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Elison, Jennifer Claire Kinyon, Ed.D.

The College of William and Mary, 1991



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REACTIONS TO SPOUSAL DEATH RESULTING FROM CANCER: A DESCRIPTIVE STUDY OF ANTICIPATORY GRIEF AND THE COGNITIVE APPRAISAL OF THE LOSS OF A SPOUSE

A Dissertation Presented to the Faculty of the School of Education The College of William and Mary

In Partial Fulfillment

of the Requirement for the Degree of

Doctor of Education

by

Jennifer Claire Kinyon Elison October, 1991

REACTIONS TO SPOUSAL DEATH RESULTING FROM CANCER A DESCRIPTIVE STUDY OF ANTICIPATORY GRIEF AND THE COGNITIVE APPRAISAL OF THE LOSS OF A SPOUSE

by

Jennifer Claire Kinyon Elison

Approved on October 1991 by

Fred L. Adair, Ph.D. Chairman of Doctoral Committee

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Charles O. Matthews, Ph.D.

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TABLE OF CONTENTS

		· · · · · · · · · · · · · · · · · · ·	age
ACKNO	WLE	DGEMENTS	i
TABLE	OF	CONTENTS	ii
LIST	OF	TABLES	iv
CHAPT	ER		
	1.	Introduction	
		Problem Statement	1
		Justification for the Study	1
		Theoretical Rational	4
		Definition of Terms	
		Research Questions	
		Sample and Data Gathering Procedures	
		Limitations	
		Ethical Considerations	
	2.	Historical Overview and Literature Review	
		Historical Overview	15
		Review of the Literature	
		Reactions to Loss Following Long-Term Illness	22
		Effect of Anticipatory Grief on Reactions	
		to Loss	37
		Summary	
		DummaLy	50
	3.	Methodology	
		Population and Selection of the Sample	53
		Procedure	
		Instrumentation	
		Design	
		Specific Hypotheses	
		Statistical Analysis	
		Deadibelouf imariplessions in the second sec	01
	4 .	Results	63
		Demographic Data	
		Summary of Demographic Data	70
		Research Question Number One	
		Summary of Research Question Number One	
		Research Question Number Two	
		Summary of Research Question Number Two	
		Research Question Number Three	81
		Summary of Research Question Number Three	84
		Research Question Number Four	84 85
		Summary of Research Question Number Four	90
		Additional Findings	91

5.	Recommendations	
APPENDIC	es	
	Appendix A Interview Schedule	110 113
REFERENC	ES	116
VITA	•••••	120
ABSTRACT		121

LIST OF TABLES

TABLE		Page
1	Types of Primary Cancer	66
2	Type of Treatment	67
3	Physical Effects of Treatment	68
4	Changes in Thoughts and Feelings as a Result of the Nature of the Disease	73
5	Self Reported Behaviors Utilized in Anticipating Spousal Death	77
6	Self Reported Responses to Loss	86

CHAPTER I

Statement of the Problem

How do anticipatory grief and cognitive appraisal affect spousal responses to loss following a cancer related death?

Justification for the Study

According to the American Cancer Society (Silberg, 1985) 462,000 Americans died from cancer in the year 1985. Of the 455,000 Americans diagnosed with cancer in 1985, more than half will be alive for at least five years. However, despite this increased longevity for cancer patients, cancer remains the second leading cause of death (surpassed by accidents for people under age 34 and heart disease for those over 35). Thus a death from cancer is by no means a statistically rare event (Koocher, 1986).

Salsbury and Johnson (1981) state that one of every four individuals who are alive today will be diagnosed with cancer. If each individual with cancer had only an estimated 20 family members, then the lives of 20 million Americans would be affected by cancer each year. It seems then, that cancer is more than just an individual concern and should be approached as a family disease (Keitel, Cramer, & Zevon, 1990).

Cancer is often thought of as a single disease instead of a generic label for over 100 diseases which have in common the general characteristic of malignant cell growth. If there is no intervention, the malignant cells will continue to divide and subdivide and eventually interfere with the functioning of nearby organs either by intrusion or by interfering with the supply of oxygen and nutrients (Prescott & Flexer, 1982). The treatment include traditional approaches to cancer chemotherapy, radiation therapy, and/or surgery. These treatment modalities are associated with a variety of adverse effects such as disfigurement, nausea, vomiting, fatique, hair loss, depressed appetite, changes in body image and sexual functioning, and changes in self-care practices. Often times these side effects are seen to be more devastating to the patient than the disease itself (Burish & Lyles, 1983). Since cancer patients do not live in isolation, the changes in lifestyle brought about by the disease and subsequent treatment(s) may dramatically effect not only the patient but also members of his/her family. Oberst and James (1985) found that lifestyle adjustments for the spouses of cancer surgery patients were more severe for the spouses than for the patients themselves.

A plethora of research is available concerning reactions of families when confronted with the loss of a member following a cancer related death. The majority of the available studies, however, were published before the advent

of the now available advances in medical technology which prolong the life of the cancer patient (Chodoff, et al., 1964, Friedman, et al., 1963, Friedman, 1967, Kubler-Ross, 1969, Vachon et al., 1977). These advances, while providing for increased longevity, also increase family stress as treatment outcomes become more uncertain. Additional stressors associated with cancer (length of illness, financial concerns, uncertainty of outcome, and amount of patient suffering, for example) need to be incorporated into the research regarding spousal reactions following a cancer related loss.

In addition to the lack of research which considers the effects of medical advances, much of the research which describes reactions to cancer have focused on a pathology based model. This model is limiting in that the population of cancer patients and their families are basically normal with regards to their psychiatric conditions (Jevne, 1987). Thus there is a need for research which describes reactions to loss following a cancer related death based on a stress-coping paradigm which focuses on cognitive appraisal rather than a pathology based model of bereavement response.

As a result of the lack of research which examines responses to loss from a non-pathology based framework, unrealistic assumptions concerning "normal" reactions to loss may be held by health care professionals as well as the families' social network. These assumptions concerning appropriate loss responses may unnecessarily exacerbate

feelings of distress among those who have encountered loss and lead to a self-perception that their responses are in someway abnormal and inappropriate considering the situation (Wortman & Silver, 1989). As Zisook and Shuchter (1986) indicated, currently "there is no prescription for how to grieve properly for a lost spouse, and no research-validated guideposts for what is normal vs. deviant mourning... We are just beginning to realize the full range of what may be considered 'normal' grieving" (p. 288). In order to offer appropriate forms of assistance to the friends and family members who have experienced a loss it is imperative that health care professionals be aware of the wide variety of responses which constitute bereavement.

This study examined spousal responses to loss following a cancer related death. The nature of the illness, the effect of anticipatory grief, and the cognitive appraisal of the death by the spouse were explored in an attempt to increase the body of knowledge concerning reactions to loss.

Theoretical Rationale

Over the past several decades there has been an increased interest in the concept of coping. Coping can be defined as the cognitive and behavioral effort made to master, tolerate, or reduce demands which tax or exceed a person's resources (Cohen & Lazarus, 1979). Thoughts about the coping process

have historically been shaped by the psychoanalytic perspective which viewed coping as a largely unconscious process in response to internal conflicts. Richard Lazarus has facilitated a change in thinking toward coping with external stressors by focusing on the role of cognitive appraisal in shaping responses to stress and guiding coping efforts (Kessler, et al., 1985).

Lazarus postulated that individuals react to stressful situations by means of a cognitive appraisal of the event. This assessment of a stressor involves the cognitive processes of primary appraisal, secondary appraisal, and of reappraisal. The primary appraisal or initial assessment of the stressor involves the question "Am I in trouble or am I being benefited?". The three outcomes of this appraisal include 1) irrelevant, 2) benign, or 3) stress. An irrelevant appraisal indicates that the situation holds no implication for the well-being of the individual. A benign appraisal is indicative of the thought that the outcome of the encounter or situation is construed as positive. Stress appraisals result when assessment indicates that the situation is viewed as a loss or harm, a threat, or a challenge. The primary appraisal determines the intensity and quality of the emotional response to any transaction (Lazarus & Folkman, 1984).

A reappraisal of the stressor allows for alterations in the quality and intensity of the resulting emotion based on changes in the person-environment relationship and a cognitive review of the transaction. Lazarus (1981) believed the determinants of this reappraisal lie in the interaction of person variables (general and specific beliefs about oneself in the environment and the pattern and strength of values and commitments) and the environmental situation. Thus the primary appraisal of a stressor may be that of a threatened loss and the reappraisal that of a challenge, or an opportunity for growth. This allowance for cognitive change depending upon situational and personal variables lends itself well to a study regarding responses to loss following a long-term illness such as cancer.

The final aspect of Lazarus' model involves a secondary appraisal which is interdependent with the primary appraisal. The secondary appraisal evaluates coping options and resources. This theory holds that the coping method chosen does not always need to be realistic. Flexibility of coping responses allow for self-regulation of emotional distress (Lazarus, 1981).

Lazarus is unique among coping theorist in that he attends to the variety of coping responses that may be employed by individuals who encounter life crises (Silver & Wortman, 1980). The responses to loss hypothesized by stage theorists such as Bowlby (1980) and Kubler-Ross (1969) do not allow for a variety of responses to or reappraisals of the stressors produced by loss.

Another feature of Lazarus' theory that distinguishes it from other models of coping is his distinction between coping responses which alter the stressful situation itself, and those that are designed to alter the emotional response to the crisis. It is thus possible that, under certain situations, one may achieve one of these coping functions at the expense For example, an of another (Silver & Wortman, 1980). individual may reduce stress by denying initial symptoms of lung cancer, thus delaying treatment and reducing the chances of a favorable outcome. As intense emotional distress may impede coping or problem-solving efforts, it is important to pay attention to responses which palliate an individual's emotional reaction. Coping responses, then, that reduce the individual's level of emotional distress to a moderate level may be adaptive or functional (Silver & Wortman, 1980).

While Lazarus offers a coping theory which broadens the view of individual responses to stress, the theory is not without its faults. His conceptualization of coping is based on the premise that individuals are able to accurately report the coping strategies which they employ. This assumes that coping responses are always conscious and therefore direct assessments can be made (Kessler, et al., 1985).

Another criticism of Lazarus' model is that it is lacking in predictive power. Once the appraisal process has been completed, there is no way to determine which particular emotional response will predominate or which coping mechanism

will be chosen. The theory fails to indicate how the components of the coping process influence each other and how they relate to the ultimate adjustment (Silver & Wortman, 1980).

Lazarus maintained that there is continuous interaction among cognitions, emotions, and coping strategies by which each individual is influenced as he/she encounters particular stressors. This model, with its allowance for flexibility and reappraisal of reactions to stressors, lends itself well to the study of coping with loss following a long-term illness.

Irrevocable losses provide for an excellent arena in which to examine the basic processes of stress and adaptation (Wortman & Silver, 1987). Bereavement following loss from a long-term illness such as cancer is unique as variables such as uncertainty of outcome, the progressive deterioration of the disease, economic factors, and intensive treatment allow for an intense accumulation of stress. The long-term course of progression of the disease also provides both the patient and the family with the opportunity to anticipate the loss, a situation termed anticipatory grieving (Koocher, 1986). These two factors, the nature of the disease and the opportunity for anticipatory grieving, allow for the application of Lazarus' paradigm of stress coping which focuses on cognitive, emotional, and behavioral appraisal and reappraisal of a stressful situation. This society's emphasis on the idea of grief at time of death tends to ignore the full range of

emotions that may be experienced by the bereaved person. The cultural directive to mourn, therefore, may be dysfunctional in that it may generate a set of discomforting feelings and attitudes when what was intended was the amelioration of emotional stress (Fulton, 1970).

This study examined spousal responses following a death by cancer. Societal expectations and clinical lore have outlined an assumed pattern of loss responses which limits the expression of the wide variety of feelings which may be present. Anticipatory grieving as well as a variety of other factors which combine to make a death from cancer unique were examined utilizing the cognitive appraisal paradigm outlined by Lazarus. This study specifically examined unconventional reported responses such as relief as a reaction to a loss of a spouse following a death resulting from cancer

<u>Definition</u> of Terms

Anticipatory grief. Anticipatory grief is a process characterized by cyclical periods of mental anguish and feelings of loss which begin at the time of an initial cancer diagnosis, in expectation of the deprivation of the significant relationship and social role, and continue through the expected death of a loved one (Welch, 1982).

Bereaved. Bereaved refers to the status or role held by one who has experienced the loss (usually by death) of a

family member or significant other. Thus, a survivor may be bereaved and yet not grieve in the classical sense (Fulton, 1977).

<u>Cancer</u>. Cancer refers to the large group of neoplastic diseases which are distinguished by the uncontrolled growth and spread of abnormal cells.

<u>Cancer related death</u>. A death which has occurred as a result of a cancerous disease process.

Cognitive appraisal. Cognitive appraisal refers to the assessment of a stressor involving the continuous interactions among cognitions, emotions, and coping strategies. This allows for flexibility and reappraisal of reactions to stressors (Lazarus, 1981).

<u>Grief</u>. Grief refers to the subjective, emotional responses to a loss.

<u>Relief</u>. Relief refers to the removal or lessening of something painful, oppressive, or distressing.

Research Questions

This descriptive study collected data which focused primarily on the following four areas of research interest:

1) What self-reported changes in thoughts and feelings about spousal loss occurred over the course of the disease process as a result of the nature of the disease?

- 2) What self-reported behaviors were utilized in anticipating the death of the spouse?
- 3) What self-reported changes in thoughts and feelings about spousal loss occurred over the course of the disease process as a result of anticipating the death of the spouse?
- 4) What were the primary self-reported responses to the death of the spouse following a cancer related death?

Sample and Data Gathering Procedures

The population of this study consisted of thirty men and/or women whose spouses had died as a result of cancer within the past two and a half years. Due to the sensitivity of the subject, a nonprobability sampling technique was utilized. The volunteers who participated in this study were reached through a variety of sources. Thirteen of the subjects' spouses had participated in the Medical College of Virginia's Cancer Rehabilitation and Continuing Care Program. Seventeen of the subjects (including the six who comprised the pilot study) were obtained via a network sampling technique. Participants in the study were asked to respond to a one hour long, in-home interview which was conducted by the researcher (Apppendix A).

Limitations of the Study

The findings of this study must be considered within at least five different areas of limitation. Due to the nonprobability sampling technique which was used caution must be utilized in attempting to generalize to all persons who have experienced a loss. The generalizability of the study is further limited by the fact that only spousal responses were Thus, loss responses of children, grandparents, and/or siblings can not be suggested from these findings. Thirdly, most respondents resided within a twenty mile radius of an urban setting and had available to them health care resources which are unique to the area. Thirteen of the participants had participated in the Medical College of Virginia's Cancer Rehabilitation and Continuing Care Program which provides a variety of supportive services including counseling. Responses to loss may differ for those who have received supportive counseling and those who have depended on family and social networking for support. Finally, despite the careful design which was used in the study to insure confidentiality, participants may have felt awkward disclosing their emotional and cognitive responses to the loss of a spouse as society mandates certain behaviors to be appropriate for this situation. Thus, to some degree, the sensitivity of the material may have limited the subject's willingness to respond openly.

