, such as for example that the dying patient does not want to know that he is dying. Thus medical doctors have been implicated in perpetuating the myths rather than destroying them, for after all they too are human and do not want to be messengers of despair any more than any of us.

Breaking the Taboo

However, Elizabeth Kübler-Ross has done much to break the taboo on death in her seminal work On death and dying which was first published in 1970. Combining compassion, energy and intelligence, she has encouraged a more open attitude to an area that was previously not considered to be a serious field of study. Countering ignorance and fear she has helped to open up the whole field of clinical thanatology.

Working with terminally ill patients in a hospital in Chicago she became increasingly aware of the callous nature of medical interventions and attitudes which she then sought to rectify. Her courageous work has provided an impetus to on-going research and more open-minded and humane attitudes in the field of clinical thanatology, as well as providing a standard against which subsequent research could be measured.

She has also, and most importantly for this study, provided inspiration for the growing hospice movement, and other writers such as Shneidman, Kastenbaum, and many others have bolstered and substantiated this work.

Thanks to an accumulation of writing in the field of clinical thanatology and a concomitant growing public awareness, perspectives are gradually shifting. However, it is important to be aware of the still partly entrenched attitudes towards death and dying which infiltrate and colour societal

expectations and behaviour. These inform the context or macrosystem within which the hospice movement is working, and thus they form the backdrop to this study.

CHAPTER 3

THE HOSPICE APPROACH

Hospice philosophy embraces a tradition stretching back to the Middle Ages when hundreds of hospices all over Europe offered hospitality and shelter for travellers and pilgrims. They also served as places of refuge for the sick, the poor and the dying (Lamerton, 1980).

These hospices also constituted what we would now call hospitals - for the separation of the living from the dying was unknown in Medieval times. Within the ethic of the time pilgrims, travellers and the dying could all be housed together for they were all considered to be travellers on a journey (Buckingham, 1983). During the Reformation monasteries were closed and the function of hospices and hospitals was differentiated. Schneidman (1976) points out that once hospices became staffed by physicians and other professionals they became hospitals.

The different ways in which the word has been used over the centuries illustrate changing societal patterns in the ways in which we care for our fellow human beings. Hospice, hospital, hospitality, host, hostel and hotel all have the same root and all these words suggest the idea of kindness and generosity to strangers or caring in some way for our fellows (Buckingham, 1983).

Gradually the care offered to the sick became increasingly technical and had as its aim the cure of the patient. As this happened so the original ethic of love and care became leached out by an over-riding investment in the preservation of life at all cost. Thus cure gained precedence over care, leading philosophically into a cul de sac, because the inevitability of death can ultimately be neither denied nor avoided by even the most grandiose physician.

Science has made spectacular contributions to the cure of disease and the prolongation of life and such was the importance of this focus that there

was eventually no place in the modern hospital to die with dignity. Hospitals have become highly specialised, impersonal, technological and efficient, and the highly individual and personal needs of dying patients and their families can no longer be met within the confines of an acute-care hospital. And yet this is precisely where most deaths are taking place (Buckingham, 1983).

This was not always so for until the beginning of this century death tended to take place in the family home. Relatives, neighbours, friends and clergy surrounded the dying, and death took place within the context of the on-going daily life of the family (Lamerton, 1980).

However, Geyman (1983) estimated that this pattern had changed to the extent that by the 1980's about 80% of Americans were dying in institutions. He makes poignant reference to the fact that the crucial ties we once had to a community of people has been replaced by ties to a community of machines.

Dr Elizabeth Kübler-Ross (1970, p.8) eloquently describes the seriously ill patient's predicament thus,

"He may cry out for rest, peace, dignity, but he will get infusions, transfusions, a heart machine, or a tracheotomy. He may want one single person to stop for one single minute so that he can ask one single question - but he will get a dozen people around the clock, all busily preoccupied with his heart rate, pulse, electrocardiogram or pulmonary functions, his secretions or excretions, but not with him as a human being."

The current trend to rehumanize the dying process has led to the growth of the modern hospice movement in Europe and America (Geyman, 1983). This, as Kastenbaum (1977) points out, has provided a major alternative to the traditional pattern of care afforded the dying.

Thus the hospice movement has come about as a reaction to the institutionalization of death and the need to make death more humanly bearable. Historically since the industrial revolution dying is a coming-apart experience for most families. Hospice care concentrates on making the

process of dying a coming-together experience for the patient and the family, which includes helping them to focus on the quality of the life that is left (Buckingham, 1983).

A great deal of credit for the development of the modern hospice movement must go to Dr. Cicely Saunders in England. She perceived the need and developed St. Christopher's Hospice in London in the 1960's where the old concept of hospitality could be combined with modern medical skills (Buckingham, 1983). The hospice philosophy spread to the United States within the next decade.

Attitudes to death were critically examined and reformulated thanks to the seminal work of Dr Elizabeth Kübler-Ross (1970), who is possibly the best known exponent of the modern hospice philosophy. She has vigorously challenged the taboo surrounding death and exposed the notion that death represents a failure in medical terms. Kübler-Ross also contributed a conceptualization of the dying process in terms of a series of stages which both the patient and family members may pass through in approaching death. These stages - denial, anger, bargaining, depression and acceptance - have provided a useful focus for understanding psychological life in the face of terminal illness.

It is interesting to note that many of the ideas that we now take for granted were once heretical. For example, in the 1960's doctors in training at a large London teaching hospital were forbidden to visit the newly founded hospice because hospice patients were seen as failures in terms of medical care rather than as objects of human compassion and subjects of ancillary care (Grahamstown doctor, personal communication, 1992). It is thus abundantly clear that ideas around the care of the dying have changed dramatically in the relatively short space of a decade or two.

However, hospice is not so much a place as a philosophy, where the person is of primary importance and the disease is secondary. The concept of hospice indicates a crucial attitude and approach to the care of the dying - whether this be domiciliary, hospice in-patient or hospital care - that does not deny the importance of modern medical care but puts it in perspective

as part of the total care and treatment process. The hospice attitude and approach can be implemented in any setting, and can help to humanize institutional as well as home care (Lamerton, 1980). Lamerton (ibid) points out that the home care or domiciliary aspect of hospice care is especially important because it significantly increases the number of patients who can be cared for by any one hospice organisation. In this way a relatively small organisation can, by means of domiciliary care, cater for the needs of more patients than would be possible if hospice only provided in-patient care.

The modern hospice ethic thus embodies a philosophy and a concept of care revolving round the notion that ideally we should not have to die alone or in pain. Different types of pain - physical, emotional, spiritual and social - are all addressed by hospice staff. The hospice concept offers us a return to humanistic medicine, revolving as it does around family centered care and treating the patient as a person (Buckingham, 1983). As Hinton (1972, p.72) puts it, "the emphasis must always lie upon tending the person, not battling with his disease, treating the one who feels the symptoms, not just treating the symptoms".

The inclusion of the family as part of the unit of care is an important part of hospice philosophy. "Hospice, whether home or inpatient, serves the whole family as the unit of care, and involves the family in the patient's care." (Buckingham, 1983, p.8) For the suffering patient is not the only one in distress - the family suffers as well. Poss (1981, p.37) puts it thus, "While the dying person is engaged in his preparation for death considerable demands are made on his relatives to adapt to the impending loss. They too appear to have some specific tasks to complete and respond to this work with intense emotion".

Not only is treatment of both patient and family one of the basic hospice tenets, but most hospices also run bereavement programmes to help family members after the death has taken place. Grahamstown Hospice has an extremely active bereavement programme, and as well as counselling family members the Hospice helps them to make supportive social contacts with other people in the same situation.

The hospice movement is a relatively recent innovation in South Africa, and has been active here only for the last decade. There are currently twenty four hospice organisations in the country, four of which also have in-patient units as well as domiciliary services.

Grahamstown Hospice, where the bulk of this study was conducted, was inaugurated in 1986 and has been operating a domiciliary service since then, initially with volunteer staff. By early 1992 three nursing sisters, two white and one black, had been employed on a part-time basis to visit patients being cared for by the Hospice, and a second black sister is to be employed from late 1992. In addition, approximately twenty trained care-givers from all race groups are available to support the patient and family through the dying process (Robin Kent, Director:Grahamstown Hospice, personal communication, 1992).

Although the Hospice originally emanated from the white community and has tended to be seen as a somewhat Euro-centric concept, it has become apparent that at least 50% of potential patients in the Grahamstown area are from the black community. Colour is critical and mentioned here not in a racist sense but as a pragmatic factor in terms of language and familiarity with the community, which are important factors in terms of well-rounded and acceptable care.

CHAPTER 4

DEALING WITH TERMINAL ILLNESS - THE FAMILY AS FOCUS

On a theoretical level the family is conceptualized in this study in terms of systems theory and this will be briefly described. Other aspects of family functioning relevant to this study will also be mentioned. Literature will then be discussed which locates the hospice patient in the context of the family. Research into aspects of family functioning with a terminally ill member will then be reviewed. As mentioned before much of the research involves cancer and thus is seen as highly relevant to this study in which 80% of families involved are coping with this particular illness.

The Systems Approach

Derived from general systems theory, family systems theory provides a theoretical framework for understanding and assessing family functioning. It provides a useful way of describing, "how family groups function as entities, rather than as collections of individuals" (Barker, 1981, p.2).

Families are not just a conglomeration of individuals living together but "an intricate emotional and communicational, as well as a cognitive system; and changes in one part of the system cannot occur without requiring reorganization of some kind in the rest of the family system" (Winder, 1978, p.155).

Noted family therapists Epstein and Bishop (1981), who initially worked with families from a psychoanalytic perspective, report their growing awareness that the family as a system was more powerful than intrapsychic factors in determining the behaviour of individual family members.

Within this conceptualization the family is considered to be an open system and some of the crucial assumptions of systems theory are as follows. The parts of the family are interrelated and one part of the family cannot be

understood in isolation from the rest of the system. Family functioning cannot be fully understood by simply understanding each of the parts because families as systems are more than the sum of their parts. Each system has a boundary which is semi-permeable, and the nature of this boundary has implications for the way in which the system works. Although family systems tend to reach a relatively steady state, growth and evolution are the norm and change can occur via a process of morphogenesis. Communication, feedback and equifinality are important concepts and a circular rather than linear concept of causality is espoused (Barker, 1981; Walsh, 1982).

