

ANTICIPATORY GRIEF IN FAMILIES OF CANCER PATIENTS

by

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ABSTRACT

Anticipatory grief has been described as a grief reaction which occurs prior to an expected loss. If cancer is perceived as a threat to life, relatives of patients diagnosed with cancer may experience anticipatory grief upon learning of the patient's diagnosis. Health professionals must have a greater awareness of the manifestations of this syndrome if they are to provide comprehensive care to these patients and their families. This study was designed to determine if a diagnosis of cancer does precipitate the manifestations of anticipatory grief first described by E. Lindemann in members of the patient's family. These manifestations include heightened preoccupation with the patient, depression, a review of the possible forms of death which may befall the patient and anticipation of the modes of readjustment that would be necessitated by his death.

Using a semi-structured interview guide with open-ended questions, the investigator interviewed twenty family members of fourteen patients. The sample included spouses, children and parents of the patients. All of the interviews were recorded on audiotapes which were used for content analysis of the data.

Of the twenty subjects, seven described all four manifestations, six mentioned three, three mentioned two, three

mentioned one, and one subject did not mention any of the manifestations. Heightened preoccupation was described by seventeen subjects, depression by sixteen, reviewing forms of death by thirteen and anticipation of modes of readjustment by nine. Other common reactions expressed were fear of the disease and its consequences, hope inspired by knowledge gained from the clinic's specialists, and a feeling of ambivalence toward the disease and its treatment. Family differences were emphasized by the subjects' expressions of concern about the reactions of other members of the family.

The results of this study indicate that Lindemann's theory can be used as a framework for assessing the anticipatory grief reactions of this population and suggest that it may also be applicable in a wider range of life-threatening situations. The fact that anticipatory grief was not experienced universally by this group was contrary to statements made in the literature that anticipatory grief is inevitable following a diagnosis of cancer and suggests that the attitude toward this disease may be changing. Further study is needed to determine if knowledge level or perception of the disease are significantly related to the experience of anticipatory grief in the early stages of the disease and if there are other factors which may be influential.

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Chapter 1

INTRODUCTION

Cancer afflicts not only the patient, but those close to him as well. Smith (1975:80) stated "serious illness of a family member has a deleterious effect on the whole family." Surely, few would deny this statement. Man is a social animal and will always be affected in some way by anything which threatens an individual who is important to him.

The American Cancer Society (1974) indicated that cancer will strike two of every three families, afflicting one of every four persons alive today. The health team must be prepared to provide comprehensive care to these patients and their families. In order to accomplish this goal, it is essential to learn how this diagnosis affects members of a patient's family. With more knowledge in this area, health professionals will be able to provide the quality of care necessary to enable families to deal with this crisis.

While the expectation of a longer life for patients with cancer is increasing with every new treatment or drug, the diagnosis of cancer is still greatly feared. Marino (1976:26) observed, "Though it may be unrealistic and illogical, the fact

is, most people (including most health professionals) view cancer with a special dread."

Creech (1975:285) supported this view:

In our society, cancer has a particularly negative connotation which compared to other chronic diseases, even those with a similar prognosis. Many people feel the diagnosis of cancer is equivalent to a death sentence, but that a myocardial infarction is less threatening and socially more acceptable.

Bahnson (1975:294) pointed out:

There are many possible explanations for this social unacceptability of cancer. Perhaps the most relevant is related to everyone's fear of prolonged and painful suffering during the terminal stages of cancer. This image contributes to its reputation as the most dreaded disease.

This fear will inevitably play a large part in determining the individual's reaction to a diagnosis of cancer in himself or a loved one.

It is true that not all patients die of cancer. In 1974 The American Cancer Society said that of six persons diagnosed with cancer, four will die. Four not six! The same source indicated that two of these deaths could be prevented by early detection. So, it should be apparent that cancer cannot always be considered a terminal or fatal disease. Thus, health professionals are becoming more optimistic about the disease and its prognosis. However, these professionals must continue to

be cognizant of the possibility that patients and their families may not view the disease in the same way as the health team.

Cancer is perceived as a threat to life. Gullo, Cherico and Shadick (1974) found that patients with cancer experience similar stages to those described by Kubler-Ross (1969) in her studies of dying patients. While the reactions were similar, the authors identified some differences and attributed these differences to a difference in perspective.

Gullo, Cherico and Shadick (1974:53) stated:

One situation involves a threat to life, the other demands a confrontation with the certainty of death. Specifically, in a life threatening illness, death is often perceived as one of several possible outcomes; in the aware terminal patient, death is recognized as the probable outcome.

Lindemann (1944) found that individuals threatened with the loss of a loved one experience genuine grief reactions which he labelled anticipatory grief. Subsequently, as cancer is often perceived as a threat to life, family members of cancer patients may experience anticipatory grief reactions upon learning of the patient's diagnosis.

Conceptual Framework

Anticipatory grief is a term which is being used more frequently in recent literature. While few authors have described

it, most agree it is a grief reaction which occurs prior to an expected loss. Aldrich (1974:4) defined the term as "any grief occurring prior to a loss as distinguished from the grief which occurs at or after the loss." Weisman (1974:15) stated that it is the first stage of bereavement: "the unique characteristic of anticipatory grief is that we mourn for a loss that has not yet happened." Gerber (1974:27) agreed: "when there is an impending death the process of grief or grief work begins well before the actual death." Meyerowitz (1974:79) saw anticipatory grief as part of a desocialization process:

These culturally peculiar ways of undoing interdependency networks reduce the cognitive and/or affective aspects of previously established relationships. They minimize the assumed disruptive effects of dissolutions.

These authors, then, agree that this syndrome does exist, but none of them described it in detail.

Erich Lindemann (1944:106) first identified the existence of anticipatory grief and described it this way:

The patient is so concerned with her adjustment after the potential death of father or son that she goes through all the phases of grief--depression, heightened preoccupation with the departed, a review of all the forms of death which might befall him and anticipation of the modes of readjustment which might be necessitated by it.

This description provides the framework for this study.

While Lindemann did not describe these reactions in more detail, it may be assumed from his statement that the reactions seen in anticipatory grief would approximate those he described in bereaved individuals. He mentioned somatic symptoms of exhaustion, lack of energy, sighing respirations and digestive symptoms. He also described anger, irritability, guilt feelings and restlessness. Most of these are associated with depression. According to Peretz, (1970:24) the depressive symptoms of grief include: "insomnia, anorexia, weight loss, inability to concentrate, restlessness, hypersensitivity, sadness, weeping and self-reproach." These symptoms would thus be indicative of depression in individuals anticipating the loss of a loved one.

The second characteristic identified by Lindemann (1944) was of heightened preoccupation with the departed. For the bereaved, this preoccupation is with the image and memories of the deceased. For those anticipating the loss, the focus of their preoccupation is the patient himself. Freud (1916) first discussed the need for this intense preoccupation, indicating that it was a method which enabled the individual to eventually give up the lost person.

It is possible for preoccupation to take many forms. Wiener (1970) found that parents of fatally ill children usually

attempt to become highly knowledgeable about their child's condition and stated that this search for information often becomes an all consuming preoccupation. The child sometimes becomes the central focus of the parents' lives with other siblings and responsibilities taking second place. The individual may find that the patient is on his mind constantly and that he has little interest in anything not related to the patient.

The third characteristic that Lindemann mentioned is reviewing the forms of death that might befall the individual. This, it would seem, corresponds to the bereaved's need to review the events leading up to and surrounding the death of a loved one. Fulton and Fulton (1972:230) concluded that families faced with the terminal illness of one of their members will rehearse the death before it occurs. This rehearsal is part of the anticipatory grief syndrome and may include thoughts about when the patient may die as well as how he may die. Family members may also think about how they will behave at the time of the patient's death or how they will cope with the actual occurrence.

The last characteristic of anticipatory grief mentioned by Lindemann was anticipation of the modes of readjustment that would be necessitated by the death. Lindemann's sample was composed of families of service men who had departed for war and he mentioned that often the family had readjusted so thoroughly

while the soldier was away, that he was not accepted back when he returned.

The modes of readjustment to be considered would differ for each member of the family. The spouse may consider the necessity of taking on the responsibilities of the patient and may think about remarriage. Wives may consider the financial problem that would be precipitated by the loss of the family's bread winner. All members might visualize changes in family relationships and attempt to determine how they might cope with these changes. Each considers these needs in his or her own way as the loss of a significant other certainly means different things to different people.

Lindemann stressed the similarities between the reactions of the bereaved and the reactions of those anticipating a loss. Aldrich (1975) agreed that there are some parallels between conventional grief and anticipatory grief but identified some very important differences. He mentioned that while conventional grief generally decelerates with time, it is possible that anticipatory grief will accelerate as the expected loss comes closer. He also noted an obvious difference in the endpoint of the two types of grief: while anticipatory grief has a definite endpoint with the occurrence of the loss, conventional grief may be indefinitely prolonged.

Aldrich observed that hope can accompany anticipatory grief while it usually does not accompany conventional grief. Thus, hope and anticipatory grief are not seen as mutually exclusive.

As in conventional grief, the mourner may experience feelings of ambivalence toward the object of his grief. These feelings may precipitate guilt in the mourner because of his perception of the vulnerability of the patient. He may feel that his thoughts, words or actions have some influence on the outcome of the patient's disease.

Robbins (1974:115) stated "there is no formula that will minimize the fears associated with cancer. Anticipatory grief is inevitable regardless of the stage of the disease." If this is so, then one would expect to see the above manifestations of anticipatory grief in the family members of patients diagnosed with cancer.

Problem Statement and Purpose of This Study

If family members are experiencing anticipatory grief reactions when cancer is diagnosed in a loved one, it is essential that nurses develop greater awareness of these manifestations in order to provide these individuals with the type of support and guidance necessary to help them cope with this threatened loss

and continue to relate to and support the patient during his remaining days, months or years.

The purpose of this study was to determine if the diagnosis of cancer precipitates an anticipatory grief reaction in the patient's family members and to determine if this is a valid concept to consider when planning nursing care for these individuals.

The study was designed to answer two questions:

1. When cancer is diagnosed, do the patient's close family members or friends experience depression, heightened preoccupation with the patient, anticipation of the modes of readjustment that would be necessitated by the patient's death and thoughts about how the patient may die?
2. What are some of the other common feelings or reactions experienced by family members or friends of recently diagnosed cancer patients?

Chapter 2

LITERATURE REVIEW

Anticipatory grief is not a new term in professional literature. In fact, it was first used by Erich Lindemann in 1944. However, it has recently returned to the foreground and a few authors and researchers have explored various dimensions of this concept. While some have stated explicitly their interest in anticipatory grief, others have described the reactions of individuals faced with an expected loss without labelling these reactions. This chapter will focus on selected publications which discuss aspects of anticipatory grief. In that Lindemann suggested that individuals who experience anticipatory grief pass through the same stages as those who experience grief after an actual loss, some of the relevant literature dealing with the grief reaction will also be discussed.

Recently two sets of researchers have attempted to determine if anticipatory grief has any effect on an elderly individual's adjustment to the subsequent loss of a spouse. Clayton, Halikas, Maurice and Robins (1973:47) attempted to determine if

...it is true that the longer the relative lives, the easier it is to accept the death, and regardless of the length of the illness, if anticipatory grief occurs

does it make the post-mortem mourning less intense or shorter or suppress it altogether.

These researchers defined anticipatory grief as a constellation of four or more depressive symptoms and asked widows and widowers (one month after the death of their spouse) to identify which symptoms they were experiencing at the time of the interview. They also interviewed the subjects thirteen months after the death of the spouse. These researchers found that the frequency of symptoms experienced by subjects whose spouses' illness was longer than six months was similar to the frequency experienced by subjects whose mate's illness was less than six months (but longer than five days). There was, however, a tendency for those who lived through the longer illness to experience more depressive symptoms. Of the eighty-one subjects nineteen experienced anticipatory grief as defined by the authors. One month post-mortem, a significantly larger number of these nineteen were still experiencing a depressive reaction compared to those who had not experienced anticipatory grief. This difference, however, was not present thirteen months after bereavement. These authors concluded that the duration of illness is not related to the prevalence of symptoms and that anticipatory grief and immediate post-mortem depression are positively related. It is unfortunate that a retrospective design was necessary, as

it is possible that many of the spouses did not give an accurate account of their mood over the entire period of their mate's illness, and this may have had some effect on the results.

Gerber, Rusalem, Hannon, Batting and Arkin (1975:225) felt that:

Anticipatory grief is almost always present, in some form, during a long term debilitating illness and one has to assume that in different ways most bereaved-to-be will attempt to utilize this period to prepare for the future.

The purpose of their investigation was to explore the preventative value of anticipatory grief on the medical adjustment of the aged bereaved. Data were collected from eighty-one widows and widowers six months after their loss. These subjects were divided into two groups: those whose spouse had died of a short term illness (less than two months) and those whose spouse had had a chronic illness. These researchers found little difference in medical adjustment of these two groups. However, when they scrutinized the chronic illness group more closely, they found that the aged bereaved of a lengthy chronic illness (more than six months) did worse than the bereaved of a shorter chronic illness. They concluded that lengthy exposure to anticipatory grief has a negative effect on the post-bereavement adjustment of the surviving spouse. These conclusions make it imperative for health professionals to learn more about anticipatory grief

and how it manifests itself. These researchers did not define it, nor did they attempt to describe it, they assumed that it exists.

While these two sets of researchers used the term "anticipatory grief", it is more common to find studies which describe an individual's reaction to an expected loss without actually labelling this reaction. The best known of these was done by Elisabeth Kubler-Ross in 1969. Kubler-Ross observed two hundred patients with terminal diseases and documented their reactions toward their imminent death. She outlined five stages of the dying process: denial, anger, bargaining, depression and acceptance.

According to her, a patient's initial reaction to learning that he is dying is shock and numbness, followed closely by the first distinct stage--denial. This stage is characterized by the "no, not me" attitude and is epitomized by the patient who seeks a different diagnosis or prognosis from several sources.

The second stage of the process is that of anger. During this period, the patient may lash out at family, friends and especially at members of the health professions. He may be heard to say "Why me?" and to blame those around him for his discomfort.

A third stage, known as bargaining, is seen in many patients. During this stage the patient may bargain with God, with the doctors or with himself for more time. Often as one request is fulfilled, another will take its place.

The fourth stage, depression, is seen most often when the patient can no longer deny his condition because of an increase in his symptoms or the loss of a body part. Kubler-Ross differentiated between reactive depression for a past loss and preparatory depression for impending losses. She described the patient's need to express this sorrow if he is to work through this stage to the final stage of acceptance.

This last stage, acceptance, was described by Kubler-Ross (1969:112) as that state during which the patient is "neither depressed nor angry about his fate....It is a stage devoid of feeling." Kubler-Ross indicated that the majority of her patients reached this stage before their death.

After describing these five stages, Kubler-Ross (1969: 138) clarified their development and use: "Th

These means (patients' coping mechanisms) will last for different periods of time and will replace each other or exist at times side by side. The one thing that usually persists through all these stages is hope.

This is an important aspect of patients' reaction and tends to sustain them when everything else becomes a strain.

Kubler-Ross (1969:139) added:

In a sense it is a rationalization for their suffering at times; for others it remains a form of temporary but needed denial....(All patients) maintained a little bit of it and were nourished by it in especially difficult times.

