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UNIVERSITY OF ALBERTA

ANTICIPATORY GRIEF IN SPOUSES/PARTNERS OF
PERSONS DIAGNOSED WITH CANCER

BY

SHIRLEY SCHOOLER



A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES
AND RESEARCH IN PARTIAL FULFILLMENT OF THE
REQUIREMENTS FOR -
THE DEGREE OF MASTER OF NURSING

FACULTY OF NURSING

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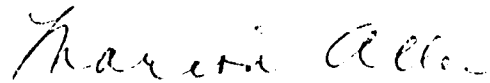
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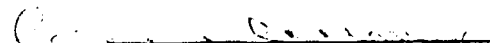
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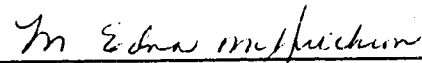
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DEDICATION

This is dedicated with appreciation to the spouses/partners who participated in this study, shared their feelings and experiences with me, and helped me learn so much.

Abstract

The purpose of this descriptive correlational study was to enhance the understanding of anticipatory grief by describing some key components of this phenomenon (anger, anxiety, and depression) and by exploring the relationship of these components to hope in persons whose spouse/partner had been diagnosed with cancer and who was receiving treatment at a regional cancer institute. A convenience sample of 52 participants who were living with the spouse/partner, read and spoke English, and had been informed of the diagnosis/prognosis was obtained over a five month period. Psychological measures administered to all the participants were the State/Trait Anger Expression Inventory (Spielberger, 1988), State/Trait Anxiety Inventory (Spielberger, Gorus, Lushere, Vagg & Jacobs, 1983), IPAT Depression Scale Questionnaire (Krug & Laughlin, 1976), and the Herth Hope Scale (1991). Demographic data and information concerning participant and medical nursing expectations regarding outcome of the illness were also collected.

The findings of this study suggest that anger, anxiety, depression, and diminished hope are clinically significant components of the anticipatory grief response in this group of spouses/partners. Also of note, levels of anger, anxiety, and hope varied according to participant expectations regarding the outcome of the illness.

The findings of this study support the conceptual framework of transition through the identification of a pattern of response to impending loss. In addition, the findings have implications for nursing assessment and caregiving to individuals whose spouse/partner is ill, as well as having implications for further research.

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CHAPTER I

Introduction

It is recognized that the diagnosis of a possible life threatening illness is often equated by spouses/partners with a particular meaning. For example, a diagnosis of cancer is often equated with death (Chekryn, 1984; Sontag, 1977; Thorne, 1985). Such a diagnosis also creates a time of uncertainty and unpredictability (Chekryn, 1984; Lewis, Ellison & Woods, 1985; Lovejoy, 1986; Maquire, 1985; Northouse, 1984; Wright & Dyck, 1984) as well as, hopefulness (Lewis et al., 1985; Lewandowski & Jones, 1988; Pruyser, 1987). A diagnosis of cancer and the anticipated loss of a spouse/partner by death is a source of intense emotional stress and may result in a set of changing emotional responses: it is also a time of transition.

According to Chick and Meleis (1986) this transition begins with an awareness that change relating to the self and one's situation are occurring because of the illness event and continues until a new life phase is established. This awareness of change and the particular meaning associated with the illness influence the pattern of response to this event, making the responses less predictable. Thus, both the anticipated loss of a

spouse/partner by death and the awareness of change result in changing emotional responses. Lindemann (1944) termed this specific response anticipatory grief.

Before Lindemann coined the term, anticipatory grief had been referred to in discussions about responses to impending loss. Freud (1916) commented that the idea of the transience of beauty or an object can lead to "a foretaste of mourning" (p. 306). It was Engel's (1961) opinion that grief, a characteristic response to the loss of a valued object such as a loved person, a possession, job, home or an ideal may be associated with real, threatened or even fantasized loss of a valued object. Specifically, acute mourning may be experienced prior to a death if that death is anticipated (Pollock 1961). The term refers to a process in which individuals who are faced with the possibility that they will experience a significant loss in the near future begin to grieve, that is, experience emotional changes in anticipation of that event.

However, Parkes and Weiss (1983) remark that "the emotional reaction to the threat of loss is different from the emotional reaction to loss itself. Evoked by each, to be sure, is separation anxiety. It is the emotional expression of the urge to stay close to or to search for a person to whom an individual is attached" (p. 58). These authors note that it is the later components of grief, a

period of despair and a conscious relinquishing or giving up of the lost object, that are rarely found before the death of the significant other, no matter how early the forewarning is given.

In fact, Seigel and Weinstein (1983) question whether the phenomenon of anticipatory grief exists at all and assert that the widespread acceptance of the concept is taken as evidence of its existence. Despite this controversy, individuals report that they do begin to grieve prior to the death of a loved one (Huber & Gibson, 1990; Rosenblatt, 1983; Zisook, Shuchter & Lyons, 1987). However, these writers do not describe the grieving process as experienced by these individuals.

Even though this controversy exists and despite clinician's widespread acceptance of anticipatory grief as a valid experience, the concept has been the focus of comparatively little investigation. The majority of these studies are exploratory in nature and describe the responses of the parents of children with malignant disease. These researchers reveal that this emotional response is characterized by shock, disbelief, anger, anxiety, and depression (Binger et al., 1969; Chodoff, Friedman & Hamburg, 1964; Friedman, Chodoff, Mason & Hamburg, 1963; Penfield, Lief & Reuter, 1976; Richmond & Waisman (1955)). These feelings fluctuate in intensity and vary in form over

the course of the illness (Futterman, Hoffman & Sabshin, 1972).

Anticipatory grief begins with and is associated with a gradual relinquishing of hope (Aldrich, 1974; Chodoff et al., 1964; Friedman, 1967; Gerber, 1964; Rosenblatt, 1983). Hope has been defined as an expectation (Bruhn, 1984; Orne, 1968) energized responses to changing life events (Owen, 1989), an anticipation of a future which is good (Miller, 1985), and a multidimensional life force (Dufault & Martocchio, 1985). Hope may be both time and non time oriented (Dufault & Martocchio, 1985). Hope is present and future oriented (Bruhn, 1984; Dufault & Martocchio, 1985; Hickey, 1986; Orne, 1968; Schnieder, 1980; Wright & Shontz, 1968). Hope springs from different sources for each person, is always changing, yet present in most persons to some degree. Hope enables human beings to cope with difficult and stressful situations, deprivations, tragedy, failure, boredom, loneliness, and suffering" (Travelbee, 1971, p. 77). Thus, hope has been linked theoretically to the experience of anticipatory grief. This link, however, has not been empirically tested.

In the majority of studies of adults faced with the terminal illness of their spouse/partner, anticipatory grief has been equated either with forewarning of loss or the length of time of the patient's terminal illness, that is,

the opportunity to grieve prior to the loss (Fulton & Gottesman, 1980; Seigel & Weinstein, 1983). However, having the opportunity to grieve prior to the loss of a loved one does not ensure that one will grieve (Fulton & Gottesman, 1980). In fact, Vachon et al. (1977) found that 40% of women who had been told their husband was dying of cancer refused to believe the warning.

More recently, researchers have attempted to investigate the emotional response of spouses/families of dying patients. Studies that have examined the nature or intensity of anticipatory grief are relatively rare; only four were found. Through retrospective questioning Clayton, Halikas, Maurice and Robbins (1973) found that 19 women (23 percent) experienced a cluster of depressive symptoms during the terminal illness of their spouse. Howell (1986) reported that spouses of terminally ill cancer patients commonly experienced feelings of anxiety (23/30), depression (18/30), fear (12/30), and emptiness (17/30). Feelings of anger (7/30) and hope (5/30) were less frequently experienced by these spouses. Jacobs et al. (1986) noted that individuals threatened with the imminent death of their spouse had lower numbness disbelief scores than early bereaved spouses but had moderately high mean scores on separation anxiety and depression in comparison with those spouses who were recently bereaved and higher scores on

numbness-disbelief, separation anxiety, and depression than those individuals whose spouses were recovering from a life threatening illness. Welch (1982) found that higher grief scores of relatives of dying patients were associated with treatment of the patient on a specialized unit, feeling uneasy that something might happen to the patient while they were absent, and crying about the diagnosis.

In summary, current research findings on the nature of anticipatory grief are limited to the presence or absence of depression in anticipatory grief, a comparison of the intensity of some components of anticipatory grief, post death grief, and grief associated with recovery, and to select variables associated with higher grief scores. These findings should be viewed as tentative because of retrospective questioning (Clayton et al., 1973), the use of newly designed measures without assessing reliability and validity (Clayton et al., 1973; Howell, 1986; Welch, 1982) and the low to moderate internal consistency of the newly designed Bereavement Index (Jacobs et al., 1986).

It is evident that few researchers have questioned the nature or intensity of anticipatory grief. It is suggested in the literature that more studies are needed to examine this response (Seigel & Weinstein, 1983; Sweeting & Gilhooly, 1990). Even though investigators have suggested that feelings of anger, anxiety, and depression are commonly

experienced by persons who are aware of the possible death of a significant other, and may be associated with a decline of hope, a concurrent examination of these variables was not found in the literature.

In this study, the researcher attempted to add to the understanding of this phenomenon by describing some components of anticipatory grief (anger, anxiety and depression) and by exploring the relationship of these components to hope in persons whose spouse/partner had been diagnosed with cancer and who was receiving treatment at a regional cancer institute. This study provides information for nurses designing interventions aimed at helping persons understand their feelings prior to the death of a spouse/partner.

Purpose

The purpose of this study was to add to the understanding of the emotional responses of persons whose spouse/partner had been diagnosed with cancer and who was receiving treatment at a regional cancer institute. The goal was to increase the knowledge of anticipatory grief by focusing on the extent to which these select components of anticipatory grief and hope are experienced by persons who are threatened with the death of a spouse/partner.

Research Questions

The following questions guided the study.

- 1a) To what extent are anger, anxiety, and, depression part of the anticipatory grief experience of persons whose spouse/partner has been diagnosed with cancer?
- 1b) What is the level of hope among these persons?
- 1c) Do differences exist in the level of State and Trait anger and State and Trait anxiety among persons whose spouse/partner has been diagnosed with cancer?
- 2) What is the relationship between State anger and hope; State anxiety and hope; depression and hope?

Definition of Terms

For this study, the following definitions were used:

Anticipatory Grief: was defined as an emotional response that is characterized by anger, anxiety, and depression; this response is related to the awareness of the potential loss of a loved one and occurs within the context of a transition.

State Anger: was defined as the dynamic and changeable individual differences in feelings that vary in intensity from mild annoyance or irritation to intense fury or rage in response to a specific situation in a given moment of time

(Spielberger, 1988) as determined by scores obtained by the ten item State scale of the State/Trait Anger Expression Inventory (STAXI).

Trait Anger: was defined as the relatively stable individual differences in the personality that predispose a person "to perceive a wide range of situations as irritating or frustrating" (Spielberger, 1988, p. 1) as determined by scores obtained on the ten item STAXI self report questionnaire.

