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A Theoretical Model for Pre-Bereavement Counseling with Hospice Families and Research Into Its Implications Regarding Prevention of Complicated Mourning

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A THEORETICAL MODEL FOR PREBEREAVEMENT COUNSELING WITH HOSPICE FAMILIES AND RESEARCH INTO ITS IMPLICATIONS REGARDING PREVENTION OF COMPLICATED MOURNING

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An Abstract Presented To The Faculty Of The Graduate
School Of Lindenwood College In Partial
Fulfillment Of The Requirements For The
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ABSTRACT

The proposal for research outlined herein is designed as a method of meeting the emotional needs of hospice patients and their families as they endure one of the most stressful situations in which any family can find itself. It proposes a heretofore untried course of prebereavement family counseling and then proposes a research model which may determine whether such intervention can positively affect the relative health of the family members during the period of mourning following the death of the patient. Included is a specific outline of the possible course the prebereavement counseling should take as well as a thoroughly comprehensive plan for the research model, including experimental groups, procedures, and materials, as well as a suggested statistical analysis method and proposals for further related research.

A THEORETICAL MODEL FOR PREBEREAVEMENT COUNSELING WITH HOSPICE FAMILIES AND RESEARCH INTO ITS IMPLICATIONS REGARDING PREVENTION OF COMPLICATED MOURNING

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A Culminating Project Presented To The Faculty Of The Graduate
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DEDICATION

Dedicated with love and gratitude to my family, William and Genevieve Miller, Shaaron Benjamin, and Bradley and Adam Benjamin. Without their patience, love and support this effort might never have materialized.

A special dedication goes as well to the late Lee Williams, who inspired it.

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CHAPTER 1

INTRODUCTION

In recent years, a focus of treatment of cancer patients which has drawn much attention is the psychological impact of the disease upon cancer patients and their families. Among the questions asked are whether certain psychological manifestations affect the course of the disease or can help or hurt the course of treatment.

The hospice movement evolved for the patient whose disease is no longer responsive to treatment. The hospice movement, now some twenty-five years old in the United States, has sought to make the transition of dying patients and their families a more comfortable experience. Hospices the world over minister to the physiological, social and practical daily needs of hospice families (hospice patient = hospice family). Often the psychological/emotional needs of hospice families go untended, due in part, to the fact that "special needs" may often go unnoticed by over-worked, under-staffed hospice administrators, social workers, nurses, physicians, and volunteers.

Hospice families may often choose not to deal with "family problems" during the course of their patients' illnesses, opting instead to handle them when their stress levels have abated after the patient has died. A possible outcome of such an approach is a course of complicated grieving following the death of the patient -- especially if the patient has been a "source" of trouble within the family unit.

The presence in the home of the hospice patient, especially in families at high risk for pathological grieving (where substance, physical or sexual abuse has been an element in the system, for example) may be a major stress factor which can only serve to aggravate any pre-existing family pathology.

This investigator believes there is a need for a model of prebereavement therapeutic intervention. Such a model may not only alleviate the stress of the current situation, but also, and perhaps more importantly, provide assistance for the long term functioning of such families. In addition, it is preferable that such a proposed course of treatment described by the model be tested to ascertain the effects upon the family as to which intervention proves to be beneficial. If the hospice staff can predict which families are most likely to benefit from psychological services and can provide these services while the patient/family is still connected to the "life-support" of the hospice program, the help could prove valuable. The post-mortem follow-up of families is not an effective outreach effort to either detect or provide assistance for grieving families. This is largely due to the unreliability of phone calls and mailings, and the distance of time and miles, thus allowing troubled families to slip through the crackes.

Long acknowledged as a major stress factor, terminal illness can provide a fertile environment for spiritual awakening as well as for resolution of long-standing family conflicts. If the hospice family has, however, demonstrated a lack of coping skills, and family dynamics seem inappropriate they can be considered "at risk" for complications resulting from the enormous stress connected with caring for their patients in the home, and the grief which follows the death of the patients.

The goal of pre-bereavement counseling would be to facilitate confrontation and resolution of conflict, promote movement toward a peaceful transition for the patient, and enable families to successfully experience both anticipatory grief reactions as well as post-mortem grieving.

To this end, a program of counseling may be established which, based on extant models of bereavement counseling (Rando, 1986) would facilitate the above mentioned goals. This method could then be experimentally applied with volunteer hospice families who would later be tested to determine what, if any, symptoms of pathological mourning were present, and to what degree, the hypothesis being that even a brief course of pre-bereavement counseling would prove beneficial.

It is the purpose of this study to ascertain what course of prebereavement intervention provides the most beneficial treatment for hospice families as they endure the stress of caring for terminally ill loved ones, as well as what effect such a course of treatment may have on the families' relative health and well-being during the period of grieving which follows the death of the patient. It is proposed that a course of prebereavement family counseling which promotes anticipatory grieving will be the intervention which will prove to provide the greatest benefit towards these ends.

CHAPTER 2

LITERATURE REVIEW

Introduction

Jimmie C. Holland, reprinted in Kitchen (1987), states that clearly, the greatest predictor of pathological grieving is the family in distress prior to diagnosis of terminal illness in one family member. In addition to the above consideration, mental health professionals must concern themselves with the response of all members of such families to the stressful conditions imposed upon them by the task of caring for terminally ill loved ones whether the family has been in distress prior to the diagnosis of terminal illness or not. This is important because family members' behavior may differ according to their ages and roles in the family system. Thus, behavior which may seem pathological if exhibited by an adult, may actually be understood to be a relatively healthy survival mechanism when exhibited by a child. The reverse may also be true.

Families, like individuals, mature in what can be described as developmental phases. A family's response to the illness and impending death of one member can be as much determined by the developmental age of the family as by the overall interactional system of the family. Thus, a family where parents and children are relatively young, may not have the maturity or experience to cope successfully with the stress of terminal illness.

If the terminally ill family member is a young child, the parents must deal with what is considered to be the most traumatic stress factor associated with family life (Holland, 1987). In addition to the need to maintain hope against tremendous odds, parents of terminally ill children must also cope with round-the-clock nursing and custodial care, the needs of other children, demands of the work place, and the guilt associated with being unable to protect the child against the ravages of the disease. According to Holland, parents must also maintain trust in physicians, while acknowledging their limitations, must love and be devoted to the child while preparing for the separation from him or her, and must deal with the additional burden of guilt associated with the experiencing of pleasure in the face of such devastating tragedy (1987).

If the terminally ill family member is a young parent, the remaining parent and young children have different circumstances with which to cope. Since attention of the healthy parent must be directed to the ill spouse, less time and attention can be given to the children. The result may be a sense of alienation and exclusion, with development of behavior problems, as well as psychiatric and psychosomatic disorders (Holland, 1987).

The family in the "middle years" (Holland, 1987) has a different set of problems associated with the likelihood of the presence of adolescent or young adult children. If the patients in such families are older children they will likely be more conscious of the serious nature and possible outcome of the illness than younger children. Such awareness can cause much the same reactions to news of life-threatening illness as is seen in adults. Anger and frustration at the loss of independence, the interruption and curtailment of future plans and activities, and most importantly, the normal developmental tasks of separation from parents and identification with peer groups, reactions to which must be seen as normal situational responses in these patients. This is an additional stress factor for parents who must daily cope with the emotions connected with the threatened and impending loss of the child.

