

PATIENT, PARENT, AND SIBLING REACTIONS
TO END-STAGE CANCER AND DEATH

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CHAPTER I

INTRODUCTION

An extensive body of literature has been developed on the subjects of mourning and object loss. This literature will be reviewed and topically organized reflecting the development of inquiry in the areas of patient reactions to imminent death, parental and sibling mourning reactions to the death of a child. First, the general processes of mourning a loss will be considered. The emergent topic of anticipatory griefwork by parents who lose a child through death will then be reviewed. Parental reactions and methods of coping with their child's death will then be summarized. Finally, the reactions of siblings to a brother's or sister's death will be reviewed.

It will become apparent that as this field has developed the specific means of coping with death have been broadly conceptualized and behaviorally documented. However, recent advances in medical treatment have introduced another consideration which may impact upon the mourning processes. Specifically, parents and pediatric cancer patients are involved in making a choice as to the nature of therapeutic treatment that is to be employed in the end-stage of the disease process. The present study assesses the effects of making a decision to choose supportive care or continued medical treatment (Phase II drugs) immediately prior to a patient's death on the processes of

anticipatory grief and mourning. The reactions by the patient, parents, and siblings were investigated.

CHAPTER II

REVIEW OF THE LITERATURE

This chapter will begin with a presentation of the theoretical considerations which underlie the recent work in the processes of mourning. This study focuses specifically upon the reactions of parents and siblings to the death of a child and the child's reactions to imminent death. Each will be considered separately in a section. The literature on parental mourning reactions covers not only the mourning which follows a death but also the anticipatory griefwork that frequently occurs beforehand. There will therefore be two sections which deal with parental mourning reactions: one to discuss anticipatory griefwork and one to discuss mourning following the actual death of a child.

A. Theoretical Processes of Mourning

Mourning is generally associated with the loss of a loved one but may also result from the loss of an object or intangible attribute in which one is invested. Most of the literature at present addresses the grieving of a deceased individual, generally one older than the bereaved, such as a parental loss in childhood.

In the words of Bowlby (1961), mourning

. . . is best regarded as the whole complex sequence of psychological processes and their overt manifestations, beginning with cravings, angry efforts at recovery and

appeals for help, proceeding through apathy and disorganization of behavior, and ending when some form of more or less stable reorganization is beginning to develop. Those (courses) which enable the individual ultimately to find satisfaction in them are commonly judged to be healthy, those which fail in this outcome, pathological (p. 319).

The ability to mourn presupposes a previous relationship. The age at which the loss occurs appears to be an important factor. Psychopathological responses to loss are sometimes traced to an earlier loss of a primary caretaker and an unsatisfactory resolution of this at an age at which the individual is unable to deal with it. Early personality development depends upon stable relationships (Rochlin, 1953). Loss of a primary relationship at an early age is associated with problems in developing contact with reality and in investment in others. The child then relies upon himself/herself for resources and does not invest enough in objects outside of himself/herself.

There is some question as to when the individual becomes able to mourn in the adult sense. Wolfenstein (1966) considers adolescence to be one of the more important developmental stages in which the capacity for mourning develops. During adolescence, the individual learns to rely less heavily upon his/her parents and to become more independent. Some of the behaviors and feelings associated with this process are said to parallel mourning. The adolescent may seem to grieve not only the loss of former ties but the lack of replacement ties. The bereaved also seem to have difficulty in relinquishing old objects and in re-investing in new ones.

Mourning, in its most popular sense, then appears to assume that the individual had developed fairly normally and has lost a loved one

since childhood. Psychopathological variants are generally traced to inadequate or inappropriate development during childhood stages.

Hostile reactions may be directed toward the lost object or at those considered by the bereaved to be responsible for the loss or lack of reunion (Bowlby, 1961). Remorse, about aggressive thoughts occurring prior to the loss, may prolong the mourning process and may indicate neurosis, the basis of which is magical thinking or "omnipotence of thought" more common among young children (Bergler, 1948).

Guilt reactions may be realistic or unrealistic, depending upon object culpability. More common is unrealistic guilt in which an individual experiences remorse for not having acted in a different fashion in the past. This may be an attempt to feel less helpless after loss (Wolfenstein, 1966).

According to Wolfenstein (1966), loss of patterns of conduct is fairly widespread. The need to be comforted conflicts with anger when others attempt to do so. There may be a tendency to withdraw, to lose interest or concentration in usual activities, or to wish not to depress or "burden" others. Withdrawal has been considered a necessary task in mourning, allowing psychological energy to reorganize and to eventually reinvest in other objects. Withdrawal as a task is gradually relinquished as everyday events promote the acceptance of the loss.

Further variations of the typical mourning process have been discussed by several authors (Bowlby, 1961; Lehrman, 1956; Bergler, 1948; Lindemann, 1944). Lehrman (1956) has found that reactions to an untimely death tend to be of a pathological variation such as obsessive and compulsive behavior, anxiety, hysterical reactions, mood swings,

an excessive withdrawal. Bergler (1948) speaks of variants involving pseudo-aggression in which repressed passivity is covered.

A prolonged or apparently nonexistent period of mourning is generally thought to be pathological. Lindemann (1944) speaks of morbid grief reactions which may take the form of delay or distortion. A delay in mourning may be the result of the bereaved having other preoccupations or important tasks at the time of the death and may involve displacement of feelings. Distorted reactions may include overactivity, the acquisition of symptoms belonging to the deceased, a recognized medical disease, alterations in relationships, furious hostility against specific individuals, loss of contact with reality, a lasting loss of patterns of social interaction, and/or the pursuit of activities detrimental to own social and economic welfare.

B. Patient Reactions to Imminent Death

Children appear to differ in their views of death according to several factors including their age, level of cognitive development, and whether or not they have had to personally confront the issue of death. Differences have been found in thought processes between healthy children and those with malignancies (Gogan, Koocher, Foster, & O'Malley, 1977). Ill children tended to show more distortion, unrealistic thinking and negative fantasy. Behaviors that accompanied these differences included inhibition, withdrawal, and less emotional response among children with malignancies. Armstrong and Martinson (1981) found that children between the ages of nine and eleven who are not fatally ill tended to have an adult-like cognitive conception of death. Healthy

children of younger ages displayed a concept of death that followed the cognitive conceptualizations thought to be appropriate to their ages.

Pre-school children appeared to view death as reversible or as a gradual sleep-like phenomena (Hankoff, 1975). In a study of Hungarian children between the ages of five and nine, the concept of death was personified, perhaps as an attempt at distancing themselves. Koocher (1974) found that American children of the same ages also attempted to distance themselves from death but did so through different means. These children focused upon concrete and stereotyped accounts of the results of death. This tendency was found even among children thought to be capable of verbal abstraction. Among school-aged children there appeared to be a distinction between death and absence and between dying and going away (Green, 1967).

Children who are fatally ill appear to become aware of the nature and severity of their illness regardless of the extent to which they are informed. Binger, Ablin, Fenerstein, Kushner, Zoger, and Mikkelsen (1969) in studying children with Leukemia have found that in most children above the age of four years there was an awareness of the severity of their illness and an anticipation of premature death. Younger children in the study showed more of a preoccupation with separation, disfigurement, and pain. Karon and Vernick (1965) further supported these findings and added that children tended to worry about their illness. Their contention was that children were more concerned by a "conspiracy of silence" and were relieved when they could discuss their concerns with an empathetic adult. They noted that children tended to become hostile when treated evasively by medical personnel or by their parents. Most children appeared genuinely

concerned about their diagnosis, prognosis and course of illness and appreciated accurate communication in these matters.

General concerns expressed by children who are terminally ill include their safety, the availability of trustworthy personnel and the severity of pain (Green, 1967). Natterson and Knudson (1960) in studying children who were dying of cancer and aplastic anemia found an age differential in expressed concerns. Children under five years of age expressed most concern about separation from their mother. Children of ages five to ten were most concerned about traumatic procedures. Over the age of ten, children began to express a fear of death and to be distressed over the death of other children in the hospital.

Spinetta, Rigler, and Karon (1974) have noticed that fatally ill children frequently appeared to become progressively distant from others. He or she began to see others as more psychologically distant and appeared to prefer it that way. Lowenberg (1970) in studying the coping behaviors of fatally ill children has distinguished between approach behaviors, which are aimed at coping with reality, and avoidance behaviors, which are aimed at denial of imminent death. Avoidance behaviors appeared to function to physically avoid the threat or to cognitively distort it. When threat can not be realistically alleviated, denial may indeed be an adaptive mechanism. Maladaptive aspects are present when a child's sense of reality has been impaired.

