

SPOUSE GRIEF NEEDS AND THEIR FULFILLMENT
BY NURSING INTERVENTION

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CHAPTER I

INTRODUCTION

To all living beings, death is certain. This universal phenomenon is always present, both in its realism and its inescapability. As all human beings must die, then death is a significant factor in our lives.

Nurses are caring for the dying patient in the hospital, but what about the patient's family? Should nurses be giving the family more thought and attention? The family is probably sharing the care of the patient, and it is the family who sooner or later will suffer an irretrievable and hopeless loss.

To the nurse, death is probably not a new experience, but to the family death may be something new and frightening. Death is difficult to think about, and certainly to accept and understand. Whether death comes suddenly or slowly, there will be trauma to the family and most particularly to the nearest relative who usually is the husband or wife. Death of a mate is recognized as the greatest stress precipitating event in the life of an individual (Holmes and Rahe 1967). When death occurs, some people behave as though nothing has happened; others

appear to be completely lost and helpless. It is difficult to predict beforehand what reaction the bereaved will exhibit. For several weeks, they may carry on an automatic existence, but in time they should come to grips with reality (Gibson 1974). Professional nurses can prepare the family for this point in time.

Most terminally ill patients succumb in a hospital setting. This provides an opportunity for nurses to plan and implement nursing intervention for the comfort of the grieving spouse. In order to comfort the spouse, nurses need to know the special needs of the grieving spouse. Determination of these needs should include input from the spouse.

Most studies about death tend to ignore the fact that the problems of loss and grief begin before the loved one's death and that there is anticipatory grief which follows notification of an unfavorable prognosis. To date, attention has been directed toward the needs of the grieving spouse after the death of the mate.

Kubler-Ross (1970) stated that if a widowed person has been helped prior the death of their partner to bridge the grief between themselves and the dying mate, half of the struggle to work through grief and guilt might have been done. Hampe (1973) found in her study

that spouses whose mates are terminally ill could identify their own needs, although these needs were not always met by health professionals. Because Hampe's (1973) study was limited to one geographical location, a replication of the study will be conducted in the northwest part of the United States. Therefore, the intent of this study will be to determine the grieving spouse's perception of nursing intervention to meet the spouse's need.

Statement of the Problem

The problem of this study was to determine the grieving spouse's perception of nursing intervention to meet the spouse's need.

Statement of the Purposes

1. To determine perception of spouses of terminally ill patients regarding the helpfulness of nursing intervention
2. To identify nursing interventions performed for spouses of terminally ill patients
3. To determine frequencies of nursing activities that were being performed to meet the needs of grieving spouses of terminally ill patients

Background and Significance

Feifel (1977) wrote that Americans' views of death seem strangely contradictory. One reads and views various media about death and there is a tendency for the public to accept death as a usual occurrence. However, the focus most often is about particular deaths rather than about death in the abstract. Death is seen as a destroyer of the American dream--the right to life, liberty, and the pursuit of happiness. It is understandable why ambivalence toward death is characteristic of America's adaptation to death (Feifel 1977).

This same attitude seems to be shared by professional people who work with dying patients in the hospital. Trained to give specialized health care to terminal patients, much of the behavior of professional persons towards death resembles that of the nonprofessional person. The education that physicians and nurses receive in schools of medicine and nursing teaches them how to deal with technical aspects of patient care. Physicians learn to save lives through treatments, but very little emphasis is placed by teachers on how to talk with dying patients or how to disclose an impending death (Glaser and Strauss 1965). Nurses have been taught

nursing care of the dying patient, but only recently have "psychological aspects" of nursing care been taught (Glaser and Strauss 1965).

Folk and Nie (1969) state,

Nurses need preparation for this event, not only to protect themselves from undue trauma, but to provide adequate care and support for the dying patient and family (p. 510).

Nurses need to be able to deal with the psychological aspects of death because over 50 percent of all deaths occur in hospitals, and many more occur in nursing homes (Fulton 1964).

The family is present much of the time while a person is dying. Dying away from home is compounded by an important trend: because health technology has vastly improved, fewer people are dying from acute diseases and more from chronic illnesses. Also, the duration of chronic diseases has increased, so terminal patients take longer to die than they did in the past (Glaser and Strauss 1965).

Supportive counseling for family members has been considered necessary to understand and prevent untoward reactions to death (Krant 1972). Lindemann (1944) believed that the family should be kept informed of the patient's condition and be given notice of change when

death draws near in order to safeguard against the impact of a sudden notice of death. The death or impending death of a family member usually increases the emotional dependency of other members upon one another. The family is usually a source of comfort.

Engel (1964) mentioned that news of impending or actual death is best communicated to a family unit, rather than to a lone individual, so as to allow the people involved to give mutual support to each other. This should be done in privacy so that they can express grief without the restraints imposed by public observation.

In terminal illness, many family members experience anticipatory grief. Peretz (1970) talks about grief that begins before loss actually occurs. In nearly all instances in which loss is imminent, those concerned experience the beginnings of grief. Anticipatory grief may range from quiet periods of sadness and tears to symptoms associated with grief over actual loss.

The physical, social, and emotional consequences of the stress of bereavement on widows and widowers have been well documented. Peretz (1970) called bereavement an illness. Maddison and Viola (1968) referred to bereavement as a crisis and psychosocial transit. Other

studies have focused on such indicators as physical and mental illness, and death, including suicide among the bereaved.

We now know that mortality rates and the incidence of somatic and emotional problems are higher among widows and widowers than in the normal population (Rogers and Vachon 1975). Despite this evidence of the extent of their needs, the widowed are seldom offered adequate ongoing help focused on the stress of bereavement (Rogers and Vachon 1975).

Kubler-Ross (1970) emphasized that the void and emptiness is felt after the funeral, after the departure of the relatives. It is at this time the family members feel most grateful to have someone to talk to, especially if it is someone who had recent contact with the deceased and who can share anecdotes of good moments toward the end of the deceased's life. This helps the person over the shock and initial grief and makes him ready for a gradual acceptance.

Glaser and Strauss (1965) described ways that awareness of death determines the behavioral expectations of hospital personnel toward the family; for example, the relaxation of visiting hours. At this time, the family wonders if everything is being done to provide

the best possible care for the loved one. It lessens the guilt of the family members if they believe that the most current medical and nursing knowledge and procedures are being used to give care. Artificial prolongation of life should be weighed against the importance of allowing the patient to die with dignity (Glaser and Strauss 1965).

Richmond and Waisman (1955) believed that the family's involvement in the physical care of the dying person is important because it allows the family members to feel that they have contributed something significant, and to some degree it reduces their guilt. Murray and Zenter (1975) stated that nurses need to help the family members to express their grief and can do this by giving support to them. Nurses must also prepare the family for sudden, worsening changes in the patient's condition or appearance to avoid shock and feelings of being overwhelmed.

These same authors (Murray and Zenter 1975) also believed that family members need to see the dead person to realize the actuality of the situation. In addition, Kubler-Ross (1970) believed it is more important for the family members to see the body in a sudden death occurrence than in a terminally ill situation.

Nurses come in frequent contact with dying patients and their families. Throughout intervention with the dying patient or his family, the nurse must consider whether the intervention was appropriate and effective, based on the specific needs of the patient and family.

Definition of Terms

The following definitions of terms were used within this study:

Anticipatory grief--grief work begun before the actual loss of mate; this is dependent upon the spouse's awareness of the impending death

Bereavement--a state of deprivation due to loss of mate through death

Grief--a special, intense form of sorrow and depression experienced at the death or impending death of mate

Loss--a state of being deprived or of being without someone or something one has had

Mate--the person who is terminally ill

Need--a requirement of the person which, if supplied, promotes his immediate sense of well-being

Nursing intervention--all actions carried out by nurses when ministering to the needs of the grieving spouse or terminally ill mate

Spouse--the husband or wife of the dying mate

Stress--physical and emotional state always present in a person, but intensified by death of a mate

Terminally ill patient--a patient who in all probability will expire within two months because of a biopathological condition

Limitations

For this study, the following limitations were recognized:

1. The sample was limited to those who were willing to participate in the study
2. Each subject may not have perfect recall of the events because of the first stage of the grieving process, which is shock and disbelief
3. Subjects' previous experiences with death could influence their responses to the interviewer's questions

Delimitations

The following delimitations applied to the study sample:

1. The study was limited to spouses of hospitalized terminally ill patients
2. The participants were adults aged 21 years of age or older
3. The interview of the spouse was conducted during the third and seventh day interval of the mate's hospitalization
4. The study was limited to spouses who have been informed of the terminal illness of mate

Assumptions

The following assumptions were observed in this study:

1. Nurses have anxieties about death which make them uncomfortable around the terminally ill and their spouses
2. The period before the death of a mate is a stress situation in which nurses could help the bereaved meet their grieving needs

Theoretical Framework

For the purpose of this investigation, Engel's (1964) theory of normal grief was used. Successful grief and grieving usually follow certain predictable stages.

Engel (1964) formulated the sequence of events that are characteristic of the normal grieving process.

1. Shock and disbelief
2. Developing awareness of the reality of illness or death
3. Restitution: work of mourning such as various rituals of the funeral
4. Resolving the loss: talks about memories of the dead person
5. Idealization: survivors' preoccupation with the dead person progressively lessens. Begins to renew his own interests

Engel (1964) theorized that upon completion of the final stage of the grieving process, the individual will have resolved the loss. He stated,

. . . the clearest evidence of successful mourning is the ability to remember comfortably and realistically both the pleasures and the disappointments of the lost relationship (p. 96).