Other aspects of family functioning

Two perspectives are useful when evaluating a family - firstly the structure and way of functioning and secondly the developmental stage of the family in question (Barker, 1981). The former involves the systemic perspective which underlies this study, however, in terms of the latter it is also important to contextualise the family within the framework of the family life-cycle in order to more fully understand family dynamics. Understanding the life-cycle tasks of a family is crucial to understanding the effects of illness.

Espousing the concept of the family life cycle is not intended to cement a rigid or stereotypical concept of what is normal but rather aims at acknowledging the inter-generational connectedness of the family. According to McGoldrick and Carter (1981) their classification of family life cycle stages emphasises the importance of the expansion, contraction and realignment of relationships around the entry, exit and development of family members.

Stages range from the unattached young adult, to the newly married couple joining two families, to the stage of young children, then schoolgoing and adolescent children, finally to the launching of the children into the world and their eventual pairings and the birth of grandchildren.

Research evidence suggests that family stresses, which tend to occur around life cycle transition points, create disruptions in the life cycle and lead to symptoms and dysfunction. An example cited is the way in which the death of a family member leads to the disruption of the family equilibrium (McGoldrick & Carter, 1981). This has crucial implications for hospice work with families. Understanding where a particular family is in terms of life cycle tasks is crucial to the understanding of the specific stress experienced by the family when a member becomes terminally ill (Herz, 1980).

The juxtaposition of life cycle events can have crucial implications for future family functioning. Both Walsh and Orfanidis (cited in McGoldrick & Carter, 1981) found that a significant life cycle event such as the death of a grandparent, when linked closely in time to another significant family life cycle event such as the birth of a child, could correlate with patterns of symptom development later in the family life cycle.

In addition it is important to be aware of the intricacies of familial relationships. The death of an elderly person may be seen as appropriate but the death of a family member in the prime of life tends to be far more disruptive to the family (Herz, 1980).

The Patient in Context

The conventional medical model has traditionally focused on the individual and in the past little attention has been given to the family as the major context in which human lives are lived and health and illness occur. However, an increasing body of research into family functioning has emerged in the last thirty years and it is now accepted that the family plays an important role in the development and maintenance of health and sickness (Turk & Kerns, 1985).

It is also well accepted that illness in a family member has adverse affects on family functioning and the more severe and long lasting the illness the more likely it is that the family will suffer and function at a less than

optimal level (ibid). This has important implications for hospice patients and their families.

It is clear from the literature that writers in the field of clinical thanatology and hospice philosophy view the family as constituting the context in which to evaluate and work with the dying. In addition it is unquestionably accepted within the hospice movement that the family should always be included as part of the intervention and this is one of the basic tenets of hospice care (Buckingham, 1983; Kastenbaum, 1977; Parry, 1989; Singer, 1983; Corr & Corr, 1983).

Kübler-Ross, whose work is pivotal to the hospice ethic, expressed her attitude to the family succinctly when she said, "We cannot help the terminally ill patient in a really meaningful way if we do not include his family. They play a significant role during the time of illness and their reactions will contribute a lot to the patient's response to his illness" (1970, p.139).

There may be times when conflict within the family may interfere with the comfort of the patient and at these times the focus of care must unambiguously be the patient (Koff, 1980). However, as Pattison (1977, p.323) puts it, "To ignore the family of the dying is to ignore the social system that forms the matrix of existence for the dying person".

Benoliel (1977, p.124) describes dying as a social passage and says "What happens to anyone defined as dying is affected by the actions and choices of the other people who comprise his or her social world". But not only is the patient affected by the family but individual family members are also affected by the dying process. The loss of a family member may be the single most upsetting and feared event in our life histories and the death of a spouse has been shown to be the most significant life-change in terms of stress produced (Kalish, 1977).

The way in which the dying process impacts on various family members varies as a function of innumerable factors such as the nature of the terminal condition, the personality of those involved, the prior history of

family relationships, the importance of the dying person to each family member and the openness of communication within the family (Kalish, 1977; Herz, 1980).

Within the system constituted by the family various forces are constantly at play. Families tend to operate to keep emotional tension down and stabilize equilibrium (Herz, 1980). However, terminal illness in the family disrupts the equilibrium and thus demands reaction from family members.

Herz (ibid, p.232) emphasises the importance of openness which he defines as, "the ability of each family member to stay non-reactive to the emotional intensity in the system and to communicate his or her thoughts and feelings to the others without expecting the others to act on them". This in turn depends on the level of differentiation or emotional maturity and the level of family stress.

As a way of protecting each other from the reality of the terminal illness, families may reduce the level of communication. Relationship issues cannot be resolved unless the system remains open (Herz, 1980). In addition the significance of the terminally ill person in terms of the role he/she plays within the family system is crucial to the family reaction. The more the family depends emotionally on the dying person the greater the reaction. Role changes also have a major impact on the family (ibid).

Kalish (1977) points out that the dying process elicits a range of emotional reactions in family members - for example guilt, anger, money worries, fear and anxiety - and that the fragility of the nuclear family places a great deal of pressure on its members. The fragility of the nuclear family is a theme taken up by Barton (1977) who points out that the extended kindred family in the past was better able to deal with the internal stress generated by the illness of a family member than is the contemporary nuclear family.

Hospice care-givers are able to help the family in various ways. As Kastenbaum (1977) points out, the family is both the agency and the recipient of care. Family members can be trained to cope better on a practical level, allowed to express their fears and anxieties, encouraged to

articulate conflicted feelings, and helped with the preparatory mourning process - the anticipatory bereavement which Kalish (1977, p.230) describes as "a kind of psychological rehearsal" for death.

Poss (1981, p.37) refers to the specific tasks the family has to complete, saying "While the dying person is engaged in his preparation for death considerable demands are made on his relatives to adapt to the impending loss. They too appear to have some specific tasks to complete and respond to this work with intense emotion". Kübler-Ross (1970) points out that relatives also pass through stages of adjustment parallel to those that the dying person experiences.

Within the hospice movement the tendency with regard to families is to draw the family members into helping to care for the patient and also to help them to work through their conflicted feelings around the imminent demise of their loved one. The focus is to allow the patient to die as good a death as possible.

And yet within the context of imminent death and the caring that this entails on a practical and emotional level, the family must also continue to meet members' needs, function as a social unit and provide a structure for the growth and development of its members (Barton, 1977).

On various levels the on-going functioning of the family changes with the presence of a dying member. Responsibility for expressive and instrumental functions may change. Marital, nurturant, relational, communicative, emancipative and recuperative functions may all change and the extent of this change may depend on the role of the ill person within the family and the extent to which this is inhibited or altered by his or her illness (ibid).

Kalish (1977, p.230) talks about the need for an "appropriate death" to occur in a context in which good human relationships continue to the time of death, while these relationships simultaneously become ready to become detached. Thus traditionally much of the hospice work with families has revolved around the process of anticipatory mourning.

As Buckingham (1983, p.8) puts it, "In the process of dying, it is extremely important that the relationships between patient and family are lived out and concluded as productively as possible".

However, Buckingham (ibid, p.28) goes on to say that, "Family problems cannot be ignored..... for if they remain unresolved they affect the peace of the dying patient". Thus he is making a jump from problems and issues which impact directly on the patient and other problems or issues which may affect the functioning of the family itself which then indirectly affects the patient. These issues are further away from the area traditionally regarded by Hospices as grist for their mill but it is the contention of this researcher that this constitutes an area worthy of investigation and intervention where necessary.

Family Functioning in the Context of Terminal Illness

Although a great deal of emphasis has been placed in the literature on the instinctive realisation that working with individual family members forms a crucial part of the Hospice treatment approach, there is a relative paucity of research on the actual functioning of the family with a dying member (Pattison, 1977).

Bishop and Epstein (1980) refer to the lack of rigorous studies into the precise nature of dysfunction in families where a member is disabled in some way and the way in which working with such families has to rely on clinical judgment and intuition.

As discussed, the family and not just the patient experiences both the crisis and the long-term impact of the impending death. Members of the family are directly affected by the demands and stresses of illness. The family adapts to intense and disruptive stresses by internal reorganisation which may result in major changes in family structure, function and identity (Geyman, 1983). This can be disorienting and confusing for families and the struggle to cope with impending death may be exacerbated by the struggle to cope with role changes and other structural alterations within the family system.

However, current knowledge in this area is limited. As Lewis (1986) points out there is scanty and limited research on the family's response to cancer when data are obtained from other than the patient, and she suggests the necessity for looking at the perceptions of other family members. According to her, studies suggest that family members may not be perceiving or prioritizing the same types of issues or problems as the patient - in fact perceptions may be totally different. This can lead to clinical support being mistargetted, whereas as she points out clinical help will be more efficient when we have a better understanding of the heterogeneity of the family's response and the multiple transitions involved in the process of living through impending death.

In her paper, Lewis (*ibid*) provides a review of the research literature on the impact of cancer on the family, and it is immediately apparent that there is a paucity of data in this area. As she points out reviewing the research done in this field tends to create an inflated view of how much we really do know about families experiencing cancer, and this can, she feels, be dangerous. In addition Lewis points out that the research carried out thus far appears to focus on specific areas of family functioning rather than giving a global picture of how families cope. There is thus an urgent need to obtain a global evaluation of family functioning.

Lewis (*ibid*) identifies and discusses research carried out in eleven areas, viz. emotional strain, physical demands, uncertainty, fear of the patient dying, altered roles and lifestyles, finances, ways to comfort the patient, perceived inadequacy of services, existential concerns, sexuality and non-convergent needs among household members. However, in terms of the multiple transitions that Lewis mentions, research can also be focused in terms of the stage of illness being assessed. In her review of the impact of cancer on the family Northouse (1984) divides research into that done on the initial, the adaptation and the terminal phase of the cancer.

Northouse points out that most research has been conducted on the impact of the terminal phase of the illness. In addition few studies have concurrently assessed both the patient and family members. She reviews

research on the impact of cancer on the family from a systems perspective and reports that cancer and other terminal illnesses generate considerable anxiety within the family system and that communication patterns, roles and relationships within the family may be altered as a result.

Northouse aims to identify areas and phases in which family members may require increased professional help. She points out that the initial stage has been reported as one of the most stressful times for both patients and family. She cites research by Giacquinta who talks of the despair, isolation and vulnerability of family members at this stage; and by Thomas who refers to the sense of shock, confusion and uncertainty of the family. Examining research carried out on the initial stage of cancer she identifies three major potential problem areas for family members. Firstly family members may feel excluded from both receiving and participating in care and the cause of this exclusion can be the staff, the patient or themselves.