This is a crucial part of a dying patient's reaction. Sister Madeleine Clemence Vaillot (1970:271) elaborated on this discussion and implied that hope is often a significant factor in a person's response to his illness:

Hope is opposed to despair. The one who despairs gives up....Any situation justifying hope is by definition, not amenable to strictly ordinary means, and hope sets its goals beyond mere human provisions.

She stressed the importance of nurses' maintaining hope for their patients in order to inspire hope in them.

Kubler-Ross opened up the area of care of the dying; she stimulated interest in these patients and her five stage theory has become widely accepted if not totally understood.

Many other authors have commented on the many characteristics of the dying patient but the most common controversy is the question of the patient's denial versus his awareness. The question often asked is "how much does the patient know". Kubler-Ross stated that all the patients in her study knew they were dying. On the other hand, Shneidman (1973:4) maintained that "No one can really ever know he is about to die because

there is always the intermittent presence of denial."

Hutschnecker (1959:238) agreed with Kubler-Ross: "If we discount accidents and homicide, it seems to me almost certain that deep within themselves most people know when they are going to die and most of them are ready." These statements typify the controversy between these two schools of thought.

Closely related to awareness is the patient's use of denial. Weisman (1972) wrote that there are degrees of denial: denial of facts, denial of implications and denial of extinction. Saunders (1971) spoke of the need to respect the patient's wish to deny and pointed out that denial exists more or less depending on the day. She said the patients cannot bear too much reality, so if they would like to talk about the weather, they should be given the freedom to do so. While the controversy remains, most authors agreed that denial and awareness are not mutually exclusive.

While most publications on death and dying deal directly with the patient, Kubler-Ross devoted one chapter of her book to the family. She stated (1969:168) "Family members undergo different stages of adjustment similar to the ones described for our patients." Unfortunately, it is difficult to determine in her discussion whether the data were gathered systematically from a large sample similar to her patient sample or haphazardly

from family members she met by chance. She described family members progressing through the same stages as the patient and claimed that the more grief is expressed before death, the less unbearable it becomes afterward. While this statement may seem to conflict with the findings of Clayton et al (1973) and Gerber et al (1975), essentially it does not. Kubler-Ross stressed the need for expression of the grief and there is no evidence that any of the subjects in these studies expressed their feelings prior to the death of their mate.

Recently, nurses have begun to show an interest in the needs of families of dying patients. Hampe (1975:3) set out to "determine whether the spouse whose mate is terminally ill feels that nurses recognize his needs and help him cope with the impending death as well as the actual death of his mate." Her sample was drawn from the population of spouses whose mates had been determined by the medical staff to be terminally ill and included only those spouses who lived within one hundred miles of the university medical center where the patients were hospitalized. The spouses were interviewed prior to and after their mates' deaths. Hampe identified eight needs she felt had been shown to be significant in the literature; she then interviewed the subjects to determine if they had perceived these needs. The needs identified were: to be with the dying person,

to feel helpful and of assistance to the dying person, to be assured of the comfort of the dying person, to be kept informed about the dying person's condition, to be aware of the impending death, to ventilate emotions, to receive comfort and support from family members, and to receive acceptance, support and comfort from the health professionals. Of the twenty-seven spouses interviewed prior to their mates' deaths, twenty-five identified all eight needs and the other two identified five and seven needs respectively. Eighteen spouses were interviewed following their mates' deaths and Hampe found that the death event did not alter their perception of their needs or concerns. It is important to note that although these needs were identified, they were not consistently met for this sample. Those needs which were met least often are those relating to the emotional needs of the patient and spouse. A not unexpected finding was that spouses generally felt that the nurses' primary responsibility was to the dying patient and that they were too busy to help the family.

In addition to the eight needs previously identified, Hampe (1975:127) found there were another eight areas of concern expressed by the spouses:

(1) need for religious support (2) concern about anticipatory grief (3) maintenance of hope for the spouse's survival (4) concern about loneliness and companionship (5) concern for continuity by health professionals in perceiving and meeting the needs of the patient and spouse (6) concern about ambivalent feelings in regard to the treatment and care of the mate (7) confidence in the health professionals (8) concern for personal daily problems.

While the generalizability of Hampe's findings may be limited due to her use of a non-representative sample, this study has implications for nursing service, education and research, and provides a baseline from which further studies in this area may develop.

In fact, Friehofer and Felton (1976) have since studied twenty-five pairs of terminally ill patients and their loved ones to determine nursing behaviours which offer the greatest support, comfort and ease of suffering to the loved ones. Using a Q-sort methodology, these researchers found that the most desirable behaviours were those related to the patient rather than the spouse and that the least desired were those behaviours which applied exclusively to the spouses. The authors (1976:336) assumed that their findings negated the opinions of experts who feel that a high priority need during grieving is to be allowed to express emotions. Before this assumption can be accepted, however, the influence of societal values on the responses of the subjects must be considered.

When a spouse or loved one is dying, it may not be considered acceptable to express one's own needs in preference to the patient's. Perhaps relatives need to receive explicit permission to identify and discuss their own needs. Also, it is possible, in fact probable, that health professionals continue to support the perception that while the patient is their responsibility, the family must cope on its own. Perhaps if time were specifically allotted for family members, their perceptions might change. It would be less difficult for individuals to identify a behaviour as helpful if they had experienced that particular behaviour in the nurses with whom they had had contact.

The patient with cancer is the one most often studied in research about the dying process. When describing a patient's reaction to the diagnosis of cancer, many authors specify distinct stages in the disease process which elicit different reactions in the patient. The three stages usually described are the pre-diagnosis, the diagnosis and treatment and finally the advanced or terminal stage. (Abrams 1966; Day 1966; Schmale 1970; Creech 1975 and Bahnson 1975). While most of the recent literature focuses on the final stage, it will be only briefly mentioned here as it corresponds closely to the previously discussed material on the dying patient.

The pré-diagnosis stage is often characterized by delay in seeking diagnosis (Shands et al 1951; Schmale 1971; Bahnson 1975). Schmale (1971:92) outlines the basic reasons for this delay:

1. ... The patient may label such symptoms, as weight loss, anorexia, fatigue, dyspnea, muscle and bone aches as related to overwork, depression, aging, trauma, neuralgia, etc.
2. Preoccupation with work, interpersonal relationships and other activities may lead to a decrease in perception or a disregard for bodily changes.
3. Anxiety or fear over the possibility of a diagnosis of cancer or its treatment... may become so threatening that the conscious awareness of the need for treatment will be temporarily blocked out or ignored.
4. Cancers involving the breast and genito-urinary tract may be neglected because of an embarrassment or shame which makes the individual unwilling to be examined in these areas.

These thoughts are supported by the other authors on the subject.

In describing the second phase of the process, the diagnostic and treatment stage, the most widely discussed problem is that of "when and what to tell the patient". Generally, there is agreement among the authors that the patient and his family should be informed of the patient's diagnosis (Francis 1969; Bahnson 1975; Creech 1975; Rosenbaum 1975 and Dunthy 1976). Most of these authors (as well as others) assumed that physicians are not always willing to discuss the diagnosis openly. Abrams (1966:317) said this explicitly: "in cancer the physician hesitates to communicate readily about the diagnosis as he does

in other medical situations, primarily because he is uncomfortable in this area."

The patient's initial reaction is usually described as anxiety (Shands et al 1951; Day 1966; Francis 1969; Bahnson 1975) yet, Abrams (1966:318) found that "When there is reason for hope, there is little reason for subterfuge, little anxiety on the part of the patient or the physician. Anxieties can be lessened by direct answers to questions asked." Abrams (1966:318) indicated that this stage is characterized by "direct and truthful communication, faith in physicians, maintenance of good relations, absence of depression and hostility and an ability to maintain a healthy equilibrium." This stage lasts as long as active treatment is given and is proving effective in controlling if not eradicating the disease.

Klagsburn (1971), Bahnson (1975) and Creech (1975) indicated that anger or hostility is another reaction commonly observed during this stage. The anger is similar to that described by Kubler-Ross (1969) and frequently manifests itself with "Why me?" questions.

Another reaction sometimes related to this stage of the disease process is depression. Francis (1969) indicated that depression is a stage associated with most diseases and that cancer is no different. Shands et al (1951:1167) supported

this assumption stating "patients who develop malignant lesions almost invariably show some degree of depression."

While these are the most commonly mentioned reactions, others identified include regression, (Francis 1969) dependency, (Shands et al 1951; Francis 1969; Schmale 1971) and paranoid reactions (Shands et al 1951).

When the patient enters the terminal stage of cancer (when no further curative treatment is prescribed) it is generally agreed that his reactions are typically the same as those described by Kubler-Ross. In fact, Kubler-Ross (1969:29) said "It is often said that people equate a malignancy with terminal illness and regard the two as synonymous." Many of Kubler-Ross' subjects were dying of cancer, so attempts to distinguish between reactions to dying and reactions to the disease seem virtually impossible.

Gullo, Cherico, and Shadick might dispute this last statement. They distinguished between the process of dying and the prospect of dying and stated (1974:53) "in a life-threatening illness, death is often perceived as one of several possible outcomes; in the aware terminal patient, death is recognized as the probable outcome." Based on this premise they carried out an exploratory study with the following objectives: 1. to investigate the experience of and the response to life threat-

ening illness in the adult cancer patient, 2. to investigate whether response to life threatening illness can be described in terms of a continuum or stage theory, 3. to find if stages exist in the response to life threatening illness; and if so, (a) do they differ from stages experienced by the dying patient as described by Kubler-Ross (b) if they differ, what is the nature of the apparent differences and similarities, and 4. to investigate the issue of generalized or predominant response style which endure throughout the illness.

The authors gathered the data for their study through extensive interviews with five patients and members of their immediate families. While their findings suggested that some response patterns exist and that these patterns differ in some significant ways from those described by Kubler-Ross, it is difficult to generalize these findings due to the small sample size. However, they identified that some differences may be present and thus paved the way for further research in this area.

Most authors describe the patient's emotional response to a diagnosis of cancer. Few discuss the family's response and of those who do, most have studied parents' reaction to a diagnosis of leukemia in one of their children. Because of this paucity of literature, it is imperative to review the available studies on these parents carefully.

In the early 1950's Bozeman, Orbach and Sutherland studied the mothers of twenty children ages eighteen months to six years who had been diagnosed with leukemia. The sample, one of convenience, included only those mothers whose children were hospitalized at a specific center during the time allotted for the study. While all interviews occurred during the child's hospitalization, there was no other control over the time period when the mothers were interviewed. Thus, the initial interview for some was during the child's first hospitalization when he was beginning treatment, while for others it was during a subsequent hospitalization when previously untried drugs were being used because of failure to respond to other forms of treatment. This discrepancy makes it difficult to compare the data between subjects and the authors identified this as an important limitation to their study. Another limitation of this design is the fact that some of the data is based on the mother's recall of events that took place up to nineteen months previously.

The authors indicated that as the project progressed, they developed interview schedules which allowed them to systematically direct the interview toward providing comparable data for each of the mothers as well as toward completing gaps in information. They identified specific difficulties in completing the schedules: 1. the death of the child resulted in termination

of contact; 2. the mother's resistance to repeated interviewing during the critical condition of the child; and 3. the frequently encountered need on the part of the mother to ventilate her feelings or to discuss practical problems arising from hospitalization was given priority over the highly detailed information called for by the schedule. It might have been more beneficial to the study to have used a less structured guide as it is possible that important data may have been lost while the interviewer attempted to concentrate on completing the schedule. While generalization from this study is limited by the sample selection and design, the findings nevertheless have implications for further research as well as medical and nursing practice.

The mother's initial reaction to the diagnosis was disbelief, followed by an attempt to disprove it or deny the implications of the diagnosis; none of the mothers attempted to deny the illness itself. Many mothers expressed guilt and assumed personal responsibility for their child's illness. Hospitalization precipitated separation anxiety in the mothers and the children with the reaction of one frequently intensifying that of the other. During this period, the mothers utilized existing relationships or developed new ones to deal with their most acute needs. The most frequently expressed needs were for tangible services such as transportation or housekeeping, for temporary

escape from the oppressive awareness of the illness and approaching loss, and for emotional support to bolster functioning.

In 1963, a more extensive study of parents of leukemic children was conducted by researchers at the National Institute of Health (NIH) (Friedman et al 1963). This study covered a two year period and included forty-six subjects representing one or both parents of twenty-seven children. All of the parents were contacted within twenty-four hours of the child's first admission to NIH and invited to participate. In that admission to the NIH usually occurred between two to five weeks following diagnosis of the disease by the child's physician, the subjects were likely in comparable stages. Of the forty-six subjects, thirty-five lived some distance from the NIH and were admitted to a ward of the hospital where they remained during all or a portion of the time the child was hospitalized. The other eleven subjects lived close by and were less available for study.

The parents studied in the ward setting were interviewed once a week and were seen almost daily on the ward. In addition, the nurses on their ward made and recorded observational notes. Each morning the parents filled out a brief questionnaire regarding their activities in the previous twenty-four hours. The parents seen on an outpatient basis were interviewed once every two weeks while the child was hospitalized as well as during periods of remission when the child was at home.

The interviews were primarily concerned with each parent's perception of his child's illness and clinical course, the defenses utilized by the parent to protect himself from the impact of the stressful situation and the threatened loss, and the individual's ways of dealing with the many problems that arise when caring for a seriously ill child.

The authors recognize the uniqueness of the setting in which their study was performed but feel justified in generalizing their findings due to the similarity of behaviour observed in both the parents on the ward and those who lived at home. However, the differences in data collection between the two groups suggest that some important data on the parents not admitted may not have been recorded. This fact limits the acceptability of their assumption.

The findings of these researchers were similar to those described by Orbach, Bozeman and Sutherland. The parents initially described feeling stunned or shocked on learning of the diagnosis. However, these researchers found that only an occasional parent registered disbelief, and most parents appeared to accept intellectually the diagnosis and its implications. Hope was revived when children were admitted to the NIH. Invariably the parents expressed a sense of guilt and tended to blame themselves for not having paid more attention to the early, nonspecific manifesta-

tions of the disease. This sense of guilt tended to be a transient phenomenon as the parents readily accepted assurance from the physician that the course of the disease was essentially the same no matter when the diagnosis was made. A minority of parents did, however, dwell on feelings of self blame. Another common characteristic seen in these parents was an insatiable need to know everything about the disease and most sought information from a variety of sources, for example staff, friends, other parents, newspapers, and magazines.

Parents coped with the stress of the situation in several ways. One of the most obvious defences was an intellectualization of the stressful event. There was often a lack of affective or emotional reaction. The parents were often aware of this paucity of emotional feeling, explaining it on the grounds that they could not break down in the presence of the children or their physician. However, Friedman et al (1963:617) suggested that there was some uneasiness about their apparent lack of emotional expression, evidenced by the fact that parents would occasionally verbalize their confusion and even guilt over not feeling worse. Denial, the intellectual disclaiming of a painful event or feeling, was another defence identified in many parents. Motor activity also served a coping function and the parent usually was at least partially aware of

the motivation behind such activity. The authors pointed out the value of these defences in allowing the parents to continue to be effective in caring for their children.

Most parents had some difficulty in coping with the reactions of relatives and friends who typically were less accepting of the diagnosis than the parents themselves. While these relatives or friends would not allow the parents to express feelings of hopelessness, they paradoxically expected the parents to appear grief stricken. Parents were not expected to take part in normal social activities and were often made to feel guilty if they did. The major source of emotional support for most parents was the parents of other leukemic children.