A good understanding of the sequence of events characterizing normal grief is essential to nurses in helping grieving families. Knowledge of what is normal enables nurses to identify the pathological coping mechanisms in dealing with grief.

Summary

Nurses are aware of the needs of grieving spouses. Hampe (1973) found that many of the spouses she interviewed were able to identify their own needs, but spouses stated that nurses were not meeting these needs. The problem was to determine if nurses are meeting the perceived needs of the grieving spouse in another geographical area.

Chapter II contains a review of literature. The view of death in America, nurses' attitudes towards death, anticipatory grief, and the grieving process are discussed. Abnormal grief reactions, needs of the grieving family, and families in crisis are also presented.

The procedure for collection and treatment of data is described in Chapter III. The data were collected through the use of a semistructured interview. The questionnaire was designed to validate the needs of the grieving spouse and to assess the spouse's perception of the nurses' role in meeting these needs.

Chapter IV describes the analysis of data which was accomplished through the calculation of a frequency distribution. A summary of findings, conclusions drawn as a result of the study, implications for nursing, and

recommendations for further studies are contained in Chapter V.

CHAPTER II

REVIEW OF LITERATURE

Introduction

Death belongs to life as birth does.
The walk is in the raising of the foot
as in the laying of it down.

Tagore, from Story Birds, CCXVII

We will all die; it is just a matter of time.

Death is as much a part of living, of human growth and development, as being born. It is one of the few things in life we can count on, that we can be assured will occur. Death is not an enemy to be conquered. It is an important part of our lives that gives meaning to human existence. It sets a limit on our time in this life, urging us to do something productive with our lives (Kubler-Ross 1975).

In the following review of literature, the view of death in America, nurses' attitudes towards death, anticipatory grief, and the grieving process are discussed. Abnormal grief reactions, needs of the grieving family, and families in crisis are also presented.

View of Death in America

Feifel (1977) wrote, "discussion of death in America today has increased, which is a surprising

outgrowth of a culture described as death-denying" (p. 4). Our society has developed a "cult of youth" and a strong aversion to the idea of death. No social institution or group has been free from the attempt to deny our mortality. In the home, at school, from the church to the "slumber" room of the mortuary, we have attempted to hide ourselves from the prospect of our own death as well as from the death of others (Fulton 1979).

Traditionally, in American society, the question of death was answered within a religious context (Jackson 1969; Fulton 1979). Today, in contrast, death has become, for many, a secular matter (Gorer 1965; Jackson 1969; Fulton 1979). Death is viewed almost exclusively as a physical matter--the outcome of a disease process or the result of an accident (Feifel 1977; Fulton 1979).

The many issues and problems associated with dying and death have taken on a new significance as the circumstances surrounding death and dying have changed in our society. One change has been that progress in medical science and the general enhancement of life have meant that the proportion of elderly persons in our society has greatly increased. Twenty-two million people in America are currently over 65 years of age (Fulton 1979).

A second change is that death is primarily the experience of aged persons today. Of those who will die in the United States this year, approximately two-thirds will be 65 years of age or older (Fulton 1979).

A third change is that there is a difference in the context in which dying and death are experienced. At the beginning of the century, most people died at home. Of two million deaths that occurred in America in 1977, more than 70 percent took place either in a hospital or a nursing home (Feifel 1977; Fulton 1979). The trend toward increased hospitalization of the chronically ill and dying patient is expected to continue.

These changes have a direct effect on family relations. The elderly in today's society are increasingly retired from work and often live physically removed from children and grandchildren (Feifel 1977; Fulton 1979). In addition, the geographical mobility of our population deprives the elderly of traditional family and community assistance. So when death comes into our lives, we do not have the previous existing emotional and family supports. Quint (1969) wrote that the American denial of death is increased by our small family system that provides us with an intense emotional attachment to a few

select people, but offers no easy solution to the problems of replacement once they are gone.

Out of these changes emerge a social milieu in which the elderly find themselves isolated. The young reject the elderly as constant reminders of our brief mortality and the elderly sense this rejection. While many problems are associated with old age in the United States, they are frequently aggravated to an intolerable degree by the death of a spouse. Rich memories are set aside by financial worries, health problems, personal insecurity, as well as loneliness, filling the life of an elderly widow or widower with disappointment in our youth-oriented society (Kubler-Ross 1969; Feifel 1977; Fulton 1979).

American society is experiencing rapid social change with regard to death and death customs. We are currently in the process of redefining grief, bereavement, and loss, as well as death itself. The trend toward the diminishment of the funeral and the abandonment of mourning customs is further manifestation of this upheaval. The wearing of black and the funeral wreath have virtually disappeared as signs of mourning in the United States. There has also been a growing dissatisfaction with traditional funeral practices (Feifel 1977; Fulton 1979).

In summarization, Feifel (1977) expressed that,

. . . in a society which emphasizes achievement and the future, the prospect of no future at all and loss of identity is detestable. Death is seen as the ruin of the American vision, the right to life, liberty and the pursuit of happiness. Hence, death and dying invite our hostility and denial (p. 5).

In light of these vying and contradictory facts forcing us toward both accepting and denying death, it is understandable why ambivalence is so characteristic of modern America's adaptation to death.

Nurses' Attitudes Toward Death

Hospitals, ironically, become a center of frustration and conflict when confronted with the dying patient. On the one hand, most Americans, separated from death most of their lives, call on the hospital for professional skills to help the dying patient. On the other hand, the mainstream of the work of the hospital places greatest value on cure or rehabilitation, which leads away from the dying patient (Krant 1972)

With over 50 percent of all deaths occurring in hospitals, nurses are subjected to many situations in which they must interact with dying patients and grieving families. Nurses share the same basic attitudes toward death as the American culture does.

Until recently, nursing curricula have been bound by the attitude that death is unnatural and never appropriate. Nurses, thus, are frequently unable to deal therapeutically with the dying, unless, through circumstances outside their professional education, they have found release for themselves (Strauss, Glaser, and Quint 1964). Recent curriculum changes in schools of nursing, which have stressed the psychological care of patients, have helped newer nursing graduates to become more sensitive to the problem of the dying. Even so, Benoliel (1970) found that despite this breakthrough in understanding the needs of the dying, nurses for the most part were still "ill-equipped to cope with the conversational difficulties" (p. 255) encountered in such situations. According to Yeaworth, Knapp, and Winget (1974), if nurses' previous training has not prepared them to cope with the realities of death, they may react to persons who are terminally ill with indifference, hostility, or detachment.

How much change occurs in the attitudes of nursing students regarding death and dying? Assuming that attitudinal behavior is learned, it follows that attitudes may be modified by further learning (Lemon 1974). Five studies examining attitudes of nursing students toward death have been found in the literature.

Golub and Resnikoff (1971) studied the influences of nursing education and experience on attitudes toward death by comparing the attitudes of eighty-two graduate registered nurses with those of seventy first-year nursing students. Using a fifty-seven item multiple-choice questionnaire, they found statistically significant differences between graduates' and students' attitudes toward treatment of the terminally ill and the influence of psychological factors upon death. The graduate nurses had less anxiety than the first year nursing students about these processes. Golub and Resnikoff (1971) attributed these differences to nursing education in general rather than any particular death education curriculum.

Yeaworth, Knapp, and Winget (1974) utilizing a questionnaire entitled "Understanding the Dying Person and His Family" reported that their findings suggested important shifts in attitude about death and dying can result from nursing education. Yeaworth, Knapp, and Winget (1974) compared attitudes toward dying patients and death using 108 freshmen and 69 seniors of a baccalaureate nursing program. The senior students tested were the first class to complete a new curriculum which provided: (1) experiences in caring for the dying patient; (2) classes on loss, grief, and death; (3) small group

discussion; and (4) the availability of one-to-one counseling for students who took care of dying patients. Compared to the freshmen, the responses of senior students indicated greater acceptance of feelings, more open communication, and broader flexibility in relating to families of dying patients. These findings did not, however, reach a level of significance.

Lester, Getty, and Kneisel (1974) examined the attitudes of 128 undergraduates, 66 graduate nursing students, and 62 faculty toward death and dying in a university school of nursing in New York. The authors made comparisons according to levels of education and areas of clinical specialization. The results indicated that fears of death and dying decreased with increased education. The results were influenced by the effects of professional education rather than a death education program.

Denton and Wisenbaker (1977) studied death experience and death anxiety among seventy-six nurses and nursing students using a questionnaire which examined three death events. These death events included: (1) death of a close friend or relative; (2) the actual experience of seeing a violent death; and (3) a subjective death experience. The authors found that experienced nurses

had higher death anxiety than nursing students who had little or no experience of seeing an actual death. Their findings suggested a need for additional research into the relationship between experiencing the death of a family member or close friend and death anxiety.

Hopping (1974) tested whether there was a measurable change in attitude toward death and the dying patient between preclinical sophomore nursing students and graduating senior nursing students. The senior student group's mean score, though greater than the sophomore student group's mean, did not reach significance. A serendipitous finding was that students who had experience with the death of a family member scored significantly ($p = .05$) lower on the questionnaire, indicating a less positive attitude toward death than did those who had not had such experience.

Nursing education on the subjects of death and the dying person should help nursing students overcome their death anxieties to some extent. Hopping's (1974) study raised the question of whether education alone can be expected to change attitudes toward death to any great extent.