If the patient is a "middle-years" parent, adolescent and/or young-adult, children may behave in ways which may seem distant and uncaring, sometimes even refusing to visit the parent. Not only does this intensify the parents' stress due to feelings of abandonment, but unless it can be seen by the parents as a survival mechanism for the children, it can put further strain on the already threatened family unit.

In the older family, where children are independent adults, and where the patient is one of the elderly parents, there exists a still different set of circumstances with which to deal. Often, the nature of prolonged illness necessitates lengthy stays in hospitals, or invasive in-home care which can intrude upon privacy and create difficulties for the process of intimacy so vital for the couple at this time.

> Fear of loss of a spouse - and the ensuing loneliness - is great in later years. These fears produce or heighten the importance of many needs in middle-aged and older terminally ill patients and their spouses - needs for expressions of affection, both physical and verbal, and for closeness and comfort. (Holland, 1987, p.69)

Clearly the developmental age and underlying structure of the family can serve to further complicate an already challenging situation.

A study published by Mulhern, Lauer and Hoffmann (1983) indicated significant differences in adjustment and symptoms of pathology amongst parents and siblings of terminally ill children when cared for in the home versus in the hospital. This study indicated that home-care increases the chances for a normal (versus pathological) course of grieving following the death of the child. There is, however, some question as to the nature of the pre-existing level of family function which may determine the initial decision to care for the patient at home.

> Parents who choose home care and those who refuse may differ with respect to some personality attributes and attitudes prior to the decision as to the terminal care of their children. For example, parents who refused home care scored significantly higher on scales measuring somatization, anxiety, and interpersonal withdrawal, which are generally stable over time (ie, "traits"). One might speculate that parents who have these tendencies are more likely to refuse than to choose home care. Indeed, parents refusing home care often cite doubts about their own ability to care for their dying child as the primary reason for refusal[13] and more frequently have difficulty in terminating attempts at curative therapy. (Mulhern et al. 1983, p.747)

Mulhern et al (1983) further states that siblings of patients cared for at home scored lower on scales measuring such symptoms as fear, sensitivity, and social isolation, and displayed fewer "neurotic and somatic behaviors" (p.745) than siblings of patients whose parents refused home care.

Mulhern et al cite the need for future research into the assessment of family function prior to decisions regarding terminal care which would then provide a basis for "adequate follow-up of adjustment status" (Mulhern et al, 1983, p.747). Their assessment can provide information as to which families are at greatest risk for complicated mourning[1] and what intervention methods could be most beneficial.

The research by Mulhern et al suggests that the choice of in-home terminal care, itself, is a "healthier" response to terminal illness than refusal. This does not mean, however, that once such a choice is made, the course of care will run smoothly for all concerned. What may be significant is that assessment will help determine which families will benefit from a course of prebereavement intervention -- which may, in fact, facilitate making the "healthier" choice.

Once the decision in favor of home-care has been made by the care-giver(s) other adjustment problems present themselves. A study by Trice, (1988) of mothers of AIDS patients, suggests that a significant occurrence (84%) of PTSD-like symptoms were reported by those women who opted for home-care as opposed to those who did not (8%). Even considering the consequences of the decision in favor of home-care, the great majority of women surveyed (21 out of 24) indicated that they would make the same choice again over non-involvement. Since the care-giving mothers varied widely in their involvement with support groups, there is no data to indicate whether such involvement made a difference in the level or severity of the mothers' PTSD symptoms. However, there is evidence that a low level of involvement with such groups post mortem indicates a lack of positive regard for them, further emphasizing the need to provide supportive intervention <u>during</u> the term of the illness.

There was no mention of any other type of prebereavement counseling for the above population, nor was there a comparison made between the symptoms of Post-Traumatic Stress Disorder and those of pathological grief, though such a comparison could certainly be made. In fact, comparison of Lindemann's and Lazare's (cited in Sanders, 1989) lists of symptoms related to complicated mourning and the symptom list of PTSD in the DSM-III-R reveal that at least seven of the latter symptoms compare significantly with those of the former. (See chart in Appendix A)

Interestingly, both the Mulhern, Lauer and Hoffman (1983) and the the Trice (1988) studies conclude that the choice to provide home care for terminally ill patients is viewed positively by the survivors of these patients and suggest that further study of pre-existing family conditions is necessary to identify at-risk families and provide counseling services accordingly.

Normal Grief Reactions

In order to understand and treat abnormal grief it is necessary to define normal grief. Edgar N. Jackson describes the symptoms of normal grief as "tightness of the throat, choking and shortness of breath, need for sighing, an empty feeling in the abdomen, lack of power in the muscles, chills, tremors, and intense subjective distress described as tension, loneliness, or mental pain" (1957, p.146). Though not all these symptoms will occur in all people, when they do they can be considered to be within the range of normal behavior. In addition, people experiencing normal grief may feel tired and weak, may have dryness of the mouth, may have a sense of unreality and disorganization, or feel that everyday activities take much longer than they normally would to accomplish. These phenomena are normally associated with immediate reactions to bereavement and must be re-evaluated if they persist past a certain period of time following the loss. Mourners experience the above symptoms because of a deep and profound longing for the deceased which reality dictates can never be fulfilled. Thus, the internal conflict between the need and the reality creates such "shock" within the bereaved, as to necessitate some healing time before the reality of the loss can be faced with anything approaching equanimity.

> This slow transformation is accomplished by means of a number of changes... by which the mourner is forced gradually to renounce his longing for the lost person and to accept the real world without the loved one. In severe grief, this renunciation requires emotional reorientation to all details of the world of reality. At first, unable to bear even the thought of the everyday occupations and activities that he associates with the lost person, the grief-stricken survivor must concentrate on every object and situation carrying the association until he can accept it emotionally without reawakening his longing. (Weiss, 1957, p.147)

Naturally, re-establishment of the normal functioning of the bereaved cannot be plotted on a timetable. But current opinion (Kitchen 1986, p.87) indicates that severe grief reactions of the kind listed above should begin to gradually abate within a few months to a year. Kitchen cites Bowlby, Lindemann and Kubler-Ross (1987) as having identified three stages of normal grief, the first being "shock and disbelief" (p.160), which lasts usually days or weeks. The second phase, called "yearning and protest" or "anguish, disorganization and despair" (p.160) lasts approximately six to twelve months, and the third -- or resolution phase, called "reorganization and restitution" (p.160) also lasts for six to twelve months. Thus much care must be taken not to rush the bereaved into resuming their normal activities, as most experts agree that the process of grief is an intensely individual and personal one. Not all bereaved people will experience all the aforementioned phases of grief, nor will they "perform" according to schedule.

The important task for the health professional who works with the bereaved is to recognize the basic accomplishments of the grief process and to note whether or not the bereaved person is achieving them.