Re-entry of the fatally ill child to the community presents further pressures as he or she returns to home and school (Kagan-Goodheart, 1977). Younger children, especially those of school age, become concerned that they are "different" from friends due to surgery,

hair loss, weight loss or amputations. These children risk becoming withdrawn and isolated from peers. They may regress to infantile, dependent behaviors. The adolescent, in addition to these concerns, has pressures arising from sports, dating, and body image. This is a particularly sensitive time.

Children who were old enough to express a preference, indicated that they would prefer to die at home (Natterson & Knudson, 1960). Some demonstrated an almost phobic reaction to the hospital. In children between the ages of four and ten, a strong factor in wanting to go home was the avoidance of medical procedures.

C. Anticipatory Griefwork Among Parents

While the child is in the process of dying, the parent, as well as the child show many reactions depending upon the type and length of illness and upon individual characteristics. These reactions, when they precede the actual death, are considered to be indicators of anticipatory grief. This process is thought to prepare an individual beforehand for the actual loss. Leyn (1976) from case study data has noticed that parents show the following reactions: regression, jealousy, suspicion, accusation or blame, denial, depression, guilt, anger, suicidal tendencies, paranoia, shock, magical thinking, cruelty, hyperactivity, anxiety, loneliness, detachment, religiosity, truth-seeking, patience, hope, acceptance, sharing of love, and providing of consolation.

McCollum and Schwartz (1972) have discussed feelings of helplessness, anxiety about not only the situation but also the defenses that parents find themselves using, and about concerns about their own death.

The imminent death of a child threatens the parental roles of protector and caretaker. Parents are no longer in control of their child's welfare. The parents may begin to experience a lack of feelings or may forget more than usual, indicative of defenses used, and these may heighten concerns about their own adjustment and perhaps their own sanity. As this is not a situation for which the culture has given expected roles and behaviors, parents are left without sufficient guidelines and wonder if others in the same situation act and feel as they do.

At times, the parents, as well as other grieving individuals, attempt to find meaning behind the imminent death. Parents may feel that the child's death is meant as punishment and may respond with guilt and depression. If they feel that they do not deserve to be punished, they may become angry and attempt to find an object upon which to place this anger. This object may be the hospital staff, another caretaker or relative, God, or the child. Often this anger may not be consciously accepted but may be denied and/or further displaced (Marcovitz, 1977-78).

Natterson and Knudson (1960), in studying mothers whose children have died after having been ill for at least four months, have noticed a triphasic reaction. The first two stages are often referred to as anticipatory griefwork. The first stage was generally characterized by denial. There was a tendency to regress, to show difficulty in accepting both the illness and the prognosis, to focus upon internal needs, and to become seemingly self-centered. This was replaced by an intermediate stage in which contact with the truth was restored, focus returned to the situation at hand, and the primary caretaker did what

he/she could do to assist the child. Efforts may have indicated a retained hope of saving the child. The second stage revealed a gradual decline in effort. The mothers gradually began to relinquish their children as they became terminally ill. Stage three began when the child actually died. Some initial acceptance of the death has been observed following anticipatory griefwork. Wishes for the child's death were expressed before the fact. Parents directed their emotions away from the child's dying process, preferring instead to focus upon the child's particular disease. These parents seemed to be less disturbed and to adjust increasingly well as these stages progressed.

Share (1972) further supports the use of anticipatory griefwork. In her discussion of open vs. closed communication, it is maintained that denial of the death leads to more severe or "all at once" reactions after the death has actually occurred.

Communication among parents in the event of a child's fatal illness appears to have a strong influence upon actual mourning and the stress which this event can place upon their relationship. Kaplan, Smith, Grobstein, and Fischman (1973) point to effective communication, in which feelings are shared openly, as a precursor to effective coping responses. Restrictive communication, on the contrary, seems to promote discrepancies in coping styles, the perception of an expressive spouse as weak, and a general prohibition of expressing grief. This strain on the expected emotional support system in conjunction with the mourning of a child can seriously strain the marital relationship.

D. Parental Reactions to the Actual Death

In interviewing parents of deceased children, a natural mourning

period of one year appears to be the pattern (Hamovitch, 1964). Lascari and Stehbens (1973) report that in half of the parental interviews, the following symptoms were present within a short period of time after the child's death: loss of sleep, loss of appetite, and constant thoughts about the deceased child. Others reported difficulties in "performing their duties."

The use of psychiatric care after the death of a child is reported to be fairly common. Binger et al. (1969) report that in over half of the cases interviewed one or more family members require psychiatric care. There were several cases that called for admission to a hospital for severe depression. Kaplan et al. (1973) in a three month follow-up found that at least one-fourth of the families had a member under psychiatric care after a child's death.

Some authors (Spinetta, Swarner, & Sheposh, 1981; Lascari & Stehbens, 1973, 1974) have failed to report a high rate of adverse reactions among parents to the death of a child. Mothers, on the whole, tend to adjust somewhat better than fathers (Hamovitch, 1964). It is suspected that this occurs more commonly in families where the mother has taken a more active role in caring for the dying child and where the father has been relatively uninvolved.

Marital relationships among those interviewed tend to be strong, as if the crisis had brought the couple closer (Hamovitch, 1964; Stehbens & Lascari, 1974; Spinetta et al., 1981). Spinetta et al. (1974) further report that a crisis of this type seems to promote family cohesiveness and a positive redefinition of values.

Spinetta et al. (1981) have found three common characteristics among parents who were considered to be the best adjusted after the

death of their child. First, these parents held a consistent philosophy of life during the course of the child's illness and this appeared to help them to accept the diagnosis and the course of the illness. Secondly, these parents all seemed to have a support group, usually family or friends, to whom they could turn. Lastly, these parents had given their child the information and emotional support that the child needed during the course of illness, taking into consideration the child's questions, age, and level of development.

The type and length of illness are important factors in determining familial mourning patterns. Tietz, McSherry, and Britt (1977) tentatively conclude that high risk families, in which coping mechanisms might fail after the child's death, tend to be economically poor and to come from an ethnic minority group. It is also suggested that a child's death of solid tumor or sarcoma, as opposed to Leukemia, is associated with a poorer psychological outcome among family members (Hamovitch, 1964). It is thought that this is due to the amount of pain and mutilation involved in the care of a patient with solid cancer or sarcoma. Families of young adolescent patients also seem to have a poor psychological outcome after the child dies (Tietz et al., 1977). This is thought to be due to the adolescent's difficulty in coping with the bodily changes associated with the medical illness at the same time that he/she is coping with pubertal changes.

Codden (1977) stresses the circumstances surrounding the particular child's birth. The child's environment is influenced by whether he/she was planned and wanted, birth order, pregnancy and birth factors, the parental relationship, economic means, and the child's temperament. The child's position and the value placed upon his/her

contribution in the family system is determined largely by these factors. Surprisingly, Spinetta et al. (1981) report that the age and sex of the child does not seem to be related to the long-term level of adaptation of the parents.

E. Sibling Reactions to a Child's Death

Few studies have directly investigated sibling reactions to a child's death. All authors appear to agree that disturbed reactions do occur and that the most common of these is guilt (Cain, Fast, & Erickson, 1964; Weston & Irwin, 1963; Rosenzweig, 1943; Ellard, 1948; Rosenzweig & Bray, 1943).

Perhaps the most comprehensive study was conducted by Spinetta (1981). Pediatric cancer patients and their parents and siblings were assessed as to their individual emotional adjustment to the child's death. Results indicated that sibling's emotional needs were met significantly less adequately than those of either the patients or their parents. Siblings between the ages of four and six viewed their parents as more psychologically distant from themselves, showed a lower level of self-concept and had a more negative attitude about themselves than did the pediatric cancer patients. The elementary school aged siblings also saw their parents as more psychologically distant than did the patients. In addition, these siblings showed more maladaptive responses to projective test items relating to anxiety and depression than did the patients. Adolescent siblings viewed their families as higher in conflict and lower in cohesion than did the patients. More elements of punishment and mutilation were present in the stories of adolescent siblings than in those of the patients. It was concluded

that whether the patient is doing poorly or is in remission, the siblings do not get the emotional support that they need. Parents are often too pressured themselves to give this support.

Cain et al. (1964) describe both expected and disturbed reactions. Expected reactions include: an appetite loss, dazed states, incessant talk about the death, nightmares, speech disturbances, enuresis, antisocial acting out, and severe anxiety states. Ellard (1968) adds that anniversary effects, acquisition of the deceased's symptoms, and apparent absence of grief are also common among siblings.