Another study done by Hopping (1977) tested whether a change in attitude toward death and dying was associated

with a clinical course entitled, "Nursing of the Adult Patient with Malignant Neoplastic Disease" and the validity and reliability of the questionnaire entitled, "Death Attitude Indicator." Data were collected by pre- and posttesting forty senior nursing students of whom half had elected to take the course. Results showed no change in attitude in either group. Two factors were found to influence the respondent's score on the questionnaire: experience with a family death and a belief in a Supreme Being.

McEver (1977) reported the use of an inservice program in a community hospital to help nurses understand their own attitudes toward death and dying process, thus, reducing their fears and anxiety. McEver administered a multiple choice questionnaire at the beginning and the end of the course. An analysis of data was done to discover the effect of the course on the attitudes of the participants. There has been evidence that the course had a positive effect, but the sample was not large enough to be conclusive.

Anticipatory Grief

The knowledge of a terminal illness may bring about a symptom known as anticipatory grief. Lindemann

(1944) first used the term to refer to the separation of two people with one anticipating the death of the other and preparing for it to such an extent that on the return of the other there is rejection rather than happy acceptance.

Anticipatory grief is like normal grief, but occurs before the death. Anticipatory grief is almost always present in some form, during a long-term debilitating illness (Gerber et al. 1975). Knight and Herter (1969) stated that grief following long-anticipated death presents special problems. There is no initial shock phase. Preparations have already been made in detail. Friends and relatives have been informed for a long period of time of the impending end. Expressions of sympathy, acts of support have already been done. Grief has found its fullest expression long before death and has been gradually replaced by a resigned acceptance of the facts.

When mourning begins long before death, families may finish grieving before the patient dies. Glaser and Strauss (1965) caution that family members may not be able to help during the last stages of dying if, with too much advance warning, they prepare themselves so well that they give up the patient before he dies.

Ambivalence may be experienced by family members who complete their grief work before the patient dies. They may feel resentful about the time and effort spent in visiting the dying patient and the money spend on hospital care. They often find themselves wishing they could go on with their own living, other interests, jobs, and friends. Such feelings of hostility often provoke feelings of guilt (Gerber et al. 1975). To the outside world, one must assume a position of grief out of proportion to the actual sense of loss. In our culture, an expression of relief is inappropriate. So honest emotions are sublimated (Knight and Herter 1969).

Hospital staff members who are aware that anticipatory grieving is taking place will find it easier to be supportive of the family rather than to feel negatively toward relatives whom they perceive as rejecting. When staff members can be accepting of ambivalence, hostility, and feelings of guilt, they will be open to therapeutic interaction and more helpful in the maintenance of mental health and the prevention of mental illness. It can be supportive for relatives to know that such feelings are normal components of grief work (Gerber et al. 1975).

Clayton (1973) compared spouses who had suffered anticipatory grief with spouses who had not. She found

that those with anticipatory grief felt worse at one month of bereavement, and at one year were no better or worse than those who did not experience anticipatory grief. Also, her study showed that anticipatory grief did not make the mourning period less intense or shorter. The research of Gerber et al. (1975) support these findings.

Gerber et al. (1975) state that health professionals must be sensitized to the characteristics of anticipatory grief because he found that an extended period of anticipated bereavement is potentially dangerous for the elderly survivor, because they have difficulty adapting to a new lifestyle and old behavior patterns are inadequate.

Thus, the literature indicates health professionals must become aware of the families that are experiencing anticipatory grief. Health professionals need to develop an open, accepting attitude in order for families to ventilate these emotions and become aware that the feelings of guilt and hostility are normal components of anticipatory grief.

Grieving Process

A good understanding of the sequence of events characterizing normal grief and of the meaning of each is essential if one is to be helpful to the grieving person. This grieving process has been defined by many authors (Lindemann 1944;Engle 1964; Kubler-Ross 1969; Westberg 1973). There is general agreement on three main phases of the normal grieving process: (1) shock and disbelief, (2) period of grieving or developing awareness, and (3) restitution or a resolving of the loss and return to a normal social life (Engel 1964)

In the first stage of shock and disbelief, the bereaved refuses to accept the loss. The grief stricken person does not permit himself any thoughts or feelings which acknowledge the reality of death. He may sometimes try to carry on his ordinary activities. This phase may last a few minutes or hours, or even days, alternating with flashes of despair and anguish as the reality of the loss briefly penetrates into consciousness (Engel 1964). Kubler-Ross (1969) has shown that denial acts as a buffer to allow the person time to collect himself and ready other defense mechanisms. Westburg (1973) says that even though a person does come out of the initial shock, he

will undoubtedly experience times in the future when the unreality of the loss comes over him again.

The second stage is characterized by developing awareness. The reality of the death begins to penetrate the consciousness. The environment seems empty without the loved one. The person may be angry toward the doctor, nurse, hospital, or another family member whom he holds responsible for his loved one's death. Crying occurs in this stage. It is during this period that the greatest degree of despair is experienced and expressed (Engel 1964).

Engel (1964) states that professional people must be particularly observant in this second stage. Some persons suffering a loss want to cry, but are unable to. This type of inhibition of crying must be assessed to determine whether the suppression of crying is because of cultural demands, whether the dead person is not missed, or if the inability to cry is caused by ambivalent feelings toward the dead person and the survivor is experiencing guilt and shame.

Kneisel (1976) stated that during these two phases, nurses usually are present to assist relatives in their bereavement. Such assistance requires the nurse to be a good listener who understands that time spent in hearing

expressions of grief, recall of memories, and reminiscences will be very helpful in encouraging normal and successful grieving. These interventions assist persons in the movement toward the third phase of mourning--restitution. The final stage of grief is resolution of the loss. As the reality of death becomes accepted, the awareness of the loss is felt as a defect in the sense of wholeness of the self. The bereaved cannot yet accept a new love object to replace the lost person. After an extended period of restitution and reorganization, the bereaved reorient themselves socially and emotionally. Normal life is resumed. Now, the bereaved can form new relationships without feeling guilty (Engel 1964).

In the grief process, people do not always progress through the stages in an orderly fashion, and they move back and forth and incomplete work in an early stage will interfere with progress in later stages (Kowalsky 1978). The duration of grief is variable with each individual. Normal mourning usually lasts for at least one year after death (Feifel 1977).

In a study of normal bereavement, Clayton, Desmarais, and Winokur (1968) found that one one-half of their subjects experienced depressed mood, sleep disturbance and crying. In six to ten weeks after the

death, these symptoms were improved in 81 percent of their clients.

Grief may return on certain occasions, such as holidays, deceased's birthdays or anniversaries, for many years after the death (Cattell 1969; Blanchard, Blanchard, and Becker 1976). Kowalsky (1978) uses the phrase "trigger experiences," to describe these stimuli which initiate the grief process all over again. If grief were previously worked through well, it may be relatively short-lived when triggered a second time.

Abnormal Grief Reactions

When the mourner has not experienced all three phases of grieving, grieving cannot be said to have been completed, nor can the work of mourning be finished. In addition to the symptoms of normal grief, abnormal grief reactions were also identified by Lindemann (1944). Delay of reaction to grief was found to be the most common and the most dramatic. The postponement may be brief or prolonged for a period of years. This type of response usually occurs when the bereaved is confronted with the important tasks or maintaining the morale of others. Kneisel (1976) identified other abnormal grief reactions which included excessive activity with no sense of loss,

development of symptoms similar to those experienced by the deceased, medical illness, social isolation, activities detrimental to one's own social and economic existence, and agitated depression.

Failure to pass through the process of grief work has been shown to have morbid, distorted psychological and physiological consequences for the bereaved (Hinton 1967; Fulton 1970; Clayton 1973). Persons who have experienced successive losses; alcoholics and people going through other severe stress, such as job loss, at the same time, are more likely to develop both mental and physical problems related to bereavement (Myers 1975; Brown, Harris, and Copeland 1977).

Clayton (1975) found in her study that bereavement itself, rather than the effects of loneliness or social isolation, influences the occurrence of depressive symptoms one month after the loss of a spouse. Brown, Harris, and Copeland (1977) showed that past loss is one of the most important features of psychotic depression as compared with neurotic depressed patients. The psychotically depressed were older and had experienced more losses. Furthermore, when the authors divided the psychotic depressed patients into categories of most psychotic and least psychotic, they found that the most psychotic group

had increased past losses. Seventy-seven percent of the most psychotic group experienced past loss, 55 percent of the least psychotic and 39 percent for the neurotic depressed ($p < .01$).

Parkes (1975) and Maddison and Viola (1968) have demonstrated that younger people showed more physical symptoms in response to bereavement than older people. Clayton's (1975) studies support this finding. It has also been established that widowed persons high higher death rates than married persons (Rees and Lutkins 1967; Maddison and Raphael 1972; Conroy 1977).

Needs of the Grieving Family

With more people dying in the hospital, rather than at home, family members are coming into the hospital to spend time with their dying loved one (Lerner 1970). Every family goes through a crisis when a loved one of the family is admitted to the hospital (Mitchell 1976). Consequently, supportive therapy and counseling for family members have been considered important to prevent untoward reactions to death (Krant 1972; Maddison and Raphael 1972; Rogers and Vachon 1975). It is also important to include the dying patient with the family so he is able to settle affairs and see the value he is to others who are important to him (Marks 1976).

To help the family, nurses must recognize the importance of the grief reactions. Let the family know that grief is appropriate. Isolation at this time is more painful than sharing the grief experience (Marks 1976).