William J. Worden (1985) lists the following tasks of grief work:

1) To accept the reality of the loss
2) To experience the pain of the loss
3) To adjust to an environment where the deceased is missing
4) To withdraw emotional energy from the deceased and reinvest that energy in other relationships and activities. (Worden, In Kitchen, 1987, p.161)

It can be said, then that normal grieving proceeds, gradually, through a series of stages or tasks accomplished, which can take anywhere from a period of weeks through a couple of years. Through understanding of the normal grief process, it is possible to detect more easily the symptoms of pathological or abnormal grief.

Abnormal Grief

Abnormal or complicated grief seems to take two general forms -- delayed grief and prolonged grief. In the former, the bereaved seems not to experience any sadness or any other emotional or physical reaction ordinarily associated with grieving until perhaps weeks or months following the death. While some delay of symptoms of grief may be attributable to shock, the first stage of grieving, this normally only lasts a few hours or days. It is assumed (Brown & Stoudemire, 1983) that in cases of delayed or apparently absent grief, the emotions connected to the loss are considered so unbearable as to be denied utterly.

Unfortunately, family and friends may often unknowingly reinforce the delayed or absent grief behavior by commenting upon how well the mourner is holding up or praising the mourner for maintaining a "stiff upper lip". This reinforcement serves to prolong further the period of delay and cause, some feel, the process of grieving to become more acutely complicated. What this means is that severe somatic disturbances, such as colitis, dyspnea, fatigue, anorexia, headaches, insomnia, and panic attacks take the place of the normal symptoms of grieving which are being avoided. In cases of prolonged grieving, many of the same somatic symptoms are present and last for periods sometimes amounting to many years. In addition, (and the same can also occur in people with delayed grief reactions) there is often the appearance of symptoms directly related to the last illness of the deceased (conversion hysteria).

Bereaved people, especially in the first two stages mentioned earlier, typically experience many of the symptoms of a clinical depression[2]. Stroebe and Stroebe (1987) suggest that the difference is that such symptoms are considered normal for many bereaved people, though the diagnosis of Clinical Depression may be made if the symptoms are acute and/or prolonged. Still, this may tend to cause some confusion due to the fact, as stated previously, that individuals do not grieve according to a timetable. Stroebe and Stroebe mention two years as the cut-off point for diagnosis of Clinical Depression.

There are, however, so many variables to consider as to what actually precipitates abnormal grief, that any period of time seems arbitrary in considering what is and is not normal.

> Relational variables define the type of relationship the person had with the deceased. The most frequent type of relationship that hinders people from adequately grieving is the highly ambivalent one. Here an inability to face up to and deal with a high titre of ambivalence in one's relationship with the deceased inhibits grief and usually portends excessive amounts of anger and guilt which cause the survivor difficulty. Another type of relationship that causes difficulty is a highly narcissistic one, whereby the deceased represents an extension of oneself. To admit to the loss would then necessitate confronting a loss of a part of oneself, so the loss is denied. (Worden, 1982, p.53)

Worden states, relationships characterized by major dependency issues are also very difficult to grieve. The dependent survivor, feeling helpless and abandoned, may resort to "supplicating" (1982, p.54) behavior designed to achieve rescuing by someone or something else (i.e. substance abuse). In the person with a healthy personality integration, inner resources and positive self-concept can overcome the initial period of perceived helplessness associated with recent bereavement. The excessively dependent person lacks these resources and often develops a new self-concept based on the helplessness of the bereavement situation. In such persons, this new self-definition can and often does become long-term and ingrained.

Conversely, those individuals who rebel against the notion of helplessness and dependency are equally at risk for pathological grieving patterns due to denial of those unwanted feelings. Related to the above, this investigator believes that those who embrace the self-concept of "the strong one" in the family may handle all funeral arrangements and attendant details so competently as to not allow themselves the time -- or indeed -- the right to grieve.

In addition to psychological and personality factors, reports have indicated (Lazare, 1979; Brown & Stoudemire, 1983) that other significant factors involved in complicated mourning are lack of a body or mutilation of the body, or loss of multiple family members or friends (e.g. some natural disasters, or the massacre in Jonestown, Guyana).

When the body is never produced and identified (as was the case with many Viet Nam combatants) the denial of the death may be extremely difficult to overcome. In fact, in cases where the soldier is listed as missing in action -- or presumed dead, and then returns, if the "widow" has successfully completed her grief-work, the marriage is often doomed. (Worden, 1982)

The same denial mechanism is in place amongst survivors who choose not to view a body which has been severely mutilated or where decomposition has rendered a body unrecognizable. There is always the temptation, in such cases, to believe that some mistake has been made, though with modern forensic techniques, evidence of identity is usually irrefutable. (Worden, 1982)

In addition to psychological and circumstantial factors, if an individual has a history of depression and/or of complicated grieving for past losses, any current or future bereavement will serve to further compound the risk for pathological mourning. (Worden, 1982)

The social factors involved in producing pathological grief patterns must now, more than ever before, be considered by health professionals. Whenever a death has been due to a socially unacceptable cause, such as suicide or AIDS, denial of grief may literally be thrust upon survivors by family members or the community in their refusal to acknowledge the death or offer support. (Worden, 1982)

A second example of a social factor which may assist in promoting pathological grieving is the negation factor. This commonly occurs after a newborn has died or a pregnancy miscarried (Worden, 1982). This investigator has noted that a common reaction of concerned relatives and friends is, "Oh well, you can have another". If a recently bereaved couple hears this reaction often enough, they may begin to believe that their normal grief over the loss is <u>not</u> normal, and endeavor to suppress it.

A third social factor, and a very significant one, is lack of a social support network -- seen frequently amongst the elderly who have outlived many of their peers, though this situation is certainly not limited to the elderly. As people move residences more frequently, thus failing, in some cases, to establish intimacy in relations with new neighbors or develop a community, this factor will undoubtedly increase in occurrence. (Worden, 1982)

Due to the nature of the hospice situation most of the contributing factors to pathological grief are eliminated. The hospice family does, in fact, have a special opportunity to facilitate a healthy course of grieving during the term of the illness of the family member designated "the patient".

While hospice families may consider themselves overwhelmed with the enormity of their care-giving tasks, one task in particular must not be overlooked if the family is to resume a normal level of functioning following the death of the patient. Indeed, though much of the routine medical care can be and often is, managed by home health care professionals and volunteers, this most important task of anticipatory grieving can only be accomplished by family members.

> In the field of grief and bereavement, the focus of intervention is usually on assisting the survivor to cope with a fait accompli, and there is nothing that he or she can do to alter the situation; that is, the loved one is already deceased... it is in the area of anticipatory grief that the caregiver has the golden opportunity to use primary prevention strategies and to make therapeutic interventions that may facilitate appropriate grief work and a more positive bereavement experience for the survivor-to-be. (Rando, 1986, pp. 4-5)

Dying people can also benefit from facilitation of anticipatory grief, as their concerns are still an important aspect of family life and function until death becomes a reality.