Ethical Considerations

The ethical considerations which were incorporated into the study fell under three main categories. First, informed consent was obtained from all participants which included the knowledge that the study was designed to examine responses to loss, the time commitment needed from each subject, the freedom to refuse to participate in the study, and the freedom to withdraw from the study at any time. Subjects were also informed of and consent granted for the audiotaping of the interview itself. All taped conversations were erased following verification and substantiation of the data.

Secondly, the investigator made it known to the subjects that their identities would be held in confidence. All records and published reports of the data were reported as coded material.

Finally, the results of the study were made available to interested subjects. Also, follow-up counseling through the Medical College of Virginia's Cancer Rehabilitation and Continuing Care program was made available to interested subjects following the interview, if needed.

The research design met the qualifications for exemption from review by the Virginia Commonwealth University's Committee on the Conduct of Human Research. However, consent was requested by the attending physicians of the subjects whose names were procured from the Medical College of

Virginia's Cancer Rehabilitation and Continuing Care Program prior to soliciting their participation for the study. The design was also submitted to the investigator's dissertation committee as well as the Human Subjects Review Committee at the College of William and Mary.

CHAPTER TWO

<u>Historical Overview</u>

Historically, theories dealing with bereavement have not focused on cognitive appraisal and reappraisal of the loss. One of the most influential approaches to the study of loss has been the psychoanalytic model of bereavement based on Freud's 1917 publication of "Mourning and Melancholia" (Freud, 1957/1917). Freud believed that the major task of mourning was the gradual relinquishment of the psychological attachment to the deceased. The theory holds that this surrender of the love object involves an internal struggle as the individual experiences intense yearnings for the deceased yet is faced with the reality of the absence of the loved one. Inevitably this struggle is difficult and involves turbulent emotions. The bereaved may, initially, deny the loss, become preoccupied with thoughts of the deceased, and lose interest in the outside world. As thoughts and memories are reviewed, the links to the deceased person are gradually withdrawn. The mourning period is concluded when the individual is said to have worked through the loss and liberated him- or herself from the intense emotional attachment to the unavailable person. When the bereaved person once again has the psychic energy required to invest in new relationships then, according to Freud, the process of mourning is completed (Wortman & Silver, 1987).

Thus according to the psychoanalytic viewpoint, mourning is seen as an instinctual and biological process. Influenced by the psychoanalytic view, Deutsch (1937) presented observations from her cases in which a complete absence of the manifestations of mourning were apparent. This variation from the norm is seen as evidence of pathology as the unresolved grief was thought to manifest itself in some manner, from feelings of guilt to criminal behavior.

Lindemann (1944) observed the 101 survivors of the Coconut Grove Fire in Boston and postulated a distinct phenomena which occurs from sudden, unexpected loss. From his research he concluded that when an individual suffers the sudden unexpected loss of a loved one, profound physiological, psychological, and behavioral reactions can be expected. Examples include confusion, crying, digestive disturbances, searching for the deceased, and in extreme circumstances, attempts to injure self as a result of overwhelming feelings of guilt or shame. These and other psychological reactions to loss have been indelibly impressed upon society as being expected mourning responses (Fulton, 1987).

Robert Fulton (1987) examines Lindemann's classic work from historical and psychosocial perspectives. According to Fulton's critique, Lindemann based his observations on the survivors of the Coconut Grove Fire which occurred one year after the Japanese invasion of Pearl Harbor which resulted in the deaths of over 2,200 people. No studies of the survivors

of Pearl Harbor were made, therefore, the Coconut Grove tragedy held much meaning as the deceased were young men and women in the United States in 1941. For the most part they were the sons and daughters of wealthy parents who were home celebrating a Thanksgiving holiday. What the Coconut Grove Fire did was to bring the war home to the United States. "Before the advent of television the Fire made the distant trauma of Pearl Harbor an immediate living reality. The fire was a flash experience, similar to the Kennedy assassination and had the same impact on many of us old enough to remember it. It is indelibly imprinted on our minds" (Fulton, 1987, p. 247). Thus, from this singular, highly emotional historical event comes a theory on which much of our present day expectations of mourning are based.

Parkes (1970) also examined Lindemanns' 1944 observations and conclusions regarding loss responses. His critique included the fact that Lindemann's publication failed to provide figures which show the relative frequency of the syndromes which he described and does not state how frequently or at what point following the loss that the interviews were conducted. Thus, our present day expectations of bereavement behaviors are based on data which was based on a singular, highly emotional event and which lacks demographic information as well as control for other forms of variance.

Another theoretical framework which has been important in the current understanding of reactions to loss is the

attachment model of grieving originally developed by Bowlby (1980). As he developed his framework, Bowlby drew heavily on psychoanalytic thought, from the developmental literature regarding children's reactions to separations, and from the mourning behaviors of animals. Bowlby believed that individuals normally form attachments, initially between parent and child and then between adults. Attachment behaviors are considered instinctual. Bowlby maintained that when the attachment bonds are threatened, powerful attachment behaviors are activated such as clinging, crying, and angry protests. In contrast to Freud, Bowlby suggested that the biological function of the behavior is not withdrawal from the lost object, but rather, reunion (Wortman & Silver, 1987).

Bowlby (1980) identified four phases of mourning. Phase one is characterized by a sense of numbness followed by a period of yearning and searching in which the bereaved may show indications of a strong urge to uncover, find, and be reunited with the lost person. This phase may be characterized restlessness, by anger, general and The behaviors aimed at reestablishing the irritability. attachment bond usually cease, over time, and individuals enter the third phase of mourning. This phase characterized by giving up the attempts to recover the deceased. The bereaved individual may experience depression and have difficulty focusing on the future. bereaved individuals enter the last phase, in which they are

able to dissolve the attachment to the deceased and start to establish new connections with others (Bowlby, 1980).

Perhaps the most well known and accepted stage model of emotional response to loss is that of Kubler-Ross in her highly influential book, On Death and Dying (1969). Kubler-Ross identified five stages of emotional response to anticipated loss: denial, anger, bargaining, depression, and finally, acceptance. In Kubler-Ross' estimation, each year her stage theory is taught in 125,000 courses in colleges, seminaries, medical schools, hospitals, and social work institutions (Rosenbaum, 1982).

Kubler-Ross outlined her five stage process of dying based on observations of 200 patients. The usefulness of her work is limited, however, by its ambiguity, which is in large part the product of the highly subjective method in which the observations were made and interpreted. Based on the interview protocols Kubler-Ross has presented as support for her findings, it appears that she depended more on intuition to define the stages than any systematic pattern of patient responses (Schulz & Aderman, 1974). The resulting publication, On Death and Dying, has had a major impact on the societal as well as personal expectations of mourning. Although this and other stage models of response to loss are widely accepted among mental health professionals, there is little empirical evidence to support them (Silver & Wortman, 1989).

In contrast to the stage or phase theorists, Worden (1982) postulated four tasks that an individual must work through in an effort to resolve issues surrounding loss. The term "task" implies that one must actively work at ones grief and not be passive in the process. It is not the passage of time that will heal the emotional wounds, but rather how the individual uses time to cope with the loss.

Worden's first task involves accepting the reality of the loss. The grieving individual must come full face with the reality that there has been a loss by death. The opposite of this acceptance is not believing that a death has occurred and this will contribute to a sense of denial. Not only must one not deny the reality of the loss, but also not deny the meaning of the loss. Additionally, secondary losses must be acknowledged. These are the physical and/or symbolic losses that develop as a consequence of the death.

The need to experience the pain of the loss is Worden's second task. The individual must experience the hurt, pain, sadness, fear, guilt, anger and any other feelings in order for the grief recovery process to truly begin. A denial of these feelings may result in an unresolved grief reaction.

The third task outlined by Worden is the necessity to adjust to an environment without the deceased. The full impact of this task frequently does not emerge until three to six months after the loss. Not addressing this task is essentially the same as not adapting to the loss. When coping

skills are not developed, emotional isolation and social withdrawal may ensue.

The final task involves the withdrawal of emotional energy from the deceased and the reinvesting of this energy into another relationship. This task may be hindered by the inability to let go of the past relationship which disallows for the formation of new attachments.

Worden (1982) states that what the grieving individual needs most is acceptance and nonjudgemental listening. This allows for the expression of emotions and the necessary review of the relationship with the deceased. Unlike stage or phase theories of loss recovery, Worden emphasizes the process which is involved in the work of grieving. This model permits the individual the opportunity to explore the plethora of feelings which may arise as the result of a loss by death.

Review of the Literature

Due to the limited amount of research available regarding unconventional reported responses to loss, several related areas of research will be reviewed. Areas to be presented include reactions to loss following a long-term illness such as cancer and the effect of anticipatory grief on reactions to loss.

Reactions to Loss Following Long-Term Illness

Koocher (1986) details the unique characteristics involved in coping with a death from cancer. Although the survival statistics for many types of cancer have improved over the past ten years, the media often presents confusing messages to the public concerning the terminal nature of the disease along with reports of potential new cures. The subsequent emotional impact on the family and the patient is often similar to that of "learned helplessness" in which the individual patient comes to believe that nothing he/she does will alter the outcome.

The intensive treatment regimen which accompanies cancer is another unique factor to be considered. Surgical removal and radiation are commonly used cancer treatments with potentially mutilating impacts. Some types of radiation treatments may lead to the growth of a second tumor a decade or more following the original treatment (Koocher & O'Malley, 1981). Systemic chemotherapy remains the primary treatment for cancer. Often the complications of treatment are seen as worse than the original disease (Koocher, 1986).

Adverse economic factors also cause stress and depression for cancer patients and family members. The cost of hospitalization, physician's fees, medication, special equipment, and lost pay cause significant problems for the adult cancer patient (Hodgson, 1984). Although this

particular factor is often ignored when one considers the stress of a disease such as cancer, its impact on the patient and family cannot be overlooked.

Individuals who die from cancer rarely do so immediately following the diagnosis and rarely as a direct result of the malignancy. The usual cause of death is more likely to be failure of an organ system or progressive infection. The course of illness for a disease such as cancer is prolonged and marked by deterioration, pain, frequent hospitalizations, and reliance on others to have basic needs met. Symptoms related to the disease itself or to the treatment result in significant problems with nutrition such as anorexia or nausea. Thus, in the terminal phase, the patient is likely to be fatigued, cachectic, and uncomfortable (Koocher, 1986). Therefore, reactions to a loss which result from a death from cancer need to be approached from a multi-faceted perspective in order to allow for a variety of responses.

Natterson and Knudson (1960) studied patterns of death fears and responses to loss of 33 terminally ill children and their mothers. The children ranged in age from 0 to 13 years and the mothers from 24 to 45 years. All subjects were followed at the City of Hope Medical Center during the time period of June 1956 to August 1958.

The majority of the mothers (N=19) reacted to the progression of their child's disease in a similar manner. Toward the end of the child's life the mothers displayed a

calm acceptance of the fatal outcome. "There was almost no tendency to weep. In some instances, the mother expressed a wish that the child would die so that his suffering would be ended" (Natterson & Knudson, 1960, p. 462). When the children of these mothers actually died, they expressed feelings of calm sorrow and relief.

Almost half (N=14) of the 33 mothers involved in this 1960 study responded to their children's disease process with anxiety and hysteria. Natterson and Knudson speak to the fact that the majority of women who reacted less calmly at the death of their child knew about the child's terminal illness for less than four months.

The mothers whose children survived for more than four months following the time of initial diagnosis tended to follow a three phase response (initial, intermediate, and terminal) following the prognosis. During the initial phase, denial appeared to be the most prominent response while active and realistic efforts to prolong the child's life were typical responses of the intermediate phase. The terminal phase was marked by an acceptance of the death of the child and by the wish for the death to come.

Natterson and Knudson (1960) detail the reactions 33 children and their mothers to the fear of death and reactions to death. The authors isolate length of illness as an important variable to be considered in a mother's response to a child's terminal condition. Thus, the mothers who had at

least four months warning of their child's death (between the prognosis and the death) went through a variety of responses which led to a more calm acceptance of the death. The authors also examine the element of relief and its importance as a response to loss following an illness of more than four months.

Chodoff, et al. (1964)studied the adaptational techniques and coping strategies utilized by a group of parents of children with a malignant disease. The reported observations were made over the course of two years of 46 parents whose children were being treated for a neoplastic disease, mainly leukemia, at the Medical Branch of the National Cancer Institute. The parents are described as falling within the middle and lower middle economic class, being predominately caucasian and Protestant, and coming from both urban and rural backgrounds.

Although each parent responded to the stress of having a child with a terminal disease in a unique manner, a fairly uniform sequence of adaptation techniques were observed by the authors. The reaction to the diagnosis was usually received with a feeling of unreality. However, as the child's disease progressed, as the condition of other children grew more critical, or as deaths occurred, the parent became more vulnerable to the emotional impact of the fact that their child was going to die. This process constituted the greater portion of the period of the child's illness and allowed for

the development of individual coping styles. As the parents were faced with the reality of the child's death, there was a change from a purely intellectual stance to an emotional acceptance of the fatal nature of the cancer. The child's death was almost always taken calmly, almost with relief (Chodoff, et al. 1964).

This 1964 article is one of the first to focus on the ability of individuals to function effectively during times of stress. It is unfortunate that a detailed description of the population and a sample of the interview techniques are not provided as it is difficult to objectively rate an individual's ability to cope. Also, the sample was comprised completely of caucasian parents which does not allow for variety of response due to cultural influences. Despite these limitations, Chodoff, et al. focus on the adaptation of parents to an illness and death of a child from cancer and identify relief as a common response to the loss.

Friedman (1967) describes the physiological responses as well as the psychological responses of the above mentioned 46 parents of terminally ill children. The psychological adjustment of the parents of the leukemic children was studied in association with their adrenal cortical secretion levels. The 17-hydroxycorticosteroid levels have been correlated with psychological stress. The highest levels are generally observed in individuals who have judged themselves to be ineffective in their coping responses. The urinary 17-

hydroxycorticosteroid excretion rates in the 46 parents of leukemic children were studied over an eight-month period. The author notes that the highest adrenal steroid level for many parents was at the time of the child's first relapse. The child's actual death did not result in a rise in the 17hydroxycorticosteroid excretion rate indicating that this event was not cause for elevation in this indicator of stress. Friedman attributes this phenomenon to the long term nature of the illness which allows for anticipatory grief. "It was but the final step, is how one parent described the death of her child. If anticipatory grieving has taken place, most parents have prepared themselves for this terminal event and, to some degree, have rehearsed how they will act. Unlike parents of children who have unexpectedly died, parents of children with prolonged illness usually have control over their expression of grief" (Friedman, 1967, p. 503). The author presents case examples of coping techniques of these parents of children with terminal illnesses as well as data pertaining to the 17hydroxycorticosteroid levels.