The family may have the need to fulfill obligations to the patient by helping with his care (Vervoerdt 1966). When the family becomes involved with the care, their guilt is relieved to some degree through doing something significant for the patient. When family members participate in the care of their loved one, they are given the opportunity to give and receive satisfaction in the remaining time of the patient (Kalish 1963).

Some family members may want to help with the care of the patient, but are paralyzed by their ambivalent feelings. Thus, the nurse must recognize feelings which need to be discussed by the grieving family (Marks 1976). They may need to vent feelings of helplessness, frustration, and guilt.

It is known that the family needs an atmosphere of support and security to cope with serious illness (Olsen 1970). But, in most hospitals, the family is caught up in an overwhelmingly helpless situation. They are faced with the impending loss of a loved one. They

are asked to witness and accept a number of decisions they do not understand and cannot control. They must accept the introduction of new individuals, medical personnel, who invade their lives and make new demands on their lives. They also must adjust to a new environment, the hospital, and to places within the hospital where their loved one is sent or placed. This all adds up to fear, anxiety, helplessness, and frustration (Levine and Scotch 1970).

Hampe (1973) tried to determine whether the spouse whose mate was terminally ill could recognize his own needs and whether the spouse, himself, perceived that he had been helped by nurses. Hampe (1973) interviewed twenty-seven spouses during the terminal illness of their mates. Subsequently, eighteen mates died; fourteen of the spouses were also interviewed after the death event. Data were collected by means of tape-recorded semistructured interviews. Eight needs of the grieving spouses were noted and the percentage of the spouses who were able to meet these needs follows: (1) need to be with the dying person, eighteen spouses (63 percent); (2) need to be helpful to the dying person, twenty-one spouses (74 percent); (3) need for assurance of the comfort of the dying person, nine spouses (33 percent); (4) need to be informed

of the mate's condition, thirteen spouses (48 percent); (5) need to be informed of the mate's condition, thirteen spouses (48 percent); (5) need to be informed of the impending death, twenty spouses (74 percent); (6) need to ventilate emotions, eight spouses (32 percent); (7) need for comfort and support of family members, eleven spouses (41 percent); and (3) the need for acceptance, support, and comfort from health professionals, four spouses (15 percent).

Frelhofer and Felton (1976) studied twenty-five pairs of terminally ill patients and their families to determine nursing behaviors which offer greatest support, comfort, and ease of suffering to the loved ones. The Q-sort methodology, consisting of eighty-eight cards, each with one behavior was used. A three-tier classification of behaviors was derived; those that promote the dying patient's comfort; those that indicate understanding of the emotional needs of the dying patient; and those that indicated understanding of the impact on the bereaved of grief, grieving, and loss. Five of Hampe's (1973) eight identified needs of the grieving spouses--to be with the dying person, to be helpful to the dying person, for assurance of the comfort of the dying person, to be informed of the mate's condition, and to be informed of

the impending death--were found to be the most desired nursing behaviors in this study. Need to ventilate emotions, need for comfort and support of family members, and need for acceptance, support and comfort from health professionals were assigned a lesser priority.

The family needs to be kept informed of the patient's condition and be given advanced indication of change when the expectation of impending death nears. It is necessary to guard against the impact of sudden notice of death (Kalish 1977; Lindemann 1944). At the time death and dying becomes a reality, family needs help to know that it is a reality (Marks 1976). Engel (1964) suggested that the news of impending death be communicated to the family group rather than to an individual and that it should be done in private where the family can grieve without being on public display.

Families in Crisis

All families at one time or another are subjected to events which throw them into crises. The crisis of death of a loved one, may result in a life crisis for the surviving family. Crisis has been defined by Caplan (1964) as a disturbance in a steady state or homeostasis. During this time a person's usual methods of problem

solving are inadequate. The essential factor influencing the occurrence of crisis is an imbalance between the difficulty and importance of the problem and the resources immediately available to deal with it. Every family goes through a crisis when a loved one of that family is admitted to the hospital (Mitchell 1976).

When death occurs, it precipitates a crisis within the family throwing the organized family system into disequilibrium. Established roles must change to meet the crisis, and the family must reorganize. At times, this reorganization is disruptive, both functionally and emotionally, to the family members (Olsen 1970). Within a family, not all griever's work through the states at the same rate. As each individual goes through an active mental change, the family as a whole proceeds through a very extensive change. Interaction between them can cause conflicts (Klepser 1978).

Giaquinta (1977) suggested that nurses must look for serious change in family dynamics which seems to be more than just a temporary response to the crisis. By timely intervention, nurses may be able to facilitate the family coping response and mobilize their strengths to avoid emotional complications.

Summary

The preceding review of literature has been written in an attempt to examine the view of death in America and nurses' attitudes toward death. As is noted from the review, spouses of terminally ill patients begin the grieving process before the death of the mate. The stages of grieving have been identified as well as interventions needed by the dying patient and his family. Some of the grief process takes place while the patient and family are at the hospital and the nurses are in a position to assist. Information regarding the grieving process have been added to nursing curriculums. Studies examining the effects of this addition show the attitudes about death and dying can change as a result of nursing education and experiences with death and dying.

CHAPTER III

PROCEDURE FOR COLLECTION AND TREATMENT OF DATA

Introduction

In order to determine if nurses are meeting the needs of grieving spouses of terminally ill patients, a descriptive study was conducted using a semistructured interview with guided questioning. Abdellah and Levine (1965) stated that in nursing, "descriptive research has yielded important data for program planning and for decision making" (p. 426). This chapter presents the setting of the research project, the population, the protection of human rights, the tool used for data collection, the procedure for data collection, and the treatment of data.

Setting

The agency that was utilized for the collection of data was a 282 bed acute care medical center located in a northwestern area of the United States. The agency was located in a city with a population of 66,500. The medical center provides care for rural persons in a radius of 90 miles of the city. The average daily census

of the medical center is 160 adults with a 1.38 percent mortality rate. In 1978, 160 deaths occurred within this agency. Five nursing units within this medical center were utilized for this study including two medical units, one surgical unit, a rehabilitation unit, and the intensive care unit.

Population

The target population consisted of thirty-three spouses whose mates had been determined by medical staff to be terminally ill and who met the other delimitations of the study. Thirty individuals were selected from the population by convenience sampling. Abdellah and Levine (1965) supported the use of convenience sampling in the following way:

A nonprobability sample where we select for study the subjects who happen to be in location of the investigation at a certain time. There is an element of randomness in the entry of such subjects into the study (p. 310).

Four members did not wish to participate in the study after it was described to them, two individuals were dismissed to home before an interview time could be scheduled, and two individual's mates died before the interview was accomplished. The remaining twenty-two spouses comprised the study sample.

Protection of Human Rights

In order to protect the rights of the subjects, the following procedures were done prior to data collection:

1. Permission from Texas Woman's University Human Research Review committee to conduct research was obtained (Appendix A)
2. Written consent to use the medical center, approach the spouses, and collect data about the participants was obtained from the hospital administration (Appendix B)
3. Subjects signed informed written consent forms and had the right to withdraw from the study at any time (Appendix C)

Tool

A seventeen item semistructured questionnaire was administered by interview. The questionnaire entitled, "Initial Interview" (Appendix D) which was developed and used by Hampe (1973) in her study was adapted and utilized for this study. The semistructured interview was designed with a series of subquestions to remind the interviewer to probe for items that might not be mentioned or to provide clarification of the respondent's feelings and

opinions. Hampe (1973) established the content validity of an open-ended, semistructured interview tool by a thorough review of literature, as well as by using an expert in the care of oncology patients and their families. She established reliability in several ways. An abbreviated form for parallel-test reliability by varying several of her interview questions was used. In her study, all comparable questions were answered the same. Hampe (1973) also established reliability by giving a random sample of one-fourth of the interview session transcripts to the oncology clinical nurse specialist to analyze the content for expressed needs of the spouses. There was a 90 percent agreement between the analyses by Hampe (1973) and the nurse specialist.

The questionnaire was designed to validate the needs of the grieving spouse and to assess the spouse's perception of the nurses' role in meeting these needs.

The needs as identified by Hampe (1973) were:

1. to be with the dying person
 2. to be assured of the comfort of the dying person
 3. be kept informed of the dying person's condition
 4. feel helpful and of assistance to the dying person
 5. be aware of impending death
 6. to ventilate emotions
 7. receive acceptance, support, and comfort from the health professionals
 8. to receive comfort and support from family members
- (p. 46).

All eight needs were recognized by twenty-five of the twenty-seven spouses interviewed by Hampe (1973). Permission to use this questionnaire was obtained (Appendix E).

Three of Hampe's (1973) questions were reworded for this study. Interview item four was changed from: "Have there been any times that you have had to leave your mate's room?" to "Have there been any times that nursing and medical personnel have asked you to leave your mate's room?" Interview item eight was reworded to read, "Has someone talked to you about the status of your mate's illness?" from "Has anyone talked to you about your mate's chances?" Interview item eleven was changed from: "Have you any feeling of looking forward to when it is over?" to "How do you expect you are going to feel when it is all over?"

On interview item twenty: "Is there anything that you feel nurses, in particular, can do to help the husbands and wives of patients?" the researcher received from the sixth participant an answer that meetings for cancer patients and their spouses would be helpful. After obtaining the responses from the remaining sixteen participants to interview item twenty, the researcher then included the question, "Would you find meeting with other husbands and wives in a group helpful?"