Disturbed reactions are said to include: guilt reactions, distorted concepts of illness and death, disturbed attitudes towards hospitals and religion, death phobias, identifications and "misindications," and disturbances in cognitive functioning. Literature has also supported through case studies the contention that death of a child is related to the later onset of schizophrenia. This is considered to be more prevalent if there are multiple sibling deaths and if the child remaining is under six years of age at the time of the death (Rosenzweig, 1943; Rosenzweig & Bray, 1943).

Much of the literature has stressed abnormal reactions rather than general coping and adaptation mechanisms. Sourkes (1977) presents several areas of concern in normal sibling mourning. Siblings tend to hold a private version of what caused the illness. Through magical thinking, they may hold themselves responsible. Children may be confused as to the correct identity of the dying child, particularly if the illness has caused changes in the physical appearance of the child. The siblings may fear that they too will develop cancer. Other experiences in their lives have suggested that what happens to

one sibling will generally happen to the others. Siblings may feel guilty that they escaped the disease and they may experience shame that their family is "different" by virtue of having a dying child. If the sibling is older, he/she may have taken over some of the responsibilities of the parents and may resent this. The child may become preoccupied with school in order to gain some area of control over his/her life or may become disengaged from school and peers.

Factors said to influence sibling reactions are sibling age and maturity, ability to understand the meaning of illness, the relationship to the patient, honesty of communication and involvement in family adaptation (Weiner, 1974).

Lindsay and MacCarthy (1974) discuss the importance of age in determining sibling reactions. A sibling who is an infant at the time of the child's fatal illness is said to be at the highest risk. The mother's attention, at a time when the infant most needs it, is focused on the sick child. The toddler may interpret the change in direction of his/her mother's attention as rejection and may show behaviors common to a younger child. The older child may experience guilt, resentment, anger and rejection. In addition, the older child is more apt to notice the increasing anxiety among family members. The older child may act out or withdraw, school performance may drop, and he/she may complain of various physical problems. If the sibling is older than the fatally ill child, there may be a re-activation of the rivalry that existed when the younger child was born. In school-aged children, when a certain amount of competition is expected, there may be intense competition with the ill child.

Share (1972) discusses the meaning of the illness to a sibling. The illness of a sibling is often accompanied by a loss of parental attention at home and changes of routine and activities. Siblings may be angry with parents and may compete for attention with the sick child. If the fatally ill child has a remission, the sibling may become angry at the child, only to experience guilt and fear when the child has a relapse. Siblings of children with childhood cancer need more attention and more opportunity to discuss their anger and jealousy with parents (Kagan-Goodheart, 1977).

The stage of the dying child's illness appears to elicit different behaviors from siblings. Early in the illness, poor adjustment is associated with little information from the mother about the nature of the disease (Townes & Wold, 1977). Most siblings attempt to minimize the impact of the illness at the time that it occurs and may display rivalry with the ill child (Gogan et al., 1977). Siblings appear to show greater emotional difficulty after the child dies, worrying about the responsibility for the death, fearing that he/she will be the next to die, and resenting parents for both becoming preoccupied with the dying child and being unable to protect the child from dying (Binger et al., 1969).

CHAPTER III

SCOPE OF STUDY AND HYPOTHESES

In response to the needs of children whose cancer had progressed despite standard therapy, the Hematology/Oncology team of the Oklahoma Children's Memorial Hospital developed an approach which gives the child and the parent(s) the option of continuing chemotherapy (Phase II drugs) or choosing supportive care (Nitschke, Humphrey, Sexauer, Catron, Wunder & Jay, 1982). Parents are informed that Phase II drugs are anticancer agents for which the tolerated dosage and possible side effects are known. However, their effectiveness against malignancies in man has yet to be established. If the parents agreed, therapy was begun after the child was informed that his/her disease had progressed and that a new drug would be used.

The conference in which final therapeutic options were discussed was called the "Final Stage Conference" (FSC). The following subjects were covered: a review of the disease, the recent progression of the disease, the unavailability of any other effective drugs, the improbability of cure and the imminence of death. The child was told openly, "Most likely you will die from this disease very soon." Two therapeutic options were offered: the use of Phase II drugs or supportive care.

The pros and cons of these two therapeutic options are outlined in Appendix A. For a child who chooses to be treated with a Phase II drug, a cure is very unlikely. A remission, however, may occur,

resulting in prolongation of life. The Phase II drugs may produce side effects of varying severity. During the administration of the medicine, or in case of fever or infection, the patient must be hospitalized. Blood products are administered when needed. Follow-up outpatient visits, usually weekly, are necessary. The child spends as much time as possible at home. On the other hand, the child who chooses supportive care will soon die from his disease. The child is not admitted to the hospital for antibiotic therapy or for blood transfusions unless such treatment is requested. The child can remain at home if he/she wishes. Since clinic visits are not necessary, care can usually be handled by the family physician or pediatrician.

This study focused upon factors which reflected the decision made by the patient and his/her parent(s) after the Final Stage Conference and the subsequent effects upon the patient's, parent's and sibling's processes of anticipatory grief and mourning. This research examines differences in the reactions of patients and parents and siblings of patients who have elected to use Phase II drug therapy as compared to those who have chosen the supportive care option after the Final Stage Conference. Specifically, anticipatory grief and mourning sequelae exhibited by these groups were investigated.

In the choice of either option, the use of Phase II drug therapy or supportive care, the child patient is expected to die within a short time. Despite clear communication to the patient and his/her family that the child's death is imminent, it is suspected that patients and parents who elected the Phase II drug therapy option retained some hope of at least partial remission of the illness. The literature cites the use of anticipatory griefwork among family members as an

important process in promoting a relatively good psychological outcome after the child's death. Therefore, as those who choose the Phase II drug therapy option may be retaining the hope of control of the disease, they may be impeding useful anticipatory griefwork, the following hypotheses were tested:

1. It was hypothesized that patients who had chosen Phase II drug therapy would show a higher frequency of mourning behaviors and feelings than those who had chosen the supportive care option.
2. It was hypothesized that parents of patients who had chosen the use of Phase II drug therapy would show a higher frequency of mourning behaviors and feelings than parents of patients who had chosen the supportive care option.
3. It was hypothesized that siblings of patients who had chosen the use of Phase II drug therapy would show a higher frequency of mourning behaviors and feelings than siblings of patients who had chosen the supportive care option.

CHAPTER IV

METHOD

A. Subjects

Subjects are the parents of deceased child cancer patients. Forty-six children and their parents made the difficult decision as to Phase II drug therapy or supportive care. Thirty-five patients and their parents, 70% of the total group, chose the supportive care option. Fourteen patients and their parents, 30% of the total group, chose the Phase II option. (See Appendix B for treatment choice and sexual composition of the total group.)

Of the 46 questionnaires sent, 23, or 50%, were answered. Sixteen, 70%, of the returned questionnaires, were from parents of patients who had chosen the supportive care option. Seven, 30%, of the returned questionnaires, were from parents of patients who had chosen the Phase II option. The rate of return, while relatively low, appeared to reflect proportionately the total group of patients and parents available. (See Appendix B for treatment choice and sexual composition of the returned questionnaires.)

All data were gathered through retrospective parental report. Parents were asked to recall their own grief and mourning reactions as well as those of the patient and siblings. (See Appendix B for demographic characteristics of the subjects.)

Subject data was divided into six groups for the purpose of analysis: patients who have chosen supportive care, patients who have chosen Phase II drug therapy, parents of those who have chosen supportive care, parents of those who have chosen Phase II drug therapy, siblings of those who have chosen supportive care, and siblings of those who have chosen Phase II drug therapy.

B. Procedure

Each parent, identified as one whose child died while a patient on the Oklahoma Children's Memorial Hospital Oncology service between 1974 and 1980, was sent a consent form to participate in this study (see Appendix C for Consent Form) and a letter from an attending physician (see Appendix D for Physician Letter).

Upon receipt of the Consent Form, the parent was sent by mail a questionnaire covering the topics of patient, parent, and sibling reactions to the Final Stage Conference and the parent and sibling reactions to the patient's death (see Appendix F for Parent Questionnaire).

C. Analyses

A stepwise discriminant analysis was performed on the demographic and family information to identify the dependent variables which in combination discriminate best between the Supportive Care and Phase II groups. Parental mourning behavior was also analyzed through a stepwise discriminant analysis between the two groups, Supportive Care and Phase II, at three different time periods: immediately after the Final Stage Conference, immediately after the child's death, and one

year after the child's death. Sibling mourning behavior was analyzed in the same manner. Deceased child mourning behavior was analyzed by the same method but at different time periods: immediately after the Final Stage Conference, while the child was feeling fairly well, and at the time of rapid physical decline.