State Anxiety: was defined as the dynamic and changeable individual differences in feelings of tension, apprehension, nervousness, and worry that are the responses to a certain situation in a given moment of time (Spielberger, Gorush, Lushere, Vagg, & Jacobs, 1983) as determined by scores obtained on the State/Trait Anxiety Inventory (STAI) self report questionnaire.

Trait Anxiety: was defined as "anxiety proneness, which is a relatively stable baseline personality characteristic" (Spielberger et al., 1983, p. 5), that is how one generally feels, as determined by scores obtained on the 20 item State/Trait Anxiety Inventory.

Depression: was defined as disturbance of emotion characterized by feelings of sadness, discouragement or loss of interest or pleasure and associated with symptoms: appetite and sleep disturbance, psychomatic agitation or

retardation, decreased energy, feelings of worthlessness, excessive guilt, difficulty concentrating, and recurrent thoughts of death (Diagnostic and Statistical Manual of Mental Disorders, 1987) as determined by scores obtained on the 36 item IPAT Depression Scale Questionnaire, a self report questionnaire.

Hope: was defined as "a multidimensional dynamic life force characterized by a confident, yet uncertain expectation of achieving good which to a hopeful person is realistically possible and personally significant" (Dufault & Martocchio, 1985, p. 380) as determined by scores obtained on the Herth Hope Scale (Herth, 1991).

Conceptual Framework

The conceptual framework for this study was drawn from the work of Chick and Meleis (1986) on "transition." According to Chick and Meleis (1986), illness, death, and loss are events that are likely to usher in a process called "transition". Chick and Meleis note that "the noun transition is derived from the Latin verb "transire", meaning to go across". They define transition "as passage from one life phase, condition, or status to another" and as "the outcome of complex person-environment interactions" (1986, p. 239). Within a transition, there may be multiple

transitions, ambiguous entry and exit, and impediments along the way. A transition may be brief or extended in duration. The defining characteristics of transition include process, disconnectedness, perception and patterns of response (Chick & Meleis, 1986).

"Whether the event that causes the transition is anticipated or not . . ., transition is a process . . . there is a sense of movement associated with it" (Chick & Meleis, 1986, p. 240). It is an ongoing, yet bounded phenomenon, beginning with the awareness that changes are occurring and continuing until stability in a new life phase or status has been achieved. This process includes both the disruption that the transition brings about, as well as, the individual's response to that disruption. Rando (1984) comments that disruption begins even at the time of diagnosis: there is a sense of loss of the other person as he/she previously was and uncertainty about future hopes and dreams.

A transition may also signify a disruption in role definition, self concept and social identity (Chick & Meleis, 1986). A role is defined as a way of interacting with a significant other's role taking processes within a situational-social context (Meleis 1975). In this way each person's roles are created and defined. Transitions denote a change in role relationships, expectations and abilities

and require role redefinition. These roles are embodied within one's self concept. The role of spouse is likely to be central to an individual's self concept: the anticipated death of a partner will also be associated with a loss of social identity. Certain components of a person's life may be affected more than others; the particular effect on a person may vary in intensity over time (Chick & Meleis, 1986).

Chick and Meleis (1986, p. 240) write "the most pervasive characteristic of transition is disconnectedness associated with disruption of the linkages on which the person's feelings of security depend." Other characteristics associated with disconnectedness are loss of familiar reference points, "new needs that may arise, or old needs that remain unmet, and old sets of expectations no longer congruent with changing situations" (Meleis 1991, p. 105).

Transition events are perceived to have meaning by the person experiencing them; these meanings vary between individuals and are influenced by sociocultural patterns. Thus, the perceived meaning (relief, distress, neutral) may influence the personal response to such an event, making responses unpredictable.

The patterns of response are the observable and non-observable behaviours that occur in response to the

transition and may be demonstrated in a variety of ways: anxiety, depression, apathy, irritability, hostility, and powerlessness. The boundaries of these behaviours are not fixed but fluctuate depending upon other events that are occurring within the person's life. Any of these behaviours could impede a person's maintenance of health, and therefore, should be subject to empirical exploration and testing (Meleis 1986).

In sum, transition is a personal experience, occurs with an awareness of change, and is experienced differently by persons even though the circumstances are similar. "Processes and outcomes of transitions are related to definitions and redefinitions of self and situation" (Chick & Meleis, 1986, p. 243).

Implications for Nursing

Chick and Meleis (1986, p. 243) comment "that nursing's focus - responses to health-illness events - usually entails change and instability for the person concerned. The achievement of nursing's health related goals generally depends on initiation of changes in interaction between person and environment." These writers comment that nurses need to recognize whether this change has reached the level of awareness or is being denied by the person. Further,

nurses must understand how transitions are actually experienced by those undergoing them. Transitions resulting from loss may lead to health related consequences: physical and psychosocial symptoms, ineffective health and help seeking behaviours and changes in health care utilization (Chick & Meleis 1986). A nurse who has insight into feelings and changes that are being experienced is more able to design interventions that facilitate transition.

CHAPTER II

Literature Review

In this chapter, the literature discussion is divided into three sections: grief, anticipatory grief, and hope. The focus of this review will be on the emotional response and tasks associated with anticipatory grief. Because transition begins with an awareness of change and continues until a new life phase is established, this chapter will begin with a description of post death grief as presented in classic grief literature. This will be followed by a brief discussion of hope.

Grief: Described and Defined

Beginning with Freud's (1916) "Mourning and Melancholia," several descriptions of normal grief have appeared in the literature. Freud described grief as the reaction to the loss of someone who is loved; it is a struggle between two strong and opposite tendencies, one toward realizing the loss and the other toward retaining the lost one. He identified four distinguishing features associated with this reaction: a) a profoundly painful dejection, b) cessation of interest in the outside world, c)

loss of the capacity to love and d) a turning away from any activity not associated with the deceased.

In his essay "On Transience," Freud (1916) commented that "the mind instinctively recoils from anything that is painful" (p. 306) resulting in a "revolt in their minds against mourning" (p. 306). Such intense opposition is aroused in the bereaved that withdrawal from reality and a clinging to the deceased occurs. Reality testing begins to show that the deceased is irretrievably lost and reality demands that emotional energy be withdrawn from the dead person. The bereaved is gradually freed from the ties to the deceased by dwelling for a period of time on the memories of the past and hopes for the future. This process is called grief work. When grief work has been accomplished the pain grows less and the survivor's love energy is able to be transferred to other persons. The struggle to be able to let go is often prolonged and intensely demanding.

Eliot (1932) drew attention to the ways in which families responded to the loss of one of its members. It was his opinion that grief occurred "in a group bound in a functional unity of affectionate interaction" (p. 132). He noted that the typical immediate effects of bereavement are: a sense of abandonment; an inability to believe the fact; a sense of unreality and shock; blame of oneself or others for the death; and intense longing for the lost one. These, he

stated, occur in various sequences and combinations.

Another description of grief has been given by Lindemann (1944) who defined grief as a normal reaction to a distressing loss. He described grief as a definite time-limited syndrome that is characterized by: somatic complaints that occur in waves; acute tension or mental pain; intense preoccupation with the image of the deceased; hostile reactions characterized by a loss of warmth toward others, irritability, anger, guilt, social withdrawal, and aimless disorganized behaviour. Grief work involves "dealing in memory with the deceased" (p. 149) in order to free oneself from bondage to the deceased and to readjust to an environment without the deceased and in which new relationships can be formed. "Many patients try to avoid the intense distress connected with the grief experience and to avoid the expression of emotion necessary for it" (Lindemann, 1944, p. 143).

Marris (1958) reported that grief, a personal crisis, is the psychological process of adjusting to a time when the continuity of the meaning of life has collapsed due to a loss. It is the expression of a profound conflict between two contradictory impulses: the need to preserve the past and at the same time to find a meaningful life in which the loss is accepted. Each impulse checks the other, reasserting itself by reality testing and as a result, the

bereaved is repeatedly called to face the conflict. Marris summarized the typical features of grief as: physical symptoms; an inability to comprehend the loss; a loss of contact with reality; obsessive thoughts about the deceased and a sense of the presence of the dead person; intense feelings of resentment and blame against fate, God, the doctor or oneself; apathy which was marked by withdrawal from people and everything that recalled the loss; and a sense of the futility and emptiness of life. He defined grief work as detaching the familiar meanings of life from the relationship with the deceased. This means extracting what was important to the relationship and restructuring it in order to work out an interpretation of oneself and to reestablish meaning for oneself.

Engel (1961, 1964) saw grief as a characteristic response to the loss of a loved person. He believed that, at the time of bereavement, "the more or less automatic, taken for granted aspects of living are interrupted" (Engel, 1964, p. 92). The bereaved person becomes aware of the many ways in which he/she was dependent on the lost person "as a source of gratification and as an essential influence for feelings of wellbeing and effective functioning: his sense of self" (Engel, 1964, p. 92). He identified the features of grief to be: an initial period of shock and disbelief; an increasing awareness of a loss of wholeness of self and

one's environment that is often felt as a sense of emptiness within oneself; anger that erupts towards persons or circumstances that are felt to be responsible for the death; exclusive preoccupation with thoughts of the deceased; and a painful process of reconstructing a distinct mental image to replace the image of the deceased. This process serves to loosen the ties to the deceased; earlier yearnings to be with the dead person begin to be replaced more and more with a turning to life. This allows survivors to reinvest feelings in other persons. This process goes on slowly and painfully and with great sadness.

In his exploration of mourning, Bowlby (1961) defined grief as a particular blend of anxiety, anger and despair; it is a form of separation anxiety that results from the disruption of an attachment bond. This attachment to a loved one is learned early in life and is mediated by a number of instinctual response systems that are goal directed; the functioning of each partner is dependent on the presence and behaviour of the other. Any threat that endangers this bond elicits action to preserve it. Thus, the bereaved individual facing what is feared to be an irretrievable loss experiences persistent separation anxiety. He described the typical features of grief as: disequilibrium (unbelief and bewilderment); crying and angry violent feelings directed toward the dead person, the self

and other persons. This anger "is felt and expressed as part of the effort to undo the loss and to maintain intact the expected reunion. So long as it continues it is a sign that the loss is not accepted as permanent and that, realistic or not, hope still lingers on" (Bowlby, 1961, p. 334). Another prominent feature of grief is despair with disorganized behaviour. These feelings of anger, yearning, and despair come and go in irregular rhythms. After repeated disappointments at not finding the deceased, and as hopes for reunion fade, the bereaved's behaviour gradually ceases to be focused on the lost person. Through this process, the emotional attachment to a loved one is withdrawn in order that other relationships can be formed.