Procedure for Data Collection

Twenty-two spouses who had hospitalized terminally ill mates comprised the study sample. Data were collected during a four month period from January 15, 1979 to May 25, 1979. The interview was conducted in the chapel of the hospital. The chapel was selected for the interviews in order to limit interruptions and to provide some physical distance from the nursing units. Tape recordings were made of fifteen interviews. The other seven subjects refused to be tape recorded and the answers were written by the researcher during the interview. The interview period lasted from thirty minutes to two hours, depending upon the subjects' needs to talk. The interviews usually lasted an hour although the information needed was obtained within the first thirty minutes. The interview focused on the needs of spouses of terminally-ill patients and the spouses' perception on how these needs were met by nursing intervention.

Treatment of Data

After listening to each participant's taped interview or analyzing the written interviews, attitudes and significant phrases were tabulated by the investigator. Each interview item of the questionnaire was categorized

according to the eight needs of the grieving spouse as identified by Hampe (1973) and the spouse's perception of the nurses' role in meeting their needs. Frequency of responses were tabulated for each question. Descriptive statistics were used to analyze the data.

CHAPTER IV

ANALYSIS OF DATA

Introduction

This descriptive study was conducted to determine the grieving spouse's perception of nursing intervention to meet the spouse's need. The data presented in this chapter were collected through the use of a seventeen item semistructured interview from a convenience sample of twenty-two spouses of terminally ill hospitalized patients. This chapter will present the analysis and interpretation of the data.

Description of the Sample

The study sample consisted of twenty-two spouses of terminally ill hospitalized patients. The mean age of the sample was 58.5 years with a range from 31-84 years. There were eleven females or 50 percent of the total sample whose ages ranged from 31 to 34 years. Eleven males ranged in age from 44 to 77 years. Table 1 summarizes the sample distribution by age and sex.

TABLE 1
DISTRIBUTION OF SUBJECTS BY AGE RANGE
AND SEX

Age Range	Females		Males		Total	Percent
	N	%	N	%		
31-40	1	9.1	9	0	1	4.5
41-50	2	18.2	5	45.5	7	31.8
51-60	1	9.1	1	9.1	2	9.1
61-70	4	36.3	4	36.3	8	36.4
71-80	2	18.2	1	9.1	3	13.7
81-90	<u>1</u>	<u>9.1</u>	<u>0</u>	<u>0</u>	<u>1</u>	<u>4.5</u>
Totals	11	100.0%	11	100.0%	22	100.0%

Interview Item Analysis

The first two interview items were the following: "How long has your mate been hospitalized?" and "How have things been going for you during your mate's hospitalization?" The purpose of these questions was to establish rapport with the spouse and it was hoped that it would allow the individual time to become more relaxed with the interview process. The mean length of hospitalization days prior to the interview was five days with a range from three to seven days. To the second interview item six (27 percent) spouses responded that things had been

going poorly. One spouse said,

It has been a nightmare. We are losing money in our business and our hospital expenses are doubling. No matter what is happening today, something worse is happening tomorrow. It's just a nightmare.

Eleven (50 percent) of the spouses indicated that the hospitalization had been going fair. Five (23 percent) of the spouses responded that the hospitalization had been good. No spouse reported that the hospitalization had been excellent. All of the spouses evaluated this hospitalization by comparing it with previous hospitalizations. Two (9 percent) of the spouses mentioned that it was very difficult to come to the hospital this time. One spouse stated, "I didn't know if it would be the last time he would be at home."

The interaction as the individual responded to the first two interview items did serve to set the tone of the interview as respondents described and clarified their remarks. There was a trend toward qualifying earlier remarks that the spouse made referring to the mate's hospitalization.

The third and fourth interview items were to assess the need to be with the dying person. The third interview item read, "Have you been able to stay with mate as long as you have wanted?" This need was met by eighteen (82

percent) of the spouses. Five (28 percent) of the eighteen spouses were staying with their mates twenty-four hours by sleeping on a cot furnished by the hospital. Four (18 percent) of the spouses were able to be with their mates only part of the time that they felt was necessary. Two of the four spouses were unable to stay with their mates because of home and other job responsibilities. One spouse stated,

Because I've been running our business, I haven't been able to stay with . . . as long as I would like. It's not because they [nurses] wouldn't let me. If I had the time I could have stayed as long as I wanted except when he was in ICU.

Due to hospital enforced visiting hours, two (9 percent) spouses were unable to be with their mates as long as they wanted. One spouse said,

A nurse told me I could be here only during visiting hours. This is the first time. Every other time, I could stay as long as I wanted.

Three (14 percent) of the spouses lived over fifty miles from the hospital. One of these spouses was over twelve hundred miles away from home. The mate became ill while visiting friends in the area. This spouse stated,

We're a long ways from home and there is no end in sight. I have friends here but no family. It is very difficult when you live out of a suitcase.

The fourth interview item read, "Have there been any times that nursing and medical personnel have asked

you to leave your mate's room?" Seventeen (77 percent) of the spouses answered yes to this question while five (23 percent) responded negatively. The most frequent response given for leaving the room was for nurses to give the mate care. One spouse responded,

I refused to leave when asked. They [nurses aide] wanted to give the bath but I stayed in the room to help. It was embarrassing to the nurses to have me there. I've been doing her care for several months now and I didn't want her left alone!

The responses from the individuals in the sample were recorded and the frequency of the responses were ranked in Table 2.

TABLE 2

PURPOSES AND FREQUENCY OF REASONS SPOUSES
WERE ASKED TO LEAVE MATE'S ROOM

Response	Frequency
To give nursing care	15
To do respiratory treatment	1
To do vaginal exam	1
To do thoracentesis	1
Nurses are embarrassed	<u>1</u>
Total	19

Eighteen (82 percent) of the spouses stated that they felt all right about leaving the room. Four (18 percent)

of the spouses said they did not like being asked to leave the room. One spouse commented, "I wouldn't know what they were doing to her."

Eighteen (82 percent) of the spouses were able to meet the need of being with the dying patient. Five (28 percent) of the spouses were able to meet this need by staying twenty-four hours with the terminally ill mate. The other thirteen (59 percent) spouses indicated that the need was met but preferred to spend short periods of time away from the hospital in order to maintain some normalcy in their lives.

The fifth interview item read, "Do you think that nurses are interested and concerned about your mate?" This question assessed the need to be assured of the comfort of the dying person and the spouse's perception of the nurses' role in meeting his mate's needs. Twenty (91 percent) of the spouses responded that nurses were concerned about their mate. Two (9 percent) of the spouses felt that nurses were not concerned about their mates. One spouse stated,

During the last hospitalization, they [nurses] were good but on this floor, I don't know the nurses and they are not available to get to know. One nurse does not take care of him very long. I would like one nurse to care for him more than one day. All week would be nice.

Another spouse commented, "All I have to do is press the button and they [nurses] are right here." Two spouses stated that older nurses were better than younger nurses because they are more confident.

To be assured of the physical comfort of the dying person was met by twenty (91 percent) of the spouses. Fifteen (68 percent) of the spouses indicated that this need was met by the nurses giving good care to the patient. Five (23 percent) spouses had this need met by the actions and manner of the nurse toward the patient and the spouse. Such actions included making the patient comfortable and stopping in the room to see if there was anything that the patient or spouse needed. The responses from the spouses in the sample were recorded and the frequency of the responses were ranked in Table 3.

TABLE 3

RESPONSES AND FREQUENCY OF WAYS NURSES SHOWED
THEIR CONCERN TO GRIEVING SPOUSES

Responses	Frequency
Gives good nursing care	15
Smiles and is friendly	11
By her actions and manner	5
Talks with me	3

TABLE 3 (continued)

Responses	Frequency
Brings me coffee	3
Shows compassion	2
Keeps me informed about mate's condition	2
Touches me	1
Talks with mate	1
Treats me like an individual	<u>1</u>
Total	42

Meeting the need to be helpful and of assistance to the dying patient was assessed by the sixth item of the interview. The question was: "Do nurses ever ask you to feed, give fluids, or to help with the care of your mate?" Fifteen (68 percent) of the spouses responded that they were not asked to help with the care of the mate, but five (23 percent) of the fifteen spouses stated they helped without being asked. Seven (32 percent) of the spouses were asked by nurses to help with the care of the mate. The two most frequent responses to the interview item were giving back rubs and getting the mate water. One spouse replied, "I help her at home, so I'm a little relieved to have nurses help her here. Nurses can do it

better than I can." Another spouse said, "I enjoy helping him. It's part of being a family. It makes me feel useful." One spouse commented that her husband was unconscious and there was nothing she could do to help.

Twelve (55 percent) of the spouses perceived that the need to feel helpful and of assistance to the dying person was met. Five (23 percent) of the spouses fulfilled the need without being asked by the nurses. Seven (32 percent) of the spouses were included in the care of their mate by the nurses. The most frequent responses to this question are presented in Table 4.