CHAPTER V

RESULTS

Each of the dependent variables for patients, parents, and siblings was analyzed by means of a stepwise discriminant analysis between the Supportive Care and Phase II groups for three separate time periods. Parental and sibling mourning behaviors were analyzed in retrospect for the time periods occurring immediately after the Final Stage Conference, immediately after the child's death, and one year after the child's death. Deceased children's mourning behaviors, also collected through retrospective parental report, were analyzed for the time periods occurring immediately after the Final Stage Conference, while the child was feeling fairly well, and at the time of rapid physical decline. Specific dependent variables appear as items on the parent questionnaire (see Appendix E).

The four tables referred to in this chapter provide information about the relative strength of the canonical variable calculated at each time period for both the Supportive Care and Phase II groups. At each time period the dependent variables which best discriminated between the two groups were selected, and a relative weight and directional contribution were provided. The dependent variables that form the canonical variable for each time studied are listed on their respective tables in order of decreasing magnitude of the canonical weights. In general, the higher the weight assigned to a dependent variable, the

stronger a role it plays in the development of the canonical variable. In this study, lack of a directional sign before the dependent variable weight generally indicates a higher incidence among subjects in the Supportive Care group while a negative sign generally indicates a higher incidence among subjects in the Phase II group. Some dependent variables appear to be operating as suppressors which means that they are not directly interpretable.

Percentages have been provided by group for each dependent variable. The percentage indicate the incidence of the characteristics coded '1'. The incidence of the opposite characteristic (which was coded '0') is 100% minus the percentage shown.

A. Demographic and Family Information

Stepwise discriminant analysis of demographic and family information identifies six dependent variables which in combination discriminate best between the Supportive Care and the Phase II groups ($F=7.743$, $df=6,16$, $p.<.001$, $r=.86$). Table I contains the dependent variables which combine to form the canonical variable, their individual weights and percentages by group. Families of those who have chosen the supportive care option, in contrast to families of those who have chosen the Phase II option, show less education among eldest siblings, less regret in having been included in the Final Stage Conference, somewhat less agreement that child should have been included in the Final Stage Conference, a higher rating of their relationship with staff, and a lower age of siblings avoided by the patient. The dependent variable, age of eldest sibling, appears to function as a suppressor contributing indirectly to the canonical variable in a difficult to interpret fashion.

TABLE I
STEPWISE DISCRIMINANT ANALYSIS ON
DEMOGRAPHIC AND FAMILY
INFORMATION

	Variable	Weight
	Years of Education - Sibling #1	-1.87
Supportive Care (n=16):	8.13	
Phase II (n=7):	9.43	
	Parents regret having been included in the Final Stage Conference	-1.39
Supportive Care:	0%	
Phase II:	14%	
	Age of sibling #1	1.28
Supportive Care:	16.88	
Phase II:	17.71	
	Child should have been included in the final stage conference	-1.26
Supportive Care:	81%	
Phase II:	86%	
	Rating of relationship with staff	1.25
Supportive Care:	3.75/4.00	
Phase II:	2.43/4.00	
	Age of avoided sibling	-1.08
Supportive Care:	0.50 years	
Phase II:	3.14 years	

F=7.743, df=6,16, p. < .001

r=.86

B. Deceased Children's Mourning Behaviors

Stepwise discriminant analysis of observed deceased children's mourning behaviors occurring immediately after the Final Stage Conference revealed only one dependent variable which discriminated well between the two groups ($F=4.26$, $df=2,20$, $p.<.05$, $r=.55$). Table II contains all dependent variables which combine to form the canonical variables, their individual weights and their occurrence by group for each of the three times observed. Results were originally analyzed including patients' sex as a dependent variable. As all patients who had chosen the Phase II option were male, results were difficult to interpret. Patients' sex was then eliminated as a dependent variable. These results indicate that patients who had chosen the supportive care option were more likely to show no grief and to appear nervous immediately after the Final Stage Conference than patients who had chosen the Phase II option.

At the second time, while the child was feeling fairly well, no significant dependent variables which discriminated between the two groups were observed (see Table II). Behaviors recalled in patients while they were in rapid physical decline, when entered into a stepwise discriminant analysis, revealed one significant dependent variable which best discriminated between the two groups ($F=3.836$, $df=1,21$, $p.<.10$, $r=.39$). Patients who had chosen the supportive care option were more likely to appear fearful at the time of rapid physical decline than patients who had chosen the Phase II option (see Table II).

TABLE II
 STEPWISE DISCRIMINANT ANALYSIS ON DECEASED
 CHILDREN'S MOURNING BEHAVIORS

	Immediately After Final Stage Conference	While Child Was Feeling Fairly Well	At Time of Rapid Physical Decline
	Showed No Grief 0.89	No variables entered.	Fearful 1.00
Supportive Care (n=16): Phase II (n=7):	44% 0%		50% 0%
	Nervous 0.68		
Supportive Care: Phase II:	25% 0%		
	F=4.26, df=2,20, p. < .05, r=.55		F=3,836, df=1,21, p. < .10, r=.39

C. Parental Mourning Behaviors

Stepwise discriminant analysis of parental mourning behaviors observed immediately after the Final Stage Conference showed only one dependent variable which significantly discriminated between the two groups ($F=4.971$, $df=1,21$, $p.<.05$, $r=.44$). Table III contains all dependent variables which combined to form the canonical variables, their individual weights and their occurrence by group for each of the three times observed. Parents of patients who had chosen the supportive care option were more likely to feel irritable immediately after the Final Stage Conference than parents of those who had chosen the Phase II option.

There were eight parental mourning behaviors observed immediately after the child's death which in combination were found to significantly discriminate between the two groups ($F=11.819$, $df=8,14$, $p.<.001$, $r=.93$). Parents of those who had chosen the supportive care option, in contrast to parents of those who had chosen the Phase II option, were more likely to feel helpless, to sleep less, to go back to school, to do volunteer work, not to feel empty, to change jobs, and to have difficulty concentrating. The dependent variable which indicates that parents have joined a support group appears to be operating as a suppressor, which means that it is contributing indirectly to the canonical variable in a difficult to interpret fashion (see Table III).

TABLE III

STEPWISE DISCRIMINANT ANALYSIS ON
PARENTAL MOURNING BEHAVIORS

	Immediately After Final Stage Conference	Immediately After Child's Death	One Year After Child's Death
	Felt Irritable 1.00	Felt Helpless 2.76	Stopped Working 1.10
Supportive Care (n=16):	44%	81%	25%
Phase II (n=7):	0%	29%	0%
		Slept More -1.66	Moved -0.95
Supportive Care:		6%	25%
Phase II:		14%	53%
		Went Back to School 1.30	
Supportive Care:		6%	
Phase II:		0%	
		Did Volunteer Work 1.21	Did Volunteer Work 0.75
Supportive Care:		13%	45%
Phase II:		0%	0%

TABLE III (Continued)

	Immediately After Final Stage Conference	Immediately After Child's Death	One Year After Child's Death
		Felt Empty -1.21	Felt Relieved 0.62
Supportive Care: Phase II:		88%	40%
		100%	0%
			Felt Depressed 0.31
Supportive Care: Phase II:			51%
			49%
		Joined Support Group -1.14	Joined Support Group -0.20
Supportive Care: Phase II:		13%	0%
		14%	38%
		Changed Job 0.79	
Supportive Care: Phase II:		6%	
		0%	

TABLE III (Continued)

	Immediately After Final Stage Conference	Immediately After Child's Death	One Year After Child's Death
		Difficulty Concentrating 0.68	
Supportive Care: Phase II:		56% 43%	
	F=4.971, df=1,21, p. < .05, r=.44	F=11.819, df=8,14, p. < .001, r=.93	F=6.646, df=6,16, p. < .005, r=.85

One year after the child's death, a combination of six dependent variables discriminated most significantly between parents of those who had chosen the supportive care option and parents of those who had chosen the Phase II option ($F=6.646$, $df=6,16$, $p < .005$, $r=.85$). Parents of those who had chosen the supportive care option, in contrast to parents of those who had chosen the Phase II option, were more likely to stop working, not to move, to do volunteer work, to feel relieved, and not to join a support group. The dependent variable indicating that parents felt depressed appeared to be operating as a suppressor variable, which means that it is not directly interpretable (see Table III).

D. Sibling Mourning Behaviors

Stepwise discriminant analysis of sibling mourning behaviors observed immediately after the Final Stage Conference revealed two dependent variables which in combination significantly discriminated between the Supportive Care and the Phase II groups ($F=5.334$, $df=2,33$, $p < .025$, $r=.49$). Table IV contains all significant dependent variables, their individual weights and percentages by group for observed sibling mourning behaviors. Siblings of those who had chosen the supportive care option were more likely to appear sad immediately after the Final Stage Conference than were siblings of those who had chosen the Phase II option. Sibling's sex also appeared as a significant discriminator. Females tended to be represented more often among siblings of those who had chosen the supportive care option than among siblings of those who had chosen the Phase II option.