Building on Bowlby's (1961) work, Parkes (1970, 1972, 1986) described grief as an alarm reaction to a major stressor. He believed that "resistance to change, the reluctance to give up possessions, people, status, expectations" (1986, p. 31) to be the basis for grief. He defined the most characteristic feature of grief to be "acute and episodic pangs of severe anxiety and psychological pain" (1972, p. 39). At such times, the survivor pines or yearns for the lost one: there is a persistent wish for the return of the person who is gone, intense preoccupation with thoughts of the lost one and an anxious searching for and calling for the deceased. Parkes

(1970, 1972, 1986) noted an initial period of numbness or shock that is punctuated by short episodes of panic. This initial phase is followed by intense searching or pining and fluctuating feelings of intense anger and/or general irritability and bitterness. Frequent and briefer episodes of yearning may occur for months and are interspersed with feelings of anger, apathy, and despair. Despair is associated with aimlessness and disorganization of behaviour. Grief work involves intense preoccupation with thoughts of the deceased and a painful repetitious recollection of the loss experience to make sense of the loss and to integrate it into one's life. Parkes (1986) believes that individuals form affectionate ties with their life space which he described as their personal and physical environment. They build assumptions based on this life space that include the past, present and future. The death of a loved one may lead to major changes in this life space. In grief, the bereaved person must change these assumptions about the world, that included oneself in relation to the dead person, and develop other assumptions that fit in with the present circumstances.

To summarize what has been reviewed so far, several authors have sought to define grief as a complex and long lasting psychological process with social and physical dimensions. All authors agree that grief is a multi-

dimensional concept of significance to the life experience of the bereaved.

Anticipatory Grief

The Tasks of Anticipatory Grief

Lindemann (1944) extended the concept of grief work into the area of anticipation of a loss. During the Second World War, Lindemann became aware of the responses of individuals whose family member was absent and serving in the armed forces. He wrote about these individuals who were so concerned with their future adjustment in the face of potential loss that a grief response was experienced. This grief response was delineated by depression, heightened preoccupation with thoughts of the absent one and fantasies about the death as well as possible adjustment to that death. Lindemann named this process anticipatory grief. It was his opinion that this reaction might be a safeguard against the impact of sudden death: on the other hand, it might inhibit continued involvement with the loved one if death did not occur. Fulton and Fulton (1972) noted a similar observation and pointed out that a "low grief response expressed by members of a family at the time of the death of a loved one may be due to the process of

anticipatory grief as family members cope with the illness or endure separation prior to the death" (p. 230).

Futterman, Hoffman, and Sabshin (1972) interviewed 23 sets of parents with children ill with leukemia. The authors' observations led them to conceptualize anticipatory grief as a series of functionally-related processes. These are defined as: a) becoming progressively convinced that the child will die; b) experiencing and expressing the emotional impact of the loss; c) developing a sense of confidence in the child's life, in the face of death; d) withdrawing emotional investment from the child as a person with a real future; and e) developing a mental picture of the child which will endure beyond death.

Rando (1984, 1986) suggested that anticipatory grief allows for absorbing the reality of the loss over a period of time, (losses that have already occurred due to the illness, losses that are presently occurring, and losses that will occur in the future). Also, anticipatory grief allows for withdrawing emotional energy from the image of the living person as he/she previously was, and beginning to withdraw "hopes, dreams, and expectations of a long term future with that person and for that person" (1986, p. 13). During this process one may begin to change one's assumptions about life, and one's identity and "begin making plans for the future so that they will not be felt as

betrayal of the deceased after death" (1984, p. 37). The most crucial task in anticipatory grief is to establish a balance between letting go of, and remaining involved with the dying person (Rando, 1986). The tasks of grief work are associated with an emotional response.

Since the 1950's a number of researchers have studied anticipatory grief responses among parents of terminally-ill children. Others have investigated the emotional response of spouses of terminally ill adults.

Anticipatory Grief Among Parents of Terminally-Ill Children

The first studies about anticipatory grief were qualitative in nature and focused on the emotional response of parents whose child was terminally ill. Bozeman, Orbach, and Sutherland (1955) observed and described the response of mothers to the threatened loss of their children who were ill with leukemia. The mothers initial response to the diagnosis was shock, denial, or an inability to believe it. Some described it as receiving a physical blow. They experienced feelings of guilt and separation-anxiety; this was manifested by clinging to the child.

Richmond and Waisman (1955) interviewed and observed parents of 48 terminally ill children and noted the emotional stress of these parents. The parents expressed

feelings of unworthiness, withdrew and became preoccupied with thoughts of earlier experiences with the child. This was observed over a period of several weeks. They exhibited marked anxiety and voiced concern about separation from the child and its irreversibility, guilt, and depression, as well as a shattering of hopes and dreams associated with the child. The authors concluded that grief takes place prior to the death of a child.

Similar reactions were observed by Friedman et al. (1963), Chodoff et al. (1964), and Friedman (1967). They reported that the diagnosis of leukemia was received by most parents as a "stun", a shock, a feeling of unreality and/or disbelief for some days; other parents reacted with immediate hostility. All parents expressed feelings of guilt, persistent self blame, and frequent but brief outbursts of anger or hostility which reflected a bitterness toward the world in general. Most of the parents became anxious, and complained of various physical symptoms. They sighed frequently, cried for long periods, appeared depressed, and exhibited random and disorganized behaviour. They expressed the need to find meaning in the experience and became intensely preoccupied with thoughts of the ill child. As time passed, these parents exhibited some degree of emotional detachment from the child. Friedman (1967) reported one mother as describing this by saying, "I love

him so much, but we are more separate" (p. 503). Chodoff et al. (1964) described "a gradual detachment of investment from the child who became less a real object, in a sense already a memory while still alive" (p. 748).

Natterson and Knudson (1960) described the response of mothers whose children were under treatment for a malignant disease. Initially most mothers (25 out of 33) reacted to the diagnosis and prognosis in a disbelieving manner and were tense, anxious, withdrawn and inclined to weep, and exhibited a tendency to cling to their child. The mothers clung to a hope of saving their child and, at the same time, often expressed some degree of guilt. Toward the end of the child's illness the most common reaction (19 out of 33) was calm acceptance of the fatal outcome; when the child died, there was a mixture of calm acceptance and sorrow.

Binger et al. (1969) interviewed the parents of 20 children after the children had died of leukemia. The authors reported that most parents experienced symptoms and feelings of physical distress, depression, inability to function, anger, hostility, and self-blame during the first days or weeks after hearing the diagnosis. These reactions gradually subsided in intensity and most parents were able to meet the child's needs.

Futterman et al. (1972) interviewed and described the emotional stress of parents of 23 leukemic children. These

parents verbalized many feelings associated with the illness of their child, ranging from shock and disbelief near the time of diagnosis to resignation near the terminal phase. They expressed feelings of helplessness, anger, guilt, shame, fear and experienced increased conflict and anxiety about day to day separations from the child. They appeared tense and depressed and were silent, immobile, and withdrawn. The authors note that active mourning occurs while loving and retaining emotional investment in the child and while holding hope for the child's survival.

Penfield, Lief, and Reuter (1976) measured the feelings and behaviours of parents whose newborn infants were immediately transferred to an intensive care unit. Significantly more mothers than fathers reported feelings of disbelief, depression, sadness, guilt, anger, preoccupation with the baby, irritability, wanting to be left alone, and somatic symptoms. These reactions did not appear to be associated with the severity of the baby's illness.

In sum, the anticipatory grief response of parents of terminally ill children is complex. The features described seem remarkably consistent and include numbness-disbelief, guilt, anger, anxiety, and depression. Despite the consistency of these findings, a gap in knowledge still remains; the extent to which these feelings are experienced is not defined. The intensity or level of these responses

(anger, anxiety, and depression) has not been described in the literature.

Anticipatory Grief Among Spouses

Spouses have reported that they do begin to grieve prior to the death of a loved one (Glick, Weiss, & Parkes, 1974; Huber & Gibson, 1990; Rosenblatt, 1983; Zisook, Shucter, & Lyons, 1987). All of the widows and widowers who had known of the impending death of their spouse (Glick et al. 1974) and 110 (59%) of widows and widowers whose spouse had died of an illness lasting longer than three months (Zisook et al. 1987) stated that they had begun to grieve prior to the actual death of the spouse. Many of the widows and widowers whose spouse had died in a hospice setting reported that they felt that nearly half of their grief work had been accomplished prior to the actual occurrence of the death (Huber & Gibson, 1990). However, these writers do not describe this grief experience. On the other hand, Rosenblatt (1983) emits some light on the anticipatory grief response. He quotes from Sophia Sewell Wood's diary: February 16, 1810 "Less hope than ever. With what agonizing distress, void of hope do I now watch the distressed countenance of my Dear Hartley, a countenance that once beamed with pleasure, gaiety and health - Now . . . with

sorrow." (Rosenblatt, 1983, p. 42).

In several studies of anticipatory grief among spouses, anticipatory grief has been defined as forewarning of loss (Carey, 1979-80; Lundin, 1984; Maddison & Viol, 1968; Parkes, 1970; Schwab, Chalmers, Conroy, Farris & Markush, 1975; Vachon et al., 1982) or length of the terminal illness (Ball, 1976-77; Bornstein, Clayton, Halikas, Maurice & Robins, 1973; Gerber, Rusealem, Hannon, Batten & Ankin, 1975; Schwab et al., 1975). The focus of these studies has been on the exploration of the relationship between the length of illness or forewarning of loss and the intensity of post death grief and/or bereavement outcomes.

Although much of the literature concerning the impact of the threatened loss of a child on parents had been exploratory, some empirical studies have been done in which the impact of the potential death of a spouse on the surviving spouse was examined. In the first empirical study, Clayton et al. (1973) observed retrospectively the anticipatory grief response of 81 widows and widowers whose spouses had recently died. Anticipatory grief was defined as a cluster of depressive symptoms. Depression was defined as low mood characterized by feeling depressed, sad, despondent, discouraged, blue, lost or numb, plus five of the following eight symptoms for a definite depression and four of the eight symptoms for a probable diagnosis of

depression. These were: (1) loss of appetite or weight loss, (2) sleep difficulty, (3) fatigue, (4) feeling restless, (5) loss of interest, (6) difficulty concentrating, (7) feelings of guilt, and (8) wishing to be dead or thoughts of suicide. They reported that of the 81, "19 had a depressive symptom complex during the terminal phase and 62 did not" (p. 49). Their results suggest that anticipatory grief, as measured by depressive symptomatology, occurs frequently.

Welch (1982) investigated the phenomenon of anticipatory grief in 41 family members who had an adult relative who was dying of cancer. These relatives completed a 12-item questionnaire compiled from the Texas Inventory of Grief. At this time, almost one half (46%) of the patients were undergoing their first treatment experience and 18 family members were coping with new evidence of recurrent or advancing disease. Welch found that significantly higher mean grief scores were associated with treatment of the patient on a specialized unit, feeling uneasy about the possibility that something might happen to the patient while they were absent, and crying about the diagnosis. Although she regarded these grief scores as indicative of unresolved grief, she commented that anticipatory grief is a normal and expected process in coping with the anticipated loss of a loved person.