Friedman (1967) expands on the concept of coping with a terminal disease by presenting objective evidence of stress levels of parents of terminally-ill children during the course of the disease and the child's death. The sample of 46 parents presented in this article is the same as in the article by Chodoff et al. (1964) and again the population is not adequately described. It would be difficult to generalize

these findings to a population from an ethnic background other than caucasian. It is also not known if other variables (such as medication) would influence 17-hydroxycorticosteroid levels. Despite these limitations, Friedman offers an objective measurement of the levels of stress for parents of terminally-ill children and his findings indicate a decrease in stress at the time of the child's demise.

Contrary to the findings of Chodoff et al. (1964) and Friedman (1967) is the report by Vachon, et al. (1977) concerning widows' perspectives on the final stages of cancer. The authors present an overview of living with cancer from a widow's perspective, compare the illness experience of cancer with that of chronic cardiovascular disease, and briefly discuss the bereavement period.

The data was collected from a study of 162 women whose husbands had died from cancer in one of seven hospitals in Toronto. Included in the sample of 162 were 73 women whose husbands had died from cancer at the age of 67 years or less. The median age of the women involved in the study was 53 years.

A trained interviewer with a background in sociology administered the interviews and questionnaires at 1 to 2 months following the death of the spouse. Items on the questionnaire included demographic data, as well as information on the final illness, perceptions of social support and factors related to bereavement.

Forty-nine percent of the men with cancer in Vachon, et al.'s study had a period of final illness of more than six This period of final illness was rated as being months. either extremely or very stressful by 81% of the widows. When a death from cancer was compared with a death from chronic cardiovascular disease, the women whose husbands had died from cancer seemed to perceive the final stage as much more died stressful than those whose husbands had The authors state that the cardiovascular deterioration. former felt impotent in dealing with their husband's illness. This feeling of helplessness continued as they watched their husbands deteriorate and as they felt they could only provide emotional support as he coped with pain and the threat of impending death. Additional stress was felt as they often had to stand by helplessly as their husband expressed a longing The wives also for death as a release from the suffering. came to wish for this end. There were frequent feelings of guilt as the widows felt that they had not given enough emotional support to their husbands and for wishing that he would die so that the suffering would be over for everyone.

At the time that the data was gathered for this research 38% of the women whose husbands had died from cancer, compared with 23% of the other widows, reported that they felt worse than at the time of their husband's death. At the same time 34% of the women whose husbands had died of cancer, compared with 19% of the other widows, felt as if their health was

poor. Perhaps there is a summation of the stress of bereavement and the debilitating effect of the nature of the terminal illness.

The women whose husbands had died from cancer reported persistent nightmares concerning the final illness and identified the following as content of those nightmares: pain, disfigurement, facial contortions, and noises. Most, but not all of the women interviewed by Vachon, et al., eventually improved and at the end of a 2 year study by the same investigators claimed that the stress of living in the shadow of a terminal disease was far worst than the stress of widowhood.

Vachon et al. (1977) provide a detailed description of the sample studied along with a summary of the type of information requested in the interview. The investigators fail, however, to inform the reader as to how the sample was procured, if the patient had died at home, and if psychological support was available to the patient and wife during the illness. Again, it is difficult to measure coping due to its subjective nature. This study does provide valuable information regarding widow's perspectives of the terminal stages of cancer and compares the illness experience of cancer with that of a chronic cardiac disease. The study also describes a potential reaction to the terminal stage of cancer as that of wanting the situation to end and also mentions the

outcome of this feeling as that of guilt during the early bereavement phase.

The psychosocial management of families with an acutely and/or terminally ill cancer patient are discussed in a 1978 article by Cohen and Wellisch. Two case studies are presented which identify the stressors facing a family dealing with a terminally-ill member. Cohen and Wellisch speak to the medical advances which have changed cancer from an acute to a chronic catastrophe and to the fact that "... the family must deal simultaneously with the sudden impact of the news of cancer as well as the slow motion movement of the disease itself; this places everyone in a physical and psychosocial limbo" (Cohen & Wellisch, 1978, p. 561). The knowledge of the potential death keeps the family in a state of imbalance and causes the family to struggle to maintain its equilibrium.

The intent of the article is to provide guidelines for family therapists who intervene with cancer patients and their families. It adds to the body of literature regarding the impact of cancer on family systems and speaks to the feelings of grief, anger, and ambivalence which may arise in families facing this dilemma.

Spinetta. Swarner, & Sheposh also studied family coping in their 1981 article. Their focus, however, was on the adaptation of the family after the death of a child following cancer. The goals of the research included the identification of families as effectively or ineffectively coping past the

death of a child and the influence of parental handling of the diagnosis, illness, and treatment regimen on the levels of postdeath adjustment.

A semistructured interview was administered to 23 sets of parents whose child had died of cancer no more than three years prior to the study. Of the families contacted, only two sets of parents refused permission to participate in the study. The authors detail the interview schedule, the manner in which the participants were interviewed, and how and by whom the responses were rated.

The majority of the families were able to return to a semblance of normal activities, were able to reinvest in life with some positive feelings and zest, and were content that they had done all that they could for the child when he or she was alive. It is interesting to note that unresolved feelings persisted with siblings in the majority of the families. These symptoms included crying spells, health fears, feelings of remorse and guilt, and refusal to discuss the deceased sibling, even after 2 or 3 years following the death.

An analysis was also performed to examine the relationship between length of time between death of the child and the interview. There was no support for the belief that there would be a higher level of postdeath adaptation for those parents whose children had been dead for a longer period of time. The length of grieving time alone, then, does not seem to be related to the postdeath adaptation level.

The duration of the child's illness with postdeath adaptation levels was also analyzed. One would expect that the parents whose children were ill for a longer period of time would have had more of an opportunity for anticipate and prepare for the death and would perhaps be better able to cope with the loss. Spinetta et al. report a trend in this direction but also speak to the fact that the results were not statistically significant. The age of the child at death was not related to parental long-term adaptation levels nor was the gender of the child.

The parents who were best adjusted after the death of a child following cancer were those who a) had a consistent philosophy of life during the illness, b) had a viable and ongoing support person to whom they could turn to for assistance, and c) had given their child the information and emotional support needed by the child during the course of the illness. The families studied in the Spinetta et al. article expressed the positive feeling that the crisis had lead to family cohesiveness and a positive redefinition of values. These parents demonstrated that families can adjust to life without their child and that pathology and maladjustment are not the inevitable outcomes following the death of a child from cancer.

This well written article presents methodological details which would enable one to repeat this study if one so desired. The findings add to the body of literature regarding loss

reactions following a death from cancer and support the notion that families can adapt to the death of a child. Also of importance are the results of the analysis regarding length of time from the death of the child until the interview, duration of the illness, age of the child, and gender of the child on the postdeath adaptation of the parents.

Rando (1983) studied 54 parents whose children had died from cancer. The experiences and adaptation patterns of the parents were examined from 2 years to 3 years following the death. The sample selection procedure is well documented as well as the methodology. The mean parental age was forty years and the predominant racial background was caucasian. All interviews took place in the subject's homes. The sources of data for Rando's research include The Grief Experience Inventory, the Structured Interview, the Parental Experience Assessment Form, and the hospital medical charts.

Rando had anticipated that the successful resolution of past losses would predict a more favorable adaptation to loss. It was found, however, that high Subsequent Adjustment (as measured by the Parental Experience Grief Form) was associated almost twice as often with low previous loss as with high previous loss. The implication for this finding is that previous loss experiences are associated with poorer bereavement outcomes. Related to this finding is the implication that previous losses may inhibit anticipatory grief behaviors, 50% of the parents in the low anticipatory

grief group had high previous loss as compared to only 31% on the parents in the high and medium anticipatory grief groups in this study. It seems as though previous loss experience is related to poorer bereavement outcome. Rando, however, does not detail the situations concerning the previous losses. The former reactions to loss may influence the current response.

Rando also examines the relationship between parental preparation at the time of death and parental Subsequent Adjustment following the death. When the length of illness is short the parents seem unable to adequately prepare themselves well. When there is a long-term illness, (longer than 18 months in this study) the stress associated with it may influence against adequate preparation for the death. "It is possible that the long and arduous experience of such an illness saps the parents of their ability to cope as effectively as desired and thus their ability to be appropriately prepared at the time of death is compromised, as is their ability to subsequently adjust" (Rando, 1983, p. 10).

Another variable of import which was examined by Rando is that of length of time since the death and the Subsequent Adjustment of the parent. Her findings do not support the previous research which indicates that bereavement symptoms decrease over time. The findings of this 1983 study indicate that during the 3rd year of bereavement the parent's response

shifts from a positive to a negative direction. A variety of possibilities for this negative shift are presented.

Anticipatory grief was examined in relation to parental preparation and grief responses. Rando reports that parental preparation increased directly as the amount of anticipatory grief increased. The more anticipatory grieving completed prior to the death, the less abnormal grief was present following the death. Abnormal grief is not operationalized in this study thus these findings are difficult to interpret.

This 1983 study by Rando does add to the body of literature concerning parental responses and adaptation to loss. The parental responses studied were primarily those of caucasian parents which does not allow for the varieties of responses possible based on different ethnic backgrounds. The validity and reliability of the two measurement tools utilized in this study are not known which makes it difficult to interpret the findings.

Summary

The available research concerning reactions to loss following a death from cancer provide for a variety of findings. There are contrasting results regarding adaptation to the loss following a death from a long-term illness. The majority of the research in this area, however, does indicate

that there is a sense of relief at the time of death and potential for positive adaptation to the loss.

The Effect of Anticipatory Grief on Reactions to Loss

The term anticipatory grief is generally used to describe the grief an individual may feel before the death of a significant other. Lindemann (1944) was perhaps the first person to have utilized the phrase "anticipatory grief" at the close of his article, "Symptomatology and Management of Acute He observed that in addition to grief responses Grief". following separation by death there was grieving anticipation of "possible death" as a result of wartime separations. Thus the threat of death or separation may initiate a bereavement reaction. He illustrated this response by providing an example of a soldier who returned home from active duty to find that his wife no longer loved him and had demanded a divorce. Lindemann interpreted the wife's action as the work of anticipatory grief done too effectively. seems that the wife had emotionally detached herself so completely that she no longer was able to invest emotionally in her relationship with her husband. Thus, it appears that the advance preparation for loss which is provided by anticipatory grieving is not without its cost. While it may serve as an emotional safequard should death occur, it may

interfere with continued involvement if the health status of the loved one returns to normal (Rando, 1986).

The concept of anticipatory grief is included in this study as an attempt to understand the experience of grief following a loss due to cancer. The long-term nature of the disease allows time for the processes of primary appraisal and reappraisal. This cognitive assessment over time may influence one's reaction to the loss.

Responses to loss following a death from cancer have previously been reported by Chodoff, Friedman, and Hamburg (1964) and Friedman (1967). Friedman, Chodoff, Mason, and Hamburg (1963) utilized the same sample to explore behavioral patterns of parents who were anticipating the death of a child. The descriptive data for the 46 subjects included age, education, income, residential characteristics, and religion. The authors do not indicate the ethnic backgrounds of the parents who participated, a variable which may influence one's style of grieving.

The period of time spent observing the parents of terminally ill children ranged form approximately one week to eight months. Interviews, observations, and nurses' notes were utilized in this study. The primary focus of the interviews concerned the parent's perception of the child's illness and clinical course, the defense mechanisms used by the parents to protect themselves from the stressful

situation, and the parent's ways of dealing with the multitude of problems which arise when caring for a seriously ill child.

Friedman et al. (1963) refer specifically to the anticipatory grief responses of the 46 parents. The amount of anticipatory grief varied among the individual parents, and, in a few, was never obvious at any time during the study. In most, however, the process of grieving was already apparent by the fourth month of the child's illness and was frequently paired with the first acute episode in the child's disease.

The signs and symptoms of anticipatory grieving were not as well defined as the responses to acute grief as noted by Lindemann (1944). It was common, though, for the parents involved to complain of somatic symptoms, apathy, weakness, and preoccupation with thoughts of the ill child. The process of resigning oneself to the inevitable death of the child was frequently accompanied by statements of wishing "it was all over with". "The narrowing of hope and the completion of much of the grief work was described by one mother who stated: "I still love my boy, want to take care of him and be with him as much as possible... but still feel sort of detached from him" (Friedman et al., 1963, p. 621). Anticipatory grieving seems to be useful in preparing the parent for the eventual loss. The parents in this 1963 study who did not display such behaviors experienced a more prolonged and distressing reaction following the death of the child.

During the terminal phase of the child's illness the parents become increasingly involved in the care of the other children on the ward and would occasionally express a desire to return to a more normal life with the children remaining at home. In this situation, the eventual death of the child was generally taken calmly but with appropriate expressions of affect. Open expressions of self-blame or uncontrollable grief were the exception and there was usually some indication of relief at the thought of the child no longer suffering.

Follow-up observations of 18 parents seen three to eight months following the death of a child indicate that the bereavement responses following the actual loss of the child those responses of parents similar to who have are unexpectedly lost a child. The mourning usually became less pronounced, however, after three to six weeks. The parents in the follow-up study displayed a tendency for feelings of guilt and self-blame. It is possible that in some cases an unconscious or barely conscious wish for the relief of tension through the child's death during the terminal phase of the child's illness may have provided the impetus for these expressions of quilt.

One of the limitations of this study is the lack of clarification regarding the ethnic backgrounds of this sample which prompts one to question the external validity of the study. Also, there is no indication as to the type of questions asked in the interview thus making it impossible to

repeat the study. The study does provide information regarding the impact of anticipatory grief on loss responses of parents with terminally-ill children. The authors indicate that relief is a common emotional response to this loss and that follow-up observations of some of the parents in the study reveal guilt as a component of the bereavement period.

Lebow (1976) defines anticipatory mourning as the total set of cognitive, affective, cultural, and social reactions to the expected death felt by a patient and family. The definition is further narrowed to describe anticipatory grieving as the portion of anticipatory mourning involving the affective responses. Anticipatory mourning differs from other mourning processes in a number of ways. The element of uncertainty is an intrinsic element, the grief increases over time, and it is time-limited as it ends with the death of the patient.