TABLE 4
TYPE AND FREQUENCY OF SPOUSES' ACTIVITIES
HELPFUL TO DYING MATES

Responses	Frequency
Give back rubs	5
Getting mate water	4
Bathing mate	3
Feeding mate	3
Reading to mate	2
Walk, exercise mate	1
Cleaning mate up after vomiting	1
Nothing I can do	<u>1</u>
Total	21

Assessment of the satisfaction of the need to be kept informed of the dying person's condition was the purpose of the seventh item of the scheduled interview. This item read, "What have you been told about your mate's illness?" All of the spouses described their need to be kept informed of their mates' medical condition, such as current diagnosis and plan for treatment. The explanation of their condition was seen as the responsibility of the physician. Twenty-two (100 percent) of the spouses felt that they had been kept informed of their mates' medical condition. Seven (32 percent) of the spouses demonstrated the need to be kept informed of the mates' daily physical condition such as how mate did during the night, when mate received last pain medication, and temperature of mate. The spouses felt that it was the nurses' responsibility to keep them informed about daily physical condition. Five (71 percent) of the seven spouses felt that all their questions had been answered honestly about their mates' condition. Two spouses remarked that nurses were not allowed to give out any information. One spouse added, "I just have to wait and see the doctor because nurses can't tell me anything."

All (100 percent) of the spouses had met the need to be informed of their mate's medical diagnosis and

prognosis. Five (23 percent) of the spouses were kept informed of the daily physical condition of the mate by the nurses. Of the remaining seventeen spouses, only two (9 percent) spouses perceived that this need was not being met. The fifteen remaining spouses either did not perceive being kept informed of mate's daily condition as a need or were having this need met through information provided by the mate.

The eighth item on the scheduled interview read, "Has someone talked to you about the status of your mate's illness?" The significance of this question was the awareness of the spouse of impending death of mate. Twenty (91 percent) of the spouses had been informed by the physician of their mates' impending death. Two (9 percent) of the spouses knew the diagnosis of their mates but were not informed of their mates' prognosis. These two spouses were waiting for the results of recently performed tests. One of the spouses later stopped the researcher in the hospital to inform her that the results of the tests "were not good."

Fifteen (68 percent) of the spouses were informed in the patient's room of their mates' status. Two (9 percent) spouses were informed of their mates' condition standing in the hallway of the hospital. Two (9 percent)

of the spouses were informed over the telephone by the physician. Two (9 percent) spouses were informed of their mate's condition in the physician's office. One (5 percent) of the spouses was informed by her mate over the telephone.

Twenty (91 percent) of the spouses reported that their mates were aware of their diagnosis and impending death. Two (9 percent) spouses stated that their mates were aware of their diagnosis, but were hoping for some miracle to save them from death. The need to be informed of impending death of the mate was met by twenty (91 percent) of the spouses.

Interview item number nine read, "Can you remember anything that has been particularly helpful to you during your mate's hospitalization?" The purpose of this question was to determine the need to ventilate and the need to receive acceptance, support, and comfort from the nursing professionals. Twelve (55 percent) of the spouses mentioned the family as being the most helpful. Being present was the most frequent response for how family and friends were helpful. Eight (36 percent) of the spouses mentioned nurses as being helpful. Nurses were helpful by being friendly to the spouse and by giving good nursing care to the mate. One (5 percent) of the spouses stated

that "no one could be helpful" to him. The responses from the spouses in the sample were recorded and the frequency of the responses are ranked in Table 5 and Table 6.

TABLE 5
RESPONSES AND FREQUENCY OF PERSONS
PERCEIVED AS HELPFUL TO THE
GRIEVING SPOUSE

Response	Frequency
Family	12
Friends	8
Nurses	8
Pastor	6
Mate	2
Physician	1
No one	<u>1</u>
Total	38

TABLE 6
TYPE AND FREQUENCY OF HELPFUL ACTIVITIES
TO THE GRIEVING SPOUSE

Response	Frequency
Being present	11
Nurses being friendly	6
Giving good nursing care	2

TABLE 6 (continued)

Response	Frequency
Talking with spouse	2
Praying	2
Nothing was helpful	<u>1</u>
Total	24

"Can you discuss your feelings with the nurses?" was the tenth and seventeenth item of the questionnaire. The purpose of these questions was to determine if spouses could ventilate their emotions to the nurses. Twelve (55 percent) of the spouses stated that they could discuss their feelings with the nurses but only one (5 percent) spouse had discussed his feelings with a nurse. Eight (36 percent) of the spouses stated they did not discuss their feelings with the nurses because nurses are too busy. Three (14 percent) spouses indicated nurses took care of the patients and not the family. One spouse stated, "I could talk with the nurses, but I've been trying to control myself. I just don't have the time to feel sorry for myself."

Ten (45 percent) of the spouses stated that they could not discuss their feelings with the nurses. Four

(40 percent) of the ten spouses listed their reason as not liking to talk with strangers. One spouse said,

I wouldn't want to talk with the nurses because they are not my intellectual equal. I wouldn't talk to anyone that wasn't my intellectual equal . . . but you [researcher] are different.

Interview item number eleven read, "How do you expect you are going to feel when it is all over?" The purpose of this question was to determine the need to ventilate emotions and to assess anticipatory grief. Twenty (90 percent) of the spouses indicated they were aware of their anticipatory grief. Two (10 percent) of the spouses did not express anticipatory grief. One spouse stated, "My husband wants to live. So I don't give up. We don't discuss death." Although spouses expressed anticipatory grief, six (27 percent) spouses expressed the need to maintain hope for the survival of their mates.

Only six (27 percent) spouses had met the need to ventilate emotions. Three (14 percent) spouses indicated that they spoke with their children about their feelings. Two (19 percent) spouses had shared their thoughts and feelings with a clergyman. Only one (5 percent) spouse indicated that he had talked to a nurse about the death of his mate. The spouses that were able to share their thoughts and feelings with others were also more able

to discuss death with their mate. Two (10 percent) of the spouses and their mates had been able to plan the funeral together.

The need to ventilate emotions was perceived by twenty-one (95 percent) of the spouse's as being important. Only one (5 percent) of the spouses indicated that, "he was in this by himself." Eighteen (82 percent) of the spouses perceived that the interview was helpful and thanked the researcher for talking with them. Five (23 percent) of the spouses cried during the interview. Two of these spouses stated that they had not been able to cry before because they did not want to let down in front of the family or patient.

The purpose of the next four interview items was to determine if spouses of terminally ill patients received acceptance, support, and comfort from the nursing professionals. Four (18 percent) of the spouses perceived that they had received acceptance, comfort, and support from the nurses. Eighteen (82 percent) of the spouses had partially met needs for acceptance, support, and comfort from the nursing professionals. Only three (14 percent) spouses mentioned nurses specifically in giving them the most support during the hospitalization.

To interview item number twelve, "What has been the most difficult for you during your mate's hospitalization?" nine (41 percent) of the spouses answered watching their mate suffer. Seven (32 percent) spouses reported that waiting during surgery or waiting for results from biopsies as the most difficult. Thirteen (59 percent) of the spouses stated "feeling of helplessness" as being the most difficult. The most frequent responses to this interview item are presented in Table 7.

TABLE 7
RESPONSES AND FREQUENCY OF THE MOST DIFFICULT
ASPECT OF MATE'S HOSPITALIZATION

Responses	Frequency
Feeling helpless	13
Watching mate suffer	9
Waiting during surgery or for biopsies	7
Being away from home	3
Learning about illness	2
Not being able to stay with mate	2
Moving to another unit of the hospital	2
Moving to another hospital	1
Mate developed phlebitis	1

TABLE 7 (continued)

Responses	Frequency
Not knowing how to act around people	1
Coming to grips with reality	1
Mate wanting to go home	<u>1</u>
Total	45

The thirteenth interview item was the same as interview item number nine and was presented in that section. The fourteenth interview item was, "Can you remember anything that was the most helpful to you this time?" The two most frequent responses to this interview item were family and friends. The most frequent response to how family and friends were helpful was "being present." Table 8 and Table 9 present the most frequent responses to this question.

TABLE 8

RESPONSES AND FREQUENCY OF PERSONS IDENTIFIED
AS THE MOST HELPFUL DURING THE
DIFFICULT TIME

Responses	Frequency
Family	8
Friends	5
Nurses	3

TABLE 8 (continued)

Responses	Frequency
Minister	2
Physicians	2
Social Worker	1
No one	<u>1</u>
Total	22

TABLE 9

TYPE AND FREQUENCY OF ACTIVITIES THAT WERE
HELPFUL DURING HOSPITALIZATION

Responses	Frequency
Being present	16
To talk with	8
Praying	4
Communion	2
Truthfulness of physician	<u>2</u>
Total	32

Interview item fifteen read, "Who has given you the most comfort during your mate's hospitalization?" Nine (41 percent) of the spouses responded that the minister had been the most comforting by offering prayers

and giving communion. Eight (36 percent) spouses saw the family as being the most comforting while five (23 percent) spouses saw friends giving the most comfort during the hospitalization. The two most frequent responses to how family and friends give comfort was "being present" and "talking with me."

The need for acceptance, support, and comfort of health professionals was met by seven (32 percent) of the spouses. All of the spouses were receiving support and comfort from other sources besides the health professionals. Family and friends were the most frequently named for giving support and comfort to the spouses of terminally ill patients.

The spouses' perception of the nurses' role in meeting their grieving needs was the purpose of the last five items on the scheduled interview. Interview item number sixteen read, "Can you tell me how you tell a Registered Nurse from a Practical Nurse, an aide, or other hospital personnel?" Eighteen (82 percent) of the spouses were able to identify Registered Nurses from other hospital personnel. Thirteen (72 percent) of the eighteen spouses responded they could tell the difference by looking at the name tag. One spouse stated, "And, believe me, I do look at the name tag." Four (22 percent) of the

eighteen spouses reported that they could tell the difference by uniform. "Nurses wear white uniforms and aides wear pink uniforms." Five (28 percent) of the eighteen spouses also mentioned that they could tell the difference in duties, "Aides give the baths and nurses give the medication."