Jacobs et al. (1986) compared the psychological distress of 68 persons whose spouses were hospitalized with a life threatening illness with 150 persons threatened with imminent loss or who were recently bereaved. All completed the Bereavement Index which assesses numbness-disbelief, separation-anxiety, and depression. Those spouses threatened with an imminent loss had lower numbness-disbelief than those experiencing actual loss. At the first assessment (approximately one month prior to or after the actual death of the spouse) both groups of spouses scored similarly on depression and on the items that characterized separation (feeling upset when thinking of spouse; yearning to have the spouse as he or she was prior to the illness; feeling tense or nervous and preoccupied with thoughts of the spouse). However, the group experiencing actual loss manifested a greater tendency to search for the other person. Those persons whose spouse was hospitalized with life threatening illness but who recovered showed much less intense grief reactions, manifesting lower scores on numbness-disbelief, separation anxiety, and depression.

Howell (1986) explored the emotional responses of 30 spouses of terminally ill cancer patients by means of a semi-structured interview schedule designed by the investigator. She reported that these spouses experienced a variety of emotional responses. Anxiety was the most common

emotion experienced by both males and females. Depression, feelings of emptiness and fear were also commonly experienced; feelings of anger and hope were less frequently reported by these spouses. More than one half of the spouses indicated disturbances in their thought process and reported unpleasant thoughts, difficulty remembering, and difficulty making decisions and/or concentrating.

In summary, the findings of these studies, suggest that feelings of anxiety and depression are more commonly experienced, whereas, feelings of anger and hope are less frequently reported by individuals who are faced with the impending loss of a spouse.

The Process of Anticipatory Grief

Some understanding of the process of anticipatory grief has come from the observational studies of parental anticipatory grief. The overall pattern of anticipatory grieving is marked by many transitory fluctuations in the intensity and form of grieving over the course of the illness (Futterman et al., 1972). Futterman et al. (1972) reported that the intensity of grief tends to peak at times of diagnosis, relapse, and in the terminal phase; successive peaks of grief tended to decrease in strength. Grieving seemed to be more passive and less well defined than in

acute grief (Binger et al., 1969; Bozeman et al., 1955; Friedman et al., 1963). Acute grief among adults following the death of a relative has been shown to be characterized by moderate to extreme anger, (Zisook et al., 1987) and moderate to high levels of anxiety (Jacobs et al., 1986; 1990) and clinical levels of depression (Zisook et al., 1987). In fact, Futterman et al. (1972) reported that the acute emotional pain of early grief decreased but the parents became more melancholic over time. The grief process varied greatly in individual parents; in a few parents it was never obvious at any time (Friedman et al., 1963).

The anticipatory grief process was usually quite apparent within the first days or weeks after hearing the diagnosis (Binger et al., 1969); in the first month or two following diagnosis (Futterman et al., 1972); by the fourth month of the child's illness (Chodoff et al., 1964; Friedman et al., 1963; Natterson & Knudson, 1960). Friedman et al. (1963) observed that the grief process was frequently initiated by the first acute critical episode and that grief work accelerated during the terminal phase of the illness and/or actually began at this time in some individuals who had previously denied the diagnosis.

In order for a person to experience anticipatory grief it must be triggered by some kind of communication; there

must be an awareness of an event that will create a loss (Budner, 1974; Pine, 1974; Rando, 1986). This includes an intellectual awareness and an understanding of the emotional meaning of that event; there must be a perception that the loss is real and inevitable (Budner, 1974; Chodoff et al., 1974; Pine, 1974; Rando, 1986).

Anticipatory grief has a definite end point; it ceases with the death of the terminally ill person (Aldrich, 1974; Eliot, 1949). Eliot (1947, p. 2) wrote "there remains the basic adjustment to the actual presence of absence, the finality, the absoluteness ... of the loss itself". At the actual time of death, the child's death was generally taken with a mixture of sorrow and relief by most parents who had been grieving during the child's illness (Binger et al., 1969; Chodoff et al., 1964; Friedman et al., 1963; Natterson & Knudson, 1960). Natterson and Knudson (1960) observed that 6 out of 33 mothers who continued to cling to hope for their children's recovery reacted hysterically when their child died. Binger et al. (1969) commented that 4 out of 20 parents were intensely angry at the time of death.

Anticipatory grief is a subjective experience that may begin soon after diagnosis. It is an active evolving process associated with a transition and not a steady state which simply diminishes over time, even though it has an end point.

Hope

Anticipatory grief begins with a gradual relinquishing of hope (Chodoff et al., 1974; Friedman et al., 1963; Friedman, 1967; Rosenblatt, 1983). Hope generally diminishes with the progression of the disease but tends to reappear during times of remission (Bozeman et al., 1955). Yet, residuals of hope remain to the end of the person's life (Friedman et al., 1963; Futterman et al., 1972).

Hope arises in response to a felt tragedy (Pruyser, 1987) and is directed "toward a future known to be intrinsically contingent and uncertain" (Rycroft, 1979, p. 6). The grounds for hoping do not necessarily lie in the facts of reality (Pruyser, 1987) but depend on the individual's expectations which arise from the perspective of his/her own experience (Rycroft, 1979). Hope allows an individual to keep all possibilities open; "it does not close the door on the basis of given evidence." (Nowotny, 1979, p. 54)

Hope has been described as an expectation (Bruhn, 1984; Orne, 1968) and a multidimensional life force (Dufault & Martocchio, 1985). Hope may be generalized, that is, it imparts a sense of well being or an overall motivation to carry on with life. Or hope may be particularized, that is concerned with what a person sees as most important in life:

a hope object; survival of the spouse, recovery of health (Dufault & Martocchio, 1985).

Hope may be realistic (Davies, 1979) or transcendent (Nowotny, 1979). Hope requires the working through of deep disillusionment (Silberfield, 1981). It is present and future oriented; an individual imagines a way out of a difficulty or a wider perspective for life (Bruhn, 1984; Dufault & Martocchio, 1985; Hickey, 1986; Orne, 1968; Schneider, 1980; Wright & Shontz, 1968). Hope arises within a person (Hickey, 1986; Schneider, 1980; Vailliot, 1970), and is related to trust (Miller, 1985). Hope involves other people or a higher being (Bruhn, 1984; Dubre & Vogelpohl, 1980; Hickey, 1986; Schneider, 1980). Hope requires active involvement by the individual; it involves goal setting with realistic possibilities that are personally significant (Dubre & Vogelpohl, 1980; Dufault & Martocchio, 1985; Korner, 1970); it requires energy (Bruhn, 1984; Schneider, 1980) and gives energy (Owen, 1987). Hope has a reviving effect and a survival function, assisting the individual to live within limitations (Korner, 1970; Menninger, 1959; Schneider, 1980) and is associated with meaning in life (Hickey, 1986).

In sum, "hoping is not a single act but a complex of many thoughts, feelings, and actions that change over time" (Dufault & Martocchio, 1985, p. 380). However, in the

literature, there are no data describing the relationship between hope and anticipatory grief. In this study, this relationship will be explored.

Summary of the Literature Review

From the literature review there are indications that some differences and commonalities exist between anticipatory and post death grief. Writers (Parkes & Weiss, 1983; Rando, 1984) take issue with Lindemann's (1944) view that anticipatory grief is identical to grief following death. Parkes and Weiss (1983) argue that the emotional response of anticipatory grief differs from that of post death grief. Similarly, Rando (1984) claims that the grief work associated with an impending loss is different from the grief work following death. There is general agreement that both anticipatory grief and post death grief are complex and multidimensional in nature. It is also suggested by many writers that in varying degrees shock, denial, guilt, anger, anxiety, and depression are present in both types of grief. In contrast to post death grief, hope is thought to be associated with anticipatory grief. However, there still remains a lack of information concerning the intensity of these feelings as they occur among persons who are faced with the potential loss of a spouse/partner. Therefore,

there is a need to examine the level of this emotional response and to explore its relationship to hope.

CHAPTER III

Method

Some information on the nature of anticipatory grief is available. Writers have reported that this emotional response is characterized by anger, anxiety, and depression and that it is associated with a gradual relinquishing of hope. Little, however, has been reported on the intensity of these responses. Nor has the relationship between these responses and hope been described. The purpose of this study was to add to the understanding of anticipatory grief by focusing on the extent to which these select components (anger, anxiety, and depression) and hope are experienced by persons who are threatened with the loss of a spouse/partner. The focus of the study was also to describe the relationship of these responses to hope, and to compare the levels of these feelings to the feelings of the general population. A concurrent examination of anger, anxiety, depression, and hope had not been reported in the literature. Nor had the relationship of State/Trait anger and State/Trait anxiety in response to a threatened or anticipated loss been studied. Therefore, a descriptive correlational approach was considered appropriate. Brink and Wood (1989) state that descriptive methods are used to

provide a full description of variables within a given sample. As the relationship among the components of anticipatory grief and hope had not yet been explored, a correlational approach was utilized.

Sample

The participants for this study were recruited from a regional cancer institute in a large urban centre in western Canada. Eighty-five spouse/partners were approached to participate in the study. Twenty-eight spouse/partners refused; refusal responses included "no"; "too busy"; "feelings haven't hit me yet"; and "having too difficult a time". Five persons did not return the completed questionnaires. A convenience sample of 52 participants was obtained over a five month period. The participants in the study met the following selection criteria:

- 1) All participants were presently living with the spouse/partner who had been diagnosed with cancer.
- 2) All participants were able to read and speak English.
- 3) All participants were aware of the diagnosis and had been informed of the prognosis.

Data Collection

The participants for the study were obtained as follows. First, potential participants who met the chosen criteria for inclusion, were identified in consultation with the unit manager of in-patient units and during review of out-patient lists with the clinic coordinators of out-patient clinics. Second, the researcher approached these potential participants in the clinic setting to explain the study, their individual role and to seek their involvement in the study. Participants who verbally expressed interest in the study were given detailed information about the study and were given an opportunity to ask questions. Those who verbally agreed to participate in the study were asked to sign a consent form (Appendix A). Third, once the consent form had been signed, an envelope containing the four questionnaires and the data information form was given by the researcher to each participant. These questionnaires were arranged in a standardized order. The researcher gave verbal instructions about the questionnaires and data information sheet that each participant was to complete. These included the following: 1) participant's name was not to be placed on the forms; 2) to follow the instructions at the beginning of each questionnaire (these were read and explained to each participant); 3) and to answer all

questions by themselves. The majority of the participants completed the questionnaires privately, in the clinical setting, placed them in an addressed envelope and left the sealed envelope at the nursing station for the investigator. Twelve participants completed the questionnaires at home and returned them by mail to the researcher. Two of the participants preferred that the researcher stay with them while the questionnaires were completed.

Instruments

Four self report instruments, The State Trait Anger Expression Scale (STAXI), The State Trait Anxiety Inventory (STAI), The IPAT Depression Scale (IPAT) and The Herth Hope Scale (HHS) were used to collect the data on the study variables (anger, anxiety, depression, and hope). Permission to use the STAXI was obtained from Psychological Assessment Resources, and permission to use the STAI from Consulting Psychological Press. Permission to use the IPAT Scale was obtained from the Institute for Personality and Ability Testing. Written permission to use the HHS was obtained from Dr. Herth.