TABLE IV
STEPWISE DISCRIMINANT ANALYSIS ON
SIBLING MOURNING BEHAVIORS

	Immediately After Final Stage Conference	Immediately After Child's Death	One Year After Child's Death
	Sad 0.95	Sad 1.00	No variables entered
Supportive Care (n=28): Phase II (n=8):	43% 0%	68% 25%	
	Sex 0.73		
Supportive Care: Phase II:	46% M, 54% F 75% M, 25% F		
	F=5.334, df=2,33, p. < .025, r=.49	F=5.108, df=1,34, p. < .05, r=.36	

Of sibling mourning behaviors observed immediately after the child's death, only one dependent variable was found to significantly discriminate between the two groups ($F=5.108$, $df=1,34$, $p < .05$, $r=.36$). Siblings of those who had chosen the Supportive Care option were again more likely to appear sad than were siblings of those who had chosen the Phase II option (see Table IV).

One year after the child's death, no significant dependent variables discriminating between the two groups were observed. No canonical variable was developed for this time period.

CHAPTER VI

DISCUSSION

The results of this investigation do not unilaterally support a choice of the supportive care or the Phase II treatment option. Neither choice promotes healthier anticipatory griefwork and mourning for all patients, parents, and siblings. The results will initially be discussed in the order of their presentation in the RESULTS section. Following this consideration of the findings, a summary of the relative benefits of the supportive care and Phase II treatment choices at different times in the dying process will be presented.

A. Demographic and Family Information

Patients who chose the supportive care option came from families of younger and less educated siblings. Siblings avoided by the patients who had chosen the supportive care option were also younger than siblings avoided by patients who had chosen the Phase II option. Younger siblings, especially infants, are generally at higher risk when parental attention is lessened (Lindsay & MacCarthy, 1974). Siblings of those who had chosen the Phase II option were somewhat older, which might help to explain their seemingly better adjustment immediately after the Final Stage Conference and immediately after the child's death.

As siblings appeared to be younger among those who chose the supportive care option, parents tended to agree less that the child should be included in the Final Stage Conference and tended to regret less their own involvement in the Final Stage Conference. It is difficult to assess whether a child who has not reached the age generally associated with abstract thought (ages 9-11) is capable of making such an important decision without parental help. Perhaps reflecting the lack of regrets about their inclusion in the Final Stage Conference, and because of increased daily involvement in their child's dying process, parents of those who had chosen the supportive care option rated their relationship with the staff higher than parents of those who had chosen the Phase II option.

B. Deceased Children's Mourning Behaviors

In regards to the patients, results indicate that showing no grief and appearing nervous are important discriminating variables between the Supportive Care and the Phase II groups immediately after the Final Stage Conference. It is debatable as to whether showing no grief, evident among those who had chosen the supportive care option, is a healthy response supporting the normal anticipatory grief process or whether it is an indication of a pathological response involving withdrawal and denial. There is support in the literature that showing no grief is an indication of a healthy response. Lowenberg (1970) cited denial as a potentially adaptive response. The findings of Spinetta et al. (1974) indicate that distancing oneself as one approaches death is to be expected among dying children. This would

suggest that expressing grief outwardly is not common as the child approaches death.

Patients who had chosen the supportive care option, however, were also more likely to appear nervous than patients who had chosen the Phase II option. The expression of nervousness would seem to indicate that showing no grief is less helpful to patients immediately after the Final Stage Conference. This appears to contradict the findings of Lowenberg (1970) and Spinetta et al. (1974). If the combination of showing no grief and appearing nervous is considered less helpful to the patient, it is suggested that choice of the supportive care option facilitates normal healthy anticipatory griefwork to a lesser degree than choice of the Phase II option among patients immediately after the Final Stage Conference.

At the time when the child was feeling fairly well, no dependent variables discriminated best between the Supportive Care and the Phase II groups. It appears that at this time, neither choice is associated with promoting a healthier anticipatory grieving response among patients.

At the time of rapid physical decline, patients who had chosen the supportive care option appeared more fearful than patients who had chosen the Phase II option. The expression of fear at this time appears to be a normal reaction when facing one's own imminent death. It appears that choice of the supportive care option is associated with a more normal anticipatory grieving process among patients at the time of rapid physical decline.

Results of the analyses of patient reactions at all three times observed may be difficult to interpret due to treatment differences.

As patient reactions were obtained through retrospective parental report, it may have been difficult to obtain information about anticipatory grief reactions of patients while they were in the hospital. Mourning reactions of patients who were at home would perhaps be more noticeable to parents. Patients who had chosen the Phase II option spent much of their time after the Final Stage Conference at home. This is in contrast to patients who had chosen the supportive care option as they spent most of the time after the Final Stage Conference at home. It would appear that mourning behaviors among patients who had chosen the Phase II option would be reported less than mourning behaviors of patients who had chosen the supportive care option.

Natterson and Knudson (1960) found that terminally ill children prefer to die at home. It is questionable, however, whether dying at home promotes more useful anticipatory griefwork among these patients throughout the process of their illness. These results suggest that the process of dying at home, which is most common among those who have chosen the supportive care option, may be less useful in promoting useful anticipatory griefwork immediately after the Final Stage Conference. There is no indication as to whether being at home is better or worse for the patient while he/she is feeling fairly well. At the time of rapid physical decline, results tentatively suggest that being at home is more useful to the patient in facilitating normal grieving.

C. Parental Mourning Behaviors

In regard to the parent's mourning behaviors, the results indicate

that immediately after the Final Stage Conference, parents of those who had chosen the supportive care option felt more irritable than parents of those who had chosen the Phase II option. Presumably this is due to the increased pressures and activity associated with having a dying child in the home. It seems that after the Final Stage Conference, parents of those who chose the Phase II option were under less immediate strain than parents of those who chose the supportive care option. Other than this one significant variable, parents appeared to show no differences in anticipatory grieving according to treatment choice.

Immediately after the child's death, however, parents of those who chose supportive care exhibited far more mourning behaviors than did parents of those who chose the Phase II option. Results indicated that parents in the Supportive Care group, in contrast to parents in the Phase II group felt more helpless, went back to school, did volunteer work, changed jobs, and had difficulty concentrating. The parents of those who chose the Phase II option stated that they slept more and felt emptier than parents of those choosing the supportive care option. Parents in the Supportive Care and Phase II groups experienced grief differently, and as a result made different choices about handling their grief immediately after the child's death. When parents of those who chose the supportive care option felt helpless and had difficulty concentrating, indicative of depression, they chose relatively active interventions involving life changes. When the parents of those who chose the Phase II option were feeling empty, also indicative of depression, they slept more. Presumably this is a less useful means of coping with the grief because it involves withdrawal and passivity. Activity in the form of trying to help oneself

is considered useful, however, life changes may be indicative of avoidance rather than coping and resolution. Also one may make life changes during a period of mourning that one regrets at a later date. For instance, the supportive care parents changed jobs immediately after their child's death, but 25% had stopped working one year later. At this point, it is debatable as to whether the choice of the supportive care or the Phase II option is associated with healthier grieving among parents immediately after the child's death.

One year after the child's death, both groups of parents were still exhibiting griefwork. This is not to be considered unusual, however, as it supports Hamovitch's (1964) finding of one year parental mourning period. Parents of those who chose the supportive care option, in contrast to those who chose the Phase II option, were more likely to stop working, to do volunteer work, and to feel relieved. Those choosing the Phase II option reported more moving and more support group attendance than did parents who had chosen the supportive care option. The dependent variables indicating that parents stopped working, moved and performed volunteer work are hard to interpret in a positive or negative fashion. The dependent variables indicating that the parents felt relieved and joined a support group, however, do appear to be directionally meaningful. To the extent that joining a support group can be interpreted in a negative fashion, it would appear that choice of the Phase II option is associated with more grieving among parents of deceased children one year after the child's death. To the extent that the dependent variable indicating that parents felt more relieved can be interpreted in a positive fashion, it would appear that choice of the supportive care option among parents

of deceased children is associated with less mourning behavior and better adjustment one year after the child's death.

In general, the choice of the Phase II option appears to be associated with more parental comfort after the Final Stage Conference. Results do not clearly point to either choice as more helpful in promoting a healthier grief response among parents immediately after the child's death. Choice of the supportive care option appears to be associated with less grieving and better adjustment among parents one year after the child's death. Results are difficult to interpret due to a lack of information indicating the extent to which particular mourning behaviors are to be considered healthy or pathological responses at various time periods in reference to the individual parent.