Due to the nature of terminal care, the "living-dying interval" (Rando, 1986, p.5) is often of longer duration and may be characterized by many more "ups and downs" than in the past. Because modern medical technology has allowed the possibility of longer remission periods and/or greater physical freedom and mobility, terminally ill people really do enjoy the possibility of more independence and opportunity to <u>live</u> until they finally succumb to their disease. But with each "up" or "down" can come a myriad of emotions and stress because of the uncertainty and instability of the situation for patients and their families. Thus, the time when anticipatory grief can occur has "become more complex and burdensome" (Rando, 1986, p.6). This can be a double-edged sword, in that while allowing greater opportunity for anticipatory grieving to occur, at least one study (Rando, 1983) has shown that longer periods of anticipatory grief can actually have an adverse effect on post mortem grieving, due to the potential for family members to decathect from the patient long in advance of the actual death. The same is apparently true when the course of a terminal illness has been very brief so that the family has not had the time necessary to prepare themselves fully for the loss of their loved one.

In addition, if not facilitated appropriately, anticipatory grief can actually provide fertile ground for the hostile aspects inherent in an ambivalent relationship to take root, fester, and grow to the extent that it ruins the relationship between caregiver and patient. Such a course of events is an undesirable one and it is partially for this reason that it is felt the facilitation of the anticipatory grieving process by mental health professionals is desirable and even preferable to people being left to their own devices. In fact, anticipatory grief seems not to occur spontaneously in many hospice families but research has shown that there is a positive correlation between anticipatory grief and healthy resolution of grieving later on (Rando, 1986).

What, exactly, is anticipatory grief? "Anticipatory grief is not a unitary concept that remains unaffected over person, place, time, and experience. Rather, it is multidimensional: defining itself across two perspectives, there time foci, and three classes of influencing variables" (Rando, 1986, p.14). What this means is that, just as in grieving after the death has occurred, each family member has his or her role to play during the period of time before the patient dies. The period of anticipatory grief begins with the diagnosis of terminal illness, proceeds through the term of the illness, and ends with the death. So it is time-limited and the work of anticipatory grief, unlike post-death grief, has a more 'predictable" beginning, middle, and end.

In addition, anticipatory grief has the unique quality of being an experience which can be shared with the terminally ill patient, thus offering the opportunity for resolution of past conflicts, for saying and doing those things which left undone promote guilt and regret in survivors later on (Rando, 1986). The facilitation of communication with the patient can provide opportunities for life-review, resolution, and closure for the patient, leading, hopefully to the acceptance phase of dying (Kubler-Ross, 1969).

Rando (1986) defines three classes of variables which are addressed by the process of anticipatory grief, the successful resolution of which are seen as promoting normal post-death grieving. The "psychological factors" (pp. 17-18) include such things as the role occupied by the patient in the family or social system, the nature and meaning of his/her loss to survivors, the special qualities of the relationships of each family member or friend to the patient, the unique character of the patient, the nature and amount of unfinished business between the patient and his or her social support system, the grievers' image of the patients' life fulfillment, and the nature and amount of "secondary losses" (pp. 17-18) e.g., changes in the patient which cause loss of social and sexual companionship, loss of income and social standing, to dependency issues, moral support, and so on, connected to the patient's illness and death.

According to Rando (1986) the nature of the grievers must be considered. These factors include the grievers' maturity and intelligence, coping skills, personality, mental health, past experience with death and grieving, socio-cultural background, spiritual beliefs, age, conditioned gender-roles, life fulfillment, and so on. Other psychological factors have to do with the care-givers' specific feelings related to illness and death, such as their fears connected with such issues as well as previous experiences and expectations in dealing with these issues, considerations of the preventability of illness, perceptions of the "timeliness of the illness and impending death" (p.18), the length and nature of the illness, the degree of involvement with patient care, and more.

The "social factors" (Rando, 1986, p.18), while similar to the above, pertain to the patient's, families' and friends' responses to the illness and impending death along the lines of psychosocial functioning. These include patient's, friends' and families' knowledge and understanding of and methods of coping with the illness, the ability to support and communicate within the context of the social support system regarding changes in relationships as a result of the illness, the nature of the family and social constellation, the developmental stage of the family, the pre-existing characteristics of the family and social support system, "(degree of flexibility, communication style, rules, norms, expectations, values, beliefs, quality of interrelationships, ... family strengths and weaknesses, ... resources, ... methods of problem resolution...)" (pp.18-19) and literally many more considerations of psychosocial characteristics and methods of functioning. And in addition to these myriad factors, add basic considerations which have to do with socio-economic status, such as availability of quality medical care and community resources -- which access to or lack thereof -- can considerably affect the facilitation of anticipatory grief.

The third class of factors involved with the anticipatory grief process has to do with the specific physiological health and well being of the care-givers. Are they physically healthy? Is their energy depleted? Do they smoke, drink, or abuse controlled substances? Are they getting enough food, rest and exercise? Do they get any respite from the constant daily grind of caring for a sick person? All these factors must be addressed in facilitating the anticipatory grief process.

In addition to all of the above, the mental health worker must consider the evidence that "too much of a good thing" can be detrimental to survivors -- and this is especially true in many cases of hospice families where the illness and dependency of the patient persists long past the expected time and entails periods of seeming recovery or remission. There is further evidence that care-givers are particularly at risk due to the constant and extremely stressful nature of their involvement with patients.

> ...[A] daily routine that centers on the dying patient and then is shattered by the death mandates the development of a new pattern of life, with such changes in routine and roles possibly augmenting the grief to be experienced following the death. In contrast, when the survivor-to-be and the dying person did not live together and the survivor-to-be had no involvement in the care of the dying patient, the longer the period of anticipation the less the grief after the death... Obviously, this has profound implications for families of home-care hospice patients.... (Rando, 1986, pp. 23-24)

What then are the ultimate goals of a prebereavement intervention aimed at facilitation and successful completion of anticipatory grief? Simply put, the goals are to create a "comfort zone" for coping with the dichotomous nature of the anticipatory grieving process. Such a time and process allows for the "rehearsal of the death and preliminary attempts to adjust to the consequences of the loss" (Knott & Wild in Rando, 1986) and "the ability to change one's definitions of one's life and identity, and to plan for a future without the loved one so that it will not feel like a betrayal of the deceased after the death" (p.56).

In other words, to facilitate anticipatory grief before the fact does in fact facilitate recovery (Knott-Wild have called it "reinvestment") (1986, p.56) after the fact, by accomplishment of three major tasks. The first of these is "recognition and cognitive explanation of the loss" (p.56), the second is "emotional acceptance of the loss" (p.56) and the third is "assumption of the new identities and roles incumbent on the mourners in a community" (p.56).

Ultimately, the sum of the completion of these tasks is adaptation to a new set of circumstances, and it is to the process of completing these functions that the mental health professional must attend.

A Model For Prebereavement Counseling

The ideal time period for anticipatory grief is approximately six months -- a factor which is ingrained in the hospice care system, as a six month survival prognosis is prerequisite for admission to hospice in most cases (Rando, 1986). Thus it is desirable for assessment and intervention to begin immediately upon the patient's admission to a hospice program.

This investigator believes that in addition to the ordinary procedural interview which is conducted with the hospice family at the time of admission, it is possible, to simultaneously ascertain what, if any, variables within the family system would seem to indicate an "at-risk" situation for pathological grieving.

Such an interview would focus on the pre-existing factors such as alcoholism, substance abuse or dependency, other types of medical illnesses, mental illness, abusive situations, family functioning and interrelationships, any previous experiences with illness and death and reactions within the family unit to all of the above.