The State-Trait Anger Expression Inventory (STAXI)

This inventory, developed by Spielberger (1988), measures the experience and the expression of anger. Anger experience is depicted by two 10 item scales: State and Trait anger. State anger is defined as "an emotional state marked by subjective feelings that vary in intensity from mild annoyance or irritation to intense fury and rage." Trait anger is defined "as the disposition to perceive a wide range of situations as annoying or frustrating" (p. 1). Anger expression is depicted by three 8 item scales: anger out (expressed toward other persons or objects), anger in (expressed inwardly to self), and anger control.

Ten items of the scale measure State anger under, "How I feel now," and 10 items measure Trait anger under "How I generally feel." In this study, these two 10 item scales measuring State and Trait anger respectively were used. The STAXI was developed with a reading level of grade five to six ability; the inventory can usually be completed by adults in 10 to 12 minutes. The respondents are asked to indicate using a four-point Likert scale where 1) equals not at all, 2) equals somewhat, 3) equals moderately so, and 4) equals very much so, their present feelings. Participants are asked to indicate how they "generally feel" by using a four-point Likert scale where 1) equals almost never, 2)

equals sometimes, 3) equals often, and 4) equals almost always. The responses were summed to give a total score. Scores for both the State and Trait anger scales can vary from a minimum of 10 to a maximum of 40. Higher scores reflect the presence of greater anger. The writers provide a scoring grid for recording of raw scores, percentiles and t -test scores.

Internal consistences as measured by Cronbach's coefficient alpha for these two main scales are: State anger (.93) and Trait anger (.87). The writers report item-remainder correlations within the scales, providing evidence for both convergent and discriminant validity. Spielberger also reports the results of factor analysis of the scales which supports the scales construct validity. The correlation between the Trait Scale and the Buss Hostility Scale and the Hostility and the Overt Hostility Scale of the MMPI range from .73 to .66, and .59 to .43, providing evidence of the scale as a measure of anger, but also, suggesting differences between anger and hostility as personality characteristics. Norms are available for well adult men and women and medical/surgical patients. These well adults ranged in age from 18 to 67 years and were employed as managerial, technical, clerical, sales, and factory workers.

State-Trait Anxiety Inventory (STAI)

The State-Trait Anxiety Inventory (STAI) was designed by Spielberger et al. to measure State and Trait anxiety. The authors report that state anxiety is characterized by feelings of tension, apprehension, nervousness, worry, and by the arousal of the autonomic nervous system. Although, these states are often transitory, they may endure if a stressful situation persists. Trait anxiety is defined as "anxiety proneness, which is a relatively stable, baseline personality characteristic" (p. 5).

State anxiety was measured by 20 items: the respondents are asked to describe their present feelings by choosing one of four responses on a four-point Likert scale where 1) equals not at all, 2) equals somewhat, 3) equals moderately so, and 4) equals very much so. Trait anxiety was also measured by 20 items; the response was made to "how one generally feels" by selecting the most appropriate response (almost never, sometimes, often, and almost always) to each item. Each subscale contains anxiety-absent and anxiety-present items. Each item is given a weighted score of one to four. The weighted scores are summed to give a total score which can range from 20 to 80 for both State and Trait anxiety. Higher scores reflect the presence of greater anxiety. Template keys were used to score the scales. This inventory can usually be completed in 10 to 15

minutes and requires a reading ability of about grade five to six.

This scale has been used extensively to assess levels of State anxiety brought about by real life stresses. This scale is by far the most widely used scale to measure anxiety and is useful in those situations where determining a change in a person's level of anxiety is important. In this study, this inventory was used to provide two measures of anxiety (State and Trait).

Test-retest reliability for the Trait Scale ranges from .73 to .86; whereas the range for the State Scale is .16 to .65. With the use of the Kuder Richardson formula, internal reliability ranged from .83 to .92 for the State Scale. High estimates of internal consistency, ranging from .89 to .91 as indexed by alpha coefficients, are also noted for the Trait Scale. The authors report information about the validity of the scale. The correlations between this scale and other measures of Trait anxiety, the Taylor Manifest Anxiety Scale, the IPAT Anxiety Scale, and the Multiple Affect Adjective Checklist range from .85 to .73. The Trait Anxiety Scale discriminates between normal adults and different groups of psychiatric patients and between general medical and surgical patients with and without psychiatric complications. The State Anxiety Scale discriminates between high school students and military recruits who are

beginning a stressful training program, and the emotional reaction of surgical patients prior to and following surgery. Norms are available for males and females, aged 19 to 69 and are based on 1,838 working adults whose responsibilities varied from clerical to management/supervisory positions.

IPAT Depression Scale Questionnaire (or Personal Assessment Inventory)

The IPAT Depression Scale is a 36 or 40 item questionnaire developed by the Institute of Personality and Ability Tests (1976) to assess an individuals' level of depression. The scale was designed to be useful, both clinically and as a research tool, in differentiating between depressed and anxious persons. The Depression Scale generally takes about 10 minutes to complete for an individual with a reading ability of grade 5 to 6. The participant is required to choose between three answers to each question. The test is scored by the use of scoring keys. The summed score can range from a minimum of 0 to a maximum of 72. Higher scores indicate depression.

Reliability and validity have been established. Coefficient alpha reliabilities of internal consistency ranged from .83 to .95 and split half reliabilities range

from .89 to .95. The writers suggest that a test-retest reliability of around .93 might be expected based on extrapolation from another test, the Clinical Analysis Questionnaire (CAQ), which was developed and used by the authors as a starting point for this scale. The scale differentiates between normal adults and adults diagnosed as depressed. The IPAT correlates well with other scales, the CAQ, and MMPI, to conform to theoretical expectations. This scale correlates negatively, $-.32$ to $-.51$ with seven out of nine positive scores of the Tennessee Self Concept Scale. Norms are available for normal adults and depressed persons. These norms were based on a randomly selected group of 2,000 persons, aged 15 to 73 years and who were employed in a variety of occupations.

The Herth Hope Scale

The Herth Hope Scale (HHS) was developed by Herth (1991) to measure hope in both well and ill adults. Herth based her scale on Dufault and Martocchio's model of hope. Hope is defined as a "multidimensional dynamic life force characterized by a confident, yet uncertain expectation of achieving good which to a hoping person is realistically possible and personally significant" (Dufault & Martocchio, 1985, p. 380).

The HHS is composed of 30 items that contain both positive and negative statements. The respondents are asked to indicate how often each statement applied to them in the last week or two by choosing one of four responses: never applies to me, seldom applies to me, sometimes applies to me, and often applies to me. Each item is scored on a scale from 0 to 3; scoring consists of summing the ratings. The sum of scores can range from 0 to 90; higher scores denote greater hope. The HHS usually takes about ten minutes to complete and requires a reading level of grade six.

Cronbach's alpha reliability coefficients ranged from .74 to .94 and test retest reliability (at three weeks) ranged from .89 to .91. Content validity was assessed by four judges with expertise in the area of hope. Construct validity was evaluated by factor analyses; the respective alpha coefficients for each subscale were: temporality and future (.97); positive readiness and expectancy (.90); interconnectedness (.87). The scale has been shown to discriminate between well adults and cancer patients receiving chemotherapy. The HHS has been used to study the relationship of hope to grief resolution in the elderly. A negative correlation of $-.69$ was found between the HHS and Beck's Hopelessness Scale. Norms are available for well adults, bereaved elderly persons, and cancer patients. Norms for well adults are based on 185 participants. In

this study, the scale was used to provide one measure of hope.

Data Information Form

A data information form was used to collect information concerning demographic characteristics of the sample, such as age, religion, education, occupation and income (Appendix B). Further information, such as diagnosis, length of time since awareness of illness, information received from health care givers re: spouse/partner's condition, and their own expectations as to what would happen, was also recorded. This information was collected to describe the sample and assist with data analysis.

Data Analysis

Descriptive statistics using frequency tables indicating percentages, means, and standard deviations describe and summarize relevant characteristics of the participants and responses to the four questionnaires. t -tests were calculated to compare mean scores for males and females on State anger, State anxiety, depression, and hope, and to compare male and female mean scores with established well adult norms. The mean scores for males and females on both State/Trait anger and State/Trait anxiety subscales

were compared using the paired t -test. To determine whether relationships existed between State anger, State anxiety, depression, and hope, correlational analysis was performed with the Pearson Product Moment Correlation coefficient(r) statistic.

In addition to the exploration of the primary research questions, two additional questions were identified and explored. To determine the impact of participant expectations on anger, anxiety, depression, and hope, a series of one way analysis of variance with the Scheffe Post Hoc Pairwise Contrasts were performed. Chi square analysis was used to compare participant and medical/nursing expectations regarding the prognosis of the spouse/partner.

Ethical Considerations

The researcher received ethical approval from the University of Alberta, Faculty of Nursing Ethics Review Committee. Written approval was obtained from the Chairperson, Ethics Review Committee of the institution from which the sample was obtained. Participants who voluntarily agreed to take part in the study were informed about the details of the study and the purpose of the study. Each potential participant was assured of his/her right to 1) refuse to participate, 2) refuse to answer any particular

questions, 3) withdraw from the study at any time without affecting the care of their spouse/partner and 4) was informed of the potential benefits and possible risks associated with the study. Each participant signed a written, informed consent and was given a copy for his/her records. Each participant was provided with the name of a support person in the event that questions were upsetting to them. None of the participants required this type of intervention. However, some of the participants were encouraged to contact the support person because of personal concerns.

Anonymity of participants was maintained in that names were not attached to individual data collection sheets; data collection sheets were coded with a number. The identity of the participants was known only to the researcher. All participants were assured that names and individual personal characteristics would not be mentioned in data analysis or discussions of results. Participants were informed that their names, telephone numbers, and descriptive numbers would be kept in a separate, locked file and, at the conclusion of the study, would be destroyed.

CHAPTER IV

Results

The purpose of this study was to examine the level of select components (anger, anxiety, and depression) of the anticipatory grief response and hope as they occur among persons whose spouse/partner had been diagnosed with cancer. Data were obtained by pencil and paper self report instruments and review of the spouse/partners' medical records. Data were collected over a 5 month period, beginning in October 1992 and ending in March 1993. In this chapter, the results of the data analysis will be presented and will include a description of the participant and spouse/partner characteristics. Second, the research questions will be answered. Finally, two additional research questions will be discussed.

Characteristics of the Sample

The findings of this study were based on a convenience sample of 52 participants (30 females and 22 males). A description of the participant characteristics including data about age, race, religion, education, occupation, and income are presented in Table I.