D. Sibling Mourning Behaviors

In regard to the siblings' mourning behaviors, the results indicate that immediately after the Final Stage Conference and immediately after the child's death, siblings of those who had chosen the supportive care option appear sadder than siblings of those who had chosen the Phase II option. Neither group exhibits significant levels of sadness one year after their sibling's death. More sadness among siblings of those who chose the supportive care option may be in part due to the larger representation of females among this group. Siblings of those who chose the Phase II option, however, showed no sadness immediately after the Final Stage Conference. This would suggest a difference not entirely due to the sex composition of the groups.

Apparently having a sibling die at home is a far more saddening experience than having a sibling die in the hospital. Sourkes (1977)

states that the presence of an ill sibling in the home is generally accompanied by the loss of parental attention and a change in home routines and activities. Parents are often preoccupied with the care of the dying child while he or she is alive, and are grieving themselves both before and after the child's death. Parents of those choosing the supportive care option, in contrast to parents choosing the Phase II option, tended to choose active means of coping with their grief. These means often included activities outside of the home. This would suggest even less time and parental attention to siblings of the supportive care patient.

In general, it would appear that the choice of the supportive care option is less helpful for siblings in both their anticipatory and actual griefwork. Siblings of those who have chosen the Phase II option are less sad. The relative absence of sadness among siblings of those choosing the Phase II option, in comparison to siblings of those choosing the supportive care option, is consistent with Ellard's (1968) findings that an absence of grief among siblings of deceased children is common.

Choice of either option appears to have similar results one year after the child's death. No discriminating mourning behaviors are shown between the two groups. This appears to indicate that the importance of the choice made at the Final Stage Conference affects siblings immediately after the Final Stage Conference and immediately after the child's death, but does not have consequences beyond one year after the child's death. It appears that the choice of the Phase II option is more healthy for siblings immediately after the Final Stage Conference and immediately after the child's death, but that

neither choice is associated with longterm mourning behaviors among siblings. Siblings appear to become adjusted to the child's death within one year regardless of the treatment choice made at the Final Stage Conference.

Healthy anticipatory griefwork among terminally ill children appears to be associated with choice of the Phase II rather than the supportive care option after the Final Stage Conference. While the child is feeling fairly well, neither option appears to be more useful in promoting anticipatory griefwork. At the time of rapid physical decline, choice of the supportive care option appears to promote healthier anticipatory griefwork.

Parents of those who chose the Phase II option appear somewhat more comfortable after the Final Stage Conference than parents of those who chose the supportive care option. Immediately after the child's death there seems to be no clear indication as to which choice is associated with promoting a healthier mourning response among parents. One year after the child's death, choice of the supportive care option appears to be associated with less grieving and better adjustment among parents.

Siblings seem to adjust better immediately after the Final Stage Conference and immediately after the child's death if the Phase II option is chosen. One year after the child's death, siblings do not appear to be mourning significantly and treatment choice does not appear to make a difference.

Immediately after the Final Stage Conference, terminally ill children appear to show healthier anticipatory griefwork if they have chosen the Phase II option. Parents and siblings of patients appear

more comfortable if the Phase II option has been chosen presumably because the child remains in the hospital.

Immediately after the child's death, there is no clear indication as to which treatment option promotes healthier mourning responses among parents. Siblings of deceased patients appear to adjust better immediately after the child's death if the Phase II option was chosen.

One year after the child's death, choice of the supportive care option seems to indicate less grieving and better adjustment among parents of deceased patients. Treatment choice does not seem to have a significant effect on sibling mourning one year after the child's death.

Results of this study are difficult to interpret due to the unavailability of criteria by which to judge whether or not particular mourning behaviors promote healthy grieving processes among patients, parents, and siblings. It would seem useful in any future investigation to include an a priori parent and professional judgment task to assign positive or negative values for each mourning behavior.

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APPENDIXES

APPENDIX A

FINAL STAGE CONFERENCE

TWO OPTIONS

FINAL STAGE CONFERENCE
2 OPTIONS

	<u>Phase II Drug</u>	<u>Supportive Care</u>
Cure	Very unlikely	No
Remission and prolongation of life	Possible	No
Death due to disease	Yes (?)	Yes
Life expectancy	?	1-20 weeks (6 weeks)
Phase II drug side effects	Yes	No
IV Antibiotics for fever	Yes	No
Blood products if needed	Yes	No (Unless requested by patient)
Hospital stay	Yes	No (Unless requested)
Outpatient visit	Yes	As desired
Home	Yes except for therapy	Yes
Medical Care	Oncology Service	Oncology Service or family physician

APPENDIX B

DEMOGRAPHIC CHARACTERISTICS
OF THE SUBJECTS

Family Demographic Information

	Supportive Care (n=16)		Phase II (n=8)	
	\bar{X}	S.D.	\bar{X}	S.D.
Father's age	41.06	14.33	34.57	24.23
Father's education	10.88	4.92	10.14	7.06
Father's occupation	3.38	1.54	3.86	1.86
Mother's age	38.00	12.63	29.43	20.99
Mother's education	10.75	4.39	10.71	5.06
Mother's occupation	1.13	1.78	2.43	2.30
Number of siblings	2.13	1.75	2.29	2.29
Parent answering questionnaire:				
Father		12%		13%
Mother		88%		87%
Sibling #1's Age	16.88	9.08 (n=16)	17.71	12.09 (n=6)
Sibling #1's Sex	66% M, 44% F		86% M, 14% F	
Sibling #1's Education	8.13	4.26	9.43	6.21
Sibling #1's Occupation	.93	1.34	1.17	4.10
Sibling #2's Age	22.25	7.75 (n=8)	27.33	7.11 (n=3)
Sibling #2's Sex	50% M, 50% F		33% M, 66% F	
Sibling #2's Education	12.13	4.05	14.00	1.42
Sibling #2's Occupation	2.25	1.5	2.00	1.42
Sibling #3's Age	21.86	6.30 (n=7)	27.50	2.50 (n=2)
Sibling #3's Sex	71% M, 29% F		100% M	
Sibling #3's Education	12.43	3.85	14.00	2.00
Sibling #3's Occupation	1.29	1.18	3.50	.71
Sibling #4's Age	19.80	8.06 (n=5)	23.50	4.50 (n=2)
Sibling #4's Sex	40% M, 60% F		50% M, 50% F	
Sibling #4's Education	10.80	4.88	12.50	.71
Sibling #4's Occupation	1.60	1.35	0.00	0.00
Sibling #5's Age	20.50	2.12 (n=2)	19.50	4.50 (n=2)
Sibling #5's Sex	100% F		50% M, 50% F	
Sibling #5's Education	12.50	.71	11.00	1.00
Sibling #5's Occupation	1.50	2.12	1.50	1.50
Sibling #6's Age	---	--- (n=0)	22.00	0.00 (n=1)
Sibling #6's Sex	---	---	100% M	
Sibling #6's Education	---	---	10.00	0.00
Sibling #6's Occupation	---	---	3.00	0.00
Age of deceased child	12.38	4.33	10.86	6.09
Sex of deceased child	50% M, 50% F		62% M, 38% F	
Time between diagnosis and death	1.75	1.88	3.43	5.16

Occupation:

- 0 - None, Student
- 1 - Unskilled
- 2 - Semi-skilled
- 3 - Skilled
- 4 - Semi-professional
- 5 - Professional

Frequency Distribution of Diagnoses

	Supportive Care (n=16)	Phase II (n=7)
A.L.L.	5	2
A.M.L.	2	0
T.A.L.L.	1	0
C.M.L.	1	0
Other Leukemia	1	0
Phabdomyosarcoma	2	1
Lymphoepithelioma	1	0
Ewing's Sarcoma	0	2
Neuroblastoma	0	1
Ostegenic Sarcoma	1	1
Lymphoma	1	0
Embryonal Carcinoma	1	0

Treatment Choice

	Supportive Care	Phase II
Total Group	32 (70%)	14 (30%)
Returned Questionnaires	16 (70%)	7 (30%)

Sexual Composition

	Supportive Care	Phase II	Total
Total Group			
Males	19 (63%)	11 (37%)	30
Females	13 (81%)	3 (19%)	16
Returned Questionnaires			
Males	11 (61%)	7 (39%)	18
Females	5 (100%)	0 (0%)	5

APPENDIX C

CONSENT FORM

Consent Form

I, _____ voluntarily consent to participate in the study
(parent or guardian)
entitled: "Patient, Parent, and Sibling Reactions to End-Stage Cancer
and Death." I understand the following:

1. The purpose of this study is to examine differences in the reactions of patients and parents and siblings of patients who have chosen to use phase II drug therapy as compared to those who have chosen the supportive care option after the Final Stage Conference. Specifically, anticipatory grief and mourning reactions evident in patients, parents, and siblings of patients will be investigated.
2. No drugs are involved in this study.
3. Description of study: Subjects asked to participate will be parents whose child has died while a patient on the Oklahoma Children's Memorial Hospital Oncology Service Between 1974 and 1980. Each parent will be mailed a questionnaire covering the topic of patient, parent and sibling reactions to the patient's death. All data will be gathered through parental recall and report. Parents will be asked to recall their own grief and mourning reactions as well as those of the patient and the patient's siblings.
4. Benefits: Hopefully, participation in this study will help parents in reviewing and reconciling their own mourning processes and those of the patient and the patient's siblings. Participation will also assist researchers to gain a better understanding of the processes of anticipatory grief and mourning undergone by the patients, parents and patient's siblings in order to be of better service to current pediatric Hematology/Oncology patients and their families.
5. Risks: There are no known or expected risks to either parents or to patient's siblings as a result of participation in this study.
6. Whereas no assurance can be made concerning results that may be obtained (since results from investigational studies cannot be predicted), the investigators will take every precaution consistent with the best medical and psychological practice. By signing this consent form, I have not waived any of my legal rights or released this institution from liability for negligence. I may revoke my consent and withdraw from this study at any time. Should any problems arise during this study, I may take them to: The Director of Research Administration, Room 362, Biomedical Sciences Building, Phone (405) 271-2090.

Parent or Guardian's name

Mary Ann Constable, B.S.

Parent or Guardian's signature

Ruprecht Nitschke, M.D.

H. Stephen Caldwell, Ph.D.

Signature of Witness

Susan Jay, Ph.D.

Date

Investigators

UNIVERSITY OF OKLAHOMA HEALTH SCIENCES CENTER
INSTITUTIONAL REVIEW BOARD

INSTRUCTIONS TO INVESTIGATORS

- I. New Research Grant Applications and Grants:
Send TEN copies of the application; excluding budget and bibliography, and the following information to the Chair of the Institutional Review Board, Room 115, HSC Library Building.
- A. Research Proposal:
1. Title of Study Patient, Parent, and Sibling Reactions to End-Stage Cancer and Death
 2. Sponsoring Agency and Agency ID Number OCMH- Hematology/Oncology
 3. Principal Investigator Mary Ann Constable
Department Pediatrics College Medicine
Building Bielstein Rm 213 265 Telephone Extension 271-5311
 4. Collaborating Investigators/Department/College H. Stephen Caldwell, Ph.D., (OSU); Susan Jay, Ph.D., and Ruprecht Nitschke, M.D., (OCHH)
 5. Site of Study: OCMH OMH ___ VAMC ___ Other (identify) ___
- B. Description of Subjects:
1. Age; sex; special qualifications; and source: 20 parents of end-stage cancer patients (deceased)
 2. Specify the number of subjects needed for this study:
Number of patients 0 Number of healthy volunteers 20
 3. Identify any groups of subjects who will be excluded from the study: N/A.
 4. Identify any conditions under which subjects will be terminated from the study before its completion: N/A
- C. Ethical Considerations:
1. Informed consent will be obtained from any human subjects (patients or normal volunteers) participating in this study:
Yes No ___ If no, explain why.
 2. Informed consent will be obtained for administration of any investigational drug: Yes ___ No ___ If no, explain why:
N/A
 3. Informed consent will be obtained for biopsy, other surgical procedure, or other unusual procedure: Yes ___ No ___
If no, explain why. N/A
 4. Identify the benefits to be obtained from the study Identify the psychological effects of choosing supportive care or continued medical treatment on end-stage cancer patients, parents, and siblings.
 5. Identify the risks to the subject or to others: None

C. Ethical Considerations (continued):

6. Is there a risk of physical injury to subject? Yes ___ No x
 If yes, the subject must be informed about the availability of compensation and medical treatment. Check with your institutional official about policy governing such compensation and medical treatment.
- a. Will medical treatment be provided? No ___ Yes ___. If yes, will it be provided free ___ or at a reasonable fee ___?
- b. Will compensation be provided? No ___ Yes. If yes, how ill it be provided? _____
7. Identify any incentives or rewards that will be offered to the subjects. N/A
8. Identify the safety precautions that will be taken to protect the health of the subjects and/or the personnel participating in this study. N/A

D. Informed Consent:

1. If a written consent document is used, TEN copies of the form are to be included with the application. The consent form should include all elements of informed consent as described in the Institutional Assurance. (See Page 3 of instructions for sample consent form.)
2. If oral consent is used, the exact wording of the statement read to the subjects is required. The statement should contain all elements of informed consent as outlined in the Institutional Assurance. A separate document is required in addition to the oral consent statement. The separate document must be signed by the subject or the subject's legal guardian, the investigator and a third party who witnessed the oral presentation.
- E. The principal investigator agrees to the above requirements and statements, and signs in witness thereof.

2-5-82

Date

Mary Ann Constable

Signature

II. For Training Grants, Fellowships, Career Awards and Scholarships:
 Send one copy of application, excluding budget and bibliography, to the Chair of the IRB with a cover sheet.

III. Annual Review of Studies Involving Research with Human Subjects:
 The terms of our Institutional Assurance for the protection of human subjects require that the principal investigator prepare an annual progress report for review by the IRB. The Office of Research Administration will notify investigators when reports are due. The annual progress report is an important requisite for annual review. Projects which are not reported by the date requested will be placed on inactive status by the IRB.

APPENDIX D

PHYSICIAN LETTER



STATE OF OKLAHOMA TEACHING HOSPITAL
Post Office Box 26307
Oklahoma City, Oklahoma 73126

This letter is written with some hesitation because we would like to ask you for a very special favor by giving us information about our service to pediatric cancer patients and families, and especially to those with terminal illness. You may remember that we talked to you and _____ at the time when his disease recurred. We discussed the difficulties of controlling the disease in the future, the imminence of death, and the possibilities of administration of new (experimental) drugs or of discontinuation of chemotherapy. This conversation we called the final stage conference. It was developed as a response to the special need of our patients.

This open approach towards parents and children is rarely used by other physicians. After having conducted the final stage conference for several years, we need some feedback as to whether our approach towards you was indeed helpful. We also want to find out what kind of reaction parents and siblings have after the child dies. Do those who choose supportive care react differently from those who choose to continue therapy with an experimental drug?

We don't wish to open up old wounds by asking you to fill out this questionnaire. If it is too hard for you, please send the enclosed card back to us so that we will not bother you again. We respect your decision full-heartedly. We certainly appreciate it deeply if you are able to complete the forms and return to us within a month's time. Your assistance, I am sure, will help families who still have to face a similar situation through which you had to live.

Sincerely,

Ruprecht Nitschke, M.D.
Professor of Pediatrics

RN/ewh
Enclosure

APPENDIX E

PARENT QUESTIONNAIRE

Name: _____

Date of Diagnosis: _____

Diagnosis: _____

Date of Final Stage Conference: _____

Time Between Diagnosis and Death: _____

Parent's Reactions

Please place a check (✓) by those feelings and behaviors which you felt or showed immediately after the Final Stage Conference, immediately after your child's death, and one year after your child's death.