Once a family has been determined to be at risk, a series of family counseling sessions can be prescribed as a "resource for the family's use to help them get through this trying time". Since the decision to provide hospital-supervised home care is already one which indicates a level of commitment and caring, many families will undoubtedly welcome the opportunity to utilize all available resources, and it can further be stated that qualified, trained volunteers are available to "baby-sit" in the event the patient may be unable to attend some of the sessions -- though it should be emphasized that the patient's presence at sessions is most desirable. In addition, if the counselor feels comfortable making home visits, this is a viable option, as hospice families must learn to cope with a parade of helping professionals into and out of their homes during the term of the patient's illness. These options should be discussed with the family at the time services are offered.

Naturally, the choice to participate in such counseling lies entirely with the family. But if the mental health professional feels the family is particularly at risk and the family seems hesitant to participate fully, it would not be responsible on the part of the counselor to neglect to outline the nature of the risk and possible outcome should the family decline. If the family still declines, the door for delayed or follow-up participation should be left open and a warm and receptive attitude displayed.

Once the agreement to participate in the family counseling program has been made, the course of counseling must proceed as with any other course of family counseling. The counselor must initially join with the family and get a broad idea of the family's general characteristics, "such as specific roles, rules, communication patterns, and patterns of behavior that reflect their beliefs, experiences, coping strategies, system alliances and coalitions." (Rando, 1986, p.97)

This will enable the counselor to view the family with a "systems perspective" (p.97), which Rando considers vital to successfully providing the family with understanding of what is happening to it and what to expect to happen during this time of the family's life.

The counselor can explain the systems approach to the family so that the members come to view the family as "a constellation that is more than the sum of its parts" (p.97), to understand that anything that happens to one family member affects the entire family system and vice versa, and that the system itself is constantly striving to achieve "homeostatic balance and equilibrium" (p.97).

The course of family counseling must, of necessity, include much instruction, since the hospice family will undoubtedly be experiencing a great deal of confusion as to the changing roles of family members around the issues presented by the patient's illness. To this end, then, the counselor must "normalize" the situation for the family, explaining the ways in which the normal interactions of the family members can be expected to change in response to the challenges presented by home care and all its attendant complications.

Over the course of therapy, family members can be expected to confront varying aspects of the turmoil of the situation in which they find themselves. The counselor must continue to normalize the family members' responses to these stressful events and to point out to the family the paradoxical nature of the tasks associated with anticipatory grieving. Rando describes some of these tasks as:

> Holding on to the patient versus letting go.
>
> Increasing attachment to the patient during the illness versus starting to decathect from the patient in terms of his or her existence in the future.
>
> Remaining involved with the patient versus separating from the patient.
>
> Planning for life after the death of the patient versus not wanting to betray the patient by considering life in his or her absence.
>
> Communicating feelings to the patient versus not wanting to make the patient feel guilty for dying or bound to this world when the patient needs to let go.
>
> Balancing support for the patient's increased dependency versus supporting the patient's need for autonomy.
>
> Focusing on the past and recollecting with the patient versus focusing on the future.
>
> Redistributing family roles and responsibilities versus not wanting to do anything that would call attention to or cause more losses for the patient.
>
> Taking care of the patient's needs versus taking care of one's own needs.
>
> Being immersed in participating in the patient's care versus living one's own life.
>
> Experiencing the full intensity of the feelings involved in anticipatory grief versus trying not to become overwhelmed.
>
> Focusing on the patient as a living person versus remembering that the patient is dying.
>
> Continuing reinvestment in the patient who has multiple remissions and relapses and who is going to die anyway versus not reinvesting as much anymore.
>
> Treating the patient as one always has in the past versus taking into account the patient's situation and treating him or her differently.

> Rushing to create memorable experiences in the patient's last days and pushing for as much meaning in the time remaining versus allowing nature to take its course, reminiscing, and just passively being present with the patient.
>
> Identifying a loss so it can be grieved by the patient versus focusing more positively on the remaining potentials.
>
> (Rando, 1986, pp. 101-102)

These are only a few of the paradoxes which will surface for the hospice family -- but they and all others will need to be addressed by the counselor, and ways found to achieve balance even against seemingly insurmountable odds.

In addition to the role of instructor in the "how to" of surviving the hospice experience, the counselors must employ all their skill in therapeutic interventions with the emotional reactions of family members as they struggle to cope with their impending loss.

Guilt almost always surfaces when families are thrust into such stressful situations as coping with home care of a terminally ill loved one. Usually the guilt has to do with such ordinary aspects of family life as acts of omission or commission and ambivalence toward the patient as well as resentment over the time, resources and energy expended in the patient's behalf, the wish for the whole ordeal to be over, anger or revulsion toward the patient as a result of dependency or physical manifestations of the disease, and so on. The counselor must conscientiously address each member's guilt feelings, and again normalize them in the context of the situation, give family members permission to feel the negative and frightening emotions, and explain the possibility of feeling conflicting emotions simultaneously. The counselor must also delineate between acceptable and unacceptable, appropriate and inappropriate expressions of such feelings. Families may be unaware of their need to be "superhuman" in dealing with such a stressful condition, so it is also incumbent upon the counselor to suggest ways in which family members can take time out for themselves and what signals to look for to tell them when they are in need of such breaks. In some cases families are unaware that it is "permissible" to take advantage of respite care services which are provided by most hospices, so the counselor may give them permission and remind the family that such services are available.

In addition to guilt, family members of the terminally ill can be expected to experience sorrow, depression, anger, hostility and anxiety during the course of the patient's illness. The counselor must be ready and able to deal with these emotions whenever they occur and in whichever family member they occur, being always conscious of the individual context of their occurrence. This, again, necessitates normalization, reframing into more acceptable terminology than the family member may be using internally, and the reassurance that such feelings occur precisely because of the deep level of caring for the dying individual. The counselor must be prepared to frequently repeat prior interventions as the confusion of the situation may create an environment which prevents information from sinking in the first or second time around.

Counselors must continually inform family members of the utility of feelings as they relate to the grieving process, just as they must impart information, when called upon, as to what to expect in the future -- both in terms of emotions and manifestations of the illness or side-effects of drugs used to treat symptoms of the disease. Thus it is important for counselors to acquaint themselves as much as possible with these factors and to maintain an attitude of cooperation with other caregivers who may be involved with the patient and family. It may, at times, be necessary for the counselor to act as liaison between the family and the hospice staff to correct misinformation or misinterpretations of information -- as doctors or other medical personnel may be difficult for families to reach, approach or deal with.

It is important that counselors realize that patients have many of the same needs throughout the course of their illness as the rest of the family, but in addition have special needs of their own. Of primary importance, the counselor must view the patient "holistically" (Humphrey as cited in Rando, 1986, p.72). Patients are, after all, people with entire lifetimes of relationships, feelings, and experiences behind them. To neglect understanding of the totality of the patient's life experience is to negate in great part understanding of the family system as a whole.

In dealing with dying persons it is important to provide as much information as the patients need regarding their conditions and expectations for the future without giving more information than is requested or using threatening terminology. When dealing with information which could be frightening for the patient, the counselor must endeavor to deliver such information in a compassionate manner and with the support of comfortable surroundings and family members present.