Three (14 percent) of the spouses stated they could not tell the difference between a registered nurse and other hospital personnel. One (5 percent) spouse stated he could tell the difference between a registered nurse and other hospital personnel by the way nurses carried themselves.

Interview item number seventeen was, "What have the nurses done that was the most helpful?" Fifteen (68 percent) of the spouses saw nurses as being helpful in terms of giving good care to their mates. Six (27 percent) spouses reported nurses had specific interests and concern with them. Two of the six spouses stated they could call in at night to see how their mate was doing and the nurses would keep them informed. Four (18 percent) of the spouses stated nurses would talk with them and bring them coffee. One spouse (5 percent) did not feel nurses were very helpful. This spouse stated,

I would like the nurses to know what they are doing. They didn't know how to suction or put on my husband's brace. I finally learned how so I could teach the nurses . . . especially the nurses on the weekends.

The most frequent responses to this interview item are presented in Table 10.

TABLE 10
TYPE AND FREQUENCY OF NURSES' ACTIVITIES
PERCEIVED AS HELPFUL TO THE
GRIEVING SPOUSE

Response	Frequency
Give mate good nursing care	15
Friendly to spouse	6
Bring spouse coffee	4
Keep spouse informed	2
Mate being able to see children	1
Being present	<u>1</u>
Total	29

Interview item eighteen read, "Can you discuss your feelings with the nurses?" This item was the same as interview item ten and was discussed under interview item ten. Interview item nineteen is the same as interview item five and was presented in that section.

The last interview item was, "Is there anything that you feel nurses, in particular, can do to help the husbands and wives of patients?" Five (23 percent) of the spouses stated there was nothing that nurses could do to help them. Five (23 percent) spouses responded that nurses could improve communications on the units. Five (23 percent) of the spouses stated nurses could keep them better informed about their mate's condition. Seven (32 percent) of the spouses stated that giving good care to their mate was the only way nurses could be helpful. One spouse responded, "Could have a group of cancer patients and their wives meet each week for group to discuss feelings and how to cope with death and dying." After receiving this response, the researcher asked sixteen spouses during the interview if a group would be helpful. Eleven (69 percent) of the sixteen spouses thought a group would be helpful. One spouse mentioned, "Several of us [spouses] now get together and talk here on the hospital floor." One (6 percent) of the spouses thought a group might be helpful but he did not know if he would participate in a group. Four (25 percent) of the sixteen spouses did not feel a group would be of any help to them. One (6 percent) of these four spouses stated, "I have to do it on my own, no one can help me."

The responses from the individuals in the sample were recorded and the frequency of the responses were ranked in Table 11 for interview item twenty.

TABLE 11
TYPE AND FREQUENCY OF NURSING ACTIVITIES
IDENTIFIED AS POTENTIALLY HELPFUL
TO GRIEVING SPOUSES

Responses	Frequency
Group for spouses and patients	11
Give good nursing care	7
Improve communications	5
Keep spouse informed	5
Nothing would be helpful	5
Keep patients on one unit	3
Be able to see grandchildren	1
Be more sensitive to husbands and wives time together	<u>1</u>
Total	38

All of the spouses of terminally ill patients perceived nurses as being helpful in terms of giving good care to their mates. Eighteen (82 percent) of the spouses perceived nurses as being "too busy" or not responsible for the families of patients. Eleven (50

percent) of the spouses thought that a group meeting for spouses and terminally ill mates would be helpful in learning how to cope with death and dying. Ten (45 percent) spouses reported that nurses could be helpful by improving communications on the unit and keeping the spouse informed of the mate's condition.

Summary of Data Analysis

Chapter IV was concerned with the analysis and interpretation of the data collected from twenty-two spouses of hospitalized terminally ill patients. The purposes of the study were to determine the perception of spouses of terminally ill patients regarding the helpfulness of nursing intervention, to identify nursing interventions performed for spouses of terminally ill patients, and to determine frequencies of nursing activities that were being performed to meet the grieving needs of spouses of terminally ill patients. These three purposes were accomplished by presenting and identifying the various attitudes and responses to the interview items as listed in the tables.

Following is a summary of the findings of this study:

1. Spouses of terminally ill patients perceived nurses as not being responsible for their grieving needs but responsible for the care of the patients

2. There were six nursing interventions identified by spouses of terminally ill patients that were helpful in meeting their grieving needs

3. The professional nursing staff are meeting the grieving spouse's need to be with the dying person and to be assured of the physical comfort of the dying person

4. The professional nursing staff are not meeting four needs of the grieving spouse. These four needs are:

(a) to feel helpful and of assistance to the dying person

(b) to ventilate emotions

(c) to feel acceptance, support, and comfort from health professionals

(d) to be informed of mate's daily condition

5. The medical staff is meeting the grieving spouse's need to be informed of the mate's condition and to be informed of impending death

6. Spouses of terminally ill patients perceive family and friends as being the most helpful

CHAPTER V

SUMMARY, CONCLUSIONS, IMPLICATIONS, AND RECOMMENDATIONS

Introduction

This study has focused on the grieving spouse's perception of nursing intervention to meet the spouse's needs. This chapter will be concerned with the summary, conclusions, implications, and recommendations that have evolved from the study.

Summary

A descriptive study was conducted to determine the grieving spouse's perception of nursing interventions to meet the spouse's needs. A questionnaire by Hampe (1973) was adapted and utilized to collect the data.

Twenty-two spouses whose hospitalized mates were determined by medical staff to be terminally ill were selected by convenience sampling. The data were collected over a four month period from January 15, 1979 to May 25, 1979 in a city in the northwestern United States.

Phrases, attitudes, and nursing interventions derived from the spouses' responses to the seventeen item

interview were recorded. The responses of the total sample to each interview item were analyzed for content. The content was tabulated; the most frequent comments related to the specific interview item were then presented. The perception of the spouses of terminally ill patients regarding the helpfulness of nursing interventions have been presented.

Discussion of Findings

The findings of this study were:

1. All (100 percent) of terminally ill patients perceived nurses as helpful in terms of the care given to their mates. Eighteen (82 percent) of the spouses perceived nurses as "too busy" or not responsible for the spouses of patients. Nurses were seen as responsible for the care of patients

2. There were six nursing interventions identified by spouses of terminally ill patients in meeting their needs. These six nursing interventions were:

- (a) give the mate good nursing care, (b) nurses being friendly to the spouse, (c) nurses bringing the spouse coffee, (d) nurses keeping the spouse informed of the daily condition of mate, (e) being able to bring the children or grandchildren to the hospital to see the

mate, and (f) the reassurance of having the nurses present

3. The percentage of grieving spouses who had their needs met through nursing activities were:

- | | |
|-----------------------------------------------------------------|-------------|
| (a) to be with the dying person | 82 percent |
| (b) to feel helpful and of assistance to the dying person | 55 percent |
| (c) to be assured of the physical comfort of the dying person | 91 percent |
| (d) to be informed of the mate's | |
| 1. diagnosis and prognosis | 100 percent |
| 2. daily physical condition | 23 percent |
| (e) to ventilate emotions | 5 percent |
| (f) to be informed of impending death | 91 percent |
| (g) for acceptance, support and comfort of health professionals | 32 percent |

The findings of this study are similar to the findings of Hampe (1973). Hampe found in her study that 78 percent of the spouses perceived nurses as "too busy" or not responsible for the spouses of patients. Hampe also found that nurses were seen as responsible for the care of the patients, not the family. All (100 percent) spouses in Hampe's study perceived nurses as helpful to spouses in terms of the care given to their mates.

The findings of this study show that nurses are meeting four needs of grieving spouses of terminally ill

patients more frequently than in Hampe's (1973) study. The needs more frequently met are to be with the dying person, to be assured of the physical comfort of the dying person, to be kept informed of the impending death and for acceptance, support, and comfort of health professionals.

Three needs of the spouses were met less frequently in this study than in Hampe's (1973) study. These three needs were to feel helpful and of assistance to the dying person, to ventilate emotions, and to be informed of patient's daily physical condition.

Frelhofer and Felton (1976) found in their study that the most desired nursing behaviors in assisting the bereaved during the fatal illness of a loved one included: to be with the dying person, to be helpful to the dying person, to be informed of the impending death, and to be informed of the mate's condition. Need to ventilate emotions, need for comfort and support of family members and need for acceptance, support and comfort from health professionals were assigned a lesser priority. The findings of this study show that the nurses of this medical center are meeting the needs as identified by Frelhofer and Felton (1976) as most desired by spouses of terminally ill patients except for the need to be helpful to the

dying person and keeping the spouse informed of the mate's daily condition.

The higher percentage of needs met in this study as compared to Hampe's (1973) could be attributed to the increased amount of literature, that has been published in the last five years regarding death and dying and the inclusion of this information in nursing curricula. However, the nurses may still be uncomfortable and have anxiety about working with spouses of terminally ill patients as shown by the low percentage of grieving spouses that had their needs met of receiving acceptance, support and comfort from health professionals and to ventilate emotions.

According to Frelhofer and Felton (1976), spouses do not give a high priority to the need to ventilate emotions or the need for acceptance, support and comfort from health professionals. This could be the reason that spouses do not expect or demand these nursing interventions be performed for them. These two needs may be met through the support and comfort of family and friends.