Families experience a painful mixture of depression and anxiety as they anticipate the loss of a member. Plans and dreams that included the patient must be relinquished leaving the family feeling cheated and anxious about the now suspended future. There is concern and apprehension about the prospect of final separation, the altered lifestyle, and the ability to cope with the changing roles within the family. "The unpredictability of what each day will bring in the way of physical deterioration of the patient, the indefiniteness of his life expectance, and the stress of making decisions about

such matters as treatment and care compound the anxiety" (Lebow, 1976, p. 459). This condition of uncertainty also generates long-standing and unresolved issues within each of the members of the family.

With these issues in mind, Lebow presents two case studies of families with patients in the terminal stages of illness. Her thesis centers on the fact that it is usually more desirable to encourage greater family involvement than is commonly achieved during the final days of a terminally ill patient's life. This type of family involvement has led to improved coping in the mourning which follows the death.

Lebow's clients for presentation were chosen for study due to the inability of the medical staff to no longer control the progression of a terminal disease. After intensive evaluation by a social worker, the families were randomized into control groups and treatment-intervention groups. Family therapy was initiated with the intervention group. The goals for the therapy were to balance increased involvement with individuation.

This article provides a wealth of information concerning the tasks of anticipatory grieving and the therapeutic intervention required by families facing a loss of a member. It is of interest that Lebow does not report any data concerning the bereavement outcomes of the treatment-intervention group as compared to the control group. One also questions the ethical decision involved in not providing

treatment to the control group. The lack of demographic information concerning the samples and the poor methodology leads to questions concerning the validity and reliability of this study.

The impact of age and type of death on the intensity of widow's grief were examined by Ball (1976-77). She hypothesized that widows who experienced anticipatory grief would resolve their bereavement crisis in an easier manner than widows who experienced the sudden death of a mate. She also investigated the belief that younger widows would experience the effects of acute grief to a greater degree than older widows.

All widows who participated in the study were residents of Sacramento County, California and had been bereaved from six to nine months. Two hundred potential participants, whose names were procured via death certificate records, were sent a questionnaire and explanatory letter. Eighty widows successfully completed the questionnaire thus yielding a 41 percent rate of return for the study. Personal interviews were conducted with nineteen of the widows.

The questionnaire elicited basic social and demographic information about each widow as well a review of her grief symptoms. The grief symptom questions included the following possibilities: loss of appetite, sleeping problems, increased use of sleep or nerve drugs, suicidal thoughts, amount of irritability, tiredness, restlessness, and hallucinations of

the husband. The symptoms were measured on a one to five scale measuring from very slight to very severe. Also included was a scale which measured "overall grief reaction" and a question on the degree of recovery from the spouse's death which ranged from "completely" to "not at all". Social and demographic information was also obtained.

Ball operationally defined a sudden death as one which occurred less than five days from the onset of illness and was assumed to be a situation where no anticipatory grieving took place. Anticipatory grieving was assumed to have taken place with the widows whose husbands were ill for more than six days.

The widow's ages were divided into three groups: young age group (18-46), middle age group (47-59), and old age group (60-75). The mode of death and the age of the widows were set as components for the statistical analysis.

The results of Ball's research indicate that the age of the widow and also the mode of death of the husband were significantly related to the intensity of the grief response. The younger widow experienced a stronger grief reaction than the middle or older widow regardless of the mode of death. Her findings also indicate that a sudden death (no anticipatory grieving) was associated with a more intense grief reaction than the prolonged death (anticipatory grieving). A young widow experiencing the sudden death of her

husband (no anticipatory grieving) reported a more severe response than any of the other groups studied.

This well written article presents methodological details which would enable the study to be replicated. Ball's conclusions support the findings of other researchers (Natterson & Knudson, 1960, Friedman et. al., 1963, Welch, 1982) that anticipatory grieving assists in easing the process of grieving. However, the assumptions made by Ball that the length of the illness is the determining factor for the presence or absence of anticipatory grieving must be considered. It can not be assumed that anticipatory grieving behaviors will be present in a long term illness or that these behaviors will be absent in an illness experience which lasts for five days or less.

Welch (1982) defines anticipatory grief as a process characterized by cyclical periods of mental anguish and feelings of loss that began at the time of the initial diagnosis of a malignancy, in expectation of the deprivation of the significant relationship and social role, which continue through the expected death of a loved one. The purpose of Welch's study was to describe the experience of anticipatory grief in family members of cancer patients. She furthered attempted to identify those family members who were having difficulties processing feelings of unresolved grief.

A revised questionnaire originating from the Faschingbauer's Texas Inventory of Grief was completed by 41

family members of patients with cancer. Faschingbauer's original 26-item tool was reduced to 12 items based on questions appropriate for studying anticipatory grief. Subjects with high total grief scores were designated as having more problems dealing with unresolved grief.

Demographic data is included concerning gender, age, the relationship to patient, type of cancer being treated, and the type of treatment being administered. Welch utilized higher mean grief scores as indicators of unresolved grief.

The results of this study indicate that family members whose relative was being treated on a specialized oncological unit had higher mean grief scores. This result is contrary to other findings which support the notion that specialized units of care provide for the psychosocial needs of specific patient population.

Welch also reports on the concept of emotional rehearsal in anticipatory grief and the impact this has on the grief response. Her findings indicate that there are positive effects on unresolved grief responses (as measured by high grief scores) when correlated with previous experience with cancer in another family member. According to this study, even though families may have had a negative past experience with cancer, that experience may have provided them with information as to what changes to expect and to decrease the fear of the unknown. These findings are contrary to those reported by Rando (1983) which indicate that previous loss may

inhibit anticipatory grieving and thus result in poor bereavement outcomes.

Important considerations for future study are included in Welch's study on anticipatory grief reactions in family members of adult patients. It is unfortunate that important factors such as the reliability and validity of the Faschingbauer's Texas Inventory of Grief are not included. One must also consider the fact that Welch assumed subjects to have difficulty coping with unresolved grief reactions based on high mean grief scores. This is based on the premise that more intense grief responses are indicative of unresolved grief, a notion that is not supported by the literature on responses to loss.

The Center for Death Education and Research at the University of Minnesota examined the variety of grief reactions which correspond with different types of deaths. Home interviews and mailed questionnaires were used to survey 434 widowed spouses, 85 bereaved parents, and 39 surviving adult children. The findings of this study as it related to unexpected death of a child or spouse were similar to the reactions reported by Lindemann (1944). The reactions of the adult children to the anticipated death of an adult parent, however, were quite different. Contrasting the responses of the surviving spouses or parents involved in the study, the adult children replied to the questions in a controlled and rational manner. For the most part they reported no change in

attitude or behavior and no disturbance in life pattern. There were no reports of guilt or anger. Fulton (1987) speculates that the anticipation of the parents death had allowed for the discharge of feelings prior to the death and had obliterated the normally expected feelings. Anticipatory grief may serve to emancipate the survivors emotionally from the relationship prior to the actual death.

It is unfortunate that the original data from this important study involving almost 600 subjects is referenced only as a presentation of a paper in 1978. However, Fulton does provide useful information concerning reactions to the anticipated death of an adult parent as compared to unanticipated deaths of spouses or children.

Enlow (1986) provides an anecdotal account of the events surrounding the chronic illness of her mother and terms this long-term illness a "living death". She describes this situation as one which does not allow for a resolution of grief. According to the author, the process of anticipatory grief often follows stages not unlike those outlined by Kubler-Ross (1969). Schultz (1978) (in Enlow, 1986) describes the stages of anticipatory grief and identifies depression as the first phase. This anticipation of the loss allows for a period of time to practice the process of grieving.

If and when the depression stage is overcome, one moves into the stage of heightened concern for the ill person. This expression of concern is reflected in one's behavior toward

the ill person. Families who live close to the patient are able to participate in his/her care thus gaining reassurance that they have done all they can do for the loved one. Often, however, adult children are separated from their parents by great distances. A culturally imposed guilt develops as they are deprived of visible evidence of their support.

Enlow speaks to the necessity of moving beyond the depression phase of anticipatory grief by means of activating coping mechanisms which may be unappealing and counter to societal norms. Detachment is a coping response which requires that the individual separate from the patient and that energy be redirected toward more productive activities. Those who are not able to disengage from a patient who is terminal due to long-term illness often suffer from emotional and physical complaints. Thus, to move ahead to a healthy resolution of loss via the process of anticipatory grief perhaps involves behaviors which do not follow societal expectations.

This case study presented by Enlow does not provide objective data concerning the aspect of anticipatory grief in coping with loss. What it does provide, however, is a subjective account of one person's response to a long-term terminal illness. Stages of anticipatory grief are outlined as well as coping responses which may facilitate bereavement.

Summary

Research over the past two decades indicates that the variables anticipatory grief and long-term illness play an important role in determining reactions to loss and bereavement outcomes. However, the most current research available which focuses on these concepts is obsolete when compared to the advances in medical science which allow for longer lifespans for cancer patients. These advances, while providing for increased longevity, also increase stress as the treatment outcome becomes more uncertain. This research focused on anticipatory grief, long-term illness, and unconventional reported responses to loss which occur in this time of rapidly developing medical technology.

In addition to the need for research which focuses on loss reactions in the advent of increased medical knowledge of cancer treatment is the need to consider the differences in reactions to loss which occur due to cultural mores. Each of the research studies which reported demographic data utilized a predominately caucasian sample. The homogeneity of these samples limits the generalizability of the findings to more diverse populations.

The lack of an objective, reliable, and valid tool for measuring loss reactions is a major obstacle to conducting a study which focuses on bereavement responses. A semistructured interview was constructed by the researcher in

order to examine the relationships among anticipatory grief, a death which results from cancer, and to assess for the presence of unconventional reported reactions to loss.

The purpose of this study, then, was to investigate the relationships among these variables using a valid and reliable interview schedule. Kerlinger (1964) describes the interview as

probably man's oldest and most often used device for obtaining information. It has important qualities that objective tests and scales and behavioral observation do not possess. When used with a well-conceived schedule, an interview can obtain a great deal of information; it is flexible and adaptable to individual situations, and it can often be used when no other method is possible or adequate...Questions about hopes, aspirations, and anxieties can be asked in such a way as to elicit accurate information. Most important, perhaps, the interview permits probing into the context of, and reasons for, answers to questions (p. 467-468).

As the purpose of this research was to identify responses to loss, the structured interview technique is appropriate (Gordon, 1969). A realistic number of well thought out questions which followed a logical sequence were incorporated to compose the interview schedule. A series of open-ended questions were constructed to thoroughly explore the issues surrounding loss of a spouse following a cancer related death.

Almost all of the interviews took place in the subject's home. The investigator concurred with Rando's 1983 finding that participation in the study would be compromised if the subjects were required to return to the hospital in order to

participate. For many, the emotional attachments to the facility may have been too painful.

Chapter III

Population and Selection of the Sample

This study described reactions to spousal death resulting from cancer. The population for this study was composed of men and women who had lost a spouse following a cancer related death during the past two and a half years. Thirty spouses were contacted through the Medical College of Virginia's Cancer Rehabilitation and Continuing Care Program and through a network sampling procedure. All of the participants were volunteers.

The network sampling technique is useful in studies where it is difficult to locate the population (Brink & Wood, 1983). Network samples take advantage of the fact that all individuals have social networks. As people tend to associate with others who are similar to themselves, network sampling can be a very effective approach (Holm & Llewellyn, 1986).

To implement this sampling technique, the researcher initially selects subjects who are receptive and knowledgeable. After the subjects have completed the required research task, they are requested to introduce the researcher to subsequent individuals who meet the criteria for the study. With a network sample, receptivity problems are partially compensated for as some trust is established through introductions by a mutual acquaintance (Chinn, 1986).

Those subjects recruited through the Medical College of Virginia's Cancer Rehabilitation and Continuing Care Program were contacted following approval from their attending physician granting permission for their involvement in this study (Appendix B).

Procedure

Volunteers for this study were obtained in the following manner. The names of 41 spouses who met the criteria for this study were reviewed by both the counselor and the director of the Medical College of Virginia's Cancer Rehabilitation and Continuing Care Program as well as by the researcher. The appropriate sixteen attending physicians were then contacted by letter and permission to contact the potential subjects was requested. Eleven of the 16 physicians responded positively which provided the researcher with the names of 28 potential subjects. Eleven of the 28 potential subjects were not able to be reached by telephone due to changes which resulted either in unlisted telephone numbers or a move to a new city. The remaining 17 potential subjects were contacted by telephone, the study was explained, and they were invited to participate in the research. Four of the potential subjects were not willing to participate in the study. Thus, a total of 13 subjects were obtained from the Medical College of Virginia's Cancer Rehabilitation and Continuing Care Program.

Seventeen subjects (including the six which formed the pilot study) were obtained via a network sampling technique. The researcher personally knew of three spouses who met the criteria for the study. Following the interviews, all subjects were asked if they knew of other spouses who met the criteria for the study. By using this network sampling technique, the names of 17 potential subjects were identified. All 17 potential subjects were contacted via the telephone, the study explained to them, and an invitation was extended to them to participate in the study. Fourteen of the 17 potential subjects agreed to participate. In total, potential subjects were contacted by telephone and asked to participate in the study. Of the 37 potential subjects contacted, 30 agreed to participate thus resulting in a total response rate of 81%.

All subjects, with the exception of one who preferred being interviewed at a hospital, were interviewed in their homes and at their convenience. The interviews ranged from thirty minutes to three and a half hours in length with the mean length of time being one hour and forty-five minutes. Two of the subjects lived more than twenty miles outside of the urban southeastern city from which the majority of subjects were located.

The consent form (Appendix C) was read and signed by all participants. Subjects were also verbally reminded of their options to withdraw from the study at any time, to receive a

summary of the results of the study, and that all responses would be recorded anonymously. Following the interview, the participants were reminded of the counseling services available through the Medical College of Virginia's Cancer Rehabilitation and Continuing Care Program. This was done so as to provide referral services for any subject for whom issues surrounding loss may have arisen following participation in this study.

All of the interviews were audiorecorded. With the exception of one, all interviews were conducted with only the subject and the interviewer present. None of the subjects asked that the interview be stopped although two of the subjects asked permission to leave the room for short periods of time as they felt the need to compose themselves following emotionally laden responses.

<u>Instrumentation</u>

The interview schedule for this study was composed by the researcher which allowed for examination of the effects of anticipatory grief and cognitive appraisal on loss following a cancer related death. The interview was designed utilizing Backstrom and Hursh-Cesar's 1981 guidelines for effective interview schedule design. The following four research questions were addressed: 1) What self-reported changes in thoughts and feelings about spousal loss occurred over the

course of the disease process as a result of the nature of the disease?, 2) What self-reported behaviors were utilized in anticipating the death of the spouse?, 3) What self-reported changes in thoughts and feelings about spousal loss occurred over the course of the disease process as a result of anticipating the death of the spouse?, and 4) What were the primary self-reported responses to the death of the spouse following a cancer related death?