It is especially important to validate the patient's life and identity, and the counselor can model this process for family members by encouraging the patient to talk about his/her life prior to the onset of the illness and the significant people, places and other aspects of that life. In addition to opening up important lines of communication between the patient and family, the "life-review" serves the purpose of giving the patient validation for the many experiences which have comprised his life and provide a vehicle for resolution of past conflicts (and possibly even fill in missing resources for coping with present and future conflicts).

Related to the above is the importance of keeping the patient involved (to the extent that he or she is able) in the daily life and decision making functions of the family.

The counselor may wish to make time to see the patient individually if it seems that the patient needs some time and space away from the family -- respite care works both ways. Individual sessions may provide the opportunity the patient needs to vent feelings of frustration, anger, anxiety and the like, which may not feel comfortable to discuss with the family present. Naturally the counselor will want to facilitate open communication with the family if possible. But it is important for counselors to realize that a lifetime of communication style cannot be changed immediately if at all. Patients and their families must be approached therapeutically "where they are now", as trying to change a family's style of functioning or value system to be more in line with what the therapist wants for them will only alienate the family and breed disaster for the therapeutic process and all concerned.

In addition to all of the above, it may be beneficial for the patient and family to incorporate grief rituals into the grieving process. Rando (1985) prescribes such rituals as part of the "post mortem" bereavement counseling which she practices. She feels that the establishment of rituals acts as a therapeutic adjunct to more traditional counseling methods.

"A ritual is defined as a specific behavior or activity which gives symbolic expression to certain feelings or thoughts of the actor(s) individually or as a group. It may be a habitually repetitive behavior or a one-time occurrence" (Rando, 1985, p.236). For some time, therapists have encouraged bereaved clients to write letters to the deceased, talk to the deceased in "empty-chair" (p.236) exercises as in Gestalt therapy, and so on. Rando cites rituals of other types for the bereaved such as lighting a candle as a form of communication with the deceased on special occasions such as birthdays and anniversaries, planting trees to commemorate the life of a loved one, or inviting a needy or socially isolated person to occupy the deceased person's place at Christmas dinner -- all of which serve to perpetuate the loved one's memory and stabilize the connection between the survivors and the deceased.

The funeral itself is seen as such a ritual, as it entails three stages of progression in the relationship between the grievers and the deceased. These are "separation from a former state, transition into a new state, and incorporation into that new state" (Rando, 1985, p.237), which are, in effect, the goals of anticipatory grief work. The funeral functions as a "closure" phase in the anticipatory grief process, and simultaneously opens the door to the new state of bereavement. Thus funeral rituals can be seen as a long practised, and socially acceptable way of dealing with death and bereavement.

The employment of rituals in connection with bereavement is not a new concept. For example, members of the Jewish faith light candles which burn for a period of days on the anniversary of a loved one's death. This is called the Yahrtzeit and is accompanied by visits to the synagogue and recitation of the Kaddish (or prayer for the dead). There is usually mention, within the Kaddish service, of the names of the deceased whose Yahrtzeit is being celebrated. This ritual is literally thousands of years old. But the benefits of establishing rituals within the context of pre-bereavement counseling have not been explored to a great extent. Though grief counselors have traditionally encouraged the dying patient's participation in the planning of the funeral, it would be a terrifically beneficial practice to enlist the patient's participation in the creation of rituals designed to maintain and preserve his or her memory. What better way to demonstrate to the patient the family's commitment to the enduring quality of the relationship -- even in the physical absence of the deceased?

If one accepts the notion that the patients face the greatest loss -- that of self and all significant others and all "relevant" experience -- then collaboration on a specific event, or series of events, to be performed by their loved ones, not only gives the patients perhaps their last spark of autonomy, but ensures that this life has had meaning to them and those they loved.

A simple agreement to plant a tree in a local park, the type and location of which can be the patient's choice, the bequest of an amount of money to a cause or institution in the patient's name, even the knowledge that every birthday, Christmas, or wedding anniversary will be commemorated with the lighting of a candle and a brief communication from the survivors can be a gesture which will ease the patient's transition and provide comfort for the family. This is especially true if the memory of the deceased's participation in the establishment of the ritual can be recalled and appreciated.

Rando (1985) describes several functions which are served by the establishment of rituals in the grief process:

1) "The power of 'acting-out'" (p.238) which in this context indicates the transformation of thoughts and feelings into physical, tangible methods of expression, thereby providing a socially acceptable vehicle for ventilation and prevention of feelings of victimization so often associated with loss.

2) "The delimitation of grief" (p.238) which channels emotions into a "circumscribed activity" (p.238) containing a specific beginning, middle, and end

as well as a primary focus -- thus preventing the murky, nebulous sense of overwhelming grief and helplessness.

3) "The allowance of the bereaved to 'hang on' to the deceased" (p.238) in an appropriate manner, without allowing the griever to become mired in the loss.

4) Conversely, ritual can also enable the griever to confront unresolved grief and guilty feelings by providing a framework in which separation from the deceased becomes tolerable.

5) Validation of the loss. By repetitive action, ritual can provide the experience needed by some people to reinforce the reality of the loss.

6) In facilitating group interaction, rituals provide the group support necessary for the healthy resolution of the grieving experience.

7) "The structuring of 'celebrations' of anniversaries and holidays" (p.239). The participation by the grievers in a significant activity aimed at commemorating the deceased on a special day is aimed at reducing the effects of anniversary reactions which are not always readily acknowledged but are normal grief reactions and must therefore be addressed.

By incorporating some or all of the above methods (as appropriate with individuals and families of differing needs) into a comprehensive program of terminal care and counseling, it is hoped that the devastating effects of pathological mourning can be eliminated. If this proves to be the case, the implications for future generations of families will be quite promising -- not only for the grief process but for overall family functioning. For once a family has learned to experience dying and death, all its communications and interactions must, naturally, and as a matter of course, be healthier, more "open", and holistically solid.

ENDNOTES

1) "Complicated Mourning" and "Pathological Grieving" are used throughout this paper interchangeably.

2) ...(1) Poor appetite or weight loss ...(2) Sleep difficulty ...(3) Loss of energy ...(4) Loss of interest in usual activities, or decrease in sexual drive ..(5) Feelings of self-reproach or guilt ...(7) Complaints of or actually diminished ability to think or concentrate ...(8) Recurrent thoughts of death or suicide, including... wishing to be dead. (Feighner et al, 1972, p.58 cited in Stroebe & Stroebe, 1987, p.23)

CHAPTER 3

METHOD

In order to appropriately and accurately examine the effectiveness of the therapeutic approach previously described herein, it will be necessary to design an experimental program which will address the specific question of whether or not a course of pre-bereavement counseling will prove beneficial in preventing the occurrence of pathological/complicated grief in hospice families. Because the hypothesis is aimed specifically at the hospice population, all the volunteer subjects will naturally be families of hospice patients. The results will then not be generalizable to the population at large, but only to the population of hospice families.