Most parents attempted to seek some meaning in the illness; while some were content with a deferred explanation, others wanted a more definitive answer. While some parents found religion a comfort to them, others found that their child's illness caused them to doubt their previous religious convictions.

Hope was universally expressed by the parents and did not appear to interfere with an intellectual acceptance of reality. As the disease progressed in the children there was usually a corresponding curtailment of hope in the parents. The hopes changed from a long term hope for a cure to a short term hope for one more remission or even shorter term hope for some

period of comfort for the child. Friedman et al (1963:621) stated:

"This gradual dissipation of hope appeared inversely related to the increasing presence of... anticipatory grief....It was common for parents to complain of somatic symptoms, apathy, weakness, and preoccupation with thoughts of the ill child.

Usually this process was obvious by the fourth month of the child's illness and gradually evolved as the disease progressed.

When the child entered the terminal phase, there was acceleration of grief work and the parents often appeared resigned to the fact that their child would die. During this time the parents would become increasingly involved with other children on the ward and would openly express a desire to resume a more normal life. There were periods of anger and hostility usually aimed at the staff. The death of the child was usually taken calmly with the appropriate expression of affect and there was generally some indication of relief that the child was no longer suffering.

This study involved comprehensive data collection techniques and thus adds significantly to the relative paucity of knowledge in this area.

Futterman, Hoffman and Sabshin added to this body of knowledge with their report on "Parental Anticipatory Mourning" (1972:241):

In this study formal interviewing of twenty-three sets of parents with leukemic children as well as informal contact with over one hundred additional families with children suffering from a variety of malignancies formed the empirical base for generating hypotheses regarding the adaptation.

Interviews with the parents were loosely structured and took place during part of the child's illness and after his death.

The authors observed that mourning inevitably begins before the death of the child and they saw it as a series of functionally related aspects or part processes. Mourning involves the gradual relinquishment of emotional investment in the dead or dying person and the authors found that even while maintaining hope, the parents in their study began disengaging from the child before his death. This in turn led to guilt and/or compensatory efforts on the part of the parent to diminish the disengagement.

Futterman et al (1963:251) defined anticipatory mourning as:

A set of processes that are directly related to the awareness of the impending loss, to its emotional impact and to the adaptive mechanisms whereby emotional attachment to the dying child is relinquished over time.

They have identified five part processes of anticipatory mourning which which they stated (1963:252) are sequential in emergence:

1. acknowledgement: becoming progressively convinced that the child's death is inevitable
2. grieving: experiencing and expressing the emotional impact of the anticipated loss and the physical, psychological and interpersonal turmoil associated with it

3. reconciliation: developing perspectives on the child's expected death which preserve a sense of confidence in the worth of the child's life and the worth of life in general

4. detachment: withdrawing emotional investment from the child as a growing being with a real future

5. memorialization: developing a fixed conscious mental representation of the dying child which will endure beyond his death.

The authors described these processes in detail and related the findings of previous studies in an appropriate manner. They suggested that their work was only a beginning and that more work must be done to assess whether the suggested processes and part processes are valid, and whether they can be reliably measured.

In 1973, a study of families of adult patients was undertaken by Cancer Care Incorporated and the National Cancer Foundation to identify and describe the financial costs as well as other consequences of catastrophic illness on the family.

The sample was selected from among all families who received extended service from Cancer Care Incorporated and whose cases were closed over a specific fifteen month period. All cases were reviewed by the social service staff to determine whether they could appropriately be contacted to request their participation. Many were considered inappropriate for a variety of reasons and this fact severely limits the generalizability of the findings. Of two hundred seventy-five families deemed

appropriate, one hundred fifteen returned questionnaires from which come the data for this study. The authors recognized the limitations of their non-representative sample but expressed the hope that this study would encourage other studies dealing with the cost of catastrophic illness.

Most of the data were related to the financial burdens of the illness and will not be discussed here. However, the study also identified some specific areas of social and personal consequences. The most common hardship reported was emotional or adjustment problems on the part of the family members. The authors stated (1973:48):

The illness brought about a marked personality as well as physical deterioration in the patient. Children in the family became confused, frightened and insecure. Adult relationships were wrought with fatigue and anxiety. There was in fact general debilitation of the entire family.

It is probable that this study uncovered only a small portion of the problems and concerns of family members. The study was conducted after the death of the patient and data were gathered in an extremely structured and impersonal fashion which may not have facilitated expression of feelings. The findings suggest that further indepth exploration of this area is essential.

Although references to anticipatory grief in the literature are sparse, many authors and researchers have focused on grief. Lindemann (1944:142) described acute grief:

Common to all is the following syndrome: sensations of somatic distress occurring in waves lasting twenty minutes to an hour at a time, a feeling of tightness in the throat, choking with shortness of breath, need for sighing, an empty feeling in the abdomen, lack of muscular power, and an intense subjective distress described as tension or mental pain.

He found that most of the bereaved experienced somatic distress, preoccupation with the image of the deceased, guilt, hostile reactions and loss of patterns of conduct. He also expressed the belief that within a period of four to six weeks it was usually possible to resolve a normal grief reaction.

Parkes and Bowlby have since attempted to explain the underlying theory behind these reactions. While Bowlby's theory implies that grief has the biological function of promoting reunion, Parkes' (1971:8) view was that "grief is a process of realization, of making real inside the self an event that has already occurred in reality outside." Based on this theory and on their belief that the grieving process is not as short as Lindemann described, Glick, Weiss and Parkes (1974) studied widows over a thirteen month period following their bereavement. Their sample was comprised of forty-seven widows and nineteen widowers which represented 26 percent and 16 percent respectively of those who had been contacted. Their comparison of those who participated with those who refused implied there were few demographic or social and psychological differences between these

two groups. However, this assumption was based on a retrospective analysis of the situation (they called the non-participants approximately two years after their refusal) and may thus have been an inaccurate assessment of these individuals at the time of their loss. This point may or may not be crucial, but it should be considered when attempting to generalize the findings. One important difference in the two groups is that the participants were willing and able to discuss their grief while the non-participants obviously were not willing to do so.

The authors indicated the majority of those studied experienced similar stages in their grief: most experienced shock or disbelief at the time of death; 92 percent of the widows cried; 88 percent became sad and despairing; some experienced psychophysical symptoms of sleeplessness and loss of appetite, inability to concentrate and lack of energy which persisted or recurred with reduced strength throughout the first year. Most widows in the sample exhibited rigorous self control during the early period of bereavement, attempting not to break down in front of others. After the funeral the widows were forced to recognize the need to establish a new routine and to plan their future life; at this time most widows cried less but their sadness became more pervasive. This phase seemed to last from several weeks to several months. These widows seemed to have passed

through the worst of their grief within two months after the death. Glick et al (1974:120) state:

They were no longer beset by unrelenting despair...however (they) were almost constantly aware of their loss as a background to their thoughts if not the focus of them.

Widows felt that a decent length of time should elapse before they resumed their normal appearance and schedule of activities, but they began moving toward this normal state soon after the burial.

During the period of intense mourning widows compulsively reviewed the course of their husbands' illness or accident. While this aspect of their grief was distressing, they had little control over it and seemed unable to stop. This reviewing seemed to help the widows integrate the reality of the death emotionally as well as cognitively. Nearly half of the sample revealed self-reproach in their obsessional review and identified acts of omission or commission which might have contributed to the death. They also experienced guilt over other aspects of their relationship with their husbands, or their behaviour following his death. While the other half of the sample emphasized their own suffering and devotion, Glick et al (1974:128) indicated that "these widows protested excessively, and that their attitude was a defensive response to the same deep uncertainty that was expressed more directly by other widows".

Many of the sample attempted to find a "meaning" in their husbands' death. As the sample consisted of widows under the age of forty-five, this search seemed particularly perplexing because their husbands had died at a time when their deaths should have been in the future. Their question, simply put, was "Why did this happen to him?"

During the first few months of bereavement, widows tended to idealize their husbands, but, after a time, their memories became more realistic. Almost all of the widows experienced a sense of their husbands' presence. This aspect of the reaction did not diminish with time. In fact, Glick et al (1974: 147) stated "it seemed to take a few weeks to become established but thereafter seemed as likely to be reported late in bereavement as early". There was a significant difference in this reaction between the widows who had had an opportunity to prepare themselves for their loss and those who had not. The latter were more likely to develop a fantasy relationship with their dead spouse.

After a year, most of the widows were well on their way to having detached themselves from their husband and their marriage. At this time most widows believed that although they had not yet arrived at a new stability, they had done well.

In summary, this study indicated that the course of grief described by Lindemann is not over in six weeks; this is merely the end of the most acute phase. In fact, the process of recovery extends over a period of many months and is not yet complete at the end of the first year.

Engle (1964:96) summarized the process of grief and identified three important stages: shock and disbelief, developing awareness, and restitution. He provides criteria for measuring recovery: "The clearest evidence of successful healing is the ability to remember comfortably both the pleasures and disappointments of the lost relationship." This ability then may be used as an indicator that the individual has successfully accomplished the work of grieving.

Summary

Two sets of researchers considered the possibility that anticipatory grief has some effect either positive or negative on an individual's adjustment following the death of a spouse. As their studies dealt only with the elderly bereaved and were retrospective studies, there was no opportunity to actually observe and describe anticipatory grief reactions.

Kubler-Ross (1969) described in detail the reactions of dying patients. These reactions could be seen as anticipatory grief in that the individual is preparing for his own loss.

However, the reactions of an expected survivor might be expected to be different from those of the patient himself. Kubler-Ross stated that the family's reactions are similar to those of the patient but she gave no indication of the method used to study the family members.

Many of the patients observed by Kubler-Ross were dying of some form of cancer, but most, it would seem, were in the terminal stages. Some authors considered patients' reactions to cancer in more detail and identified at least three stages of the disease process which may evoke various reactions: pre-diagnosis, diagnosis and treatment, and advancing disease or terminal stage. The reactions of patients may be similar to those of their families but once again, the patient is facing his own death while the family faces the loss of one of their loved ones.

Most of the work which describes the family's response to a diagnosis of cancer in one of its members has been done with parents of leukemic children. Several studies have described parents' reactions in some detail and a few of the researchers have identified and described anticipatory grief reactions in their subjects.

Anticipatory grief by definition would precede conventional grief. One is the reaction to an expected loss, the

other to the actual loss. As closely related phenomena, they may resemble one another in the manner in which they are manifested and some work has been done in documenting grief reactions. Stimulated by Lindemann's work in 1944, other researchers have since described the bereaved's behaviour over a period of up to thirteen months following their loss. The behaviours they have described may be similar to those manifested by individuals experiencing anticipatory grief.

This study is designed to document anticipatory grief reactions in family members of patients diagnosed with cancer. That few authors have studied this reaction when the patient is an adult member of the family emphasizes the need for further research in this area.

Chapter 3

METHODOLOGY

The purpose of this study was to determine if a diagnosis of cancer (a life-threatening disease) precipitates an anticipatory grief reaction in the patient's significant others and is thus a valid concept to consider in the nursing care of these individuals. As previously mentioned (Chapter 1, page 9) this study was designed to answer two specific questions about the reaction of individuals to a diagnosis of cancer in a family member.

It was based on the assumption that cancer is perceived as life-threatening: while more cancer patients can expect to live longer periods of time with their disease, cancer is still a threat to life and is perceived as such by cancer patients and their families.

This chapter describes the various aspects of the methodology used to carry out this study. The specific topics considered include: study design, sample selection, data collection and data analysis.

Study Design

This study was designed to increase the body of

knowledge about individuals' reaction to the diagnosis of cancer in a family member or loved one. As such, it is exploratory in nature. Filstead (1970) stated that a non-experimental exploratory study is the method of choice when the purpose is to increase understanding of human behaviour. Sellitz, Wrightsman and Cook (1976) indicated that the purpose of an exploratory study is to gain familiarity with a phenomenon or to achieve new insights into it.

Sellitz, Wrightsman and Cook stated that in an exploratory study the research design must be flexible enough to permit the consideration of many different aspects of the phenomenon. While this study was designed primarily to consider the possible anticipatory grief reactions of the subjects and thus concentrated on one aspect, an attempt was made to keep the design flexible enough to warrant the term exploratory. Other aspects of an individual's reactions which were difficult to separate from the anticipatory grief reaction were also identified and described in this study.

Sample Selection

For the purpose of sample selection it was necessary to operationally define two terms: "life-threatening disease" and "significant others". The definitions follow.

Life-threatening disease: a diagnosis of cancer following the discovery of a tumour which is non-resectable, or has been surgically removed with some suspicion of metastases, or requires further treatment following surgery.

Significant other: includes spouse, parents, children, siblings, and any other individual whom the patient identifies as playing an important part in the close personal aspects of his life.

After defining these terms it was necessary to secure a location where subjects could be found. The investigation was conducted at a large urban clinic for the diagnosis and treatment of cancer patients. Patients are referred to the clinic at various stages in the disease process: some are referred for diagnosis, while others are referred following preliminary diagnosis and/or surgery for consideration for further treatment. As patients in the former category may be referred back to their family physician or surgeon for care, the investigator decided, in order to ensure access to patients, to select the sample from among the families of patients in the latter group. Further, as many cancers can be considered highly curable and thus not life-threatening, it was decided to approach only those families whose member had been diagnosed with life-threatening disease. The specific criteria for selection were:

1. Subject is a significant other of a patient (aged 20-60) who has been diagnosed with life-threatening disease and has completed his diagnostic tests at the clinic.

2. Subject is aware of the patient's diagnosis and the possible consequences (assessed briefly with the patient and the attending clinic specialist before interviewing the subject).

3. Subject lives within the Greater Vancouver area.

4. Subject understands and speaks English fluently.

5. Subject is available for interview and agrees to have the interview taped (see Appendix A for consent form).

The procedure for obtaining the sample was complicated by the fact that the clinic operates primarily as an outpatient treatment facility and relatives frequently do not accompany patients to the clinic. Thus, in order to obtain subjects, the investigator first approached the patient when he came to the clinic. The study was explained briefly and the patient was given an explanatory letter to take home to his family (see Appendix B). All patients approached expressed interest in the study and stated their willingness to have at least some of their family participate. Often patients expressed the desire that their children not be approached to participate and this wish was respected. While the reasons differed, this was as true for parents of adult children as it was for parents of younger children. Often the patient felt that older children should not have to be concerned about their parent's condition and some stated that their children were too busy to give their time for

the study. Parents of younger children often stated that the child had not been fully informed or that the child was not aware of the severity of the parent's condition. Of those children informed of the study only two expressed reluctance to participate (teenage brothers). Two adults also refused to participate: a father who also would not allow his wife to participate and a husband. Both of these men felt that having the investigator come to the house would upset the patient and refused permission. It should be noted, however, that both of these patients had expressed interest and had talked with the investigator at some length about their own reactions and feelings.

After the patients reported their family members' willingness to participate, the investigator made an appointment for an interview with each subject. This was usually done by telephone and at this time any questions the subject might have about the interview were answered.