Secondly they may experience difficulties in communicating with medical staff as well as other family members, and as a result interpersonal relationships may become strained. In addition it has been found that the limited interactions that do exist between family members and medical personnel tend to be initiated by family members rather than by physicians or nurses. As Northouse points out, the family needs information but experiences difficulty in getting it. Information may be lacking, given too abruptly or given to the family but not to the patient which places the family in a dilemma. Northouse mentions research by Krant and Johnson which shows that communication between the physician and family members in the later stages of cancer correlates highly with whether or not the physician discussed the diagnosis with the family in the early stages.

Thirdly family members may experience considerable anxiety and tension around the diagnosis, a finding which is consistent with Sontag's (1979) comments about negative societal reactions to cancer as discussed in Chapter 2. Northouse (op. cit.) reports Cassileth and Hamilton's finding that psychological distress increases as the family faces uncertainty, helplessness and loss of control. According to Giacquinta (cited in Northouse op. cit.) family members experience withdrawal and agitation, and according to Welch

(cited in Northouse op. cit.) these problematic issues can manifest in physical symptoms. In the area of emotional strain, Lewis (op. cit.) cites research by Germino who found that the most frequent major concern for spouses and children was their own level of restlessness.

Northouse (op. cit.) notes that there are mixed reports as to whether distress of family members is related to the amount of distress of the patient.

Lewis (op. cit.) reports that there is substantial evidence to suggest that the needs and perceptions of the family and the patient about the experience of cancer may be out-of-phase and even different.

Themes around uncertainty over the patient's health were found to be problematic in several studies. For example Gotay (cited in Northouse op. cit.) found that fear of the cancer diagnosis was the most frequently reported problem for both the patient and spouse, again feeding into Sontag's metaphor as referred to above. Other studies found uncertainty to be particularly stressful.

Fear of the patient dying has been found to be experienced at all stages of the disease, and Lewis (op. cit.) suggests that this indicates emotional vulnerability in the family at multiple key transition times during which the family feels threatened as a unit.

Studies, for example those by Gotay and by Holing (cited in Lewis op. cit.), also suggest that seeing the patient suffer often leads to emotional tension in the family, and this can occur at both the initial and the terminal stages.

Looking at the adaptation phase, Northouse (op. cit.) reports that research findings suggest that difficulties revolve around three areas. Firstly, the family has to adjust to role changes as well as lifestyle changes. Secondly, family members have to balance their general on-going needs with the specific needs of the ill member and failure may lead to anger, guilt or resentment. Northouse reports the contention of Steinglass and Associates that families may sacrifice developmental growth for current stability.

Thirdly the family has to cope with living with the uncertainty of not knowing what the future is going to bring. Not only do individuals involved

struggle with their own fears, but communication between them of these fears is often problematic. For example Northouse (op. cit.) cites research by Wortman and Dunkel-Schetter which indicates that family members are often unsure of how to respond to the patient's fears, and this may lead them to encourage concealment of fears. Northouse suggests that supportive relationships are often helpful during periods of uncertainty.

As Northouse points out coping with these three aspects of the adaptation stage draws some families closer together while it pushes other families further apart. This is an important point for the present study which is not attempting to prove that illness causes dysfunction but simply to establish whether there is dysfunction in the majority of hospice families.

Northouse (op. cit.) reports that the literature on the terminal phase of cancer also addresses three problems. The first is communication amongst family members around the subject of death and she refers to both Vachon's and Hinton's studies which suggest that contrary to the commonly held belief that open communication during the terminal illness is essential, denial or non-discussion may actually be a valuable coping mechanism in some cases. Hinton (cited in Northouse) suggests that there are different preferences for communication, rather than miscommunication. However, Northouse also cites various studies which suggest that open communication is vital, for example work by Vachon, by Cohen, Dizenhuz, and Winget, and by Hinton. Northouse also cites an interesting study by Worby and Babineau which suggests that before family members are able to talk openly about death, communication tends to be superficial and stilted. Health professionals may either enhance or hinder communication among dying patients and their families and Hackett (cited in Northouse) cautions against the use of faulty communication that can increase the burden. Krant and Johnson (cited in Northouse) found that many family members do not have a communication link to the physician and that there may be a discrepancy between information reported by patients and that reported by family members about the illness.

The second issue around the terminal stage is that of providing care and support to the dying person when family members may experience

considerable strain. Both Northouse and Lewis (op. cit.) cite Vachon's finding that the stigma surrounding cancer also appears to influence the provision of care. The physical demands of care are also stressful, and Vachon found that the final illness was more stressful for cancer wives than for widows of men with cardiovascular disease, and that cancer widows felt powerless in coping with their partner's illness. This is compatible with Sontag's (1979) comments as discussed in Chapter 2. Of particular interest to hospice is Krant and Johnson's finding (cited in Northouse op. cit.) that family members may actually prefer the patient to die in hospital, and as Northouse points out there may be a subtle social pressure to accept hospice care in the home.

Thirdly, in the terminal phase the family has to cope with feelings of loss and separation. Northouse cites Hampe's finding that only 15% of spouses considered that professionals had given them support at this stage, and again this finding raises questions for hospice as to what it is that families need and what is actually being provided.

In connection with the terminal stage Lewis (op. cit.) cites Krant and Johnson who found that fears and feelings of helplessness were reported by two thirds of their sample as the major complaints in both patient and family.

Lewis (op. cit.) refers to substantial evidence that household roles and lifestyle are negatively affected during terminal illness and this influences the total household's coping and functioning. According to Lewis, studies show that role changes may affect one third of cancer families.

In terms of existential concerns accumulating evidence suggests that a cancer diagnosis in one member of a family precipitates existential concerns in the family. However, although existential concerns appear to be an issue, Vachon's study (cited in Lewis) indicates that these are not necessarily discussed in the family - again coming back to the issue of communication. Even though the literature advocates open communication about death, Vachon found that 61% of wives claimed that they had never discussed death with their diagnosed spouse.

Interestingly, the same study found that of the women who said that they had talked with their husbands about death, 81% claimed that it had facilitated their own bereavement process. Thus it appears that the area of communication, which affects the systemic functioning of the family, deserves more attention.

The existence of non-convergent needs referred to by Lewis also has implications for this study in that the systemic functioning of the family may be affected by the ways in which the patient's perceptions of the cancer experience may be different to that of the family.

It is clear from research findings that optimal communication is a crucial area for successful functioning. Usher (1986) emphasises the importance of communication style for effective family functioning and points out that in healthy families there is clarity of expression of feelings and openness and directness in communication rather than obscuring and confusing communication.

However, in evaluating families with a child who has cancer, Usher (ibid) found no differences in functioning between families with open and closed communication styles around the subject of the terminal illness. This finding raises important issues for hospice as to the subtlety and uniqueness of each family's communicational style which needs to be respected. Usher (ibid) suggests that families create their own solutions and that interventions should be based on each family's unique approach to their situation.

Although many of the findings cited in this chapter do not provide indices of family functioning as a whole, they do provide valuable pointers to both researchers and therapists as to the areas of vulnerability in terminally ill families.

CHAPTER 5

FAMILY THERAPY IN THE CONTEXT OF TERMINAL ILLNESS

Conventional Hospice Approach to Family therapy

Family therapy does not form part of the mainstream of hospice philosophy and care in spite of the recognition of the importance of the family as the context of treatment. In a basic text entitled Hospice care - principles and practice, edited by Corr and Corr (1983), Hillier discusses the hospice movement in the United Kingdom, looking at its strengths, its weaknesses and future directions. No mention at all is made of family therapy and families are mentioned only in terms of providing a context and supportive care for the terminally ill patient.

In the same text Stedeford discusses psychotherapy of the dying patient and she mentions family therapy only in the context of resolving family feuds. Other basic hospice texts such as Buckingham (1983) and Hamilton and Reid (1980) make no mention of family therapy at all.

Kübler-Ross (1970), whose work provides enormous inspiration to the hospice movement, is very aware of the needs of family members and the changes - either subtle or dramatic - in the atmosphere of the home when one member of the family is terminally ill. She talks of the problems associated with role changes, communication and guilt, and the huge range of emotions present in both family members and patients which need to be given space.

However, although she offers important insights into the emotional state and functioning of the family, her work is with individual members, not with the family as a system. She displays a rich empathic response to individuals and is able to facilitate the release of major blockages, but does not offer a therapeutic model for working with the family as a whole.

Family therapy: Development and Orientations

Family therapy involves the treatment of family groups or family systems rather than individuals. The advantage is that it is quicker and more effective, and uses professional time more economically than individual therapy would. In addition it aims to deal with factors currently maintaining problems rather than exploring the past (Barker, 1981).

Disadvantages include the logistics of gathering the various members of a family together for a session, the fact that the theoretical underpinnings of family therapy are not as well established as in individual therapy and that family therapy does not tackle intrapsychic pathology (ibid).

Prior to the Second World War, psychotherapeutic treatment was carried out almost exclusively on an individual basis. However, a proliferation of family therapy orientations emerged simultaneously in the 1950's and 1960's and since then family therapy has become a well established field with its own techniques, specialists and journals (ibid).

It is indicated when the family's ability to perform its basic functions becomes inadequate and the aim is to bring about change in the functioning of the overall family system (Goldenberg & Goldenberg 1980).

Although the field of family therapy is influenced by several differing theoretical orientations, most family therapists see families as open systems, at least explicitly even if not implicitly (Barker, op. cit.). Thus systems theory is used as a model to understand how families function, but a variety of therapeutic methods can be employed to change the actual functioning of families, for example the strategic model uses paradoxical interventions and the structural model is concerned with boundaries. Systemic family therapy assumes that family problems can be traced to unspoken rules of behaviour and disagreements about who makes the rules as well as to distorted communication. The therapist's role in this case is to expose the rules and help the family to modify them and to improve the level of communication within the family (Gelder et al., 1990). In addition theoretical approaches

range from attempting to give insight to triggering off a change in behaviour in the family (ibid).

Most clinicians agree that family therapy is especially applicable for clarifying and resolving relationship difficulties within a family (Goldenberg & Goldenberg, 1980). As this is an especially important area of interest for Hospice care this would tend to suggest the importance of considering family therapy for terminally ill families where relationship difficulties are often a major focus of concern. These difficulties involve reciprocal interactional patterns to which family members contribute, whether consciously or unconsciously.