Subjects

Subjects for this study will be families of hospice patients of varying characteristics gleaned from the overall population of several hospice programs throughout the St. Louis area. Families will be asked to volunteer for the program and promised counseling as needed or desired in return for their participation. Such a plan will address the ethical question which withholding of therapeutic services from some of the participants unquestionably raises. In fact, no participant will be refused counseling, though some families in the study will receive only the standard counseling services currently provided by local hospices.[1] This normally consists of the occasional, as-needed, services of a social worker, and is not a formalized program or series of counseling sessions, but rather a crisis-intervention type of approach.

Subjects will be selected with the intent of obtaining a broad cross-section of family characteristics such as ethnicity, religion, socio-economic status, sex, age, level of education, the existence or lack of pre-morbid psychological and physiological illness in one or more family members, and other factors such as alcoholic/addictive behavior and physical and/or sexual abuse.

The term, "family", in the context of this study will include all resident (in the patient's home) first and second degree relatives, and any non-resident first and second degree relatives who choose to participate in the study.

Because it is in the nature of a pilot study, the sample will be kept small. A minimum of five families will be randomly assigned to one of each of three experimental groups, with the hope that the total number of participants can be kept to 100 people or fewer.

Procedure

Study participants will be interviewed to determine the nature of characteristics which describe the family, as stated above. Confidentiality will be strictly protected. A numerical coding system will be employed to identify participants by family and individual, ie: 1:1 would indicate the Smith family, Mr. Smith; 1:2, Mrs. Smith, etc. The demographic information concerning the subjects will be kept by the researcher and no access by any other person will be permitted.

Once all the participants have been assigned a numerical code, each family member's demographic data will be filed away under the number assigned to that family. Cards bearing the numbers 1-15 will then be shuffled, overturned, and randomly assigned to one of three groups, labeled A, B, and C. Each family having thus been assigned a group and the demographics files labeled A, B, or C, accordingly, the research phase of the sudy will begin.

Research Design

Research Groups

Group A will be considered the first control group. The families in this group will receive no treatment interventions other than that which normally occurs within the ordinary routine of hospice care.[1] Group A families will represent the nature of hospice care as it currently exists, which is a system of total patient care aimed at alleviating the symptoms of terminal illness. Currently, some but not all symptoms can be anticipated due to the nature of the disease. One symptom which is not anticipated is emotional distress of the patients and their families, who usually receive counseling only as crisis intervention or upon request. It is toward challenging and correcting this situation that this proposed study is directed.

Group B will be the experimental group. Families in this group will receive a course of pre-bereavement counseling, consisting of six weekly, one-hour sessions, each designed to address one major family problem area inherent in the hospice experience. Each family member who has elected to participate in the study will be requested to attend all six sessions. Due to the unpredictable nature of participation in a hospice program, it is necessary that the course of treatment be short-term in order that all family members may more easily commit to the counseling program. In addition, it is necessary for the effectiveness of the counseling, that the patients, themselves, attend the counseling sessions and this is another concern in keeping the course of counseling brief, as the patients' deteriorating physical condition may not allow for longer-term intervention. For these reasons, a period of six weeks may prove the optimum time period in which to provide weekly sessions.

For the sake of validity (internal consistency) within the study, all sessions within Group B will be facilitated by only one counselor who will, in the role of facilitator, throw out for discussion one major related topic per session. This procedure will not only provide fertile ground for family interaction and therapeutic intervention, but will allow for control over some of the confounding variables inherent in such a study. Time and care must naturally be taken by the counselor to normalize and reframe families' material throughout the sessions, and to repair any "damage" done by explosive, emotional confrontations occurring during the sessions.

Naturally, the counselor must be sensitive and receptive to the subjects' independently initiated subject material, deal with it effectively, and steer the subjects back to the matter at hand.

In two very important ways, this model of pre-bereavement counseling differs from Rando's (1986) prescriptions for such treatment. First, Rando prescribes a six month period of anticipatory grieving as ideal. While this may be true, there is nothing inherent in a six-week treatment plan which is known to prohibit a six-month period of anticipatory grief. Also, the very inexact nature of the hospice experience often makes such an exact time frame impossible.

Second, Rando does not suggest that therapists take control of bereavement sessions by introducing the specific topic for discussion. In the context of this study, however, certain measures must be taken to ensure internal validity. The above mentioned procedure will do this to the extent that it can be done, while still allowing for freedom within the counseling sessions for subjects' self-expression.

Any longer-term difficulties which may surface for participant families can certainly be addressed by the counselor after the six week experimental period has elapsed, as promised to the subjects in return for their participation.

The material introduced for discussion by the counselor will be arranged in order along a gradient of levels of expected emotional charge connected with each topic. It may go something like the following:

Session 1: Becoming adjusted to the hospice experience.
Session 2: Facing loss of independence/freedom.
Session 3: Facing sadness/death.
Session 4: Feeling angry/hurt/vulnerable.
Session 5: Saying good-bye/memorialization/rituals.
Session 6: Living one day at a time.

Sessions dealing with the most highly charged emotional topics will be placed in the middle of the course of counseling, so that the families will have more positive, forward-looking sessions at the end. The hope is that even a brief encounter with the ideas and thought/feeling processes addressed by these sessions will prove beneficial in the long term.

Group C would consist of the five remaining subject families in one group setting who would attend six weekly, one-hour seminar sessions addressing the same topics as Group B, but presented in lecture form, and allowing a few minutes at the end for questions. The topics may be covered only verbally, or if and when available, other materials such as videotapes, orientation materials, demonstrations of care procedures, or printed material outlining funeral/ritual options may be presented --- within the context of each topic, of course. Groups B and C will both be facilitated by the same individual to further protect internal validity.

In effect, Group C would be given information and/or access to information necessary to ease the path through the hospice experience, but would not receive actual counseling. It is not expected that such a course of instruction would have any effect upon the nature of these families' grieving processes. The procedure for Group C then, represents placebo treatment.

None of the subjects will be told the exact nature of the study, nor will hospice personnel, though the directors of the hospices from which volunteers will be taken will naturally need to be fully informed. Subjects will be told only that results of testing done after the research procedures are completed will provide hospice units with information enabling them to better serve patients and their families. This is, of course, a very general way of stating exactly what this study hopes to accomplish.

Research Facilitators

It is important that the facilitator of Groups B and C not have more information than the subjects themselves, to prevent researcher bias. Thus, the "counselor" for Group B and "lecturer" for Group C must be a person who is not conducting the research. Ads will be placed locally for a willing counselor from either a psychological or social work discipline who has achieved at least a masters level degree and who has some experience counseling dying people and their families.

The facilitator will be carefully instructed as to the tasks required for the research and the work closely monitored by the researcher. The counselor will be required to carefully document counseling sessions at the end of each one. The researcher will be present during the seminar sessions as a silent observer to oversee the proceedings and offer guidance as needed. The researcher will also review counselee's files, so as to determine by the counselor's notes whether the tasks of anticipatory grieving have been adequately addressed by the counselor and families and to note their level of participation. In this way, the researcher can monitor the proceedings and make adjustments as needed. For example, drop-out families will need to be replaced in order for the population to remain large enough to provide an adequate sample and preserve test validity.