The interview schedule was based on Spinetta et al.'s 1981 interview design which utilizes questions devised in an open-ended manner. This type of schedule helps to prevent having the spouses give socially desirable responses. The open-ended construction of the interview also allowed the spouses to talk freely concerning their loss, providing a more thorough understanding of the issues surrounding loss response. By using this schedule, the limited response options of forced-choice-type instruments was decreased. The structure of the interview was presented with flexiblilty in an effort to make the interview a helpful or even therapeutic experience for the participants.

In addition to the open-ended questions which focused on spousal responses to a cancer related death, the interview schedule also included a variety of demographic questions. This portion of the interview requested information on variables such as age of deceased spouse at time of death, length of marriage, and type of cancer (appendix A).

The variables included in the interview schedule which pertained to changes in thoughts and feelings about spousal loss which occurred over the course of the illness as a result of the nature of the disease were derived from a variety of sources. Burish and Lyles (1983), Hodgson (1984), and Koocher (1986) delineate length of time of illness, physical deterioration, pain, uncertainty of the outcome, physical and psychological changes resulting from treatment, and financial concerns to be factors which are unique to a cancer related death.

Previous research findings by Humphrey (1986), Raether (1986), Rando (1986), and Fulton (1987) were incorporated to compile the list ulilized to answer the research question which focused on anticipatory grieving behaviors. Subjects were also offered the opportunity to acknowledge their own unique method of grieving in anticipation of the death of a spouse.

The final research question which dealt with selfreported responses to spousal death was developed by utilizing
a variety of sources. Previous research results of Worden
(1982), Staudacher (1987), and Rando (1988) were compiled to
form a list of common emotional responses to loss. Again, the
subjects were provided an opportunity to voice any other
emotional response(s) which may have been present.

A pilot study of the interview schedule consisting of six interviews was conducted to remove potential researcher

biases, strengthen the interview validity, and reveal inappropriate and/or ambiguous questions. Results of the pilot study were incorporated into the final draft of the interview schedule. As the results of the pilot study did not produce significant changes in the interview schedule, the pilot study interviews were included in the research sample.

Research Design

The design of this study was primarily descriptive as the purpose of this research was exploratory in nature. The variety of potential spousal responses to loss following a cancer related death preclude the use of a more rigidly controlled design. The existence and dimensions of spousal responses to loss were the focus of this research. Borg and Gall (1989) suggest that descriptive research of the type utilized in this research may provide important leads in identifying response alternatives for a given area of interest.

In addition to describing the responses of spouses to loss, the research attempted to establish preliminary relationships among the variables associated with a cancer related death and anticipatory grief behaviors. Correlational research involves measuring two or more variables and statistically determining the degree of relatedness between them. Borg and Gall (1989) suggest that correlational

research designs are appropriate when relationships among a number of variables within a single study are to be investigated. In this research correlation procedures were used to explore potential relationships between variables. No specific hypotheses were investigated.

Specific Hypothesis

Due to the exploratory design of this study, no specific hypotheses were appropriate. Instead, this study sought to provide information relevant to the following research questions:

- 1) What self-reported changes in thoughts and feelings about spousal loss occurred over the course of the disease process as a result of the nature of the disease?
- 2) What self-reported behaviors were utilized in anticipating the death of the spouse?
- 3) What self-reported changes in thoughts and feelings about spousal loss occurred over the course of the disease process as a result of anticipating the death of the spouse?
- 4) What were the primary self-reported responses to the death of the spouse following a cancer related death?

Statistical Analysis

The taped interviews were analyzed in the following manner: individual responses to interview questions were categorized according to type of response. Frequency distributions and percentages were used to describe subject responses to the interview questions. Demographic variables were reported using the appropriate descriptive statistics including mean, median, mode, range, and standard deviation.

Demographic information obtained from the interview was correlated with the descriptive data in order to examine relationships among a variety of variables, for example, length of illness, age of spouse at time of death, length of marriage, previous loss experience, and length of time since the death. Since the descriptive data was nominal the chi square procedure was used to determine the presence or absence of relationships between variables. A probability level of (.05) was used to establish the statistical significance of any relationships.

In an attempt to describe spousal reports of anticipatory grief, cognitive appraisal, and responses to loss following a cancer related death, verbatim reports of subjects' responses were also included. These verbatim reports provided insights into the spousal responses to loss which may not have been made evident by the descriptive and correlational data. The qualitative and quantitative data which was provided by this

study will add to the understanding of responses to spousal loss following a cancer-related death.

Chapter Four

Results

The purpose of this investigation was to describe spousal responses to a cancer related death. Anticipatory grieving behaviors and cognitive appraisal factors were included to provide a better understanding of possible loss responses following a long term illness. Unconventional loss responses were also studied and described.

The data presented in this chapter represent the results of thirty interviews conducted over a five month time period. All interviews were conducted with men and/or women whose spouses had died from cancer within the past two and a half years.

<u>Demographic Data</u>

Due to the size of the sample (N=30) interval level data were described using the mean, the median, and range of responses to provide an accurate representation of the sample. Nominal level data were described using frequencies and percentages of responses in each variable category.

Sixty percent (N=18) of the sample was composed of women and 40% (N=12) of the sample were men. The subjects ranged in age from 31 years to 89 years with a mean age of 61 years and a median age of 63 years. Ninety seven percent (N=29) of the

subjects were caucasian and three percent (N=1) were afroamerican.

Subjects also described themselves in terms of the length and the quality of their marriages. The mean length of time of marriage was 34 years and the median length of time was 39 years. The subject's marriages ranged in length of time from four years to 56 years.

In describing the quality of marital relationships, 80% (N=24) of the subjects reported that their marriages were primarily positive. Thirteen percent (N=4) of the subjects described their marriages as being neutral and seven percent (N=2) of the subjects described their marriages as being primarily negative.

The mean age of the subjects' spouses at time of death was 62 years. The median age of the subjects' spouses at time of death was 66 years, spousal ages ranged from 30 to 80 years at time of death.

The time since the subject's spouses' death (in months), the length of time from the spouses' diagnoses to the spouses' death (in months), and the type of cancer diagnosed were all described by the sample. The length of time since the death of the subjects' spouses ranged in time from one month to 30 months with a mean of 14 months and a median of 12 months. The length of time that the subjects were aware of their spouses' cancer diagnosis ranged in time from one month to 99 months with a mean of 28 months and a median of 15 months.

The types of cancer which the subjects' spouses were diagnosed with fell into ten major categories. These types of primary cancers are presented in Table 1.

Cancer of the lung was the most frequently (36.7%, N=11) reported cause of death. Breast and colon cancer were cited as the second most frequent (13.3%, N=4) causes of death followed by cancer of the brain and prostate (10.0%, N=3). Leukemia (3.3%, N=1), as well as, ovarian (3.3%, N=1), esophageal (3.3%, N=1), and liver (3.3%, N=1) cancer were the least frequently reported causes of death for this sample.

The types of cancer treatment that subject's spouses underwent during the course of their illnesses are described in Table 2. The combined treatment protocol of chemotherapy, radiation therapy, and surgery was the most frequently (43.3%, N=13) reported. Chemotherapy and radiation used together was the second most frequently (26.7%, N=8) cited treatment combinations followed by combinations of chemotherapy and surgery (10%, N=3). Radiation and chemotherapy as individual treatment protocols were identified by 13.3 (N=4) of the subjects. Radiation and surgery together and no treatment were cited as the least common (3.3%, N=1) treatment protocol.

Subjects also described the physical effects that the treatment modalities had on their spouses. These treatment effects are presented in Table 3.

The combined physical side effects of nausea, vomiting, fatigue, and hair loss were reported in 30% (N=9) of the

Table 1

Types of Primary Cancer

Type	Frequency	Percent
Unknown	1	3.3
Brain	3	10.0
Breast	4	13.3
Colon	4	13.3
Lung	11	36.7
Liver	1	3.3
Prostate	3	10.0
Ovarian	1	3.3
Esophageal	1	3.3
Leukemia	1	3.3

Table 2

Type of Treatment

Type	Frequency	Percent
Chemotherapy	2	6.7
Radiation	2	6.7
Chemotherapy and Radiation	8	26.7
Chemotherapy and Surgery	3	10.0
Radiation and Surgery	1	3.3
Chemotherapy, Radiation, and Surgery	13	43.3
No treatment	1	3.3

Table 3

Physical Effects of Treatment

<u>Effect</u>	Frequency	Percent
Nausea and Vomiting	1	3.3
Fatigue	6	20.0
Nausea, vomiting, and fatigue	6	20.0
Nausea, vomiting, and burns	2	6.7
Nausea, vomiting, fatigue, and hair loss	9	30.0
Nausea, vomiting, fatigue, hair loss, and burns	1	3.3
Other effects	2	6.7
No effects	3	10.0

sample. Fatigue and the combination of nausea, vomiting, and fatigue were each reported in 20% (N=6) cases. Ten percent (N=3) of the sample reported that their spouses experienced no side effects from their treatment protocol. Nausea, vomiting, and burns, as well as other effects were reported by 13.3 (N=4) of the sample. Ten percent of the subjects (N=3) reported that their spouses experienced no effects from treatment. Other effects were described by 6.7% (N=2) of the subjects.

In questions pertaining to the subject's loss history, 50% (N=15) of the subjects reported having lost only a parent to death. The loss by death of a parent and/or other significant person was reported by 33.3% (N=10) of the sample. The remaining five subjects (16.7%) stated that they had experienced losses by death of a sibling, a child, or a sibling and a parent.

When asked if other deaths by cancer had occurred, 70% (N=21) reported that they had had previous experience with a cancer related death. The loss of their spouse, was, for thirty percent (N=9) of the sample, their first experience with a cancer related death. Twenty seven percent of the sample (N=8) indicated that the previous experience or inexperience with a cancer related death affected how they responded to their spouses illness. Seventy three percent (N=22) reported that their previous experience or inexperience

with cancer had little or no influence on their response to their spouse's illness.

Subjects also responded to a question pertaining to the location of the spousal death. Sixty percent (N=18) of the spouses died at home, 36.7% (N=11) of the spouses died in a hospital, and 3.3% (N=1) died in a location other that a hospital or home.

All subject's spouses were hospitalized at some point during their illnesses. Sixty three percent (N=19) were located on a special oncology unit. Thirty seven percent (N=11) were hospitalized on a general medical/surgical floor. When the spouses were not hospitalized, 90% (N=27) of the sample stated that they were the primary caretakers at home for the spouse. Ten percent (N=3) of the subjects described others as primary caretakers for the spouse at home.

Summary of Demographic Data

The sample for this investigation was composed of 30 men and/or women whose spouses had died within the past two and a half years as a result of a cancer related death. The majority of the sample was caucasian. The subject's average age was 61 years and the mean length of time that they were married to their deceased spouses was 34 years. The majority of the sample described their marriages as positive.

The mean age of the spouse at time of death was 62 years with 14 months being the average length of time since death. The mean length of the illness was 28 months. Cancer of the lung was the most common cause of spousal death and chemotherapy, radiation therapy, and surgery together were the most practiced forms of treatment protocol. Nausea, vomiting, fatigue, and hair loss were the most frequently reported physical effects of the treatment.

Seventy percent of the sample stated that they had had personal experiences with cancer related deaths prior to their spouses illnesses. Seventy three percent of the sample indicated that their prior experience or inexperience with cancer did not affect how they responded to their spouses' illnesses.

The majority of the spouses died at home. All spouses were hospitalized for a part of their illness and most were housed on a special oncology unit. Nearly all of the subjects described themselves as the primary caretakers for their spouses during the illness.

Research Question Number One

Research question number one addressed the self-reported changes in thoughts and feelings about spousal loss which occurred over the course of the disease process as a result of the nature of the disease. The length of the illness,

possible physical deterioration, possible pain or discomfort, the uncertainty of the outcome, possible physical and/or psychological changes resulting from the treatment, and possible financial concerns were all incorporated in an attempt to describe how the nature of the illness affected changes in thoughts and feelings regarding spousal loss.

Widely varying responses were recorded as subjects described changes in their thoughts and feelings regarding spousal loss as a result of the nature of the disease. Responses were reviewed by the researcher and found to fall generally into the following four categories: 1) hope for recovery - realistic about disease outcome - wishing for death, 2) realistic about disease outcome - wishing for death, 3) hope for recovery throughout illness (no change in thoughts and feelings), and 4) pessimistic about outcome - difficulty accepting the reality of the death. These responses are summarized in table 4.

Responses such as the following were typical of the 23.3% (N=7) subjects whose thoughts and feelings followed the hope for recovery - realistic about disease outcome - wishing for death pattern. "At first I thought we had a chance but after the first radiation treatment I knew we were going downhill. It became a living hell and I was delighted when she died". Another subject stated "I was hopeful until two weeks before she died. Then the doctor told me she had 48 hours to live.

Table 4

Changes in Thoughts and Feeling

as a result of the Nature of the Disease

	Frequency	<u>Percent</u>
Hope for recovery- Realistic about disease outcome- Wishing for death	7	23.3
Realistic about disease outcome- Wishing for death	8	27.0
Hope for recovery throughout illness (No change in thoughts and feelings)	12	40.0
Pessimistic about outcome- Difficulty accepting reality of death	3	10.0

It's hard to say this but then we prayed together that she would die to end the nightmare".

Eight of the subjects (27.0%) stated that they were realistic about the disease outcome from the initial diagnosis and that their thoughts and feelings changed from being realistic about the outcome to wishing for the death as the disease progressed. Examples such as the following quotes were common. "I knew it was fatal from the very beginning. There was no hope for this disease. It was like living with death and as he got worse, I felt like the person was already gone, I felt very alone. Near the end I wished and prayed for him to die". Another subject stated "I was realistic from the start and after two years of agony I wanted him to go, I prayed for him to die".

The most frequent response, 40% (N=12), fell in the category of hope for recovery throughout illness (no change in thoughts and feelings over the course of the illness).

In describing the feelings which accompanied the ability to remain hopeful for recovery throughout the illness, one subject stated "I hoped and prayed that she would recover, I still had hope for her till she died. It was the uncertainty that allowed me to continue hoping". Another subject declared "I knew that if I could just get him to eat, he would get better. I never reached the point of being discouraged about it." One widow described her response to the diagnosis as "inoperable did not mean untreatable to me, I never gave up

hope that he would get better". Another subject recalled how he felt during the course of his thirty year old wife's illness. He stated "the ignorance was a blessing. We thought she was getting better until three days before she died.

I kept thinking it would take longer, that there would be more time. Her death took me by surprise".