Conclusions and Implications

Based on the findings of this study, the following conclusions and implications are derived:

1. Grieving spouses did not perceive nurses as being responsible for their grieving needs. Therefore, education be presented to the public regarding services professional nurses can provide to patients and their families

2. Nurses were not meeting all the needs of the grieving spouse. Thus, professional nurses and nursing students be made aware and prepared to assess the needs of grieving spouses and families of terminally ill patients

3. The professional nurse may be uncomfortable in meeting the needs of grieving spouses of terminally ill patients. Nursing education provide students with experiences to become more comfortable with spouses and families of terminally ill patients and to better understand their attitudes and concerns

4. The need to ventilate emotions was not met by spouses of terminally ill patients through professional nurses. Therefore, communication be encouraged between the professional staff and spouses of terminally ill patients

5. Because the need to feel helpful and of assistance to the dying person was not met by the spouses, the professional staff be made aware of the importance of

the inclusion and support of the terminally ill patient's significant family members in planning nursing care

Recommendations

Based on the findings of this study, the following recommendations are made:

1. A similar study be conducted in the future using a larger sample
2. This study be repeated using all family members rather than limiting the study to spouses
3. This study be repeated with families of dying children
4. Professional nursing staff be included in the study sample to compare their perceptions of nursing interventions performed to meet the grieving spouse's needs with those of the spouses
5. A study be done to determine if the needs to ventilate emotions and to receive support, acceptance and comfort from health professionals are important needs to be met by the nursing professionals or if family and friends can sufficiently meet these needs for the spouses of terminally ill patients

APPENDIX A

TEXAS WOMAN'S UNIVERSITY

Human Research Committee

Name of Investigator: Gail Ann Bucko Center: DallasAddress: 317 42 Street North,
Great Falls,
Montana 59401Dear Ms. Bucko:
Your study entitled Spouse Grief Needs and Their Fulfillment
by Nursing Intervention

has been reviewed by a committee of the Human Research Review Committee and it appears to meet our requirements in regard to protection of the individual's rights.

Please be reminded that both the University and the Department of Health, Education and Welfare regulations require that written consents must be obtained from all human subjects in your studies. These forms must be kept on file by you.

Furthermore, should your project change, another review by the Committee is required, according to DHEW regulations.

Sincerely,

Chairman, Human Research
Review Committee
at Dallas.

APPENDIX B

TEXAS WOMEN'S UNIVERSITY
COLLEGE OF NURSING
DALLAS, TEXAS

DALLAS CENTER
1010 Inwood Trail
Dallas, Texas 75235

HOUSTON CENTER
1130 M.D. Anderson Blvd.
Houston, Texas 77025

AGENCY REQUEST FOR CONDUCTING STUDY*

THE Montana Diagnostics Medical Center

GRANTS TO Lore Bucko

a student enrolled in a program of nursing leading to a Master's Degree at Texas Women's University, the privilege of its facilities in order to study the following problem: To determine if nursing intervention meets the needs of the spouse of a hospitalized terminally ill patient.

The conditions mutually agreed upon are as follows:

1. The agency (~~may~~) (~~may not~~) be identified in the final report.
2. The names of consultative or administrative personnel in the agency (~~may~~) (~~may not~~) be identified in the final report.
3. The agency (~~wants~~) (~~does not want~~) a conference with the student when the report is completed.
4. The agency is (~~willing~~) (~~unwilling~~) to allow the completed report to be circulated through interlibrary loan.
5. Other: _____

Date 1/2/79
Lore Bucko
Signature of student

Estelle D. Kurt
Signature of Agency Personnel

Estelle D. Kurt
Signature of Faculty Advisor

*Fill out and sign three copies to be distributed as follows: Original - Student; first copy - agency; second copy - T.W.U. College of Nursing.

APPENDIX C

TEXAS WOMAN'S UNIVERSITY

(Form A--Written presentation to subject)

Consent to Act as a Subject for Research and Investigation:

The following information is to be read by or to the subject:

1. I hereby authorize Gail Bucko
to perform the following procedure(s) or investigation(s)
(Describe in detail)

My name is Gail Bucko. I am a graduate student working on my Master's thesis at Texas Woman's University. I am doing a study to learn what extent nurses meet the needs of husbands and wives of seriously ill patients. I am interested in knowing your ideas in order to assist nurses to plan better nursing care for these patients.

I will talk with you and ask you a few questions. You may refuse to answer any question that makes you feel uncomfortable. There are no right or wrong answers to these questions. The answers will be confidential and your name will not be connected with the study. The time involvement will be about one hour.

It will in no way influence the care your husband or wife receives by the nursing staff.

You may refuse to consent or discontinue participation at any time. Thank you very much for your interest and participation in this study.

2. The procedure of investigation listed in Paragraph 1 has been explained to me by Gail Bucko.
3. I understand that the procedures or investigations described in Paragraph 1 involve the following risks or discomforts:
(Describe in detail)

Public embarrassment due to improper release of information. May experience discomfort from expression of feelings and emotions.

Concern for quality of nursing care of mate if spouse refuses to participate in the study.

4. I understand that the procedures and investigations described in Paragraph 1 have the following potential benefits to myself and/or others:

To assist nurses to plan better nursing care for patients and their families.

Will provide an opportunity to express feelings and emotions concerning illness of husband or wife.

5. An offer to answer all of my questions regarding the study has been made. If alternative procedures are more advantageous to me, they have been explained. I understand that I may terminate my participation in the study at any time.

Subject's signature

Date

APPENDIX D

SCHEDULED INTERVIEW

A. Establishment of Rapport

1. How long has your mate been hospitalized?
2. How have things been going for you during your mate's hospitalization?

B. To be with the dying person

3. Have you been able to stay with your mate as long as you have wanted?
4. Have there been any times that nursing and medical personnel have asked you to leave your mate's room?
 - (a) What purpose?
 - (b) How do you feel about leaving the room?
 - (c) Have the treatments been explained to you?
 - (1) to your satisfaction?
 - (2) in terms that you could understand?
 - (3) were you told to expect any changes in your mate as a result of the treatments?

C. To be assured of the comfort of the dying person

5. Do you think that the nurses are interested and concerned about your mate?
 - (a) Why do you feel this way?
 - (b) How do they show their concern?

D. Feel helpful and of assistance to the dying person

6. Do the nurses ever ask you to feed, give fluids, or to help with the care of your mate?
 - (a) If no, would you like to do something?
 - (b) If yes, how do you feel about doing this?
 - (c) If helped, do you feel that you should not be asked to help, why?
 - (d) Why do you feel that you are asked to help?

E. Be kept informed of the dying person's condition

7. What have you been told about your mate's illness?
 - (a) Who explained this to you?

- (b) How did learning about his illness make you feel?
- (c) When you have had questions, have they been answered?
 - (1) to your satisfaction?
 - (2) in terms that you could understand?

F. To be aware of impending death

- 8. Has someone talked to you about the status of your mate's illness?
 - (a) Who did this?
 - (b) Was there anyone else present with you?
 - (c) How were you told of this?
 - (d) How did you react to it?

G. To ventilate emotions

- 9. Can you remember anything that has been particularly helpful to you during your mate's hospitalization?
 - (a) What was it?
 - (b) Who was helpful?
- 10. Can you discuss your feelings with the nurses?
- 11. How do you expect you are going to feel when it is all over?
 - (a) Can you explain how you feel about this?
 - (b) Have you been able to talk to anyone about your feelings?
 - (1) to whom?
 - (2) were they helpful in resolving them?

H. Receive acceptance, support, and comfort from the nursing professionals?

- 12. What has been the most difficult for you during your mate's hospitalization?
 - (a) What has been done about this?
 - (b) Who has been most helpful to you?
 - (c) Would anything else have been helpful?
 - (d) Would anyone else have been helpful?
- 13. Can you remember anything that has been particularly helpful to you during your mate's hospitalization?
 - (a) What was it?
 - (b) Who was helpful?
 - (c) If identifies more than one, ask which was most helpful?

14. Can you remember anything that was most helpful to you during this time?
 - (a) What was it?
 - (b) Who was helpful?
15. Who has given you the most comfort during your mate's hospitalization?
 - (a) How have they been comforting?
- I. Spouse's perception of the nurses' role in meeting his/her needs?
 16. Can you tell me how you tell a Registered Nurse from a Practical nurse, aide, or other hospital personnel?
 - (a) by uniform?
 - (b) by duties performed?
 17. What have the nurses done that was the most helpful?
 - (a) What is a (helpful, friendly, kind, nice, etc.) nurse?
 18. Can you discuss your feelings with the nurses?
 19. Do you think that the nurses are interested and concerned about your mate?
 - (a) Why do you feel this way?
 - (b) How do they show their concern?
 20. If there anything that you feel nurses, in particular, can do to help the husbands and wives of patients?
 - (a) How can they make your stay easier?
 - (b) If no,
 - (1) have you ever asked the nurses for help?
 - (2) would you ask the nurses for help if you needed help?
 - (3) what do you expect from a nurse?

APPENDIX E

717 Highland Ave.
Iowa City, Iowa 52240
November 16, 1977

Mrs. Gail Bucko
317 42nd Street North
Great Falls, Montana 59405

Mrs. Bucko:

I am pleased to give you permission to use the questionnaire from my master's thesis for your research. Please keep me informed as to the results of your study.

Sincerely,

Sandra Kay Oliver
Sandra Kay Oliver, R.N., M.A.

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