Instruments

The MMPI

The Minnesota Multiphasic Personality Inventory will be administered to all participants prior to the start of the course of treatment to which they have been assigned. The responses of the subjects to the 550 questions in the MMPI will then be scored and interpreted to detect responses indicating abnormal behavior amongst ten clinical scales and several supplementary scales. The interpretation will give the researcher a reasonably reliable indicator as to the overall clinical profile of each participant. This information will provide diagnoses (if present) of such factors as psychoses, depression, alcoholism/substance abuse, and other significant aspects of personality which may have an effect upon an individual's overall level of function.

The DAS

The Death Anxiety Scale, a twenty-item questionnaire with six possible responses each, ranging from "strongly disagree" to "strongly agree" measures with strong validity ($p<.01$) the level of death anxiety experienced by an individual. The DAS will be administered following the MMPI, prior to the start of experimental procedures, to subjects in all three groups in the study. The results will provide information as to the level of death anxiety with which each subject enters the hospice experience and further data as to personality orientations which may be expected to complicate mourning.

The ETIG

The Expanded Texas Inventory of Grief consists of a 58-item questionnaire, scored on a Likert Scale ["1 = completely false... 5 = completely true" (Zisook, DeVaul and Click, p.1591, 1982)] which measures acute symptoms of bereavement. The ETIG will be administered to all subjects every three months for two years after the death of the patients in the subject families, and then once after three years following the death. Zisook, DeVaul and Click (1982) discovered that acute symptoms peak at the two year interval and decline thereafter, though some symptoms were still present even after ten years. For the purposes of this study it will be sufficient to note whether there is a significant decline in symptoms three years post-mortem, the absence of which will be an indication of complicated mourning.

In addition to the ETIG, the MMPI and the DAS will be administered at the first, second and third year points in the hope that significant personality and anxiety factors will correlate to scores on the grief inventory scale, providing further possibilities of assessing the at-risk population amongst hospice families.

All demographic information will be charted and test scores correlated as well as possible by the use of a MANOVA and the results written up and discussed following the conclusion of the research phase of the study.

ENDNOTES

1) Normally, hospice patients receive three or so visits per week from visiting nurses, at least occasional visits from social workers, and possibly weekly or twice weekly visits from volunteers, depending on the patients' and families' needs.

CHAPTER 4

DISCUSSION

Upon completion of the statistical analysis of the test scores of all participants, it is possible that a significant correlation may be seen between indicators of pathological grief and a lack of pre-bereavement psychological intervention. If members of Group B (the experimental group which will have undergone a six-week course of pre-bereavement counseling) are shown to suffer significantly fewer symptoms of pathological grief than either Group A (the group which will have had no counseling other than that which is currently provided in hospice programs) or Group C (the group receiving the placebo/seminar treatment), then it is likely that pre-bereavement intervention has played some role in that outcome.

It is hoped that should this study be completed and the results shown to be conclusive, hospices will wish to routinely offer pre-bereavement counseling to patients and their families as a method of easing their way through such trying times, providing coping skills and hope for the future. It is, in fact, possible that such intervention may obviate the need for medical and/or psychiatric care resulting from issues of unresolved grief, thereby lightening the financial burden on our already overly taxed insurance and health care systems, and be especially important in preserving hospice families, healthy and intact.

The research proposed herein, is designed to ultimately provide further relief for families experiencing one of life's most stressful and challenging events -- the process of caring for a terminally ill family member. Though hospice, by its very nature, provides a more nurturing and humane environment (the home) than that of the hospital with its accompanying accoutrements and intrusive apparatus, certain

Suggested Areas For Further Research

The research proposed herein could provide fertile ground for research into related topics on the subject of grief and illness. An example of such a topic might be whether an analysis of personality assessment materials and death anxiety scores would yield information pertaining to who is at risk for pathological grief. If certain conclusions could be drawn from the data gathered from this proposed project, research models could be designed to detect patterns of personality and/or behavior which, by their very nature, can act as predictors of probable complicated grieving problems.

Another possibility for future, related research is the investigation into a relationship between complicated grief and Post Traumatic Stress Disorder. Such research could yield valuable information to psychologists and others in terms of preferred and successful treatment modes which may have previously gone unrecognized. In addition, treatment modes and assessment of at risk situations for families of patients with terminal illnesses or PTSD may be made more readily and automatically available in hospital settings.

Truly, research into all areas of grief and loss can provide humankind with answers to some fundamental questions related to human "beingness" and what exactly that means. As Herman Feifel states:

> Refinement in the pursuit of our craft... will not be sufficient unless it is carried on in the context of healing the humanity of the dying patient and wounded mourner. Our model of understanding and treatment must be the humanity of the person. The requisite is not just to succor the body but also to speak to the soul... death and grief bring with them a preoccupation with a vision of life. (1990, p.542)

If, as existential psychotherapists believe, the inevitability of death and the meaning of life are basic human concerns, then certainly an empirical investigation into how we function when faced immediately with such questions can only serve to benefit humankind by providing answers and, therefore, comfort.

APPENDIX A

Comparison of Symptoms of Complicated Grief With Those of Post Traumatic Stress Disorder

APPENDIX A

Symptoms of
Lindeman - Pathological Grief (Sanders, 1989, p.113)

1) Overactivity without a sense of loss
2) Acquisition of symptoms belonging to the last illness of the deceased.
3) Psychosomatic conditions such as ulcerative colitis, rheumatoid arthritis, or asthma.
4) Alteration in relationship to friends and relatives.
5) Furious hostility against specific persons.
6) A wooden formal affectivity or conduct resembling schizophrenic reactions.
7) Lasting loss of patterns of social interaction.
8) Acting in unusual says that are detrimental to social or economic existence.
9) Agitated depression with bitter self-accusation.

Symptoms of
Lazare - Pathological Grief (Sanders, 1989, p.114)

1) A depressive syndrome of varying degrees of severity, beginning with the death.
2) A history of delayed or prolonged grief.
3) Symptoms of guilt, self-reproach, panic attacks, and somatic expressions of fear, such as choking sensations and breathing attacks.
4) Somatic symptoms representing identification with the dead person, often the symptoms of the terminal illness.
5) Physical distress under the upper half of the sternum accompanied by expressions such as "there is something stuck inside me" or "I feel there is a demon inside me".
6) Searching behavior.
7) Recurrence of depressive symptoms and searching behavior on specific dates such as anniversaries of the death, birthdays of the deceased, and holidays, especially Christmas.
8) A feeling that the death occurred yesterday, even though the loss took place months or years ago.
9) Unwillingness to move the possessions of the deceased.
10) Change in relationships following the death.
11) Diminished participation in religious and ritual activities.
12) The inability to discuss the deceased without crying or the voice cracking, particularly when the death occurred over 1 year ago.
13) Themes of loss.

Partial List of Symptoms of
DSM-III-R-PTSD (APA, 1987, p.250)

B.4) Intense psychological distress at exposure to events that symbolize or resemble an aspect of the traumatic event, including anniversaries of the trauma.
C.4) Markedly diminished interest in significant activities...
C.5) Feeling of detachment or estrangement from others.
C.6) Restricted range of affect, e.g., unable to have loving feelings.
D.2) Irritability or outbursts of anger
D.4) Hypervigilance.
D.6) Physiologic reactivity upon exposure to events that symbolize or resemble an aspect of the traumatic event...

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