	<u>Immediately After Final Stage</u>	<u>Immediately After Child's Death</u>	<u>One Year After Child's Death</u>
Avoided family	_____	_____	_____
Avoided friends	_____	_____	_____
Felt guilty	_____	_____	_____
Felt depressed	_____	_____	_____
Discarded or gave away child's possessions	_____	_____	_____
Got physically ill	_____	_____	_____
Had trouble sleeping	_____	_____	_____
Needed to talk about the meaning of death	_____	_____	_____
Had trouble concentrating	_____	_____	_____
Felt ashamed	_____	_____	_____
Felt confused	_____	_____	_____
Slept a lot more	_____	_____	_____
Felt empty	_____	_____	_____
Drank more	_____	_____	_____
Felt angry	_____	_____	_____
Lost my appetite	_____	_____	_____
Had more problems coping	_____	_____	_____
Felt helpless	_____	_____	_____
Felt hopeless	_____	_____	_____
Questioned my religion	_____	_____	_____
Had less desire for sex	_____	_____	_____

	<u>Immediately After Final Stage</u>	<u>Immediately After Child's Death</u>	<u>One Year After Child's Death</u>
Felt tired more often	_____	_____	_____
Felt fearful	_____	_____	_____
Began to have additional marital problems	_____	_____	_____
Ate more	_____	_____	_____
Became more religious	_____	_____	_____
Felt relieved	_____	_____	_____
Couldn't stop thinking about my child	_____	_____	_____
Felt irritable	_____	_____	_____
Kept my child's room exactly the same	_____	_____	_____
Felt nervous	_____	_____	_____
Felt shocked	_____	_____	_____
Blamed self for my child's death	_____	_____	_____
Blamed others for my child's death	_____	_____	_____
Visited by child's grave frequently	_____	_____	_____
Had trouble socializing with others	_____	_____	_____
Felt frustrated	_____	_____	_____
Felt lonely	_____	_____	_____
Sought counseling	_____	_____	_____
Brooded	_____	_____	_____
Wanted to replace my child by becoming pregnant	_____	_____	_____

Siblings Reactions

Please answer the following for your son or daughter:

Name of son or daughter: _____

Age at time of child's death: _____ Sex: _____

Occupation or current grade in school: _____

Did you discuss with the brother or sister the likelihood of your child's death? _____ Yes _____ No

Was the brother or sister aware of the likelihood of your child's death? _____ Yes _____ No

Please place a check (✓) by those feelings and behaviors which you saw in your son(s) and/or daughter(s) immediately after the Final Stage Conference, immediately after your child's death, and one year after your child's death.

	<u>Immediately After Final Stage Conference</u>	<u>Immediately After Child's Death</u>	<u>One Year After Child's Death</u>
Seemed nervous	_____	_____	_____
Cried alot	_____	_____	_____
Tried to avoid being at home	_____	_____	_____
Had nightmares	_____	_____	_____
Ate more	_____	_____	_____
Seemed sad	_____	_____	_____
Was physically ill more often	_____	_____	_____
Seemed confused	_____	_____	_____
Showed no grief	_____	_____	_____
Seemed angry	_____	_____	_____
Seemed afraid of dying	_____	_____	_____
Seemed afraid of getting sick	_____	_____	_____

	<u>Immediately After Final Stage Conference</u>	<u>Immediately After Child's Death</u>	<u>One Year After Child's Death</u>
Had unusual ideas about religion	_____	_____	_____
Seemed to feel guilty	_____	_____	_____
Worried about other's grief	_____	_____	_____
Seemed jealous of patient	_____	_____	_____
Had unusual ideas about sickness and death	_____	_____	_____
Had behavior problems in school	_____	_____	_____
School grades dropped	_____	_____	_____
Had trouble paying attention in school	_____	_____	_____
Began wetting bed or clothes	_____	_____	_____
Constantly talked about death	_____	_____	_____
Misbehaved more	_____	_____	_____
Began stuttering	_____	_____	_____
Ate less	_____	_____	_____
Seemed to feel rejected	_____	_____	_____
Was alone much of the time	_____	_____	_____
Seemed fearful	_____	_____	_____
Claimed to be sick like brother or sister	_____	_____	_____
Spent less time in school	_____	_____	_____
Had fearful ideas about doctor	_____	_____	_____
Had fearful ideas about hospitals	_____	_____	_____

Deceased Child's Reactions

Please answer the following:

Name of son or daughter: _____

Age at time of death: _____ Sex: _____

Please place a check (✓) by those feelings and behaviors which you saw in your son or daughter after diagnosis, immediately after the Final Stage Conference, and between the Final Stage Conference and death.

	<u>After Diagnosis</u>	<u>Immediately After Final Stage Conference</u>	<u>Between Final Stage Conference and Death</u>
Seemed nervous	_____	_____	_____
Cried alot	_____	_____	_____
Tried to avoid being at home	_____	_____	_____
Had nightmares	_____	_____	_____
Ate more	_____	_____	_____
Seemed sad	_____	_____	_____
Was physically ill more often	_____	_____	_____
Seemed confused	_____	_____	_____
Showed no grief	_____	_____	_____
Seemed angry	_____	_____	_____
Expressed fear of dying	_____	_____	_____
Religious beliefs became stronger	_____	_____	_____
Seemed to feel guilty	_____	_____	_____
Worried about others' grief	_____	_____	_____
Had unusual ideas about sickness and death	_____	_____	_____
Had behavior problems in school	_____	_____	_____

	<u>After Diagnosis</u>	<u>Immediately After Final Stage Conference</u>	<u>Between Final Stage Conference and Death</u>
School grades dropped	_____		
Had trouble paying attention in school	_____		
Began wetting bed or clothes	_____	_____	_____
Constantly talked about death	_____	_____	_____
Misbehaved more	_____	_____	_____
Began stuttering	_____	_____	_____
Ate less	_____	_____	_____
Seemed to feel rejected	_____	_____	_____
Was alone much of the time	_____	_____	_____
Seemed fearful	_____	_____	_____
Spent less time in school	_____	_____	_____
Had fearful ideas about school	_____	_____	_____
Had fearful ideas about hospitals	_____	_____	_____
Had sleep difficulties	_____	_____	_____
Refused to see friends	_____	_____	_____
Refused to see brother(s)	_____	_____	_____
Refused to see sister(s)	_____	_____	_____
Communicated much less with mother	_____	_____	_____
Communicated much less with father	_____	_____	_____

How would you describe your relationship with the Oncology Staff and Physicians?

Very Poor	Marginal	Acceptable	Positive	Very Positive
--------------	----------	------------	----------	------------------

Did you talk about the possibility of dying with your child before the Final Stage Conference?

_____ Yes _____ No

Did you talk about the possibility of dying with your child after the Final Stage Conference?

_____ Yes _____ No

How much did your child talk about death before the Final Stage Conference?

Not at all	Rarely	Sometimes	Frequently	Constantly
---------------	--------	-----------	------------	------------

How much did your child talk about death after the Final Stage Conference?

Not at all	Rarely	Sometimes	Frequently	Constantly
---------------	--------	-----------	------------	------------

What was your child's activity level in the first weeks after the Final Conference?

Slept most of time	Somewhat less active	Normal activity	Somewhat more active	Constantly on the go
--------------------------	----------------------------	--------------------	----------------------------	-------------------------

During the first weeks after the Final Stage Conference, did your child:

Return to school	_____yes	_____no
Continue to do homework	_____yes	_____no
Attend school activities	_____yes	_____no
Continue hobbies	_____yes	_____no
Continue sports activities	_____yes	_____no
Go on special trips or a vacation	_____yes	_____no

How much did your child interact with his brother(s) or sister(s)?

Wanted to be	Somewhat isolated	Normal amount	Rarely wanted to be alone	Always Together
-----------------	----------------------	------------------	------------------------------	--------------------

In what room in your house did your child spend most of his/her time?

Was there any one brother or sister your child wanted to be with?

_____ Yes _____ No

Was there any one brother or sister your child avoided being with?

_____ Yes _____ No

Did anyone in your family have a dream or preminition about your child's disease or death?

_____ Yes _____ No

Do you believe that your child should have been included in the Final Stage Conference?

_____ Yes _____ No

What suggestions would you make in regard to the use of the Final Stage Conference or the general management of your child?

VITA ²

Mary Ann Constable

Candidate for the Degree of

Master of Science

Thesis: PATIENT, PARENT, AND SIBLING REACTIONS TO END-STAGE CANCER
AND DEATH.

Major Field: Psychology

Biographical:

Personal Data: Born in Evanston, Illinois, April 7, 1954, the daughter of Eugene Sullivan Constable and Jeanne Welch Constable.

Education: Graduated from Regina Dominican High School, Wilmette, Illinois, in June, 1972; received Bachelor of Science degree in Psychology and Sociology from Loyola University, Chicago, Illinois, in June, 1976; attended Harvard University, Cambridge, Massachusetts, 1976-78; completed requirements for the Master of Science degree at Oklahoma State University in May, 1983.

Professional Experience: Research assistant, Laboratory for Clinical Physiology, Chicago, Illinois, 1975-76; research assistant and Mental Health Assistant, Massachusetts Mental Health Center, 1976-78; graduate research assistant, Department of Psychology, Oklahoma State University, 1978-80; mental health assistant, Stillwater Medical Center, 1978-79; psychological associate, Psychological Services Center, Oklahoma State University, 1979-80, 81; graduate teaching assistant, Department of Psychology, Oklahoma State University, 1980; psychological associate, Larimer County Mental Health Center, Fort Collins, Colorado, 1980; clinical traineeship, Central State Hospital, Norman, Oklahoma, 1981-82; psychological associate, Marital and Family Counseling Services, Oklahoma State University, 1981-83; clinical traineeship, Lloyd E. Rader Diagnostic and Evaluation Center and Intensive Treatment Center, 1982-83.