Ten percent (N=3) of the subjects indicated that their feelings changed from being pessimistic about the disease outcome from the initial diagnosis to having great difficulty accepting the reality of the spousal death. One widow described her reaction as "there was absolutely no hope from the beginning. I thought of his body as a monstrous thing and seeing him didn't let you forget that there was no hope. I was afraid to be with him by myself, afraid that he would die and afraid that he wouldn't die". She then described how after the death "it all felt like a dream, there is intense disbelief that he has died, this can not be real".

Summary of Research Question Number One

The responses varied as the subjects to described changes in their thoughts and feelings regarding spousal death as a result of the nature of the disease. After the responses that were made were reviewed by the researcher it was found that they fell generally into four categories. The majority, or 40% (N=12) of the subjects experienced no change in their

thoughts and feelings about spousal death from time of diagnosis to time of death. They remained hopeful for recovery during the entire illness. Twenty seven percent (N=8) of the subjects experienced changes in thoughts and feelings during the course of the disease from being realistic about the disease outcome to wishing for the spouse to die. Seven of the subjects' (23.3%) thoughts and feelings changed from having hope for their spouses' recovery to being realistic about the disease outcome to wishing for the spouse to die. The remaining ten percent (N=3) experienced changes in their thoughts and feelings from being pessimistic about the disease outcome to having difficulty accepting the reality of the death.

Research Question Number Two

Research question number two asked for the following information: What self-reported behaviors were utilized in anticipating the death of the spouse? The subjects were asked to respond either "yes" or "no" to a variety of documented anticipatory grieving behaviors. The subjects were also provided with the opportunity to add any possible responses which may not have been included. A summary of the findings are presented in table 5.

During the course of the illness, 63.3% (N=19) of the subjects discussed the illness and the death with the spouse.

Table 5
Self Reported Behaviors Utilized in
Anticipating Spousal Death

Discuss illness and		Frequency	<u>Percent</u>
death with spouse	yes no	19 11	63.3 36.7
Plan funeral arrangements with spouse	yes	15 15	50.0 50.0
	no		50.0
Discuss distribution of personal effects			
with spouse	yes	15	50.0
	no	15	50.0
Subject's pre- occupation with			
spouse's death	yes	12	40.0
	no	18	60.0
Decline in subject's health during the			
spouse's illness	yes no	15 15	50.0 50.0
	110	15	50.0
Decline in amount of time spent in spousal			
caretaking	yes	6	20.0
	no	24	80.0
Change in roles to accommodate the declining health			
of spouse	yes	27	90.0
	no	3	10.0

The remaining 36.7% (N=11) of the sample chose not to discuss the illness or death with their spouses. Reasons for not wanting to discuss the illness or death varied. As one subject stated "I felt that even to mention the word cancer would dash his hopes". Several subjects stated that they never reached a point of being discouraged so they never felt the need to discuss the illness or death. One subject cried as he shared the "great regret" he has felt over not discussing with his wife her illness and death.

Planning for funeral arrangements is another documented anticipatory grieving behavior. The sample was equally divided, 50% answering yes and 50% answering no to the question which addressed this behavior. Those subjects who had prearranged with their spouses what was to be done with their (the spouses) remains felt satisfied and comforted that these had been mutual decisions. The sample was also equally divided in how it responded to the question which asked whether or not the couple had discussed how the spouse's personal effects were to be distributed after the death.

Forty percent of the sample (N=12) stated that they were preoccupied with thoughts of their spouse's death. Sixty percent (N=18) denied being preoccupied with these thoughts. However, three of the subjects who denied being preoccupied with thoughts of their spouses dying also stated that they spent a great deal of time and energy attempting to locate someone who would "end the misery for my wife". One subject

who would speed up the process". Another subject shared how she and her spouse explored possible methods which her ill husband could have used to commit suicide.

Subjects were also asked about their health status during the course of their spouses' illnesses. For 50% (N=15) of the subjects, there was no reported change in health. For the other 50% (N=15) of the sample, there were obvious changes in status from mild (increased number of respiratory infections) to severe (cardiac arrhythmias, myocardial infarction, urinary tract infections, exhaustion, gastric disturbances, and metastasis of pre-existing cancer).

Twenty percent (N=6) of the sample felt that they had experienced a decline in the amount of time that they spent caretaking as the spouse became more and more ill. Eighty percent (N=24) of the subjects stated that they did not decrease the time involved in the caretaking responsibilities for their spouses. One subject who stated that she felt herself "pulling away" from her dying spouse described the feeling which accompanied this behavior. "I couldn't stand to watch him any more, I couldn't stand to hear him groaning". Another subject described the feeling as " a detachment necessary for survival" and stated "I feel such enormous guilt for staying away".

As the subjects were anticipating the death of their spouses, almost all (N=27) reported a change in personal roles

to accommodate the declining health of their spouses. Most of the role changes occurred in the areas of financial management, home and car maintenance, and childcare.

Other changes in roles identified by subjects included the following responses. One wife reported "I became more protective of my husband, I was determined that he would not die alone". Another subject who was left with three small children declared "I worked very hard to keep those happy memories that we had shared alive, not only for the children, but so his last days could be peaceful". One woman, whose husband had always been the caretaker, stated "I had to become the healthy one, something I've never had to be before". These and other anticipatory grieving behaviors will be discussed in detail in chapter 5.

Summary of Research Question Number Two

Subjects were asked to answer either "yes" or "no" to a variety of documented behaviors which are indicative of anticipatory grieving. They were also provided with an opportunity to include any responses which may not have been included in the interview schedule.

The majority of the subjects (63.3%) indicated that they had discussed death and dying with their spouses. The sample was equally divided in the response to the question which asked if the subjects had made funeral arrangements with the

spouse. The sample was also divided equally in the response to the question which asked if there had been a discussion with the spouse as to how he/she wanted their personal effects distributed after death.

Sixty percent of the subjects responded "yes" to the question which pertained to feelings of preoccupation with thoughts of the spouse's death. The sample was divided equally in response to the question which sought information regarding a decline in the health of the subject during the spouse's illness. Most of the subjects who answered affirmatively to this question experienced major health difficulties.

The majority of the sample (80%) stated they did not decrease the amount of time they had spent caretaking for the ill spouse as the disease progressed. Ninety percent of the subjects agreed that they had experienced changes in their personal roles to accommodate the declining health of their spouses.

Research Question Number Three

Research question number three focused on self-reported changes in thoughts and feelings about spousal loss which occurred as a result of anticipating the death of the spouse. Subject's awareness of changes in thoughts and feelings due to anticipatory grieving behaviors appeared to be limited as the

responses were difficult to elicit. The responses that were made by the subjects were reviewed by the researcher and found to fall into the following four categories: 1) no change in thoughts and feelings, 2) changes which promoted adjustment to spousal death, 3) other, and 4) unable to answer.

The majority of the subjects, 46.7% (N=14) stated that the anticipatory behaviors which they utilized did not alter their thoughts or feelings regarding their spouses' deaths.

Thirty percent (N=9) stated that by actively anticipating the death of the spouse, the adjustment to the loss was promoted. Responses such as the following were common: "I went through all the stages of grief three or four times before he died. There are things worst than death and this was it". Another subject stated "I did a lot of my grieving when he was ill, it made it a lot easier to be strong". One widow shared that "I had done my crying before he died, it made it easier to carry on".

Responses which were not easily categorized were made by 13.3% (N=4) of the subjects. Three (10.0%) of the subjects were unable to answer the question.

In an effort to better communicate the question regarding changes in thoughts and feelings regarding spousal death based on anticipatory grieving behaviors, the question was posed to twenty seven of the subjects in an alternative manner. The following question was asked: If you are someone who prays, how did your prayers change as you were preparing for the

death of your husband/wife? By changing the wording of the question the subjects were more easily able to respond.

In response to the prayer question, fifty two percent (N=14) of the subjects stated that their prayers did not change over the course of their spouses' illness. A common focus of the prayers which represented this response was for strength, for a cure, and/or for guidance. None of these fourteen subjects prayed for their spouses to die.

Thirty seven percent (N=10) of the subjects responded that their prayers changed as they were preparing for their spouse to die. The following sequence of prayers was common:

1) Prayers for strength, for a cure, for god to heal the spouse, 2) Prayers that the death would come at a time when the subject would be best prepared, that the spouse would not suffer much, and 3) Prayers for the spouse to die. One subject stated "At first I prayed for a miracle, for him to get well. Then I prayed that I would be able to handle his death. Finally, I prayed for this to be over, we were disappointed each morning when he would wake up, we so hoped that the Lord would take him".

Three of the subjects (11%) were unable to answer the question. All three stated that praying was not a typical coping response for them.

Summary of Research Question Number Three

Research question number three pertained to changes in thoughts and feelings regarding spousal death as a factor influenced by anticipatory grieving behaviors. The responses to this question were widely varied frequently did not specifically address the question. The responses which were made tended found to fall into four categories. The majority of the subjects (46.7%) stated that they experienced no changes in thoughts and feelings as a result of anticipatory grieving behaviors. Thirty percent indicated that they found anticipatory grieving behaviors to promote adjustment to the spousal loss. Four of the subjects gave responses which did not fit into either category and three of the subjects were unable to answer.

In an effort to communicate the question more effectively to the sample, the wording of the question was changed. Twenty seven of the subjects were asked a question regarding a change in their prayers as they prepared for the death of their spouse. Fifty two percent indicated that their prayers remained the same. Thirty seven percent indicated that their prayers changed from a focus on cure and strength to a focus on relieving the spouse from their suffering. Three of the subjects were unable to answer due to their lack of use of prayer as a coping technique.

Research Question Number Four

The fourth research question focused on the primary selfreported responses to the death of a spouse following a cancer
related death. The subjects were asked to respond either
negatively or affirmatively to nine common, documented loss
responses. Subjects were then provided with the opportunity
to share with the researcher any other emotions that they may
have felt at the time of the loss. These responses are
presented in table 6.

Fifteen of the subjects (50%) answered affirmatively to the question regarding anger as a possible response to the loss. Common focuses of this anger were the spouse, the physicians, the disease, and god. Fifty percent (N=15) felt that anger was not a felt response at the time of the death of their spouse.

The majority of the sample, 96.7% (N=29) stated that they felt sadness at the time of their loss. Only one subject (3.3%) felt that this emotion did not describe his response to the loss of the spouse. Common responses for the 96.7% who stated that they had felt sadness include "there is a terrible, deep sadness always" and "it is as if everything that I had was gone".

Subjects were also asked if the feeling of guilt pertained to their emotional set following the death of their spouses. Forty percent (N=12) answered affirmatively to this

<u>Table Number 6</u> <u>Self Reported Responses to Loss</u>

	Frequency	<u>Percent</u>
Anger Yes No	15 15	50.0 50.0
Sadnes Yes No	29 1	96.7 3.3
Guilt Yes No	12 18	40.0 60.0
Relief Yes No	22 8	73.3 26.7
Disbelief Yes No	12 18	40.0 60.0
Anxiety Yes No	21 9	70.0 30.0
Loss of Faith Yes No	3 27	10.0 90.0
Longing Yes No	24 6	80.0 20.0
Confusion Yes No	10 20	33.3 66.7

question. Sixty percent (N=18) did not feel that this corresponded with their feelings at the time of spousal death.

Those subjects who stated guilt as a response to the spousal death indicated that this guilt was a result of a variety of factors. Common factors include guilt associated with feeling relieved at the time of spousal death, guilt at not being with the spouse at time of death, guilt at insisting that the spouse seek aggressive treatment, and guilt related to the belief that they had not done enough for the spouse.

The majority of the subjects (73.3%, N=22) stated that they felt relief at the time of the spouses' death. Eight (26.7%) did not feel this response related to their feelings at the time of their spouses' death.

Those subjects who answered affirmatively to the response "relief" gave poignant examples of their feelings. One widow stated "it was a relief for him to be out of his living hell". Another subject cried as he shared "I was overjoyed when she finally died, our misery was over with". It was not uncommon to hear responses such as "my prayers had been answered".

Forty percent (N=12) of the subjects described feelings of disbelief at the time of their spouses' death. Sixty percent (N=18) denied these feelings and, for them, their loss was very real. Those subjects who stated there were feelings of disbelief described this situation in a variety of ways. One widow wept as he stated "I still just can't believe it. I visit her grave every week but it's just to satisfy the

children, I don't think of her as dead - I don't think of her as in the grave". Another subject stated that "it is like being on the verge of believing. I wanted him back so badly that I was afraid to believe that he was dead".

Anxiety was also a common response following the loss of a spouse. Seventy percent (N=21) of the subjects answered affirmatively to this response. Many stated that the cause of the anxiety stemmed from feelings of not being certain of how to care for themselves. Thirty percent (N=9) denied feelings of anxiety following the loss of their spouses.

The subjects were also asked about feelings of loss of faith following the loss of their spouse. Ninety percent (N=27) denied this feeling. Many stated that, if anything, their faith had been strengthened by the process of the illness and death of their spouse. Ten percent (N=3) answered affirmatively to this query and all had sought guidance from their respective clergy as they felt discomforted by this loss of faith.

Eighty percent (N=24) stated that they longed for their deceased spouse. Many thought that there would be "one more day to spend together" and that "it is difficult to go on without him/her". The other six subjects responded negatively to this question. The subjects were also asked about feelings of confusion following the deaths of their spouses. Ten subjects (33.3%) felt this response was appropriate to their situation and 66.7% (N=20) denied these feelings.

Finally, the subjects were provided with the opportunity to share with the researcher any other feelings which may have been present at the time of spousal loss. The quality and intensity of the responses to this question varied. Feelings such as frustration, resentment, fear, terror, shock, bitterness, and apathy were voiced. Loneliness was a frequently stated feeling as 20% (N=6) of the subjects indicated that this feeling pertained to them in their experience with loss.

Twenty three percent (N=7) of the subjects discussed the fact that their feelings were more intense than relief at the time of their spouses' deaths. Examples such as the following illustrate these emotional reactions to the loss. One subject stated that she felt "extreme gratitude, extreme thankfulness that the suffering was over. We had been looking forward to his death and felt happiness that we could go on with our lives". Another subject shared "the most powerful feeling for me was intense happiness, to get everything over with was a relief". For some of the subjects, these feelings of "delight" or "peace" were not easy to discuss. One subject declared "I've never told anyone this before, I feel a little awkward saying this, but I felt happiness at the time of his One widower was distraught over the fact that he death". experiences recurring nightmares in which his wife is still alive. The peace which he has felt since her death is complicated by intense guilt as "I'm not supposed to feel

happy that my wife is dead". These unconventional loss responses will be discussed further in chapter five.

Summary of Research Question Number Four

The focus of research question number four was on subject's self-reported responses to the loss of a spouse following a cancer related death. The subjects were asked to answer either "yes" or "no" to a variety of documented emotional responses to loss. An opportunity to disclose additional feeling was also provided.