This method of sample selection provides a non-random sample as only patients who fit the criteria and were attending the clinic at the time of the study were approached. This type of sample has been described by Abdellah and Levine (1965:310) as a convenience sample, "where we select for study the patients who happen to be in the hospital at a certain time". The authors

pointed out that while there is an element of randomness to this type of sample, it is not truly random as all members of the larger population do not have the same chance of selection. It is therefore a non-probability sample which may not be representative of the population. As this was an exploratory study aimed at learning more about the feelings of individuals rather than at proving or disproving a given hypothesis, this limitation was not a major concern. In fact, Phillips (1971:95) stated :

If the definition of the problem emphasizes the context of discovery, a superior strategy (to a random sample) for a given problem might be to secure detailed data on a non-probability sample.

Data Collection

The method chosen for collection of the data was a semi-structured interview with open-ended questions. Sellitz, Wrightsman and Cook (1976) suggested that the interview is the technique of choice for revealing information about complex, emotionally laden subjects and as such it seemed appropriate for this study. The format of the interview was similar to the focussed interview described by Merton (1956). While there were specific topics to be covered in each interview, neither the wording of the questions nor the order of the topics was constant. Smith (1975) stated that this format gives the respondent more responsibility and freedom of expression in formulating his answers.

The semi-structured interview has some specific advantages. According to Phillips (1966), this less standardized format has advantages in the context of discovery. Quint (1976) stated that this method is preferable when dealing with sensitive areas because it allows for a shift in sequence of topics if such a change is in keeping with the readiness and mood of the respondent. Sellitz, Wrightsman and Cook (1976) suggested that it also helps to overcome the major disadvantage of an unstructured interview which is the inability to compare one interview with another. With this approach it is possible to ensure that the same topics are covered in each interview.

The topics covered in this particular study included: the individual's reaction to first learning of the diagnosis, his knowledge of the condition of his relative and his past contact or knowledge of cancer, his most important concerns at the present time, the effect of the patient's diagnosis on the individual's activities of daily living, his thoughts on the future effect of the diagnosis, effect on the relationship between subject and patient and any other topic that the subject felt was important to mention. (see Appendix C for interview guide).

Open-ended questions were used to permit the subject to answer the questions in his own terms. While this produces

some difficulty in analyzing the data, it is essential if the issue is complex or the relevant dimensions are not known.

Because open-ended questions were to be used, it was possible that the data collected would not be relevant to the study questions. Thus, prior to beginning actual data collection, the investigator conducted two pilot interviews to test the validity of the interview guide.

While the interview seemed to be the method of choice for data collection, it had its disadvantages. An interview is a social interaction between two individuals and the complexities of each must be considered. Sellitz, Wrightsman and Cook (1976) stated that bias in the interview situation appears to come about through the respondent's perception of the interviewer and the interviewer's perception of the respondent. Denzin (1970) stated that common errors in an interview are tacit assumption of understanding and the fact that the respondent does not always tell the interviewer what he wants to know. These sources of bias needed to be recognized and considered. The fact that all interviews were conducted by the investigator who was aware of these sources of possible bias helped to minimize their effect.

Once the method for collecting data was chosen, it was necessary to decide upon some method of recording the data.

Recording of interview data may be done by several methods: writing it up from memory, verbatim recording, field coding or mechanical recording. A tape recorder was selected for use in this study in order to have accurate verbatim accounts of the interviewee's responses. Sellitz, Wrightsman and Cook indicated that a tape recorder sometimes inhibits responses. All of the subjects in the study were assured that their replies were confidential and that the tapes were strictly for the use of the investigator. The investigator frequently spent a few minutes with the respondent before turning on the recorder in order to develop rapport. Only one subject showed awareness of the recorder during the interview and became more talkative when it was turned off. Kahn and Cannell (1957) stated that the respondent is usually willing to accept the recorder on the interviewer's explanation of its importance and this was found to be true in this situation.

After the decisions of what (an interview) and how (tape recording), it was necessary to decide "when". The subjects were all interviewed within three months of the patient's diagnosis and first contact with the cancer clinic, and all patients had completed their diagnostic tests at the clinic. This time period was chosen to decrease problems caused by poor or selective memory. Kahn and Cannell (1957:44) pointed out that

"we tend in memory to modify, change and distort past situations in order to make them fit more comfortably with other experience and with our image of ourselves". While it might have been more advantageous to approach subjects immediately following the patient's first contact with the clinic and thus decrease the memory loss even more significantly, the investigator found through the pilot study that family members were under too great a strain before the diagnostic tests were completed and treatment scheduled to begin. Once treatment was decided upon, many of their fears had been alleviated and they were more capable of discussing their feelings.

Most of the subjects (all but two) were interviewed in their homes. This provided them with the security of familiar surroundings and was intended to promote their comfort during the interview. Two subjects were seen at their places of work at their request. Many of the subjects expressed an initial reluctance when they thought they might have to come to the clinic and were relieved when the investigator stated she would see them at home.

When all of the decisions related to what, how, when and where had been made, the procedure of collecting the data began. The interview proceeded in a supportive, nonthreatening manner. The investigator explained that she was particularly

interested in the subject's reaction and feelings following learning of the diagnosis of cancer in their relative and assured subjects that whatever they could tell her would be helpful. Many of the subjects expressed pleasure that the family was being recognized and that their feelings were considered important enough to be investigated. Some subjects felt they had little to offer the investigator. This was particularly true of three husbands who insisted that the patient remain with them during the interview. With assurance that there was no right or wrong way to respond and with the encouragement of their wives these individuals became willing respondents.

The interviews ranged from twenty to eighty minutes with the average being approximately forty minutes. While this is the time period of actual data collection, the investigator spent at least one hour with each subject. Often following the interview, the patient joined the subject and spent some time talking with the investigator.

Data Analysis

Collection of data using a semi-structured interview with open-ended questions provided an abundance of data from each subject. The interviews were analyzed using a qualitative method -- the presence of specific indications of anticipatory grief was noted. Holsti (1969:10) stated:

Qualitative content analysis, which has sometimes been defined as the drawing of inferences on the basis of appearance or nonappearance of attributes in messages, has been defended most often, though not solely for its superior performance in problems of applied social science.... The single appearance or omission of an attribute in a document may be of more significance than the relative frequency of other characteristics.

As the purpose of the study was to identify if the subject had experienced any manifestations of anticipatory grief, the presence of these characteristics was determined and recorded on a specific coding tool. (see Appendix D)

The coding tool is composed of specific behaviours which the investigator and two other nurses (a member of the investigator's thesis committee and the director of nursing at the cancer clinic) felt were indicative of the manifestations of anticipatory grief outlined by Lindemann. The behaviours indicative of depression were found in Peretz's (1970) description of depressive symptoms of grief, with the addition of suicidal thoughts which were mentioned by one of the subjects in the pilot study. The behaviours selected to represent the other three manifestations were identified through reference to the literature, past experience with patients and their families and the pilot interviews. The two pilot interviews were analyzed by the investigator and the two nurses mentioned above, using a

preliminary version of the coding tool. The investigator then developed the final version using the comments and suggestions of the two independent coders.

After conducting the interview of each subject, the investigator listened to the tapes with the specific purpose of identifying the presence of any of the behaviours deemed indicative of the manifestations of anticipatory grief. When she heard a statement which she felt represented any of these behaviours, she made a check mark in the appropriate space on the tool, as well as an indication of the time of the statement on the tape. The tapes were subsequently transcribed and notations made in the margins beside those statements which described the behaviour.

To check the reliability of the investigator's coding method and to ensure that bias was not influencing the results, the two nurses mentioned above were asked to code a random sample of the tapes. Each independent coder was asked to listen to the same five tapes and using the coding tool, to note the presence of specific behaviours. The investigator then compared the three analyses to determine if the presence of the same manifestations had been identified by each coder.

Summary

The study was designed to determine if family members

of cancer patients experienced the manifestations of anticipatory grief described by Erich Lindemann in 1944. The sample was selected from among the families of patients referred to a large urban cancer clinic. The data were collected through the use of a semi-structured interview and the analysis of the data was qualitative in that the presence of specific behaviours indicative of anticipatory grief were noted.

Chapter 4

RESULTS

The purpose of the study was to determine if family members of patients recently diagnosed with cancer experienced the manifestations of anticipatory grief first outlined by Erich Lindemann -- depression, heightened preoccupation with the patient, a review of the forms of death which might befall him and anticipation of the modes of readjustment that would be necessitated by his death. Using a semi-structured interview guide, the investigator interviewed twenty family members of fourteen patients. The interviews were tape recorded and the recordings used to code the data. Several quotations from these tapes are presented in this chapter. In addition to a description of the sample and a discussion of the results of the interviews, this chapter includes a brief summary of the results of the pilot study and the coding reliability test.

Pilot Study Results

The pilot study consisted of interviews with two subjects -- the twenty-five year old daughter of a man with an inoperable lung tumour and the forty-three year old wife of a man with a recently diagnosed lymphoma. The tapes of these two

interviews were listened to by the investigator, the chairman of her thesis committee and the director of nursing at the cancer clinic. Each of these interviews lasted approximately forty-five minutes. The three listeners agreed that the data collected were relevant and appeared sufficient to identify similarities between the subjects. It was agreed that the interview guide was an acceptable tool for data collection.

The method of analysis was designed at this time. A preliminary draft of the data analysis tool was used by each of the three listeners to note the presence of the specific behaviours for each subject. All three raters identified identical behaviours for each subject and agreed that each of these subjects had experienced all four manifestations. Some behaviours or feelings mentioned by these subjects which had not been included on the preliminary draft were subsequently added to the final version of the coding tool.

Reliability of Coding Method

To ensure that the bias of the investigator did not influence the coding of the results, the two nurses mentioned above were asked to code a random sample of the tapes. Before beginning the interviews, the investigator used a table of random numbers to determine which tapes would be selected for this reliability check. Five tapes were selected so that one quarter of the interviews were analyzed by three independent raters.

The results of this reliability check were more than encouraging. For four of the five interviews all three coders were in complete agreement. Each identified behaviours indicative of the same manifestations; three of these subjects experienced all four of the manifestations and one described all but anticipation of modes of readjustment. When analyzing the fifth interview, one of the external coders felt that the subject was expressing some feelings of heightened preoccupation which were not identified by either the investigator or the other external coder. This was, then, a minor discrepancy in the three analyses.

An important finding was the fact that every manifestation noted by the investigator was identified by each of the external coders; that is, she did not identify manifestations which were not evident to others. It can be assumed, therefore, that any bias on the part of the investigator would not increase the number of manifestations attributed to each subject.

Sample Description

The sample consisted of twenty family members of fourteen patients. Table 1 shows that this included twelve spouses, three parents and five children. The patients ranged in age from twenty-one to fifty-nine and the subjects from twelve to fifty-nine. The patients' diagnoses varied consider-

TABLE 1

Age and Relationship of Subject to Patient

<u>Patient</u>		<u>Subject</u>	
<u>Tumour Location</u>	<u>Age</u>	<u>Relationship</u>	<u>Age</u>
Prostate	59	Wife	55
Skin	28	Husband	28
Breast	36	Husband	42
Testicle	21	Father	55
		Mother	53
Breast	46	Husband	50
		Daughter	22
		Daughter	14
Brain	44	Wife	36
Endometrium	42	Husband	43
Nasopharynx	24	Wife	23
Breast	43	Husband	50
		Daughter	21
		Daughter	16
		Daughter	12
Lung	49	Wife	49
Breast	47	Husband	48
Breast	33	Husband	33
Breast	50	Husband	51
Breast	29	Mother	59

ably. Of the fourteen, seven had tumours of the breast, and one each of the brain (astrocytoma), the lung, the testicle (teratoma), the endometrium, the skin (melanoma), the prostate and the nasopharynx. Only one of these patients had a non-resectable tumour with obvious presence of a metastatic lesion.

The educational background of the subjects varied widely. The youngest was still in grade seven and one spouse had his Doctorate in Philosophy. All of the adults had completed at least the equivalent of grade eleven: four attended a trade or technical school following high school; four had had some university; and one was a registered nurse.

The length of time between learning of the diagnosis and being interviewed ranged from five to thirteen weeks with the average being approximately eight weeks. During this time, the patient had had some surgery, had been referred to the clinic where he had undergone further tests and had been scheduled to begin further treatment. All but two of the patients were receiving Cobalt therapy at the time of the interview. Of the exceptions, one had begun a course of immunotherapy; the other was scheduled for further surgery following some diagnostic tests at the clinic.

Manifestations Experienced

Of the twenty subjects, nineteen described at least

one of the manifestations mentioned by Lindemann. Table 2 shows the specific manifestations experienced by each subject. Seven of the twenty described all four; these seven included four spouses, two daughters of one patient and one mother. Six of the subjects described three of the four manifestations. This included two spouses: a wife who did not discuss any thoughts about her husband's death and a husband who did not anticipate the readjustments that would be necessary should his wife die; two daughters of one patient and both parents of another, none of whom considered the modes of readjustment necessary following the patient's death. All of the three subjects who described only two of the four manifestations were husbands. While all three of these men mentioned some depression, each described a different second manifestation. The three subjects who experienced only one of the manifestations all described some heightened preoccupation with the patient. Only one subject, a husband, did not describe any of the four manifestations.

The most commonly experienced manifestation was heightened preoccupation described by seventeen subjects. Depression was mentioned by sixteen and anticipation of modes of readjustment and reviewing forms of death by nine and thirteen respectively.

TABLE 2

Manifestations of Anticipatory Grief
Described By Subjects

No. of Patients	Subject Relation- ship	Depression	Heightened Preoccupation	Anticipated Modes of Readjustment	Reviewing Forms of Death	TOTAL Number of Manifestations Experienced
1	Wife	x	x	x		3
2	Husband	x	x			2
3	Husband*	x	x		x	3
4	Father	x	x		x	3
	Mother	x	x		x	3
5	Husband	x	x	x	x	4
	Daughter	x	x		x	3
	Daughter	x	x		x	3
6	Wife*	x	x	x	x	4
7	Husband	x		x		2
8	Wife		x			1
9	Husband*	x			x	2
	Daughter		x			1
	Daughter	x	x	x	x	4
	Daughter*	x	x	x	x	4
10	Wife*	x	x	x	x	4
11	Husband		x			1
12	Husband	x	x	x	x	4
13	Husband					0
14	Mother	<u>x</u>	<u>x</u>	<u>x</u>	<u>x</u>	4
TOTAL number Experiencing Specific Manifestations		<u>16</u>	<u>17</u>	<u>9</u>	<u>13</u>	

* Random tapes used for reliability check

Table 2 also shows that all family members of a specific patient did not experience the same manifestations. In one family group the father described all four, but the two daughters did not mention any thoughts about necessary readjustments following the possible death of their mother. In the other family group, there were more obvious differences: two of the daughters described all four of the manifestations while the third daughter only mentioned some heightened preoccupation with her mother. The patient's husband (the girls' stepfather) alluded to some depression and thoughts about the possibility of his wife's death. These differences in the way individuals experienced their grief caused some conflict in this last family and will be discussed in more detail later.

Each of the four manifestations of anticipatory grief were experienced in different ways by different individuals. The following quotations from the interviews were selected to depict these differences as well as the similarities.

Depression

Sixteen of the subjects mentioned some aspect of depression with some describing the feeling more thoroughly than others. Table 3 shows the specific number of subjects who described each behaviour.