Table I

Characteristics of Male and Female Participants

Variables	Males N=22	% 42.3	Females N=30	% 57.7
AGE				
Range	30-69		26-67	
Mean	51		50.83	
S.D.	13.016		11.29	
RACE				
White (caucasian)	21	95.5	28	93.3
Oriental	1	4.5	1	3.3
Native			1	3.3
RELIGION				
Protestant	12	54.5	23	76.7
Catholic	6	27.3	5	16.7
Other	3	13.6	2	6.7
Missing Data	1	4.5		
EDUCATION				
Less than high school	6	27.3	8	26.7
High school graduate	2	9.1	6	20.0
Some university/college	9	40.9	11	36.7
University degree	2	9.1	4	13.3
Post-graduate university degree	3	13.6	1	3.3
OCCUPATION				
Retired	8	36.4	3	10.0
Housewife			10	33.3
Professional	5	22.7	6	20.0
Small business owner	2	9.1	5	16.7
Clerical and sales	1	4.5	4	13.3
Skilled manual	5	22.7	2	6.7
Missing data	1	4.5		
INCOME				
10,000 to 20,000	3	13.6	2	6.7
20,001 to 30,000	3	13.6	6	20.0
30,001 to 40,000	7	31.8	8	26.7
Over 50,000	7	31.8	11	36.7
Missing data	2	9.1	3	10.0

Participants were the spouses/partners of cancer patients who had many different primary sites of cancer, and varying durations of illness. Illness related characteristics are presented in Table II.

Table II
Illness Related Characteristics of Spouses/Partners

	Spouse/Partners N = 52	%
PRIMARY SITE OF CANCER		
Esophagus	1	1.9
Colon/Rectum	4	7.7
Pancreas	1	1.9
Larynx	1	1.9
Hematopietic Cancer	18	34.6
Skin Melanoma	1	1.9
Breast	6	11.5
Ovary	2	3.8
Uterus	2	3.8
Prostate	4	7.7
Bladder	1	1.9
Kidney	1	1.9
Endocrine	1	1.9
Oral Cavity	1	1.9
Lung	4	7.7
Unknown	2	3.8
Other	2	3.8
LENGTH OF ILLNESS		
Less than four months	20	38.5
Four months to one year	8	15.4
One to three years	13	25
Three to five years	5	9.6
More than five years	6	11.5

Research Questions

Research Question 1a

What is the level of anger, anxiety, and depression among persons whose spouse/partner has been diagnosed with cancer?

The means, standard deviations, and t -test scores for male and female responses to the State anger subscale of the STAXI, the State anxiety subscale of the STAI, and the IPAT (Depression) are presented in Table III. As seen in Table III, the mean for the State anger subscale is slightly higher for males ($M=14.71$) as compared with females ($M=13.9$). Male participants scored slightly lower on the State anxiety subscale ($M=44.65$; $F=47.37$) and on depression ($M=18.57$; $F=20.5$) as compared with female scores. t -tests, used to determine differences between male and female scores for State anger, State anxiety, and depression demonstrated that differences between male and female means were not significant.

Table III
Means, Standard Deviations, and t-test Scores for State Anger, State Anxiety, and Depression

Variable	Gender	Mean	SD	t-test Score
State Anger	Male	14.71	6.43	0.49
	Female	13.9	4.89	
State Anxiety	Male	44.65	14.85	0.63
	Female	47.37	15.08	
Depression	Male	18.59	6.57	0.70
	Female	20.5	12.76	

The means, standard deviations, well adult norms and the t -test scores for the State anger subscale, the State anxiety subscale and IPAT (Depression) are presented in Table IV. The means for male and female participants were compared with established normative data of the State anger subscale, the State anxiety subscale, and the IPAT revealing that for both males and females all subscales were higher than the norm. t -tests were performed to determine if there were any significant differences between participant scores on State/Trait anger, State/Trait anxiety, depression, and established normative data.

Table IV
Means, Standard Deviations, Well Adult Norms, and t-test
Scores for State Anger, State Anxiety, and Depression

Variable	Gender	Mean	SD	t-test Score
State Anger	Males	14.71	6.43	
	Well Male Norms	11.29	3.17	2.44*
	Females	13.9	4.89	
	Well Female Norms	12.82	4.83	1.21
State Anxiety	Males	44.65	14.85	
	Well Male Norms	37.72	10.40	2.69*
	Females	47.37	15.08	
	Well Female Norms	35.20	10.61	4.42*
Depression	Males	18.59	6.57	
	Well Male Norms	16.95	10.03	1.14
	Females	20.5	12.76	
	Well Female Norms	18.99	11.00	0.99
Trait Anger	Males	18.43	5.02	
	Well Male Norms	18.65	4.81	0.20
	Females	17.13	4.26	
	Well Female Norms	19.44	5.11	2.97*
Trait Anxiety	Males	34.75	9.16	
	Well Male Norms	34.89	9.19	0.072
	Females	38.13	10.89	
	Well Female Norms	34.79	9.22	1.69

* < .05

As may be determined from Table IV, the t-tests indicated that, compared to well established male adult normative data, male participants in the study had significantly higher means for State anger ($t(22)=2.44$, $p=.05$) and State

anxiety ($t(22)=2.69$, $p=.05$). Compared to well female adult normative data, female participants had a significantly higher mean score for State anxiety ($t(30)=4.42$, $p=.05$) and a significantly lower mean score for Trait anger ($t(30)=2.97$, $p=.05$). However, the mean for State anger among female participants and depression among both male and female participants did not differ significantly from well adult normative data. The means for Trait anger among male participants and Trait anxiety among both male and female participants did not differ significantly from well adult normative data.

Research Question 1b

What is the level of hope among persons whose spouse/partner had been diagnosed with cancer?

To answer this question, means on the Herth Hope Scale for male and female participants in the study were calculated. These means and standard deviations are presented in Table IV. As seen in Table V, the difference in the mean for males ($M=70.04$) in comparison with the mean for females ($M=70.82$) is negligible. A t -test, used to determine differences between participant means and established well adult normative data ($M=80$), indicated that compared to well adult normative data both male and female participants had a significantly lower level of hope ($t(22)=4.24$, $p=.05$; $t(30)=4.13$; $p=.05$).

Table V
Means, Standard Deviations, and t-test Scores for Hope

Variable	Gender	Mean	S.D.	t-test Score
Hope	Male	70.04	11.02	
	Norm	80	7.1	4.24*
	Female	70.78	12.23	
	Norm	80	7.1	4.13*

* < .05

Research Question 1c

Do differences exist in the level of State and Trait anger, and State and Trait anxiety among persons whose spouse/partner had been diagnosed with cancer?

The means, standard deviation, and t-test scores for male and female responses to State/Trait anxiety and State/Trait anger are reported in Table VI. Paired t-tests were computed to determine if there were significant differences in the means for both State and Trait anxiety and anger. Spielberger (1983) states that "the mean State anxiety score for a group will be approximately equal to its mean Trait anxiety score when the State anxiety scale is given under neutral conditions. State anxiety scores are higher when this scale is given under stressful conditions" (p. 5). Since the scales theoretically have the same mean,

raw scores were used in these calculations. However, since State and Trait anger scores do not have approximately equal means raw scores were transformed so that both scales had a mean of 50 and a standard deviation of 10 before calculations were undertaken.

Table VI
Means, Standard Deviations, and t-test Scores for State/Trait Anxiety and State/Trait Anger

Gender	Variable	Mean	S.D.	t-test Score
Males	State Anxiety	44.65	14.85	3.37**
	Trait Anxiety	35.50	9.24	
Females	State Anxiety	47.37	15.08	4.76***
	Trait Anxiety	38.13	10.8	
Males	State Anger	55.54	14.16	2.82**
	Trait Anger	49.0	12.58	
Females	State Anger	54.50	10.61	3.25**
	Trait Anger	46.2	9.29	

** < .01

*** < .001

As determined by paired t -tests the level of State anxiety differed significantly for both males ($t(20)=3.37$, $p=0.003$) and females ($t(30)=4.76$; $p=0.000$) from Trait anxiety. The paired t -test also indicated that, compared to Trait anger, both male and female participants had a significantly higher level of State anger: males ($t(22)=2.82$; $p=0.01$), females ($t(30)=3.25$, $p=0.003$).

Research Question 2

What are the relationships among State anger, State anxiety, depression, and hope?

The relationship among these major variables was assessed using Pearson product moment correlation coefficients. The results are reported in the Table VII.

Table VII

Correlation Matrix for Hope Scores, State and Trait Anger Scores, State and Trait Anxiety Scores, and IPAT Depression Scores

	Herth Hope	STAXI State Anger	STAXI Trait Anger	STAI State Anxiety	STAI Trait Anxiety	IPAT Depression
Herth Hope	1.000	-.598 p=.000	-.188 p=.093	-.648 p=.000	-.610 p=.000	-.573 p=.000
STAXI State Anger			.253 p=.037	.680 p=.000	.533 p=.000	.505 p=.000
STAXI Trait Anger				.216 p=.068	.185 p=.097	-.046 p=.373
STAI State Anxiety					.665 p=.000	.567 p=.000
STAI Trait Anxiety						.821 p=.000
IPAT Depression						1.000

As demonstrated in Table VII, Pearson's correlation procedures indicate significant correlations among the variables. Significant negative correlations were found between hope and State anger, hope and State anxiety, and hope and depression. These negative correlation suggest that lower levels of hope were associated with higher levels of anger, anxiety, and depression. Significant positive correlations were found between State anger and State anxiety, State anger and depression, and State anxiety and depression, meaning that higher levels of State anger were associated with higher levels of State anxiety and depression. Also of note, higher levels of State anxiety were associated with higher levels of depression.

In addition to the exploration of the primary research questions, two additional questions were explored. Major findings relating to these questions are discussed.

Research Question 3

What is the Impact of Participant Expectations on Anger, Anxiety, Depression, and Hope?

Participants were asked to respond to the question, "What do you think will happen?" Participant expectations naturally divided into three categories: death of spouse (N=24), uncertainty (N=12), and cure of spouse (N=16). Descriptive statistics (means and standard deviations) on

State-anger, State anxiety, depression, and hope were calculated for the three expectation groups. These means and standard deviations appear in Table VIII.

Table VIII
Means and Standard Deviations on State Anger, State Anxiety, Depression, and Hope for Group Expectations

Variable	Participant Expectations		
	Death	Uncertainty	Cure
State Anger			
M	16.17	13.83	11.75
S.D.	6.11	5.67	3.34
State Anxiety			
M	52.6	45.0	37.1
S.D.	14.12	14.45	12.83
Depression			
M	20.5	21.66	17.0
S.D.	9.99	13.24	9.03
Hope			
M	65.31	70.42	78.25
S.D.	9.82	13.56	8.84

As can be noted, in the Table, the means on each variable: anger, anxiety, depression, and hope, are different. Therefore, a series of one-way analysis of variance were conducted to determine if the means were statistically different. Results for the one-way analysis of variance are reported in Table IX.