The subjects were divided equally in their feelings of anger at the time of spousal loss. The majority of the sample felt sadness, relief, disbelief, guilt, confusion, longing, and anxiety at the time of the spouses' death. Ninety percent (N=27) denied feeling which would indicate a loss of faith at the time of spousal loss.

Other feelings which were disclosed by the subjects included frustration, resentment, loneliness, terror, and bitterness. Seven of the subjects stated that they felt intense happiness or gratitude when their spouses' died as it indicated that the "hell was over". This feeling was, at times, accompanied by feelings of guilt.

Additional Findings

In addition to the four major research questions addressed in this study, relationships between a variety of loss responses and demographic variables were explored. In cases where demographic data were measured at the interval level, relationships were explored using analysis of variance. In cases where both demographic variables and loss response variables were measured at the nominal level the chi square procedure was used to determine degree of relatedness. Demographic variables were explored in relation to both self-reported anticipatory grieving behaviors and self-reported responses to loss. Additionally, anticipatory grieving behaviors were explored in relation to self-reported loss responses.

Two hundred and twenty one possible relationships based on demographic variables were assessed. Only one significant relationship was observed following this assessment. relationship was between length of marriage and a decrease in subject health during spousal illness. Seventy possible relationships were explored between anticipatory behaviors and self-reported loss responses. Three relationships were found to be significant at the 0.05 level. Those were talking about the funeral and reported anxiety, preoccupation with death and reported quilt, and changes in

roles and reported guilt. Limitations and implications of these findings will be discussed in chapter 5.

CHAPTER 5

Summary, Conclusion, Discussion, and Recommendations

This chapter provides a summary of the research, reviews the research questions, reports the findings of the study and discusses the results and the conclusions. Recommendations for future research are suggested based on the findings of this study.

Summary

The purpose of this study was to examine spousal responses following a cancer related death. Anticipatory grieving behaviors as well as a variety of other factors which combine to make a death from cancer unique were examined utilizing the cognitive appraisal paradigm outlined by Lazarus. This study specifically examined unconventional reported responses such as relief as a reaction to a loss of a spouse following a death resulting from cancer.

Thirty men and/or women whose spouses had died from a cancer related death within the past two and a half years were interviewed by the researcher. All subjects were volunteers and were recruited either through the Medical College of Virginia's Cancer Rehabilitation and Continuing Care Center or by a network sample technique.

The majority of the research which is available concerning reactions to loss following a cancer related death

was published before the advent of the now available advances in medical technology. These advances, while providing for increased longevity, also increase family stress as the treatment outcome becomes more uncertain. To address possible changes in loss responses associated with the technological advances in medicine, stressors associated with cancer (length of illness, financial concerns, and the amount of patient suffering, for example) were incorporated into the present research. This research also investigated the use of anticipatory grieving behaviors and the relationships between these behaviors and changes in the subjects' thoughts and feelings regarding the spousal loss from the time of diagnosis and the time of death.

For the purposes of this research an interview schedule was constructed by the researcher which addressed the following four research questions: 1) What self-reported changes in thoughts and feelings about spousal loss occurred over the course of the disease process as a result of the nature of the disease?, 2) What self-reported behaviors were utilized in anticipating the death of the spouse?, 3) What self-reported changes in thoughts and feelings about spousal loss occurred over the course of the disease process as a result of anticipating the death of the spouse?, and 4) What were the primary self-reported responses to the death of the spouse following a cancer related death?

With the exception of one subject who preferred to be interviewed in the hospital, all interviews were conducted in the subject's homes. The interviews ranged in length of time from thirty minutes to three and a half hours with the mean length of time of one hour and forty five minutes.

All of the interviews were audiorecorded and the results were categorized according to types of responses. Frequency distributions and percentages were utilized to describe subject responses to the interview questions. Relationships between demographic variables and the descriptive data were explored using the chi square procedure. A probability level of 0.05 was used to establish the statistical significance of any relationships. In an attempt to describe spousal reports of anticipatory grief, cognitive appraisal, and responses to loss following a cancer related death, verbatim reports of the subjects' responses were also included.

Statement of Findings

The analysis of the data presented in this investigation yielded the following descriptive results:

1. Forty percent (N=12) of the subjects experienced no change in thoughts and feelings about spousal death from time of diagnosis to time of death. They remained hopeful for recovery during the entire illness. Twenty seven percent (N=8) of the subjects experienced changes in thoughts and

feelings during the course of the disease from being realistic about the disease outcome to wishing for the spouse to die. Seven of the subject's (23.3%) thoughts and feelings changed from having hope for their spouses' recovery to being realistic about the disease outcome to wishing for the spouse to die. The remaining ten percent (N=3) experienced changes in their thoughts and feelings from being pessimistic about the disease outcome to having difficulty accepting the reality of the death.

The majority of the subjects (63.3%) indicated that they had discussed death and dying with their spouses. Half of the sample stated that they had prearranged funeral plans and distribution of personal effects with their spouses and half of the sample stated that they had not prearranged the funeral plans or discussed the distribution of the spouses' personal effects. Sixty percent of the subjects stated that they were preoccupied with thoughts of their spouses' death. Half of the sample experienced no change in their health status during their spouse's illness and half of the sample did experience a decline in their health status during the spouses' illness. The majority of the sample (80%) did not decrease the amount of time spent with the ill spouse as the disease progressed. Ninety percent of the sample agreed that they had experienced changes in their personal roles to accommodate the declining health of their spouse.

3. Many of the subjects (46.7%) stated that they experienced no change in their thoughts and feelings about spousal death as a result of anticipatory grieving behaviors. Thirty percent indicated that they found anticipatory grieving behaviors to promote adjustment to the spousal loss. Four of the subjects gave responses which did not fit into either category and three of the subjects were unable to answer.

Of the 27 subjects who were asked whether the nature of their prayers had changed over the course of the spouses' illness, 52% indicated that their prayers remained unchanged. Thirty seven percent indicated that their prayers changed from a focus on cure and strength to a focus on relieving the spouse from their suffering. Three of the subjects were unable to answer the question.

4. Half of the subjects described feelings of anger at the time of spousal death. The majority of the sample described feelings of sadness, relief, disbelief, guilt, confusion, longing, and anxiety at the time of the spouses' death. The majority of the sample stated that they did not experience a loss of faith at the time of the spouses' death. Other feelings which were disclosed included frustration, resentment, loneliness, terror, and bitterness. Seven of the subjects stated that they felt an intense happiness or gratitude when their spouses' died.

Conclusions

The following conclusions were drawn from this descriptive study as a result of the findings of the research:

- 1. The majority of men and/or women whose spouses have died from a cancer related death within the past two and a half years appear to experience changes in their thoughts and feelings (for example, from being realistic about the disease outcome to wishing for the spouse to die) regarding spousal loss from the time of diagnosis to the time of death as a result of the nature of the disease.
- 2. The majority of men and/or women whose spouses have died from a cancer related death within the past two and a half years appear to discuss death and dying with their spouses, feel preoccupied with thoughts of their spouses' death, do not decrease the amount of time spent with the spouse as the disease progresses, and experience changes in their roles to accommodate the declining health of the spouse. Half of the men and/or women whose spouses have died from a cancer related death within the past two and a half years indicate that they do not make funeral arrangements with the spouse, do not discuss distribution of the spouses' personal effects, and do not experience a decline in their health as their spouses' health deteriorated.
- 3. Men and/or women whose spouses have died from a cancer related death within the past two and a half years do not appear to experience changes in their thoughts and

feelings regarding spousal loss from time of diagnosis to time of death as a result of anticipatory grieving behaviors.

4. Men and/or women whose spouses have died from a cancer related death within the past two and a half years report a variety of feelings at the time of spousal death including sadness, relief, disbelief, guilt, confusion, longing, anxiety. Loss of a spouse to cancer does not appear to result in a loss of faith for the surviving spouse. Men and/or women whose spouses have died from a cancer related death within the past two and a half years frequently experience anger at the time of the spousal death. Men and/or women whose spouses have died within the past two and a half years as a result of cancer may also experience feelings of frustration, loneliness, resentment, terror, bitterness, intense happiness, and/or gratitude at the time of the spouses' death.

Discussion

The conclusions drawn from the findings of this descriptive study must be considered within several areas of limitation. The relatively small sample size (N=30) and the nonprobalility sampling technique suggest that extreme caution must be used in generalizing the results to other samples. In addition, the location from which the sample was obtained and the fact that the subject's responses may have been influenced

by a societal directive to "grieve appropriately" both limit the generalizability of the findings.

As the majority of the subjects involved in this study were caucasian, the findings of this research are also limited to caucasian persons whose spouses have died from a cancer related death over the past two and a half years. The intent of the research was to expand the body of knowledge regarding loss responses to include a variety of cultural perspectives. There are several possible reasons for the lack of cultural diversity among the subjects. Forty three percent (N=13) of the subjects were obtained through the Medical College of Virginia's Cancer Rehabilitation and Continuing Care Program. According to the rehabilitation counselor employed by this program, a patient must carry health insurance in order to be eligible for the services provided by the Cancer Rehabilitation Continuing and Care Program. The rehabilitation counselor stated that most of the patients who carry insurance and thus are involved in the program are caucasian.

The focus of this research was on subjects whose spouses had died from a cancer related death. Again, according to the rehabilitation counselor employed by the Cancer Rehabilitation and Continuing Care Program, many of the non-caucasian patients served by the program are involved in relationships which are not considered legal marriages. Thus, many of the

non-caucasian potential subjects may not have qualified for the study.

The stress-coping paradigm developed by Lazarus was used as the framework of this research as it allows for cognitive appraisal and re-appraisal of events. It appears that changes in thoughts and feelings from time of a cancer diagnosis to the time of spousal death do occur as a result of the nature of the disease. The self-reported changes in thoughts and feelings identified by the subjects as they processed the loss of health and impending death of their spouse are findings which are unique to this field of research. The findings appear to differ from the stage theory paradigms (Kubler-Ross, 1969, Bowlby, 1980) which predict a set pattern of responses to loss regardless of the circumstances of the loss. For example, Kubler-Ross' 1969 publication delineates denial, following pattern of loss responses: bargaining, depression, and acceptance. Half of the subjects interviewed for this present research stated that their feelings changed from hoping for recovery or being realistic about the illness to wishing for their spouses to die. These responses do not appear to follow the pattern outlined by Kubler-Ross. Also, forty six percent of the subjects indicated that there were no changes in their thoughts and feelings about their spouses' failing health and impending death. Again, this appears to contradict the social expectations which mandate a set pattern of response to loss.

These findings are important for professionals who are involved with individuals who have experienced loss(es). The changes in thoughts and feelings which occur from time of diagnosis to the time of death as a result of the nature of the disease must be considered within the circumstances which are unique to each individual. Health care professionals need be aware of the variety of individual responses to losses in order to promote health and assist the client toward accommodation of a world view which does not include the deceased.

The research findings regarding self-reported anticipatory grieving behaviors and self-reported changes in thoughts and feelings about spousal death based on the anticipatory grieving behaviors will be discussed together. Many of the subjects interviewed for this study identified anticipatory grieving behaviors as they prepared for the deaths of their spouses. Perhaps of greater importance is the fact that some of the subjects interviewed did not report engaging in behaviors common to anticipatory grief. Perhaps the difficulty some subjects experienced in discussing changes in thoughts and feelings regarding spousal death based on anticipatory grieving behaviors is due to the complex, subjective nature of anticipatory grieving.

Anticipatory grief has traditionally been operationalized according to the length of time of the terminal condition.

Ball (1977) for example, utilized a time frame of illness of

five days to distinguish between sudden death and prolonged It was assumed that anticipatory grief would occur with the prolonged death group. The present research also assumed that a long term illness would warrant anticipatory grieving behaviors. The findings of this research, however, support the notion that length of illness does not dictate the presence or absence of anticipatory grieving behaviors. Fulton and Gottesman (1980) state "our retrospective classification of an illness as terminal in fact tells us little about how a prospective survivor viewed the situation prior to the death. Indeed, the fact that a death was medically viewed inevitable does not tell us the degree to which prospective survivors anticipated the death" (pg. 48). It appears crucial that health care providers realize that many perspectives about the length of an illness and anticipatory grief are based on assumptions about reactions to loss and fail to consider the individual beliefs or psychosocial orientation regarding the health status of the patient.

This study also explored loss reactions following a cancer related death. The majority of the sample identified common emotional responses to loss such as sadness, longing, anger, confusion, and anxiety. Relief had been previously identified as a potential loss response by Chodoff, et al. (1964), Friedman, et al. (1963), Vachon (1977) and Worden (1982). However, the majority of subjects involved in this descriptive study (73.3%, N=22) identified relief as a common

response following a cancer related death of a spouse. This finding is closely linked to another unconventional response to loss which was also identified in this study. Seven of the subjects (23.3%) indicated feelings of extreme gratitude, peace, and intense happiness following the cancer related death of a spouse. These unconventional responses to loss are the antithesis of the socially mandated directives bereavement behavior. When one considers, however, the intense emotional and physical strain experienced by both the spouse and the subject during the illness, these responses could be considered not uncommon following a cancer related death. The social dictum to grieve following a death, regardless of the circumstances prior to the loss, may interfere with the process of mourning as relieved persons may feel "abnormal" in their response to the loss.

It is considered socially desirable for bereaved persons to mourn their loss. This belief may have interfered with the degree to which subjects honestly answered questions regarding their feeling following the loss of a spouse by a cancer related death. It can be recalled that the majority of the subjects interviewed stated that they were not preoccupied with thoughts of their spouses' impending death. However, several of these subjects related their attempts to find a way to "end the misery" for their spouses. Perhaps these subjects did not feel comfortable admitting the presence of these

disturbing thoughts (a preoccupation with death) as it was not considered appropriate for someone with their bereaved status.

The subjects involved in this study were also asked to provide a loss history and were asked to specify if other losses had been cancer related. The finding of this research contradict the conclusions made by Welch (1982) and Rando (1983). In her 1982 study, Welch indicated that there were positive effects on unresolved grief responses (as measured by high grief scores on the Revised Faschingbauer's Texas Inventory of Grief) when correlated with previous experience with cancer in another family member. Her findings suggest that past experiences with cancer may have provided the family with information as to what changes to expect and may have lessened fears of the unknown.

Rando's 1983 research findings contradict those of Welch as it was found that previous loss experiences were associated with poorer bereavement outcomes as measured by Parental Experience Grief Form. It is not made clear in the Rando research if the previous losses resulted from cancer.