TABLE 3

Behaviours Described by Subjects which were Indicative of Depression

Behaviours Described	<u>Subjects:</u>																Total Subjects Describing Specific Behaviour
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	
Insomnia	x		x	x				x	x						x		6
Anorexia			x						x								2
Weight Loss									x								1
Inability to Concentrate			x		x						x						3
Restlessness			x		x			x						x	x		5
Hypersensitivity								x	x								2
Sadness	x	x		x	x	x	x	x	x	x	x	x	x			x	13
Crying	x	x			x	x		x				x				x	7
Self-reproach									x				x				2
Suicidal Thoughts																	0
Crying During Interview				x										x			2

The most commonly described behaviour was a feeling of sadness, with thirteen of the sixteen mentioning it. Crying or weeping was cited by seven of these subjects and another two cried during the interview. Six subjects described some difficulty sleeping and five mentioned a feeling of restlessness. Three found that their power of concentration was disturbed. Two individuals experienced some anorexia and one of these two described a large weight loss. Two mentioned feelings of hypersensitivity and self-reproach. All but three of these subjects described more than one of these behaviours. The three exceptions only mentioned a feeling of sadness.

Each of these subjects used different words to describe their feelings, and some were able to convey these feelings more easily than others. Thirteen individuals mentioned a general feeling of sadness, of being "down" or being "upset". One wife described her feeling when she first learned of her husband's brain tumour:

I was really really upset; we have no family in Canada. We are here all on our own and I just sat here by myself with four children and just dying inside.

Another subject, the wife of a patient with a non-resectable lung tumour said:

It's a shattering thing but you know deep down inside yourself that worrying excessively

isn't going to help him. You worry but you can't make it obvious.....being a woman you have to prevent yourself from bursting into tears at every little thing.

Two daughters of one patient both expressed a feeling of sadness. The twelve year old described it in a few words:

"I was sad and mad also". Her sixteen year old sister was less succinct but conveyed a similar feeling:

I guess I feel weak to the whole situation 'cause you can't do anything about it, I mean I know she's got it and I know I feel really terrible but I don't know, it's a hard thing to say, it's a terrible feeling and it's always in the back of my head kind of, I try not to let it bring me down.

Three husbands in the sample found it difficult to put their feelings into words. One husband who was near tears throughout the interview stated: "I'm more withdrawn, more serious...I just know it's very bad, very serious and that was enough for me". The youngest husband in the group could not describe his feeling precisely but stated: "You think its a bit ridiculous going to work; I was really down when S. (the patient) was first sick." Another whose wife had had bilateral mastectomies was also near tears when he said: "There's been a few times -- it's been pretty tough, I can tell you."

The parents of a twenty-one year old patient spoke very little about feelings during their interviews. However, the father did say: "You experience a feeling of shock and

confusion, and there is an underlying feeling of despair."

This man's wife began to cry during her interview and reacted to her own tears:

I'm surprised at myself, I haven't really -- I've been concerned and distressed but very hopeful. (I've had) a feeling of anxiety for two months, but it's easing off now. It's something that you need to learn to live with....You don't have much enthusiasm for doing things.

This same mother also mentioned that she had experienced some crying:

I get a little weepy at times, but not too frequently...I'd like to be able to really release it by stomping up and down and screaming but I'm not made that way and I couldn't, I just couldn't so there's no point in saying it would help....It obviously helps other people.

The other mother in the sample also cried during the interview. Her twenty-nine year old daughter had had a mastectomy and had extensive lymph node involvement. After she had dried her tears she remarked: "B. (the patient) has seen no tears or upset." The mothers were not the only ones in the sample who mentioned crying. The twenty-eight year old husband of a patient also stressed the fact that his tears had not been seen by the patient: "I cried, but not around (the patient). I wanted her to see me as someone who was helping." Another spouse, the wife of a fifty-nine year old patient mentioned that she had been able to remain calm when she first learned of the diagnosis

from her husband but "when I got home I wasn't quite as calm, I was really upset -- I'd been crying." Three of the five daughters interviewed also cried at some time after learning of their mothers' diagnoses. The two daughters of one patient shared their tears upon learning of their mother's condition. The oldest daughter stated: "We hashed it out together and both of us had a good cry." This daughter also spoke of having to "fight off the tears" and "keep from breaking down in front of mother." The twelve year old daughter of another patient said:

Well, at first I was crying a lot....When I go to bed, she comes down to say goodnight and she's so warm and comfortable and after she leaves I just cry....Now when I get into trouble I cry at the very littlest thing.

In addition to a feeling of sadness and crying, some subjects mentioned other symptoms of depression. Some degree of insomnia was described by six of the subjects. One husband describing the period of time shortly after his wife's mastectomy stated: "Sleeping was a problem, I was only getting about four hours a day." Another husband describing the similar time period said: "I didn't sleep very much." The father of the twenty-one year old patient admitted that his sleeping was disturbed shortly after learning of his son's diagnosis: "Yes, there was an inability to sleep at the early point." Another

patient's mother described a similar difficulty:

I did a lot of thinking the first few nights,
I don't think anyone slept too well but I think
now you learn to live with it.

The twenty-two year old daughter of a patient described the night she learned of her mother's diagnosis: "I was awake most of the night and since then I'm often up prowling around the house." Another subject, the wife of a patient hospitalized for six weeks during his treatment stated: "I didn't sleep too well. I sort of kept one ear open for the children. It's a big house and we're vulnerable."

Several subjects mentioned an inability to concentrate or a feeling of restlessness. The two mothers in the sample described this reaction most clearly. One said: "I was nibbling and eating and fussing about; you know, I was -- I certainly wasn't relaxed." The other remarked: "you find you're distracted at times. I find I make mistakes when I'm not thinking about what I'm doing."

Two wives mentioned feelings of guilt or self-reproach --one for her behaviour toward her husband before his brain tumour was discovered:

The worst thing was that we'd been having a few fights before and I was -- I was getting the guilts -- that it was something to do with all this and -- it's a strange feeling you go through.

The other wife was concerned about her anger at being deserted by the patient. She said:

I'm afraid I have certain guilt feelings 'cause my worst reaction was 'I'll be working forever!' It's selfish but I -- you do get the feeling that the easiest part is for him. He won't be there to cope with the rest of the problems as they come.

Most of the subjects experienced a combination of at least two or three of the symptoms and often described them at different times during the interview. As can be seen, each found different words to describe their feelings.

Heightened Preoccupation

Seventeen of the subjects described at least one of the behaviours indicative of heightened preoccupation. Table 4 shows that the most commonly described behaviour was the development of a protective attitude toward the patient (experienced by eleven of the seventeen). Ten of the subjects mentioned that the patient was thought of often and nine described a need to learn as much as they could about the patient's disease. Only three subjects mentioned not wanting to leave the patient alone. Two described a disinterest in social activity and two others discussed their inability to carry on other responsibilities in view of the patient's condition. Several subjects mentioned that their business and personal responsibilities could not be ignored and felt that it was these responsibilities

TABLE 4

Described Behaviours Indicative of Heightened Preoccupation

Behaviours	Subjects:																	TOTAL - #'s of Subjects. Des- cribing specific behaviour
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	
Ignores responsibilities other than patient			x				x											2
Cancels planned vacation away from patient																		0
Continually thinks of patient	x		x	x	x			x	x	x		x	x		x			10
Patient is main topic of conversation																		0
Discontinues social activities					x											x		2
Dislikes or attempts to prevent patient being alone							x									x	x	3
Seeks new informa- tion about patient's diagnosis		x	x	x		x		x	x	x					x		x	9
Has developed protective attitude toward patient	x	x		x		x		x	x		x	x	x	x		x		11

that had helped them to deal with this crisis. None of the subjects in this sample mentioned cancelling planned vacations or finding that the patient was usually their main topic of conversation -- two behaviours which were mentioned by both of the subjects in the pilot study.

No matter how it was expressed, the common feeling identified by these seventeen subjects was a narrowing of their perspective with the focus of their attention becoming the patient.

The parents of the twenty-one year old man with a testicular tumour described how they had found their interest in people and things other than the patient had decreased. The patient's father said:

We're concerned with him and no one else....
Worry is with you and no matter how hard you try to dispel it from your mind, you can't. (There is) dis-interest in some things but (you are) driven by necessity and obligations to continue and to do other things.

His mother's reaction was similar:

You don't have any enthusiasm for doing anything beyond the essentials....We haven't invited people over, we like to have friends in for dinner but I literally haven't felt like inviting anyone. It just didn't seem like I had time to do it, which isn't quite accurate but we didn't....We were too turned in and concerned with ourselves I guess to be looking outward which is our usual pattern....I find I'm distracted at times and make mistakes when I'm not thinking of what I'm doing. My mind is not up to its best capacity since all this has happened. E. (the patient) is on my mind a great deal of the time.

The third parent in the sample also mentioned a similar curtailment of activity. She said: "We've been keeping ourselves free so that we could bring her in (to the clinic) or do anything she needed. So we're home a little more." Two other subjects, both husbands, indicated that they too had changed some of their habits to spend more time with their wives. One, who ran his own business, stated:

I slowed down...I didn't take on any extra work. I spent more time at home, I didn't hustle for business. If it came, I took it but I didn't go out after it. I stayed home more.

The other also changed his work habits somewhat:

I rarely used to get home before seven and this affected evening activities. Since the operation I've made every effort to be home by five-thirty and even though I take work home, I seldom open it. But, I get up earlier and often leave before she's up; it's a trade off, breakfast for evenings. I have certain commitments that can't be handed on to others. I have unloaded some things on to others....I think it's fair to say that I have been more sympathetic to her problems, all of them not just the cancer, since her diagnosis.

Two daughters interviewed found that thoughts of their mothers were with them constantly. The twenty-two year old mentioned that her mother was on her mind most of the day, but especially in the morning when she attended the clinic for treatment:

I 'phone Mom everyday when she gets home. I even stop what I'm doing to 'phone her and if she's not home when she usually is, I get worried.

The sixteen year old daughter of another patient was disturbed by this preoccupation:

It's a terrible feeling and it's always in the back of my head, kind of. I try not to let it bring me down. Sometimes I feel like not doing anything, I just feel like I want to forget about everything.

Others were not so explicit about their preoccupation. This last subject's twenty-one year old sister lived away from home and mentioned that her visits had increased and she called her mother more often than before her surgery. The twelve year old daughter in this same family also indicated that some of her habits had changed since her mother's illness had been diagnosed: "R. (her step-father) always used to correct me and it gets on my mother's nerves, so now I do everything right." The twenty-three year old wife of a patient stressed that her attitude toward her husband had also changed since his surgery:

I decided to care more about him and to do everything to make him comfortable and feel he has more time to rest....I'm always thinking about the end of treatment and I just think that he'll be okay and everything will be all right.

A common reaction among these subjects was a desire to learn all that they could about the patient's condition. One wife began reading about possible causes for her husband's symptoms before he was diagnosed. She said that he had been getting little information from the doctor and so:

You're going to read and find out for yourself
...I went down to the library and took out some
medical books and read them to find out exactly what
was what.

Even the fourteen year old daughter of a patient felt the need for more information than she was given. She wanted to know what was happening to her mother so she "looked it up in the encyclopedia." The mother of the twenty-nine year old woman with breast cancer had taken several books on the subject out of the public library and had also attended a Cancer Forum held recently in the city.

Some other subjects stressed the value of sources other than books. Two daughters of one patient had watched a television special on breast cancer. One patient's wife mentioned seeking information from a friend: "I went to see a lady from the church who was a nurse and asked her to tell me everything she knew." The twenty-eight year old husband of a patient with melanoma also stressed that he was interested in the knowledge of his friends: "I've done a lot of asking questions and a lot of listening to other people."

Two spouses mentioned that they had sought further information directly from the attending physicians. One husband was so concerned about his lack of knowledge that "I even phoned, one Sunday, I phoned the surgeon at home because I was so worried."

The other, the wife of the patient with lung cancer indicated that she had sought information from the clinic's specialist and the family doctor:

I asked questions of Dr. D. (the specialist) but the answers fell like lead balloons so I stopped asking....I have been to see the doctor (family physician). I went to see him to find out what I was up against, what I had to look for.

In some cases, then, the patient became the focus of attention for the individual's thoughts and actions; some habits were changed in order to be more attentive to the patient's needs or desires and an abundance of information was sought by several individuals.

Anticipation of Modes of Readjustment

Table 5 shows that nine of the subjects discussed some anticipation of readjustments that would be necessitated by the patient's death. Six mentioned their concern about life without the patient and five discussed the possibility of changes in their life style. Four of the spouses mentioned some thoughts about remarriage and four discussed their thoughts about possible changes in the family relationships. Three individuals indicated that they had begun to take over some of the patient's responsibilities and one of these three also described a need to learn more about some of the other chores normally carried out by the patient.

TABLE 5

Described Behaviours Indicative of Anticipation of Modes of Readjustment

<u>Behaviour</u>	<u>Subjects:</u>									<u>TOTAL</u> Number of Subjects describing spec- ific behaviour
	1	2	3	4	5	6	7	8	9	
Caring for remaining parent										0
Changes in life style		x	x			x	x	x		5
Thoughts of remarriage		x				x	x		x	4
Attempts to learn about responsibilities of patients							x			1
Takes over responsibilities of patient		x			x		x			3
Changes in family relationships	x	x	x						x	4
Concern about life i without patient	x		x	x	x		x	x		6

While some subjects talked openly about their thoughts in this area, others merely hinted at them. One subject specified that she had deliberately thought about and planned for these anticipated readjustments while the others indicated that these thoughts were transient and unplanned.

The one who stressed the need to consider these things was the wife of a patient with lung cancer whose tumour was non-resectable. She said:

As to making preparations, that I haven't done. I've thought the subject through as to what I'll do when he's gone....I've decided what I can do financially and hopefully that will work. I've decided to rent part of my house and hopefully I can cope.

The wife of the patient who had a brain tumour had asked herself many questions about the future but had not arrived at any satisfactory answers:

All I could think of was if he goes, I've got four little children and really this is a company house -- we have a little cottage out in the country -- and I was thinking what do I do, where do I go, what happens to us and -- I haven't worked since I was married and that's fifteen years ago. I haven't got a clue what goes on. I don't even have a bank account or anything and if he goes what did I do for money. All of these awful, awful thoughts, you fight them off and tell yourself to stop thinking like that but they come in.

The husband of one patient mentioned thoughts about arranging care for his fourteen year old daughter:

If something drastic happened, I'd have to get a housekeeper to look after things and J. (the daughter)....These thoughts just went through my mind, it wasn't a positive thing, not a conscious effort.

Another husband found it difficult to put his thoughts into words, but he said:

We started from scratch with nothing and we -- well, the house is not quite paid for yet but we're -- I mean now that things would go easier and would go better, something like this happens. I mean it took two to build all this up, to have a house and a home; I couldn't do it alone.

Some spouses considered the possibility of remarriage. The thirty-three year old husband of one patient was also concerned about his step-children:

I worried that she might die and that the (older) kids would have to go back to their other father and then I thought well, that'd be okay but then I thought well what would I do? Who'd look after C. (the youngest) while I go to work? I thought -- I don't want to go and live with my mother...I thought maybe I'll make things a little different next time, I won't get married.

The husband of another patient did not have children to consider, but he mentioned that he and his wife had discussed the possibility of his remarriage:

One always thinks about what would happen if we weren't as lucky as we think we're going to be...it did come up, discussion of whether I would marry again, I said no because I'd probably be disappointed....These thoughts are inevitable even though I'm very positive.