Table IX

Analysis of Variance Summary Table for State Anger, State Anxiety, Depression, and Hope by Participant Expectations

Source of Variation	MS bet	MS Within	Df	F
State Anger	93.60	27.96	2.48	3.348*
State Anxiety	1120.99	183.736	2.49	6.101**
Depression	89.20	112.177	2.49	.795
Hope	803.44	107.84	2.49	7.449*

* < .05

** < .01

As demonstrated in Table IX, the means for State anger ($F=3.348$, $p=.0435$), State anxiety ($F=6.101$, $p=.0044$) and hope ($F=7.449$, $p=.0015$) varied significantly according to participant expectations. The Scheffe Post Hoc Pairwise Contrasts, used to determine which of the specific means were statistically different, revealed that participants whose expectation was death had significantly higher levels of State anger ($t=2.90$; $p=0.006$) and State anxiety ($t=3.69$; $p=0.001$) but lower levels of hope ($t=4.47$, $p=0.000$) in comparison with participants whose expectation was cure. Levels of depression were not significantly different between the two groups.

Research Question 4

What is the relationship between participant expectations (death, uncertainty, cure) and medical/nursing expectations (poor prognosis, no guarantee, good prognosis)?

To answer this question a chi square analysis was computed to compare the number of participant and medical/nursing expectations in each category with the number expected. The chi square analysis was computed based upon Erickson and Nosanchuk's (1977) criteria that chi square analysis can be used appropriately for tables larger than 2x2 if the mean of the expected values equals 6 or more. The mean of the expected values for this analysis equals 5.78. The frequency distribution for these two variables is depicted in Table X.

Table X
Frequencies and Chi Square Analysis of Participant and
Medical/Nursing Expectations

		Poor Prognosis	No Guarantee	Good Prognosis	Row Marginals
Expectations of Participants	Anticipated Death	21	3	0	24
		Ex = 12.9	Ex = 5.5	Ex = 5.5	
	Uncertainty	4	3	5	12
		Ex = 6.5	Ex = 2.8	Ex = 2.8	
	Cure	3	6	7	16
		Ex = 8.6	Ex = 3.7	Ex = 3.7	
Column Marginals		28	12	12	

The computed chi square value of 22.57 ($p=0.0002$) is statistically significant, suggesting a strong association between medical/nursing and participant expectations.

Summary of Findings

The findings of this study indicate that participants who were faced with the potential loss of a spouse/partner do report higher levels of State anger, State anxiety, and depression, as well as, lower levels of hope in comparison with well adult normative data. Also of note, participants reported higher levels of State anger and anxiety in comparison with their levels of Trait anger and anxiety. Levels of State anger, State anxiety, and hope varied according to participant expectations regarding outcome but levels of depression did not. Significant positive correlations were found between State anger, State anxiety, and depression. Hope was found to be significantly and negatively associated with State anger, State anxiety, and depression. Male and female participants did not vary significantly in their reported levels of State anger, State anxiety, depression, and hope. One other finding is of note. A strong association was found between medical/nursing and participant expectations regarding outcome.

CHAPTER V

Discussion

The nature and existence of anticipatory grief have been debated in the literature since Lindemann (1944) first introduced the concept. Since then, different perspectives of anticipatory grief have been presented by other writers. The majority of studies dealing with anticipatory grief in spouses of terminally ill adults have inferred, rather than measured, the presence of this emotional response. Therefore, the ultimate goal of this study was to obtain a better understanding of the nature of the anticipatory grief response of these persons. The emotional components of anticipatory grief studied are those frequently mentioned in descriptions of both anticipatory and post death grief.

A number of writers have suggested that anticipatory grief begins with and is associated with a gradual relinquishing of hope. Miller (1991) defines hope as "a state of being characterized by an anticipation for a continuing good state, an improved state, or release from a perceived entrapment" (p. 307). Therefore, another goal of this study was to empirically test the relationship between hope and the components of anticipatory grief.

Data from a convenience sample of 52 spouses/partners of cancer patients were obtained by self report paper and pencil instruments and review of patient medical records. This final chapter will include 1) a summary and discussion of the major variables, 2) implications of the findings for nursing research and practice, and 3) limitations of the study.

Anger

As previously stated, in comparison with well adults, the mean State anger score for males was high and the mean State anger score for females was not. The mean Trait anger score for males was comparable to well adult norms, but the mean Trait anger score for females was lower than the norms. Both male and female participants had significantly higher levels of State anger in comparison with their levels of Trait anger.

The clinical significance of these anger scores may be assessed by comparison with scores from Spielberger's original data. Spielberger (1988) reported that anger "scale scores between the 25th and 75th percentile fall into what might be considered the normal range . . . Individuals with anger scores above the 75th percentile are likely to experience

and/or express angry feelings to a degree that may interfere with optimal functioning. The anger of such individuals may contribute to difficulties with interpersonal relationships or dispose them to developing psychological or physical disorders." (p. 4)

In this study, three (16.3%) female participants had Trait anger scores above the 75th percentile in comparison to 12 (40%) females whose State anger score was above the 75th percentile. Five (23.8%) male participants reported Trait anger scores above the 75th percentile whereas 12 (59%) males had State anger scores above the 75th percentile. In conclusion, a number of participants (30.8%) experienced a significant increase in levels of anger in response to the illness of the spouse/partner. These findings are in agreement with those of other researchers (Binger et al., 1969; Chodoff et al., 1963; Friedman, 1967, Friedman et al., 1964; Hoffman & Futterman, 1971; Penfield et al., 1976) who reported that anger is common in the normal anticipatory grief response.

In comparison with the above findings, 27% of the widows and widowers, studied by Zisook et al. (1987) approximately two months after bereavement, reported feeling quite or extremely angry at themselves. These findings suggest that feelings of moderate to strong anger may be

equally common to both anticipatory and post-death grief.

Anxiety

In comparison with well adults, the mean State anxiety scores for both male and female participants were high, whereas the mean scores for Trait anxiety among both males and females were comparable to well adult norms as identified by Spielberger et al. (1983). Also of note, both male and female participants had high levels of State anxiety in comparison with their levels of Trait anxiety. In a further comparison with Spielberger's anxiety reaction group ($M=49.02$) 21 of the participants (42%) manifested levels of clinical anxiety. Also, 19 of the 50 participants (38%), who completed this questionnaire, evidenced levels of clinical anxiety in comparison with psychiatrically depressed patients as reported by Spielberger et al. (1983).

These findings are in agreement with those of other researchers (Chodoff et al. 1963; Friedman, 1967; Friedman et al., 1964; Hoffman & Futterman, 1971; Natterson & Knudson, 1960; Richmond & Waisman, 1955) who commented that anxiety is a common response in anticipatory grief. This finding of a clinical anxiety rate of 38% is comparable with the reported rate of Jacobs et al. (1990) who found 38.9% of widows/widowers to be anxious according to DMS III R

criteria, 6 to 12 months following bereavement.

Depression

In this study, the mean depression scores for males (18.51) and females (20.5) are considered to be within the normal range. However, when one looks at the range of scores differences begin to emerge. Krug and Laughlin (1977) have recommended a cut off score of 25 as discriminately between depressed and normal persons. According to this criterion 11 (21%) of the participants in this study were experiencing some level of depression. Krug and Laughlin (1976) also advise that higher scores, especially Sten scores of eight to ten, "should be taken seriously . . . and call for some follow-up (p. 31). Using this criterion, 7 of the above 11 participants (13.5%) evidenced levels of clinical depression.

The findings of this study are consistent with those of other researchers (Binger et al., 1969; Chodoff et al., 1964; Friedman, 1967; Friedman et al., 1964; Hoffman & Futterman, 1971; Richmond & Waisman, 1955) who suggested that depression is a common emotional response to the impending loss of a significant other. The findings of a depression rate of 21% is comparable with the reported depression rate of Clayton et al. (1977) but the rate of

clinical depression was low when compared to the findings of Zisook et al. (1987) who found 28% of widows/widowers to be depressed by DSM III criteria two months following bereavement. These findings do not support the work of Parkes and Weiss (1983) who stated that depression was not part of anticipatory grief but do suggest that clinical levels of depression may occur more often in post-death grief than in anticipatory grief.

Anger, Anxiety, and Depression

The findings of this study suggest that anger, anxiety, and depression are significant components of the emotional response to the potential loss of a spouse/partner. Sixteen participants (30.8%) manifested levels of anger above the 75th percentile; 21 participants of 50 (42%) manifested levels of clinical anxiety (above Spielberger's anxiety reactive group); and 11 of 52 (21%) participants experienced some level of depression. Thus, these findings support the definition of anticipatory grief used in this study.

Also of note, significant positive correlations were found among anger, anxiety, and depression, suggesting that participants who had higher anger scores also had higher anxiety and depression scores. Similarly, participants who had higher anxiety scores also had higher depression scores.

This finding regarding anxiety and depression is in agreement with Jacobs et al. (1990) who found that newly bereaved spouses who had higher anxiety scores also had higher scores on depression.

However other factors may influence the levels of anger, anxiety, and depression. Trait anger and Trait anxiety were significantly and positively associated with State anger. Trait anxiety was significantly and positively related to both State anxiety and depression. These findings imply that the participants who were more angry and anxious as individuals may be more angry, anxious, and depressed when faced with the impending loss of the spouse/partner. One other factor that may have influenced these levels of anger, anxiety, and depression is the awareness of change relating to oneself and one's situation because of the illness event or the potential loss of a spouse/partner (Chick & Meleis, 1986). These writers comment that loss of feelings of security, unmet needs, unfulfilled expectations, and changes in role relationships and responsibilities and self identity may result in changing emotional responses.

One other finding of this study is of significance. Two participants (9.5%) of the 21 participants who had been given a poor prognosis and expected the death of the spouse/partner did not manifest increased scores on any of

the variables of interest in this study. This is consistent with the findings of Friedman et al. (1964) who reported that some parents did not manifest evidence of grief. Rando (1984) commented that not all people who accept a warning of a poor prognosis will commence to grieve prior to the impending death. It may be that these participants had not yet entered into transition. Chick and Meleis (1986) comment "that if changes have not yet reached the level of awareness or are being denied either totally, or in terms of their implications - then that person is not yet in transition" (p. 241). On the other hand, the emotional responses of anticipatory grief may have been experienced and partially worked through over the course of the illness (Huber & Gibson, 1990) resulting in a low grief response (Fulton & Fulton, 1972).

Hope

Levels of hope for the participants in this study were low; the mean score being significantly lower than well adult norms. This finding is consistent with those of other researchers (Aldrich, 1974; Chodoff et al., 1964; Friedman, 1967; Gerber, 1964; Rosenblatt, 1983) that anticipatory grief is associated with a gradual relinquishing of hope.

As anticipated, higher levels of State anger, State anxiety, and depression were related to less hope. Trait anxiety was also significantly negatively correlated with hope indicating that participants who were more anxiety prone were also less hopeful. This is one factor that may have influenced the level of hope in these participants; participants who are generally more anxious may be less hopeful as individuals.

Anger, Anxiety, Hope, and Participant Expectations

Chick and Meleis (1986) comment "that meanings attributed to transition events may vary between persons" (p. 241) and suggests that differences in these perceptions may influence the response to such events. In this study, levels of hope, anger, and anxiety varied according to participant expectations regarding the outcome of the illness, but levels of depression did not. Further study is needed to explain the relationship of depression to expectations.