The research findings of this study indicate that 73% (N=22) of the subjects reported that their previous experience or inexperience with a cancer related death had little or no influence on their response to their spouses' illnesses. It is important to note that both Welch (1982) and Rando (1983) utilized objective measurement tools as indicators of bereavement outcomes and the findings of this research are

based on self-reports. Still, these findings are relevant to mental health persons who are professionally involved with families and individuals who are living with a terminal disease condition. It is not appropriate to assume that a previous experience with a cancer related death will provide the psychological tools necessary for healthy resolution of the loss.

Extreme caution must be exercised when considering the relationships found between loss responses and demographic variables, and between anticipatory grief behaviors and loss responses. While some correlations were found to be significant at the 0.05 level, these must be considered in relationship to the sample size (N=30). Also, many of the variables were responded to in a like manner by nearly all of the subjects (this was especially true for some of the self-reported responses to loss) which makes relationship analysis difficult. In addition, the sheer number of relationships examined greatly increases the probability that some relationships would appear to be statistically significant when indeed they are an artifact of the number of correlations examined.

With the above cautions in mind, it is curious to note that there appears to be a relationship between the length of marriage and a decrease in the health of the subject during the spousal illness. However, no significance was found between age of the subject and a decrease in the health of the

subject during the spousal illness. This finding suggests that the marital relationship, not just the age of the subject, may be a primary factor in the health status of individuals whose spouses are living with terminal illness.

The positive correlation between talking about the funeral and reported anxiety may be interpreted in the following way. Anxiety appears to be a common response to loss. Those subjects who discussed funeral arrangements with their spouses appeared to be aware of the terminal nature of the illness and their feelings of anxiety most likely were present prior to the death of a spouse as well as at the time of death.

There was also a positive correlation between preoccupation with death and reported feelings of guilt. Many of the subjects who stated that they were preoccupied with thoughts of death indicated that these thoughts centered on the hope that death would come for the spouse and he/she would be released from their suffering. It is understandable that feelings of guilt would correlate positively with this anticipatory grieving behavior as it is not socially expected nor accepted to hope for one's spouse to die, no matter what the circumstances surrounding the death may be.

It is difficult to interpret the positive correlation between changes in roles and reported feelings of guilt. Ninety percent of the subjects indicated that they had experienced changes in their personal roles to accommodate the declining health of their spouses. With only three respondents indicating there was not a change in roles as the health of their spouses' declined, it is likely that the above correlation was influenced by the responses of only a few subjects. As the theory and research on loss responses does not suggest any plausible explanation for this correlation, it is probably best to assume that it is spurious.

Recommendations

The following recommendations are offered based on the findings of this research. These were generated from the results and conclusions of this study and are presented in consideration of future research and professional practice.

- 1. Further research is recommended to identify and describe loss responses of persons who are not caucasian. The majority of the published research regarding loss responses are based on findings which result from studies which primarily utilized caucasian subjects. Counselors who are professionally involved with bereaved persons need to be aware of the impact that cultural differences may have on loss responses.
- 2. It would be beneficial for educational programs designed for those individuals who are professionally involved with the bereaved to incorporate recent research findings regarding loss responses into their curricula.

- 3. An increase in counselor education and training regarding issues of loss and bereavement would greatly assist those who are in the process of accommodating themselves to a loss by death.
- 4. It would be beneficial to further pursue the effects of anticipatory grieving behaviors on changes in thoughts and feelings regarding spousal loss following a cancer related death.
- 5. An assessment tool designed to determine and measure the intensity of loss responses needs to be developed.
- 6. To better understand changes in thoughts and feelings regarding spousal loss over the course of a long-term illness such as cancer, it would be desirable to assess the feelings at the time of diagnosis as well as the feelings present at the time of spousal death.
- 7. The physical and mental health of spousal caretakers during the course of a long-term illness such as cancer must be considered a priority by those who are professionally involved with counseling or case management of such couples.
- 8. The feeling of relief or even happiness at the time of spousal death following a cancer related illness needs to be incorporated into both professional and lay persons understanding of possible loss responses.

APPENDIX A INTERVIEW SCHEDULE

REACTIONS TO SPOUSAL DEATH RESULTING FROM CANCER: INTERVIEW SCHEDULE

Dem	ographics:				
1.	Gender of subject				
2.	Age of subject				
3.	Subject's ethnic identity				
4. Age of deceased spouse at time of death					
5. Length of marriage					
6.	 Description of marital relationship Length of time since spouse's death (in months) 				
7.					
8.					
	months)				
	Type of cancer				
10.	Primary treatment: chemotherapy radiation				
	therapy other				
11.	Primary physical effects of treatment				
12. What other losses (by death) have you experienced					
13.	Have any of your previous losses resulted from cancer				
14.	If yes, how did your previous experience with cancer influence				
	your reaction to your spouse's illness				
	Did your spouse die at a hospital at home				
то.	Did your spouse spend any time on a special oncology unit while				
2 -7	in the hospital? yes no				
т/•	Were you the primary caretaker for your spouse during his/her				

- Section 1: What self-reported changes in thoughts and feelings about spousal loss occurred over the course of the disease process as a result of the nature of the disease?
- 1. As you think back over the length of time that your spouse was ill, describe how your thoughts and feelings about his/her death may have changed from the time of initial diagnosis to the time of death.
- 2. How do you think your thoughts and feelings about your spouse's death may have changed from the time of initial diagnosis to the time of death as a result of his/her physical deterioration?

з.	As you think back over the discomfort or pain that your spouse
	may have experienced over the course of the illness, describe
	how this may have changed your thoughts and feelings about
	his/her death from the time of initial diagnosis to the time
	of death.

- 4. Modern medical treatments help prolong the life of the cancer patient. Along with the lengthening of the patient's life comes an uncertainty as to the outcome of the disease. Describe how this uncertainty may have changed your thoughts and feelings about your spouse's death from the initial diagnosis to the time of death.
- 5. Describe how your thoughts and feelings regarding your spouse's death may have changed from the initial diagnosis to the time of death as a result of your witnessing physical and psychological changes due to the radiation and/or chemotherapy treatment.
- 6. Describe how your thoughts and feelings regarding your spouse's death may have changed from the initial diagnosis to the time of death as a result of possible changes in your financial status.
- Section 2: What self-reported behaviors were utilized in anticipating the death of the spouse?

An increase in physical illness for the subject_____

	A change in subject's roles to accomodate spouse's decrease ability to attend to specific tasks Other
•	
	on 3: What self-reported changes in thoughts and feeling about spousal loss occurred over the course of the disease process as a result of anticipating the death of the spous
	As you think back over the behaviors you used to anticipal your spouse's death, describe how your thoughts and feeling about his/her death may have changed from the time of initial diagnosis to the time of death.
ti,	on 4: What were the primary self-reported responses to t death of the spouse following a cancer related death?
	death of the spouse following a cancer related death? It is possible to feel many emotions at the same time. Plea
	death of the spouse following a cancer related death? It is possible to feel many emotions at the same time. Plea describe the emotions you felt at the time of your spouse
:	death of the spouse following a cancer related death? It is possible to feel many emotions at the same time. Plea describe the emotions you felt at the time of your spouse death. Possible responses include:
	death of the spouse following a cancer related death? It is possible to feel many emotions at the same time. Plea describe the emotions you felt at the time of your spouse death. Possible responses include: Anger
	death of the spouse following a cancer related death? It is possible to feel many emotions at the same time. Plea describe the emotions you felt at the time of your spouse death. Possible responses include: Anger
	death of the spouse following a cancer related death? It is possible to feel many emotions at the same time. Plea describe the emotions you felt at the time of your spouse death. Possible responses include: Anger
	death of the spouse following a cancer related death? It is possible to feel many emotions at the same time. Plea describe the emotions you felt at the time of your spouse death. Possible responses include: Anger
	death of the spouse following a cancer related death? It is possible to feel many emotions at the same time. Plea describe the emotions you felt at the time of your spouse death. Possible responses include: Anger
	death of the spouse following a cancer related death? It is possible to feel many emotions at the same time. Plea describe the emotions you felt at the time of your spouse death. Possible responses include: Anger
	It is possible to feel many emotions at the same time. Plea describe the emotions you felt at the time of your spouse death. Possible responses include: Anger Sadness Guilt Relief Disbelief Anxiety Loss of faith Longing
	death of the spouse following a cancer related death? It is possible to feel many emotions at the same time. Plea describe the emotions you felt at the time of your spouse death. Possible responses include: Anger Sadness Guilt Relief Disbelief Anxiety Loss of faith Longing
	death of the spouse following a cancer related death? It is possible to feel many emotions at the same time. Plea describe the emotions you felt at the time of your spouse death. Possible responses include: Anger Sadness Guilt Relief Disbelief Anxiety Loss of faith Longing
	death of the spouse following a cancer related death? It is possible to feel many emotions at the same time. Plea describe the emotions you felt at the time of your spouse death. Possible responses include: Anger

APPENDIX B ATTENDING PHYSICIAN CONSENT FORM Jennifer C. K. Elison, RN, MS. 5005 King William Road Richmond, Virginia 23225 (804) 232-0310

March 7, 1991

Dear Dr.

I am currently a doctoral candidate in the Department of Counseling of the School of Education at the College of William and Mary. I am conducting research for my dissertation which focuses on reactions to loss following a spouse's death by cancer.

Permission had been granted by Dr. Susan Mellette to obtain subjects whose spouse has died within the past two years from the Cancer Rehabilitation and Continuing Care Program at the Medical College of Virginia Hospital. This study will involve an in-home interview which will require approximately one hour of the subject's time.

The following list includes the names of patients who were under your care and whose spouses qualify as potential subjects for this research:

Please indicate your approval for these potential subjects to participate in this study by signing where indicated and returning this letter in the enclosed stamped, self-addressed envelope.

Thank you for your time and cooperation. Please feel free to call me with any comments, questions, or concerns you may have about this study (804) 232-0310.

Jennifer C. K. Elison

I ______, authorize the above listed patient spouses to participate in the research study described above and to be conducted by Jennifer C. K. Elison, RN, MS.

APPENDIX C SUBJECT CONSENT FORM

REACTIONS TO SPOUSAL DEATH RESULTING FROM CANCER: A DESCRIPTIVE STUDY OF ANTICIPATORY GRIEF AND THE COGNITIVE APPRAISAL OF THE LOSS OF A SPOUSE

CONSENT FORM

The purpose of this form is to request your help by volunteering to participate in a study which will be conducted in your home and at your convenience. This form is designed to ensure that you understand what this project is about. Please read the following information carefully, then sign your name in the section marked "Informed and Voluntary Consent to Participate" if you are willing to cooperate in this study.

Purpose of the Research

The purpose of this study is to examine responses to loss which may occur following a spouse's death from cancer. Results of this study will be used to benefit others whose spouses have died from cancer.

Amount of Time Involved for Subjects

The interview which you have been asked to participate in will take approximately one hour of your time. This will be conducted in your home by the researcher. All interviews will be audiorecorded.

Assurance of Confidentiality

All individual interviews responses, audiotapes, and collected data from this study will be kept strictly confidential in an effort to maintain and protect the privacy of each subject. All interview responses will be identified by a numbering system. Only the researcher will have access to the individual information collected. No data will be used for any purpose except that expressly specified in this study.

Assurance of Voluntary Participation

Your participation in this study is voluntary. You have the right to withdraw from this study at any time. You also have the right to refuse to respond to any particular question or aspect of the interview.

Availability of Results

A written summary of the results of this study will be made available upon request from:

Jennifer C. K. Elison, Researcher

5005 King William Road

Richmond, Virginia 23225

(804) 232-0310

(804) 221-2321

or

Dr. Fred L. Adair, Sponsor Professor of Education Department of Counseling, School of Education College of William and Mary Williamsburg, Virginia 23185 Either of the above individuals is available to speak with you if questions, comments, or concerns about the study occur.

Availability of Follow-up Services

If any distress is caused by the following interview please feel free to contact the Cancer Rehabilitation and Continuing Care Program for counseling services. The number is (804) 786-9901.

Informed Voluntary Consent to Participate

in the study described above.	and hereby consent to participate y right to decline to participate at any time has been guaranteed.
Subject's Signature	Date
Posparcheris Signaturo	Date

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Abstract

REACTIONS TO SPOUSAL DEATH RESULTING FROM CANCER:
A DESCRIPTIVE STUDY OF ANTICIPATORY GRIEF AND
THE COGNITIVE APPRAISAL OF THE LOSS OF A SPOUSE

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The College of William and Mary in Virginia, October 1991

Chairman: Fred L. Adair, Ph.D.

The purpose of this study was to describe spousal reactions to loss following a cancer related death. Anticipatory grieving behaviors and variables unique to cancer were examined using Lazarus' cognitive appraisal paradigm. Thirty men and/or women whose spouses had died from a cancer related death over the past two and a half years were interviewed by the researcher. All participants were volunteers and were recruited for the study either through the Medical College of Virginia's Cancer Rehabilitation and Continuing Care Program or by means of a network sampling technique.

An interview schedule was developed by the researcher which examined the following research questions: 1) What self-reported changes in thoughts and feelings regarding spousal loss occurred over the course of the disease process as a result of the nature of the disease?, 2) What self-reported behaviors were utilized in anticipating the death of the spouse?, 3) What self-reported changes in thoughts and feelings about spousal loss occurred over the course of the disease process as a result of anticipating the death of the spouse?, and 4) What were the primary self-reported responses to the death of a spouse following a cancer related death?

Individual responses to the interview questions were categorized according to type of response and yielded the following results. The findings suggest that the majority of men and/or women whose spouses have died from a cancer related illness over the past two and a half years experienced changes in thoughts and feelings about spousal death from time of diagnosis to the time of death as a result of the nature of the disease. These changes in thoughts and feelings followed a variety of patterns, most commonly, a change from being realistic about the outcome to wishing that the spouse would die. Forty percent of the subjects indicated that their thoughts and feelings remained unchanged throughout the illness.

The findings also suggest that most men and/or women whose spouses have died from a cancer related death over the past two and a half years discuss death and dying with their spouse, were preoccupied with thoughts of their spouses' death, did not decrease

the amount of time spent with the spouse as the disease progressed, and experienced changes in their personal roles to accommodate the declining health of their spouse. Fifty percent of the men and/or women whose spouses have died from a cancer related death over the past two and a half years do not prearrange the funeral plans, do not discuss distribution of the spousal personal effects, and do not experience a decline in health during the spouses' illness.

Almost half of the sample of men and/or women whose spouses have died from a cancer related illness over the past two and a half years do not appear to experience changes in their thoughts and feelings regarding spousal death as a result of anticipatory grieving behaviors.

The findings also suggest that men and/or women whose spouses have died from a cancer related death experience feelings of sadness, disbelief, guilt, confusion, longing, anxiety, and relief at the time of spousal death. They do not appear to experience a loss of faith at the time of spousal death.