A fifty-nine year old wife married for thirty years expressed similar thoughts:

I did think about what life would be without M. -- I didn't want that.....I don't want life without M. I don't think I would want to get married again, but I don't think I'd want to live alone; but I'm quite happy with the husband I've got, so I'll keep him.

Thoughts of readjustments were not confined to the spouses of patients. The mother of the twenty-nine year old patient with cancer of the breast expressed her concern about the effect her daughter's death might have on the family:

We sort of sat around here and talked; she has a nine year old daughter. We talked about that. She's divorced from her husband and of course has custody but you think of all these things. He has, you might say, been no good; now whether he would show up at some point and decide that he should bring up the little girl -- of course that'll all become a legal problem -- I don't know.

The twelve and sixteen year old daughters of one patient had not considered the possibility of readjustments in much detail. However, they implied that they had thought of the possibility of life without their mother. The twelve year old said: "I just want her to live...everytime I look at her, I think what am I going to do without her." Her older sister expressed it similarly: "I've thought about whether Mom's going to be here or not, and if she's not going to be here then I think what am I going to do."

While some of these subjects considered the possibility of their readjustment needs in more detail than others, it can be seen that each of them recognized that the death of the patient would necessitate some changes in their lives.

Reviewing Forms of Death

In Table 6 it can be seen that thirteen subjects showed some indication of considering the possibility of their relative's death. All of these thirteen questioned in some way the length of time left for the patient. Some expressed their thoughts openly while others merely hinted at their fears. Three subjects discussed their need to know what to expect in the future in relation to their relative's possible death: they each mentioned their concern about when and how the patient might die. One of these three also mentioned her concern about her husband's final illness and hospitalization. Four subjects described their feeling that cancer was equivalent to death and had thus considered death to be a probable outcome of their relative's illness.

While thirteen subjects experienced this manifestation of anticipatory grief in some way, only a few spoke directly of their thoughts. Two spouses expressed their feelings quite clearly. The thirty-three year old husband of a patient who had had a radical mastectomy and who had extensive lymph node involvement said:

TABLE 6

Behaviours Indicative of Reviewing Forms of Death

Behaviour	<u>Subjects:</u>													<u>TOTAL</u> Number of Subjects describ- ing specific Behaviour
	1	2	3	4	5	6	7	8	9	10	11	12	13	
Seeks information about when the patient may die							x				x	x		3
Seeks information re: how patient may die							x				x	x		3
Questions length of time left with patient	x	x	x	x	x	x	x	x	x	x	x	x	x	13
Expresses concern re: patient's final hospital- ization											x			1
Considers death as consequence of cancer	x	x		x	x									4

I think one of the biggest fears is if she is going to die then you want her to go fast. You don't want her one of these lingering deaths where you see her disintegrate into nothing.

The wife of the patient with the non-resectable lung tumour had obviously had many thoughts about her husband's possible death.

She stated:

If he asked me to do anything to help him end the thing towards the end, I would do it. Perhaps that's the wrong attitude but I can't wish suffering on anyone and his primary source is lung and he probably will suffer....If a patient doesn't want to go through with it I don't think we should make them.

She also mentioned her concern about her ability to care for her husband when he began to deteriorate:

Fortunately my job is flexible and it would be possible to keep him at home....(My most important concern is) can I cope with the actual illness when it gets worse. Can I stay dignified and calm -- this is the only thing I pray about. The work I can cope with. It's your brain that has troubles; can you be strong enough to care for him without blubbering.

Most of the subjects were not this direct, but did express some concern about when or how the patient might die. The three parents in the sample all described similar feelings. The mother of the twenty-nine year old patient said:

If anyone's going to beat it it's her, unless there is too much to cope with...I think basically as long as she's well and doesn't suffer too much pain and miserable problems that can come up -- but basically we're looking on the bright side not the dull side, so whether

she has many years to live or a few years to live or whether she has lots of pain and misery, I mean, we don't know, you've got to take it as it comes.

The other mother in the sample also had fears about her child's future:

You try and shut it out of your mind. That it may possibly have spread, that there may be future operations for him, that he may not be the strong healthy person in the future that he is now. You just hope it won't come to that, you pray that it won't, that he'll be spared that much of a problem. You try not to think about it too often.

...The mere term cancer to us in the past has been frightening and very often it's been a death sentence so unless you keep hearing about the progress and the changes in treatment you go back to that 'Oh, I wonder how long it will be' sort of thing, how long a life can you have with the cancer.

This subject's husband also indicated that he thought of similar things:

There is an underlying feeling of despair in that, um, there was this risk of all this upbringing and training and the love and care that's gone into bringing up a young man, is all at risk and suddenly; and it can be devastating for a while....I've never prayed as much or more as I have over the last month and at this point in time we feel our prayers have been answered.... We're concerned about it being a serious impairment of his health. There is the possibility, naturally, that he may have some further problem from it, we recognize that, we think that the risk factor at this time is low, but there is always an element of insecurity or uncertainty in this type of disease.

One husband's attitude and mood seemed to indicate that he had thought of the possibility of his wife's death but he

found it hard to put into words. He said that his most important concern was "that we stay together as long as possible." Earlier in the interview he had said: "I know it's very serious, very bad and that's enough for me." When asked what thoughts he had had on the effect of this diagnosis on their future he said: "We'll do a lot more together, just be together more than ever.....I'm stuck. If only I could come out with it -- I have certain days when I could just -- no, I don't know what to say."

The wife of the patient with a brain tumour expressed her need to know what to expect in the future:

The main thing is I just wish someone would tell us so I'd know what's going on -- whether this thing can come up again; no one has told me anything. I've asked but it's sort of evaded.....I can live with the day to day things.

Before her husband's surgery she thought "If he's operated on he could go on the table or he could hemorrhage and go anytime." After his surgery and during treatment she remarked: "Nothing can ever be as bad again."

Another subject, the husband of a forty-nine year old patient, expressed a similar desire to know what to expect:

I don't long range myself. I try to take things as they come. You can't stop fate.....I wonder where is it going to quit.....I wish the doctors would give us more information, I just want to know what to expect.

This subject's twenty-two year old daughter said she fought off any negative thoughts:

At the very beginning it was terrible, inside me....She (the patient) had to go through her own mother's death with breast cancer and it was a long, drawn out deterioration. During that first night, I kept saying she's going to be all right but my eyes filled with water and I kept telling myself that there were so many things they could do now.

Her younger sister said it plainly: "I was scared and worried; cancer meant instant death."

In another family the husband openly denied any thoughts about his wife's possible death. He said:

I don't believe this business of two years or five years or whatever and I'm not predicting my life or hers or ours on the possibility of a termination in a short time.

However, he also said:

If you do have two years, why be concerned about another working day; let's be practical, if it's only two years or five years let's really enjoy ourselves, not blow everything but enjoy every minute.

Two of this man's three step-daughters feared their mother's death. The sixteen year old said:

I know I've heard her say that she's not sure how long she has to live -- a couple of years or something ...and that's what's hit me most of all...that it could be she doesn't have that long to live -- that's hard to believe too...it's really a terrible feeling, thinking that without your own mother you feel so all alone... that's been about the worst of the whole thing.

Her younger sister said: "I don't think she'll live as long as she normally would so I just want her to live."

While only two of these subjects explicitly described their thoughts about the possible death of their relatives, the others indicated in some way that they had considered this possibility and that they had thought about when or how the patient might die.

Additional Common Reactions

In addition to the manifestations of anticipatory grief described above, many of the subjects experienced other common reactions upon learning of their relative's diagnosis.

Fear. One of the most frequently expressed emotions was fear. Several subjects mentioned this aspect of their reaction and some explained that this fear was often related to the term "cancer". This reaction seemed to be most prominent immediately after the initial diagnosis and before the patient was seen at the cancer clinic. The twenty-eight year old husband described the feeling:

As soon as anyone mentions cancer, you think you're going to die, right? You start thinking about people dying, you get a lot of gray hairs, eh?...It was fear, you can't express that when you're afraid someone is going to die.

Another husband said: "Well, it was very frightening...it's terrible, it's a frightening thing."

The only father in the sample stated:

You naturally have a feeling of shock and confusion....does this signal a person's high risk of dying from this disease?...We've got over that feeling of fear or fright from the thing because we've filled in with knowledge.

This man's wife labelled the feeling - panic:

When it was diagnosed as cancer, real panic sets in but also numbness too, because you don't want to believe that that's what it is....The mere term, cancer, is frightening and has been a death sentence in the past.

The fourteen year old daughter of one patient described it this way:

I guess I was worried and sort of scared and stuff. You know, cancer! Ah! Instant death. But now it's different, I've learned more about it.

Another patient's wife said: "He was really sick and I was scared ...I was really getting quite panicky." The twenty-one year old daughter of a patient said:

It really took me, you know, I got all choked up and I was trying to remain calm...I couldn't, I didn't, it was such a shock.

One wife stated that her immediate fear was not based on reality:

"The immediate fear was based on other experiences with cancer rather than what my husband has." Another subject, a husband said: "I was kind of scared, I guess I was just worried about her, you know, you don't know that much about cancer."

Thus, fear was an early reaction to the diagnosis and was experienced by several of the subjects.

Hope. Much of the fear was dispelled when the subjects learned more about their family member's particular disease. After some contact with the specialists at the clinic, many of the subjects discussed their feelings of hope and their belief in the need for positive thinking. Related to this for some individuals was some type of faith; whether a religious faith or faith in the power of the individual to be well, this seemed to play an important role for some of the subjects.

One husband said:

I believe you have to look positively at things.
If you think negatively, then bad things happen to you.
If you have positive thinking, then positive things happen.

A wife of a patient had a similar point of view:

I believe that your attitude can affect your health.
If you have a positive outlook, you have a better chance to escape illness. The first day or two, I thought about him dying, but now I have faith.

The father of a twenty-one year old patient identified the importance of his faith:

I never prayed as much or more than I have in the last month.....One has to turn to something, at a time like this and one's faith comes up and hits one right in the face. I've made a recommitment to my faith and my prayers have been pretty constant and so far it seems that they've been answered.

This man's wife stressed positive thinking: "You try to think of positive things.....The presentation of hope is important."

Another patient's husband also talked of positive thinking:

I think positive all the time and I don't think anyone should give up. She'd get down a little and I'd force her to look at the positive aspects.

Another husband said:

One must be positive. I'm sure there is a psychosomatic factor involved....Thoughts about loss don't do any good; I'd be afraid that I'd created a negative environment for her to recover in.

A young wife stressed her feeling of optimism:

I was optimistic because he looks healthy and he's happy and he himself is optimistic too....I just think that he'll be okay and everything's all right, and after his treatments his cancer will maybe disappear completely and I hope that he'll get enough rest and be happy again and have enough time to do everything he wants.

Ambivalence. Hope and fear were often experienced almost simultaneously and this was a reaction which the investigator felt could appropriately be called ambivalence. This ambivalence was expressed in several ways. Some felt some ambivalence about learning more about the patient's condition, others expressed ambivalence toward their own reactions or those of the patient, and others expressed a feeling of uncertainty about the whole situation.

One husband identified his need for information, but his inability to ask questions:

There were too many things, I don't, you can't jump right in and ask right away a thousand questionsHe said it was very bad and that was enough for me...I haven't spoken to him since, and the surgeon who performed the operation even he wouldn't come out and say, he just, hum, would try to give you hope but he wouldn't commit himself, he wouldn't say -- I should say that I didn't ask like what stage my wife was in but I wouldn't; other than that the doctors wouldn't tell me very much...I know it was bad enough, but you can't ask at a time like that.

Another husband expressed similar feelings when he said:

The day of the operation, I was on day shift and I kept putting it off to 'phone the doctor; you don't know whether you want to know...I'd keep thinking -- should I 'phone and find out or should I not 'phone and then I won't find out.

(Before the operation) he didn't tell me anything mind you, I didn't ask him 'cause I don't think you really want to know too much.

One husband identified the insecurity he felt in the situation:

The confusing thing is that we're talking about a high cure area but there's always the unsettled feeling that we really don't know where we stand.... It's possible that I don't ask enough questions but I often wonder just how far you should go and how you should treat someone in the medical profession. Do you trust them to tell you or do the right thing or do you treat them as suspect and ask questions.

One husband showed his ambivalence toward the disease and the entire situation in several ways:

I'm optimistic that its well contained, but it's been a series of bad news....I know I should be volunteering and helping and assisting because it's bad news emotionally but the problem is you lend emphasis to something that maybe should be neutralized and it's this balance that is most difficult to achieve....If I could

help her in any way, that's fine, but I don't want to give undue weight to something she can handle by herself....

There is a problem in keeping a balance. There's a tendency to capitulate in all those areas one would normally hang tough in -- normal routine arguments. I felt I had to be careful that my emotional or empathy didn't overcome or overshadow all the things that are important to maintain balance. One feels like a rat-fink because one is determined not to capitulate -- it's rough not to know -- one is torn far more than normally would be because you love someone and you want her to have nice things yet as a matter of principle you must deny; when a short life expectancy is placed on someone it makes it difficult to balance.

Another husband seemed to weight the positive and negative aspects of the situation:

The immediate impact was that it was damn bad luck. But, it was found when it was small and the lymph nodes were negative so that augers well....I was concerned when radiation treatment was prescribed ...I'm aware that although statistics say you're better off having had the treatment than not having had it, nevertheless, the mere act of irradiating healthy tissues has its hazards as well and I think it's one treatment I'd rather avoid. I'm sure if I were in that position, I would unquestionably opt for the treatment but it leaves a nasty taste simply because of what one knows about effects of radiation in general....I don't have any choice about treatment, I'll buy the treatment 'cause it's the best thing to do in the circumstances.

One patient's mother, a nurse, who had asked many questions of the doctor, and was reading books on her daughter's condition, indicated that she felt ambivalent about her level of knowledge:

Althought I don't know whether I know anything really -- I mean, it hasn't done me any good to know

anything. If you don't know you don't worry, maybe -- I sometimes think the less you know the better off you are. We're really anxious to know what these new biopsies show.

Concern about the reactions of other family members.

Several of the subjects mentioned some concern about the manner in which other members of the family were reacting to the patient's diagnosis. Often, this concern was expressed when the other's reaction was quite different from that of the individual and when no sharing of feelings had taken place between the individuals involved.

Two wives talked about their children's reactions.

One said:

In regards to the children, the three young ones were really quite oblivious to everything that was going on. They were sort of in their own little world and it was quite fascinating just to see how children react and they weren't at all upset as such. I find children a little callous somehow, a little hard. I was sort of disturbed to see their reaction; with their daddy really, really sick and they knew he was really sick. The oldest one was really upset, but he kept a lot inside, he would just hover all the time if I was on the 'phone or anything and I was really glad my brother was here to be able to talk to him and calm him. But the others, that really fascinated me, I think children can really bounce back from almost anything. The boy's thirteen and he's the one who felt it and the girl's eleven and a boy nearly eight and a boy nearly four -- the youngest, okay, I didn't expect anything or the two youngest, but I wondered about my girl -- that was really -- during all this our little dog got run over and that she really reacted to, so I know she does have feelings.

The other stated:

My children know their father has cancer but they don't recognize the implications. My son maybe does but my daughter doesn't. Everything she does seems so selfish, she's only normal but -- her first reaction was "what would happen to her horse!"