However, as Goldenberg and Goldenberg (ibid, p.137) point out, "Family therapy is not a panacea for all psychological disturbances but rather a valuable addition to a therapist's repertoire".

Although systems theory is used in this study as a model to understand how families function, as mentioned above the adoption of this theoretical stance does not limit family interventions in any way. From a systemic perspective any intervention which changes how a family functions would be regarded as changing the system (Barker, 1981).

Family Therapy in the Context of Illness

Family therapists have tended to regard the concept of illness with suspicion and as a result there are abundant and largely untapped opportunities for working with families with an ill member (Wynne et al., 1992).

Wynne et al. (ibid, p.4) suggest that family therapists have tended to have a "jaundiced view" of the concept of illness for various reasons. However, they state that family therapists do not have to buy into a biotechnical, reductionistic reframing of illness as disease. Rather they prefer to see illness not simply as a personal experience but as a transactional, communicative and social experience.

Thus illness can be conceptualized as a narrative which involves sharing responsibility for coping and finding solutions without becoming side-tracked in causal disputes.

Disease in contrast is the physician's construction - thus illness is experienced by patients and disease is diagnosed by the doctor (ibid). Disease can be diagnosed whether or not the person accepts the role of patient and this can have important implications for the patient with a terminal diagnosis. Thus the success of any therapeutic effort demands that the therapist first understand the experience of the family in the context of illness and disease.

It is important to be aware of the negotiated nature of the treatment process and the right of the patient to be compliant or non-compliant with treatment. Being a patient and complying with treatment is a responsibility in which the patient is an active agent. The illness concept for the individual is socially and cross-culturally accepted so a degree of pressure may be seen to be legitimately applied to individuals. However, applying the concept of illness to families is not supported by the same comparable cultural tradition. This has the crucial implication that the relationship of clinicians with families has to be negotiated in each case as there may be strong resistance to the concept of the family as patient (ibid).

Thus one of the difficulties of suggesting family therapy to a family is that this could be construed as implying that the family is ill. Wynne et al. (ibid) point out clinical and conceptual difficulties with the family systems formulation, for example that locating the responsibility for a problem within the family system may in some situations be seen as unfair and inappropriate. The family may feel that it is being blamed for the family member's illness and could then be sensitive to the implications of a recommendation for family therapy. Of particular relevance for this study is the fact that cancer is considered to be an illness in which psychosocial factors may modify the course of the disease - at the same time it is well recognized that cancer imposes a significant burden on the family (Wynne et al., ibid). Usher (1986) sees the family as co-evolving around the cancer,

and looking at families from a systemic perspective she refers to the family as actually having the cancer.

Family Therapy with Terminally Ill Families

The primary focus of interventions used in the context of terminal illness has been the patient, a logical result of the emphasis within health care on the individual. Thus there is a paucity of information in the literature as to what interventions can be utilized to help terminally ill families (Northouse, 1984).

Various writers have discussed the distress caused to the family but have offered little in the way of constructive therapeutic approaches. For example, Kübler-Ross (1970) has demonstrated the suffering and distress experienced by the family of terminally ill patients arising from their inability to communicate thoughts and feelings. Given the fear, suspicion and denial with which death is viewed in our society - as discussed in Chapter 2 - it is apparent that a conspiracy of silence has descended on families which has tended to make them both needy of and yet ironically inaccessible to family therapy.

In addition, as discussed in Chapter 2, cancer is acutely feared and causes both individuals and families to be shunned. Families thus often become inadvertent contributors to the sense of isolation and abandonment experienced by all involved (Winder, 1978).

Thus although societal attitudes to death tend to militate against acknowledging the impact impending death has on each member of the family and the family system as a whole, some therapists do insist on the importance of family therapy in cases of terminal illness and it is described as a necessary part of the cancer patient's care by Winder (1978). He advocates a number of family therapy sessions as a routine part of the treatment approach once a terminal illness has been diagnosed as he feels that this will help the family to learn to live while the patient learns to die.

He suggests that the therapist's work with the family revolves around creating a new relational balance in the family, given that the patient tends to slide out of a close relationship with the rest of the family system. He also suggests that the family should work together while the patient is still alive as this can prevent much of the severe distress suffered by the survivors.

Adler et al. (1975), discussing approaches to intervention with dying patients and their families, also focus strongly on helping the family by means of family therapy before the death in order to facilitate the bereavement process. However, the focus is very much on the emotional health and family functioning of the survivors post death rather than working with problems before the death to improve the quality of death for the entire family.

The serious illness of a family member leads to disruption in the family equilibrium and the openness of the family system influences the degree of disruption to the family system (Herz, 1980). She feels that most family interventions around death are directed toward opening up the family emotional system to prevent family symptomatology and dysfunction.

She mentions the importance of various interventions such as using factual and open terminology and information; establishing at least one open relationship within the family; respecting the hope of life and living; remaining unreactive; checking on the progress of relationships; and utilizing family rituals and customs.

Hackett (1976), talking of psychological assistance for the dying patient and his family, discusses the problems that arise when problematic patterns of communication develop. He points out that in a family where there is poor communication this situation is likely to continue during the course of a terminal illness.

He feels that the physician must ensure that faulty communication does not exacerbate the patient's situation and says that families often need guidance about what to say. His suggestions seem to have far more to do with

content than with process issues and contribute little in the way of insight into how the family can be helped as a whole.

Northouse (1984) suggests a three-pronged intervention which involves firstly assessing needs of family members, secondly providing support to families, and thirdly providing information and assistance to families. Reviewing studies involved with assessing needs she concludes that the physical rather than the emotional aspects of care tend to be addressed; this may leave families unsupported emotionally.

In terms of providing support, Northouse (ibid) suggests that whether individual or family support is offered depends on the personal orientation of the clinician involved. She points out that studies suggest that even if the intervention is only with one member of the family - be it the patient or not - this can have positive effects on their relations with other members of the family. For example, Linn et al. (cited in Northouse) report that easier communication with family members has been reported by some cancer patients who received individual counselling.

Northouse reports that interventions described in the literature involving the entire family aim to facilitate better intra-family communication and to increase the level of mutual support within the family (ibid). The family interview is seen as an intervention that facilitates discussion and communication within the family thanks to the presence of a supportive professional (Worby & Babineau cited in Northouse). Other interventions mentioned by Northouse are aimed at the multi-family level and involve a group experience which can even involve a weekend retreat. However, as Northouse points out, there is a need for a systematic evaluation of possible interventions as not enough is known about how best to meet specific needs in different families.

The third category of intervention aimed at family members involves providing information and assistance. This can be carried out at the individual or group level and involves the dissemination of practical information on topics such as chemotherapy, nutrition and breast prostheses (ibid).

C H A P T E R 6

METHODOLOGY

In this project a number of hospice families were visited and asked to complete the FAD (Family Assessment Device), a questionnaire based on the McMaster Model of Family Functioning. Families were asked to provide background data and relevant clinical observations were obtained by the interviewers.

Key concepts will first be defined and discussed, the origins, development and validity of the FAD will be discussed briefly, and the implementation of the data collection process will then be described.

Definition of Family

Defining the word "family" involves a consideration of factors such as biological relationship, multi-generational co-existence and mutual support, some of which may be seen to be essential and some not. Epstein and Bishop (1981, p.447) state that "the primary function of today's family unit appears to be that of a laboratory for the social, psychological, and biological maintenance of family members".

Epstein and Bishop (1981) refer to the three task areas that families have to deal with. The first is the basic task area which includes fundamental instrumental tasks such as the provision of food and shelter. Secondly the developmental task area involves the growth and development of individuals and the family over time, for example the individual progresses from infancy via adolescence to old age and the family progresses through the stages of marriage and birth of children to the empty nest and old age. Finally the hazardous task area involves the crises of life such as job changes, moves, illness and death. These task areas are of crucial importance since failure to negotiate them often leads to clinical presentation (ibid).

Turk and Kerns (1985, p.2) provide a useful and appropriate definition of "family" for the purposes of this project when they say, "In our view, families are groups composed of members who have mutual obligations to provide a broad range of emotional and material support". They do not assume that families are blood relatives - nor do they even assume that members live together, though in this project only family members who do live together have been included. The crucial part of their definition for this study is the concept of "mutual obligations". In addition they say that families have a structure, functions and assigned roles, modes of interacting, resources, a life cycle, a history and a set of individual members with unique histories.

Parry (1989, p.64) makes the definition more concrete in hospice terms when he defines the family as, "those who provide the primary care for the dying patient; family can be a spouse, parent, child, sibling, aunt, nephew, friend, lover, or whatever person serves as the primary caretaker".

Wu (1990/91, p.140) describes the family as the best primary group that fulfills social support functions in times of mental and physical crisis. She refers to a social support system being made up of "the continuing social aggregates who express relative alliance and genuine concern and give behavioral and emotional feedback ..."

Thus in this study the family is neither being conceptualized in terms of a simple nuclear nor a more complex extended family, but rather in terms of whoever lives with the patient - whether it be one or several people, relatives or otherwise - in a mutually supportive relationship. In terms of this definition a live-in domestic servant was interviewed in one family, although the data for this particular family was later discarded for other reasons.

The McMaster Model of Family Functioning

The McMaster Family Assessment Device (FAD) is based on the McMaster Model of Family Functioning (MMFF), a systems oriented conceptualization of

how families function. The MMFF describes structural and organizational properties of families and the patterns of transactions among family members which have been found to distinguish between healthy and unhealthy families. Six dimensions of family functioning are identified - problem solving, communication, roles, affective responsiveness, affective involvement and behaviour control (Epstein et al., 1983).

Drawing on Epstein and Bishop (1981) and Epstein et al. (1983) these six dimensions are defined as follows:

Problem solving: refers to the family's ability to resolve problems that threaten the integrity and functional capacity of the family in such a way that effective family functioning is maintained. Problems may be instrumental or affective in nature. Clinical experience suggests that if there are instrumental problems in a family, there will almost always be affective problems, but affective problems can occur without instrumental problems.

Communication: refers to the exchange of information among family members. It involves both instrumental and affective areas and may be clear or masked, direct or indirect.

Roles: refers to the established or recurrent patterns of behaviour within a family whereby individuals fulfill functions within the family. These functions include the provision of resources, nurturance and support and an analysis of roles looks at how they are assigned within a family and how responsibly they are carried out.

Affective responsiveness: refers to the range - in terms of quantity and quality - and the appropriateness of affect which family members experience.

Affective involvement: refers to the degree to which individual family members show interest and concern for other family members, and may range from no interest to an over-involvement, neither extreme being considered healthy.

Behaviour control: refers to the way in which a family handles and controls the behaviour of family members in situations involving (a) physical danger, (b) meeting and expressing psychobiological needs or drives, and (c) interpersonal socializing.

Development of the FAD

Epstein, Baldwin and Bishop, in a paper published in 1983, describe the development of the FAD which was developed as a screening instrument. It was designed to obviate problems encountered with other methods of collecting information about family functioning such as observations of family members interacting and extensive interviews with individual family members. These methods have the potential to produce vast amounts of data but are time-consuming and expensive to implement.

Noting that the family may not be perceived in the same way by different observers or even by different family members, Epstein et al. (1983) draw on the richness of these differences as an area worthy of empirical study which can provide the clinician with valuable information. In fact they make the point that the FAD was designed to be useful not just to researchers but also to family clinicians.

The FAD is made up of seven scales - one for each of the above dimensions of functioning and a seventh which assesses the overall health/pathology of the family. The FAD has been found to differentiate significantly between healthy and unhealthy families. It is a paper and pencil questionnaire and can be administered to all family members over the age of twelve years, including the patient. It has the additional advantage of being easy to administer and unskilled researchers are able to utilize it.

The questionnaire consists of sixty items which are statements about families. These items are derived from the seven scales. Each person filling in the questionnaire is asked to read through the questionnaire and decide how well each statement describes his/her family and circle one of four responses accordingly. The responses are "strongly agree", "agree", "disagree" and "strongly disagree".

In developing the FAD, Epstein et al. (1983) used the MMFF to define the domain which the instrument was to assess, thus insuring adequate coverage within the item pool of the areas of family functioning which were considered to be crucial. During the process of refinement of the

questionnaire, they describe how items were selected for the six dimensions according to three criteria. The first was that items had to be written for the relevant dimension, the second that items making up a scale had to be as highly intercorrelated as possible so that the scale had maximal internal consistency and the third that items in a scale had to correlate more highly with that scale than with either the General Functioning scale or the other five scales. The seven scales of the FAD are reported to have acceptable reliability (ibid). Further research conducted by Miller et al. (1985) suggests that the FAD has adequate test-retest reliability. In addition it was found that social desirability does not appear to exert a strong influence on FAD scores.

Validity of the FAD

Epstein et al (ibid) report two findings which suggest that the FAD has validity. Firstly the FAD scores of individuals from 218 non-clinical and 98 clinical families were used to predict whether the family came from the clinical or non-clinical group. The results were highly statistically significant ($p < .001$).

Secondly, they conducted a study of retirement adjustment, interviewing a random sample of 178 couples. They used the FAD as well as the Locke Wallace Marital Satisfaction Scale which is in current use. They found that the two scales were measuring related phenomena but that the FAD was the more powerful predictor.

Research conducted by Miller et al. (1985) comparing scores on the FAD with scores on the Family Unit Inventory showed correlations very close to a priori predictions. This provides good evidence for the concurrent validity of the FAD. Discriminative validity of the FAD was assessed by comparing an experienced family therapist's clinical ratings of a family with the family's FAD scores. Results showed that the FAD scores correspond to the clinician's ratings of healthy and unhealthy families in six out of the seven dimensions. The exception was Behaviour Control which approached significance ($p = .12$) (ibid).

Health/Pathology Cut-off Scores

Although it has been shown that the FAD differentiates significantly between healthy and unhealthy families, Miller et al. (1985) established specific cut-off scores on each dimension in order to give the FAD greater clinical utility.

These cut-off scores have been shown to have acceptable rates of sensitivity and specificity as well as high rates of diagnostic confidence and can effectively identify significant family dysfunction on at least six of the seven dimensions. Data with respect to Behaviour Control are weaker and in need of further investigation (ibid).

The Data Collection Process

A team approach was used to collect data. Three researchers were involved - one clinician (who is also the supervisor of this thesis), one post-graduate student and the current writer. A total of 21 families were interviewed in their own homes by a member of the team.

Selection criteria were that the family had a terminally ill member living at home and that family members were able to communicate fluently in English. Black families were excluded because of the difficulties of language and this omission will be considered further in the discussion section - Chapter 8. It appeared that the obvious gratitude for the help given by the hospice organisation greatly facilitated access to these families, and no families refused to be interviewed.

Fourteen families were seen through the auspices of the Grahamstown Hospice Association, and this sample constituted all the families being seen by the Hospice at the time of the data collection who fulfilled the above criteria. Entrance to the families was arranged through the Hospice Director, and the hospice nurses involved with the various families briefly described the project to the families involved, requested the families' permission for a

researcher to visit and then prepared them for the visit. Initial contact was then made by telephone by the relevant researcher and an appointment was arranged.

The first three families interviewed were visited by two researchers working together in order to share initial impressions of the data collection process. By chance these families consisted of relatively elderly members and it was found to be helpful having two people to help guide the subjects through the questionnaire, and where necessary read the questions for subjects with poor eyesight. All other families were visited by one researcher. Of the Grahamstown families one was excluded from the final data analysis because verbal feedback from family members contradicted many of the responses on the questionnaire, thus the validity of the responses was questionable.

A total of five families were interviewed in Cape Town by the clinician involved in the project. Although these families were not procured through the hospice organisation in Cape Town, telephone contact was made with them by means of personal contacts the researcher had made with cancer sufferers and an appointment arranged.

In order to ensure a statistically adequate sample a further two families were interviewed in Port Elizabeth through the auspices of the St Francis Hospice. These families were selected by the Hospice Director based on the criteria mentioned above and the families were prepared for the visit by the hospice nurse involved. They were telephoned by the researcher involved and an appointment made. Data from both these families has been used.

To summarize: data from a total of twenty families was utilized - thirteen families from Grahamstown, two from Port Elizabeth and five from Cape Town.

One visit was made to each family and members were asked to all be present at the same time. The purpose of the research was explained thus:

"We are doing research for the Hospice to help us understand what sorts of problems there are in families where one member is ill. All families face stress at various times - we are interested in the particular stresses and

problems facing a family with an ill member. This will help the Hospice to be of more assistance to families."

Identifying data and information about the family circumstances were collected: names, ages, type of cancer or other illness, when diagnosed and treatment. Also collected was additional information about support received from friends or community, religious affiliation and financial status. Where appropriate the psychological effect of any bodily disfigurement resulting from the illness was probed. This additional information was sought to gain a picture of any possible external factors which could be problematic to family functioning. Clinical impressions were also noted.

Each family member over the age of 12 was then asked to complete the FAD questionnaire while sitting together. Members were asked to carry out this task without discussion with each other and they were also told that the information would be confidential and would not be communicated to other members of the family. In this way each person was assured that his or her responses would be private and would not be used in an embarrassing manner, for example, to show them up in any way with their family.

Individuals who did not understand a particular item were able to ask the researcher for help. Families generally took about half an hour to complete the questionnaire and the total duration of each visit was about one to one and a half hours. Time spent talking casually with the family was deemed to be important, firstly to help family members feel comfortable about the questionnaire, and secondly to allow the researcher to collect qualitative impressions of the family. In several cases where a member or members of the family were not available a questionnaire was left for them with the request that it be completed and it was later collected (Grahamstown families) or posted on to the researcher (Cape Town families).

CHAPTER 7

RESULTS

1. Descriptive Data

Twenty families, comprising fifty nine individuals, were interviewed.

a) Family Composition:

Of the families interviewed, eight are composed of two people, eight of three people, two of four people, one of five people and one of six people. Of the 20 index patients a total of 9 are male (45%) and 11 are female (55%). The average age of the IP's is 54,3 years.

b) Diagnosis:

Of these 20 patients a total of 16 have a diagnosis of cancer. Two patients have emphysema and two have multiple sclerosis. A further breakdown of the cancer diagnoses is as follows:

Brain Tumour	-	2 cases
Bone Cancer	-	3 cases
Breast Cancer	-	2 cases
Bowel Cancer	-	1 case
Sarcoma	-	1 case
Lung Cancer	-	4 cases
Ca Colon	-	1 case
Ca Bladder	-	1 case
Ca Oesophagus	-	1 case

c) Duration of Illness:

In terms of duration of illness, thirteen of the index patients had been ill for a year or less. The exact breakdown is as follows:

<u>Duration</u>	<u>N of cases</u>
0 - 12 months	13
13 - 24 months	2
25 - 36 months	1
37 - 48 months	2
49 months and over	2

d) Religious Affiliation:

Of the twenty families interviewed, four families described themselves as non-religious, three as occasional church goers and thirteen as regular church goers - in other words going to church every week.

Fourteen families described themselves as Christian, one as Jewish and one as Hindu, and four had no religious affiliation.

2. Family Functioning

The level of functioning of the twenty families in the study was calculated by means of the FAD (Family Assessment Device). Table 1 shows the mean scores of the twenty families.

Table 1: The FAD scores for the twenty families on the seven dimensions of the McMaster Model of Family Assessment

	Mean	S	Range
Problem Solving	2,07	0,21	0,9
Communication	2,34	0,19	0,8
Roles	2,30	0,20	1,0
Affective Responsiveness	2,29	0,27	0,9
Affective Involvement	2,16	0,21	0,8
Behaviour Control	2,04	0,25	1,2
General	2,19	0,29	1,1

Miller et al. (1985), in developing the FAD, demarcated cut-off points for each of the seven dimensions. Scores higher than the cut-off point indicate dysfunction within that dimension. In terms of the cut-off scores, Table 2 shows the proportion of families in two categories - above and at or above these. The reason for both calculations is discussed in the final chapter. The more conservative estimate shows that as far as General Functioning is concerned 65% of the families in the study are dysfunctional.

Table 2: Proportion of Hospice Families above FAD cut-off scores*, and at or above FAD cut-off scores.

	Cut-off	N above	N = or below	% above	% At or above
PS	2.2	4	16	20	30
C	2.2	14	6	70	85
R	2.3	6	14	30	75
AR	2.2	11	9	55	70
AI	2.1	11	9	55	65
BC	1.9	12	8	60	85
G	2.0	13	7	65	75

2 Families scored above cut-off scores on all 7 dimensions

2 Families scored above cut-off scores on 6 dimensions

3 Families scored above cut-off scores on 5 dimensions

4 Families scored above cut-off scores on 4 dimensions

2 Families scored above cut-off scores on 3 dimensions

2 Families scored above cut-off scores on 2 dimensions

5 Families scored above cut-off scores on 1 dimension

No families failed to score above the cut-off scores on at least one dimension.

Correlations between the seven dimensions of the FAD were calculated by means of the Pearson Product Moment Correlation, and these are shown in Table 3. These show a significant correlation between all of the dimensions except for the following: Behaviour Control does not correlate significantly with Communication, Affective Responsiveness or Affective Involvement, and Affective Responsiveness does not correlate significantly with Roles.

Table 3: Pearson Product Moment Correlations among FAD Scores

	PS	C	R	AR	AI	BC	G
PS	--	.63**	.39**	.38**	.40**	.23*	.60**
C	.63**	--	.45**	.51**	.41**	.20	.62**
R	.39**	.45**	--	.07	.36**	.30**	.41**
AR	.38**	.51**	.07	--	.40**	.06	.63**
AI	.40**	.41**	.36	.40**	--	.20	.63**
BC	.23*	.20	.30**	.06	.20	--	.24*
G	.60**	.62**	.41**	.63**	.63**	.24*	--

Note: - Above correlations based on all subjects' responses (N = 59).
 - Correlations show extent to which scales are dependent/ independent and extent to which scores on one scale are predicted by scores on the other.
 - ** = $p < 0.01$
 * = $p < 0.05$

The means scores of the terminally ill member of each family, the IP, were compared with the mean scores of the family members by means of a t test, and the differences were found to be not statistically significant. These results are shown in Table 4.

Table 4: Mean scores of the IP compared with means scores of the family on all 7 dimensions.

	Index Patient	Family Members
Problem Solving:	$\bar{x} = 2.05$ $s = 0.24$ $p = 0.80$	$\bar{x} = 2.07$ $s = 0.25$ $t = 0.26$ $df = 38$
Communication:	$\bar{x} = 2.36$ $s = 0.31$ $p = 0.91$	$\bar{x} = 2.35$ $s = 0.25$ $t = 0.11$ $df = 38$
Roles:	$\bar{x} = 2.30$ $s = 0.30$ $p = 0.75$	$\bar{x} = 2.28$ $s = 0.18$ $t = 0.32$ $df = 38$
Affective Responsiveness:	$\bar{x} = 2.37$ $s = 0.34$ $p = 0.16$	$\bar{x} = 2.22$ $s = 0.28$ $t = 1.43$
Affective Involvement:	$\bar{x} = 2.26$ $s = 0.29$ $p = 0.17$	$\bar{x} = 2.13$ $s = 0.28$ $t = 1.39$
Behaviour Control:	$\bar{x} = 2.00$ $s = 2.05$ $p = 0.86$	$\bar{x} = 1.98$ $s = 1.90$ $t = 0.18$
General:	$\bar{x} = 2.21$ $s = 0.32$ $p = 0.36$	$\bar{x} = 2.12$ $s = 0.30$ $t = 0.93$

The significance of several variables involved in the study was assessed. The mean level for General Functioning for families where the patient has been ill for twelve months or less is 2.2 (N = 13); and where the patient has been ill for over twelve months the mean is 2.1 (N = 7).

The Pearson Product Moment Correlation ($r = -0.14$) is non-significant ($p = 0.56$), indicating that there is no relationship between duration of illness and

General Functioning. Thus, overall, length of illness shows no significant difference in the category of General Functioning.

In terms of the relationship between family size and General Functioning, the Pearson Product Moment Correlation

($r = -0.22$) is also non-significant ($p = 0.35$), indicating that there is no relationship between these two factors.

CHAPTER 8

DISCUSSION AND CONCLUSIONS

This pilot study, which evaluates the functioning of families with a terminally ill member, forms part of an on-going body of research which aims to illuminate different facets of terminal illness within the hospice context in South Africa, both from the perspective of the dying person and from the perspective of the family.

The motivation for the research is to help hospice to improve and extend the service offered to families who are trying to cope with a terminally ill member. In this way hospice is able to work more closely towards the ethic of helping the terminally ill patient to be able to die in a way that is non-defensive, has meaning for the patient and is open and dignified. In order to do this, research is needed which provides a baseline from which the hospice movement can grow in terms of expertise, thus enhancing its value in society.

A crucial facet of this study is that it stems from a theoretical base. Lewis (1986) criticises the atheoretical approach of the studies she evaluates, pointing out that simply providing a list of problems in terminally ill families is insufficient. She maintains that future research needs to make its theoretical linkages more explicit. The present study has attempted to do this, in using as a research tool the FAD, which is based on the McMaster Model of Family Assessment which conceptualizes families from a systems perspective.

Hospice work stemmed initially from the desire to help terminally ill patients to die with more dignity than the prevailing medical technological approach would allow, and also to allow the patient to die at home if this was desired. The family was involved right from the start as constituting the context in which or from which the dying person had to negotiate this final stage of life.



However, helping the family has tended to mean helping individual members of the family to come to terms with the impending death, helping to ameliorate interpersonal difficulties involving the patient and any other family member, and helping the family on a practical level in its role of care giver. Global family functioning and any pathological functioning in the family which is not directly connected with or obviously caused by the terminal illness has been deemed to lie outside the orbit of hospice care and attention.

The dying process often appears to be complicated by difficulties within the family. Sometimes these difficulties are undoubtedly caused by the stress of having a terminally ill member, but at other times it is impossible or incorrect to blame the terminal illness for family malfunctioning. However, for whatever reason the family is functioning in a problematic manner, the patient is likely to suffer. If the purpose of hospice is to facilitate the dying process, and if family dysfunction will impede that goal, then whether or not the cancer or other terminal illness caused that dysfunction is not important. What is important is that family dysfunction at whatever level may well constitute an impediment to the goals of hospice, and needs to be addressed by hospice.

What clearly emerges from this pilot study is that the hospice families investigated constitute a clinical sample and tend to be functioning at a pathological level at this most crucial and sensitive family life-stage. In terms of General Functioning, 13 families (65% of the sample) are functioning above the FAD cut-off score, and this figure rises to 15 families (75% of the sample) if scores falling on, as well as above, the cut-off score are included. In other words, for whatever reason, these families are experiencing difficulties in functioning.

In describing the FAD cut-off scores, Miller et al. (1985) do not make it clear where they place scores which are exactly on the cut-off point, and for this reason the scores in this study have been computed both above, as well as on and above, the cut-off point. Including families who score exactly on the cut-off point has increased the number of dysfunctional families quite substantially on several dimensions. For example, in terms of

Roles the figure jumps from 30% above the cut-off point to 75% on and above the cut-off point. Given that research findings reviewed earlier suggest that roles and role changes tend to be problematic in terminally ill families, the figure of 30% of families above the FAD cut-off point appears to be relatively low. It is suggested, therefore, that including the families on the cut-off point and bringing the dysfunctional families up to 75% on this dimension may be more realistic in the light of previous research.

If, at the very best, the 'borderline' families whose score falls on the cut-off point are seen as coming close to being dysfunctional or potentially dysfunctional, then it is important that hospice be aware of and sensitive to this potential for dysfunction, as well as to clearly demonstrated current dysfunction. In other words, it is argued that cognisance should be taken both of the scores on the cut-off point as well as scores above the cut-off point.

Compatible with findings reported in the literature, the dimension of Communication is a problematic area, and in this study it has emerged as the most dysfunctional of the dimensions evaluated. A total of 17 families (85%) score on or above the FAD cut-off point on this dimension. In her survey of the literature, Northouse (1984) refers to the difficulties the terminally ill person experiences in the early stages of illness in communicating both with medical personnel as well as with other family members. She reports problems that occur during the adaptation phase of illness when family members find it difficult to communicate their fears to each other, which may lead to the concealment of fears. Again, communication features as one of the problem areas reported by Northouse in the terminal stage of illness. Much research has been carried out in this area and it has been shown in many studies to be a problematic area for terminally-ill families. In addition, significant correlations (see Table 3, Chapter 7) indicate that where there is a problem with Communication, there is also likely to be a problem with Roles, Affective Responsiveness, Affective Involvement and General Functioning.

In terms of the dimension of Roles, if - as discussed above - it is accepted that 75% of families are experiencing problems in terms of roles, this can be

seen to be consistent with findings in the literature. For example, as Geyman (1983) points out, impending death leads to structural changes in the family system and these include role changes. The family's efforts to cope with the terminal illness may be exacerbated by these role changes. In her review, Northouse (1984) refers to the problems surrounding role changes in the adaptation phase of the illness. Lewis (1986) also refers to the difficulties experienced in the area of roles in terminally ill families.

A problematic score for Affective Responsiveness and Affective Involvement can be seen to be consistent with many of the research findings cited earlier. For example Giacquinta, cited in Northouse (1984), refers to the despair, isolation and vulnerability of family members, and Singer (1983) talks of the difficulties cancer families experience in feeling and sharing emotional states. However, scores for these two dimensions need to be interpreted with caution because in the case of terminal illness there may be a need on the part of both the patient and the individual family members to start a process of withdrawal and disengagement on an emotional level (Bertman, 1980). In addition, dysfunction in the area of Communication can be seen as a crucial factor in difficulties in the areas of Affective Responsiveness and

Affective Involvement. The Pearson Product Moment correlations between both Communication and Affective Responsiveness and Communication and Affective Involvement are statistically significant.

Problem Solving has emerged as the least dysfunctional area in this study. However, there appears to be little research directly involving the dimension of Problem Solving with which to compare the finding of this study. This shows that Problem Solving constitutes a dysfunctional area for 20% of the families if the figure is taken above the cut-off point, and 30% of families if the figure is taken at and above the cut-off point. However, Lewis' (op. cit.) report that the patient and family members may be perceiving or prioritizing different problems suggests that there is tension in this area. In addition, Northouse (op. cit.) cites different research projects which talk of the confusion, uncertainty, helplessness and loss of control in the family and it is suggested that these could be seen as consistent with dysfunction in the area of Problem Solving.

It is interesting to speculate as to why Problem Solving has emerged as very much less dysfunctional than the other dimensions studied. It may simply be that it is a less dysfunctional dimension in this particular group of families. However, it is noteworthy that in the study Problem Solving and Communication are highly significantly correlated which would suggest that difficulties in the one dimension suggest difficulties in the other dimension. In addition it may be that the family members in this study tended to perceive problem solving as reasonably satisfactory within their families but no objective data has been collected to substantiate this. It may simply be that terminally-ill families rely on habitual problem solving styles, as suggested by Cohen and Cohen (cited in Usher, 1986) and perceive these as satisfactory because they have seemed to be adequate in the past.

The dimension of Behaviour Control has emerged in the study as one of the more dysfunctional dimensions. However, very little has been reported in the literature with which to compare this. This finding could perhaps be seen as consistent with Gayman's (1983) comment that the stress of terminal illness may result in major changes in family structure, function and identity. However, it is important to note that in developing the FAD, Miller et. al. (1985) report that although the health/pathology cut-off scores on the FAD have been shown to effectively identify the presence of significant family dysfunction on six dimensions, this is not the case with Behaviour Control. On this dimension they report that the data are weaker and in need of further study. The result in this study should therefore be treated with caution.

Comparing the difference between the score for the IP and the score for the rest of the family there appears to be no significant difference on any of the dimensions, including General Functioning. Thus there appears to be a shared perception of the way in which the family functions.

It is interesting to compare this finding with research cited in Lewis (ibid) which suggests that there is a marked disparity between the patients' and family members' needs and perceptions of the experience of terminal illness. It is important not to conflate these two distinct concepts, but rather to be

aware of the way in which they illuminate the infinite complexity of family functioning.

It is noteworthy that although 13 of the families involved in the study describe themselves as regular church-goers and another three attend church on an irregular basis, the total group of 20 families constitutes a clinical sample. This is perhaps at variance with the popular conception of the church as serving an important supportive function. In a study of depressed patients at Valkenberg Hospital, Welman (personal communication, 1992) found that the readmission rate was lowest for the Coloured population. The only obvious distinguishing feature reported by Welman is that 98% of the Coloured sample was very religious and the inference is that the church serves a supportive function.

Given the results of the current study religion appears not to be as strong a support as might have been expected. It would be interesting to know more about the religious preferences of individual family members and at what stage the family became religious. It is possible that the IP and/or the family became religious when the terminal illness was diagnosed but this was too late and too little to prevent family dysfunction. It is also possible that religious faith can support the individual but it may not be sufficient to improve family interactions.

Family size appears to make no significant difference to the level of General Functioning in the family. This tends to suggest that the view that the modern nuclear family is less able to deal with the stress of an ill family member than the extended family of the past, as portrayed by, for example, Barton (1977), is not necessarily correct.

Dividing length of illness into two categories of under and over one year, there is no significant difference between these scores when compared with General Functioning. Findings in the literature (especially as reviewed by Northouse, 1984) suggest that families experience different kinds of problems at different stages and this needs to be further explored. It would be extremely useful to hospice to have more information as to which specific areas of difficulty to be sensitive to as the terminal illness progresses along

its course. Information of this type has emerged in the literature in connection with difficulties in the area of communication. As reported earlier, both Northouse (1984) and Lewis (1986) have reported findings as to the types of communication difficulty which have emerged at the various stages of the terminal illness, and this type of data for the other dimensions could have great practical application for hospice workers.

This pilot study has thus highlighted the extent to which the hospice families interviewed constitute a clinical sample in terms of family functioning. On six of the seven dimensions from 13 to 17 families are experiencing difficulties in functioning. In terms of General Functioning, 15 families or three quarters of the sample score on and above the cut-off point. Communication has emerged as the most dysfunctional dimension with 17 families (or 85%) functioning on or above the FAD cut-off point. The dimension of Problem Solving appears to be far less problematic, with only six families functioning on and above the cut-off point. In addition, factors such as family size, length of illness and whether the perspective is that of the patient or other family members do not appear to affect the dimension of General Functioning in any significant way. The role of religion in supporting the families appears to be ambiguous.

Before discussing directions for future research, overall cognisance needs to be taken of the limitations of this pilot study in order that any future research may be more finely tuned and directed in appropriate areas. Apart from the problems in the FAD with the dimension of Behaviour Control, there are other areas in which this present study has limitations.

It is important to note that the implication of using a single-group design means that causal links cannot be made with any certainty. Lewis (1986) raises this as a limitation of current research and it is true also of this study. However, the aim here is merely to assess whether or not terminally ill families function in a dysfunctional manner. Comparative data could be collected to give us indices of family functioning in "well" families. However, if a sample of non terminally ill families is also found to be functioning above the FAD cut-off scores - which is quite possible given the current social upheaval and turmoil in South Africa - this would in no way

diminish the importance of the current findings in terms of the utility of the data for hospice.

As Lewis (*ibid*) points out, longitudinal studies are needed to give us more insight as to what extent the terminal illness is a contributing or causal factor of family dysfunction. She points out that studies have tended to aggregate data across disease types and stages and this is a limitation of this study in that although most patients suffer from cancer, no attention has been given as to the stage of the illness in terms of, for example Northouse's analysis.

In addition more research needs to be done comparing the effects of different types of illness on family functioning, extending work done, for example, by Vachon (cited in Lewis), because although hospice deals mainly with cancer this is neither exclusively the case nor is it a stated policy of hospice organisations.

Although the FAD has several advantages as a measure of family functioning and also has demonstrated reliability and validity, Miller et al. (1985) suggest that further research needs to be carried out in order to extend its usefulness. For example, the FAD cut-off scores need to be cross-validated with a larger and more heterogenous sample.

A self-report instrument is limited in that it provides only one window into the experience of the family members, albeit a crucial one. Lewis (1986) suggests that the data will be far richer and more complete if, for example, the physicians, nursing staff and clinician involved with the family also provide a rating of the family's coping and functioning. Included here could be the input of hospice staff. It is possible that previous studies in this area may suffer from extreme sampling biases (Lewis 1986). Although no families refused to participate in this project, it should be borne in mind that this was fortuitous and future studies should be wary of a possible sample bias caused by refusal to participate.

However, a very definite limitation of the present study is that no black families were included. Lewis (*ibid*) comments that most studies are based

on white, middle-class samples. In terms of socio-economic status this is true of the current study. In terms of "colour" the present sample includes several Coloured and Indian families, but no black families. This omission was deliberate because of the problem of language, however, it is a vitally important area of future research and a proposed extension to this study will hopefully rectify this gap in our understanding.

Hospice organizations in South Africa are moving rapidly into the black community. For example, at the beginning of 1991, Grahamstown Hospice had no black patients but by the middle of that year five black patients were being cared for. At the time of writing (October 1992) five new referrals a week are being received. The Hospice employs one Xhosa nursing sister and a second one is to be employed shortly. Seventeen working-class Xhosa families with a terminally ill member, as well as bereaved families, are currently being cared for. Thus it is vital that research be extended in this area.

Another limitation of the current study is that it does not either take into account or even specify the stage of the illness. As mentioned earlier most of the studies carried out tend to focus on crisis periods and Lewis (1986) points out that more studies are needed on the experience of the family during the on-going phases in between the crises of for example the initial diagnosis and the terminal phase. Northouse (1984) says much the same, pointing out that most research concentrates on the initial and terminal stages, whereas the adaptation stage tends to be ignored. This criticism does not detract from the basic conclusion of the current study that hospice families tend to function at a problematic level. However, a better understanding of the specific problems likely to be encountered at various stages would be of great practical use to the hospice.

It is important to be aware of the fact that the FAD does not pick up anxiety, depression and so on in one person, and pathology in any one individual in the family may also be extremely damaging to family functioning. For example, as Barker (1981) points out, if a family member suffers from Bi-polar Affective Disorder, lithium would be the treatment of

choice and no amount of family or even individual therapy would necessarily be able to ameliorate the situation.

Many of the directions for future research arise from the limitations of the current study mentioned above. For example longitudinal studies and looking at family functioning in terms of the family life cycle and the phase of the illness (for example initial, on-going or end phase) would be extremely useful.

However, possibly the most vital area of future research is extending this project to black families. Because of their generally lower socio-economic status in the Grahamstown area and because of cultural differences, including differences in the concept of family, it is quite possible that the FAD administered to black families will reveal many subtle differences in functioning and perceptions that may be important for Hospice.

Looking at neglected study areas, it is interesting to note that very little work has been done on the effects on children of having a terminally ill member in the family. Children under the age of twelve were not included in this project, because the FAD has been designed for and standardized on a population aged over twelve. It is important that the long term effects on small children be investigated and it is possible that any potential trauma can be avoided or ameliorated by means of, for example, individual play therapy. This might provide a more appropriate therapeutic treatment than simply participating in family therapy sessions.

Another area that needs further research concerns the exact status of the dying member in terms of how much the family depends on that person. For example, is the dying member the bread winner and if so how does the family negotiate the inevitable change in roles. Economic constraints may play a vital part in exacerbating family functioning and creative strategies in terms of role changes and problem solving may need to be implemented.

A final limitation of this study is that no account has been taken of the amount of hospice contact experienced by each of the families in the study. Hospice contact may well have improved family functioning in certain of the

families without this being a specific stated target of the hospice intervention.

As Farkas (cited in Usher, 1986) points out, psychological research on death and dying encounters great limitations due to practical and ethical considerations. Working through the hospice movement has facilitated entry into terminally ill families in a way that might otherwise have been difficult if not impossible, and has thus allowed valuable research to be carried out. Thus, a strength of this study is that it has permitted this sensitive area to be explored in a non-intrusive and acceptable manner.

Given that the study shows that many hospice families function at a problematic level, it is clear that there is a place for family therapy within the hospice organisation. Since 15 families are functioning at or above the FAD cut-off point in terms of General Functioning, the relevant questions are, firstly, how to refine the assessment process to reveal which of these families are most urgently in need of this additional help, and, secondly, how to negotiate the logistics of offering family therapy to hospice families.

In terms of the first question it might well be appropriate to automatically offer all families several sessions of family therapy, and this has been recommended by, for example, Winder (1978). The clinician involved would then in the course of these sessions be able to assess whether or not the family functioning was sufficiently pathological for the family to benefit from further sessions.

Alternatively, the Hospice Director and Nursing Sisters have a great deal of experience of families in distress and their clinical experience permits them to detect at least the most problematic families. In the past they have not known how to address the issue of seemingly difficult family functioning which their intuition told them was pathological. The results of this study may help to validate the often intuitive awareness of hospice staff that there are problematic areas in many families. Thus they may be encouraged in this way to trust their clinical judgment.

If the services of a family therapist were to be made available to the hospice, these families could then be referred on to the therapist. It is suggested that it is important to encourage caregivers and all those involved with hospice families to use their intuition and experience to detect problematic family functioning. Equally it is important to educate all caregivers about family therapy and its potential for ameliorating problems in families. It is suggested that hospice be encouraged to include a section on family therapy in the training programme for caregivers so that this potential becomes known to them. In this way family therapy can be included as yet another resource available to the hospice movement.

Problematic family situations are often only detected belatedly and it might be preferable to include an assessment of the family in its entirety very early in the family's relationship with Hospice. This could perhaps happen once the patient has been introduced to Hospice and has been assessed.

However, an important part of the hospice ethic is that families should take responsibility for themselves as far as possible. For example, the family has to make the initial approach to the hospice for help - hospice will never approach a family uninvited by that family. Thus it might be more beneficial if the family can be helped by the caregiver to see the usefulness of family therapy and then be encouraged to request it for themselves. The family would in this way be empowered to make the decision for themselves. Again this would mean educating hospice staff and caregivers about the nature and benefits of family therapy.

A practical means of detecting dysfunction at an early stage in the hospice's relationship with a family might be for additional questions to be included into the initial assessment of the patient. For example, the questions in the FAD aimed at illuminating general functioning and the questions aimed at illuminating communication might be useful as an initial screening device.

Not all families can afford the services of a therapist. Medical needs in these circumstances are supplied inexpensively through hospitals, as determined by a means test. Psychological services are available in the same way through the auspices of, for example, Fort England Hospital in

Grahamstown. However, there is no state provision for the professional services of a clinical psychologist/family therapist within the home as would often be necessitated in the case of a terminally ill family.

One possibility is that a training institution such as the Rhodes Psychology Clinic or Fort England Hospital could be persuaded to provide a family therapy service for hospice clients in the families' own homes when necessary. The problem with this suggestion is that the Clinical Masters students - certainly at first year level - may lack sufficient experience and it would be a risk imposing an inexperienced therapist on a family with a dying member. In addition families may not perceive a relatively young and inexperienced therapist as someone whom they can relate to and have confidence in at this particularly stressful stage of the family life-cycle. Alternatively, hospice funds could be utilized to pay private clinicians to see families who cannot afford to pay. Another possibility is that experienced clinicians may choose to donate their services at substantially reduced rates or even free where necessary as their contribution to the work of hospice. It is important that this should not be over-exploited by the hospice as it could lead to resentment by the clinician.

However, simply an awareness of the results of this study and an increased knowledge of the dimensions of family functioning and the specific areas to be sensitive to may already allow hospice staff to pick up on areas requiring more attention. A suggestion is that, in the light of this project, hospice personnel involved in assessing families or seeing families on a regular basis be given a more thorough training course in family functioning and family therapy than is offered in the initial hospice course. For example, the Witwatersrand Hospice offers caregivers an intensive eighteen months long training course, at the end of which they are able to work with more confidence and competence on psychological issues - both with individuals and families - than for example the caregivers of the Grahamstown Hospice are trained to do. If caregivers could be trained specifically to work with families they could perhaps be supervised by a qualified family therapist.

In conclusion, the implications of the findings of this study are that hospice is currently failing to provide a necessary support in the form of family

therapy. As Wynne et al. (1992) suggest, the potential for family therapy within the field of physical illness is much wider than has been realised in the past. Given the degree of dysfunction within hospice families demonstrated in this study, it is felt that family therapy should be incorporated forthwith into the resources utilized by hospice organisations.

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FAD

APPENDIX

The following items are statements about families. Please read each statement carefully and decide how well it describes your own family.

For each statement there are 4 possible responses.

- circle strongly agree if you feel that the statement describes your family very accurately.
- circle agree if you feel that the statement describes your family for the most part.
- circle disagree if you feel that the statement does not describe your family for the most part.
- circle strongly disagree if you feel that the statement does not describe your family at all.

Try and respond to each question as quickly as possible. If you have trouble with a statement, answer with your first reaction. Please be sure to answer EVERY statement by circling a response below it.

1. Planning family activities is difficult because we misunderstand each other.

strongly agree agree disagree strongly disagree

2. We resolve most everyday problems around the house.

strongly agree agree disagree strongly disagree

3. When someone is upset the others know why.

strongly agree agree disagree strongly disagree

4. When you ask someone to do something, you have to check that they did it.

strongly agree agree disagree strongly disagree

5. If someone is in trouble, the others become too involved.

strongly agree agree disagree strongly disagree

6. In times of crisis we can turn to each other for support.

strongly agree agree disagree strongly disagree

7. We don't know what to do when an emergency comes up.

strongly agree agree disagree strongly disagree

19. Some of us just don't respond emotionally.
- | | | | |
|-------------------|-------|----------|----------------------|
| strongly
agree | agree | disagree | strongly
disagree |
|-------------------|-------|----------|----------------------|
20. We know what to do in an emergency.
- | | | | |
|-------------------|-------|----------|----------------------|
| strongly
agree | agree | disagree | strongly
disagree |
|-------------------|-------|----------|----------------------|
21. We avoid discussing our fears and concerns.
- | | | | |
|-------------------|-------|----------|----------------------|
| strongly
agree | agree | disagree | strongly
disagree |
|-------------------|-------|----------|----------------------|
22. It is difficult to talk to each other about tender feelings.
- | | | | |
|-------------------|-------|----------|----------------------|
| strongly
agree | agree | disagree | strongly
disagree |
|-------------------|-------|----------|----------------------|
23. We have trouble meeting our bills.
- | | | | |
|-------------------|-------|----------|----------------------|
| strongly
agree | agree | disagree | strongly
disagree |
|-------------------|-------|----------|----------------------|
24. After our family tries to solve a problem, we usually discuss whether it worked or not.
- | | | | |
|-------------------|-------|----------|----------------------|
| strongly
agree | agree | disagree | strongly
disagree |
|-------------------|-------|----------|----------------------|
25. We are too self-centred.
- | | | | |
|-------------------|-------|----------|----------------------|
| strongly
agree | agree | disagree | strongly
disagree |
|-------------------|-------|----------|----------------------|
26. We can express feelings to each other.
- | | | | |
|-------------------|-------|----------|----------------------|
| strongly
agree | agree | disagree | strongly
disagree |
|-------------------|-------|----------|----------------------|
27. We have no clear expectations about manners.
- | | | | |
|-------------------|-------|----------|----------------------|
| strongly
agree | agree | disagree | strongly
disagree |
|-------------------|-------|----------|----------------------|
28. We do not show our love for each other.
- | | | | |
|-------------------|-------|----------|----------------------|
| strongly
agree | agree | disagree | strongly
disagree |
|-------------------|-------|----------|----------------------|
29. We talk to people directly rather than through go-betweens.
- | | | | |
|-------------------|-------|----------|----------------------|
| strongly
agree | agree | disagree | strongly
disagree |
|-------------------|-------|----------|----------------------|

30. Each of us has particular duties and responsibilities.
- | | | | |
|-------------------|-------|----------|----------------------|
| strongly
agree | agree | disagree | strongly
disagree |
|-------------------|-------|----------|----------------------|
31. There are lots of bad feelings in the family.
- | | | | |
|-------------------|-------|----------|----------------------|
| strongly
agree | agree | disagree | strongly
disagree |
|-------------------|-------|----------|----------------------|
32. We have rules about hitting people.
- | | | | |
|-------------------|-------|----------|----------------------|
| strongly
agree | agree | disagree | strongly
disagree |
|-------------------|-------|----------|----------------------|
33. We get involved with each other only when something interests us.
- | | | | |
|-------------------|-------|----------|----------------------|
| strongly
agree | agree | disagree | strongly
disagree |
|-------------------|-------|----------|----------------------|
34. There's little time to explore personal interests.
- | | | | |
|-------------------|-------|----------|----------------------|
| strongly
agree | agree | disagree | strongly
disagree |
|-------------------|-------|----------|----------------------|
35. We often don't say what we mean.
- | | | | |
|-------------------|-------|----------|----------------------|
| strongly
agree | agree | disagree | strongly
disagree |
|-------------------|-------|----------|----------------------|
36. We feel accepted for what we are.
- | | | | |
|-------------------|-------|----------|----------------------|
| strongly
agree | agree | disagree | strongly
disagree |
|-------------------|-------|----------|----------------------|
37. We show interest in each other when we can get something out of it personally.
- | | | | |
|-------------------|-------|----------|----------------------|
| strongly
agree | agree | disagree | strongly
disagree |
|-------------------|-------|----------|----------------------|
38. We resolve most emotional upsets that come up.
- | | | | |
|-------------------|-------|----------|----------------------|
| strongly
agree | agree | disagree | strongly
disagree |
|-------------------|-------|----------|----------------------|
39. Tenderness takes second place to other things in our family.
- | | | | |
|-------------------|-------|----------|----------------------|
| strongly
agree | agree | disagree | strongly
disagree |
|-------------------|-------|----------|----------------------|
40. We discuss who is to do household jobs.
- | | | | |
|-------------------|-------|----------|----------------------|
| strongly
agree | agree | disagree | strongly
disagree |
|-------------------|-------|----------|----------------------|

41. Making decisions is a problem for our family.

strongly agree disagree strongly disagree

42. Our family shows interest in each other only when they can get something out of it.

strongly agree disagree strongly disagree

43. We are frank with each other.

strongly agree disagree strongly disagree

44. We don't hold to any rules or standards.

strongly agree disagree strongly disagree

45. If people are asked to do something, they need reminding.

strongly agree disagree strongly disagree

46. We are able to make decisions about how to solve problems.

strongly agree disagree strongly disagree

47. If the rules are broken, we don't know what to expect.

strongly agree disagree strongly disagree

48. Anything goes in our family.

strongly agree disagree strongly disagree

49. We express tenderness.

strongly agree disagree strongly disagree

50. We confront problem involving feelings.

strongly agree disagree strongly disagree

51. We don't get along well together.

strongly agree disagree strongly disagree

52. We don't talk to each other when we are angry.

strongly agree disagree strongly disagree

53. We are generally dissatisfied with the family duties assigned to us.

strongly agree disagree strongly disagree

54. Even though we mean well, we intrude too much into each other's lives.

strongly agree disagree strongly disagree

55. There are rules about dangerous situations.

strongly agree disagree strongly disagree

56. We confide in each other.

strongly agree disagree strongly disagree

57. We can cry openly in front of each other.

strongly agree disagree strongly disagree

58. We don't have reasonable transport.

strongly agree disagree strongly disagree

59. When we don't like what someone has done, we tell them.

strongly agree disagree strongly disagree

60. We try to think of different ways to solve problems.

strongly agree disagree strongly disagree