Participants who expected their spouse/partner to be cured had levels of anger, anxiety, and hope equal to well adult norms. Those participants who were uncertain regarding the outcome of the spouse/partner's illness had higher levels of both anger and anxiety (slightly below

Spielberger's anxiety reaction group, $M=49.02$) and less hope in comparison with well adults and participants whose expectation was cure. Participants whose expectation was the death of the spouse/partner were significantly more angry, anxious, and less hopeful in comparison to well adults and participants whose expectation was cure. Also of note, these participants were more angry, anxious, and less hopeful than those whose expectations was uncertainty.

These findings suggest a pattern of response, to the illness event. Chick and Meleis (1986) comment that pattern recognition is an important part of developing a typology of transitions. They comment that some of the other possible dimensions by which transitions can be described are duration, reversibility, scope, magnitude, and the extent to which the transition is anticipated. This knowledge would be useful for guiding nursing practice.

Gender

Males did not differ from females as to their level of hope, anger, anxiety, and depression. The influence of gender on anticipatory grief had not been previously studied; the present study, therefore, begins to add to knowledge in this area. Given the small sample size, these findings are tentative. More research with a large sample

is required to increase knowledge in this area.

Congruency of Spouse/Partner and
Medical/Nursing Expectations

In this study, 28 participants had been warned of the poor prognosis and impending death of their spouse/partner. Of these 28 participants, 21 (75%) commented they believed the spouse would die. This finding differed significantly from that of Vachon et al. (1977) who reported that 40% of the women who had been informed of the impending death of their spouse refused to accept the warning. The differences in these findings regarding acceptance of information about the impending death of a spouse may be due to several factors. In contrast, 16 percent of Vachon's widows said they had never been told and had no idea that their husband was dying. Many of these widows tended to see the husband's illness as a lingering long term disease in which death was not expected within a given time frame (Vachon et al., 1977). Many of these participants who accepted the medical/nursing prognosis expected death within a limited time. In further comparison, many of these spouse/partners were physically declining and were being treated for symptomatic relief.

Implications for Nursing

The present study illustrates, that among this non randomized sample, anticipatory grief is characterized by anger, anxiety, depression, and diminished hope. Levels of anger, anxiety, depression, and hope did not differ between males and females. The findings also suggest that not all persons will manifest evidence of grief prior to the impending loss of a significant other. Findings from this study have implications for nurses caring for spouse/partners of cancer patients. An understanding of the intensity of the psychological distress experienced by a significant number of these participants and the pattern of response associated with spouse/partner expectations provides a beginning base from which to develop appropriate nursing interventions for spouses/partners of cancer patients. Effective nursing practice must a) observe and reflectively listen to the spouse/partner; b) must take account of how the illness is perceived by the spouse/partner; c) make use of the pattern of response to guide nursing assessment; d) actively listen to spouse/partners helping them get in touch with thoughts and behaviors associated with their feelings; and e) recognize a spouse partner who is at risk psychologically or physically and refer to appropriate resources.

This study has demonstrated that hope is significantly related to spouse expectations and to lower psychological distress. Therefore assessment of hope by nurses caring for spouse/partners of cancer patients is most important. The definition of hope used in this study could serve as the theoretical base for the assessment of hope and the development of appropriate nursing intervention strategies. This definition of hope, based on Dufault and Mortocchio's (1985) model of hope, conceptualizes hope as composed of two distinct but related spheres (generalized and particularized hope) with six common dimensions (affective, cognitive, behavioral, affiliative, temporal, and contextual).

Dufault and Martocchio (1985) define these six dimensions as follows: 1) The affective dimension centers on a wide range of emotions (feeling positive, trustful, lighthearted, anxious, doubtful, sad, uneasy) related to confidence or uncertainty about the outcome. 2) The cognitive dimension identifies a desired outcome or goal that to the hoping person is realistically possible. Unsolicited comments of the participants in this study provide support for this dimension. Participant comments included: "I'm trusting in her fighting spirit"; "hope she lives to see her first grandchild"; "hoping for quality time together before she goes"; "hoping for a peaceful, painless death". 3) The behavioural dimension focuses upon actions

(psychological, physical, social, and religious) persons may take to bring about the desired outcome. Dufault and Martocchio (1985) report that these behaviours include thinking, reality scanning, learning, interpreting, making decisions, caring for another, seeking help of others, and praying in order to create a climate in which the outcome can be fulfilled. 4) The affiliative dimension centers upon the hoping person's sense of belonging or involvement with others, and shared mutual hopes. 5) Within the temporal dimensions some hopes are time specific and others are non time specific. Some hopes involve the immediate next moment while others are projected into a far distant future. 6) The contextual dimension focuses upon those life situations that surround, influence, and are part of the person's hope. Unsolicited comments by the participants also support this dimension. Contextual situations that influenced participants particular hopes included: type and site of cancer, spouse/partner's general condition and response to treatment, physician presented cure rates, previous experience with cancer within family members, view of the diagnosis as a challenge, not a threat, and view of cancer as a chronic illness.

Dufault and Martocchio (1985) comment that an "awareness of hope as multidimensional can guide listening, observing, and interacting to detect the presence or absence

of each dimension and to determine ways in which each dimension is present" (p. 389). An insight into how hope is operative may enable nurses to facilitate or support hope in spouses/partners of cancer patients. Further research on hope in spouses/partners of cancer patients and how it may be facilitated is imperative.

Recommendations for Further Research

Based on the findings of this study, the following recommendations for further research in this area are as follows.

- 1) Conduct a longitudinal study to explore the level of emotional response of spouse/partners over the course of the illness and in the bereavement period.
- 2) Replicate the present study, using a larger sample to explore the intensity of feelings, and at the same time, extend the study to include thoughts and behaviours associated with the emotional response.
- 3) A further study is needed to explore the relationship of influencing factors, such as participant situational and illness related characteristics, on the anticipatory grieving process.

- 4) Further study is needed to examine 1) the emotional response and factors associated with incongruency between spouse/partner and medical/nursing expectations; 2) factors related to spouse/partner expectation of death and a non apparent grieving process; 3) the relationship between separation anxiety and generalized anxiety; 4) the effects of personality factors (Trait anger and anxiety) on the grieving process; and 5) health related changes that occur during the process of transition.

Limitations

The following limitations of this study are recognized.

1. The small sample size, the non random method of selection, and the relatively high refusal rate restrict the generalization of the findings to the sample.
2. In using self report questionnaires one is unable to guarantee that the participant can and will accurately describe their feelings.
3. Spouses/partners were approached and questioned at only one point in time during the patient's illness. The responses, therefore, capture one point in time and the

changes that occur day by day and over time cannot be detected.

Conclusion

The present study and the literature support the assumption that individuals threatened with the loss of a spouse/partner do experience psychological distress and a significant number do experience moderate to high levels of such distress. These results are supportive of the study's conceptual framework; a pattern of response associated with spouse/partner expectations was identified. It is hoped that studies such as this will provide nurses with a beginning understanding of the emotional response of individuals to the illness and threatened loss of the spouse/partner. Ultimately, it is the goal to have nurses possess the necessary knowledge to assess individual responses and to design nursing interventions to promote better overall long term care for these individuals.

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**ANTICIPATORY GRIEF IN SPOUSES/PARTNERS OF
PERSONS DIAGNOSED WITH CANCER**

(Feelings of persons whose spouse/partner has been diagnosed with cancer.)

CONSENT FORM

This consent form, a copy of which has been given to you, is only a part of the process of informed consent. It should give you the basic idea of what the research project is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

The purpose of this study is to learn more about the feelings of people whose spouse/partner has been diagnosed with cancer. This is a nursing research study that is being done as part of a master's degree in nursing at the University of Alberta.

You will be asked to answer questions about your feelings on questionnaires and to answer some general questions about yourself: age, income, education and so on. About 45 minutes will be needed to do this. The questions can be answered in private and returned to the researcher. If you wish, the researcher will stay with you while the questions are answered. It is important that you answer the questions yourself.

You do not have to take part in the study if you do not want to. You are free to drop out of the study at any time just by calling the researcher at 429-6411. Taking part or dropping out of the study will not affect the care of your spouse/partner. You may refuse to answer any questions on the questionnaires.

Participation in this study may be of no personal benefit to the spouses/partners of patients. However, based on the results of this study, it is hoped that, in the long term, spouse/partner care can be improved.

If during or after answering the questions you feel a need to talk with someone, you may call Dr. Michael Handman, Director, Department of Psychology, 492-0896. He will talk to you about your feelings. The researcher will call you once you have completed the questions to check if you have any concerns.

Your name will not appear on any of the forms. You will be identified by a number. Only the researcher will know this number. All information including names and telephone numbers will be kept in a locked drawer. Only the researcher and her committee will have access to the study data. The findings of this study may be used in reports or articles. In either talks about the study or in written reports or articles, names will not be used and there will be no way of knowing who took part in the study. At the end of the study all names and phone numbers will be destroyed. The completed questionnaires will be kept in a locked drawer for seven years for possible future studies. The data obtained from this study may be used for future study only after receiving approval from an ethics committee.

Participants initials _____

Date _____

My signature on this form indicates that I have understood to my satisfaction the information regarding my participation in the research project, and agree to take part as a volunteer. In no way does this waive my legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities.

I am free to withdraw from the study at any time without jeopardizing my spouse/partner's health care. My continued participation will be as informed as my initial consent, so I am free to ask for clarification or new information throughout my participation.

I understand that Shirley Schooler (researcher) or her thesis co-supervisors, Dr. Marion Allen at 492-6411 or Dr. Karin Olson at 492-7751 will answer any questions that I have about the research project.

If at any time during the course of this study I feel that I have been inadequately informed of the risks, benefits, or alternatives, or that I have been encouraged to continue in this study beyond my wish to do so, I can contact the Patient Advocate at (403)492-8585.

A copy of this consent form will be given to me to keep for my records and future reference.

Name of Spouse/Partner of Patient

Signature of Spouse/Partner of Patient

Name of Witness

Signature of Witness

Name of Investigator

Signature of Investigator

Date

APPENDIX B

Demographic Data Form

Male: _____ Female: _____

Age: _____

Occupation: _____

What is the highest level of education you have completed?

Grade School	1	2	3	4	5	6
Junior High				7	8	9
High School				10	11	12
College or Technical School			1	2	3	4
University	1	2	3	4	5	6

Your total income last year was: (self and spouse)

less than \$10,000
 \$10,001 - \$20,000
 \$20,001 - \$31,000
 \$31,001 - \$50,000
 over \$50,000

Race: White _____ Black _____ Oriental _____ Other _____

Religion: Protestant _____ Catholic _____ Jewish _____ Other _____

Date of diagnosis: _____

Date of current hospitalization: _____

How long have you been aware of your spouse's/partner's condition?

What have you been told about your spouse/partner's condition? _____

What do you think will happen? _____