Another subject spoke with surprise of the reactions of his son and daughter:

Our son is a large concern; he's a high school drop out and is bumming around and we have no way of getting in touch with him; we don't even know where he is...the fact that he has not been sufficiently interested in her well being to even 'phone has hurt her but there's nothing I can do....

I don't subscribe to any particular fear or anxiety over cancer being catchy or anything like that. You know I'm not worried by contagion or so on. But, curiously enough, our daughter who is currently staying with us...she raised a question yesterday which rather surprised me, which suggested that she had a little sneaky feeling in the back of her mind that it might not be a very good thing to use the same face cloth or something like that. It surprised me, I thought she'd have known better than that and it may be that this is the reason our son hasn't approached -- but the trouble is, we don't know because we can't get in touch with him. So that's the only thing that came as a bit of a shock!.

In one family, four members were interviewed and each of them made some comments about the reactions of others. While there had been a little communication between the youngest daughter and her oldest sister, none of the others had talked with one another about their feelings or concerns. The twenty-one year old daughter was most concerned with her sisters' behaviour toward their mother:

The only thing that upsets me is that my sisters don't do any work around the house....It's just too bad that they can't, especially V. who's sixteen, can't take things into her hands and sort of -- but that's sort of the age that's bad!

The twelve year old also was concerned about her older sister's reaction: "At first I was crying a lot and V. didn't look upset; maybe it was just to support me, I don't know." The sixteen year old mentioned her younger sister but was most disturbed by her stepfather's actions:

My little sister was really upset, I never really, the older-younger sister relationship never seems to be too good until later on so I don't know what to say. I tried to say that there's no point in thinking about why it's happened to her but I don't think that kind of thing is, you know, I'm not really geared into what to say to a younger kid....

I know I wish that R. could be more of a help to her (the mother). I don't think he really knows how to handle the situation -- 'cause I know sometimes when she feels bad, he could be a lot more supportive toward her. As a husband he should be carrying out the main role of supporting her when she's like that and if I could do it I'd be happy to, but I think she needs him to fall on and I don't think he knows how to handle the position as well as he should be able to....Especially one night when there was a really bad argument...he just got mad and that would be because he doesn't know how to handle the situation. That really bugs me, it's not right that Mom should have that to turn to, she should be able to have something better than that; some one who really knows how to, what to do when she feels like that. It must be really hard on her when she feels like that and R. doesn't know how to handle it. She needs someone to fall back onI just think if he could see, I think he could handle it if he would think about it. I just don't think he has really, maybe he's just not really mature enough in that field to know what's right.

The patient's husband voiced his perception of the girls' reactions:

The children are interested only in themselves and that's bad news, and their mother doesn't seem to be able to get their attention into perspectiveThe kids are indifferent and that's a problem, their mother has difficulty accepting their reaction.

Summary

All of the subjects but one experienced at least one of the manifestations of anticipatory grief and thirteen of them experienced at least three. All of the subjects had their own way of expressing their feelings, but there were some commonalities among them.

In addition to the manifestations of anticipatory grief, there were several other commonly experienced feelings or reactions. These included fear, hope, ambivalence and a feeling of concern about the reactions of the other family members.

Chapter 5

DISCUSSION

This study focused generally on the family's reactions to a diagnosis of cancer and specifically on those reactions which are indicative of anticipatory grief. In the previous chapter the subjects spoke for themselves; their own words described their feelings and reactions. The purpose of this chapter is to integrate these findings with the conceptual framework and previous research findings.

Robbins (1974) stated that anticipatory grief is inevitable when cancer is diagnosed. Armstrong (1975:15) said:

Regardless of the more optimistic prognosis of patients with cancer, death as a probable outcome of the disease and anticipatory grief are present from the time of diagnosis.

The findings of this study did not fully substantiate these statements. Only seven of the twenty subjects described all of the manifestations of anticipatory grief as first outlined by Lindemann (1944). It may also be assumed that six others who mentioned three of these were expressing anticipatory grief. However, three experienced only two of these manifestations, three only one, and one subject did not acknowledge any of these reactions. Such findings cast doubt on the inevitability of

anticipatory grief being precipitated by a diagnosis of cancer. Nevertheless, the assumption that family members may experience this grief reaction early in the course of the disease is supported.

All of the subjects had learned of their relative's diagnosis within the three months prior to the interview and all of the patients had completed their diagnostic tests and begun treatment at the clinic. There was, however, a wide variation in the subjects' descriptions of their reactions. Two factors should be considered in order to interpret these differences: most importantly, the individual's perception of the patient's condition, and the subject's difficulty in expressing negative thoughts.

An individual's perception of his relative's condition seems to have the greatest effect on his response to the diagnosis. The seven subjects who experienced all four manifestations of anticipatory grief all had reason to believe that the patient's life was severely threatened by his illness. The five adults in this group had each been given some evidence that the patient's disease would not be easily controlled and the two adolescents had overheard their mother say that her life span was probably very limited. These seven individuals, then, perceived the patient's condition as a definite threat to life and thus grieved for the anticipated loss.

The six subjects who described only three of the manifestations expressed some conflicting thoughts about their perception of the patient's condition. Each of these subjects indicated they were aware of the seriousness of the disease and five of them expressed thoughts about the possibility of the disease being a threat to the patient's life. However, all but one of the subjects in this group described a strong faith, or a need to think positively and to maintain hope. Each of these five stressed their knowledge of possible treatment modes. Thus, while these individuals may have shared the perception of the disease as a threat to life, they differed from the first group in that the emphasis of their thoughts was on the positive aspect of advances in treatment modes. They all maintained hope and were determined not to anticipate the loss of the patient.

The three subjects who described two of the manifestations were husbands. Each of these men had a slightly different perception of his wife's condition, dependent on his knowledge of cancer or his ability to acknowledge the conditions. The specialist assured one man that his wife's condition was highly controllable with adequate treatment and that while the chance of reoccurrence did exist, it was not high. The second man relied on the fact that the doctor had not told him that the disease was uncontrollable (the "no news is good news" attitude)

and stressed that to his knowledge, her type of cancer had a high probability of cure. The third man, in this group, acknowledged that his wife's condition was serious but emphasized the belief that her life span would not be shortened by the disease. Friedman et al (1963) found that a few parents in his study denied the seriousness of the illness and the prognosis. Orbach (1955) found similar use of denial of the implications of the disease in two of twenty mothers of children with leukemia.

Three subjects, who only described some heightened preoccupation with the patient, expressed a common belief that the patient's disease was not life threatening. One of these subjects, the husband of a patient who had had a partial mastectomy and had no lymph node involvement, supported his belief with his knowledge of recent morbidity and mortality statistics of this condition. The other two expressed a belief that the patient's condition was easily controlled by treatment. One of these subjects was a daughter who did not live with the patient. Her belief was based on her awareness of breast cancer in general rather than her mother's actual condition. The third subject was the twenty-four year old wife of a patient who had had a nasopharyngeal tumour removed and was having Cobalt treatment. She had not talked to any of the doctors and stated that her husband had told her it was not a serious type of cancer,

that it had all been removed during surgery and that he would be cured after treatment. Thus, each of these individuals stressed that their preoccupation was due only to the disease condition itself and the patient's present state of health. None of them expressed any thoughts about the disease being life-threatening.

One subject did not describe any of the manifestations outlined by Lindemann. This subject's wife had had a partial mastectomy and had no lymph node involvement. He expressed the feeling that this situation did not compare with an incident two years previously when his wife had had a cerebral aneurysm and had been unconscious for two weeks. At that time, he felt her life was in great danger; the threat posed by this disease was minor in comparison. Thus, his perception was influenced by a past more serious threat of loss.

Each of these groups of subjects perceived their relative's condition in slightly different ways. Another factor which must be considered, however, is the respondent's willingness to recognize and discuss his symptoms of grief. Aldrich (1975:6) pointed out that in anticipatory grief, family members often feel ambivalent toward the patient and this ambivalence causes a serious impact:

The target of the ambivalent feelings is not only still alive but also particularly vulnerable, balanced

between life and death. This vulnerability makes a death wish appear particularly potent and dangerous. This factor may contribute to the clinical impression that anticipatory grief appears to be more readily denied than conventional grief.

This fear of the vulnerability of the patient was hinted at by several subjects. One mentioned a fear about creating a negative environment for his wife to recover in; others emphasized the need to maintain hope and positive thoughts. These feelings may have inhibited some subjects from describing any grief reaction they had experienced.

While there was wide variation in the combinations of manifestations exhibited by the subjects, there were some common patterns. The most frequently described manifestation was heightened preoccupation with seventeen subjects mentioning it. Depression followed closely, being experienced by sixteen subjects. Thirteen of the twenty described some thoughts about the patient's eventual death and nine had anticipated the modes of readjustment that would be necessitated by it. These findings deserve to be discussed in more detail.

Heightened Preoccupation

The most commonly experienced manifestation was described by seventeen subjects including the three individuals who did not identify any other manifestations. Friedman et al (1963)

found that preoccupation with thoughts of the ill child were common in the parents of fatally ill children. Futterman, Hoffman and Sabshin (1972) stated that at some time during the child's illness, parents exhibited some preoccupation with the child which was often manifested in clinging behaviour or by indulging his needs at the expense of other family members. While this behaviour may not be quite so overt in adults anticipating the loss of another adult, it is nevertheless present in a large majority of these subjects. Futterman et al (1972) indicated that this preoccupation is an expression of the need to hold on to the soon-to-be lost person and is an important aspect of the detachment process. Freud (1916) first described heightened preoccupation with a deceased loved one as a process by which the individual prepared himself to give up the lost object.

There is, of course, another possible explanation. Beland (1970) indicated that when an individual is ill, he often regresses to a less mature level of functioning and becomes more dependent on those who care for him. The family may react by doing too much for him and making him the center of their attention. Thus, illness itself may precipitate a preoccupation with the patient; it is not necessarily a part of the grieving process. This would account for the expression of preoccupation by those individuals who denied any threat to the patient's life.

Depression

Sixteen of the subjects described some feelings of depression following learning of the patient's diagnosis. This depression manifested itself in several ways including a general feeling of sadness, crying, difficulty sleeping or eating, restlessness and hypersensitivity. Futterman (1972:255) found that parents of leukemic children experienced a similar period of depression:

...Shock and numbness were common as immediate reactions....Numbness quickly gave way to pain, sadness and crying. Hyperactivity, psychosomatic manifestations and insomnia were also most often present in the first month or two following diagnosis.

Orbach (1963) noted similar signs of depression in parents anticipating the death of their child.

One manifestation of depression is guilt or self-reproach. This reaction has been seen frequently in the parents of fatally ill children. In fact, Friedman et al (1963), Futterman et al (1972) and Orbach (1963) all indicated that guilt was experienced without exception. Only two subjects in this sample described any guilt feelings. The most probable explanation of this difference is that parents feel more totally responsible for a child than one adult does for another. The guilt experienced by the two subjects in this sample was aroused not only because of past behaviour toward the patient but also, particu-

larly in one wife, because of feelings of anger at being deserted by the patient.

The depression experienced by the subjects in this sample never existed in isolation from other manifestations. Every subject who described depressive symptoms also mentioned at least one of the other manifestations of grief.

Reviewing Forms of Death

Thirteen of the subjects in this sample mentioned thoughts about the possibility of the patient's death. However, only two of these thirteen were able to verbalize their thoughts about the way the patient might die or their ability to cope with that form of death. Fulton and Fulton (1972) described this as a rehearsal of the patient's death. The other eleven talked about the possibility of the patient's death in a more abstract fashion. They frequently mentioned the limited time left with the patient or thoughts about how long he had to live. They also talked about "what might happen" if the disease was not controlled by treatment and mentioned worry about pain or suffering and a reoccurrence of the disease.

The subjects' reluctance to think about this possibility was evident in statements such as "I try not to think about it" or "You try to put those things out of your mind". This phase of the grieving process is obviously very painful

and unpleasant and it is probable that some subjects just could not bring themselves to acknowledge these thoughts. Aldrich (1974) accounted for this with his discussion of the vulnerability of the patient. Thoughts about the patient's death could be viewed as a form of death wish.

Anticipation of Modes of Readjustment

Nine subjects described some thoughts about the readjustment that would be necessitated by the patient's death. Only one subject indicated that these thoughts were a conscious effort at planning for the future. The others indicated that the thoughts were unintentional and disturbing. It is interesting to note that this manifestation was the one described most infrequently. Thoughts of readjustment might be too painful to consider while the patient is still alive and undergoing treatment. Also, there is one important difference between this sample and that of Lindemann (1944). In this group the patient was still present, alive and fairly active. In Lindemann's sample, the soldier had already departed, forcing the subjects to adjust to his absence. Thus his sample was in reality not anticipating readjustment but actually accomplishing it.

Other Manifestations

There were three other reactions which were experienced

frequently by the subjects in this sample: fear, hope and ambivalence.

Fear was mentioned by over half of the sample. This fear was associated with the disease itself and the unknown implications of the diagnosis. Most of these individuals noted that the fear decreased as their knowledge of the patient's specific condition increased. A significant decrease in anxiety or fear was felt after the subject had had some contact with the specialists at the clinic. Day (1966:83-84) stated:

Overwhelming anxiety is practically a constant concomitant of the diagnosis cancer, even though this may bear no relation to the facts in the individual case....The panic response to the word "cancer" is felt subcortically even by physicians and surgeons acquainted with the facts of curability....The antidote is calm forthright review of the facts by a knowledgeable and understanding doctor, reinforced by the passage of time.

This statement would seem to be substantiated by the experiences of the subjects in this sample. Most indicated that the fear was greatest immediately upon learning of the diagnosis, and in many cases it was during this period (between learning of diagnosis and talking to the clinic's specialist) that the subjects experienced the manifestations of anticipatory grief described above. These manifestations often decreased after their fears were dissipated by an increase in knowledge about the patient's condition.

Several subjects expressed a feeling of hope or a need to think positively about the situation. Aldrich (1975) pointed out that hope is commonly associated with anticipatory grief. Friedman et al (1963:620) found that hope was emphasized by the parents of leukemic children:

The element of hope...was universally emphasized by the parents....Unlike massive denial, hope did not appear to interfere with effective behaviour and was entirely compatible with an intellectual acceptance of reality. That the persistence of hope for a more favourable outcome does not require the need to intellectually deny the child's prognosis is of clinical significance, as it differentiates hope from defence patterns that potentially may distort reality.

These authors also found that as the disease progressed, the parents' hopes for the child became much more short term and seemed inversely related to their expression of anticipatory grief. The period of the most long term hope was at the beginning of treatment, a stage similar to that being experienced by the subjects in this sample.

Some of the subjects described a feeling of ambivalence toward the disease: fear and hope were experienced simultaneously. Some spoke of the desire to maintain hope or a positive attitude toward the disease, but admitted that at the same time the fear, experienced when they first learned of the diagnosis, often returned to their thoughts. Some individuals indicated that while they might have wanted more information

about the patient's condition, they did not ask questions because they feared the answers. While Abrams (1951), Friedman et al (1963), and Futterman et al (1972) all commented on the presence of hope and the presence of fear, they tended to isolate them as separate sequential phenomena. No one described them as being coexistent. Yet, many of the subjects in this sample did express these feelings simultaneously.

Concern About the Reactions of Other Family Members

Several subjects expressed some concern about the manner in which other family members were reacting to the diagnosis of cancer. Three parents discussed their concern about the reactions of their children and three daughters expressed their distress at their step-father's reaction. Everyone experiences a crisis in a slightly different way and each thus reacts differently. The reactions of others are, nevertheless, compared with one's own reaction. If there is little communication among the individuals concerned, misunderstandings are inevitable. Parad and Caplan (1960) pointed out that the communication network in a family may be much more restrictive in relation to unpleasant or anxiety laden situations than it is for pleasant or gratifying situations.

The most obvious disruption in the family members' ability to cope with the reactions of the other members was in

a family in which the patient was the mother. The daughters were distressed with their step-father's reaction and he with their reactions. There was little communication among the family members. Pritchard (1974) stated:

It is this writer's contention that the death of a parent, particularly of a mother, can be the most catastrophic experience in the life of a family where there are young or adolescent children. A husband facing the possible death of his wife is preoccupied with his own sense of impending loss and often finds he has little emotional reserve for his children.

This seemed particularly true for this family. Perhaps the distress was intensified because the girls had not learned to relate to their step-father in a meaningful way.

There are many aspects of a family's interaction patterns which might influence each individual's reaction to the illness of one of their members. This study was not designed to investigate these aspects but it has shown that this would be another fruitful area to research in the future.

Chapter 6

SUMMARY AND CONCLUSIONS

In 1944 Erich Lindemann observed that family members of service men who had left for war exhibited the same manifestations as those experienced by individuals who had recently been bereaved. He stated that these wives and mothers experienced the four distinct phases of grief: depression, heightened preoccupation with the departed, a review of the forms of death which might befall him and anticipation of the modes of readjustment that would be necessitated by his death. He termed this reaction "anticipatory grief" as their reaction was, he felt, in response to an expected loss rather than an actual loss.

Since that time, anticipatory grief has frequently been discussed as a reaction experienced by cancer patients or their families. While many authors have assumed that anticipatory grief is experienced following learning of a diagnosis of cancer in a loved one, few have attempted to describe this reaction. This study was designed to determine if a diagnosis of cancer actually precipitates an anticipatory grief reaction, as described by Lindemann, in patients' family members and if it was thus an important concept to consider in planning nursing care for these individuals.

The study was exploratory in nature. The sample, selected from among families whose member had been referred to a large urban center for the diagnosis and treatment of cancer, consisted of twenty family members of fourteen patients, all of whom had been referred to the clinic after initial surgery. Included in the sample were spouses, children and parents of the patients.

Using a semi-structured guide with open-ended questions, the investigator interviewed each of the subjects and recorded the interview on tape. All but two of these interviews took place in the subject's home, with the two exceptions being at the subject's place of business. The interviews ranged in length from twenty to eighty minutes and covered the following topics: the individual's reaction to first learning of the diagnosis, his knowledge of the condition of his relative and his past contact or knowledge of cancer, his most important concerns at the present time, the effect of the patient's diagnosis on the individual's activities of daily living, his thoughts on the future effect of the diagnosis, effect on the relationship between subject and patient and any other topic that the subject felt was important to mention.

A coding tool which identified specific behaviours indicative of anticipatory grief was developed. The interviews

were then analyzed using content analysis: the presence of specific behaviours was noted and recorded on this tool. Two independent raters coded a random sample of the tapes to test the reliability of this method.

Of the twenty subjects interviewed, seven described all four manifestations of anticipatory grief, six mentioned three, three mentioned two, three mentioned one, and one subject did not describe any of the manifestations. Heightened pre-occupation with the patient was described most often, being mentioned by seventeen subjects. Sixteen described some feelings of depression; thirteen mentioned some thoughts about the patient's possible death and nine talked about anticipation of modes of readjustment that would be necessitated by the patient's death.

Four other reactions were commonly experienced by several subjects: fear of the diagnosis itself and the effects of treatment; a feeling of hope in new methods of medical treatment and a need for positive thinking; a feeling of ambivalence toward the situation; and a concern about the reactions of other family members.

This study provides insight into the ways that family members of cancer patients experience anticipatory grief. Although the sample was small and may not be representative of the

entire population of family members of cancer patients, it is possible to draw some conclusions based on the data collected from these subjects. The fact that these individuals experienced various combinations of the four manifestations of anticipatory grief outlined by Lindemann supports the assumption that his theory can be used as a framework for assessing this reaction in individuals who had recently learned of a family member's diagnosis of cancer. Lindemann's original sample consisted of family members of service men who had left for war, a group far different from the individuals in this sample. Perhaps, then, Lindemann's description of anticipatory grief may be applicable to a still wider range of situations where threat of loss is present.

The fact that some family members experienced all four of these manifestations of anticipatory grief supports the assumption frequently stated in the literature that a diagnosis of cancer is often perceived as equivalent to a death sentence. However, that this reaction was not universal among these subjects may indicate a changing trend in this attitude. The individual's perception of the patient's condition as well as his past knowledge of cancer seemed to play a significant role in determining his initial reaction and anticipatory grief symptoms often began to diminish as the subject learned more about the disease and

possible modes of treatment. As more people learn about the positive results of cancer treatment, it may be that the diagnosis of cancer will lose its fearsome quality and individuals will be less likely to equate the diagnosis with imminent death.

Just as the level of knowledge varies from one individual in a family to another, so does the perception of the illness. Each family member may perceive the patient's condition in a slightly different manner and consequently react quite differently from all other family members. This is an important finding as it indicates that an individual's reaction to his relative's disease is not always related to the patient's actual condition but more likely to his own perception of that condition. These discrepancies in perception and reactions can cause family conflict if not identified and discussed early in the course of the patient's illness.

In the past, discussion of reactions to the diagnosis of cancer were often not encouraged among family members. The willingness of patients to have their family involved in this study and the subjects' eagerness (in some cases) to discuss their concerns with a health professional emphasizes the need for this type of contact. This need was most obvious in the case of children, two of whom stressed the fact that they had had no one to talk to about their feelings and fears. Being open

about their feelings with an outsider may be a first step toward more freedom of discussion among the family members.

It has been suggested that talking about feelings, especially those associated with loss or threat of loss, is most difficult and that an interviewer would have to probe deeply and spend much time with the subject to learn about these feelings. The results of this study do not support this suggestion. Most of the subjects in this sample were quite open about their feelings and concerns even though the interviewer was non-directive and the subjects had not had any personal contact with her prior to the interview. However, the ability of the researcher to develop rapport with patients and their families must be considered an important factor in this finding.

This study has several implications for nursing including some for practice, education and research. While some of these implications result directly from the data analysis, others are related to the methods of data collection and the reactions of the patients and families to the study itself.

In caring for cancer patients and their families, nurses are frequently asked to give emotional support as well as physical care. This study suggests that individuals may experience anticipatory grief soon after learning about the diagnosis of cancer, and provides insight into the various ways in which

individuals experience and describe this anticipatory grief reaction. The nurse who can recognize anticipatory grief can better assess the family members' reactions and intervene to help individuals cope with these feelings where necessary.

The expression of anticipatory grief may indicate how the family member perceives the disease and the patient's condition. The nurse is often the family's primary contact person and, as such, may be the first one to identify manifestations of anticipatory grief in these members. The nurse must be prepared to determine if this perception is accurate or if the individual requires more information about cancer and the modes of treatment available for the patient. Lindemann's theory can be useful in providing a framework for this assessment.

The willingness of patients and their families to discuss their feelings and concerns with the investigator implies a need for this type of service. Nurses are available to patients and their families and must be able and willing to listen when the need arises. More importantly, they must provide patients and their families with the opportunity and encouragement to talk. If they are not encouraged to discuss their concerns, family members may never learn that their reactions are not peculiar or unnatural and may begin to feel guilty about their feelings.

Some families in this study could not discuss their feelings among themselves and this led to conflict. Nurses can help the entire family cope with this crisis by facilitating communication between members. Although this may be done by working extensively with one or two members, a more effective approach involves counselling the entire family. As nursing becomes more family centered, nurses must prepare themselves to accept this facilitator role.

Peer support groups are instrumental in helping families to see the need for inter-family communication. Often seeing a problem in another family helps one to see his own problem more clearly. Nurses, with their understanding of family dynamics and the disease process, and their awareness of anticipatory grief manifestations, can be effective resource persons for these groups. Nurses working with such groups must also offer individual help to the families who have identified the problem but are unable to resolve it.

Nursing education must take the responsibility to prepare the nurse to assess an individual's anticipatory grief reaction and to help patients and their families to cope with this reaction. Thus, this study has implications for all levels of nursing education. All programs should include the concept of loss and threat of loss in their core curricula. The diploma

program, which concentrates on the patient, must include some discussion of anticipatory grief and provide students with opportunities to talk with individuals experiencing loss. The baccalaureate program must emphasize family relationships and the effect of the threat of loss on the entire family system. Finally, in a master's degree program, students should concentrate not only on increasing their skill in working with individuals and their families but on developing a greater understanding of group dynamics and the ability to work with groups of patients and their families.

In addition to practice and education, this study has implications for nursing research. While it provides further knowledge about the concept of anticipatory grief, it is only a beginning. This study indicated that Lindemann's theory of anticipatory grief may also be applicable in other areas where threat of loss is present; perhaps relatives of patients diagnosed with other disease conditions also experience similar manifestations. Future investigations using this theory as a framework could provide valuable data about the concept itself and family reactions to other acute and chronic conditions.

This study was conducted during a limited time period following diagnosis. A longitudinal study following the progress of the subject from his immediate reaction to the knowledge of

his relative's diagnosis over the entire course of treatment and follow-up would provide greater insight into the anticipatory grief reaction. Many questions about the development of the syndrome could only be answered by this type of study: How does anticipatory grief develop and manifest itself over the entire course of the disease? What events in the disease process precipitate the reaction? If the manifestations subside after treatment has begun, do they appear again later in the course of the disease? Are there some individuals who never experience anticipatory grief? If so, how do these individuals differ from those who do? These are only a few of the questions which might be answered by further study.

While some subjects in this sample did, others did not experience anticipatory grief during this early stage. It would be interesting to determine if there are distinct differences in these two groups and if this early reaction affects the individual's ability to cope with the progression of disease in his relative.

The fact that this study was conducted at a highly specialized urban treatment unit also has implications for further research. A comparative study with families of patients who are not referred to the clinic might produce strikingly different results; several subjects mentioned that fact that

their hope was revived when the patient attended the clinic and was offered further treatment.

While this study, then, may have added to the body of knowledge of anticipatory grief in families of cancer patients, it also stimulated many more questions about the concept. In addition to research aimed at answering more of these questions, nurse researchers must begin to conduct clinical studies to develop and test nursing interventions which will help these families to cope with their feelings of anticipatory grief. By identifying, testing and evaluating interventions, nurses will be able to develop a greater repertoire of behaviours which are helpful to patients and their families in this situation.

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APPENDIX A

Consent Form

CANCER CONTROL AGENCY OF BRITISH COLUMBIA.

Consent to participate in Research Study conducted by Barbara Warren R.N.

I, _____, agree to participate in the research study being conducted by Barbara Warren. I understand that this study deals with an individual's feelings and reactions when a close family member or friend has been diagnosed with cancer. I understand that my participation will involve one interview of approximately one hour and I have agreed to have this interview tape recorded. I understand that I will remain anonymous and that the tape of the interview will be available only to the investigator and the members of her thesis committee. I also understand that this tape will be erased when the investigator's thesis has been accepted.

I understand that I am free to withdraw from the study at any time.

Signed: _____

Witnessed: _____

Date: _____

APPENDIX B

Explanatory Letter to Family

As part of the data collection for my Master Thesis in Nursing, I am conducting interviews with family members of patients being treated at the British Columbia Cancer Institute. These interviews are informal and are designed to allow family members to discuss the feelings and reactions they have experienced upon learning of the patient's diagnosis.

As a nurse, I have been concerned about helping families to cope with the stress of this illness and I hope that by learning more about the reactions experienced at this time nurses will be better able to provide the assistance that families may require.

I hope that you will consider participating in this study. I will contact you by phone within the next week to answer any further questions you may have in regard to the study and to discuss the possibility of your participation. I look forward to talking with you.

Thank you.

Yours sincerely,

Barb Warren, R.N.,
U.B.C. School of Nursing.

BW:g

APPENDIX C

Interview Guide*

1. Could you begin by telling me about when you first learned about _____'s illness?
If necessary: (a) clarify what the subject has been told and by whom.
(b) clarify what feelings or reactions were experienced at this time.
(c) clarify what feelings are now.
2. Past experience or knowledge of cancer.
3. What are your most important concerns at this time in relation to the patient, yourself, other family members?
4. Have you thought about what effect your patient's diagnosis may have on your future?
 - (a) can you tell me about your thoughts on this?
 - (b) have you discussed these thoughts with anyone? If so, who? If not, is there any reason?
 - (c) how do you feel about having these thoughts?
5. What effect has your patient's diagnosis had on your everyday life, particularly eating, sleeping, social activities, work? Perhaps ask subject to describe a typical day now versus pre-diagnosis.
6. Has your relationship with your patient been affected in any way by his diagnosis? If so, can you describe the effect?
7. Is there anything else you feel is important to mention?

* The exact wording and order of questions was not standardized. The patient's relative title (eg: father, husband) was used.

APPENDIX D

Coding Tool

Interview #

Date:

Date of patient's diagnosis:

Patient's diagnosis (from chart):

Subject's understanding of diagnosis:

Subject's relationship to patient:

Length of relationship:

Lives with subject:

or distance:

Previous experience with cancer:

Other family members -- participation in study.

Nonverbal behaviour during interview:

Comments:

Interview #:

Depression

Verbal Statements		Present
Insomnia		
Anorexia		
Weight Loss		
Inability to concentrate		
Restlessness		
Hypersensitivity		
Sadness		
Weeping (crying)		
Self-reproach		
Suicidal thoughts		
Nonverbal Cues		
Sighing		
Crying		

Comments:

Heightened Preoccupation with Patient

<u>Verbal Statements</u>	<u>Present</u>
Ignores responsibilities (other than patient)	_____
Cancels planned vacation away from patient	_____
Continually thinks about patient	_____
Patient is main topic of most conversations	_____
Discontinues social activities to spend more time with patient	_____
Dislikes or attempts to prevent patient being alone	_____
Constantly seeks new information about patient's diagnosis (eg. readsoor seeks books and magazines related to cancer).	_____
Has developed protective attitude toward patient.	_____

Comments:

Anticipation of Modes of Readjustment

<u>Verbal Statements</u>	<u>Present</u>
Expresses concern about caring for remaining parent	_____
Thinks about changes in life style that may be necessitated by patient's death	_____
Expresses thoughts about remarriage	_____
Attempts to learn about jobs or responsibilities normally carried out by patient (or considers the need)	_____
Takes over responsibilities usually held by patient	_____
Thinks about possible changes in family relationships following loss of patient	_____
Expresses concern about life without the patient	_____

Comments:

Reviewing Forms of Death that Might Befall Patient

<u>Verbal Statements</u>	<u>Present</u>
Seeks information about when patient may die	_____
Seeks information re: how patient may die	_____
Questions length of time left with patient	_____
Expresses concern about patient's final hospitalization	_____
Belief that "cancer" is equivalent to "death"	_____

Comments: