

EVALUATION OF THE BEREAVEMENT PROGRAM  
OF THE PALLIATIVE CARE UNIT AT  
ST. BONIFACE GENERAL HOSPITAL  
a pilot study

by

© Tracy L. Hildebrandt

submitted in partial fulfillment  
of the Master's of Nursing Degree

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Dear Ms. Hildebrandt:

I am pleased to grant you permission to use the Bereavement Experience Questionnaire that Dr. Schroeder and I developed. If you use the BEQ for research purposes please send me the raw data that you collect so that I may continue to assess the instruments psychometric properties.

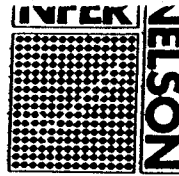
An article describing the BEQ's development and a copy of the BEQ are enclosed.

Sincerely,

Alice S. Demi, R.N., D.N.Sc.  
Professor and Chairperson

ASD/bgt

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EVALUATION OF THE BEREAVEMENT PROGRAM OF THE PALLIATIVE  
CARE UNIT AT ST. BONIFACE GENERAL HOSPITAL  
A PILOT STUDY

BY

TRACY L. HILDEBRANDT

A thesis submitted to the Faculty of Graduate Studies of  
the University of Manitoba in partial fulfillment of the requirements  
of the degree of

MASTER OF NURSING

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## ABSTRACT

The period of bereavement has been linked with changes in physical and mental functioning of the individual, with the precipitation of illness or death, with the increase of health threatening behaviors such as drinking, smoking and drug use, and with the increased use of health services. The strain on the health status of the individual has implications for society and the health care system. Different types of interventions have been postulated to ameliorate the effects of bereavement such as mutual support groups, hospice programs, and psychotherapy. It is unclear which intervention is most effective. As competition for health care dollars increases, it is crucial that the most effective way to provide care for bereaved individuals be delineated. Therefore, it was proposed that the bereavement program at St. Boniface General Hospital be evaluated.

The study used a quasi-experimental design with one experimental group and one non-equivalent control group. A pretest measure was taken within seventy-two hours of the patient being admitted to the institution to determine the presence of anticipatory grieving. Outcome measures were taken at six weeks and six and twelve months post death. The primary measurement tools used in the study were the

Goldberg (1978) General Health Questionnaire and the Demi  
and Schroeder (1985) Bereavement Experience Questionnaire.

The results of this quasi-experiment did not demonstrate a statistically significant difference between individuals who participated in a bereavement program and those who did not. Since a small sample size was used, the investigator had only a 51% chance of detecting a large difference between the groups. Therefore, the differences found between the groups were "clinically significant". At six-weeks post death the bereavement program appeared to decrease the intensity of the grieving response especially in the areas of anger, meaninglessness, yearning, and morbid fears. As the process of bereavement continues after the six week period, concrete recommendations will be withheld until the final measurements have been made.



DEDICATION

To

DR. PAUL HENTELEFF

for his support and encouragement and philosophical  
questioning of care for the dying patient and family  
which were crucial elements in my personal and  
professional development

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The process of developing a thesis requires extensive support and assistance from many sources. Without the help of the following people the task would not have produced the degree of growth or happiness. An acknowledgement simply cannot convey my thoughts of gratitude to the following people.

Firstly, my thesis committee who provided guidance and support especially in the difficult times of the learning process. Dr. Lesley Degner whose dedication to her own work provided inspiration. Lesley's independent teaching style provided me with the confidence to create and to expand research in a manner that was my own. Lynn Scruby, who challenged me to expand my horizons by looking at bereavement from a community focus. Fred Nelson, a colleague who shared a similar dream and was a source of support through the expansion of the bereavement program. And Dr. Henteleff whose provocative thoughts challenged me to stand up for the rights of patients and tuned my ear to listen carefully to what they had to teach me.

The statistical guidance for the thesis was provided by Jeff Sloan who spent many hours patiently re-explaining the statistical procedures.

The task of contacting the family members was made considerably easier through the efforts of the nursing staff at the Winnipeg Municipal Hospital and the St. Boniface General Hospital. Individuals who lent extensive support were Debbie Miller, Denis St. Laurent, Ophie Bredonia, Ellen Harmer and all of the staff nurses at the Princess Elizabeth Hospital and Janet Banks and the staff nurses at the St. Boniface Hospital.

There were many individuals who were crucial to the functioning of the bereavement program. Firstly, the volunteers whose dedication to the care they provided was tremendous. Their support to the study was present in their excellent recording and sharing of the experiences of the visits. Secondly, the program could not have functioned without the excellent coordination of Bunty Anderson. Bunty provided many hours of support, encouragement and examination of the issues which caused me to examine not only the experiences of loss of the respondents but also my own. I will always be indebted to her for challenging me to be all that I could and for providing a safe haven when I couldn't.

There were many individuals who provided unconditional support throughout the process of this educational endeavor. My family who was there to encourage me and to share my greatest fears. My husband, James, who had to deal with my day to day frustrations and my sorrow in hearing what others

were going through. And who provided me with endless hours to do much of the computer work. My friends and fellow graduate students who taught me so much in the process of learning. I am especially indebted to Chris, Judy, Loretta and Linda who understood what I was going through.

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## Chapter I

### STATEMENT OF THE PROBLEM

The growth of the hospice or palliative care movement throughout the world appeared simultaneously with the death-awareness movement in society. The death awareness movement began in an attempt to reverse or uncover the denial of death in society and ultimately to improve the quality of care for the dying individual and family. The pioneering work and writings of Elizabeth Kubler-Ross (1969) and Avery Weisman (1979) have stimulated initial work in the area and encouraged others to explore it further.

The term "hospice" was used in the Middle ages to signify a "way station" for pilgrims or travellers where they would receive refuge and sustenance (Taylor, 1983 & Zimmerman, 1981). The religious orders who managed the hospice later began to care for the homeless and sick (Cohen, 1979). The first modern hospice, St. Christophers, was established in 1968 in London by Dame Cicely Saunders to provide care for terminally ill patients (Hillier, 1985).

The hospice movement spread from Great Britain to the United States and Canada. Independent or free-standing hospices were the norm in the United States while in Canada the hospice movement became apparent in the development of

palliative care units attached to major hospital facilities. The term "hospice" can be used to designate many different facilities and is really a philosophical orientation as opposed to a particular place. The philosophy is practiced by a multidisciplinary team and consists of providing care to the patient and family which is holistic in nature, taking into consideration the physical, psychological, and spiritual realms of the human being and extends to include the bereavement process (Doyle, 1983; Kutscher, Klagsbrum, Torpie, DeBellis, Hale & Tallmer, 1983).

The need for palliative care units arose out of the inadequacy in care for terminally ill patients who were receiving care which was "cure-oriented" rather than comfort-oriented, creating situations of isolation and depersonalization (Mount, 1976). The curative orientation within the institutions resulted in patients' symptoms being treated with little attention to discomforting symptoms and psychosocial concerns.

In 1975 the first two Canadian palliative care units were opened, in Montreal at the Royal Victoria Hospital and in Winnipeg at the St. Boniface General Hospital (Ley, 1985). Since that time many other programs have been established and as of 1982 there were one hundred and sixteen programs with a total of two hundred and sixty-six palliative care beds. Ninety-five percent of patients cared for in palliative care beds have terminal cancer (Southall, 1982).

Even though palliative care has many benefits to offer the dying patient, only ten percent of patients with cancer are cared for in a palliative care program (Southall, 1982). One of the reasons for this situation lies in the fact that little evaluative research has been done in palliative care settings to establish its effectiveness in providing an alternative within the health care system (Ley, 1982).

The palliative care unit of the St. Boniface General Hospital opened in November, 1974 and provided service in the inpatient setting and in the community through the home care department. Ninety percent of all individuals admitted to the palliative care program are affected by cancer. Cancer is the second major cause of death of individuals in Manitoba and the incidence of new primaries is on the rise (Manitoba Cancer Foundation, 1984). Not only are more people being diagnosed with cancer but slightly more individuals are dying of the disease (See Figure 1.1). Approximately seventeen deaths per month occur on the palliative care unit (Palliative Care Program, 1985). As the death rate due to cancer is high, many families in the province are left to cope with a period of bereavement.

The palliative care program recognizes that bereavement is a normal part of the human experience and it is given consideration before the patient dies by keeping families informed, helping them to communicate openly about decision-making and assisting them to deal with unresolved emotional

# Manitoba Cancer Treatment & Research Foundation

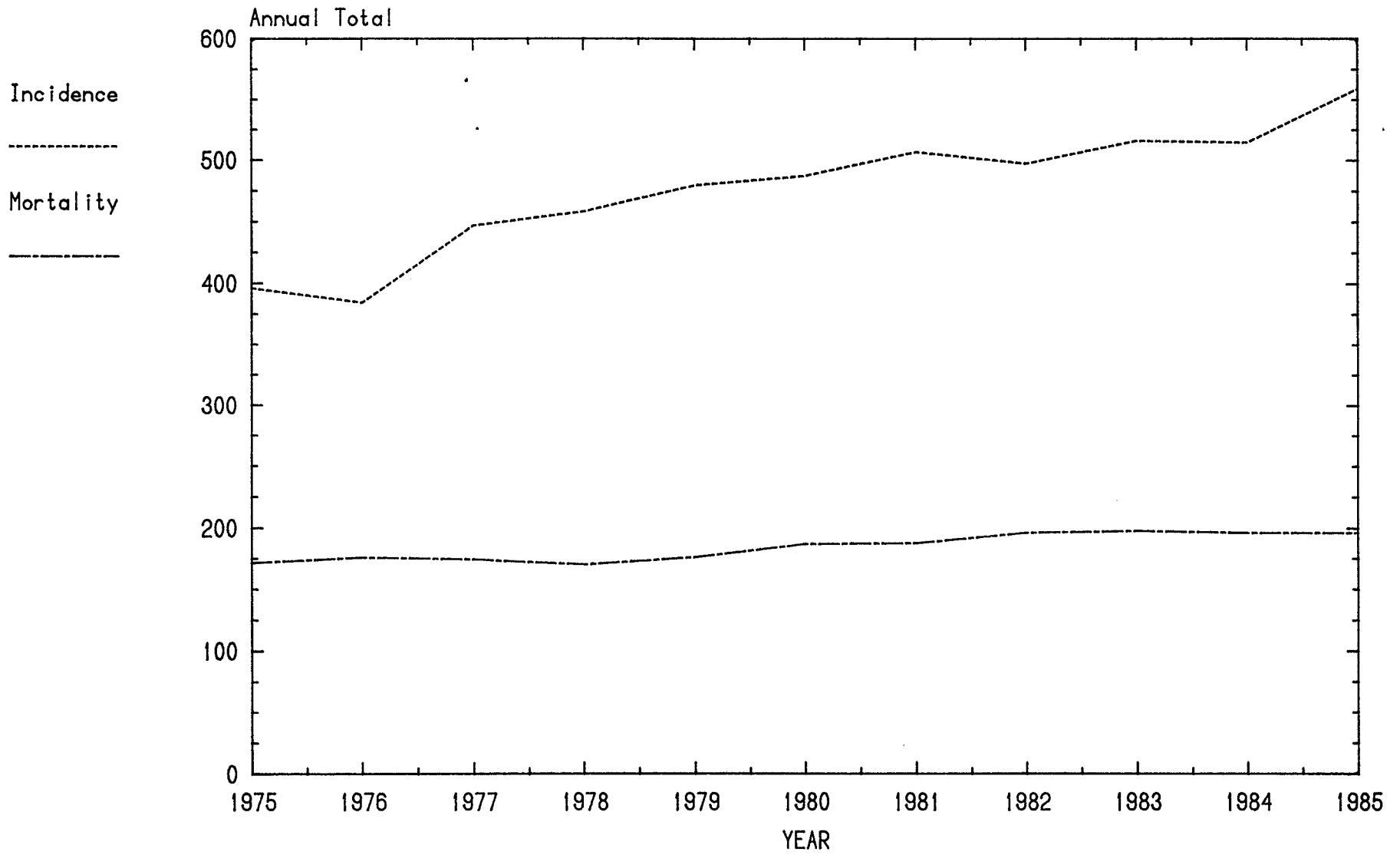


Figure 1.1: Cancer Incidence and Mortality, 1975 to 1985

issues (Palliative Care, 1985). Intervention in the period of bereavement currently consists of sending a bereavement card at four weeks post death as this is the time many of the familiar supports are withdrawn from the bereaved individual. Further contact in the form of a bereavement social evening is made with the bereaved individual or family from six to nine months after the death. The form of intervention currently employed by the palliative care unit does not appear sufficient when considering the results of a needs assessment conducted at St. Boniface Hospital and in examining a review of the literature.

Bereavement, like death, is an unavoidable fact of life, and causes pain. Vachon (1976) defines bereavement as "the loss of, or separation from an object depended upon for sustenance, comfort and security, and grief as the emotional state normally resulting from such a loss" (p. 35). Bereavement is a time that may involve "significant role changes; the loss of one's best friend, sexual partner, financial security; and changes in one's identity and sense of self" (Vachon, 1983, p. 451). Bereaved individuals often feel they have lost part of themselves or that their lives have become void of meaning. People respond to loss in a variety of ways. This great variation in response is what makes it difficult to determine what is normal or abnormal grieving, or expression of loss.

The symptomatology of grief was first described by Lindemann in 1944 after observing survivors of the Coconut Grove Nightclub disaster. Common grief reactions consisted of: (a) sensations of somatic distress (tightness in the throat, a need to sigh, shortness of breath); (b) intense preoccupation with the image of the deceased; (c) strong feelings of guilt; (d) loss of warmth towards others; (e) disoriented behavior patterns (restlessness, decreased ability to concentrate); and (f) appearance of traits of the deceased. Other researchers have corroborated these earlier observations (Clayton, Desmarais, & Winokur, 1968; Glick, Parkes & Weiss, 1975; Parkes & Weiss, 1983; Raphael, 1977). The normal symptoms of grief often cause fear and anxiety within the bereaved person so that they feel they are going out of their mind (Olsen, 1985).

The period of bereavement has been linked with changes in physical and mental functioning; with the precipitation of illness or death; with the increase of health threatening behaviors such as drinking, smoking, and drug use; and with the increased use of health services. Examination of the effects of bereavement on the individual has revealed conflicting evidence. Studies indicate that for men under the age of seventy-five, there is an increased risk of mortality in the first year of bereavement, especially if they do not remarry (Helsing & Szklo, 1981; Kraus & Lilienfeld, 1959; Rees & Lutkin, 1967; Young, Benjamin &



Wallis, 1963). The studies examining the effects of bereavement on widows are conflicting. In general, it was found that there was no increase in mortality in the first year of bereavement. An increase in mortality was found in the second year of bereavement by one researcher (Cox & Ford, 1964) while other researchers, (Clayton, 1974; Clayton, 1979; Gerber et al., 1975b; Ward, 1976) found there to be no significant differences in mortality in the widowed population. The suicide rate has been found to be greater in the bereaved population than in the non-bereaved population, with the greatest increase being evident in males (MacMahon & Pugh, 1965; Shepard & Barraclough, 1974).

Morbidity is also affected by the bereavement period. An increase is noted in the occurrence of depressive symptomatology, as well as in increased consumption of tranquilizers and or sleeping pills, and tobacco and drug usage, which may compromise the health status of individuals (Clayton, 1974; Maddison & Viola, 1968; Parkes, 1964a; Parkes & Brown, 1972; Paykel, Myers, Dienelt & Klerman, 1969; Raphael, 1977). Some studies have linked specific types of illness to individuals in the bereavement period but most of the studies are inconclusive due to small sample sizes, weak methodologies and vague methods of defining loss. Schmale and Iker (1965) reported an association between loss and different types of cancer, especially cancer of the cervix, while Greene (1954) found an

association between recent loss and the incidence of leukemia and lymphoma. The most common link between loss and a specific disease entity relates to the cardiovascular system with arrhythmias, infarcts and congestive heart failure being prominent conditions (Engel, 1971; Parkes & Weiss, 1983). Helsing, Comstock and Szklo (1982) found widows who died had an increased percentage of deaths due to cirrhosis of the liver while widowed men were at increased risk for infectious diseases, accidents and suicide.

Examination of the use of health care facilities by the bereaved population also presents conflicting evidence. Most studies report no increase in physician visits amongst the bereaved population (Clayton, Herjanic, Murphy & Woodruff, 1974; Parkes & Brown, 1972) while in England and one study in the United States in which there were prepaid health plans there was an increase in physician visits (Parkes, 1964a; Parkes, 1970b; Wiener, Gerber, Battin & Arkin, 1975). It has been suggested that economic factors may play a role in seeking out health services (Osterweis, Solomon & Green, 1984). In a recent study Mor, McHorney and Sherwood (1986) found an increase in physician visits amongst the bereaved population but no greater occurrence of hospitalization, suggesting the physician was used as a means of emotional support.

Even though some of the evidence in regard to the effects of bereavement on morbidity and mortality is conflicting,

there is enough evidence to conclude that the period of bereavement puts a strain on the health status of the bereaved individual. This increase in morbidity and mortality has implications for society and the health care system. Time and money are lost in sick benefits, employment time, treatment costs, and incalculable expenditures in individual and family functioning. Bereavement is a time of stress that takes a toll on the individual experiencing it, and may affect the quality of the bereaved individual's life. As members of the health care profession, it becomes imperative to identify a way to deal effectively with the consequences of bereavement.

The need to ameliorate the effects of bereavement is obvious. Different types of intervention have been postulated to soften the effects of bereavement such as mutual support groups, (Barrett, 1978; Silverman, 1976; Vachon, Lyall, Rodgers, Freedman -Letofsky & Freeman, 1980) hospice programs (Cameron & Brings, 1980; Parkes, 1981) and various types of psychotherapy (Forrest, Standish & Baum, 1982; Gerber, Wiener, Battin & Arkin, 1975b; Horowitz, Marmar, Weiss, DeWitt & Rosenbaum, 1984; Raphael, 1977). It is unclear which intervention is most effective and for which group of people in mitigating the effects of bereavement. As competition for health care dollars increases, it is crucial that the most effective way to provide care for bereaved individuals be delineated. Some

of the difficulty in analyzing bereavement programs lies in the fact that they are often run by lay individuals who are untrained in research, or who have not wished to be placed under the scrutinizing eye of research teams (Osterweis, Solomon, & Green, 1984). Comparative evaluations are difficult due to the diversity in goals, structure, and content of the various programs and also due to the diversity in research methodologies which are used.

It is now urgent that the health care system find an answer to the question, "Which bereavement intervention is most effective in assisting individuals with the process of grief?" The answer to this question will expand research by establishing recommendations for the intervention and care of bereaved individuals. To begin to answer this question, it was proposed that an evaluation of the expanded bereavement program of the palliative care unit of the St. Boniface Hospital be undertaken. The two primary questions to be answered by this study are as follows:

1. What effect does the bereavement follow-up program of the palliative care unit of the St. Boniface General Hospital have on the bereavement experience of the individual?
2. Is the bereavement follow-up program of the palliative care unit of the St. Boniface General Hospital effective in promoting physical health,

psychological health, and social functioning of the individual?

## 1.1 CONCEPTUAL FRAMEWORK

The conceptual framework chosen to guide this research in the area of bereavement is crisis theory. This section will be discussed from the perspectives of the development of crisis theory, development of a crisis, application to bereavement, crisis intervention, and strengths and limitations of the theory.

### 1.1.1 Development of Crisis Theory

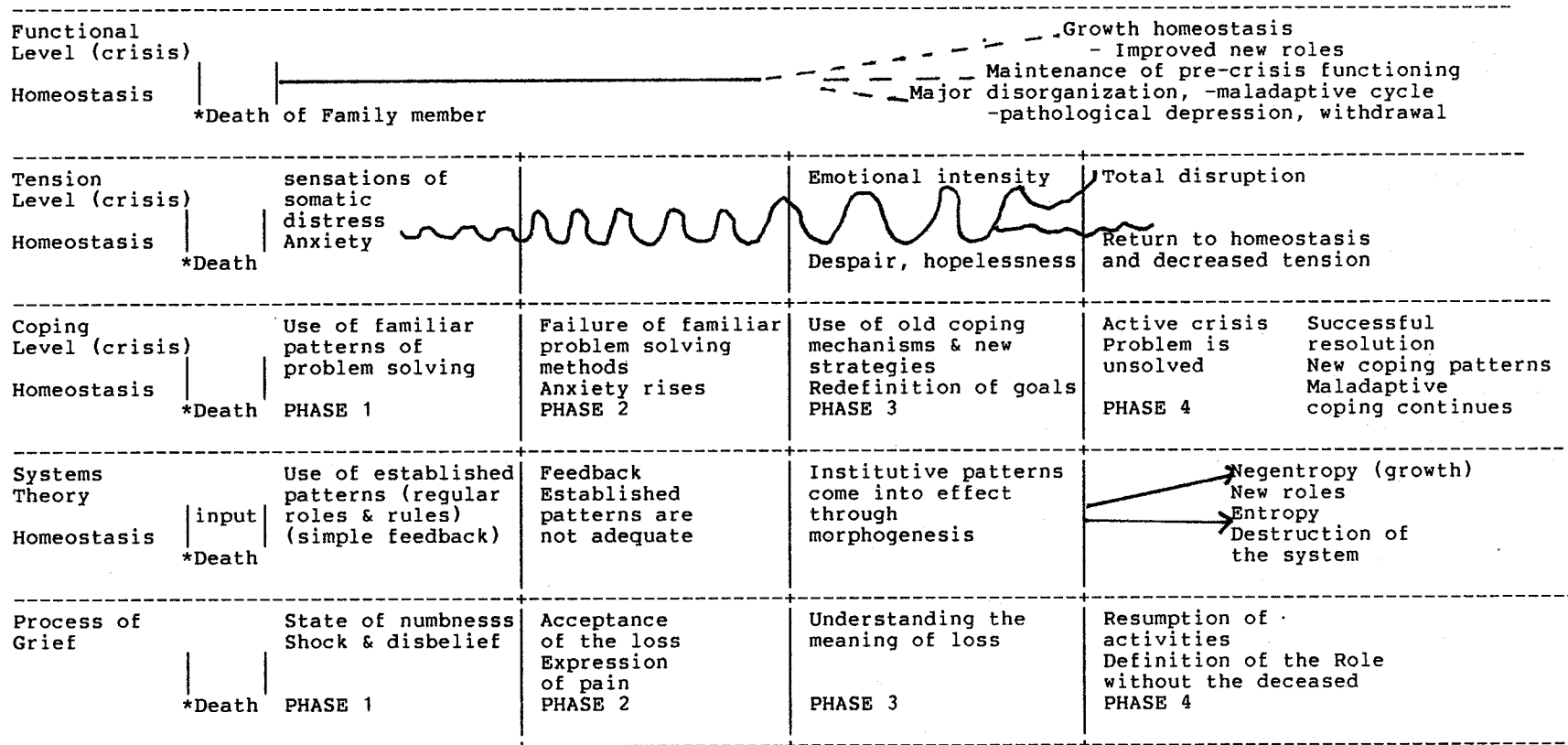
Crisis theory is based on the components of systems theory which had its origins in the biological sciences. An organism, which is the main component of life in systems theory, is viewed as being "composed of mutually dependent parts and processes standing in mutual interaction" (Von Bertalanffy, 1968, p. 33). The whole functions as a whole because of the interdependence and the whole is greater than the sum of its parts. Crisis theory uses the concept of interdependence to expand the focus of the individual who is never observed as a separate entity but rather in interaction with its internal and external environment. Since a system is interdependent there is also an implied relationship that change in one portion of the system will create change in all other portions (Braden & Herban, 1976).

A system is characterized by the preservation of a state of equilibrium or homeostasis. Equilibrium is not a static state but is rather dynamic and is maintained by the flow of energy into, through, and out of the system. Feedback mechanisms are used to monitor progress towards a goal, to correct an ambivalent response, or to change the goal (Broderick & Smith, 1979). Simple or stereotypical feedback uses old ways and patterns to cope with a situation and may be effective for handling known or minor problems. However morphogenesis or the creation of new coping mechanisms or patterns may be necessary when the system does not contain in its repertoire a mechanism with which to cope with the situation. The system has the potential to move towards growth and homeostasis (negentropy) or towards disorganization and decreased energy exchange (entropy) (Hall & Weaver, 1985).

#### 1.1.2 Development of a Crisis

Caplan (1964) described four phases in the development of a crisis (See Figure 1.2). Tension may rise steadily, it may fluctuate through various peaks or it may rise quickly and then plateau. Phase one occurs when an event causes an initial rise in anxiety. The individual usually responds by using familiar problem solving mechanisms to reduce or eliminate the stress and discomfort coming from the anxiety. In phase two, the individual's usual problem solving ability

Figure 1.2: Conceptual Framework



\* Adapted from Schwenk, T.L. & Brittle, S.P. (1979)  
cited by P. Graves in M. Stanhope & J. Lancaster, Community Health Nursing (1984)

fails and the stimulus continues. Phase three is characterized by a further rise in anxiety, where the individual uses all available resources to deal with the problem. These may be old coping mechanisms, new strategies or redefinition of the goal. In phase four the individual's problem is unsolved and the tension and anxiety rise to an unbearable degree resulting in a state of active crisis which occurs when internal strength and social support are lacking. A crisis situation has the potential to be successfully resolved or to produce further maladaptive coping mechanisms in any of these phases.

Crisis is described as being an acute condition rather than chronic, and its development follows a specific pathway. This pathway is affected to a certain degree by the social context in which it occurs as well as the particular meaning the event has for the individual (Burgess & Baldwin, 1981; France, 1980; Morrice, 1976). Many authors state that it is not the events in an individual's life that activate crisis per se, but rather how they are interpreted and the coping mechanisms and social resources available to deal with the situation which determine whether or not it results in crisis (Burr, 1973; Hill, 1949; Hoff, 1984; Umana, Steven & McConville, 1980). According to Caplan (1961), coping encompasses two components, adaptation which is the modification of environmental factors, and adjustment which is the intra-psychic manipulation. A precipitating



event which upsets the homeostasis of the individual usually causes the crisis state but stress can also be viewed as cumulative. Stress over time which is not resolved may also result in a crisis state as depletion in coping reserves occurs (Burgess & Lazare, 1976; Jacobson, 1980; Specter & Claiborn, 1973). Caplan (1964) stated that 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" (p. 39).

### 1.1.3 Crisis Theory and Bereavement

Crisis theory is an effective concept in viewing bereaved individuals. Crisis, can be defined as "a turning point" (Miller & Keane, 1978, p. 253). A crisis can be described as situational or maturational. A situational crisis as defined by Murray and Zentner (1975) is

"an external event or situation, one not necessarily a part of normal living, often sudden, unexpected, and unfortunate, which looms larger than the persons' immediate resources or ability to cope and which demands a change in behavior" (p. 209).

Maturational crisis as described by Helvie (1981) is the "stress experienced by all human systems during the transition period of moving from one stage of physical, social, psychological, and intellectual growth to another" (p. 246). With the decrease in death rates prevalent in North American society due to improvements in medical care and technology, death is often a novel experience and the

individual does not have an abundance of coping mechanisms with which to handle bereavement, thus creating a situational crisis (Uhlenberg, 1980). The individual experiences situational crisis due to the fact that bereavement taxes coping abilities and forces new behavior patterns. The crisis is also maturational in nature, as all people experience grief, it is a transitional stage in which all must participate.

An individual is maintained in homeostasis through the meeting of various needs such as security, survival, love, and self-esteem (Dixon, 1979). Therefore, when a relationship (a means of meeting the need for love) is lost, the individual's sense of homeostasis may be disrupted and a crisis may result. Depending on the relationship which is lost, adjustments may be major or minor. Major adjustments occur when roles must be redefined and when the individual has played a key role for other members in the family (Campbell, 1977; Langsley & Kaplan, 1968). Even though bereavement is a painful experience, the individual has the potential to grow from it (negentropy), by learning new ways of coping, new roles, and by defining new abilities (Caplan, 1974).

#### 1.1.4 Crisis Intervention

According to Aguilera and Messick (1982), crisis intervention is useful in breaking the crisis process. This is done by assessing and planning with the individual or family in crisis. The process of crisis intervention is consistent with the nursing process which uses the steps of assessment, planning, implementation, and evaluation. What is important for the health care worker is that they deal with the problem through a form of activity rather than through avoidance (Caplan, 1964). According to the theory, an individual in crisis has a desire for help and is in a state where learning can take place. Morley (1967) suggested that crisis intervention could be done by (a) assisting the individual to become aware of the crisis; (b) helping the individual to understand his/her feelings; (c) exploring possible coping strategies; and (d) reopening the social world. Resolution of the crisis is possible when adaptive coping mechanisms have been reinforced and tension and anxiety have been reduced.

The process of readjustment or the return to homeostasis after a bereavement has been termed grief work (Demi, 1984; Lindemann, 1944; Parkes, 1975; Johnson-Soderberg, 1981) and is seen as a necessary process for the bereaved to experience to resolve their grief. This process consists of four phases and illustrates where crisis intervention can be applied. The first stage of grief work is characterized by

numbness which may last a few hours or days. During this phase the individual is unable to face the reality of the situation. In the second phase the individual begins to accept the pain of the loss, which usually involves the open expression associated with the pain. During the third phase the individual begins to have some understanding of the meaning of the loss to them (internal adjustment--intra-psychic manipulation), and that the reactions experienced are normal. In the fourth phase, the resolution of grief becomes apparent as the individual begins to resume activities and social relationships and to redefine their role without the deceased (environmental or external adaptation). This stage corresponds to a state of "new equilibrium".

#### 1.1.5 Strengths and Limitations of Crisis Theory

A major strength of using crisis theory to explore bereavement is the fact that it does not look at the situation from an illness perspective but rather as a normal situation which results from stress where problem solving skills are appropriate. This is important as the bereaved individual needs to be reassured that what they are experiencing is normal and they will be able to get through it.

Since crisis is based on a dynamic state, the concepts of change and growth or learning can be incorporated into its

explanation. This portion of the theory illustrates that the goal of therapy with the bereaved individual is not to bring them back to their pre-bereavement functioning state but rather to stimulate growth, which will assist them in achieving a higher level of health (new homeostasis). Crisis theory can also be incorporated into the nursing process through assessment, planning, intervention and evaluation and can therefore, be easily used and communicated to nursing personnel. The theory stresses that coping and growth do not occur in a vacuum but are influenced by the interpersonal relationships which an individual has as well as the larger influence of the community. Crisis therapy can be applied at the aggregate level which is important for nursing as larger groups of people can be assisted (Lindsay, 1975). The final major strength of using crisis theory in the approach to bereavement is the fact that it incorporates an interdisciplinary perspective which is consistent with the palliative care philosophy of "team" functioning.

One of the difficulties with the crisis framework is that crisis is viewed as a self-limiting experience lasting from four to six weeks (Hoff, 1984). The crisis of bereavement is not seen to be resolved until at least one year from the time of death if it really is ever truly resolved (Parkes, 1972a). Caplan (1974b) questions whether bereavement is one crisis or a series of short crisis periods, that make up a

period of life or psychosocial transition. Parkes (1970a) views a psychosocial transition as the way in which the individual must restructure his/her view of the world. This orientation is consistent with combining the two types of crisis (situational and maturational) in the bereavement period.

Lindsay (1975) comments that another difficulty with crisis theory is that its usefulness in terms of predictability is low, that the theory is not able to predict who will label a situation a crisis and who will not. However, for certain crisis producing situations such as bereavement, determinants of outcome that will help to expand the model are becoming clearer.

#### 1.1.6 Summary

The growth of the hospice movement throughout the world brought about innovations in care for the terminally ill patient and family. An important component of palliative care is bereavement follow-up. Bereavement can place an additional stress on the individual/family which has the potential of escalating to a crisis situation. With proper intervention a crisis can be prevented and the health and social functioning of the individual enhanced.

## Chapter II

### LITERATURE REVIEW

The literature review was compiled from a variety of sources: a manual search, computer search, tracking of citations, and from personal contact with researchers in the area of loss, grief, and bereavement. Literature has been taken from the fields of nursing, medicine, thanatology, religion, psychology and sociology. The literature will be reviewed from the following perspectives; socio-cultural, historical, symptomatology, grief as a process, the morbidity and mortality of bereavement, determinants of bereavement outcome, pathological grief, family response, and bereavement interventions.

#### 2.1 SOCIO-CULTURAL PERSPECTIVE OF DEATH AND BEREAVEMENT

The manner in which an individual responds to death and bereavement is in part affected by the values held by the society in which the individual lives, but the mourner also determines to some extent how others will react to him/her (Parkes, 1985). Every society has its own mores, values, and ideas surrounding death. In North American society, the approach to death is influenced by the large variety of cultures of which it is formed and at the same time takes on a cultural perspective of its own.

Stephenson (1985) described the changing views of death in the United States prior to the nineteenth century to the present day as consisting of the Puritan conception, secular conception, and the contemporary conception. The Puritan view of death (prior to the 19th century) saw death as sacred. Death was a time when the individual would meet God, the creator, and confront ultimate judgement. Death was seen as the result of original sin, and therefore the Puritan spent his time on earth in servitude to God, trying to live according to His precepts. Death was viewed as having a special purpose because it was "the will of God" which also implied individuals had little control over the laws of nature. Prior to the nineteenth century death was very visible as infant mortality was high and life expectancy was low and therefore, people came to accept death as a fact of life (Kastenbaum & Aisenberg, 1972; Rando, 1984). Most members of the immediate community participated in death rituals since interdependence was a way of life and death was hidden from no one. Little emphasis was placed on assisting the bereaved to cope because most concerns were focused on the next world.

According to Stephenson (1985), the secular view of death became prominent in the nineteenth century when there was a movement toward having greater contact with the dead. Spiritualism and mysticism were important in maintaining contact with lost persons and the bridge between the dead



and the living decreased. Science was also coming of age in the nineteenth century and when Darwin published the "Origin of the Species" in 1859, God as creator of the universe was challenged. Death was no longer seen as a sacred event between God and the individual but rather as a natural event where the fittest survive (Fulton & Geis, 1965). Death was viewed as being caused by disease, and since disease was subject to the laws of nature, man could intervene to change the course of events. As a result of this process, man began to rely on himself rather than God as death became a matter of organization and rationality as opposed to spirituality. Financial security became the way of supporting the family rather than relying on the extended community or religious interventions. Extensive mourning and expensive rituals surrounding death were a means of displaying wealth and social standing.

Contemporary views of death are an extension of what occurred in the secular era. North American society is characterized as "death-denying" in which death is a forbidden or taboo topic. Due to improvements in medical care and technology death has been removed from the larger society and placed in institutions where others are insulated from its effects. Terminology such as "passing away" or "laid to rest" are used to keep death hidden. Death has been removed from the home where the individual may be surrounded by familiar members and objects and placed

in the hands of "specialists" such as funeral directors, physicians, nurses, and clergy. In a society where progress, action, materialism, and health are highly valued, death represents failure.

Since the late sixties and early seventies the "death awareness" movement has begun to reverse the denial prevalent in society. Writings such as Kubler-Ross's (1969) On Death and Dying and Kavanaugh's (1972) Facing Death have done a great deal to make others aware of societal attitudes to the dying and bereaved. Kastenbaum and Aisenberg (1972) suggested that a return to the awareness of dying is related to facts such as fear of annihilation through a nuclear holocaust, the presence of violent deaths, less faith in material progress, and a heightened awareness that a rapid technological way of life has lethal components of its own such as pollution and stress.

Just as the perception of death is affected by the culture in which the individual lives, so is bereavement affected by the cultural mores and values. The emotions of bereavement can be displayed in many ways but are usually a manifestation of cultural expectations. In a society which is death-denying, little emotional expression would be best accepted as it allows other members to hide the fact that death has occurred. The period of bereavement is dispensed with as quickly as possible, so living and denial can again proceed. In some cultures the bereaved have specific

periods where they are permitted to mourn or certain behaviors they can enact, such as wearing mourning apparel which assists them in their expression of grief. In North America, the prescription most commonly followed is "get it over as quickly as possible". This quick doing away with death often has negative consequences.

## 2.2 THEORETICAL CONCEPTS OF GRIEF AND BEREAVEMENT

The experience of grief and bereavement is one which most people cannot avoid. Despite the universality of grief it is expressed as a unique experience for each individual. Grief is unique in the sense that each person has a history of contact with loss and develops a set of beliefs and behaviors in relation to past life experience (Benoliel, 1985). Grieving does not take place at a particular point in time but is rather a process that may continue (Bowlby, 1961; Parkes, 1972a; Weisman, 1979). Initially it was assumed that grief had a specific starting and ending point, that it was resolved as time passed (Lindemann, 1944; Parkes, 1970b) but now it is speculated that grief never really is totally resolved but rather the individual learns to live with it and adjust to it (Flemming, 1986--personal communication; Lattanzi, 1986--personal communication; Rubin, 1984; Silverman, 1986--personal communication; Weisman, 1986-- personal communication).

Engel (1961) posed the question, "Is grief a disease?" Grief is a painful condition characterized by the disruption of normal functioning; anorexia, sleep disturbances, somatic complaints of pain, loss of interest in usual activities and psychological manifestations such as crying and yearning. These characteristics resemble a disease process. Added to these manifestations is the notion that the symptoms of grief run their course and then the person is said to "recover", much in the same way they would from an illness. From a social perspective, grief is a time where close friends and relatives can gather around the bereaved individual to provide consolation, much in the same way that relatives gather to care for a sick person (Parkes & Weiss, 1983).

Grief can also be seen as the normal experience when loss has been encountered. In fact it is regarded as "abnormal" when the expression of grief does not accompany a major loss (Deutch, 1937). Parkes and Weiss (1983) draw an analogy between grief and physical trauma. For example, the nausea and vomiting which occurs when a poison has been ingested may be seen as a sickness but can also be seen as a normal reaction to protect the body from further harm. Inflammation surrounding a wound is a signal that infection is present but it is also a sign that the body's defense mechanisms are being activated so healing can occur. In the same way the reactions to bereavement can be seen as the body's way of correcting a disrupted psychological system.

Freud (1917) in his classic paper identified the similarities between mourning and melancholia (depressive disorders). Freud's interest in mourning stemmed from trying to identify why melancholic patients directed reproaches originally aimed at the lost object at themselves. The features of melancholia were identified as "profoundly painful dejection, cessation of interest in the outside world, loss of the capacity to love, inhibition of all activity, and a lowering of the self-regarding feelings to a degree that finds utterance in self-reproaches and self-revilings, and culminates in a delusional expectation of punishment" (Freud, 1917, p. 244). Mourning was identified as having the same characteristics as melancholia except the disturbance in self-regard was not apparent. Freud stated that depressed people feel an emptiness within them whereas bereaved individuals feel an emptiness around them.

Freud (1917) viewed mourning as a normal experience and grief work as a means of healing the psychological system. According to Freud (1917) mourning consists of "reality testing" which identifies that the loved object no longer exists and requires libidinal energy to be withdrawn. No one relinquishes a "libidinal position" easily and therefore opposition is created which may result in a turning away from reality and clinging to the object through "hallucinatory wishful psychosis". Reality will generally

prevail; however, it is a slow process in which libido is bound to the object through memories and each of the memories must be "hypercathected" so detachment can occur. When the work of mourning is complete the ego becomes "free and uninhibited again" (Freud, 1917, 244-245).

Klein (1940) was influenced by the work of Freud in developing her own theory related to mourning. Like Freud she also studied individuals from the perspective of depressive illness. Klein (1940) saw mourning as a phase of disorganization which progressed to a state of reorganization and was accompanied by a great deal of pain. The grief work was a means of testing reality whereby the individual was able to renew the links with the external world and to rebuild the inner world which was in a state of collapse. Klein (1940) believed the manner in which an adult responded to loss was patterned after how the individual had responded to loss as an infant or young child. Much of Klein's work was also based on the work of Abraham (1911). Abraham (1911) believed paranoid anxieties preceded depressive anxieties in the development of the infant, which led Klein (1940) to conclude that the pain of grief is mixed with persecutory anxiety and guilt.

Many other researchers have continued to explore the concepts of bereavement from the time of Freud. Those who adhere to psychoanalytic theory emphasize reactions to loss as a result of psychic conflict in early years and are

usually prone to view grieving as an illness (Peretz, 1970). Up until this time most of the research was based on anecdotal notes rather than scientific findings.

### 2.3 THE SYMPTOMATOLOGY OF GRIEF

Lindemann (1944) identified grief as a crisis situation and delineated the symptomatology of grief. He studied one hundred and one survivors of the Coconut Grove Nightclub fire in California. Through interviews he found that grief was associated with a syndrome consisting of the following common characteristics: (a) somatic distress; (b) preoccupation with the image of the deceased; (c) guilt; (d) hostile reactions; (e) loss of patterns of conduct; and (f) appearance of traits of the deceased (Lindemann, 1944, p. 142). He also concluded that grief would progress normally if grief work was successful. Grief work consists of (a) emancipation from bondage to the deceased; (b) readjustment to the environment in which the deceased is missing; and (c) the formation of new relationships (Lindemann, 1944, p. 143). Lindemann (1944) also identified morbid grief reactions which were distortions of the normal grieving response and were related to shifts in the timing of the syndrome or in the intensity of particular parts. Morbid grief reactions were characterized by items such as delayed, distorted and absent grief reactions.

Lindemann's work was the first semi-structured research design. Subsequent research builds on Lindemann's findings and opposition to the psychoanalytic approach begins.

#### 2.4 THE PROCESS OF GRIEF

Attachment theory as proposed by Bowlby (1961) presents an alternative to psychoanalytic theory. Bowlby's research was done primarily by examining the reactions of children who were cared for in hospitals by unfamiliar individuals when separated from their parents. Mourning as a process is viewed as adaptation to a loss. Bowlby (1961) equates the separation of an infant from its parents to loss.

Attachment theory initially conceived of mourning as three major phases and viewed the individual's attachment to the loved object as mediated by a number of instinctual response systems (Bowlby, 1980). In the first phase the system is focused on the original object. Because the object is absent, whenever the system is activated the stimulus cannot be stopped creating disappointment and separation anxiety in the individual experiencing it. As long as the system is focused on the original object the person will make an effort to recover it which requires energy. The first phase is characterized by yearning and searching behavior and may last for months and often years (Bowlby & Parkes, 1979). The same type of searching behavior was observed in animals when separated from their



young, mate, or members of the same species to try to bring about reunion with the lost object (Darwin, 1872).

In the second phase the system's focus on the lost object diminishes and efforts to recover the object subside. The second phase is characterized by disorganization and despair as invested energy has been removed from the lost object but has not yet been reinvested in another relationship. In the second phase of Bowlby's framework, disorganization and despair are characterized by withdrawal from activities which are familiar to the individual. In a child separated from its mother, Bowlby (1961, 1969a) reported the child relinquishes searching behavior and becomes despondent. Parkes (1972a) characterizes this phase as a stage of depression.

In the third phase the work of mourning becomes complete and a different state is present in which some energy remains invested with the image of the lost object and other energy is reinvested with new objects. Parkes (1972a) labels this phase as "recovery".

In 1970, Bowlby and Parkes expanded on the three phases to add an initial phase which was characterized by a sense of numbness. The numbness was usually short-lived, lasting from a few hours to a week and often alternated with periods of intense distress or anger (Bowlby & Parkes, 1979). Bowlby (1969b) proposed that certain behaviors seen in the

bereaved individual such as crying could be equated with behaviors seen in a child who is experiencing separation anxiety. Crying is an adaptive behavior to the individual as the lost object (person) may be brought back. Anger may also be present during this initial phase in bereavement and also served an adaptive role in childhood as anger directed at the lost object (mother) often insured the behavior would not be repeated. Anger, in the bereaved, may be directed at those who are seen as being responsible for the loss or those who are hampering the reunion. Both anger and crying ensure the survival of the child.

Parkes (1972a) describes grief as a process of realization in which the bereaved individual moves from a state of avoidance of the reality of the loss to acceptance of the loss. The process as described by Parkes is painful as the bereaved respond with feelings of internal mutilation and alarm reactions. As the bereaved begin to loosen the ties with the deceased (emancipation) and undergo a period of identity reconstruction the pain of the loss dissipates. Parkes (1972a) stated that the phases which are evident in the process of grief are not clearly distinguishable, they fade into each other with symptoms overlapping. Parkes' work has been criticized due to the variability in the phases and lack of definitive statements as to which category each of the symptoms fits into (Solomon, 1977).

## 2.5 THE EFFECT OF BEREAVEMENT ON HEALTH

Bereavement has been hypothesized to predispose individuals to illness or death, to lead to the exacerbation of health-threatening behaviors and to stimulate increased use of health care services. Research into the effects of bereavement on the above conditions presents conflicting evidence. This section will be discussed from the perspectives of mortality, suicide, physical health, mental health, and life-threatening behaviors. For a summary of the results see Table 2.1.

### 2.5.1 Mortality

It has been postulated that bereaved individuals are at greater risk of dying than the non-bereaved population. Kraus and Lilienfeld (1959) conducted one of the earliest studies identifying mortality in the bereaved population. They examined vital statistics based on a national report and found that married people experienced a lower mortality than did single persons (widowed, divorced) from all causes and at all ages. The greatest excess in mortality was in the younger age groups (twenty to thirty-four) and was consistently greater in males than females. The primary causes of death in the young age groups were vascular lesions of the central nervous system, arteriosclerotic heart disease, non-rheumatic chronic endocarditis, hypertension with heart disease, general arteriosclerosis,

tuberculosis, influenza and pneumonia. However, it was not reported how long these individuals had been bereaved before death occurred.

In an attempt to determine the "duration effect" of bereavement, Young et al. (1963) identified four thousand, four hundred and eighty-six widowers, fifty-five years and older, whose wives had died in 1957. They followed the widowers over a period of five years and found an increased mortality rate in the first six months of bereavement with no differences being evident after that time. Cox and Ford (1964) were looking for the same type of effect as Young et al. (1963). They re-analyzed data from vital statistics of 60,000 widows who had applied for pension in 1927 and identified those who died in the next five years. They compared actual to expected death rates and found an increase in mortality only in the second year of bereavement. This difference was greatest in the sixty to sixty-eight age group.

Rees and Lutkin (1967) used a prospective design to follow nine hundred and three relatives of deceased individuals in villages of Wales for six years. The bereaved group was compared with a matched control group and the researchers found a general increase in mortality for the widowed group as compared to the control group. The mortality rate was greatest for widowers in the first six months of bereavement, supporting the findings of Young et al. (1963).

Other researchers have found no increase in mortality in the period of bereavement. Clayton (1974) followed one hundred and nine widowed persons for four years and did see a slight increase in mortality in the bereaved as compared to the control group; however, these results were not statistically significant. Gerber et al. (1975b) followed one hundred and sixty-nine bereaved persons and found no increase in mortality in the first year of bereavement as compared to controls, but did find a slight increase in mortality in the second and third years amongst the bereaved, although these results were not statistically significant. Ward (1976) found similar results with an increase in mortality for widowers in the first six months; however the results were again not statistically significant.

Helsing and Szklo (1981) and Helsing, Comstock and Szklo (1981, 1982) conducted a twelve year prospective study of 92,000 people using a matched pairing technique of bereaved with nonbereaved individuals. They found no increase in mortality in the first six months of bereavement but did find a significant difference in widowers after that time. Widowers were more at risk if they did not remarry. There was no difference in mortality rates for widows.

It can be concluded that the results of the studies do not demonstrate an increased risk of mortality for the widow

at any time. For the widowers there does appear to be increased risk of death in the first year of bereavement.

### 2.5.2 Suicide

Shephard and Barraclough (1974) published the only study to comment on the mortality of the bereaved following a death by suicide. They reported data on seventeen widowers and twenty-seven widows followed for fifty-eight months. In the first year of bereavement there was no increase in mortality in the bereaved group, but by fifty-eight months post suicide there was a trend indicating that as a group, the bereaved due to suicide are more at risk for death than widows due to other causes or than their matched married controls. It must also be noted that half of the bereaved individuals who died had been "mortally ill" before the suicide and the effects of their illness may have predisposed them to death.

Vital statistics from the United States indicate that the suicide rate for the bereaved is greater than for the general population (Bock & Webber, 1972; Gergen & Gergen, 1981-82; Helsing et al., 1981; Kraus & Lilienfeld, 1959; Stroebe & Stroebe, 1983). The increase in suicide is particularly evident in elderly widowers. The suicide rate for widows is not as high as for the divorced or separated.

MacMahon and Pugh (1965) based their study on the fact that the widowed have a higher incidence of suicide than the general population and tried to determine if suicide occurred at any particular point after bereavement. They studied three-hundred and twenty widows and widowers who had committed suicide in Massachusetts between 1948 and 1952. A control group of widowed persons who had died of other causes was used. They concluded that deaths from suicide clustered in the first four years after bereavement, with the greatest difference being apparent in the first year. Men sixty years and older accounted for most of the difference in the first year.

### 2.5.3 Mental Health

Bereavement has been linked with depressive symptomatology since Freud began his study in 1917. However, it is difficult to recognize when bereavement moves from affecting the mood state of the individual into what might be termed a mental illness.

Parkes and Brown (1972) in the "Harvard Study" followed forty-nine widows and nineteen widowers under the age of forty-five. They found higher rates of depressive symptoms in the widowed than the controls with more counselling being used by young widows. Reports of depressive symptoms in the bereaved were also found in other investigations (Blanchard, Blanchard & Becker, 1976; Bornstein, Clayton, Halikas,

Maurice & Robbins, 1973; Clayton, 1979; Clayton, Halikas & Maurice, 1972; Gallagher, Breckenridge, Thompson & Peterson, 1983).

Bereavement has also been considered a cause of psychiatric hospitalization. Frost and Clayton (1977) studied three-hundred and forty-four psychiatric inpatients who were matched with non-psychiatric inpatients and found only three of the psychiatric patients and none of the controls had experienced a death six months prior to admission. Paykel et al. (1969) did find an increased risk of depression following bereavement. The researchers studied one-hundred and eighty-five depressed outpatients and inpatients and a matched control group from the community. They found that sixteen of the depressed patients and four of the controls had experienced the death of an immediate family member in the six months prior to the onset of illness. Five patients had experienced the death of a child, indicating the traumatic nature of this type of death. Stein and Susser (1969) found that widows are likely to enter psychiatric care in the first year of widowhood rather than later.

In summary, depressive symptomatology accompanies the period of bereavement and in many cases is severe enough to warrant admission to a psychiatric facility. Further investigation into the nature of the depression which results and the extent of the consequences is required.



#### 2.5.4 Health-threatening Behaviors

The increase in health-threatening behaviors in the bereaved population has been adequately documented. Parkes (1964) found that sedative drugs were prescribed seven times more frequently for widows under sixty-five than they were before the death. Parkes and Brown (1972) found that 25% of sixty-eight widows reported an increase in consumption of tranquilizers, alcohol and tobacco. Maddison and Viola (1968) in a sample of three-hundred and seventy-four widows between the ages of forty-five and sixty found an increased consumption of sedatives, hypnotics, alcohol and tobacco during the thirteen months after bereavement. Clayton (1974) in her study found an increase in sleeping pills but no difference in tranquilizer use between the bereaved and the controls.

Thompson, Breckenridge, Gallagher, and Peterson (1984) studied an elderly population (two hundred and twelve widows and widowers) over fifty-five and a matched control group of one-hundred and sixty-two participants. They reported an increase in medication use, not only for previously used medication but also for new medications. Fifty-four percent of the medications consisted of analgesics, sedatives, sleeping pills, or antidepressants.

### 2.5.5 Physical Health

The effect of bereavement on physical health has generally been studied by self-reporting techniques which may not always provide a true picture of the respondent's health. The effect of bereavement on health has been explored through the examination of various types of behaviors such as crying, changes in sleep or appetite patterns, the occurrence of medical conditions or exacerbation of previous conditions, and measures of anxiety.

Crisp and Priest (1972, 1973) administered a self-rating inventory of neurotic illness to bereaved spouses, ages forty to sixty-five years who had been contacted through a private practice. They found little difference between the bereaved and the controls and commented that the bereaved withstood stress in a "robust way".

As part of a study for the Duke University Center for Aging, Heyman and Gianturco (1973) examined a population before they were widowed and after the death of a spouse. They found only time-related (due to aging) health deterioration. There were no differences on scores of health, leisure activities, anxiety or hypochondrias before or after the death of a spouse.

An interesting study conducted by Valanis and Yeaworth (1982) on sixty elderly widows found that the subjective

ratings of physical health were generally positive and were better than the objective ratings of the investigator, especially where elderly women were concerned. The author concludes that there may be a cultural bias operating in regard to the aging process. The interviewer may have worked primarily with ill elderly and therefore expects most elderly individuals to be ill, or the interviewer may be influenced by cultural expectations of the elderly population.

In Parkes' (1970a) study using a longitudinal design over a thirteen month period, he found that six of twenty-two widows reported their health as worse. In a later study in Boston, Parkes and Brown (1972) found no difference in the self-reports of health between widows and controls. They also found that widowers reported more severe symptoms and anxiety than the controls; however, there were no differences in general health noted.

Other authors have found significantly different results in terms of the health of bereaved as compared to the non-bereaved population. Maddison and Viola (1968) compared two samples of widows, one in Boston (one-hundred and thirty-two) and one in Sydney, Australia (two-hundred and forty-three) and found the widows to complain of more physical conditions than did the control group. Differences were found between the two groups of widows but generally complaints of psychological symptoms were prevalent.

Reports of physical symptoms such as gastrointestinal upset or increases in health-threatening behaviors were dependent on the particular area or culture.

Parkes and Weiss (1983) found an increase in symptoms reflecting somatic anxiety in the bereaved, but found no difference in the reporting of chronic symptoms or perceived general health. However, Thompson et al. (1984) in a study of the elderly widowed found an increase in existing conditions and a higher reporting of new illness than in the controls. The bereaved were also more likely to report having poorer general health than were the controls.

It appears from the above literature, that self-reports of deterioration in health status are evident in the bereaved population although not to the same extent as might have initially been expected. Reports of symptoms related to anxiety are most prevalent.

Bereavement has also been linked to many types of illness or disease. In a review of the literature Klerman and Izen (1977) reported bereavement or loss as a predisposing factor to illnesses such as cancer, cardiovascular disease, lupus erythematosus, pneumonia, rheumatoid arthritis, and ulcerative colitis. The evidence to support a link between bereavement and a particular disease entity is limited. It

is hypothesized that if an individual has a predisposition to a particular disease, bereavement may act as a stressor to activate the illness.

Bereavement has been thought to cause many types of cancer. Schmale and Iker (1965) reported a connection between loss and cervical cancer, while Greene (1954) linked loss to lymphomas and leukemia and Cooper (1984) linked loss to breast cancer. A British study conducted by Jones, Goldblatt and Leon (1985) examined longitudinal data from the Office of Population Censuses and Surveys and found only "slight" evidence to suggest a greater than expected incidence of cancer after the death of a spouse and only a weak indication of increased mortality due to cancer.

Bereavement has also been suggested to affect the cardiovascular system with conditions such as arrhythmias, infarcts, or congestive heart failure. Chambers and Reiser (1953) found that emotional stress was a factor in the precipitation of congestive heart failure. Engel (1971) studied one-hundred and seventy sudden deaths which occurred during periods of psychological stress and found 39% of the women and 11% of the men died immediately following the death of someone close and another 23% of the women and 20% of the men died within sixteen days of someone close. Engel (1971) suggests that many of these deaths were due to cardiac arrest in individuals with existing cardiac disease.

The above conditions may also be exacerbated by the increase in health-threatening behaviors associated with bereavement such as increases in alcohol consumption and smoking. Individuals who exhibit these behaviors or have pre-existing medical conditions may be particularly at risk in the period of bereavement.

The use of health care services by the individual has also been suggested to increase in bereavement. The use of services may indicate a greater increase in morbidity but it may also illustrate the need for a support system. It is possible that in North American culture it is more acceptable for an individual to seek help for a medical condition as opposed to emotional support. However, studies examining the use of health care services amongst the bereaved do not show a dramatic increase in utilization. Most studies report no increase in physician visits amongst the bereaved population (Clayton et al., 1974; Parkes & Brown, 1972; Thompson et al., 1984) while in England and one study in the United States in which there were prepaid health plans, there was an increase in physician visits (Parkes, 1964a, 1970a; Wiener et al., 1975). There is a suggestion that economic factors play a role in seeking out health services (Osterweiss et al., 1984). In a recent study Mor et al. (1986) reported an increase in physician visits by the bereaved population but no increase of

hospitalization, suggesting the physician was used as a means of emotional support or for the presence of a minor illness.

#### 2.5.6 Summary of the Effect of Bereavement on Health

Even though the evidence in regard to the effects of bereavement on the health status of the individual is conflicting, it can be concluded that the period of bereavement puts a strain on the health of the bereaved individual, especially the individual experiencing conjugal bereavement (Windholz, Marmar, & Horowitz, 1985). The increased risk of mortality from suicide or illness in the widower within the first year of bereavement would suggest that intervention should be directed toward this group of individuals during the first year of bereavement. The general occurrence of depressive symptomatology and increases in health-threatening behavior suggest that research into prevention of this disruption is appropriate. Research might also be directed at what aspects of bereavement contribute to the decrease in health status of the bereaved. For example, is it the loneliness or social isolation of the bereaved which contributes to the increase in morbidity and mortality, or is it poor nutrition as a result of eating alone? What other factors in the bereavement experience might be contributing? It is necessary to identify the aspects of the grieving experience

that are most stressful so that the most effective interventions can be designed.



Table 2.1: The Effect of Bereavement on Health Mortality and Bereavement

STUDY	DESCRIPTION	OUTCOME
Kraus & Lilienfeld (1959) - retrospective study from vital statistics	- bereaved spouses from deaths in the U.S (1949-51) - matched married controls	- increased mortality in all age groups with the greatest increase in the young bereaved (20-34) - most apparent in men
Young et. al. (1962) - cohort of widowers	- 4,486 recent widowers over age 55 were compared with death rates for married men of the same age - followed for 5 years	- significantly higher death rate for widowers in the first 6 months than for married controls
Cox & Ford (1964) - retrospective study from vital statistics	- 60,000 widows under the age of 70 who applied for widow's pension in 1927 - followed for 5 years	- increased mortality for widows in the second year of bereavement - greatest increase apparent in the 60-65 age group
Rees & Lutkin (1967) -cohort of bereaved relatives	-903 bereaved relatives - 878 non-bereaved matched controls - followed for 6 years	- increase in mortality for the widowed - greatest increase for widowers in the first 6 months
Clayton (1974) - cohort of bereaved spouses	- 169 bereaved spouses - matched married controls - followed for 4 years	- no increase in mortality in the first year - slight increase in mortality in 2nd and 3rd years, but not statistically significant
Ward (1976) - cohort of bereaved spouses	- 87 widowers - 279 widows - compared with age and sex rate statistics	- slight increase in mortality in first 6 months, but not statistically significant
Helsing & Szklo (1981) - prospective study	- 92,000 people - followed for 12 years - matched married controls	- no increase in mortality in first 6 months - significant increase in mortality in widowers after 6 months

Table 2.1 (continued): Suicide & Bereavement

STUDY	DESCRIPTION	OUTCOME
<p>Shepherd &amp; Barraclough</p> <p>- cohort of bereaved spouses</p>	<p>- mortality after suicide death - 44 spouses of suicides, - 17 widows, - 27 widows - non-suicide widow group - follow-up 5 years post-bereavement</p>	<p>- no increase in mortality in first year - after 58 months a trend was begun which would indicate that widows of suicide are more at risk</p>
<p>MacMahon &amp; Pugh (1965)</p> <p>- review of death certificates</p>	<p>- 320 Widows and widowers who committed suicide in Massachusetts (1948-52) - matched control group of widows and widowers for death other than suicide</p>	<p>- clustering of suicide deaths in the first 4 years - greatest increase apparent in first year in men over 60</p>

Table 2.1 (continued): Mental Health & Bereavement

STUDY	DESCRIPTION	OUTCOME
Stein & Susser (1969) - longitudinal study	- outpatient widows in England - control group was not matched for age	- more widows enter psychiatric care earlier than latter
Parkes & Brown (1972)	- 49 widows, 19 widowers under the age of 45 - matched married controls - followed for 4 years	- higher rates of depressive symptoms in the widowed than controls - more use of counselling by young widows
Clayton (1974) - cohort of widows and widowers	- 109 widows and widowers - matched controls - followed for 4 years  - 140 female and 45 male depressed	- more depressive illness in the bereaved than in the controls  - increased risk of clinical
Paykel et al. (1969) - cohort of depressed outpatients	patients - matched controls from an epidemiological community survey	depression in individuals experiencing life stress
Frost & Clayton (1977) - cohort of psychiatric inpatients	- identification of incidence of recent bereavement - 249 psychiatric inpatients - matched controls, non-psychiatric hospitalized patients	- no evidence of recent bereavement in psychiatric inpatients

Table 2.1 (continued): HEALTH-THREATENING BEHAVIOURS & BEREAVEMENT

STUDY	DESCRIPTION	OUTCOME
Parkes (1964 b) - case study approach	- 94 bereaved patients admitted to the Bethlem Royal and Maudsley Hospitals (1949-51)	- sedative drugs were prescribed seven times more frequently for widows under 65 than in the period before bereavement
Parkes & Brown (1972) - cohort of bereaved widows and widowers Maddison & Viola (1968) - retrospective study	- 49 widows, 19 widowers under the age of 45 - matched married controls - followed for 5 years  - 132 Boston widows - 98 Boston matched controls - 243 Australian widows - 101 Australian controls matched only for age	25% of the widowed reported increased consumption of tranquilizers, alcohol and tobacco  - increased use of sedatives and hypnotic drugs, alcohol and tobacco during the 13 months post-bereavement
Clayton (1974) - cohort of widows and widowers	- 109 widows and widowers - matched controls - followed for 4 years	- increased use of sleeping pills in the bereaved - no difference in use of tranquilizers between bereaved and controls
Thompson et al. (1984) - cohort of widows and widowers	- 212 older widows and widowers interviewed at 2 months after the death of their spouse - 162 comparison controls	- increased use of previous and new medication were reported by the bereaved - 54% of the medications were analgesics, sedatives, sleeping pills or anti-depressants

Table 2.1 (continued): PHYSICAL HEALTH (SELF-REPORTS) & BEREAVEMENT

STUDY	DESCRIPTION	OUTCOME
Crisp and Priest (1972, 1973) - retrospective study	- 777 people between the ages of 40-65 years - 129 bereaved individuals - 648 controls	- no difference between the bereaved and the controls in reports of physical health - the bereaved withstood stress in a "robust way"
Heyman & Gianturco (1973) - prospective study	- 256 volunteers over the age of 60 participating in a longitudinal study - 27 females - 14 males	- no difference in before death and after death scores on health, leisure activity, anxiety and hypochondrias
Parkes (1970) - cohort of widows	- 22 London widows under the age of 65 were followed for 13 months - no control group	- at 13 months, 6 of the 22 widows reported their health as worse
Parkes & Brown (1972) - cohort of widows and widowers	- 49 widows, 19 widowers under the age of 45 - matched married controls - followed for 5 years	- no difference in the self-reports of health in the widows and controls - widowers reported more severe symptoms and anxiety than the controls - no difference reported in general health
Maddison & Viola (1968) - retrospective study	- 132 Boston widows - 98 Boston matched controls - 243 Australian widows - 101 Australian controls matched only for age	- an increased number of complaints and symptoms in the widowed population
Parkes & Weiss (1983) - prospective study	- matched married controls - followed for 5 years	- increase in symptoms reflecting the somatic effects of anxiety in the bereaved - no difference in worsening of chronic symptoms or perceived general health
Thompson et al. (1984) - cohort of widows and widowers	- 212 older widows and widowers interviewed at 2 months after the death of their spouse - 162 comparison controls	- the widows had an increase in existing conditions and more new illnesses than the controls, also reported poorer general health

## 2.6 DETERMINANTS OF BEREAVEMENT OUTCOME

Although most people survive the death of a close family member or significant other with few deleterious effects, there are some individuals who become ill during the period of bereavement. Research in the area of bereavement outcomes is particularly difficult as there is little agreement on what constitutes a good or bad bereavement outcome. Negative effects to physical or mental health and social functioning are usually used as indicators of outcome. Identification of individuals at risk is important not only in the prevention of deleterious effects of bereavement but also in the wise allocation of health care resources. In conducting research in the area of bereavement, it is often difficult to obtain a representative sample due to the ethics involved in studying the newly bereaved. Therefore much of the research identifying bereavement outcomes has been done on a particular population, making generalization to other populations difficult. Comparison of the studies is also difficult as measurements are not made at the same time and there is no consistency in what the researchers are measuring.

The effects of several variables on bereavement outcome will be divided into sections consisting of immediate reaction, age, sex, advance warning of the death, relationship to the deceased, concurrent life crises,

personality and coping capacity, social network, socio-economic status, religion, and observation of mourning customs. As the results of the studies are somewhat conflicting a table has been compiled to summarize them (See Table 2.2).

#### 2.6.1 Immediate Reaction to Bereavement

The "Harvard Project" (Parkes & Brown, 1972) was one of the first studies to isolate factors which would predict bereavement outcome. Sixty-eight American widows and widowers under the age of forty-five were interviewed as Parkes (1964a) had found this group to be at risk for a poor bereavement outcome. Interviews were done at three, six and thirteen months. Parkes (1972b) suggests that immediate reactions to bereavement may indicate outcome. Individuals who experience severe distress, yearning, anger, or self-reproach which does not subside by six weeks are thought to be at greater risk in bereavement. Lindemann (1944) documented that the development of traits of the deceased by the bereaved in the early phases of bereavement was indicative of poor adjustment later.

Clayton et al. (1972) and Bornstein et al. (1973) conducted a prospective study using structured interviews on a sample of ninety-two randomly selected males and females after the death of a spouse. The average age for participants in this study was sixty-one, which is older

than the participants in the study conducted by Parkes and Brown (1972). They interviewed respondents at one month post-bereavement and again at twelve to twenty months and found that the presence of clinical depression at one month was a good predictor of depression at one year. Their study also indicated depressed individuals were more likely to perceive themselves as being in poor physical health and of having less environmental support. An interesting finding in this study was that individuals who had experienced a previous major loss were less likely to become depressed.

A study by Heyman and Gianturco (1973) did not confirm the above findings. They interviewed forty-one elderly widowed individuals soon after bereavement and found no differences in bereavement outcome related to reports of depression. They concluded that this effect may be related to the fact that these bereaved individuals had lived in the same community for many years and had strong social networks for support.

#### 2.6.2 Age

Young age has generally been found to be a factor hampering adjustment to widow status. This may be related to reduced limitations in financial status for the young widow and the added strain of caring for dependent children. Older widows are more likely to be financially secure, have independent children and have had some opportunity to



practice the new social role of being widowed through previous short-term separations. They are also more likely to consider what it will be like to be a widow as they have friends who are going through the same experience.

Parkes (1964a) found an increase in consultations to the physician among young as opposed to older widows in London. Maddison and Walker's (1967) study of one hundred and thirty-two American widows over the age of forty-five revealed age as a primary determinant of health in bereavement; the younger the widow, the higher the illness score. The same study on two hundred and twenty-one Australian widows did not replicate the American findings, suggesting that cultural variables may be important in modifying outcome (Maddison & Walker, 1968). Ball (1977) used a cross-sectional design to study eighty widows who had been bereaved for six to nine months and concluded the younger the widow the more intense the grief reaction.

Stern, Williams and Prados (1951) and Confrey and Goldstein (1959) found that illness in later life was correlated with marital status. Single persons, those widowed or divorced, had more physical illnesses than married individuals of the same age.

Sanders (1980-81) interviewed forty-five bereaved spouses shortly after the death and eighteen months later. The spouses were divided into two groups on the basis of age;

sixty-five years and older and sixty-three years and younger. She found that initially the younger spouses exhibited greater intensity of grief symptoms than did the older group of spouses, however, at follow-up the trend had been reversed and the older spouses showed exacerbation in grief symptoms. Grief in the younger spouses was identified as initially producing shock, confusion, personal death anxiety and guilt. In the older spouses, Sanders (1980-1981) concluded that denial was operating in the initial assessment and at follow-up the exaggerated grief reaction which was present was related to the loneliness and isolation, often associated with being a widow. This is an important finding as it suggests follow-up may need to be extended to gain a full understanding of the process of grief.

In their study of one-hundred and sixty-one widows Vachon and her colleagues found young age was correlated with a pattern of high distress at one month (Vachon, Rogers, Lyall, Lancee, Sheldon, & Freeman, 1982). At twenty-four months follow-up young age was no longer correlated with high distress. This is consistent with the findings of Sanders (1980-81).

### 2.6.3 Sex

It has been postulated by many authors (Carey, 1979; Carter & Glick, 1976; Greenblatt, 1978; Kraus & Lilienfeld, 1959; Helsing & Szklo, 1981) that there are sex differences in the health risks of the widowed. On the other hand, Bornstein, et al. (1973), Clayton (1974, 1979) and Clayton et al. (1972) concluded there are no sex differences in the health risks of widowed individuals. After completing an extensive review of the literature, Stroebe and Stroebe (1983) concluded that men suffer more in the period of bereavement. They hesitated in coming to this conclusion, as they point out; almost all of the studies have a major methodological weakness in not providing an adequate control group. Stroebe and Stroebe (1983) suggest that it is necessary to use a control group which comes from non-bereaved individuals and is of the same sex to account for the main effects of the general population.

In a review of the literature identifying sex differences in depression for the general population, Lehman (1971), Silverman (1968), and Weisman and Klerman (1977) concluded that women experienced more depression than did men. Men were more likely to turn to alcohol to cope with problems and were therefore not assessed as experiencing a depressive illness. When the effect of greater numbers of depressed females in the general population is taken into consideration, it becomes apparent that widowed men exhibit

more depression than do widowed women (Parkes & Brown, 1972; Carey, 1979; Radloff, 1975).

In identifying sex differences in the widowed population as they relate to mental illness, the health status of the general population must again be considered. Gove and Tudor (1973) and Hammen and Padesky (1977) found that women in the general population were reported to experience more mental illness and were more likely than men to be institutionalized. Dohrenwend and Dohrenwend (1974) and Paykel et al. (1969) found that loss was a powerful predictor of mental illness, while Clayton (1979) concluded that bereavement does not cause mental illness.

In general, widowed individuals consult the physician more (Parkes, 1964a), use more drugs (Parkes & Brown, 1972) and report more symptoms and a higher illness rate (Maddison & Viola, 1968) than non-bereaved individuals. However, there are few studies which examine sex differences in the widowed as they relate to physical health. In the general population, Gove and Hughes (1979) found that men reported more chronic illness while women reported more days of restricted activity, acute conditions and visits to the physician. This difference in the general population is seldom taken into consideration when looking at differences in a widowed population.

Heyman and Gianturco (1973) in their study of forty-one bereaved elderly did not find health differences in the widowed as compared to the larger population and also did not find any sex differences in health status amongst the widowed. They concluded that these findings which in contrast with other studies may be related to the strong social network found in this particular geographic community. A number of investigators found that widowed men did not adjust as well in the period of bereavement, relating this to lack of an adequate social network (Berardo, 1970; Gerber, Rusalem, Hannon, Arkin, & Battin, 1975a; Haas-Hawkings, 1978; Schwab, Chalmer, Conroy, Farris & Markush, 1975).

In examining the studies related to mortality in the widowed it was found that the death rate for widowers in the first six months was greater than for widows (Young et al., 1963; Parkes et al., 1969; Helsing & Szklo, 1981). For widows, the highest risk period appeared to be after the first year (Cox & Ford, 1964). Suicide rates which in the general population are greater for men than women (Carter & Glick, 1976) are also greater in widowers as compared to widows (MacMahon & Pugh, 1965).

#### 2.6.4 Advance Warning of the Death

Advance warning of the death has been postulated as a factor determining outcome. Individuals who know of the coming death, for example with a terminal illness such as cancer, generally do better than individuals who are suddenly bereaved (eg. heart attack). Advance warning of the death (also termed anticipatory grieving) is suggested to be important as it allows the survivor to make restitution for any perceived wrongs through care and attention to the dying individual and allows the survivor to work through emotional reactions and anticipate and prepare for social readjustment.

Doka (1984-85), Lehrman (1956), Pentney (1964) and Vachon, Formo, Freeman, Lyall, Rogers and Freeman (1976) documented that grief reactions tended to be more intense and lasted longer if death was sudden or preparation time was not adequate while Clayton (1968) reported more weight loss and anorexia in individuals who lost a close relative after a short illness as compared to those with a lengthy illness. Parkes (1975b) concluded that when death was sudden or advance warning was minimal, individuals responded with more lasting disorganization in the period of bereavement. Respondents who had time to prepare for the death saw it as a relief from a painful or prolonged illness. Parkes (1975b) also found that these individuals experienced little self-reproach as they had been able to participate in the care before the death.

Ball (1977) divided widows into three age groups; eighteen to forty-six, forty-seven to fifty-nine and sixty to seventy-five and compared reactions to sudden death and an illness which lasted longer than six days. She found that anticipatory grieving was important only for younger widows, which may relate to the findings of Sanders (1980-81) and Vachon et al. (1982) who found high distress patterns in the early phases of bereavement for young widows.

Sanders (1982-83) interviewed eighty-six survivors shortly after the death of a family member and again at eighteen months to two years later. Respondents were divided into three groups according to the type of death; sudden death, short-term chronic illness and long-term chronic illness. Although her findings were not statistically significant, trends indicated that survivors of a sudden death exhibited longer lasting physical symptoms and more guilt and anger than the survivors of short-term chronic illness. Survivors of a death resulting from a long-term chronic illness showed greater feelings of isolation and alienation resulting in prolonged grief and loss of emotional control. Survivors of a death resulting from a short-term chronic illness appeared to adjust the best in the period of bereavement.

Schwab et al. (1975) found that sixty-eight percent of subjects whose relative died of an illness lasting longer

than one year had intense grief reactions while thirty percent of subjects of relatives who died of an illness of less than one year had intense grief reactions. Sixty-five percent of Schwab et al. (1975) respondents were over sixty-five years. Gerber et al. (1975a) actually found that anticipatory grieving or preparation time before the death hindered the adjustment of the bereaved individual. A chronic illness of greater than six months was associated with poor medical adjustment and more intense grief reactions for the survivor. Gerber et al. (1975a) concluded that when caring for an individual with a chronic illness, the primary care giver may have neglected his/her own physical and emotional needs; may themselves have a serious illness, or that watching a spouse slowly die may exacerbate an existing chronic illness.

Silverman (1972a) concluded from her work with bereaved widows that anticipatory grief simply is not possible. She believes that grief work cannot occur until the final door is closed and the person is no longer present.

Real grieving and coming to terms with the changes death makes in a wife's life can come only after the husband has died. When he lives it is her reality to care for him, to be his wife in sickness and so forth...Some people even talk about the coming death but this is not grieving in advance. Engagements are not marriages. Neither is a rehearsal for widowhood the real thing. This only happens when the other person is no longer there to interact with--no matter what shape he is in (1972a, p. 21).



### 2.6.5 Relationship to the Deceased

The relationship to the deceased is also an important determinant of bereavement outcome. Relationships characterized by clinging or ambivalence are prone to have a poor outcome for the survivor (Parkes, 1975b). Any relationship will be characterized by some degree of ambivalence or mixture of love and hate. Individuals who are in an ambivalent relationship often feel guilt and bitterness when the relationship comes to an end. Parkes (1975b) suggested that these individuals are likely to experience self-reproach and turn anger inward. Individuals who exhibit clinging behavior have a tendency to idealize the memory of the deceased and are often unable to examine the reality of the situation. Fenichel (1946) suggested that relationships characterized by immature or passive love may also present problems in the period of bereavement for the spouse.

### 2.6.6 Concurrent Life Crises

Maddison (1968) and Parkes (1975b) suggested that concurrent life crisis in the period of bereavement may create additional stress and predispose the individual to difficulty. Prebereavement crises which seem to be of relevance in determining outcome relate to disruption in the marital relationship such as infidelity, pregnancy, separation, and loss of family income. Post-bereavement

crises which put additional strain on the bereaved individual are concerns about finances, housing, children, employment, and social relations.

In examining life crisis or additional stress in the individual's life, it is important to keep in mind that how an individual reacts to what is perceived as stress will be an important determinant in how an individual copes. How they have coped with past losses and separations will affect how they handle a current loss (Simos, 1979).

#### 2.6.7 Personality and Coping Capacity

Personality factors have been related to coping styles, appraisal of life events and perception of control (Andrews, Tennant, Hewson & Vaillant, 1978; Dohrenwend & Dohrenwend, 1974; Dohrenwend & Martin, 1979; Johnson & Sarason, 1978). Vachon et al. (1982), studying distress patterns of one-hundred and sixty-two widows over a period of two years, found that women who maintained a low level of distress had personality characteristics of: (a) emotional stability; (b) conscientiousness; (c) regard for social reputation; and (d) tolerance of traditional difficulties, which provided them with protection from the stressful event. Alarcon (1984) reports a single case study where an individual with a history of a personality disorder had a great deal of difficulty adjusting to the period of bereavement. More information is needed in regard to other individuals who have experienced similar difficulties.

### 2.6.8 Support Network

The support network of an individual may consist of interpersonal, social role and community. Ball (1977) and Lopata (1969) stated that the most common problem expressed in bereavement is loneliness. Lopata (1969) describes different types of loneliness as expressed by the widow such as;

"loneliness for the deceased husband as: an individual, an object of love, the person making the woman an object of love, a companion, someone whose presence organizes times and work, a partner in the division of labor, a source of status and a source of lifestyle" (p. 248)

It has been postulated that a social or support network is effective in mitigating the effects of loneliness so often found in the bereaved population. Maddison (1967), Parkes (1975b) and Raphael (1977) suggested that the subjective rating of supportiveness is another determinant of outcome. If the bereaved do not perceive themselves as receiving support, then it is likely they will not do as well in the period of bereavement.

Clayton et al. (1971) found that interaction with family members was effective in preventing depression in both male and female elderly bereaved individuals. Heyman and Gianturco (1973) identified stability in the social network as crucial for the bereaved elderly. If the elderly individual was able to maintain the same or similar relationships after the death of a spouse, then adaptation was usually easier.

Haas-Hawkings (1978) and Lowenthal and Haven (1968) found that a confidant relationship with one other person was important for the elderly in the period of bereavement. A widow with a confidant exhibited higher morale than a married woman without a confidant. Lowenthal and Haven (1968) describe a confidant as creating a "buffer effect" which serves as a barrier to negative feelings such as depression.

Vachon, Rogers, Lyall, Lancee, Sheldon and Freeman (1982) interviewed one-hundred and sixty-two widows at one, six, twelve and twenty-four months after bereavement to determine which variables were related to particular distress patterns. They found that at one month a high distress level was most common and was related to perceived lack of support, prebereavement stressors, young age, or lack of acculturation to the attitudes toward bereavement and mourning. At twenty-four months after bereavement the researchers found most of the widows experienced low distress. Individuals who experienced high distress at twenty-four months reported distress at one month related to the following variables; dissatisfaction with support, continued sense of husbands presence, multiple stressors before bereavement, if she did not find religion helpful and if she had not participated in the widow-to-widow program.

Social customs may also impede the flow of natural grief in situations where the death may be termed "abnormal".

Cases where the loss is socially unacceptable (suicide), or where a loss is socially negated (abortion) may present particular difficulty not only for the bereaved individual but also for the larger society (Lazare, 1979). Generally there is little discussion with the bereaved surrounding these types of death which removes one of the most effective interventions for dealing with a loss, the ability to talk about it.

#### 2.6.9 Socio-economic Status

Parkes (1975b) was the first researcher to identify low socio-economic status as a predictor of poor outcome in bereavement. Other factors which were associated with low socioeconomic status were a large number of children under the age of six, short terminal illness other than cancer, high incidence of divorce or separation from husband, alcoholism in the husband, self-defeating behavior and social disorganization.

Gallagher, Thompson and Peterson (1981-82) in a review of the literature point to four studies which indicate that widowhood is made more difficult if the financial status of the survivor is limited due to inability to maintain the sense of self and to participate in meaningful activities (Barrett, 1978; Berardo, 1967; Berardo, 1970; Elwell & Maltbie-Crannell, 1978). Individuals with greater income reported better health and life satisfaction.

#### 2.6.10 Religious Commitment or Affiliation

Religious commitment or affiliation may enhance the individual's coping capacities and therefore make the period of bereavement easier. As research is minimal in the area, it is not known whether the social participation inherent in religious practices, rituals, or the importance of particular religious beliefs are factors in adjustment. Peterson and Briley (1977) suggest that belief in the temporary nature of loss (presence of an afterlife) helps individuals to cope. Vachon et al. (1982) found that widows who did not find religion helpful were more likely to experience patterns of high distress two years after bereavement.

#### 2.6.11 Observation of Mourning Customs

The benefit or hindrance of observing mourning customs has been given very little attention in the literature. It has been suggested by some that death "American" style may be fraught with difficulties (Mitfor, 1963; Harmer, 1963). The funeral can be seen as a rite of passage, as a means of saying good-bye, or as an affirmation of the importance of the deceased (Bynum, 1973; Fulton, 1970; Glaser & Straus, 1969). The therapeutic nature of the funeral has been suggested by many authors (Kastenbaum, 1969; Parkes, 1972; Raether, 1971) but little scientific research has been done in the area.

Parkes (1975b) suggested that participation in mourning rituals would enhance bereavement outcome but did not find conclusive evidence to support the claim. Carey (1979) found widows were appreciative of clergy who permitted them to be involved in the planning of the service but did not identify if this was helpful in attaining a positive bereavement outcome. Doka (1984-85) interviewed fifty primary survivors at twelve to eighteen months post death and found that individuals reported participation in the funeral as helpful but, on the Carey Adjustment Scale these individuals did not demonstrate statistical significance in grief adjustment as compared to those who had not participated in the funeral.

Table 2.2: Determinants of Bereavement Outcome

Factor	Study	Description	Outcome
Reaction to Bereavement	Parkes & Brown (1972) - cohort of widows and widowers	- 49 widows, 19 widowers under the age of 45 - matched married controls - followed for 5 years	- presence of severe distress, yearning and self-reproach early in bereavement correlated with difficulty adjusting to bereavement
	Lindemann (1944) - cohort of bereaved individuals	- interviews with 101 bereaved relatives of the nightclub disaster	- development of traits of the deceased by the bereaved was correlated with poor bereavement outcome
	Clayton et al. (1972) Bornstein et al. (1973) - cohort of widows and widowers	- 109 widows and widowers - matched controls - followed for 4 years	- depression at 1 month was a good predictor of depression at 1 year - depression at 1 month was also correlated with perception of poor physical and mental health and lack of environmental support at 1 year
	Heyman & Gianturco (1973) - prospective study	-256 volunteers over the age of 60 participating in a longitudinal study - 27 females - 14 males	- depression shortly after bereavement was not correlated with maladjustment in bereavement

Table 2.2 (continued): Determinants of Bereavement Outcome



Factor	Study	Description	Outcome
Age	Stern et al. (1951) - case study approach	- 25 elderly individuals	- more physical illness found in single (widowed, divorced) elderly individuals than in married elderly
	Parkes (1964a) - case study approach	- the files of 44 widows were reviewed from a general practitioners office - no control group - figures compared to average consultation rates in England	- increase in physician consultations (psychiatric symptoms) for younger widows (under 65)
	Maddison & Walker (1967) - retrospective	- 132 Boston widows over the age of 45 - 98 matched controls	- the younger the widow the higher the illness score
	Maddison & Viola (1968) retrospective	- 243 Australian widows - 101 controls matched only for age - review of health over the preceding 18 months	- no correlation of age and illness score
	Ball (1977) - cross-sectional study	- 80 widows bereaved 6-9 months divided into age groups (18-46), (47-59), (60-75)	- the younger the widow the more intense the grief reaction
	Sanders (1980-81) - cohort of bereaved spouses	- 45 bereaved spouses interviewed at 2 and 18 months post-bereavement divided by age (over 65), (under 65) - 52 matched controls	- at 2 months young age was correlated with a greater intensity of grief symptoms - at 18 months, old age was correlated with a greater intensity of grief symptoms
	Vachon et al. (1982) - cohort of widows	- 162 widows interviewed at 1, 6, 12, and 24 months post bereavement divided into an intervention and control group	- young age was correlated with a high distress level at 1 month

Table 2.2 (continued): Determinants of Bereavement Outcome

Factor	Study	Description	Outcome
Sex	Young et al. (1963) - cohort of widowers	- 4,486 recent widowers over age 55 were compared with death rates for married men of the same age - followed for 5 years	- increased mortality in the first 6 months for the widower
	Parkes (1969) - cohort of widows	- 22 London widows under the age of 65 were followed for 13 months - no control group	- increased mortality in the first 6 months for widowers
	Clayton et al. (1972) Bornstein et al (1975) Clayton (1979)	- see reaction to bereavement	- no difference between widows and widowers in depressive symptoms in the period of bereavement
	Cox & Ford (1964) - retrospective study from vital statistics	- 60,000 widows under the age of 70 who applied for widow's pension in 1927 - followed for 5 years	- increased mortality for widows in the second year of bereavement
	Parkes & Brown (1972) - cohort of widows & widowers	- see reaction to bereavement	- widowers reported more depressive symptoms and poorer physical health than widows
	Heyman & Gianturco (1973) - prospective study	- see reaction to bereavement	- no difference in adjustment and physical health between widows and widowers
	Gerber et al. (1975) - cohort of bereaved spouses	- 169 bereaved spouses - matched married controls - followed for 4 years	- widowed men did not adjust as well to bereavement - thought to be related to lack of social support
	Carey (1979) - retrospective	- 78 widows - 41 widowers - interviewed at 13-16 months post-bereavement	- widowers demonstrated a more difficult adjustment in bereavement
	Helsing & Szklo (1981) - prospective study	- 92,000 people followed for 12 years - matched married controls	- increased mortality in widowers in the first year of bereavement

Table 2.2 (continued): Determinants of Bereavement Outcome

Factor	Study	Description	Outcome
Advance warning of the death	Clayton (1968) - cohort of widows & widowers	- 109 widows and widowers - matched controls - followed for 4 years	- more weight loss and anorexia reported in survivors of individuals who died of a short illness
	Gerber et al. (1975) - cohort of bereaved spouses	- see sex factor	- a chronic illness greater than 6 months was associated with poor medical adjustment and intense grief reactions in the survivor
	Parkes (1975) - cohort of widows & widowers	- 49 widows, 19 widowers under the age of 45 - matched married controls - followed for 5 years	- survivors of sudden death reported a greater impact and longer lasting disorganization
	Ball (1977) - cross-sectional study	- see age factor	- anticipatory grieving was only important for young widows
	Vachon (1976) - cohort of widows (part of larger study)	- 100 widows interviewed at 4-8 weeks after their husbands death	- more reports of depressive symptoms in survivors of individuals of sudden death
	Sanders (1982-83) - cohort of bereaved participants	- 86 bereaved participants divided into short-term chronic illness, long-term chronic illness and sudden death - interviewed shortly after death and 18 months later	- results were not statistically significant but showed a trend. - survivors of sudden death showed longer lasting physical symptoms and more guilt and anger - survivors of long-term chronic illness had greater feelings of isolation and alienation, prolonged grief and loss of emotional control - survivors of short-term chronic illness showed the best adjustment
	Doka (1984-85) - retrospective	- 50 primary survivors interviewed 12-18 months after the death	- more intense and longer lasting grief reactions in survivors of sudden death

Table 2.2 (continued): Determinants of Bereavement Outcome

Factor	Study	Description	Outcome
Relationship to the deceased	Parkes (1975) - cohort of widows and widowers	- see advance warning factor	- a relationship which was characterized by clinging or ambivalence correlated with poor adjustment in bereavement
Concurrent life crises	Maddison & Viola (1968) retrospective	- see age factor	- bereaved individuals who experienced additional crisis, pre- or post-bereavement were more likely to adjust poorly in bereavement
	Parkes (1975) - cohort of widows and widowers	- see advance warning	- additional crisis, pre- or post-bereavement correlated with poor adjustment
	Vachon et al (1982) - cohort of widows	- see age factor	- additional pre-bereavement stressors correlated with high distress at 1 and 24 months
Personality & coping capacity	Vachon et al. (1982) - cohort of widows	- see age factor	- a personality style of emotional stability, conscientiousness, regard for social reputation and tolerance for traditional difficulties was correlated with low distress levels throughout the bereavement period
Socio-economic status	Parkes (1975) - cohort of widows and widowers Barrett (1978) Berardo (1967) Elwell & Maltbie-Crannell (1978)	- see advance warning	- low socio-economic status was correlated with poor adjustment in bereavement - limited financial status was correlated with poor adjustment in bereavement - individuals with a greater income reported better health and life satisfaction

Table 2.2 (continued): Determinants of Bereavement Outcome

Factor	Study	Description	Outcome
Support Network	Maddison (1968) - retrospective study	- see age	- lack of social support was correlated with a poor bereavement outcome
	Clayton et al. (1971) - cohort of widows and widowers	- see reaction to bereavement	- family interaction was an important factor in preventing depression in bereavement
	Heyman & Gianturco (1973) - prospective study	- see reaction to bereavement	- stability in the social network was correlated with positive adaption in bereavement
	Parkes (1975) - cohort of widows and widowers	- see advance warning of death	- lack of social support was correlated with poor bereavement outcome
	Vachon et al. (1982) - cohort of widows	see age	- perceived poor support was correlated with high distress levels throughout bereavement
	Raphael (1977) - retrospective study	- 31 widows - 33 matched controls - measurement at 13 months post-bereavement	- perceived lack of support was correlated with with poor bereavement outcome

Table 2.2 (continued): Determinants of Bereavement Outcome

Factor	Study	Description	Outcome
Religion	<p>Heyman &amp; Gianturco - prospective study</p> <p>Parkes (1975) - cohort of widows and widowers</p> <p>Vachon et al. (1982) - cohort of widows</p>	<p>- see reaction to bereavement</p> <p>- see advance warning of the death</p> <p>- see age</p>	<p>- individuals who found religion helpful were better adjusted in the period of bereavement</p> <p>- religion was shown to be helpful but the results were not statistically significant</p> <p>- widows who rated religion as not helpful were more likely to experience high distress</p>
Observation of mourning customs	<p>Parkes (1975) - cohort of widows and widowers</p> <p>Doka (1984-85) - retrospective study</p>	<p>- see advance warning of the death</p> <p>- see advance warning of the death</p>	<p>- bereaved individuals reported participations in mourning customs as helpful but the results were not statistically significant</p> <p>- participation in the funeral was helpful but the results were not significant</p>

Table 2.2 (continued): Determinants of Bereavement Outcome

#### 2.6.12 Summary of the Determinants of Bereavement Outcome

From a review of the literature it appears that there needs to be further investigation into the area of bereavement outcome. How an individual copes in the period of bereavement is a complex process and appears to involve the interaction of many variables.

According to the literature, prediction of outcome in bereavement can be based on the immediate reactions of the individual to the death. An individual of young age appears to be at risk during the early phase of bereavement while an older individual may be at risk later. It is crucial that longitudinal studies be conducted so the entire process of the grief experience can be delineated. The best predictor of bereavement outcome found in the literature is the presence or absence of a support system. If the individual perceives themselves as having an effective support network they will generally do well in the period of bereavement.

Studies identifying outcome as dependent on sex point to males as having greater difficulty in the period of bereavement. Methodological improvements need to be made on these studies to account for the sex differences in the general society.

Areas such as relationship to the deceased, concurrent life crises, socio-economic status, religion and observation of mourning customs are suggested as playing an important

role in determining bereavement outcome. There needs to be further investigation into these areas to ascertain the effects of these factors.

## 2.7 PATHOLOGICAL GRIEF

Pathological grief generally refers to distortions or exaggerations in the normal process of grieving and usually results from factors which discourage the expression of normal grief or factors which prevent the resolution of grief (Parkes & Weiss, 1983; Schneider, 1980). Horowitz, Wilner, Marmar, and Krupnick described pathological grief as "the intensification of grief to the level where the person is overwhelmed, resorts to maladaptive behavior, or remains interminably in the state of grief without progression of the mourning process towards completion" (1980, p. 1157).

Schneider (1980) identified some clear distinctions between normal and pathological grief on six dimensions. In normal grief the most intense reactions are generally seen within the first six months; in pathological grief the reactions last longer than six months with little sign of resolution. Reality testing is disrupted in pathological grief as the individual will not admit that the lost object or person will not return. In normal grief the person would like to believe the lost object will return but knows this is not true. As a result of the disruption in reality the individual experiencing pathological grief is constantly



preoccupied with the deceased even to the extent of dreams or imagination being affected whereas the person who is grieving normally gradually gives this up. The person who is grieving normally has an intellectual and emotional awareness of the loss and may have ambivalent feelings about dealing with the loss but is willing to do so. In pathological grief the individual lacks awareness and avoids any reminders of loss which would force them to deal with the reality of the situation.

Pathological grief can be divided into three categories: chronic, delayed, and inhibited (Parkes & Weiss, 1983). Different authors divide the types of pathological grief differently. Chronic grief reactions were described by Worden (1982) and consist of grief expression which was prolonged and excessive in duration. Often the individual experiencing chronic grief has the need to move on and get the grieving out of the way.

Delayed grief reactions were first described by Lindemann in 1944 and were thought to result as the individual did not have time to grieve due to other important tasks, or because there was a need to maintain the morale of others. At the time of the loss the individual does not experience the emotional reaction which might be considered appropriate. At a later date when another loss is experienced or a reminder of the deceased occurs such as in listening to a song or watching a movie, the individual will experience a grief reaction which is exaggerated.

Inhibited or masked grief reactions occur when an individual presents with symptoms and behaviors which are causing them difficulty but which they are not able to link to the loss. Persons who for various reasons (personality characteristics, societal pressure) do not allow themselves to experience the loss are likely to react in this way (Raphael, 1975). Shoor and Speed (1963) suggest that delinquency is a manifestation of masked grieving. Zisook, Shuchter, and Schuckit (1985) found that patients with unresolved grief had a "higher incidence of multiple losses, a history of difficulty of getting along with their mothers and present complaints of depression and physical distress" (p. 497). Understanding what type of pathological grief reaction the individual is having and the reasons for it is one of the first steps to intervening in the situation.

The previous sections have dealt with the individual and his/her response to the grieving experience. The next section focuses on a review of the literature looking at grief from the perspective of the entire family. Organization of the next section (family response to bereavement) was assisted by the work of M. Harrison (unpublished master's thesis).

## 2.8 FAMILY RESPONSE TO BEREAVEMENT

The impact of bereavement on the nuclear family was first studied by Waller (1951) who examined the change in configurations of interactions and roles. In 1955, Elliot pointed out the importance of identifying the interpersonal effects of grieving.

It has become obvious that grieving is a family affair (Gelcer, 1983; Jensen & Wallace, 1967). Increased emotional and physical illness have been identified in the family system following the death of one of its members (Reilly, 1978; Williams, Polak, & Vollman, 1972).

Goldberg (1973) identified that the family also has mourning tasks to be accomplished before adjustment can occur. The tasks are related to the tasks of the individual and are as follows: (a) the family must allow the grieving process to occur in the individual; (b) family members must share their sense of loss with each other; (c) the memory of the deceased must be relinquished as a force in family activities; and (d) there must be a realignment of intra and extra familial roles.

Important issues to consider for the grieving family are the openness/closedness of the family, its communication patterns, distribution of roles, the intergenerational patterns of dealing with loss, and the stage in the family life cycle.

### 2.8.1 Openness/closedness of the Family System

The sense of "openness/closedness" in the family can be viewed as a protective boundary which allows some information or people to cross its path while it keeps out other aspects. The openness of a system is dependent upon the degree of permeability across the boundary. Families might be considered relatively open or closed, depending on the amount of exchange that passes over the boundary.

In relation to the larger society, Vollman, Ganzert, Picher and Williams (1971) identified three different ways in which a family might interact, which has implications for how they adjust in the period of bereavement. The first group of families was seen as having a "contrived social system". They did not have a close kin network but used the social resources of church, school and community club as a means of support. They were seen as frequently using the resources of professionals and therefore, could also seek help in the time of crisis of bereavement. This type of family is seen as being selectively open, and with the proper type of support is able to adjust in the period of bereavement.

The second group of families has little contact with the mass society but does belong to a cohesive cultural subgroup. These families exchange support within the group which is functional in terms of adaptation. This type of

family does not usually need help, but if help is required it may be difficult to intervene as it may be seen as intruding on the cultural system.

The third group of families is seen to be at risk in the period of bereavement. They are relatively closed as they have few contacts with the larger society and do not have the support of an immediate group. They are exclusively tied up in the family, and the loss of a member is seen as a great tragedy. They have few resources to deal with the situation, and may try to cope on their own by using maladaptive behaviors.

#### 2.8.2 Communication Patterns of the Family System

Communication patterns can also be identified as either open or closed, and are seen as the flow of energy within the family system. As communication expands from individual to individual to include the whole family, the degree of complexity of interaction also increases. Communication patterns also form the basis of family rules. Bowen (1978) views an open family as one in which inner thoughts and feelings can be communicated and the other individuals can reciprocate. A closed system exists when the individuals protect each other from the stresses surrounding them. Herz (1980) identified bereavement as a time in which family members may want to protect each other from the pain and inadvertently block communication.

According to Vollman et al. (1971) families identified as using open communication patterns were likely to look at the reality of the situation and were less likely to use denial to cope, which was important in positive adjustment. Cohen, Dizenhuz and Winget (1977) speculated that if communication flowed easily in the family, they were more likely to use internal support systems during the period of bereavement. The more families were able to share feelings, information and decision-making, the more likely they were to adjust positively in the period of bereavement. Openness in communication was frequently found to depend upon the mother. In families where the mother had died, there appeared to be faulty communication and greater perception of a crisis state.

### 2.8.3 Role Allocation in the Family System

Many authors have studied the effects of bereavement on role allocation in the family (Bowen, 1978; Cohen et al., 1977; Herz, 1980; Vollman et al., 1971). Role allocation is an important factor in family rules. Role reallocation is seen as the process where established patterns are no longer effective and institutive or new patterns must come into effect. Cohen et al. (1977) commented that it is important to understand the circumstances surrounding the death as role redistribution may begin before the death if the family has been coping with a terminal illness.

When the family is bereaved it may need to find members to take over the roles that were filled by the deceased. The more difficult it is for others to occupy these roles, the more difficult the adjustment period will be and the greater the disorganization will appear (Vess, Moreland, & Schwebel, 1985- 86). Role reallocation occurs at the intra and extra familial levels. As it may not always be possible for the roles to be filled, the family may drop out of social functions or redefine its goals. For example, it may be difficult for a wife to take on the role as bread winner, while keeping up the household and raising the children. Some of the household tasks may be taken on by the children who then may need to make adjustments in the roles they currently employ. If these changes produce increased stress in the family unit, they may not have the energy to deal with the grieving process.

Vess and associates (1985-86) differentiated between person oriented families, which are characterized by achieved roles and open communication, as opposed to position oriented families which are characterized by ascribed roles and closed communication. Families in which the roles are allocated on the basis of achievement rather than culturally prescribed norms adjust more easily to the death of a member, as role reallocation is less stressful.

Bowen (1978) and Herz (1980) stated that it may be difficult for the family to fill the socio-emotional role of

the deceased, and the more emotionally significant the deceased individual is, the more disruption there will be in bereavement. The deceased may have played a deviant role within the family system. This deviant role may have been the source of "holding the family together" and given the members a means of tension release. When death occurs, the family may be at a loss, as anger and resentment may have been directed at this individual. With the individual no longer present, there is no "scapegoat" for these emotions. If however, the deviant role placed an additional strain on the family system, such as in the case of an alcoholic member, death may be seen as a relief and a chance for the system to return to equilibrium. Adjustment in the bereavement period will be relatively easy (Vollman et al., 1971).

#### 2.8.4 Intergenerational Patterns of Dealing with Loss

The loss of a family member has an emotional impact on the survivors. The depth of this impact is not always immediately known, and may manifest months or years later. Studies conducted by Paul and Grosser (1965) indicated there was an important loss in the family just before the birth of a symptomatic member (schizophrenic or psychoneurotic). The family tasks seemed to be concentrated around resisting changes in homeostasis, and any move on the part of individuals to move outside the family system were met with



resistance. These families were seen as attempting to minimize their losses.

Mueller and McGoldrick Orfanidis (1976) found that 40% of schizophrenics had been born within two years of a grandparent's death. Other studies concur with these findings. Framo (1972) sees ineffective mourning as a factor in family pathology. Boszormenyi-Nagy and Spark (1973) and Pincus (1975) identified postponed mourning related to the family of origin, as a detriment to the ability to experience loss in the current family. Paul and Paul (1982) identified the role of long-denied grief in marital disorders.

Bowen (1978) labelled intergenerational effects as an "emotional shock wave". The wave is seen as a network of aftershocks which may permeate the family for months or years following the death of a family member, and has the potential to throw the family into disequilibrium.

#### 2.8.5 Stage in the Family Life Cycle

Death in the family may have various effects depending on where the family is in the family life cycle. This phenomenon may be related to the fact that different roles are required at different periods, and available coping resources may fluctuate. For example, the death of the bread-winner, in a young family with children, may strain

the family due to role overload. An elderly widow who has lost her spouse may find herself in a difficult situation as she no longer has the economic resources to cope with her life situation. Much energy can be lost in worrying about where the next meal will be found, rather than putting energy into the grieving experience (Vess et al., 1985-86).

#### 2.8.6 Summary

Bereavement places a stress on the family system, which has the potential to move into a state of crisis depending on the the ability of the family to alter roles to a new state of functioning, and the internal and external resources available to them. Bereavement has the potential to cause disorganization and ultimate collapse in the system if it is unable to respond with appropriate coping patterns, but it also has the potential to stimulate growth as the family members increase their sense of solidarity, by developing new communication patterns, roles, resources and relationships.

As the family is a vital system in the functioning of society it is crucial that care be taken to maintain and promote its functioning. Increases in morbidity and mortality can place undue strain on the health care system, create unemployment, and has the potential to decrease the quality of life for the family. Intervention into the period of bereavement has the potential to promote family

functioning and move the family into a state of growth (Cameron & Brings, 1982; Cassem, 1975; Harvey & Bahr, 1980)

## 2.9 BEREAVEMENT INTERVENTIONS

Now that some variables have been identified to predict bereavement outcome, it is important to find the most effective program to assist individuals at risk of poor outcomes. There are many different ways in which a bereavement program can be established. Regardless of whether it is a formal or informal support mechanism, or whether it is run by the lay public or trained professionals, the goal of the program will be the facilitation of the grieving process and prevention of the negative occurrences of bereavement. Worden (1982) describes the four tasks of mourning as consisting of (a) accepting the reality of the loss; (b) experiencing the pain of grief; (c) adjusting to an environment in which the deceased is missing; and (d) the withdrawal of emotional energy from the deceased and reinvestment in another relationship. Bereavement interventions are generally directed at facilitating the tasks of mourning.

Bereavement interventions consist of three basic forms: mutual support groups, palliative care or hospice programs, and psychotherapy. Each of these types of interventions will be discussed the specific type of intervention used and in terms of evaluations that have been done to determine the effectiveness of the intervention.

### 2.9.1 Types of Interventions

The following sections will discuss the various types of intervention available to people in the period of bereavement.

#### 2.9.1.1 Mutual Support Groups

The mutual support approach developed out of needs expressed by the consumer in society (Killilea, 1982; Lieberman & Borman, 1979). Parkes (1981) stated the philosophy behind support groups is that the person best qualified to help, is another individual who has been through a similar experience. According to Osterweis, Solomon and Green (1984), support groups are an effective means for sharing coping strategies and for receiving feedback on how one is managing. Education is a primary goal of many support groups, and usually involves educational opportunities for both lay and professionals alike. Other goals of support groups consist of the development of problem solving skills and the formation of friendships or support networks.

There are two basic types of support groups surrounding the time of bereavement: those which deal with normal grief reactions and adjustment to the new role, such as Widow to Widow programs; and those which deal with grief as a result of difficult circumstances, such as homicide, suicide or the

death of a child, such as Mothers Against Drunk Drivers (MADD), and Compassionate Friends. The primary purposes of these types of groups are support and social advocacy. The means of intervention usually consists of one-to-one outreach, group sessions and peer counselling.

Many of the widow to widow programs are based on Silverman's (1972b) model, which stressed that widowhood was a time of transition and change. Her model was developed after extensive research and involved intervention at three to six weeks after the death (after the state of numbness has subsided), by another widow (role model), and is initially offered on a one to one basis as the individual is not yet ready for group interaction. Intervention consists of assisting the individual with practical problems, encouraging the expression of feelings, and general adjustment into a new role. As many widows reported they never actually recover from the death of a spouse, the program was centered around change as opposed to recovery. From her research with widows, Silverman (1972b) concluded that the bereavement process extended over a period of years and guilt and anger were not important issues as identified by the widow. Many of the self-help groups currently incorporate both widows and widowers into their program, but there are few programs for men alone (Gartner, 1984). There may be more widows in society but men are often identified as having a more difficult time in the period of bereavement and therefore, intervention is also appropriate.

Support groups such as MADD or Compassionate Friends each have a different purpose but are designed to help the participants find meaning in the death, or at least to be able to live with the loss. A death that is viewed by society as "inappropriate", such as in the death of a child, often produces estrangement for the survivors as friends and family withdraw from the situation as they feel uncomfortable and ill-prepared to help (Klass, 1982). Mutual support groups are effective in decreasing estrangement through the sharing of experiences. Estrangement is also decreased by sharing feelings and behaviors which might be termed by others "abnormal" (Miller, Moore & Lexius, 1985). Segal, Fletcher and Meekison (1986) in a survey of bereaved parents found that the most consistently preferred source of support in their grieving was another parent or couple whose child had died, especially if the death was similar. Attributes of the support person which were deemed most helpful were knowledge of the normal range of grief reactions, "an ability to facilitate discussion, warmth and sincerity, good listening skills and flexibility in times that he or she would be available to the family" (Segal et al. 1986, p. 41).

Groups for survivors of suicides are coordinated with the self-help framework as well. The programs are generally run with volunteers with the assistance of professional supervision. One-to-one visiting may be done by a volunteer

who has been through the experience of suicide or by an individual who has experienced a major loss in their life. Rogers, Sheldon Barwick, Letofsy and Lancee (1982) suggest that caution must be used in using volunteers who have been through a suicide in the family themselves as unresolved feelings may arise.

A suicide in the family represents a special type of crisis as it is associated with the rejection of the survivors, society and life itself (Stephenson, 1985). Classical theories of suicide usually point to a psychological or sociological explanation for the act. Durkheim (1951) differentiates between four types of suicidal behavior: egoistic, altruistic, anomic and fatalistic. Egoistic suicides occur when the bond between the individual and the larger society is weak such as in the case of unmarried persons. Altruistic suicides exist when the social bonds of the individual are totally tied to the values of the larger group such as a soldier dying in defense of his country. According to Durkheim (1951), anomic suicides belong in a group of behaviors which indicate that the individual does not have a particular place in society. A fatalistic suicide occurs when the individual is overregulated by the society. The overbearing nature of society no longer makes life worth living and the individual commits suicide. Generally speaking, suicidal behaviors stem from a sense of isolation and from

the feelings of some intolerable emotion on the part of the victim (Shneidman, 1977). This sense of isolation may be communicated to the survivors as their fault which is often converted to guilt in the period of bereavement. According to Kastenbaum (1981), whatever else a suicide attempt might be, it is a form of communication.

Lindemann and Greer (1953) in their study of suicide survivors found that there was a tendency to look for a scapegoat. The individual chosen to be the scapegoat was often the person who was least likely to be able to cope with the added strain. Suicide survivors may also be afraid that they will commit a similar act as a strand of "weakened character" may run in the family. A study conducted by Calhoun, Selby and Abernathy (1984) indicated that friends and acquaintances perceived difficulty in interacting with the surviving family members which may place the family at particular risk as the social network is diminished. However, when respondents indicated they personally knew the family, the difficulty in interaction was not as great. The use of a self-help approach was viewed as appropriate as it was a means of ensuring the support network remains intact. Wroblewski (1984-85) recommends that groups for family members of individuals who have committed suicide should be conducted separately from other bereavement groups as the stigma attached to suicide can be extremely damaging to the participants.



### 2.9.1.2 Palliative Care/Hospice Programs

Bereavement intervention can also be offered in the form of a hospice/palliative care program. A hospice is a philosophy rather than an actual place, whose focus is on the management of symptoms, as opposed to the cure of disease. The patient and family are considered part of the care team, and their autonomy and dignity are of great importance. Bereavement programs used by hospices vary considerably. Preparation for bereavement begins before the death, but is usually addressed in unstructured ways such as education and emotional support.

Intervention after the death may occur in the form of telephone calls, letters, or social events. Intervention in the period of bereavement can be done by professional staff such as nurses or social workers, but is often done by trained volunteers who have either been through a similar experience, have a commitment for this type of work, are sensitive, and have good listening and communication skills. Training consists of education in the bereavement process, community resources, communication skills and hospice philosophy. Generally speaking, involvement occurs within the first year after bereavement, with referrals made to other agencies if the need arises. Some hospices or palliative care units use different volunteers for inpatient and bereavement services as they feel it is less stressful for the nurse and because families often need to tell their

stories again and again and may feel more comfortable doing this in the presence of a stranger who has not heard it before (Lattanzi, 1982).

Hospice bereavement programs are similar to self-help groups in that they are directed at individuals who are able to work through their grief without the assistance of a professional (Osterweis, Solomon & Green, 1984). According to Lattanzi the major goals of a hospice bereavement program are

(a) to provide family members with information about the normal grief process; (b) to provide grieving family members an opportunity to review and reflect on the experience of caring for their loved one and their loss experience; (c) to assess and monitor individual coping ability, stress levels and available support; and (d) to encourage family members to utilize existing support systems or to seek and create additional sources of support (1982, p. 56).

#### 2.9.1.3 Psychotherapy

The last form which bereavement intervention programs have taken is that of psychotherapy. The difficulty with looking at research in this area is the fact that the interventions vary greatly depending upon the therapist. Psychotherapy is generally used when individuals are deemed to be at high risk or when pathological occurrences are apparent. It is not usually viewed as a preventative strategy, but rather used to restore health and social functioning when pathological grief becomes apparent. Only

a small portion of the literature in this area will be discussed as it does not specifically apply to the study.

The type of treatment used by a psychotherapist will be dependent on their training (Osterweis, Solomon & Green, 1984). A therapist trained in psychoanalytic theory may use an approach which concentrates on the individual's psychological well-being, while the behaviourist may concentrate on specific behaviors and the cognitive approach will deal with re-living the experience. Therapy may also be family oriented. The different types of intervention may be short such as in crisis management or of long duration.

The purpose of therapy is similar to other types of interventions in that it assists the individual to work through the grieving process and restore social functioning. Psychotherapy may not only be used at the time of bereavement to assist the individual with the grieving process but also to explore deeper aspects of the personality.

#### 2.9.2 Evaluation of Bereavement Interventions

Evaluation research into the area of bereavement intervention is minimal and is complicated by inadequately identified variables and definition of terms. Evaluations which have been done usually center on anecdotal data which is helpful in understanding the bereavement process but does

little to evaluate specific interventions (Osterweis, Solomon, & Green, 1984). Evaluation is further complicated by the diversity in program goals, structure and content. For a summary of the research see Table 2.3.

#### 2.9.2.1 Evaluation of Mutual Support Groups

Vachon, et al. (1980), conducted a study to test the efficacy of the Silverman model. She studied widows whose husbands had died at sixty-seven years of age or younger. The one hundred and sixty two widows were randomly assigned to an intervention or control group. The intervention consisted of one to one support, practical help and small group meetings. Interviews, using the Goldberg General Health Questionnaire, were conducted at one, six, twelve and twenty-four months after the death. A self-administered instrument was also used to identify demographic and situational variables, social support and physical symptoms. Findings indicated that at six months the psychological adaptation of the experimental group was better than the control group; at twelve months, interpersonal adaptation was better; and at twenty-four months the experimental group was better on all measures. It was found that the best predictor of bereavement adjustment was perceived social support.

Barrett (1978) compared three different mutual support approaches, where each group concentrated on a different

aspect of widowhood. The groups met for two hours over seven weeks. The self-help group focused on the practical problems of widowhood, the confidant group focused on the development of new friendships; and the consciousness raising group focused on women's roles in society. At the end of the sessions, the consciousness raising group showed the most positive changes, while the self-help group showed the least positive changes on measures of personality, attitude, and behavioral measures such as physical, emotional and social functioning.

Lieberman and Borman (1981) surveyed seventy-one chapters of THEOS (mutual support group for widows and widowers) and found that results on psychosocial, behavioral and physiologic measures, varied with the intensity of the involvement in the group. Items that were specifically explored were indices of mental health such as depression, anxiety, somatic symptoms, psychotropic drug use, self-esteem, coping mastery, and well-being. For example, the greater the involvement with the group, the better scores that were obtained for depression and self-esteem and less use of psychotropic drugs and alcohol.

Videka-Sherman (1982a, 1982b) and Videka-Sherman and Lieberman (1985) surveyed one-hundred, ninety-four parents of children who had died in the past eighteen months from eighteen chapters of Compassionate Friends (monthly support group for bereaved parents). Measures of psychosocial

adjustment, mental health, social functioning, parental functioning and attitudes were considered. Videka-Sherman (1982a) found no significant differences in depression as a result of involvement in the group, but did identify that reports of self-growth were dependent on the involvement in the group.

Videka-Sherman and Lieberman (1985) found participation in a self-help group did not make any impact on mental health, marital or parental role functioning. Participation in the group however, was correlated with changes in attitude toward parental bereavement. The active members increasingly externalized their anger over time and saw others as unresponsive to the emotional needs of bereaved parents and believed that there was "a good way" to respond to bereaved parents. They also believed discomfort in discussing the death was the problem of the outsider rather than the parent. Respondents believed that as a result of participation in Compassionate Friends they had become more self-confident, more in control of their situations, happier, less depressed, less anxious, less guilty, less angry, less isolated and freer to express feelings. Even though the respondents felt the group had been of some benefit, it was not identified in measurements of mental health or social functioning. The authors suggest that lack of effect may be due to extreme disfunction which results when a child dies.

Rogers et al., (1982) developed a support program for the survivors of a suicide. The "Survivors Support Program" is a nonprofessional time-limited, structured program directed towards understanding and resolving the stresses that are unique to bereavement as a result of suicide. Members of a family would meet with two trained volunteers for eight, two-hour sessions. The SCL-90 which is a psychosomatic symptom check list was used to describe the reactions experienced by the participants. The rating on the SCL-90 suggested the suicide survivors were at risk for pathological grief reactions such as guilt, isolation and idealization of the deceased. The survivors also concentrated more heavily on emotional as opposed to cognitive goals. At follow-up the mean scores on the SCL-90 were considerably lower than on admission into the program; however since a control group was not used the significance of these findings can not be estimated.

As can be seen from the review of the research, there is much conflicting evidence in regard to the benefits of mutual support groups.

#### 2.9.2.2 Evaluation of Palliative/Hospice Programs

A hospice or palliative care bereavement program is in a particularly good position to be used as a preventative measure against pathological grief reactions. As members of the hospice get to know the family before the death, they

are in a prime position to identify individuals at risk and apply early intervention strategies. Research into the area of hospice care has basically been in the area of symptom control with little attention to other areas of the program. With the advancement of pain control measures evaluations of other areas of the program are being undertaken.

Cameron and Brings (1980) and Cameron and Parkes (1983) from the Royal Victoria Hospital in Montreal, report a study in bereavement which began upon the opening of the palliative care unit in 1975. Twenty close relatives of patients who had died on the palliative care unit were matched with relatives of patients who had died on the acute wards of the hospital. The families from the palliative care unit received pre-death support and bereavement counselling. Pre-death support consisted of facilitating the expression of anticipatory grief, providing optimal care and symptom control, fostering open communication between the patient and family and encouraging the family to be present at the death. Bereavement counselling consisted of one to two visits by the palliative care nurse and two to three telephone calls over a period of six months. At fifty-four weeks after the death, a telephone questionnaire was arranged, which explored changes in lifestyle since bereavement, anniversary activities, grief reaction, and adjustment as measured by physical and psychological health and by social behavior. The palliative care group showed



significantly more signs of adjustment and reorganization, while the control group showed more signs of grief and counter-productive coping.

Parkes (1981) described the use of trained volunteers to provide support and practical advice to high risk survivors of individuals whose relatives died at St. Christopher's Hospice in London. One hundred and eighty-one individuals were divided into three groups (imperative need, high-risk, and low risk), then the high-risk group was randomly assigned to intervention and control groups. The two high-risk groups were examined at twenty months after bereavement on scales of physical symptoms, depression, habit changes, index of worry, and general health changes. The intervention group had become more like the low-risk group, with changes being more apparent in men.

#### 2.9.2.3 Evaluation of Psychotherapy

Comparison between the various psychotherapy techniques as previously stated is made difficult due to the variety of interventions and measures used. Gerber et al. (1975b) describes a longitudinal study which offered brief psychotherapy to the aged bereaved who had lost a spouse due to cancer or cardiovascular disease. After being randomly assigned to a control or an intervention group, the individuals were followed for three years. Weekly contact with a psychiatric social worker or nurse took place for six

months following the death and focused on moral, support, grief work, and environmental manipulation. Indicators were used to report on medical, psychological and social adjustment. During and shortly after the intervention, the experimental group reported less drug use, less illness and fewer visits to the doctor. By the time of the final evaluation, fifteen months after bereavement, there was no difference in reported health status. Subjects who appeared to have benefited most from the therapy were those that were healthy at the time of bereavement.

Raphael (1977) studied high-risk widows at six to twelve weeks after the death. High-risk was defined as lack of social support and ambivalence in the marital relationship. The individuals were randomly assigned to control and intervention groups. The intervention consisted of support, emotional expression, and review of the relationship. At thirteen months high-risk widows who had the intervention appeared to be more like the low-risk widows (especially in areas of reported symptoms and visits to the doctor). The perceived supportiveness of the social network was seen as the key predictor of outcome.

Williams and Polak (1979), Williams, Polak and Vollman (1972) and Polak, Egan, Vandenberg and Williams (1975) studied the effects of immediate crisis intervention (beginning within hours) of a sudden death, and continuing for ten weeks. Intervention consisted of focusing on family

coping. The authors report no major differences in the experimental and control groups at six and eighteen months after bereavement. In fact, the authors postulated that intervention at an early period may actually interfere or delay the normal grieving process.

Constantino (1981) used bereavement crisis intervention on a group of widows to try to decrease levels of depression and improve social functioning. The widows were divided (not random assignment) into a crisis intervention group, a socialization group or a control group. Group meetings conducted by a psychiatric-mental health nurse, were held for six weeks for widows whose husbands had died in the past six months. Depression was found to increase in the control group and decrease in the socialization and crisis groups. Socialization decreased in the control group, increased slightly in the socialization group and increased considerably in the crisis group. The intervention appears to be successful in this case, but as random assignment of subjects to groups was not used, caution must be used in the interpretation of the results.

Horowitz, Marmar, Weiss, DeWitt and Rosenbaum (1984) studied the impact of psychotherapy on self-referred adults who had lost a parent through death. Twelve therapy sessions focused on the relationship with the deceased and the facilitation of grief. Assessments in the areas of symptoms of psychological distress, adjustment, functioning,

self-concept, life events, perceived social support and sociodemographic variables were done at two, seven and thirteen months. Initially the distress level of the experimental group was high, but by thirteen months, the distress levels were reduced. An interesting aspect of this study, is that perceived social support had little bearing on the outcome measures.

There is a great deal of variability in the interventions used in these studies, and conflicting reports abound. It is also difficult from many of the studies to identify what the intervention actually was.

### 2.9.3 Summary of Bereavement Interventions

There is a great deal of variability in how an individual grieves, and which type of approach is most helpful to facilitate the grieving process is unclear. Research from the three types of bereavement programs: mutual support, hospice/palliative care, and psychotherapy would indicate that an intervention may lessen the time spent in the bereavement period, and may make the adjustment period less stressful. Evidence from the widow to widow programs indicates that individuals may not be ready for intervention, outside of their immediate social network, immediately following bereavement. Hospice programs suggest that intervention around six weeks may be most effective, as this is when the familiar social supports are beginning to

withdraw. The use of a formal support group does not appear to be appropriate until a few months from the time of death. It is not conclusive which interventions are most appropriate as few studies have been conducted. It is also important to keep in mind that certain interventions may produce negative consequences.

The review clearly indicated that further studies into the area of bereavement interventions are required. It is also necessary that measures of bereavement outcome for both normal and abnormal grief, be defined before systematic evaluations of bereavement programs will be possible. Finally, it is vital to control for variables such as culture, perceived social support, high and low risk individuals, and age and sex in designing such evaluations.

Table 2.3: Bereavement Interventions

**Format utilized has been borrowed from Dr. L. Degner ** E= experimental group C= control group O= observation X= intervention R= randomized trial								
Authors	Year	Design	Sample	Independent Variable(s)	Dependent Variable(s)	Methods of Analysis	Results	Critique
Barrett, C. J.	1978	comparison of support groups R E ) 0 X 0 0 1 E ) 0 X 0 0 2 E ) 0 X 0 0 3 C) 0 0 0 -observations were made initially, 7 weeks and from 13-15 weeks	70 urban widows responded to a newspaper add --average length of bereavement was 5 years	2 hour sessions for 7 weeks --groups were led by 2 doctoral students in clinical psychology E1 ) Self-help group --focused on the practical problems of widowhood E2 ) confidant group --focused on the development of new friendships E3) consciousness raising group --focused on women's roles in society C) designated as a waiting list	personality, attitude, behavioral, physical and social functioning	indices of physical, emotional and social functioning	--at the post-test all (E) and (C) subjects had higher self-esteem, more intense grief and negative attitudes to remarriage --at follow-up the most positive changes occurred in the consciousness raising group, while the fewest positive changes occurred in the self help group	--volunteered sample --results in post-test, may indicate the researcher conveyed the type of responses expected

Table 2.3: Bereavement Interventions (continued)

Authors	Year	Design	Sample	Independent Variable(s)	Dependent Variable(s)	Methods of Analysis	Results	Critique
Vachon, M. L. S.	1980	2 year longitudinal study (prospective)  R E) X 0 0 0 0 C) 0 0 0 0  observations were made at 1, 6, 12, and 24 months	--162 newly bereaved widows under the age of 67  --mean age of the widows was 52  --45% of the husbands died of cancer; 38% died of chronic cardiovascular disease	--the intervention consisted of trained widow's helper who offered one to one support, practical advice and small group meetings  --there was no predetermined number of meetings or time limit for the length of the intervention	intrapersonal adaptation, interpersonal adaptation	--Hollingshead two factor SES index  --Goldberg General Health Questionnaire (ability to carry out normal functioning, role satisfaction and outwardly observable behaviour  --pre-bereavement situational variables, socio-demographic variables, circumstances surrounding the death and funeral  --correlates of distressful response --structured interviews, self administered questionnaires	--final illness period was rated as extremely or very stressful by 81% of the widows  --no differences between the (E) and (C) groups at 1 month  --at 6 months, (E) group did better on intrapersonal adaptation  --at 24 months there were overall differences between the (E) and (C) groups--the high-risk widows appeared more like the low risk widows --perceived social support was an important indicator of outcome --deficits in social support and health and financial problems were correlated with high distress at 24 months after death	--high attrition rate (common in studies of bereavement)

Table 2.3: Bereavement Interventions (continued)

Authors	Year	Design	Sample	Independent Variable(s)	Dependent Variable(s)	Methods of Analysis	Results	Critique
Constantino, R. E.	1981	E ) 0 X 0 1 E ) 0 X 0 2 C) 0 0	--widows between the ages of 30 and 69 years of age, whose husbands had died in the six months prior to the study from a malignancy or heart disease  --widows could not participate in the study if they had a history of psychiatric illness, were currently receiving psychiatric intervention or were on psychotropic medications E ) bereavement 1 crisis intervention group, N= 7  E ) socialization 2 group, N=10 C) control group, N=10	--bereavement crisis intervention, conducted by a psychiatric-mental health nurse and widowed individuals  --goal is to reduce depression and increase socialization	--depression, social adjustment	--demographic data sheet  --Depression Adjective Check List (Form E)  --Social Adjustment Scale--Self-Report (assess performance in work, social and leisure activities, relationships with extended family, role as a parent, economic independence)	--depression was found to increase in the control group and decrease in the bereavement crisis intervention and socialization groups  --socialization decreased in the control groups, while it increased slightly in the socialization group and increased considerably in the bereavement crisis intervention group  --loneliness was a difficulty reported by all subjects	--small sample size  --not a randomized trial  --reliability and validity of instruments were not reported for this population  --difficulty identifying what the intervention consists of

Table 2.3: Bereavement Interventions (continued)



Authors	Year	Design	Sample	Independent Variable(s)	Dependent Variable(s)	Methods of Analysis	Results	Critique
Lieberman M. A. and Borman, L. D.	1981	--survey questionnaire (mail) E) X 0 0 C) 0 0	--current and former member of 71 chapters of THEOS (mutual support group for widows and widowers)  --also sent questionnaires to those who had declined to participate in the group --93% of the respondents were widows --initially 721 responses --one year later there were 502 responses	--intensity of involvement with the group and leadership roles in the group	--bereavement outcomes, such as depression, self-esteem, anxiety, somatic symptoms, psychotropic drug use and well being	--self reports --health questionnaire	--the more intense the involvement with the group, the better the outcomes, especially in the areas of depression and self-esteem	--how a control group was used is not clear  --not a randomized trial

Table 2.3: Bereavement Interventions (continued)

Authors	Year	Design	Sample	Independent Variable(s)	Dependent Variable(s)	Methods of Analysis	Results	Critique
Videka-Sherman, L.	1982	--survey questionnaire (mail) E) X 0 0 C) 0 0	--members and nonmembers of 18 chapters of Compassionate Friends (a mutual support group for bereaved parents)  --194 parents who had lost a child in the last 18 months  --70% were mothers	--intensity of involvement in the group	--bereavement outcomes, such as psychosocial adjustment, depression, self-reported personal growth	--self-reports	--no significant differences found in depression in relation to involvement in the group  --self reports of personal growth varied directly with involvement in the group	--control group is unclear --not randomized

Table 2.3: Bereavement Interventions (continued)

Authors	Year	Design	Sample	Independent Variable(s)	Dependent Variable(s)	Methods of Analysis	Results	Critique
Cameron, J. and Brings, B.	1980	E) X 0 C) 0  --the observation was made at 54 weeks post bereavement	--20 close relatives of patients who died on the palliative care unit were matched with 20 close relatives of patients who had died on the active wards of the same hospital  --all the patients had cancer	--the intervention consisted of total hospice care prior to the death  --for 6 months after the death a nurse offered reassurance and active listening in person and by telephone	--physical and psychological health, social behaviour	--questionnaire that identified current living arrangement, changes in lifestyle, anniversary activities and grief reactions	--hospice group showed more signs of adjustment and reorganization  --hospice group required fewer sedatives and tranquilizers, were less preoccupied with thoughts of the dead person, and were less angry and guilty	--not a randomized experiment  --process by which patients are admitted to the various wards, may contribute to bias

Table 2.3: Bereavement Interventions (continued)

Authors	Year	Design	Sample	Independent Variable(s)	Dependent Variable(s)	Methods of Analysis	Results	Critique
Parkes, C. M.	1981	R E) X 0 C) 0  --the observation was made at 20 months post-bereavement	--181 bereaved individuals who had relatives that were patients at St. Christopher's Hospice in London  --individuals were divided into 3 groups; imperative need, high-risk and low risk --the high risk group was further broken down into an intervention group, N=32 and a control group N=35 --high-risk was determined by nursing staff by the following behaviors; clinging to the patient before death, angry or self-reproachful behavior, lack of supportive family, low socioeconomic status, young age, and intuitive assessment on the part of the nursing staff	--intervention consisted of trained lay volunteers to provide support and practical advice	--physical symptoms, depression and habit changes	--check list of new or worse symptoms  --measure of increase in alcohol, drug and tobacco consumption  --index of worry  --general health index --change in health status (predictive questionnaire, developed at Harvard)	--individuals in the intervention group had become more like the low risk group--differences were greater for men than women (this change was not initially apparent at 1 year, but became apparent after 3 years)	--the actual intervention is difficult to identify

Table 2.3: Bereavement Interventions (continued)

Authors	Year	Design	Sample	Independent Variable(s)	Dependent Variable(s)	Methods of Analysis	Results	Critique
Gerber, I., Weiner, A., Battin, D., and Arkin, A.M.	1975	--prospective longitudinal study (3 year follow-up)  R E) X 0 0 0 0  C) 0 0 0 0 --the observations were made at 2, 5, 8, and 15 months	--elderly individuals who were members of a prepaid medical plan and who had lost a spouse due to cancer or cardiovascular disease  E)= N=116  C)= N=53	--intervention consisted of weekly meetings with a psychiatric social worker or nurse, for 6 months which focused on moral support, grief work, (review of the relationship to the deceased, making plans for the future, and dealing with practical problems), environmental manipulation  --53% of the contact was made over the telephone, while the rest was made on a one to one basis	--medical, psychological and social adjustment	--review of medical records --data from the questionnaires	--during and shortly after the treatment, the intervention group reported less drug use, less illness and fewer visits to the doctor than the controls  --at 15 months there was no significant difference in health status  --those who benefitted most, were the individuals who were physically healthy at the time of bereavement	

Table 2.3: Bereavement Interventions (continued)

Authors	Year	Design	Sample	Independent Variable(s)	Dependent Variable(s)	Methods of Analysis	Results	Critique
Raphael, B.	1977	<p>--initial interviewer assessment to place in a high risk category -- N=200</p> <p>R E) X 0 C) 0</p> <p>--the observation was made at 13 months post-bereavement</p>	<p>--individuals in both groups were rated as highrisk, on the basis of 1) perceived non-supportiveness, 2) traumatic circumstances surrounding the death and moderate perceived non-supportiveness, 3) highly ambivalent marital relationship with the deceased and traumatic circumstances surrounding the death, 4) concurrent life crisis</p> <p>--widows were less than 60 years of age</p> <p>--obtained through the social security department, when they applied for widow's pension E)= N=31 C)= N=33</p>	<p>--subjects were contacted 6-12 weeks after bereavement</p> <p>--intervention consisted of ego support, support for grieving and mourning processes, expression of bereavement affects (grief, sadness, anger, anxiety, hopelessness), review of the relationship with the deceased</p> <p>--sessions were 2 or more hours in length and were nondirective in nature--the mean number of sessions was 4, with a range from 1-9</p>	--post-bereavement morbidity	<p>--health questionnaire, developed by Maddison &amp; Walker (measures the extent to which the bereaved see their families as unsupportive, their bereavement as traumatic, their marriage as ambivalent, their life as complicated by crises other than bereavement</p>	<p>--at thirteen months, there were fewer reports of new or worsening symptoms in the intervention group</p> <p>--the high risk widows appeared to be like the low-risk group</p>	

Table 2.3: Bereavement Interventions (continued)

Authors	Year	Design	Sample	Independent Variable(s)	Dependent Variable(s)	Methods of Analysis	Results	Results cont.
Williams, W. V. and Polak, P. R.	1979	2 x 3 repeated measures R E) X 0 0 C ) 0 0 1 C ) 0 0 2  E)= preventative crisis services C1)= no crisis services after sudden death C2)= no recent death and no crisis services -observations were made at 6 and 18 months post-bereavement	--obtained from the Denver, Colorado county coroner's office  --beginning of study  E)= N=54 C)= N=122 C)= N= 158  --6 month observation  E)= N=39 C)= N=66 C)= N=56  --18 month observation  E)= N=32 C)= N=54 C)= N=40	--intervention occurred within 1 hour of the death and lasted from 1-10 weeks (mean was 5.56 sessions)  --intervention focused on increasing the effectiveness of the family in coping with feelings, decisions and problems of adjustment	--coping abilities, social adjustment	--medical and psychiatric rating scales  --questionnaire identified circumstances surrounding the death, coping behaviors and family functioning  --factor analysis	--no significant differences on pretreatment dimensions when the death and no death groups were compared --at 6 months post death, the experimental group showed higher concern for work, family, and socioeconomic well being-- they also tended to be slightly more depressed with a need to seek help, had more illness, more coping problems and disturbed social functioning than the non-	bereaved group --at 18 months post-bereavement more practical problems (financial) were evident in the experimental group --short term crisis intervention produced no major differences between experimental and control subjects at 6 and 18 months --intervention may have delayed or interfered with the normal bereavement process  CRITIQUE  high attrition rate in the study -- mismatching of control and support groups

Table 2.3: Bereavement Interventions (continued)

Authors	Year	Design	Sample	Independent Variable(s)	Independent Variable(s) c.	Methods of Analysis	Results	Results cont.
Mawson, D., Marks, I. M., Ramm, L., and Stern, R. S.	1981	waiting period R E ) X 0 1 E ) X 0 2	--after 2 weeks on a waiting list 12 patients were randomly assigned to one of two treatments  --inclusion into the study identified individuals who had complained of distress that was longer than one year duration  --the loss that was experienced was between 1 and 10 years  --11 of the subjects were women  E )= N=6 1 E )= N=6 2	--guided mourning treatment  --6, 1 1/2 hour sessions given 3 times a week for a 2 week period  --follow-up was done 28 weeks after entering the trial  --intervention was conducted by a psychiatrist or a nurse therapist  --the first intervention group was encouraged to face cues concerning their bereavement such as painful or avoided memories--they were encouraged to write at least a page a day about the deceased	-the second intervention group was encouraged to avoid thinking of the deceased and used distraction and relaxation as thought stopping mechanisms  -they were encouraged to write a page a day about friends	--pathology of grief  --physical symptoms of grief	--patients rated themselves at weeks 0, 2, 4, 8, 12, and 28 weeks  --there were no observer ratings  --bereavement avoidance tests  --13 physical symptoms associated with grief developed by Maddison & Viola  --hostility, anger and guilt scale  --Texas inventory of grief  --attitude to self and deceased scale  --Wakefield depression questionnaire  --Anxiety scale developed by Watson & Marks  --fear questionnaire	--the first intervention group showed improvement in behavioral avoidance tests and distress, which was maintained at 28 weeks  --the second intervention group showed no significant signs of improvement -compulsive activity checklist -social adjustment scale  CRITIQUE  -small sample -no control group

Table 2.3: Bereavement Interventions (continued)



Authors	Year	Design	Sample	Independent Variable(s)	Dependent Variable(s)	Methods of Analysis	Results	Critique
Horowitz, M. J., Marmar, C., Weiss, D. S., DeWitt, K. N., and Rosenbaum R.	1984	E) 0 X 0	--52 bereaved patients, who came seeking therapy after the death of a parent or spouse, presenting with symptoms related to the grief response (sleep disturbance, anxiety, guilt, anger)  --average time from death to therapy was 35 weeks	--time limited dynamic psychotherapy --goal was to reduce symptoms and disturbances in social and work functioning  --sessions were conducted by faculty therapists in a university clinical research center  --12 time limited sessions, once a week for stress response syndrome--focus was on the implications of the loss of a relationship to self conceptualization and to facilitate the normal grieving response	--stress specific symptoms  --general psychiatric symptoms  --work and interpersonal functioning	--identified the relationship between dispositional, process and outcome variables  --Hollingshead & Redlich educational classification --Impact of Event scale --patient self-reported questionnaire  --Stress Response Rating scale --Hopkins Symptom checklist --Brief Psychiatric Rating scale  --Patterns of Individual Change scale --Factor Analysis --ANOVA --Therapeutic Alliance scale --Measures of therapist and patient action --Patient motivation for psychotherapy assessment --Developmental level of the self-concept assessment	--symptoms improved more than did the social and work functioning  --more exploratory actions were more suitable for highly motivated and/or better-organized patients and less suitable for patients with low levels of motivation or organization of self-concept  --more supportive actions were more suitable for patients at lower dispositional levels and less therapeutic for patients at higher levels --predictors of outcome were related to the organizational level of the self-concept for therapy and motivation for therapy	--reliability and validity of the instruments were not reported for this population  --no control group

## 2.10 SUMMARY TO THE LITERATURE REVIEW

In summary, research into the area of bereavement has revealed a wealth of information. The basic symptomatology of grief has been explored, as well as the effects of bereavement on morbidity and mortality. It is clear from research on the effects of bereavement on physical and mental health that bereavement places added stress on the individual which may result in illness or even death. Prediction of individuals at risk for a poor bereavement outcome is complicated by the fact that there is little agreement as to what actually constitutes a good or bad bereavement outcome. The strongest predictor of positive adjustment in the period of bereavement is an effective social network. There needs to be further research into the variables which predispose the individual for a good or bad outcome. Interventions useful in facilitating the grieving process and preventing the consequences of bereavement are beginning to be explored. The literature suggests that adjustment is enhanced through techniques such as the mutual support approach or hospice follow-up. Evidence from the mutual support approach would indicate that individuals who become actively involved in the group are more likely to benefit from its effects. This raises the question of which approach is most helpful for individuals who attend groups but are not actively involved. Research from palliative care areas would indicate that families cared for in the setting are more likely to have positive adjustment in the

period of bereavement than are matched control groups. Research can be expanded in two major ways. Firstly, research needs to be directed at the identification of individuals at risk in the period of bereavement. From this point effective interventions can then be explored to ameliorate the effects of the grieving process. This information has the potential to guide nursing practice, and most importantly to promote a better quality of life for the bereaved individual.

## Chapter III

### METHODS

The following chapter will discuss the methodological considerations for the study. Items to be considered are the design, the variables, review of measures, sampling, threats to validity, procedures, and data analysis.

#### 3.1 DESIGN

The design for the study was quasi-experimental with one experimental group and two nonequivalent control groups. The study used a one-way longitudinal repeated measures design.

A pretest measure was taken within seventy-two hours of the patient being admitted to the palliative care unit to try to determine the effects of anticipatory grieving. At St. Boniface General Hospital a second pretest measure was initially planned to be taken at one month from admission if the patient had not died to analyze the effect of the length of the dying trajectory. However, when a situation like this arose the patient was near death and the investigator did not feel it was appropriate to disrupt the family at that time. The treatment for the experimental group was implemented from admission to approximately six months post-

death. At the time of the death of the patient the experimental and the control groups were divided into high and low risk categories based on the work of Parkes and Weiss (1983) and Raphael (1977). The palliative care unit at the St. Boniface Hospital used a form devised by the Boulder County Hospice in Colorado. The rating of risk at St. Boniface Hospital was part of the bereavement program and not part of the actual study. Outcome measures were taken at six to eight weeks, six months, and twelve months post-death. Analysis of the data for this thesis consisted only of information from the pretest and the first posttest at six weeks post bereavement. For a visual description of the treatment and testing measures, see Figure 3.1.

The quasi-experimental design was chosen in preference to a randomized experiment because of the ethical issue of withholding treatment from a control group of subjects. This investigation was designed to be a pilot study to determine the treatment effects of a bereavement follow-up program in the absence of randomization.

		admission	2-4 weeks post death	5 weeks post death	6 months post death	12 months post death
GROUPS	EXP.					
	High Risk	symptom control, ed.	card	phone call home visit	bereavement social evening	phone call
	Low Risk	symptom control, ed.	card		bereavement social evening	
	CONTROL 1					
	High Risk					
	Low Risk					
CONTROL 2						
High Risk	symptom control, ed.	card	phone call home visit	bereavement social evening	phone call	
Low Risk	symptom control, ed.	card		bereavement social evening		

Figure 3.1: Time Line of Treatment of Study Population

Figure 3.1 (continued)

Time Line of Measurement of Study Groups

GROUPS			admission	death of patient greater than 4 weeks from admission	6-8 weeks post death	6 months post death	12 months post death
EXP	High Risk	pretest			posttest	posttest	posttest
	Low Risk	pretest			posttest	posttest	posttest
	High Risk	pretest			posttest	posttest	posttest
	Low Risk	pretest			posttest	posttest	posttest
CONTROL 1	High Risk	pretest			posttest	posttest	posttest
	Low Risk	pretest			posttest	posttest	posttest
	High Risk	pretest			posttest	posttest	posttest
	Low Risk	pretest			posttest	posttest	posttest
CONTROL 2	High Risk	pretest	pretest		posttest	posttest	posttest
	Low Risk	pretest	pretest		posttest	posttest	posttest
	High Risk	pretest	pretest		posttest	posttest	posttest
	Low Risk	pretest	pretest		posttest	posttest	posttest

### 3.2 THE INDEPENDENT VARIABLE

The independent variable for the study was a bereavement follow-up program which began before the death of the patient and extended into the period of bereavement. Pre-death support consisted of facilitating the expression of anticipatory grief, providing optimal care and symptom control, fostering open communication between the patient, family, and health care workers, encouraging the family to participate in care and death activities (if appropriate), and making families aware of the bereavement services which existed after the death had occurred.

Bereavement counselling offered to the family was slightly different depending on whether the families were assessed as high or low risk. For low risk families a bereavement card signed by the staff of the palliative care unit was sent at four weeks postbereavement. At six to nine months a bereavement social evening was held where the families were invited back for an informal evening providing the opportunity of renewing old acquaintances.

For families rated as high risk the bereavement card signed by the palliative care staff was sent between two and four weeks after the death. Individuals who were thought to be particularly at risk were generally contacted by the unit social worker rather than a trained volunteer. Inside the bereavement card the volunteer who had been assigned to the

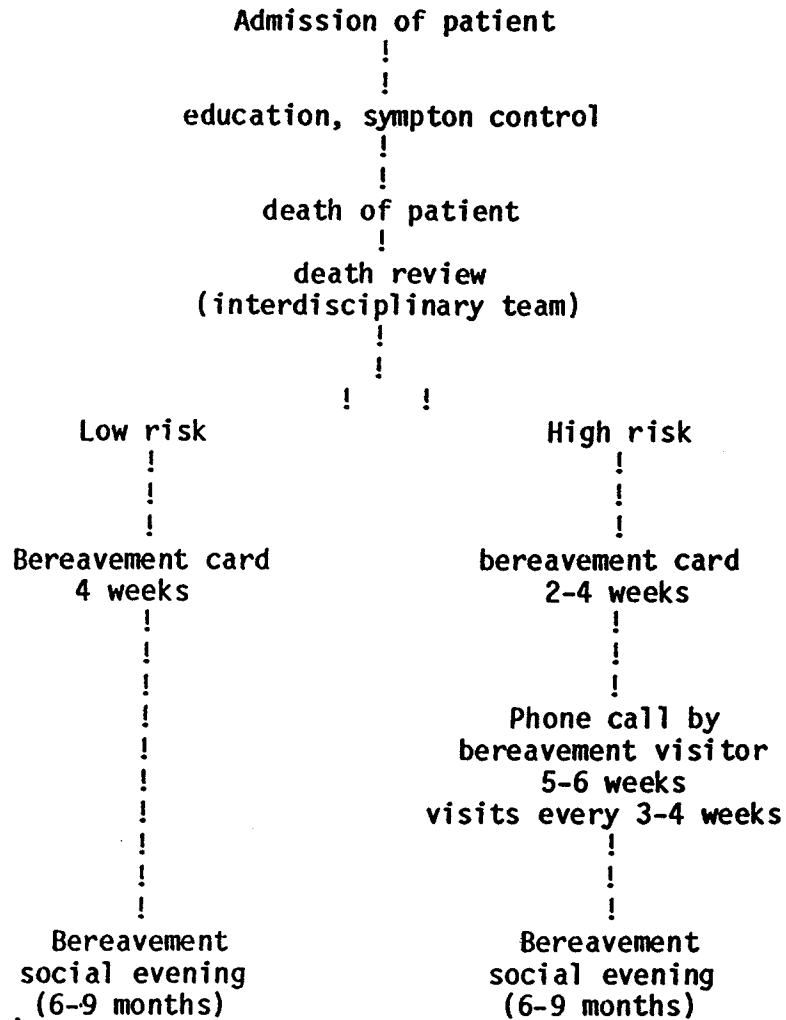


family would write a personal note indicating that he/she would be contacting the family in a short time. At five to six weeks the volunteer contacted the family by telephone to assess how they were doing and to offer further contact by telephone or an in-home visit. Contact continued every three to four weeks for a period of six months. Contact was renewed at one year, the anniversary date of the death. Bereavement counselling was directed at assisting the individual with the tasks of mourning. At six to nine months postbereavement, the high risk families were also invited to the bereavement social evening.

The volunteers for bereavement counselling were nurses, lay individuals, or social workers who were provided with twelve and a half hours of training which consisted of; (a) normal and abnormal grief; (b) children's grief; (c) general interviewing techniques; (d) community resources; (e) grief counselling; (f) the caregiver's stress and how to handle it; and (g) implementation of the program. The volunteers were also provided with twelve and a half hours of training in palliative care philosophy when they first began working in the area as well as ongoing education. The majority of the volunteers had been working in the area for years and had well developed communication skills. For a visual description of the program see Figure 3.2.

Figure 3.2:

## SBGH Palliative Care Bereavement Program



### 3.3 THE DEPENDENT VARIABLES

The first dependent variable for the study was bereavement experience. The following theoretical definitions were used to guide the study in the effect of the bereavement program on the bereavement experience.

1. Bereavement: "the loss of, or separation from an object depended upon for sustenance, comfort, and security" (Lindemann, 1957). This definition was also used by Vachon (1976) to guide her research.
2. Grief: "the normal state resulting from a loss" (such as bereavement) (English & English, 1958).
3. Bereavement Experience: was viewed as consisting of the following items:

guilt: "A sense of being accountable for violating a standard or for failing to live up to one's own or society's expectations. Guilt may result from actual or perceived acts of omission or commission, manifest as feeling at fault; responsible, evil, wrong, remorseful, sinful, or blameworthy" (Demi & Schroeder, 1985, p. 6-7).

anger: "A feeling ranging from mild irritation to rage. This anger may be directed at self, other persons, or at situations or objects" (Demi & Schroeder, 1985, p. 7).

yearning: "Thoughts and feelings focused on the deceased. Includes searching and ruminative behavior, and a sense of closeness to the deceased. May be manifested as dreams or hallucinations, or as intense efforts to recall the deceased" (Demi & Schroeder, 1985, p. 7).

depersonalization: "A sense of unreality, shock, or numbness, feeling apart from the world, or being unable to control one's thoughts and feelings" (Demi & Schroeder, 1985, p. 7).

stigma: "A feeling of being discredited, ashamed, tainted, or discounted. Results in avoiding of people or being avoided because the stigmatized person makes others feel uncomfortable. This, in turn, leads to feelings of blame and rejection" (Demi & Schroeder, 1985, p. 7).

morbid fears: "Feelings of fear and anxiety related to death or threat of death, or preoccupation with thoughts of death" (Demi & Schroeder, 1985, p.7).

meaninglessness: "A feeling of loss of interest and loss of relevance of persons and activities previously meaningful. A sense of being without purpose for living or without interest in living" (Demi & Schroeder, 1985, p. 7-8).

isolation: "Social isolation, characterized by feeling shut off from involvement with others or feeling a need for an intimate relationship with another person" (Demi & Schroeder, 1985, p. 8).

For the purpose of this study, bereavement experience was operationalized as scores on the Bereavement Experience Questionnaire (Demi & Schroeder, 1985). Consent for the use of the scale was obtained from the authors. Bereavement Experience was also assessed by using a qualitative questionnaire developed by the author with input from F. Nelson (Social Worker) and A. Neufled-Wiens (Volunteer-Coordinator). Items on the questionnaire addressed themselves particularly to aspects of the bereavement program such as the card, counselor and the social evening (see Appendix A).

The second and third dependent variables were physical and psychological health. The following theoretical definitions were used to guide the study with respect to the effects of the bereavement program on physical and psychological health.

1. Health: as based on the adaptation model was not simply the absence of disease but rather existed when the organism was in a condition where it could engage in effective interaction with its physical and social environment. Conversely, disease was viewed as a

failure in adaptation where the organism was no longer able to cope with changes in its environment (Dubos, 1965). Health was not viewed as a static state but was rather dynamic and fluctuating. Individuals experienced varying degrees of health and illness.

2. Physical Health: was the absence of biological symptoms indicating disease and signifying the individual's inability to adapt to changes in the environment. Physical health was also present when biological symptoms were present but the individual was coping effectively with them.
3. Psychological Health: was the absence of psychological symptoms indicating mental illness and signifying the individual's inability to adapt to changes in the environment. Psychological health was also present when psychological symptoms were present but the individual was coping effectively with them.

For the purpose of this study physical health was measured on a questionnaire which was compiled by considering literature in the area of physical health and bereavement (Glick et al., 1974; Maddison & Viola, 1968; Parkes, 1972) (see Appendix A). Psychological health was operationalized as scores on the 28-item General Health Questionnaire (GHQ) (Goldberg & Hillier, 1979). Consent for the use of the scale was obtained from NFER publishing company.

The fourth dependent variable was social functioning. The following theoretical definition was used to guide the study with respect to the effect of the bereavement program on social functioning.

1. Social Functioning: "is the interplay between the individual and the social environment. Specific ways of behaving, referred to as roles, are commonly accepted as appropriate and the individual is perceived in terms of the way his role performance conforms to the norms of his referent group" (Weissman, 1975).

Social functioning was also operationalized on the General Health Questionnaire which focused on the individual's ability to carry out one's normal functioning, role satisfaction, and outwardly observable behavior (Goldberg, 1978).

### 3.4 REVIEW OF MEASURES

The two primary tools used in the study were reviewed from the perspectives of reliability, validity and use in bereavement research to determine their applicability for the study.

### 3.4.1 The Bereavement Experience Questionnaire

The bereavement experience questionnaire was a self-administered, sixty-seven item scale which had a four point scoring system: never, sometimes, often, and almost always (Demi & Schroeder, 1985). The questionnaire requested that the respondent consider the past four weeks when responding. The scale was used in the pretest with slight alterations in wording. Minor changes in terminology consisted of changing the word "deceased" to patient and "death" to illness. (see Appendix A for the Bereavement Experience Questionnaire and necessary revisions).

The questionnaire was initially designed for use in a bereaved parent population. It was tested on a group of bereaved parents with revisions made on the basis of their suggestions and was further tested for content validity by two experts in the area of bereavement. Because there was a need for the questionnaire to be applicable to a larger population, the scale was again revised. The manifestations of bereavement were further explored and bereavement experience was identified as consisting of the following subscales: guilt, anger, yearning, depersonalization, stigma, morbid fears, meaninglessness, and isolation.

Reliability of the subscales was tested in a group of sixty-six respondents. "The alpha coefficients for the subscales were as follows: guilt, .80 (17 items); anger,



.72 (9 items); meaninglessness, .88 (8 items); yearning, .82 (10 items); depersonalization, .71 (5 items); stigma, .65 (6 items); morbid fears, .79 (6 items); and isolation, .78 (4 items)" (Demi & Schroeder, 1985, p. 9). All the subscales met the 0.70 minimum standard for internal consistency reliability except the stigma subscale.

Overall distress was evaluated by using a Likert scoring method of one to four for each of the responses, totalling the number and dividing by sixty five. Questions six and sixty-two were not part of any subscale and were therefore omitted from analysis. Evaluating the distress found in each subscale was done by totalling the perspective category and dividing by the number of items found in it.

#### 3.4.2 The General Health Questionnaire

The General Health Questionnaire (GHQ) is a self-administered screening test originally used to detect nonpsychotic psychiatric disorders in a general medical practice setting and concerns itself with two major classes of phenomena: inability to carry out one's normal healthy functions, and the appearance of new phenomena of a distressing nature (Goldberg, 1972; Goldberg & Hillier, 1979). The scale was initially designed to include sixty items but to try and decrease the time taken to complete the test, shortened versions were attempted. The 28-item scaled questionnaire was composed of four subscales: somatic

symptoms, anxiety and insomnia, social dysfunction and severe depression (Goldberg & Hillier, 1979). The scores ranged from 0 to 28 (0,0,1,1) when a single severity score was needed, and a score of five or more indicated a level of distress sufficient to warrant further assessment. When assessment of the individual subscales was required a scoring system of 0,1,2,3 with a range of 0 to 21 was used as this correlated more closely with clinical measures. Vachon (1980) previously used the scale to assess overall disturbance rather than case identification.

Two types of reliability for the 60-item GHQ and the 30-item GHQ were computed. The scores of the 60-item test are provided first, followed by the 30-item GHQ. Split-half reliability was computed by dividing the test items into two closely comparable subpopulations and was found to be +0.95 and +0.92 (Goldberg, 1972). Test-retest reliability which was done by administering the test to the same respondents on different occasions was also conducted. Methodologically this was difficult to implement but was important as the sensitivity of the scale to changes over time or stability was crucial. Three groups of patients were used to assess test-retest reliability. Those who used the questionnaire and were also rated by the psychiatrist on each occasion (reliability +0.90), patients who rated themselves as staying the same (reliability +0.76 and +0.77), and those who in their doctors opinion stayed the same (reliability +0.51 and +0.53) (Goldberg, 1972).

Validity, which looks at whether the quality measured has some relationship to an external variable that is thought to be relevant and important, was found to be +0.80 and +0.80 in general practice and +0.77 and +0.72 for patients of a medical outpatient department (Goldberg, 1972). Correlation coefficients between the 28-item GHQ scale scores and independent clinical measures were taken for three of the scales (somatic symptoms, anxiety and insomnia and severe depression). Correlations ranged from 0.32 to 0.73. Intercorrelations between the four scales and the total GHQ ranged from 0.69 to 0.90. Goldberg and Hillier (1979) stated that the scaled version of the GHQ was particularly useful if administered before and after a treatment as it allowed the clinician/researcher to examine where the external event had its greatest effect. This characteristic of the scale made it especially useful for the examination of the effectiveness of a bereavement program.

Studies by Goldberg (1978) and Goldberg, Rickels, Downing and Hesbacher (1976) indicated that the GHQ score correlated fairly well (.70 or better) with clinical assessments and a 35-item Hopkins symptom distress checklist. Both the GHQ and the SCL worked better with men than women and with whites as compared to blacks but neither was affected by social class or the age of the respondent (Goldberg et al., 1976).

The 30-GHQ had been previously used in bereavement research by Vachon et al. (1980) and Forrest et al. (1982). The scale was particularly useful for the study as changes which occurred in psychiatric disturbance over time could be identified. As the American version of the 30-item scale was no longer available, the 28-item American version was used in this study.

### 3.5 SAMPLE AND SETTING

The population for this study was taken from two intact groups, from areas where palliative care services were offered. Non-probability sampling was used. Initially it was planned to obtain twenty subjects from each group but because of the already stated difficulty with the second control group it was dropped from the sample (see Figure 3.3).

FIGURE 3.3 DESCRIPTION OF SAMPLE SIZE		
	high risk	low risk
E	10	10
C-1	10	10
C-2	10	10

1. The Experimental Group: St. Boniface General Hospital, Palliative Care Unit--family members or significant others of individuals who died within one month of being admitted to the unit.
  
2. The First Control Group: Winnipeg Municipal Hospitals, Princess Elizabeth Hospital, Palliative Care Unit--family members or significant others of individuals who died on the unit.
  
3. The Second Control Group: St. Boniface General Hospital, Palliative Care Unit--family members or significant others of individuals who did not die after being on the ward one month.

The palliative care unit at the Princess Elizabeth Hospital was chosen as a control group because it did not have an established bereavement program. Pre-death support at the Princess Elizabeth Hospital centered around symptom control and comfort measures with minimal "formalized" consideration given to the facilitation of the grieving experience of the family. The Princess Elizabeth Hospital also did not provide the family with after-death support in the form of a card, visitation or other type of follow-up. This differed from the care provided at the St. Boniface General Hospital where a structured program for the facilitation of anticipatory grief (education, involvement

of the family in care) was used and coordinated bereavement follow-up was provided.

Criteria for admission to the study applied to the family member or significant other and included the following:

1. ability to read, speak and write English
2. 18 years of age or older
3. family member's (ie., the patient) first admission to the palliative care unit
4. family member's (ie., the patient) admitted to the hospital less than seventy-two hours
5. informed written consent

The individual chosen from each family was the person deemed the primary caregiver or contact person by the staff nurses in the respective hospitals. In most cases this person was a spouse, child, or sibling of the patient.

### 3.6 THREATS TO VALIDITY

Threats to validity can occur in the absence of a randomized experiment (Cook & Campbell, 1979). Each of the following threats to validity- statistical conclusion, internal, construct, and external (as discussed by Cook & Campbell, 1979)- were taken into consideration in the design and analysis of the investigation. Examples of each of the particular threats as they applied to the study are discussed.

### 3.6.1 Statistical Conclusion Validity

Threats to statistical conclusion validity dealt with errors related to the statistical analysis of the data and to the interpretation of acceptance or rejection of the null hypothesis (Shelley, 1984). As the sample size for the study was low (N = 40) there was low statistical power and a chance of making a Type II error, or concluding there was no effect from the treatment when there really was. To compensate for this limitation the results of the study were used primarily to detect or describe changes which occurred over time in the experimental and control groups.

The second threat to statistical conclusion validity was the reliability of treatment implementation. The treatment offered by different persons may have varied as may treatment offered by the same person over time. In bereavement follow-up there had to be some variability in the treatment due to the individual differences in the clients. An attempt to standardize treatment as much as possible was undertaken through the education of the volunteers implementing the program. A total of twelve and a half hours were initially used to educate volunteers in; (a) normal and abnormal grief; (b) children's grief; (c) community resources; (d) general interviewing techniques; (e) grief counselling; (f) the care giver's stress and how to handle it and; (g) implementation of the program. The total number of educational hours was not as extensive as

some bereavement programs since the volunteers were taken from the group of palliative care volunteers and had received previous training (twelve and a half hours). As the ability to standardize the treatment in this situation was weak, data was collected on the variability of the treatment over time and between volunteers through information collected on the bereavement reports.

Statistical conclusion validity was also threatened by random irrelevancies in the experimental setting. The treatment may have been enhanced or decreased by factors such as support from other sources, additional life crises, and factors affecting the quality of care such as the use of large numbers of causal staff, etc. Many of the irrelevancies in the experimental setting would naturally affect how an individual adjusts in the bereavement period or the expected bereavement outcome. It was not possible to minimize the irrelevancies in the environment but data could be collected to detect if they were present.

Random heterogeneity of respondents may have also affected statistical conclusion validity. Respondents who chose palliative care over active care may have been different on some measures which made them more likely to participate in a bereavement program. Heterogeneity was dealt with by using a pretest--posttest design to identify differences within subjects over time (Cook & Campbell, 1979).



### 3.6.2 Internal Validity

Internal validity looks at the causal link between the independent and dependent variables (Shelley, 1984). It was imperative to identify any threats to the internal validity of the experiment as this would provide information as to what type of variables other than the treatment brought about the observed effect.

The first threat to internal validity was history. This threat relates to an event which may occur between the pre and posttest which is not related to the intervention. History may have been present in either group in the form of additional life crises, traumatic circumstances surrounding the death, etc. These events could not be controlled for but data could be collected to detect their presence.

Maturation is the threat that an observed effect may be due to the respondents growing older or wiser, and may have been particularly operative between the pretest and the first posttest measurement. When the dying period is lengthened (greater than one month from admission) the family could possibly react in one of two ways. The extended dying period may be a source of positive adjustment as the potentially bereaved person has greater time to adjust to the impending death and life without the deceased, or it may be a source of negative stress as the physical and emotional resources of the potentially bereaved person

become depleted. To understand the possible effect of maturation a second control group was used from the palliative care ward to measure change in functioning which occurred after one month of hospitalization.

Testing may also have been a threat to validity as the individual remembered the responses of the previous test. This was minimized by encouraging the respondent to concentrate on the time period from the previous testing phase. Caserta, Lund, and Dimond (1985) assessed the effects of the interviewer in a longitudinal study of bereaved elderly adults. They found that there was no difference in response depending on whether the assessment was conducted by an interviewer or mailed out by questionnaire. The one difference they were able to identify was the fact that response rates were greater for the interviewers than for the questionnaire.

It was possible that there was selection bias between the experimental and the control groups. There may have been differences in age, socio-economic status, relationship to the patient, and education between the groups from the two hospitals.

Attrition is generally high in studies of bereavement. Vachon (1980) found some evidence to suggest that bereaved individuals who dropped out of the research were different than those who remained. Individuals who withdrew from the

study often lacked social support, had younger husbands, more psychological and health problems, a higher initial score on the General Health Questionnaire and were of lower social class than those who remained in the study. Therefore, it appeared that individuals who dropped out of the study may actually have shown some benefit from the intervention. Attrition was decreased by the fact that this study was being conducted for the purpose of program evaluation rather than directly concentrating on the bereaved person.

### 3.6.3 Construct Validity

Construct validity consisted of determining that the construct or operation was measuring what it says it was measuring (Shelley, 1984). Hypothesis guessing in which the respondent wished to guess the "correct" or desired response was not of difficulty as individuals were asked to rate a program. Pressure to create a good impression was further removed by the fact that the interviewer was not directly associated with the bereavement program and therefore did not have any vested interests.

Evaluation apprehension, in which the respondent wants to appear competent and healthy, was removed by stressing that the program was being evaluated and not the person. Experimenter expectancies may have operated in the study as the interviewer was expecting certain outcomes based on the literature. Continual checks for objectivity were employed.

#### 3.6.4 External Validity

External validity is "the extent to which results of a research study can be applied or generalized to other persons, settings, and times" (Shelley, 1984, p. 238). As intact groups were used and one particular program was evaluated, generalizability of the study was limited.

### 3.7 PROCEDURES

A self-administered questionnaire was compiled by the investigator (see Appendix A). The first portion of the questionnaire requested information on potentially confounding variables such as age, sex, socio-economic status, relationship to the patient/deceased, education, religion, length of illness and employment status. The second portion of the questionnaire requested information relating to the respondents health. The third and fourth portions of the questionnaire consisted of the Demi Bereavement Experience Questionnaire and the Goldberg General Health Questionnaire. The final portion (section five) of the questionnaire asked the respondent's opinion of specific aspects of the program such as the bereavement card, the telephone call and the bereavement social evening. Following the questionnaire, a short interview was held with the respondent to discuss items such as the circumstances surrounding the illness/death, perceived social support and additional life crises. The technique of using a short

interview section was suggested by Vachon (1980) as a means of obtaining sensitive data. The pretest consisted of using sections one to four and the short interview. The posttests at six weeks and six months consisted of sections two to four and the short interview. The posttest at one year also used section five. Section five was not administered to the first control group. Each of these sessions took approximately forty-five to sixty minutes of the respondent's time. When tested on six non-stressed individuals, the questionnaires and interview took approximately thirty minutes to complete.

After the study had received approval from the University of Manitoba School of Nursing Ethical Review Committee, and University of Manitoba, Faculty of Medicine, Committee on the use of Human Subjects in Research, permission for entrance into The St. Boniface General Hospital and The Winnipeg Municipal Hospitals was cleared with both the medical and nursing divisions. After approval from all areas was granted, arrangements were made with each of the palliative care wards to begin data collection. Procedures for the collection of data at both the Princess Elizabeth Hospital and St. Boniface Hospital were the same before the death occurred. At both hospitals the investigator called the ward daily to see if any patients had been admitted to the unit. If there had been an admission the staff nurse approached the family member and requested permission to

forward the respondent's telephone number to the investigator. The investigator then contacted the family member by telephone to explain the purpose and gain their interest in the study. An appropriate meeting time was arranged. The respondent had the option of meeting with the investigator in the respondent's home or in the hospital. At the time of the meeting the respondent was supplied with a cover letter which explained the purpose, risks etc of the study, a consent form and a questionnaire (Appendix A). The consent form was signed and collected prior to any information being supplied. After obtaining informed consent the investigator supplied the respondent with explanations regarding questionnaire completion. After the questionnaire was completed the investigator administered the interview, writing down the respondent's answers. When the procedure was complete the investigator thanked the respondents for their participation and reminded them of the follow-up contact.

The only difference in the procedure for data collection between the St. Boniface and Princess Elizabeth Hospitals was the rating of "risk" of the family at the death of the patient. At the St. Boniface Hospital, after the patient had died, risk status of the family member was determined at an interdisciplinary meeting called "Death Review". Death Review notes were examined to determine the health care workers perception of the circumstances surrounding the

death. The bereavement contact forms were used to gather information on the specific type of intervention which was provided by the bereavement counselor. At the Princess Elizabeth Hospital risk status was determined by the head nurse or team member who had closest association with the family, in consultation with the investigator.

A similar procedure occurred at each of the posttest sessions. The respondent was asked to sign a second consent form at the first posttest meeting (Appendix A).

The matching of the pre and posttest questionnaires was accomplished by a coding system which used the respondent's first and last initials and the month and year of their birth. Coding of the questionnaires was done to maintain the confidentiality of the respondent. Raw data was stored in a locked filing cabinet at the investigator's residence.

### 3.8 PROTECTION OF THE RIGHTS OF THE SUBJECTS

A potential risk to the subjects consisted of the fact that they were asked to discuss or recall potentially distressing subject matter. This risk was minimized by informing the subjects that they were permitted to answer only questions with which they felt comfortable. As this risk could not be eliminated, it was the investigator's responsibility to be sensitive to the verbal and non-verbal actions of the respondents and to discontinue the interview

when necessary. Worden (1982) commented that allowing individuals to talk about their bereavement experience is the most beneficial way of assisting them with the process of mourning. The actions taken by the investigator in cases where the subjects became upset were based on the expertise of the investigator in working with dying and bereaved families. After assessing the situation, the investigator took actions which interrupted or discontinued the interview and provided support through presence, touch and discussion. In extreme cases of distress the investigator took on the role of counselor and discarded the data. The subject was not left until the investigator deemed this to be appropriate. In such cases the social worker from the respective hospital was also contacted so that follow-up could be accomplished.

The family member was experiencing stress before and after the death of the patient occurred which may have resulted in fatigue. Completing the questionnaire may have added to the sense of stress and fatigue, and the respondent was encouraged to stop the procedure at any time should fatigue result. The investigator as previously stated was sensitive to what the respondent was conveying.

Formal protection of the subject was supplied by submitting the proposal to the University of Manitoba, School of Nursing, Ethical Review Committee, Faculty of Medicine, Committee on the use of Human Subjects in



Research, and each of the agencies before data collection began. All participation in the study was voluntary and subjects were requested to sign a consent form after reading an explanation about the study. Subjects were given a copy of both the written explanation of the study and the consent forms for their records. Participants were also informed of their right to withdraw from the study or withhold answering questions without it affecting their care. The confidentiality of the respondent was maintained by using a coding system and data was analyzed from a group perspective so individual responses could not be detected. The investigator, her thesis committee, and a statistician were the only individuals who had access to the raw data. Raw data from the bereavement experience questionnaire will be made available to A. Demi for further development of the scale. A summary of the results of the study will be made available to respondents who request this information.

### 3.9 LIMITATIONS OF THE STUDY

There were a few limitations to the study which may affect its effectiveness but which if recognized, still made it possible to glean important information. The first difficulty with the study was the fact that it was impossible to standardize the treatment. In looking at the benefits of the intervention it was difficult to ascertain

which portion of the intervention was most helpful. To minimize this effect records were kept on how the intervention varied between counselors and varied with the same counselor over time.

The second limitation of the study was that generalizability of the findings was limited due to the use of intact groups. As the purpose of the study was to assess the effectiveness of a particular program, this limited generalizability was acceptable.

### 3.10 SUMMARY

This chapter has discussed the methods used for the study to determine the effect of the St. Boniface General Hospital bereavement program on the bereavement experience, physical and psychological health, and social functioning of the individual. The study used a one-way repeated measures design with one control and one experimental group. The study was designed in light of the threats to validity as discussed by Cook and Campbell (1979).

## Chapter IV

### DATA ANALYSIS

The analysis of the data is presented in a way as to illustrate the analytic process which the researcher used in interpreting the data. First the sample size was analyzed to determine its statistical power, and to determine if there were any differences in the demographic characteristics between the experimental and control groups. A check for the normality of the data was then run; the mean scores on each of the dependent variables were analyzed; and an analysis of covariance was conducted to determine the effect of the bereavement program on the dependent variables. After the quantitative analysis of the data had been conducted, qualitative analysis of the interview guides was done to assist the investigator in understanding the quantitative results.

#### 4.1 SAMPLE SIZE AND POWER ANALYSIS

The sample size was analyzed to determine response rates at the pretest and attrition at the posttest (see Table 4.1). Ninety individuals were approached to participate in the study. Of the ninety who were approached, thirty-eight or 42% did not participate. There were no major differences

in participation rates between the control and experimental groups. The primary reasons for not participating in the study were: (a) the situation was currently too stressful; (b) the patient died before an interview could be accomplished; and (c) the patient was discharged before an interview could be conducted. See Table 4.2 for a summary of the results. No attempt was made to determine if the individuals who participated in the study were different from those who did not participate. As the most common reason given for not participating in the situation was that it was too stressful, it might be assumed that these individuals would have fallen into the high risk categories.

	Participants Approached	Negative Response	Positive Response
Control	45	20 (0.44)	25 (0.56)
Experimental	45	18 (0.40)	27 (0.60)
Total	90	38 (0.42)	52 (0.58)

No differences were apparent between groups.

The attrition rate at the first post test was 12% with no differences apparent between the experimental and control groups (see Table 4.3). As no bereavement studies in the literature had been conducted with a pretest prior to the

Table 4.2 Reasons for not Participating in the Study

Situation was too stressful	EEEECCCC	9
Patient died	EEEECCC	7
Patient discharged	EEEEC	5
Low comprehension	EECCC	5
Unable to reach respondent	EC	2
Unable to set time to meet	EE	2
Lack of knowledge of the unit	EC	2
Respondent became ill (cancel)	E	1
Interview was not completed	E	1
Investigator stopped interview	C	1
Did not want to talk about family	C	1
Too busy to participate	C	1
Too old to participate	C	1
TOTAL		38

death it was not known whether this drop-out rate was comparable. For bereavement studies in general, an attrition rate of 12% was low. The primary reason for attrition was related to the lack of desire on the part of the respondent to discuss the circumstances surrounding the death and the subsequent bereavement. Most of the respondents who did not want to continue in the study felt that the stress incurred during the discussion would not be of any benefit to them. All individuals who continued to participate stated that it was beneficial for them to do so as it provided them a means of airing some of their feelings and frustrations. One individual from the control low-risk group was omitted from further analysis as the results of the respondent's scores showed a great deviation from the remainder of the scores.

Table 4.3 Attrition Rate for the Study			
Attrition			
	No Death	Negative Response	Positive Response
Control	5 (0.20)		
High		2 (0.08)	7 (0.28)
Low		1 (0.04)	10 (0.40)
Experimental	7 (0.26)		
High		1 (0.04)	6 (0.22)
Low		2 (0.07)*	11 (0.41)
Total	12 (0.23)	6 (0.12)	34 (0.65)

\* Respondent omitted from the sample as the patients' death did not occur on the PCU

A retrospective power analysis was performed to determine the investigator's ability to detect the effect of the bereavement program on the dependent variables given the analytic models used and the sample sizes which were collected. The power analysis was conducted by J. Sloan (statistician) using Cohen's (1969) method. The probability of correctly detecting a small difference between the groups was 7%; a moderate difference between the groups was 21%; and a large difference between the groups was 51%. As can be seen the ability to detect differences between the groups was very limited and therefore looking for trends and nuances in the data was crucial.

#### 4.2 CHARACTERISTICS OF THE SAMPLE

The sample was also examined to identify differences in the demographic characteristics of the participants. The primary characteristics to be analyzed were age, sex, religious preference, educational background, employment status, socioeconomic status, and relationship to the patient/deceased. All of the variables except age were calculated using frequency tables and then subjected to chi-square analysis.

Chi-square analysis is primarily used on nominal data and determines whether the "frequencies observed in a sample deviate significantly from some theorized population frequency" (Knapp, 1985, p. 247). The sex distribution of the two groups did not differ significantly. In examining the data there did appear to be slightly more females in the control group and slightly more males in the experimental group although this difference was not significant (see Table 4.4).

Religious preference was also examined to see if there were any differences between the groups. The chi-square test revealed that the samples were the same. As 50% of the cells had expected counts less than five, the test may not have been valid. Investigator analysis revealed no differences in the frequency distribution. There were equal numbers of individuals who reported their religious

TABLE 4.4 SEX BY GROUP			
SEX	GROUP		
FREQUENCY PERCENT COL PCT	EXP.	CONTROL	
			TOTAL
MALE	13 25.49 48.15	6 11.76 25.00	19 37.25
FEMALE	14 27.45 51.85	18 35.29 75.00	32 62.75
TOTAL	27 52.94	24 47.06	51 100.00
CHI-SQUARE = 2.913      DF = 1      P = 0.088			

preference as Protestant, Catholic or none in both groups (see Table 4.5). This was an unexpected finding as St. Boniface Hospital is a Catholic teaching hospital.

The educational background of the two groups was not statistically different. However, as 66% of the cells had less than counts of five the analysis may not have been accurate. The experimental group had more individuals with trade certificates or diplomas than did the control group. The experimental group had more individuals who were college graduates while the control group had more individuals with some college background. If the two categories were combined the distribution between the groups was roughly the same (see Table 4.6).



TABLE 4.5 RELIGION BY GROUP			
RELIGION	GROUP		
FREQUENCY PERCENT COL PCT	EXP.	CONTROL	TOTAL
PROTESTANT	17 33.33 62.96	14 27.45 58.33	31 60.78
CATHOLIC	8 15.69 29.63	7 13.73 29.17	15 29.41
OTHER	0 0.00 0.00	1 1.96 4.17	1 1.96
NONE	2 3.92 7.41	2 3.92 8.33	4 7.84
TOTAL	27 52.94	24 47.06	51 100.00
CHI-SQUARE = 1.185      DF = 3      P = 0.757			

The employment status of the two groups was different. 33% of the categories had less than five counts so the data may not be accurate. The control group (11) had a considerably larger number of home-makers than did the experimental group (2) (see Table 4.7).

The socio-economic status of the two groups did not differ significantly. 16% of the respondents in the study did not answer the question and 85% of the cells had less

TABLE 4.6 EDUCATION BY GROUP				
EDUCATION	GROUP			
	FREQUENCY PERCENT COL PCT	EXP.	CONTROL	TOTAL
LESS THAN GRADE 9	1 1.96 3.70	1 1.96 4.17	2 3.92	
SOME HIGH SCHOOL	6 11.76 22.22	7 13.73 29.17	13 25.49	
HIGH SCHOOL GRAD	5 9.80 18.52	6 11.76 25.00	11 21.57	
TRADES CERT./DIP	7 13.73 25.93	2 3.92 8.33	9 17.65	
SOME UNIVERSITY	3 5.88 11.11	5 9.80 20.83	8 15.69	
UNIVERSITY GRAD	5 9.80 18.52	3 5.88 12.50	8 15.69	
TOTAL	27 52.94	24 47.06	51 100.00	
CHI-SQUARE = 3.782      DF = 5      P = 0.581				

than five in them making the results questionable. Two differences appeared the data. The control group had five more people in the \$15,000 to \$19,999 group, while the experimental group had five more people in the 30,000 to

TABLE 4.7 EMPLOYMENT STATUS BY GROUP			
EMPLOYMENT	GROUP		
FREQUENCY PERCENT COL PCT	EXP.	CONTROL	
			TOTAL
EMPLOYED	21 41.18 77.78	9 17.65 37.50	30 58.82
HOME MAKER	2 3.92 7.41	11 21.57 45.83	13 25.49
RETIRED	4 7.84 14.81	4 7.84 16.67	8 15.69
TOTAL	27 52.94	24 47.06	51 100.00
CHI-SQUARE = 10.892      DF = 2      P = 0.004			

39,999 income group (see Table 4.8). This difference may have had some effect on the resources available to each group.

There did not appear to be any differences in relationship to the patient/deceased but again 62% of the cells had less than five count. The control group had more daughters than did the experimental group which was consistent with the larger number of home-makers. The experimental group had more sons than did the control group (see Table 4.9).

TABLE 4.8 INCOME BY GROUP				
INCOME	GROUP			
	FREQUENCY PERCENT COL PCT	EXP.	CONTROL	TOTAL
\$5,000 TO 9,999	1 2.33 4.35	1 2.33 5.00	2 4.65	3 6.98
\$10,000 TO 14,999	1 2.33 4.35	2 4.65 10.00	6 13.95 30.00	7 16.28
\$15,000 TO 19,999	4 9.30 17.39	2 4.65 10.00	3 6.98 15.00	6 13.95
\$20,000 TO 24,999	3 6.98 13.04	1 2.33 5.00	7 16.28	7 16.28
\$25,000 TO 29,999	6 13.95 26.09	5 11.63 25.00	12 27.91	12 27.91
\$30,000 TO 39,999	7 16.28 30.43	20 46.51	43 100.00	43 100.00
\$40,000 AND OVER	23 53.49	20 46.51	43 100.00	43 100.00
TOTAL	23 53.49	20 46.51	43 100.00	43 100.00
CHI-SQUARE = 8.307      DF = 6      P = 0.216				

An ANOVA (one-way analysis of variance) was run on the variable age to determine if there were any significant

TABLE 4.9 RELATIONSHIP BY GROUP			
RELATIONSHIP	GROUP		
FREQUENCY PERCENT COL PCT	EXP.	CONTROL	TOTAL
HUSBAND	3 5.88 11.11	2 3.92 8.33	5 9.80
WIFE	7 13.73 25.93	7 13.73 29.17	14 27.45
DAUGHTER	4 7.84 14.81	10 19.61 41.67	14 27.45
SON	8 15.69 29.63	3 5.88 12.50	11 21.57
FATHER	1 1.96 3.70	0 0.00 0.00	1 1.96
SISTER	2 3.92 7.41	1 1.96 4.17	3 5.88
BROTHER	0 0.00 0.00	1 1.96 4.17	1 1.96
OTHER	2 3.92 7.41	0 0.00 0.00	2 3.92
TOTAL	27 51.92	24 48.08	51 100.00
CHI-SQUARE = 9.233      DF = 7      P = 0.236			

differences between the mean scores of the two groups. All assumptions of the ANOVA were met. These included: (a) continuous data should be used for the dependent variable; (b) the groups should be mutually exclusive; and (c) the dependent variable should be normally distributed (Munro, Visintainer & Page, 1986). The groups did not differ significantly on the variable age. The F value was 0.12 and the p-value was 0.73.

In summary, the experimental and control groups were generally well matched on all demographic characteristics. The one primary difference was in the employment status of the two groups. The control (21.57%) group had a higher percentage of homemakers than did the experimental group (3.92%). This difference may have been indicative of a more traditional value system where the woman's place was to care for the home and family. The traditional value system may have been beneficial to the adjustment of the woman in bereavement as she felt she had carried out her role to the fullest or it may have been to her detriment as she was unfamiliar with functioning independently in society.

#### 4.3 ANALYSIS OF NORMALITY

The data was also subjected to the Shapiro-Wilks test of normality. The determination of normality was necessary in making the decision of which statistical tests to use. The Shapiro-Wilks test was chosen because "the W statistic

provides a generally superior omnibus measure of non-normality" (Shapiro, Wilk, & Chen, 1968, p. 1343).

The age of the respondents participating in the study was normally distributed about the mean with the mean being 52.8 with a standard deviation of 12.2. The oldest individual participating in the study was seventy-five and the youngest was twenty-nine. The distribution was slightly skewed to the left indicating a slightly higher portion of older participants. There appeared to be a slightly larger portion of younger participants in the experimental group.

The age of the patient/deceased was also distributed normally throughout the sample with a mean of 79.1 and a standard deviation of 15.0. The oldest patient was ninety-seven and the youngest was twenty-eight. It was interesting to note the mean age of the population. As the data indicated, most of the sample had lived out their seven score and five. Therefore, the death of these individuals might have been seen as following a "natural" course of events and might have had some effect on bereavement adjustment.

The risk status of the population was normally distributed with the mean being 19.2 and the standard deviation 5.6. The median and the mean coincided. The highest risk score was 31 and the lowest was 10.

The variable indicating the time from admission to death was not normally distributed. The mean number of days was 30.2 with a standard deviation of 26.0 days. The data was skewed to the right with a median of 20. The findings indicated that most people died less than thirty days from admission, which was a relatively short period for adjustment. This finding may have had some implications for social support and the length of the dying trajectory.

The time from admission to the first interview was also not distributed normally. The mean time for the interview was 114.8 hours from admission with a standard deviation of 82.5 hours. The majority of people were interviewed within seven days of being admitted to the palliative care units. This was double the time the investigator had intended, and may have had some implications affecting adjustment to the setting.

Of the two primary measures used in the study the total General Health Questionnaire and the Bereavement Experience Questionnaire were distributed normally on the pretest but not on the posttest. The subscales of the scales were not normally distributed at the pretest except for yearning, although some of them were on the post test. Generally the subscales were skewed to the right indicating a low level of scale experience. More individuals reported fewer symptoms on the scales than many. The one exception to this was the social dysfunction subscale on pretest. This scale was



skewed to the left indicating a higher level of scale experience. For a summary of the results see Table 4.10.

VARIABLE	PRETEST	POSTTEST
	NORMAL--NONNORMAL	NORMAL--NONNORMAL
AGE	> 0.15	
AGE OF PATIENT	> 0.15	
RISK STATUS	0.15	
ADMISSION TO DEATH	< .01	
TIME OF FIRST INTERVIEW	< .01	
GHQ	> 0.15	< .01
SOMATIC SYMPTOMS	< .01	< .01
ANXIETY & INSOMNIA	0.032	0.052
SOCIAL DYSFUNCTION	< .01	0.079
SEVERE DEPRESSION	< .01	< .01
BEQT	0.065	0.044
GUILT	< .01	< .01
ANGER	< .01	< .01
MEANINGLESSNESS	< .01	< .01
YEARNING	> 0.15	0.329
DEPERSONALIZATION	< .01	< .01
STIGMA	< .01	0.011
MORBID FEARS	< .01	< .01
ISOLATION	< .01	0.064

#### 4.4 RELIABILITY OF THE INSTRUMENTS

Levels of internal consistency reliability were calculated for the Bereavement Experience Questionnaire, the General Health Questionnaire and each of the subscales at the pretest and the first posttest (see Table 4.11). Reliability of the instruments was checked to ensure they

were measuring the data consistently. As can be seen from the table, most of the scales and subscales met the minimum standard for alpha of 0.70. The exceptions to this were the subscales of social dysfunction, anger, yearning, stigma and morbid fears at the pretest and stigma, morbid fears and isolation on the posttest. The stigma subscale behaved very strangely for this specific population. It was interesting to note that many individuals commented on how "ridiculous" many of the questions in this subscale were. Examples of the questions that brought the most negative responses were; QT17 Felt blamed by others for the illness/death; QT19 Felt ashamed of the way he/she lived/died; QT40 Felt compelled to change my residence because of what some people thought about the illness/death. Analysis of the questions illustrated that they might be more acceptable for a death related to suicide or a socially unacceptable cause such as acquired immune deficiency syndrome. The sample Demi and Schroeder (1985) used to calculate the reliability of the scale did have a few individuals who were bereaved because of accident, suicide, or homicide which may have helped to increase the reliability.

The second minor difficulty which arose on the posttest was that some of the items had zero variance. Questions on the total GHQ which had zero variance were (a) been thinking of yourself as a worthless person; (b) thought of the possibility that you might do away with yourself; and (c)

found the idea of taking your own life kept coming into your mind. All of these questions were part of the "severe depression" subscale. The questions on the BEQT which showed no variance were; (a) Felt blamed by others for the death; (b) Felt ashamed of the way he/she died; (c) Thought that the death was a punishment for things I did in the past; (d) Felt that I have nothing to live for; (e) Felt compelled to change my residence because of what some people thought about the death; and (f) Felt that I caused the illness/death. Three of the questions were from the stigma subscale, two were from the guilt subscale and one was from the meaninglessness subscale.

TABLE 4.11:  
INTERNAL CONSISTENCY RELIABILITY FOR THE BEQT,  
THE GHQ AND THEIR SUBSCALES

SCALE	STANDARDIZED ITEM ALPHA PRETEST	STANDARDIZED ITEM ALPHA POSTTEST
GHQ	0.8622	0.9359
SOMATIC SYMPTOMS	0.8319	0.8612
ANXIETY & INSOMNIA	0.8629	0.8981
SOCIAL DYSFUNCTION	0.6603	0.8399
SEVERE DEPRESSION	0.7730	0.8926
BEQT	0.9294	0.9275
GUILT	0.8322	0.8468
ANGER	0.6974	0.8323
MEANINGLESSNESS	0.8595	0.8539
YEARNING	0.6181	0.7487
DEPERSONALIZATION	0.7402	0.7126
STIGMA	-0.0120	0.3434
MORBID FEARS	0.6799	0.6615
ISOLATION	0.7692	0.6544

#### 4.5 SELECTION EFFECTS

The analytic model was selected with the help of the decision tree described by Egger and Miller (1984) for the analysis of data from pretest-posttest designs. Egger and Miller (1984) stated that it was important to analyze the data logically, based on its statistical characteristics rather than choosing a method that makes the results look more significant. For the purpose of analysis, the four-point likert scaling of the Bereavement Experience Questionnaire was converted to a percentage system. The General Health Questionnaire was left in the original scoring method.

#### 4.5.1 Effect of the Bereavement Program on Bereavement Experience

The first step taken in the analysis of the data was to compare the mean scores of each group on the Bereavement Experience Questionnaire and each of the subscales. See Table 4.12 for a summary of the means of each group. The raw mean scores were also compared to the adjusted mean scores as calculated by the analysis of covariance. The adjusted mean scores took into consideration where each group started on the pretest. In an attempt to understand what was happening with each subscale the individual questions were analyzed for the presence of the themes and

TABLE 4.12 MEAN SCORES ON THE BEREAVEMENT EXPERIENCE QUESTIONNAIRE BY GROUP						
GROUP	PRETEST			POSTTEST		
	N	MEAN	SD	N	MEAN	SD
E-HIGH	8	18.718	8.870	6	18.120 (15.392)	8.567
C-HIGH	10	20.256	9.382	7	24.982 (17.351)	7.899
E-LOW	13	12.465	6.872	11	12.168 (15.135)	6.858
C-LOW	10	9.077	2.406	9	9.060 (13.187)	3.314

N = NUMBER OF RESPONDENTS IN THE GROUP  
 E = EXPERIMENTAL  
 C = CONTROL  
 HIGH/LOW DESIGNATE RISK CATEGORIES  
 ( ) ADJUSTED MEAN SCORE ON THE POSTTEST

feeling tones.

Comparison of the raw scores indicated that there was a trend towards stability for the experimental high-risk group who received the treatment of the bereavement program. The bereavement experience of the control high-risk group intensified six weeks post-bereavement. There was very little movement in the low-risk groups although the control group started with a lower level of bereavement experience than did the experimental group. Analysis of the adjusted mean scores indicated that the control high-risk group improved slightly but not as greatly as did the experimental group. When the scores of the low-risk groups were compared on the adjusted means, they had shown some intensification of bereavement experience with the experimental group reporting more grieving responses. In an attempt to understand the subcomponents of bereavement experience better, the mean scores of each of the subscales was also compared. For a summary of the results see Tables 4.13 to 4.20.

The guilt subscale indicated that the high-risk groups started at higher levels of perceived guilt than did the low-risk groups (see Table 4.13). It did not appear that the bereavement program had any particular effect on the guilt experience of the individual as both the experimental and control high-risk groups' perception of guilt increased after the death. When the adjusted mean scores were

compared, the control high-risk group did slightly better than the experimental high risk group. The greatest difference occurred for the low-risk groups who experienced more guilt after the death. In fact, the control low-risk group actually experienced more guilt than did the control high-risk group when adjusted means were calculated. Analysis of the individual questions revealed that the high risk-groups experienced guilt as a result of enjoying themselves and over little non-specific things. All groups reported some guilt over things they had said or done before and after the illness/death. It was interesting to note that both high-risk groups reported some guilt over a sense of not having coped correctly with the illness and death. Both low-risk groups moved very little in their perception of guilt. The control low-risk group's perception of guilt increased while the experimental low-risk group's perception of guilt decreased.

Table 4.14 illustrates that the perception of anger of the experimental high-risk group had decreased from the pretest to the posttest whereas in the control high-risk group anger had actually increased. When the adjusted means were examined, the data indicated that the experimental group expressed less anger than did the control group. Both high-risk groups experienced anger that was directed at the self. The control high-risk group expressed anger directed at almost every source, the self, friends, relatives and the

TABLE 4.13 MEAN SCORES FOR THE SUBSCALE GUILT BY GROUP						
GROUP	TIME					
	PRETEST			POSTTEST		
	N	MEAN	SD	N	MEAN	SD
E-HIGH	8	11.029	7.768	6	13.399 (11.248)	8.805
C-HIGH	10	16.078	13.420	7	19.888 (9.754)	9.832
E-LOW	13	6.184	5.874	11	4.100 (7.739)	2.835
C-LOW	10	3.333	2.622	9	5.664 (10.532)	5.498

N = NUMBER OF RESPONDENTS IN THE GROUP  
 E = EXPERIMENTAL  
 C = CONTROL  
 HIGH/LOW DESIGNATE RISK CATEGORIES  
 ( ) ADJUSTED MEAN SCORES

patient. Anger directed at this many sources may have ultimately decreased the support available to the respondent. Three of the primary roles of the bereavement program were to clarify why certain treatment decisions were made, to encourage the various family members to discuss their feelings surrounding the illness and death, and to reinforce and explore the feelings experienced by the respondent. These three areas of intervention may have successfully removed the sources of anger which were the self, others (especially relatives) and health care workers.



Both low-risk groups' anger scores decreased slightly on the posttest, although the control group decreased by more than the experimental group. When the adjusted mean scores were taken into consideration, the low-risk groups manifested more anger than the initial scores indicated with the experimental low-risk group expressing more anger than the control group. All groups expressed some degree of

GROUP	TIME					
	PRETEST			POSTTEST		
	N	MEAN	SD	N	MEAN	SD
E-HIGH	8	18.056	13.048	6	15.432 (13.602)	11.090
C-HIGH	10	20.741	12.246	7	22.751 (16.804)	13.763
E-LOW	13	11.111	10.692	11	10.774 (13.287)	13.903
C-LOW	10	10.000	9.729	9	6.173 (8.984)	5.238

N = NUMBER OF RESPONDENTS IN THE GROUP  
 E = EXPERIMENTAL  
 C = CONTROL  
 HIGH/LOW DESIGNATE RISK CATEGORIES  
 ( ) ADJUSTED MEAN SCORES

anger towards health care workers.

The subscale of meaninglessness tried to identify the feelings of loss of interest or relevance of people, objects

or the self which were once meaningful to the individual. As Table 4.15 illustrates, the sense of meaninglessness for the control high risk individuals increased above the pretest scores of the experimental high-risk group. When the adjusted means were taken into consideration, the control high-risk group continued to express more signs of meaninglessness. Generally, the high-risk respondents of both groups reported feelings of meaninglessness such as loss of purpose in life, loss of interest in activities, and feeling that there was nothing to live for. The control high-risk group however reported more feelings of emptiness, loss of interest in work, and loss of religious faith. Two primary sources of support, work acquaintances and religious involvement, may have been lost for these individuals. From this data it appeared that the bereavement program was effective in decreasing feelings of loss of relevance by encouraging individuals to maintain involvement in important activities. The low-risk groups showed basically no change in the mean scores although both groups worsened slightly by the posttest. When the adjusted scores were taken into consideration, the experimental low-risk group expressed more meaninglessness than did the experimental high-risk group. The fact that this particular occurrence was present between the two groups of the same agency may lend support to the value of the bereavement counselor.

TABLE 4.15 MEAN SCORES FOR THE SUBSCALE MEANINGLESSNESS BY GROUP						
GROUP	PRETEST		TIME		POSTTEST	
	N	MEAN	SD	N	MEAN	SD
E-HIGH	8	23.958	21.217	6	18.750 (13.068)	22.477
C-HIGH	10	20.417	11.858	7	25.000 (18.194)	12.955
E-LOW	13	7.692	9.749	11	9.470 (13.308)	8.758
C-LOW	10	2.917	7.096	9	5.092 (9.483)	5.424

N = NUMBER OF RESPONDENTS IN THE GROUP  
E = EXPERIMENTAL  
C = CONTROL  
HIGH/LOW DESIGNATE RISK CATEGORIES  
( ) ADJUSTED MEAN SCORES

Yearning, which can manifest itself as intense efforts to recall the deceased person, increased for all groups on the posttest. However, as can be seen in Table 4.16, the scores of the control high-risk group increased the greatest (16.6%). When the scores were adjusted, the control high-risk group continued to show more signs of yearning than did the experimental group. As in the anger subscale, the experimental low-risk group moved above the experimental high-risk group in the expression of yearning. Although all groups manifested signs of yearning, the analysis of the individualized questions revealed that the control high-risk

group experienced more extreme manifestations, such as sensing the patient's presence and hearing the patient. The control high-risk group reported more preoccupation with thoughts of the deceased and difficulty in parting with the patient's belongings. The bereavement program may have been effective in decreasing yearning as it provided the bereaved individual with the opportunity of participating in a relationship review and provided other sources of social support. The bereavement program also provided acknowledgement of the normal grieving process, giving sanction to discuss feelings such as hallucinations.

TABLE 4.16 MEAN SCORES FOR THE SUBSCALE YEARNING BY GROUP						
GROUP	PRETEST			TIME	POSTTEST	
	N	MEAN	SD	N	MEAN	SD
E-HIGH	8	20.417	10.755	6	22.778 (21.875)	9.526
C-HIGH	10	20.000	6.086	7	36.667 (32.253)	7.454
E-LOW	13	14.615	11.348	11	19.697 (23.310)	14.941
C-LOW	10	16.000	7.981	9	17.407 (17.027)	12.558

N = NUMBER OF RESPONDENTS IN THE GROUP  
E = EXPERIMENTAL  
C = CONTROL  
HIGH/LOW DESIGNATE RISK CATEGORIES  
( ) ADJUSTED MEAN SCORES

Depersonalization represented the sense of shock or unreality; the sense of not feeling part of the world or feeling out of control of the situation. The two high-risk groups started with basically the same mean scores on the pretest but on the posttest the experimental high-risk group's score decreased while the control high risk score increased slightly (see Table 4.17). However, when adjusted for the pretest differences, the control group did slightly better than the experimental high-risk group. The experimental low-risk group manifested more signs of depersonalization than did any of the groups when the adjusted means were considered. The control high-risk group experienced more thoughts of losing their mind. This may be directly related to the states of hallucination which many of them were experiencing. The bereavement program assisted individuals by clarifying and interpreting the normal grieving process thus removing the stress associated with the feeling that you are losing your mind. The bereavement counselors often inquired whether or not a respondent was having hallucinations. Thus the individual was able to recognize the normality of the situation and talk about what was happening.

The stigma subscale which looked at the individual's perception of being discredited or ashamed often resulting in withdrawal, behaved very differently than the other scales. The high-risk groups both perceived more stigma on

TABLE 4.17 MEAN SCORES FOR THE SUBSCALE DEPERSONALIZATION BY GROUP						
GROUP	TIME					
	PRETEST			POSTTEST		
	N	MEAN	SD	N	MEAN	SD
E-HIGH	8	27.500	16.110	6	23.333 (18.715)	23.758
C-HIGH	10	27.333	15.540	7	28.571 (15.621)	11.362
E-LOW	13	14.872	9.871	11	16.364 (20.640)	14.716
C-LOW	10	8.667	8.917	9	5.926 (13.851)	10.773

N = NUMBER OF RESPONDENTS IN THE GROUP  
 E = EXPERIMENTAL  
 C = CONTROL  
 HIGH/LOW DESIGNATE RISK CATEGORIES  
 ( ) ADJUSTED MEAN SCORES

the posttest than on the pretest (see Table 4.18). The direction of the movement of the groups was also supported by the adjusted means. The question which seemed to differentiate the high from low risk groups dealt with the respondent's perception that the patient contributed to his/her own illness and subsequent death. More high-risk persons believed the patient had in some way contributed to his/her own death. In most cases the patient had smoked and was now dying of lung cancer. Generally, most questions were responded to in a negative fashion. The one question which brought up the general scale score was "Felt I

have/had a good relationship with the patient". Most people responded to this question very positively. The experimental high-risk group consistently responded to the question positively which may have accounted for the slightly higher scores. One aspect the investigator found totally missing from the scale was the perception of stigma attached to taking on a new role. (For example, the role of a single widowed person in an otherwise couple oriented society.) As the reliability of the stigma scale was very poor in this population, the results need to be interpreted carefully.

TABLE 4.18 MEAN SCORES FOR THE SUBSCALE STIGMA BY GROUP						
GROUP	PRETEST			TIME POSTTEST		
	N	MEAN	SD	N	MEAN	SD
E-HIGH	8	18.750	9.361	6	22.222 (20.091)	3.514
C-HIGH	10	16.111	12.409	7	19.048 (18.711)	11.940
E-LOW	13	18.803	6.627	11	18.182 (17.877)	6.616
C-LOW	10	13.889	8.917	9	14.198 (16.252)	8.385

N = NUMBER OF RESPONDENTS IN THE GROUP  
E = EXPERIMENTAL  
C = CONTROL  
HIGH/LOW DESIGNATE RISK CATEGORIES  
( ) ADJUSTED MEAN SCORES

The morbid fears subscale dealt with the thoughts or preoccupation with thoughts of death. As can be seen in Table 4.19, all of the respondents exhibited more thoughts of death when the patient was in the terminal stage, which was to be expected. All of the groups' mean scores except the control high-risk group dropped substantially at six weeks post death. This may be related to the fact that the control high-risk group had an increased yearning level and morbid thoughts may have been viewed as a way of uniting with the deceased person. When the adjusted mean scores were considered, the control high-risk group's score also decreased although it remained at a level higher than the other groups. The bereavement program may have been beneficial in this area as it provided the opportunity to review the circumstances of the death, allowing the person to release the thoughts.

The isolation subscale measured the degree to which individuals felt shut off from involvement with others. As Table 4.20 illustrates, isolation is greater in the high-risk groups than in the low-risk groups. The sense of isolation also increased for the high-risk groups at six weeks bereavement as compared to the slight decrease in intensity for the experimental low-risk group and the relative stability of the control low-risk group. When the adjusted mean scores were compared the experimental high-risk group manifested more isolation than did the control



TABLE 4.19 MEAN SCORES FOR THE SUBSCALE MORBID FEARS BY GROUP						
GROUP	TIME					
	PRETEST			POSTTEST		
	N	MEAN	SD	N	MEAN	SD
E-HIGH	8	18.056	16.197	6	9.259 (9.781)	12.505
C-HIGH	10	22.778	17.656	7	20.635 (16.588)	14.242
E-LOW	13	18.376	12.706	11	12.626 (13.148)	10.271
C-LOW	10	12.222	8.198	9	7.407 (9.569)	8.333

N = NUMBER OF RESPONDENTS IN THE GROUP  
E = EXPERIMENTAL  
C = CONTROL  
HIGH/LOW DESIGNATE RISK CATEGORIES  
( ) ADJUSTED MEAN SCORES

group. The control group actually showed a decrease in the intensity of isolation. The control low-risk group showed an increase in isolation while the experimental group decreased very slightly. The literature supported the claim that perception of support was a good indicator of adjustment in the period of bereavement. Respondents who felt isolated (lack of support) did indeed fall into the high-risk categories. More of the experimental high-risk individuals reported feeling emotionally distant from people.

TABLE 4.20 MEAN SCORES FOR THE SUBSCALE ISOLATION BY GROUP						
GROUP	PRETEST		TIME		POSTTEST	
	N	MEAN	SD	N	MEAN	SD
E-HIGH	8	28.125	17.782	6	31.944 (28.618)	20.694
C-HIGH	10	30.833	20.050	7	33.333 (23.648)	11.785
E-LOW	13	25.000	15.590	11	21.212 (23.550)	17.624
C-LOW	10	15.000	12.298	9	15.741 (22.634)	12.108

N = NUMBER OF RESPONDENTS IN THE GROUP  
 E = EXPERIMENTAL  
 C = CONTROL  
 HIGH/LOW DESIGNATE RISK CATEGORIES  
 ( ) ADJUSTED MEAN SCORES

#### 4.5.2 Summary

From the comparison of the mean and adjusted mean scores it would appear that the bereavement program decreased the overall intensity of the grieving response for the experimental high-risk group as measured on the bereavement experience questionnaire. This was particularly evident as the six week bereavement period is often a time when the grieving experience intensifies. The areas where the bereavement program seemed particularly effective were in the areas of anger, meaninglessness, yearning and morbid

fears. In analyzing many of the adjusted subscales it could be seen that the low-risk groups worsened, especially the experimental group. It might be concluded that without intervention the groups did not do as well. From a clinical perspective what seemed to be happening especially in the experimental low-risk group was that two individuals should actually have been classified as high-risk. It was interesting to note that both of these individuals were rated as low-risk because they had a strong religious faith. It was felt that the faith and the support networks available through the faith would assist them in the period of bereavement. What appeared to have happened was that the support network was relatively "closed", inhibiting the expression of grief, resulting in feelings of guilt, anger and isolation. These two individuals were bringing up the scale scores of the entire group.

#### 4.5.2.1 Testing for Statistical Significance

The next step according to Egger and Miller (1984), was to check the groups for noncomparability at the pretest by using one-way analysis of variance (ANOVA) on the scores of each dependent variable. As it was decided that the statistical method of analysis of covariance (ANCOVA) would be used, the pretest scores were not checked for comparability as the ANCOVA adjusted for any differences found on the pretest. ANCOVA did this by using the pretest

scores as the covariate. A covariate was defined as "a nonmanipulated, nonexperimental independent variable capable of predicting Ss' performance on the dependent variable (Waltz & Bausell, 1981, p. 227). The underlying assumptions of ANCOVA were as follows:

1. the groups should be mutually exclusive
2. continuous data should be used for the dependent variable
3. the dependent variable should be normally distributed
4. the covariate must be measured at the interval level
5. the covariate must be linearly correlated with the dependent variable ( $>$  or  $= 0.30$ )
6. the covariate must be immutable across time
7. the covariate must not be related to the purposes of the study
8. the covariate must demonstrate homogeneity of regression across groups (the covariate must be similarly related to the dependent variable within each treatment group) (Munroe, Visintainer & Page, 1986; Shelley, 1984; Waltz & Bausell, 1981).

It must be noted that the assumption of a normal distribution was violated by some of the scales and subscales. According to J. Sloan (personal communication, 1987), the ANCOVA model behaves in a "robust" way tolerating violation well and therefore can still be used. The results of the bereavement experience questionnaire were subjected

to the ANCOVA to determine if the bereavement program had any effect on the bereavement experience of the respondents. The first measurement undertaken was to determine if the mean pretest bereavement experience scores were a useful covariate and indeed they were with an F-value of 46.69 and a p-value of 0.0001. A check was made for covariate adequacy to determine if the pretest scores (covariate) correlated with the posttest scores using the Pearson correlation coefficient. The correlation was excellent at 0.886 considerably above the minimum standard of 0.30. The second test which was made was to determine that the covariate's effect on the dependent variable was uniform across the groups which is to say that the covariate should be uncorrelated with the treatment variable (pretest was uncorrelated with status). There was no correlation found ( $R = -0.155$ ,  $p = 0.389$ ). These two tests supported the decision that the ANCOVA was the correct statistical procedure to use.

Then the ANCOVA determined if there were any significant differences between groups as a result of the bereavement program. Thirty-three observations were used to calculate the ANCOVA. No significant differences were found at the  $p=.05$  level. The reported F-value was 0.84 with a  $p=0.484$ .

Because one of the assumptions of the ANCOVA had been violated it was decided that nonparametric tests should be conducted so the results of the various tests could be

compared (see Table 4. 21). Nonparametric tests required few assumptions about the population from which the sample was drawn and provided the investigator with less power to detect differences between groups as the conclusions were more general (Knapp, 1985; Volicer, 1984). The Wilcoxon rank sums test and the Kruskal-Wallis test were examined for effect. As can be seen from the results of the nonparametric test the groups did not demonstrate any statistical differences and the investigator had to conclude that the bereavement program did not have a statistically significant effect on the bereavement experience of the individual at this particular time.

Each of the subscales of the bereavement experience questionnaire was also subjected to the ANCOVA technique. Thirty-three observations were again used to calculate the ANCOVA. For a summary of the results see Table 4.21. All of the established covariates for the subscales were useful at the  $\alpha = .05$  level. A check for covariate adequacy and uniformity across groups was done (see Table 4.22). All scales met the minimum standard of 0.30 for covariate adequacy. The stigma scale indicated that the covariate affected the dependent variable differently across groups. Again it could be identified that the stigma subscale behaved very strangely in this population. Only the ANCOVA run on the subscale yearning identified any differences in the groups. Individual contrasts were run to identify where

TABLE 4.21 COMPARISON OF STATISTICAL TESTS FOR THE VARIABLE TOTAL BEREAVEMENT EXPERIENCE AND SUBSCALES		
VARIABLE	ANCOVA (parametric)	KRUSKAL-WALLIS (non-parametric) DF =3
BEQT	F = 0.84 p = 0.484	CHISQU = 0.70 p = 0.874
GUILT	F = 1.13 p = 0.352	CHISQU = 4.52 p = 0.211
ANGER	F = 0.88 p = 0.463	CHISQU = 0.84 p = 0.840
MEANINGLESS	F = 0.73 p = 0.544	CHISQU = 0.95 p = 0.814
YEARNING	F = 3.58 p = 0.026	CHISQU = 9.67 p = 0.022
DEPERSON	F = 0.67 p = 0.579	CHISQU = 6.17 p = 0.104
STIGMA	F = 0.31 p = 0.818	CHISQU = 0.37 p = 0.946
MORBID FEARS	F = 0.86 p = 0.471	CHISQU = 0.06 p = 0.997
ISOLATION	F = 0.34 p = 0.800	CHISQU = 3.93 p = 0.270

the differences existed. The control high-risk group was statistically different from the control low-risk group. The individual contrasts also identified that the difference between the experimental high-risk group and the control high-risk group was almost statistically significant ( $p=0.054$ ). As the ability to detect a difference between these groups was very small, this finding was clinically significant.

To insure the accuracy of the ANCOVA results the data was also subjected to nonparametric testing. The results were identical with the subscale yearning being the only scale to detect differences between the groups (see Table 4.21).

From the data it appeared that the experimental low-risk group had two individuals who were misclassified. Because the sample size was small these respondents may have greatly affected the data. To try and determine what would have happened if they had been properly classified, they were omitted from the analysis. They were not included in the experimental high-risk group because they had not received any intervention. When these individuals were removed from the sample, the findings indicated that the experimental low-risk group behaved more like the control low-risk group. The raw and the adjusted mean scores for this group both dropped. It however did not change the statistical significance of the data.



TABLE 4.22 CHECK FOR COVARIATE ADEQUACY FOR THE BEREAVEMENT EXPERIENCE QUESTIONNAIRE AND SUBSCALES		
VARIABLE	COVARIATE ADEQUACY	HOMOGENEITY OF REGRESSION
BEQT	R = 0.886 p = 0.0001	R = -0.155 p = 0.389
GUILT	R = 0.886 p = 0.0001	R = -0.110 p = 0.542
ANGER	R = 0.708 p = 0.0001	R = -0.070 p = 0.698
MEANINGLESSNESS	R = 0.699 p = 0.0001	R = -0.220 p = 0.219
YEARNING	R = 0.676 p = 0.0001	R = 0.111 p = 0.538
DEPERSONALIZATION	R = 0.751 p = 0.0001	R = -0.181 p = 0.314
STIGMA	R = 0.531 p = 0.0015	R = -0.350 p = 0.046
MORBID FEARS	R = 0.638 p = 0.0001	R = -0.032 p = 0.858
ISOLATION	R = 0.741 p = 0.0001	R = -0.183 p = 0.309

#### 4.5.3 Effect of the Bereavement Program on Health Status

As previously done, the first step taken in the analysis of the health data was to compare the mean scores of each group on the General Health Questionnaire and each of the subscales. The raw means were then compared to the adjusted mean scores. In an attempt to understand the scale better

each question was analyzed for content and feeling tone. See Table 4.23 for a summary of the means of each group. The scores on the General Health Questionnaire were not converted to a percentage as calculating the score as 0 to 28 for the total score and 0 to 21 for each of the subscales made comparison to the existing literature easier. A score of five or greater on the Health Questionnaire represented sufficient concern to warrant further investigation.

The total Health Questionnaire provided an assessment of over all health. As Table 4.23 illustrates, both experimental groups remained relatively stable from the pretest to the posttest while the control groups both improved slightly. When the adjusted means were analyzed the experimental high-risk group also improved slightly and the movement of the other groups emulated the raw scores.

The subscale somatic symptoms recorded the respondent's perception of physical complaints of health or lack of it. Both high-risk groups reported slightly more physical complaints at the posttest than on the pretest while both low-risk groups reported fewer physical complaints (see Table 4.24). When the adjusted means were compared the scores of the high-risk groups dropped slightly with the experimental group reporting less physical complaints. The low-risk groups dropped slightly in their perception of somatic symptoms. When the individual questions were analyzed it could be seen that there were generalized

TABLE 4.23 MEAN SCORES ON THE GENERAL HEALTH QUESTIONNAIRE BY GROUP						
GROUP	TIME					
	PRETEST			POSTTEST		
	N	MEAN	SD	N	MEAN	SD
E-HIGH	8	11.250	5.849	6	10.333 (7.409)	8.262
C-HIGH	10	10.900	5.626	7	7.143 (4.774)	5.047
E-LOW	13	5.615	3.709	11	4.273 (5.622)	6.084
C-LOW	10	3.900	3.784	9	0.889 (3.031)	1.616

N = NUMBER OF RESPONDENTS IN THE GROUP  
 E = EXPERIMENTAL  
 C = CONTROL  
 HIGH/LOW DESIGNATE RISK CATEGORIES  
 ( ) ADJUSTED MEAN SCORES

feelings of ill health for all groups at the pretest. By the posttest the high-risk groups reported feeling unwell especially with symptoms of general fatigue and headaches. The control high-risk group especially reported more headaches and temperature fluctuations which could be indicative of stress.

As can be seen in Table 4.25, the experimental high-risk group was the only group that reported more signs of anxiety and insomnia on the posttest. This was consistent with the reported feelings of fatigue expressed in the somatic

TABLE 4.24 MEAN SCORES ON THE SUBSCALE SOMATIC SYMPTOMS BY GROUP						
GROUP	PRETEST		TIME		POSTTEST	
	N	MEAN	SD	N	MEAN	SD
E-HIGH	8	6.750	4.301	6	6.833 (6.051)	4.446
C-HIGH	10	7.800	4.541	7	8.286 (7.222)	5.122
E-LOW	13	4.462	3.099	11	3.636 (4.108)	3.264
C-LOW	10	4.000	2.981	9	2.889 (3.662)	1.764

N = NUMBER OF RESPONDENTS IN THE GROUP  
 E = EXPERIMENTAL  
 C = CONTROL  
 HIGH/LOW DESIGNATE RISK CATEGORIES  
 ( ) ADJUSTED MEAN SCORES

symptoms subscale. What was very interesting was that the control high-risk group's perception of anxiety dropped considerably on the posttest. It appeared that the circumstances surrounding the initial period of hospitalization were an anxious time for these family members. When the adjusted mean scores were compared, the experimental high-risk group's perception of anxiety also dropped although remaining considerable above the other groups. On the adjusted scores the experimental low-risk group showed more signs of anxiety than did the control high-risk group. The subscale of anxiety and insomnia was

used to look at the individuals's perception of mental health. All of the adjusted scores were greater than five indicating the degree of stress felt by all of the respondents. All groups of respondents manifested some anxiety on the pretest especially in areas such as felt constantly under strain, the presence of sleep disturbances and feeling that everything was getting on top of you. On the posttest the experimental high-risk group expressed more of these similar feelings. One area where the experimental high-risk group consistently reported feelings was in the area of feeling nervous and uptight.

TABLE 4.25 MEAN SCORES ON THE SUBSCALE ANXIETY AND INSOMNIA BY GROUP						
GROUP	TIME					
	PRETEST			POSTTEST		
	N	MEAN	SD	N	MEAN	SD
E-HIGH	8	11.875	3.796	6	12.000 (10.417)	6.481
C-HIGH	10	13.100	3.348	7	8.571 (6.392)	1.397
E-LOW	13	7.538	3.755	11	6.000 (7.060)	4.817
C-LOW	10	6.000	4.472	9	4.000 (5.392)	1.658

N = NUMBER OF RESPONDENTS IN THE GROUP  
 E = EXPERIMENTAL  
 C = CONTROL  
 HIGH/LOW DESIGNATE RISK CATEGORIES  
 ( ) ADJUSTED MEAN SCORES

The social dysfunction subscale measured the degree of disruption of the socialization experience for the individual. As can be seen in Table 4.26, all of the groups except the experimental high-risk experienced less social dysfunction on the posttest than on the pretest. This movement was also consistent with the adjusted means. All of the groups manifested a marked degree of social dysfunction as can be seen by the fact that all of the scores were above five. In the individual questions, people felt that it took longer to carry out their normal tasks and were less satisfied with how they did their job. The experimental high-risk group reported considerably less enjoyment in day to day activities on the posttest.

As can be seen in Table 4.27, none of the respondents experienced what would be termed "severe depression" at the pre or posttest as all of the scores were under five. The scale particularly looked at "hopelessness" and "suicidal ideation". From a clinical perspective many of the respondents in the high-risk categories appeared depressed to the investigator. The high-risk groups had a tendency to perceive themselves as "worthless" people which may give some indication of personality characteristics which may ultimately affect coping style. The high-risk groups were also more likely to report that life was "hopeless" and not worth living. When the adjusted means were compared, the experimental high-risk group did slightly better than the

TABLE 4.26 MEAN SCORES ON THE SUBSCALE SOCIAL DYSFUNCTION BY GROUP						
GROUP	PRETEST		TIME		POSTTEST	
	N	MEAN	SD	N	MEAN	SD
E-HIGH	8	8.250	3.059	6	9.667 (9.674)	3.141
C-HIGH	10	9.200	2.936	7	8.714 (8.553)	1.890
E-LOW	13	8.000	1.633	11	7.700 (7.797)	3.343
C-LOW	10	8.300	1.567	9	6.556 (6.569)	1.333

N = NUMBER OF RESPONDENTS IN THE GROUP  
 E = EXPERIMENTAL  
 C = CONTROL  
 HIGH/LOW DESIGNATE RISK CATEGORIES  
 ( ) ADJUSTED MEAN SCORES

control group. The experimental low-risk group experienced more depression than any of the groups.

TABLE 4.27 MEAN SCORES ON THE SUBSCALE SEVERE DEPRESSION BY GROUP						
GROUP	PRETEST		TIME		POSTTEST	
	N	MEAN	SD	N	MEAN	SD
E-HIGH	8	4.250	4.590	6	2.833 (1.172)	4.665
C-HIGH	10	3.500	0.972	7	2.714 (1.506)	1.704
E-LOW	13	0.538	0.776	11	0.800 (2.000)	1.619
C-LOW	10	0.900	1.287	9	0.222 (0.941)	0.441

N = NUMBER OF RESPONDENTS IN THE GROUP  
 E = EXPERIMENTAL  
 C = CONTROL  
 HIGH/LOW DESIGNATE RISK CATEGORIES  
 ( ) ADJUSTED MEAN SCORES

#### 4.5.4 Summary

From the analysis of the mean and adjusted scores it did not appear that overall the bereavement program had any effect on the health status of the individual. When the subscales were analyzed it appeared as if the program may have had some effect on the reporting of somatic symptoms and the presence of severe depression.



#### 4.5.4.1 Tests for Statistical Significance

The scores of the General Health Questionnaire and the subscales were again subjected to analysis of covariance. Thirty-three responses were used in the analysis except in the anxiety and social dysfunction subscales where thirty-two responses were used. The covariate was useful except for the subscale social dysfunction ( $F= 1.49$ ,  $p=0.234$ ). A check was done to determine covariate adequacy and homogeneity of regression (see Table 4.28). The social dysfunction subscale did not meet the minimum requirement of 0.30 and was not a useful covariate. Evidence of this could also be seen in the fact that the raw mean scores and the adjusted scores did not vary. The ANCOVA did not identify any statistically significant differences between any of the groups.

To insure the ANCOVA results were appropriate, nonparametric testing was again used. They also did not demonstrate any statistically significant results (see Table 4.29 for a summary). Since the pretest scores of the social dysfunction subscale were not useful as a covariate, the data was subjected to ANOVA. No statistically significant results were identified.

To detect any differences which were present in the findings as a result of having misclassified two of the experimental low-risk respondents, they were omitted from

the analysis of the data. The mean scores of the group decreased and the group behaved more like the control low-risk group. No statistically significant differences were found between the groups on the total General Health Questionnaire. Some differences were found within the subscales. The groups differed significantly on the somatic symptom subscale and when the individual contrasts were run the differences were evident between the control high-risk group and each of the low-risk groups. The pretest scores of the subscale social dysfunction became a useful covariate when these individuals were omitted. The groups also differed significantly with the individual contrasts revealing a difference between the experimental high and low-risk groups. As is demonstrated in the data, the statistically significant results always appeared between the high and low-risk groups supporting the effectiveness of the rating system.

As the results did not demonstrate significant differences between the groups, the investigator had to conclude that the bereavement program did not have a statistically significant effect on physical health, psychological health, or social functioning. As the process of grieving extends over a longer period of time, it may have been too early to detect the effects of the program.

TABLE 4.28 CHECK FOR COVARIATE ADEQUACY OF THE GHQ AND SUBSCALES		
VARIABLE	COVARIATE ADEQUACY	HOMOGENEITY OF REGRESSION
GHQ	R = 0.728 p = 0.0001	R = -0.282 p = 0.112
SOMATIC SYMPTOMS	R = 0.702 p = 0.0001	R = -0.131 p = 0.467
ANXIETY & INSOMNIA	R = 0.649 p = 0.0001	R = -0.221 p = 0.217
SOCIAL DYSFUNCTION	R = 0.137 p = 0.456	R = 0.086 p = 0.634
SEVERE DEPRESSION	R = 0.845 p = 0.0001	R = -0.180 p = 0.317

TABLE 4.29 COMPARISON OF THE STATISTICAL TESTS FOR THE GHQ AND SUBSCALES		
VARIABLE	ANCOVA (parametric)	KRUSKAL-WALLIS (non-parametric) DF = 3
GHQ (TOTAL)	F = 1.18 p = 0.337	CHISQU = 4.70 p = 0.195
SOMATIC	F = 2.56 p = 0.075	CHISQU = 4.80 p = 0.187
ANXIETY	F = 2.36 p = 0.092	CHISQU = 4.92 p = 0.178
SOCIAL DYS	F = 1.78 p = 0.176	CHISQU = 4.69 p = 0.196
DEPRESSION	F = 1.02 p = 0.400	CHISQU = 7.15 p = 0.067

#### 4.6 QUALITATIVE ANALYSIS

According to Wilson (1985), qualitative analysis "is the nonnumerical organization and interpretation of data in order to discover patterns, themes, forms, and qualities found in field notes, interview transcripts", etc (p. 397). The pretest and bereavement interview guides were used to elicit information on variables which might effect the bereavement experience of the individual. Because the data collected was of a large magnitude, only some of the variables were explored. Responses received from the qualitative data were subjected to content analysis from the perspectives of semantics and feeling tone. The data was analyzed by dividing the experimental and control groups into high and low-risk categories. In cases where the patient had not died the respondent was omitted from the analysis as their risk status had not yet been determined.

##### 4.6.1 Prebereavement Variables

The variables chosen for analysis from the pretest interview consisted of perception of coping ability, perception of support available to the respondent, changes which have occurred as a result of the illness, and stressors other than the illness which the respondent was currently experiencing.

#### 4.6.1.1 Perception of Coping Ability

The respondents were asked the question: How much difficulty would you say you are having coping with the illness? The responses to the question fell into three primary areas: (a) I'm coping well; (b) I'm coping well with some type of qualifier to express the concept of well; and (c) I'm not coping well at all. See Table 4.30.

Two of the experimental and one of the control high risk subjects reported coping well. The two experimental respondents appeared to have some difficulty expressing feelings and were highly educated so that expressing a difficulty with coping may not have been socially acceptable. The respondent from the control group was an elderly individual who took the illness as a natural course of events and appeared to be relatively prepared for what would happen. The one respondent from the control group qualified that she was coping well now that the patient was admitted to the hospital and her care-giving responsibilities were relieved. Prior to the patient's hospitalization the respondent felt she was coping poorly. Six of the experimental subjects reported that they did not feel they were coping well with the situation. One respondent based her assessment on the fact that she was crying a lot and having difficulty making decisions. The other respondents did not verbalize how they arrived at their perception of coping. Three of the control subjects

expressed that they were coping better than they ever thought they would but they still did not feel they were doing well. Two respondents based their coping on the fact that they were very tired and cried a lot. One respondent attached blame to the health care system for not helping them to cope with the situation. This was an unusual case in the sense that the patient and respondent had requested active euthanasia and did not feel they were supported in their decision. When the individual questions of the bereavement experience questionnaire were examined, both high-risk groups reported feeling a sense of guilt at having not coped correctly with the illness.

Five of the respondents from the experimental group and six of the respondents from the control group (low risk) thought they were coping fairly well with the situation. The subjects in this category expressed the notion that "his/her" time had come and seemed to be accepting of the situation. Some of the responses provided by the individuals who qualified their coping were "I'm coping with it fairly well, I'm so busy sometimes I think I'm trying to avoid it"; "now that she's in the hospital I feel very relieved and ready to cope with almost anything". Two of the control group and five of the experimental low risk subjects felt that they were not coping well. The control group subjects came to this conclusion because they felt very tired. The five experimental subjects all talked about

"what was to come" and the thought of the impending death seemed to cause enough anxiety to decrease their perception of their coping ability. The subjects talked about the "changes" and "loneliness" which were to come. This was perhaps a form of anticipatory grieving.

#### 4.6.1.2 Summary

From the qualitative data it appeared that respondents in the high risk categories had a higher perception of coping poorly than did the low risk subjects. This finding might be related to the personality characteristics of the respondents or to the heavy care responsibilities which many of them were subjected to during the illness resulting in fatigue. The finding would suggest that intervention could be directed at improving the respondent's coping abilities or at least improving the perception of coping. If the individual does not feel able to cope well in a situation they probably will not. Therefore, it was crucial that positive reinforcement be provided for good coping skills.

#### 4.6.1.3 Perception of Support Network

It was important to determine which groups of individuals in the study felt supported and who provided the support. The work of many authors supported the claim that perception of support was an important factor in mitigating the

TABLE 4.30 PERCEPTION OF COPING			
	COPING WELL	COPING WELL QUALIFIED	NOT COPING
E (high) N=8	2 (0.25)	.	6 (0.75)
E (low) N=13	5 (0.42)	2 (0.17)	5 (0.42) *
C (high) N=9	1 (0.11)	1 (0.11)	7 (0.78)
C (low) N=11	6 (0.54)	3 (0.27)	2 (0.18)
E=EXPERIMENTAL GROUP C=CONTROL GROUP *=MISSING RESPONSE			

negative consequences of bereavement (Clayton et al., 1971; Heyman & Gianturco, 1973; Maddison, 1967; Parkes, 1975b, Raphael, 1977; Vachon et al., 1982). Therefore, if an individual had a strong social network they may not have had as great a need for bereavement intervention. The qualitative analysis in this area was done to determine if high and low risk subjects had the same perception of supportiveness (see Table 4.31). The support variable was divided into three categories on the basis of who provided the support: the family, friends or the health care system. The analysis was also used to determine what activities or actions were deemed "supportive". The respondents generally did not convey a total lack of support in any category. The



**TABLE 4.31 SUPPORT NETWORK**

<b>TABLE 4.31 SUPPORT NETWORK</b>						
<b>STRONG SUPPORT</b>				<b>SUPPORT LACKING</b>		
	<b>FAMILY</b>	<b>FRIENDS</b>	<b>NURSES</b>	<b>FAMILY</b>	<b>FRIENDS</b>	<b>NURSES</b>
<b>E-HIGH N=8</b>	5 (0.625)	3 (0.375)	5 (0.714)	3 (0.375)	5 (0.625)	2 * (0.286)
<b>C-HIGH N=9</b>	3 (0.375)	3 (0.333)	4 (0.444)	5 * (0.625)	6 (0.667)	5 (0.556)
<b>E-LOW N=13</b>	11 (0.917)	7 (0.583)	9 (0.750)	1 * (0.083)	5 * (0.417)	3 * (0.250)
<b>C-LOW N=11</b>	10 (0.909)	8 (0.800)	9 (0.818)	1 (0.091)	2 * (0.200)	2 (0.182)
<b>E=EXPERIMENTAL GROUP</b> <b>C=CONTROL GROUP</b> <b>*=RESPONSE MISSING</b>						

support lacking category expressed the desire of the respondent for more support than they currently received.

In the high risk category five of the experimental and three of the control group members reported feeling supported by their families. Three of the experimental and five of the control subjects reported some degree of support but also some lack of support. When support was lacking most of the respondents pointed to the fact that other family member's needs were so great that they simply did not have time or energy to support anyone else. Other reasons why support was lacking related to no extended family members to rely on or lack of help with practical matters. Support was provided in one of two ways, either emotional or practical support. Emotional support occurred in the form of listening or talking to the respondent and practical support was identified as helping with the patient's care, taking over some of the household responsibilities or giving the respondent a ride to the hospital.

Almost all of the low-risk respondents in both groups reported strong support from their families. In both cases where there was some degree of support lacking it was because there was no family for support or the family lived out of the city and could not be of practical help. It was difficult to get the low-risk respondents to identify why their families were supportive to them. The family appeared to serve a global function for what ever need might arise.

The low-risk respondents were more likely to say that the illness had brought the family closer together.

Friends and acquaintances of the respondent may also be a source of support in difficult times. As can be seen in Table 4.31, the high-risk groups reported some degree of support lacking in their friendship circles. Two respondents stated that they did not use their friends for support in family matters. Three respondents reported a desire to be with friends but did not have enough time to do this as all of their time was spent at the hospital. Two respondents did not have any close friends they could turn to. One individual commented that friends called so often and at inappropriate times that he/she was unable to get any rest. When friends were supportive to the respondents, it was either because they were able to share similar experiences or because they shared a religious faith.

The low-risk families generally had many friends to turn to for support. Four of the respondents did not feel it was appropriate to share "private" family matters with friends. Two respondents would have liked to have been in contact with friends but they simply did not have time and one individual simply did not find any of her friends helpful. When friends were used as a source of support they were occasionally used to share experiences and make inquiries about the patient. Generally friends were used by the low-risk respondents as a means of "getting away from it all".

Friends were used to attend activities and hobbies with and to do things that brought "happiness" and didn't remind the individual of the illness. The low-risk group appeared to be able to take themselves away from the illness situation whereas the control group seemed to be encompassed by it.

Health care workers could also be seen as a source of support. All of the groups except the control high-risk group found the health care workers to be generally supportive. Support or the lack of it was manifest in one of three areas: (a) the role performed by the health care worker; (b) the general health care system; and (c) the facilities (see Table 4.32 for a summary of the results). The primary roles performed by health care workers which were deemed supportive were understanding, compassionate care and information delivery. Lack of support in this area was identified by the respondents as not being involved in the care and decision-making process. One individual commented "I was told the family would be involved in decision-making and that doesn't seem to be happening. By the time you get here you shouldn't have to try so hard to get what you need". The choice of the word "need" dramatically indicated the lack of understanding on the part of the health care system.

The facilities of the institution were seen as supportive if they provided a "home-like" atmosphere and were seen as unsupportive if they lacked "basics" such as humidifiers,

**TABLE 4.32 DESCRIPTION OF THE SUPPORTIVENESS OF THE HEALTH CARE SYSTEM**

	<b>SUPPORTIVE</b>	<b>LACK OF SUPPORT</b>
<b>PERFORMANCE OF ROLE</b>	<ul style="list-style-type: none"> <li>--UNDERSTANDING COMPASSIONATE CARE</li> <li>--PROVISION OF INFORMATION</li> <li>--OPPORTUNITY TO SHARE CONCERNS AND FEELINGS</li> </ul>	<ul style="list-style-type: none"> <li>--LACK OF INVOLVEMENT OF FAMILY IN CARE AND DECISION-MAKING</li> <li>--LITTLE TIME SPEND IN SHARING CONCERNS AND FEELINGS</li> <li>--LACK OF TIME SPENT WITH THE PATIENT</li> </ul>
<b>FACILITIES</b>	<ul style="list-style-type: none"> <li>--PROVISION OF HOME-LIKE ATMOSPHERE</li> </ul>	<ul style="list-style-type: none"> <li>--LACK OF EQUIPMENT SUCH AS HUMIDIFIERS AND AIR MATTRESSES</li> <li>--FEW PRIVATE ROOMS</li> <li>--LIMITED FACILITIES FOR THE FAMILY TO MAKE COFFEE ETC.</li> </ul>
<b>HEALTH CARE SYSTEM</b>	<ul style="list-style-type: none"> <li>--PROVISION OF OPEN VISITING HOURS AND WEEKEND PASSES</li> </ul>	<ul style="list-style-type: none"> <li>--LACK OF CHOICE IN CARE INSTITUTION</li> <li>--DIFFICULTY ACCESSING CARE</li> </ul>

air mattresses, and private rooms. The health care system was deemed supportive when it provided mechanisms such as open-visiting hours and weekend passes. It was seen as unsupportive if the patient was not given a choice as to which institution to go to or when it was difficult to be admitted to palliative care.

#### 4.6.1.4 Summary

From the above discussion it appeared that high-risk respondents lacked sources of support while the low-risk groups could more directly access support and it was available in varied forms. It was also interesting to note that while the low-risk groups found the greatest amount of support in their families the high-risk groups found the greatest amount of support in the health care workers. This finding supports Vachon's (1976) claim that when the patient dies not only does the bereaved individual lose a family member or significant other, but they also lose a primary source of support creating a multiple grief experience. As the health care worker is the primary source of support for the high-risk individual, it makes sense to continue the relationship after the death.

#### 4.6.1.5 Changes in the Respondent's Life as a result of the Illness

The respondents were also asked to talk about the changes that had occurred in their lives since the patient's illness. This question was asked to help determine what type of effect the bereavement program had on the social functioning of the individual. Generally it was very difficult to ellicit specific changes in people's lives. There was either no perception of change or life had changed so drastically that they could hardly remember what it was like before. Four individuals in the control high-risk group reported no particular changes while five individuals reported that there were major changes in their life. The people who reported change stated that their whole life was disrupted as their entire focus was the illness. As a group, they felt they had to take on more responsibilities, they didn't go out as much or see other people. One respondent summed up the feelings of all of them when she said "its just not as happy when we are together". Two of the experimental high-risk group reported no major changes in their lives while six respondents stated that their life was totally disrupted. There appeared to be a lot of despair in the voices of people who answered the question and a sense that they felt totally out of control. Financial difficulties and child care responsibilities were mentioned as tasks that they never had to do alone before which was requiring considerable adjustment. Another major

change mentioned by individuals where the spouse was dying was that they could no longer do things as a couple.

The control low-risk group also reported changes in their lives as a result of the illness. But generally the changes were minor such as disruption of routine due to spending time at the hospital. Seven of the control group reported no changes while four individuals reported minor changes. It was interesting to note that all of the experimental low-risk respondents reported changes in their lives as a result of the illness. The changes at times were rather encompassing such as "I just feel lost now", "just not as happy as I used to be". Other individuals were able to point to specific disruptions such as changes in social life, added responsibilities, and loss of a companion. The disruption apparent in the experimental low-risk groups' life was consistent with the higher levels of disruption in social functioning they reported on the General Health Questionnaire.

#### 4.6.1.6 Current Stressors Experienced by the Respondent

In an attempt to determine if factors other than the illness were creating disruption for the respondents they were asked the question, "Are there any other aspects of your life that are currently stressful for you?". The control low-risk group reported .45 stressors per person. Most of the stressors were time limited such as being off



work with an injured hand or minor health troubles. The control high-risk group reported 1.44 stressors per person. The stressors generally represented long term difficulties such as a recent divorce, long term financial instability, serious health problems (multiple sclerosis), other care responsibilities and previous deaths in a short period. The coping abilities of the high-risk group individuals appeared to be severely taxed.

The experimental high-risk group reported 1.13 stressors per person and were of similar magnitude to the control high-risk group. What was particularly interesting was that the experimental low-risk group reported 1.16 stressors per person a fraction higher than the high-risk group. Most of the stressors reported by the low-risk group were time limited such as feeling the stress of working in a department store during the Christmas rush and having to find someone to look after the children while the respondent visits at the hospital. What was important however was that these individuals felt stressed by the situations they were currently in and perhaps would have benefited from some type of intervention.

#### 4.6.2 Bereavement Variables

The variables chosen for analysis from the bereavement interview guide consisted of perception of preparation for the death, support network, changes as a result of

bereavement and stressors currently experienced which were unrelated to a death in the family.

#### 4.6.2.1 Perception of Preparation for the Death

As the literature supported the notion that preparation for the death may be an important factor in determining adjustment in the period of bereavement, the respondents were asked the question of how prepared they felt when the death actually happened. As can be seen from Table 4.33, there was a fairly even mix of individuals who felt prepared and those who did not. The individuals in the high-risk groups who reported feeling unprepared for the death appeared to be unaccepting of the fact that it would ever happen. The people in the low-risk groups who were unprepared knew the death was going to happen, they just felt it had come more suddenly than they had expected. One experimental low-risk respondent commented that she felt that being on a palliative care unit was helpful as it gave her a chance to adjust to the people who were dying around her in an environment in which the nurses explained what was happening.

#### 4.6.2.2 Perception of Support Network

After the death occurred the respondents were again asked the question where they received their support and in what form was it provided. As Table 4.34 indicates, both high-

TABLE 4.33 PREPARATION FOR THE DEATH		
GROUP	UNPREPARED	PREPARED
E-HIGH N=6	3 (0.50)	3 (0.50)
C-HIGH N=7	4 (0.57)	3 (0.43)
E-LOW N=11	6 (0.55)	5 (0.45)
C-LOW N=10	4 (0.40)	6 (0.60)
E=EXPERIMENTAL C=CONTROL N=NUMBER OF RESPONDENTS		

risk groups found minimal support within their family systems. Family members were generally found to be nonsupportive when they did not allow the respondents to talk about the circumstances surrounding the death or his/her feelings. The death of the family member was classified as a "closed subject". The low-risk respondents found family to be very supportive around the time of the death and in the subsequent period of bereavement. Support was provided in the form of open communication where they were able to share their feelings with one another.

For the high-risk groups the ability of friends to provide support had increased. Friends were not usually used as a confidant to share experiences with but rather as a means of diversion to take the respondent's mind off the

**TABLE 4.34 SUPPORT NETWORK**

	STRONG SUPPORT			SUPPORT LACKING		
	FAMILY	FRIENDS	NURSES	FAMILY	FRIENDS	NURSES
E-HIGH N=6	2 (0.330)	3 (0.500)	5 (0.833)	4 (0.667)	3 (0.500)	1 (0.167)
C-HIGH N=7	3 (0.428)	6 (0.857)	5 (0.714)	4 (0.571)	1 (0.143)	2 (0.286)
E-LOW N=11	9 (0.818)	6 (0.545)	8 (0.727)	2 (0.182)	5 (0.454)	3 (0.273)
C-LOW N=10	8 (0.800)	8 (0.800)	8 (0.800)	2 (0.200)	2 (0.200)	2 (0.200)

E=EXPERIMENTAL  
C=CONTROL  
N=NUMBER OF RESPONDENTS

current circumstances. Friends were used as a source of companionship to go out to dinner or other social gatherings. The control low-risk group also used friends as a source of support. The experimental low-risk group did not find friends particularly helpful. This seemed to be because many respondents in this group were busy with other things and did not have time to stay in contact with their friends. Many friends had been lost during the course of the illness creating feelings of isolation.

All groups reported that health care workers were supportive during the final stage of the dying process. The control high-risk individuals perceived health care workers as more helpful during the terminal stage of the dying process than when first admitted to the unit. Three of the five individuals in the control high-risk group who found the health care workers supportive, commented that they would have found it helpful to talk to these individuals after the death. The nurse had been instrumental in providing information and was a person the respondent could talk to. These persons had many questions concerning the circumstances surrounding the death that remained unanswered. All members of the experimental high-risk group who found the health care workers supportive commented on the contact they had with them after the death. The respondents commented that they were able to discuss what had happened when the person died and how they felt about

the situation. Having contact with the palliative care unit also conveyed the message that someone cared.

#### 4.6.2.3 Summary

After the death, the low-risk groups continued to find support from many sources. The control high-risk group perceived more support from the different sources than they did before the death, relying primarily on friends and the health care workers at the time of the death. The primary source for the experimental high-risk group remained the health care worker. This group of respondents was able to identify the manner in which the bereavement counselor provided them with support.

#### 4.6.2.4 Perception of Changes in Respondents Life after Bereavement

Of the six high-risk experimental subjects, five commented that there were major changes in their lives after the death. What was particularly evident was the sense of loneliness and despair which accompanied the description of the changes. Respondents talked about not having anyone to share ideas with, the loss of a friend, increased responsibility in the form of decision-making and physical activities such as yard work. One respondent summed it up when she said "you realize its going to be like this for the rest of your life". All of the control high-risk

individuals reported major changes in their lives. The themes and the feeling tone of the discussion was identical to the experimental high-risk group.

The low-risk groups also reported major changes in their lives as a result of the death. What distinguished the low-risk groups from the high-risk groups was the sense of feeling tone. The low-risk group was sad about many of the changes but was not in a state of utter despair. They also had insight into some of their feelings and could find ways to remedy the situation. For example, one lady commented that she felt a funny sort of loneliness that she attributed to missing the sense of positive regard that her mother gave her for helping her. So when she felt lonely, she would go and visit someone in the block she could help which boosted her sense of self. The low-risk groups also seemed to have a sense of symbolism about them. One lady told a story about a plant she and her mother had saved after her father died. The plant had not bloomed since his death which had been ten years previously. The day after the mother died the daughter walked into the living room and saw that the plant had two blooms close together on one side and one bloom on the opposite side. The respondent interpreted this to mean that her mother was with her father and was happy but because a single bloom was left on the plant it conveyed that her parents had not forgotten about her. Nine of the eleven experimental low-risk individuals reported changes in

their lives and nine of the ten control group subjects reported changes.

#### 4.6.2.5 Stressors Currently Experienced by the Respondent

The respondents were again asked if there were any other stressors in their lives. Most of the stressors reported by the high-risk groups were the same ones which existed before the death, indicating the long-term nature of the problems. The low-risk group reported new stressors which would be time limited such as caring for the grandchildren while the respondent's daughter had another baby. The experimental high-risk group reported 1.33 stressors per person, the control high-risk group reported 1.71 stressors per person, the experimental low-risk group reported .54 stressors per person and the control low-risk group reported .70 stressors per person. It could again be seen that the low-risk groups reported fewer stressors than did the high-risk groups.

#### 4.6.2.6 Description of the Treatment

As it was difficult to standardize the treatment each individual would get due to the variability in need and volunteer style, a record was kept to describe exactly what the volunteers did. The social worker followed four individuals, the volunteers followed three and one individual was unable to be reached. All contact except two home visits was made over the telephone. 1.25 contacts per



person were made during the six-week period after the death. The most common strategy used was discussion. Aspects covered in the discussion were as follows:

1. exploration of feelings
2. clarification of the circumstances surrounding the death
3. reinforcement of positive coping behaviors
4. development of open communication within the family (primarily accomplished through the use of role modeling)
5. use of problem-solving techniques
6. provision of resources such as books and tapes

The first three strategies were used most frequently and consistently by the volunteers. The teaching of communication and problem-solving techniques was primarily done by the social worker. As can be seen, there was not a great deal of variability within the treatment perhaps because of the training sessions in which each volunteer participated.

#### 4.6.3 Summary

The datum from this quasi-experiment were analyzed using descriptive statistics to understand the sample. Both parametric and nonparametric tests were used to determine the effect of the bereavement program on each of the

dependent variables. The qualitative data was then used to further explain what was happening in the quantitative results.

## Chapter V

### DISCUSSION AND IMPLICATIONS

It is the belief of the investigator that this thesis expanded nursing research by examining a bereavement intervention and had the potential to change the care provided to bereaved individuals and families. The findings must be discussed in light of the limitations of the study and threats to validity. The findings must also be discussed in a time limited framework. Grieving is a long process and the results indicated only the beginning of that process. Therefore, it was not expedient to predict the effectiveness of the bereavement program on the basis of one follow-up measurement. The final chapter will discuss the threats to validity, the findings, application to the theoretical framework, implications for the bereavement program, and plans for future research.

#### 5.1 THREATS TO VALIDITY

As discussed in Chapter 3, there are certain threats to validity in any study where random assignment is not used. Statistical conclusion validity was threatened by a small sample size and random irrelevancies in the experimental settings. Individuals in either setting had expectations as

to what the institution would be like which probably affected their adjustment into the setting. As could be seen from the qualitative data, the treatment was implemented relatively consistently across individuals. There may have been some differences based on the timing of calls which could be attributed to the needs of the respective respondents.

Internal validity was primarily threatened by uncontrollable circumstances which occurred between the pre and posttest. Information was collected on stressors other than the illness/death which were operating. The attrition in the study was 12% which did not represent a severe threat in comparison to other studies of bereavement.

Construct validity was threatened by the interaction between testing and treatment. Most individuals reported that participating in the study was helpful as it allowed them to express their feelings. Testing across time provided them with another source of support. External validity was threatened by the fact that intact groups were used making generalizations to other populations difficult.

## 5.2 DISCUSSION OF THE FINDINGS

Although many of the results of the study were not statistically significant they did have clinical relevance. One of the threats to validity as outlined by Cook and Campbell (1979) was a small sample size. As has been previously stated, the investigator had very little power to detect a difference between the groups. There was only a 51% chance of detecting a large difference. Therefore, the chance of making a Type II error which is concluding there is no effect when there actually is, was very great.

One of the most obvious findings of the study was the relative accuracy of the risk-rating system. There was clearly a difference between the high and low-risk groups not only in quantitative measures but also in qualitative reporting. The difference between groups was clearly more evident when the two missclassified individuals were omitted from the experimental low-risk group. Both individuals were missclassified for the same reason. It was the belief of the interdisciplinary team that the religious beliefs and support network inherent in religious activities would support these individuals. In these two cases that was not evident.

Six-weeks after the death has generally been viewed as one of the most difficult times for bereaved individuals as many of the familiar supports withdraw. Any improvement in

the grieving response at six-weeks for individuals who participated in the program is then clinically significant.

#### 5.2.1 Effect of the Bereavement Program on the Grieving Response

At six-weeks post-death the bereavement program appeared to have the greatest effect on the high-risk group in decreasing the intensity of the grieving response. This conclusion was derived from the data of the bereavement experience questionnaire. The program had the greatest effect on the experiences of anger, meaninglessness, yearning, and morbid fears.

##### 5.2.1.1 Anger

The bereavement experience questionnaire measured anger that was directed at many sources: the self, family, friends and health-care workers. Both high-risk groups directed anger at the self, although the control high-risk group directed more anger at the self as well as the other sources. The bereavement program which began before the death of the patient was crucial in reducing the anger of the respondent. Time was spent enhancing communication between family members thus encouraging the expression of positive feelings and the identification of problem situations that the individual might have otherwise kept inside. Dealing with problems as they occurred had the

potential to decrease angry feelings, allowing family members to spend quality time together.

The bereavement volunteer continued to encourage open communication between the respondent and the family or friends after the death. The qualitative data indicated that after the death the experimental high-risk group used friends more than family as a source of support. The greatest support for the high-risk group was the health care worker. At six-weeks post death he/she may be the one who demonstrated the greatest understanding of the situation. In a time of isolation, when familiar supports have been withdrawn, this source of support was acceptable. Ideally the bereavement volunteer would want the respondent to find other sources of support thus decreasing the need for the program.

The involvement of the family as a member in the decision-making team also decreased the anger directed at others in the period of bereavement as they were involved in what was happening to the patient. Instead of decreasing control in the family unit by making all of the decisions for them, control of the situation was enhanced. One of the primary roles of the bereavement volunteer was to explore the respondent's feelings. Once feelings of anger were identified, the volunteer and the respondent were able to utilize problem-solving mechanisms to decrease these feelings. Some of the strategies that were utilized were to

encourage the respondent to phone the physician when he/she had questions about the care or the manner in which the patient died, or to call family members or friends to discuss their behavior patterns. Discussion and problem solving techniques appeared to have been successful in decreasing the sources of anger.

#### 5.2.1.2 Meaninglessness

Feelings of meaninglessness were identified when the respondents had lost interest in people or things that had once been meaningful to them. Both high-risk groups reported feeling a loss of purpose in life and a loss of interest in activities. The control group reported more general emptiness and loss of interest in work and religious activities. The bereavement program may have been useful in decreasing feelings of meaninglessness because it directly conveyed the message "I care about you", "you're worth while". Activities of the bereavement volunteer consisted of encouraging the respondent to stay involved with activities and social acquaintances, and provided reinforcement for positive roles performed by the respondent. The volunteer discussed with the respondent aspects in his/her life that they were directly contributing, to thus removing some of the source of lack of purpose.



### 5.2.1.3 Yearning

All groups of respondents experienced greater manifestations of yearning after the death, which was to be expected. The control high-risk group had many more manifestations of intense yearning such as hallucinations and preoccupation with thoughts of the deceased. The ANCOVA nearly detected statistically significant results between the high-risk groups ( $p=.054$ ). As the sample size decreased the power to detect the difference this finding was important. The bereavement volunteer participated in a relationship review with the respondent which may have been a positive way to release some thoughts about the deceased. The bereavement volunteer was also a source of companionship to the respondent thus providing a source of emotional support. Having contact with individuals who were grounded in reality assisted the respondent in dealing with what was happening today. Occasionally the bereavement volunteers and the respondents attended social gatherings together thus creating a diversion from the bereavement experience. One of the roles of the volunteer was also to interpret the normal grieving experience for the individual. Once the respondent knew that what they were experiencing was normal, they didn't feel as anxious about having it present. Instead of feeling as if they were losing their mind, they relaxed knowing that other people experience the same things.

#### 5.2.1.4 Morbid Fears

The control high-risk group also showed considerably more signs of morbid fears in the form of preoccupation with death. This finding may be directly related to the intensity of the yearning reaction. Because the control high-risk group had such an intense longing for the deceased person, morbid thoughts may be viewed as a way of uniting with the deceased. The bereavement program may have been effective in decreasing these thoughts as it allowed the individual to review the circumstances of the death and then to move on to other things.

#### 5.2.2 Effect of the Bereavement Program on the Health of the Individual

The bereavement program appeared to have had very little effect on the health status of the respondent. There was little difference in the scores of the experimental and control groups on each of the subscales. The experimental group did manifest more signs of poor health than did the control group. One finding that was a little disturbing was the fact that the experimental high-risk group experienced more anxiety and insomnia than did the control group. The experimental group reported more sleep disturbances and feelings of nervousness than did the control group and slightly less manifestations of depression. Perhaps this was indicative of life-long disturbances or differences in

health initially. Another explanation for the anxiety and lack of sleep experienced by the experimental group may have been the depth of grief work they were currently engaging in. The scores on the Bereavement Experience Questionnaire indicated that these individuals were making some progress in their grief work. Kallenberg (1987) stated that individuals who opened themselves up for grief work would ultimately learn and grow from it, but the process was not easy as it required a great deal of strength and emotional fortitude. Therefore, the anxiety experienced by the experimental high-risk group might be a sign of "working" through a difficult time.

### 5.2.3 Other Findings

Neither the Bereavement Experience Questionnaire nor the General Health Questionnaire had been used before the death to try and determine if anticipatory grieving was present. It was the investigator's belief that the General Health Questionnaire identified manifestations of stress and fatigue which may have been unrelated to the grieving response and therefore were a good measure of social functioning but not conclusively of anticipatory grieving.

The Bereavement Experience Questionnaire captured the components of the grief response, especially areas such as yearning, meaninglessness, depersonalization, and morbid fears. All of the raw mean scores except for the control

high-risk group decreased after the death of the patient. This was to say that the intensity of the grieving response decreased. When the adjusted mean scores were taken into consideration all of the groups' scores decreased at six-weeks after the death. Therefore, it could be concluded that responses associated with grieving were present before the death occurred and in slightly greater intensity. When the individual questions of the Bereavement Experience Questionnaire were analyzed it appeared that before the death the respondent grieved more for the patient who was suffering and experiencing changes in roles and status. After the death the respondent appeared to grieve more for him/herself and the loss which he/she was individually experiencing. This is perhaps justification for the concept of anticipatory grieving.

### 5.3 IMPLICATIONS OF THE FINDINGS FOR THE BEREAVEMENT PROGRAM

Before any major changes should be made in the bereavement program, the six-month follow-up interview should be done with the respondents to determine what long-term effects the program is having. The first clear recommendation from the study was that minimal follow-up needs to be provided to low-risk individuals. As the data clearly indicated, low-risk individuals generally had adequate support networks to provide them with assistance. They also perceived themselves as better copers and seemed to have problem-solving mechanisms at their disposal.

The second recommendation was that a more formal mechanism be built into the system for identifying individuals at risk later in the period of bereavement. This could be implemented within the program's functioning by making the scheduled telephone calls before the bereavement evening. Staff and volunteers need to be educated about what to look for if a person is having a difficult time in bereavement. It was unlikely that these individuals would attend the bereavement evening. If the volunteer identified some problems then follow-up could be started. The difficulty with this plan was that an individual in trouble would only be identified after approximately six-months. It would be more effective to make one phone call at about one-month to individuals who there was border line concern for to determine how they were functioning.

The third recommendation was that the program continue with the use of volunteer visitors with access to the unit social worker when necessary. Evidence of the excellent work done by the volunteers was identified in the qualitative data. The use of volunteer workers supported the philosophy that grieving is a normal process and was also cost containing.

The final recommendation was that the bereavement program be continued. The greatest impact occurred with the following strategies. It is important that anyone involved

with the bereavement program be knowledgeable and comfortable using the techniques.

1. Involvement of the family in decision-making and care provided to the patient.
2. Encouraging open communication
3. Interpretation of the normal grieving experience
4. Encouraging the development of problem-solving skills
5. Conducting a relationship review
6. Assisting the respondent in establishing a social network
7. Providing positive regard

#### 5.4 APPLICATION OF THE FINDINGS TO THE CONCEPTUAL FRAMEWORK

The conceptual framework used to guide the research was crisis theory which was derived from systems theory. The major component in systems theory is an organism which is composed of mutually dependent parts, standing in mutual interaction. The respondents in the study were in interaction with family, friends, the health care system and his/her own internal being. What appeared to happen was that high-risk individuals had fewer persons available to them to interact with and generally had a less satisfying or supportive interaction when it did occur. This situation appeared to arise because all of the family members were overcome with grief and simply did not have the strength to

reach out to others. What caused a situation to be interpreted as a crisis was the meaning of the event for the individual, the social context in which it occurred and the social resources and coping mechanisms available to deal with the situation.

Kallenberg (1987) believed that the "view of life" the person held affected the interpretation and resolution of the crisis state. Jeffner (1973, 1982) in Kallenberg (1987) described view of life as "those theoretical and evaluative assumptions that make up or are of vital importance for forming an overall view of man and the world" (p. 2). An integrated view of life was one in which there was agreement between the conscious and unconscious levels of a psychic structure. A person with an integrated view of life would have a basic attitude of trust, enabling them to have a certain degree of acceptance in a time of grief. The sense of acceptance would allow them to move on to social readjustment and reorientation. Individuals with an integrated view of life would demonstrate more flexible adaption and more existentialistic interpretations when confronted with trauma (Kallenberg, 1987).

The death of a family member had the potential of creating a crisis situation as equilibrium was upset, requiring role redefinition. For all groups of respondents the crisis state did not appear to begin at the time of the death but rather in the terminal state of the illness. This

was evidenced by the fact that both the grieving response and the disruption in general health were present before the death. Crisis in bereavement as a result of a terminal illness was composed of cumulative stress that started before the death. The presence of cumulative stress indicated that the coping reserves were being taxed and may have resulted in their depletion.

The interpretation of the stressful situation appeared to be different for high and low-risk subjects. High-risk subjects generally reported total disruption in their lives as a result of the illness/death whereas low-risk subjects reported relatively minor, time-limited changes. The feeling tone of the high-risk respondents reflected the total disruption as despair and lack of control were noted. Kallenberg (1987) referred to this as "boundless grief". According to Caplan (1961), coping, encompassed the components of adaptation which was environmental manipulation and adjustment which was intra-psychic manipulation. The low-risk individuals were able to adapt and adjust to the situation more easily as it appeared they had a larger repertoire of coping mechanisms. Therefore, established or familiar patterns could be used to cope with the situation. For example, the low-risk respondent who felt lonely was able to think of a solution to his/her state. The qualitative data supported the notion that low-risk individuals had more confidence in their own coping



abilities. Confidence created the security and trust that the situation would be resolved. Low-risk individuals also approached the situation from an existential viewpoint looking for meaning in what had happened. For example, the respondent who was able to find a connection with his/her parents in the blooms of a plant, found peace and security. The sense of stability provided the individual with a new homeostasis through the process of negentropy. Kallenberg (1987) would have classified these individuals as having an integrated view of life. Because the low-risk subjects had confidence in their own abilities and had a well developed support network, they had little need for the bereavement program.

High-risk subjects lacked confidence in their coping abilities and had few established or familiar patterns of problem-solving to rely on during a crisis state. As their familiar coping patterns failed they experienced more anxiety. What was needed for the resolution of the crisis state was for these individuals to develop new or institutive patterns of coping through the process of morphogenesis. Because they lacked confidence in their coping abilities they were unable to do this. The bereavement program intervened in the situation to break the crisis process by helping individuals understand the meaning of the loss for them (adjustment-intrapsychic manipulation), helping them to develop new coping patterns or providing

reinforcement for effective patterns, and reopening the world through social support (adaptation-environmental manipulation). According to Kallenberg's (1987) theory, these individuals might be seen as disintegrated and the primary purpose of the bereavement program was to help the individuals to establish trust in their world. Intervention then was able to bring about a new level of wellness or equilibrium by stimulating growth or negentropy in the individual. Without intervention the individual might move to further disruption and entropy.

#### 5.5 IMPLICATIONS OF THE FINDINGS FOR FURTHER RESEARCH

The first step to be taken was to complete the final measurements of the study at six-months and one year after the death. This provided information to answer the research question "What long-term effect does the bereavement program have on the adjustment of the individual?".

As the study was intended only as a pilot project the ultimate direction of the research would be to make a few methodological changes and to conduct the study again with a larger sample. As it was very difficult to control for random irrelevancies in the institutional settings, it would be desirable to conduct a random experiment within the St. Boniface General Hospital. This would imply that treatment (bereavement follow-up) would be withheld from a group of subjects. The effectiveness of the bereavement counselor as

opposed to the card and the evening would then be able to be delineated. The two primary variables which need to be added into the study were religious involvement and participation in decision-making. These two areas appeared to have a primary effect on adjustment to bereavement but inadequate data had been collected to determine their effect.

Another direction the research could take was in the development of an assessment tool to predict who would have difficulty in the period of bereavement. The scale devised by Parkes and Weiss (1983) was a starting point but further testing was required as some missclassifications were made. The study supported the claim that only a small percentage of individuals do not cope well in the period of bereavement. Therefore, it was crucial that an effective screening tool be developed for the wise use and allocation of resources.

Research also needs to be conducted to determine the adjustment of individuals bereaved from different sources. For example, the stigma scale identified very little disruption in this population but might have been a crucial element in the adjustment of individuals bereaved as a result of a socially stigmatized disease such as acquired immune deficiency syndrome (AIDS). As AIDS is becoming more prevalent in society, it is important to understand the grieving process for the survivors and know how to help.

The final research direction to come out of the thesis process had basically nothing to do with the actual study but rather with the process of the investigator. The transition from the role of clinician to researcher was fraught with stress and anxiety. It would be helpful to understand the process so that teaching strategies could be evolved to assist the student in making the transition.

#### 5.6 CONCLUSION

The results of this quasi-experiment did not demonstrate a statistically significant difference between individuals who participated in a bereavement program and those who did not. However, the results must be interpreted in light of the threats to validity. The major threat to validity was a small sample size which implied the investigator had only a 51% chance of detecting a large difference between the groups. The differences found between the groups were however, clinically significant. At six-weeks post death the bereavement program appeared to decrease the intensity of the grieving response especially in the areas of anger, meaninglessness, yearning, and morbid fears. As the bereavement process continued long after six-weeks, it was too early to determine the long-term effects of the bereavement program. Concrete recommendations for the bereavement program would have to wait until the final follow-up measurements had been made.

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Appendix A



WRITTEN EXPLANATION  
OF THE STUDY--SBGH

You are invited to participate in a study designed to evaluate the effectiveness of the counselling on the palliative care unit for families with a serious illness. The information obtained from this study may be helpful in improving the care for families with a serious illness. Your assistance will be greatly appreciated.

The study is being conducted by Tracy Hildebrandt, RN, BN, who is a Master of Nursing student at the University of Manitoba. Participation in the study will involve completing 4 or 5 questionnaires and answering some interview questions. It will take approximately 45 to 60 minutes of your time. The study extends for a year after care of the patient has been completed on the palliative care unit. The study involves meeting with Tracy Hildebrandt now, when your family member has been admitted to the palliative care unit and also 6-8 weeks after care of the patient has been completed and 6 and 12 months later. Each of these four sessions will take between 45 and 60 minutes of your time. If your family member is on the ward after being admitted for one month, the investigator would again like to meet with you.

Participation will not affect the care of the patient or family on the palliative care unit in any way. Although there will be no immediate benefits to the participants, the study may produce information that will help improve the care of families with seriously ill members in the future.

The questionnaires will ask information about your background such as your age, educational background and religious preferences. The second questionnaire asks questions about how you perceive your physical health. The third and fourth questionnaires deal with how you are managing daily activities and your social life. The fifth questionnaire will ask you about the specific aspects of the care you receive. The short interview consists of questions about how the illness has affected your family, your sources of personal support and other circumstances in your life which are currently stressful. You may find some of the questions distressing as they address sensitive matters surrounding the illness. It is perfectly acceptable to respond only to the questions you feel comfortable with or to discontinue the interview at any time. In the case you become distressed by the questions, the investigator will ask you if you wish to interrupt or discontinue the interview or may interrupt or discontinue it on her own. The investigator will provide you with support if the questions are distressing. The investigator will write down your responses to the questions.

There are no right or wrong answers to the questions. Remember it is the palliative care service which is being evaluated and not you.

Your name will not appear on any of the questionnaires or interview forms. Your confidentiality will be maintained by using a coding system which consists of your initials and the day, month and year of your birth. The investigator requests that you record all this information every time you complete a questionnaire. The questionnaires, interview forms, and consent forms will be locked in a filing cabinet accessible only to the investigator. The investigator, her thesis committee, statistician, and the author of one of the scales will have access to the responses. The data will be destroyed following the completion of the study.

You may decide not to participate in the study which is perfectly acceptable. You do not have to answer all of the questions, only those you feel comfortable with. You may withdraw from the study at any time without it affecting the care you or the patient receive from the palliative care unit.

The results of the study will be based on group data and not individual responses, so that your specific response to a question will not be identified. The study results may be published in a journal article. A summary of the results of the study will be provided to those requesting it.

If you have any questions which you would like answered before making a decision to participate, these will be provided for you now. If you have questions later, you may reach Tracy Hildebrandt at

Thank-you for taking the time to read this explanation.

WRITTEN EXPLANATION  
OF THE STUDY--PEH

You are invited to participate in a study designed to evaluate the effectiveness of the counselling on the palliative care unit for families with a serious illness. The information obtained from this study may be helpful in improving the care for families with a serious illness. Your assistance will be greatly appreciated.

The study is being conducted by Tracy Hildebrandt, RN, BN, who is a Master of Nursing student at the University of Manitoba.

Participation in the study will involve completing 4 or 5 questionnaires and answering some interview questions. It will take approximately 45 to 60 minutes of your time. The study extends for a year after care of the patient has been completed on the palliative care unit. The study involves meeting with Tracy Hildebrandt now, when your family member has been admitted to the palliative care unit and also 6-8 weeks after care of the patient has been completed and 6 and 12 months later. Each of these four sessions will take between 45 and 60 minutes of your time.

Participation will not affect the care of the patient or family on the palliative care unit in any way. Although there will be no immediate benefits to the participants, the study may produce information that will help improve the care of families with seriously ill members in the future.

The questionnaires will ask information about your background such as your age, educational background and religious preferences. The second questionnaire asks questions about how you perceive your physical health. The third and fourth questionnaires deal with how you are managing daily activities and your social life. The short interview consists of questions about how the illness has affected your family, your sources of personal support and other circumstances in your life which are currently stressful. You may find some of the questions distressing as they address sensitive matters surrounding the illness. It is perfectly acceptable to respond only to the questions you feel comfortable with or to discontinue the interview at any time. In the case you become distressed by the questions, the investigator will ask you if you wish to interrupt or discontinue the interview or she may interrupt or discontinue it on her own. The investigator will provide you with support if the questions are distressing. The investigator will write down your responses to the questions.

There are no right or wrong answers to the questions. Remember it is the palliative care service which is being evaluated and not you.

Your name will not appear on any of the questionnaires or interview forms. Your confidentiality will be maintained by using a coding system which consists of your initials and the day, month and year of your birth. The investigator requests that you record all this information every time you complete a questionnaire. The questionnaires, interview forms, and consent forms will be locked in a filing cabinet accessible only to the investigator. The investigator, her thesis committee, statistician, and the author of one of the scales will have access to the responses. The data will be destroyed following the completion of the study.

You may decide not to participate in the study which is perfectly acceptable. You do not have to answer all of the questions, only those you feel comfortable with. You may withdraw from the study at any time without it affecting the care you or the patient receive from the palliative care unit.

The results of the study will be based on group data and not individual responses, so that your specific response to a question will not be identified. The study results may be published in a journal article. A summary of the results of the study will be provided to those requesting it.

If you have any questions which you would like answered before making a decision to participate, these will be provided for you now. If you have questions later, you may reach Tracy Hildebrandt at

Thank-you for taking the time to read this explanation.

CONSENT FORM

This consent form is to certify that I

\_\_\_\_\_ (print full name), agree to participate in a study which evaluates the effectiveness of the counselling on the palliative care unit for families with a serious illness. I have been told that the study is being conducted by Tracy Hildebrandt, who is a Masters of Nursing student at the University of Manitoba.

I have received written and verbal explanation of the study and understand that as a participant I am asked to complete four or five questionnaires at various intervals. I will then participate in a short interview with Tracy Hildebrandt. I understand that some of the questions may be distressing as they address sensitive issues surrounding the illness. I also understand that I may answer only the questions I feel comfortable with and may discontinue the interview at any time. I understand that in the case that I become distressed by the questions, the investigator will ask me if I wish to interrupt or discontinue the interview or that she may interrupt or discontinue the interview herself. I understand that the investigator will provide me with support if the questions are distressing for me. I have had the opportunity to ask questions and have received satisfactory answers. I know I am able to ask Tracy Hildebrandt further questions at any time and that she can be contacted at 256-9240.

I understand that my decision to participate in the study is voluntary and that I have the option to withdraw my participation at any time, without it affecting my care or the care of the patient in any way.

My signature indicates that I am informed and that I agree to participate as a volunteer respondent. I have received a copy of this form and a written explanation of the study to keep. I understand that I may receive a copy of the results of this study upon request.

Date: \_\_\_\_\_

\_\_\_\_\_  
Signature of Participant

Date: \_\_\_\_\_

\_\_\_\_\_  
Signature of Investigator  
Tracy Hildebrandt  
Telephone: \_\_\_\_\_

Please print your name and address if you wish to receive a copy of the results of this study.

Name: \_\_\_\_\_

Address: \_\_\_\_\_  
\_\_\_\_\_

CONSENT FORM

This consent form is to certify that I

\_\_\_\_\_ (print full name), agree to participate in the second phase of a study which evaluates the effectiveness of the counselling on the palliative care unit for families with a serious illness. I have been told that the study is being conducted by Tracy Hildebrandt, who is a Masters of Nursing student at the University of Manitoba.

I have received written and verbal explanation of the study and understand that as a participant I am asked to complete four or five questionnaires at various intervals. I will then participate in a short interview with Tracy Hildebrandt. I understand that some of the questions may be distressing as they address sensitive issues surrounding the illness. I also understand that I may answer only the questions I feel comfortable with and may discontinue the interview at any time. I understand that in the case that I become distressed by the questions, the investigator will ask me if I wish to interrupt or discontinue the interview or that she may interrupt or discontinue the interview herself. I understand that the investigator will provide me with support if the questions are distressing for me. I have had the opportunity to ask questions and have received satisfactory answers. I know I am able to ask Tracy Hildebrandt further questions at any time and that she can be contacted at 256-9240.

I understand that my decision to participate in the study is voluntary and that I have the option to withdraw my participation at any time, without it affecting my care or the care of the patient in any way.

My signature indicates that I am informed and that I agree to participate as a volunteer respondent. I have received a copy of this form and a written explanation of the study to keep. I understand that I may receive a copy of the results of this study upon request.

Date: \_\_\_\_\_

\_\_\_\_\_  
Signature of Participant

Date: \_\_\_\_\_

\_\_\_\_\_  
Signature of Investigator  
Tracy Hildebrandt  
Telephone:





6. INCOME: Check the one response that comes closest to the approximate annual income of your family.

- \_\_\_\_\_ under \$5,000
- \_\_\_\_\_ \$5,000 to \$9,999
- \_\_\_\_\_ \$10,000 to \$14,999
- \_\_\_\_\_ \$15,000 to \$19,999
- \_\_\_\_\_ \$20,000 to \$24,999
- \_\_\_\_\_ \$25,000 to \$29,999
- \_\_\_\_\_ \$30,000 to \$39,999
- \_\_\_\_\_ \$40,000 and over

7. What is your relationship to the patient? (husband, wife, daughter, son etc.)

PHYSICAL HEALTH QUESTIONNAIRE

Initials: \_\_\_\_\_ Date \_\_\_\_\_

Date of Birth: \_\_\_\_\_  
                  day           month           year

Physical Health Questionnaire

INSTRUCTIONS: The following questions relate to your physical health. Please answer them as truthfully as possible.

1. How would you rate your overall health at the present time? (circle the appropriate response)

          excellent                   good                   fair                   poor

2. Do you have any specific health problems?

\_\_\_\_\_ yes                   \_\_\_\_\_ no

If yes, is this something recent?

\_\_\_\_\_

When did the problem start and has it been worse in the last month?

\_\_\_\_\_

\_\_\_\_\_

3. Do you have any of the following illnesses at this time? (check those that you are currently experiencing)

arthritis \_\_\_\_\_  
kidney disease \_\_\_\_\_  
diabetes \_\_\_\_\_  
high blood pressure \_\_\_\_\_  
ulcers or stomach problems \_\_\_\_\_

4. When was you last check-up with the doctor?

\_\_\_\_\_

5. How much do your health troubles stand in the way of your doing the things you want to do? (circle the appropriate response)

not at all                      a little                      a great deal

6. How would you rate your appetite? (circle the appropriate response?)

excellent                      good                      fair                      poor

Has there been a change in your appetite in your past month?

\_\_\_\_\_ yes                      \_\_\_\_\_ no

If yes, has your appetite increased or decreased?

\_\_\_\_\_

7. Is alcohol a part of your diet?

\_\_\_\_\_ yes                      \_\_\_\_\_ no

If yes, how much would you consume in one week?

\_\_\_\_\_

Would you say your consumption has increased in the past month?

\_\_\_\_\_ yes                      \_\_\_\_\_ no

If yes, by how much? \_\_\_\_\_

8. Have you noticed a change in your weight in the past month?

\_\_\_\_\_ yes                      \_\_\_\_\_ no

If yes, how much have you lost or gained?

\_\_\_\_\_

9. Do you have trouble sleeping at night? (circle the appropriate response)

never                      rarely                      sometimes                      often

Do you take any medication to help you sleep?

\_\_\_\_\_

10. Are you currently taking any prescribed medication?

\_\_\_\_\_ yes                      \_\_\_\_\_ no

If yes, what kind?

\_\_\_\_\_

How long have you been taking it?

\_\_\_\_\_

11. Are you currently taking any over-the-counter medications?

\_\_\_\_\_ yes                      \_\_\_\_\_ no

If yes, what kind?

\_\_\_\_\_

How long have you been taking them?

\_\_\_\_\_

12. Are there any other concerns about your health which you would like to share?

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

# GENERAL HEALTH QUESTIONNAIRE

GHQ-28  
(North American Version)

Please read this carefully:

We should like to know if you have had any medical complaints, and how your health has been in general, *over the past few weeks*. Please answer ALL the questions on the following pages simply by underlining the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those that you had in the past.

It is important that you try to answer ALL the questions.

Thank you very much for your co-operation.

## HAVE YOU RECENTLY

A1 – been feeling perfectly well and in good health?	Better than usual	Same as usual	Worse than usual	Much worse than usual
A2 – been feeling in need of some medicine to pick you up?	Not at all	No more than usual	Rather more than usual	Much more than usual
A3 – been feeling run down and out of sorts?	Not at all	No more than usual	Rather more than usual	Much more than usual
A4 – felt that you are ill?	Not at all	No more than usual	Rather more than usual	Much more than usual
A5 – been getting any pains in your head?	Not at all	No more than usual	Rather more than usual	Much more than usual
A6 – been getting a feeling of tightness or pressure in your head?	Not at all	No more than usual	Rather more than usual	Much more than usual
A7 – been having hot or cold spells?	Not at all	No more than usual	Rather more than usual	Much more than usual
B1 – lost much sleep over worry?	Not at all	No more than usual	Rather more than usual	Much more than usual
B2 – had difficulty in staying asleep?	Not at all	No more than usual	Rather more than usual	Much more than usual
B3 – felt constantly under strain?	Not at all	No more than usual	Rather more than usual	Much more than usual
B4 – been getting edgy and bad-tempered?	Not at all	No more than usual	Rather more than usual	Much more than usual
B5 – been getting scared or panicky for no good reason?	Not at all	No more than usual	Rather more than usual	Much more than usual
B6 – found everything getting on top of you?	Not at all	No more than usual	Rather more than usual	Much more than usual
B7 – been feeling nervous and uptight all the time?	Not at all	No more than usual	Rather more than usual	Much more than usual

PLEASE TURN OVER

**HAVE YOU RECENTLY**

C1	– been managing to keep yourself busy and occupied?	More so than usual	Same as usual	Rather less than usual	Much less than usual
C2	– been taking longer over the things you do?	Quicker than usual	Same as usual	Longer than usual	Much longer than usual
C3	– felt on the whole you were doing things well?	Better than usual	About the same	Less well than usual	Much less well
C4	– been satisfied with the way you've carried out your task?	More satisfied	About same as usual	Less satisfied than usual	Much less satisfied
C5	– felt that you are playing a useful part in things?	More so than usual	Same as usual	Less useful than usual	Much less useful
C6	– felt capable of making decisions about things?	More so than usual	Same as usual	Less so than usual	Much less capable
C7	– been able to enjoy your normal day-to-day activities?	More so than usual	Same as usual	Less so than usual	Much less than usual
<hr/>					
D1	– been thinking of yourself as a worthless person?	Not at all	No more than usual	Rather more than usual	Much more than usual
D2	– felt that life is entirely hopeless?	Not at all	No more than usual	Rather more than usual	Much more than usual
D3	– felt that life isn't worth living?	Not at all	No more than usual	Rather more than usual	Much more than usual
D4	– thought of the possibility that you might do away with yourself?	Definitely not	I don't think so	Has crossed my mind	Definitely have
D5	– found at times you couldn't do anything because your nerves were too bad?	Not at all	No more than usual	Rather more than usual	Much more than usual
D6	– found yourself wishing you were dead and away from it all?	Not at all	No more than usual	Rather more than usual	Much more than usual
D7	– found that the idea of taking your own life kept coming into your mind?	Definitely not	I don't think so	has crossed my mind	Definitely has

A  B  C  D  TOTAL

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Code 4075 05 4  
1 (10.85)

Your Initials: \_\_\_\_\_

Date: \_\_\_\_\_

Birthdate \_\_\_\_\_  
                  day month year

## BEREAVEMENT EXPERIENCE QUESTIONNAIRE

Demi, © 1984

On the left side of the page are thoughts and feelings that bereaved people sometimes have. Read the item on the left; then in the right column circle how often you have experienced this thought or feeling in the past month (4 weeks), including today.

Thoughts and Feelings I've Had in the Past Month (4 weeks)	Never	Sometimes	Often	Almost Always
1. Felt angry at friends	1	2	3	4
2. Felt that life has no meaning.	1	2	3	4
3. Found myself searching for the person who died.	1	2	3	4
4. Thought I saw the deceased person.	1	2	3	4
5. Felt guilty when I enjoyed myself.	1	2	3	4
6. Felt I had a poor relationship with the deceased person.	1	2	3	4
7. Felt fearful that something else bad might happen.	1	2	3	4
8. Lost interest in people that I formerly cared about.	1	2	3	4
9. Thought that I contributed to the death.	1	2	3	4
10. Yearned for the deceased person.	1	2	3	4
11. Lost my religious faith.	1	2	3	4
12. Felt fearful that I might die.	1	2	3	4
13. Lost interest in my work.	1	2	3	4
14. Thought I was losing my mind.	1	2	3	4
15. Felt a need for physical intimacy.	1	2	3	4
16. Lost interest in activities that I formerly cared about.	1	2	3	4
17. Felt blamed by others for the death.	1	2	3	4
18. Felt fearful that another of my loved ones might die.	1	2	3	4
19. Felt ashamed of the way he/she died.	1	2	3	4
20. Felt like a part of me was/is dead.	1	2	3	4
21. Felt that he/she contributed to his/her own death.	1	2	3	4
22. Felt like I was watching myself go through the motions of living.	1	2	3	4
23. Felt I should have done more for him/her during his/her life.	1	2	3	4
24. Felt that the deceased person was/is guiding me.	1	2	3	4

Thoughts and Feelings I've Had in the Past Month (4 weeks)	Never	Sometimes	Often	Almost Always
25. Heard the deceased person's voice, cry, cough, etc.	1	2	3	4
26. Thought that the death was a punishment for things I did in the past.	1	2	3	4
27. Sensed the deceased person's presence.	1	2	3	4
28. Felt a need to be emotionally close to someone.	1	2	3	4
29. Felt angry at strangers.	1	2	3	4
30. Felt that some person was responsible for the death.	1	2	3	4
31. Felt guilty about my sexual needs.	1	2	3	4
32. Was preoccupied with thoughts of death.	1	2	3	4
33. Felt angry over local, national, or world events.	1	2	3	4
34. Felt guilty about some things I said or did <u>since</u> the death.	1	2	3	4
35. Spent time looking at the deceased person's pictures, clothing, or belongings.	1	2	3	4
36. Felt angry at relatives.	1	2	3	4
37. Felt that I have nothing to live for.	1	2	3	4
38. Felt that the deceased person is located within me.	1	2	3	4
39. Felt guilty because I'm doing so well since the death.	1	2	3	4
40. Felt compelled to change my residence because of what some people thought about the death.	1	2	3	4
41. Felt emotionally distant from people.	1	2	3	4
42. Thought that there are some very real reasons why I have felt guilty.	1	2	3	4
43. Felt angry at God.	1	2	3	4
44. Felt that I caused the death.	1	2	3	4
45. Felt guilty about some things I said and did <u>before</u> the death.	1	2	3	4
46. Felt angry at myself.	1	2	3	4
47. Thought that there isn't any real reason for me to feel guilty, yet I do.	1	2	3	4
48. Felt relieved that he/she died.	1	2	3	4
49. Felt I could have done something to prevent the death.	1	2	3	4



Thoughts and Feelings I've Had in the Past Month (4 weeks)	Never	Sometimes	Often	Almost Always
51. Felt angry at the deceased person.	1	2	3	4
52. Felt I had a very good relationship with the deceased person.	1	2	3	4
53. Felt guilty because I have lived longer than he/she did.	1	2	3	4
54. Felt that I did not grieve correctly.	1	2	3	4
55. Felt angry at people who provided care to the deceased person (doctors, nurses, therapists, etc.).	1	2	3	4
56. Was preoccupied with thoughts about the deceased person.	1	2	3	4
57. Felt guilty about my sexual behavior.	1	2	3	4
58. Felt afraid to be alone.	1	2	3	4
59. Felt empty.	1	2	3	4
60. Felt my life has no purpose.	1	2	3	4
61. Felt a need to be touched or held.	1	2	3	4
62. Felt that my presence makes people uncomfor- table.	1	2	3	4
63. Was unable to reach out to others for help.	1	2	3	4
64. Could not bear to sort or part with the deceased person's belongings.	1	2	3	4
65. Felt unable to reach out to others for help.	1	2	3	4
66. Felt I would welcome death.	1	2	3	4
67. Felt afraid of losing control of my emotions.	1	2	3	4

Demi, Alice S.

Your Initials: \_\_\_\_\_

Birthdate: \_\_\_\_\_  
                  day       month       year

Date: \_\_\_\_\_

## REVISED EXPERIENCE QUESTIONNAIRE

Demi c 1984  
revised (T. Hildebrandt) August, 1986

On the left side of the page are thoughts and feelings that relatives of dying patients sometimes have. Read the item on the left, then in the right column circle how often you have experienced this thought or feeling in the past month (4 weeks), including today.

Thoughts and Feelings I've Had in the past Month (4 weeks)	Never	Sometimes	Often	Almost Always
1. Felt angry at friends.	1	2	3	4
2. Felt that life has no meaning.	1	2	3	4
3. Found myself searching for the patient when I am alone.	1	2	3	4
4. Thought I saw the patient when I was alone.	1	2	3	4
5. Felt guilty when I enjoyed myself.	1	2	3	4
6. Felt I have a poor relationship with the patient.	1	2	3	4
7. Felt fearful that something else bad might happen.	1	2	3	4
8. Lost interest in people that I formerly cared about.	1	2	3	4
9. Thought that I contributed to the illness.	1	2	3	4
10. Yearned for the patient.	1	2	3	4
11. Lost my religious faith.	1	2	3	4

Thoughts and Feelings I've had in the Past Month (4 weeks)	Never	Sometimes	Often	Almost Always
12. Felt fearful that I might die.	1	2	3	4
13. Lost interest in my work.	1	2	3	4
14. Thought I was losing my mind.	1	2	3	4
15. Felt a need for physical intimacy.	1	2	3	4
16. Lost interest in activities that I formerly cared about.	1	2	3	4
17. Felt blamed by other for the illness.	1	2	3	4
18. Felt fearful that another of my loved ones might become seriously ill.	1	2	3	4
19. Felt ashamed of the way he/she lived.	1	2	3	4
20. Felt like a part of me was/is dying.	1	2	3	4
21. Felt that he/she contributed to his/her own illness.	1	2	3	4
22. Felt like I was watching myself go through the motions of living.	1	2	3	4
23. Felt I should have done more for him/her during his/her life.	1	2	3	4
24. Felt that the patient was/is guiding me.	1	2	3	4
25. Heard the patient's voice, cry, cough etc. when I was alone.	1	2	3	4
26. Thought that the illness was a punishment for things I did in the past.	1	2	3	4
27. Sensed the patient's presence when I was alone.	1	2	3	4
28. Felt a need to be emotionally close to someone.	1	2	3	4

Thoughts and Feelings I've had in the Past Month (4 weeks)	Never	Sometimes	Often	Almost Always
29. Felt angry at strangers.	1	2	3	4
30. Felt that some person was responsible for the illness.	1	2	3	4
31. Felt guilty about my sexual needs.	1	2	3	4
32. Was preoccupied with thoughts of death.	1	2	3	4
33. Felt angry over local, national, or world events.	1	2	3	4
34. Felt guilty about some things I said or did since the illness.	1	2	3	4
35. Spent time looking at the patient's pictures, clothing, or belongings.	1	2	3	4
36. Felt angry at relatives.	1	2	3	4
37. Felt that I have nothing to live for.	1	2	3	4
38. Felt that the patient is located within me.	1	2	3	4
39. Felt guilty because I'm doing so well since the illness.	1	2	3	4
40. Felt compelled to change my residence because of what some people thought about the illness.	1	2	3	4
41. Felt emotionally distant from people.	1	2	3	4
42. Thought that there are some very real reasons why I have felt guilty.	1	2	3	4
43. Felt angry at God.	1	2	3	4
44. Felt that I caused the illness.	1	2	3	4
45. Felt guilty about some things I said and did before the illness.	1	2	3	4

Thoughts and Feelings I've had in the Past Month (4 weeks)	Never	Sometimes	Often	Almost Always
46. Felt angry at myself.	1	2	3	4
47. Thought that there isn't any real reason for me to feel guilty, yet I do.	1	2	3	4
48. Felt relieved when he/she was diagnosed.	1	2	3	4
49. Felt I could have done something to prevent the illness.	1	2	3	4
50. Felt guilty about little, unimportant things.	1	2	3	4
51. Felt angry at the patient.	1	2	3	4
52. Felt I have a very good relationship with the patient.	1	2	3	4
53. Felt guilty because I will live longer than he/she will.	1	2	3	4
54. Felt that I did not cope with the illness correctly.	1	2	3	4
55. Felt angry at people who provided care to the patient (doctors, nurses, therapists, etc.)	1	2	3	4
56. Was preoccupied with thoughts about the patient.	1	2	3	4
57. Felt guilty about my sexual behavior.	1	2	3	4
58. Felt afraid to be alone.	1	2	3	4
59. Felt empty.	1	2	3	4
60. Felt my life has no purpose.	1	2	3	4
61. Felt a need to be touched or held.	1	2	3	4
62. Felt that my presence makes people uncomfortable.	1	2	3	4

Thoughts and Feelings I've had in the Past Month (4 weeks)	Never	Sometimes	Often	Almost Always
63. Was unable to reach out to others for help.	1	2	3	4
64. Wanted to sort or part with the patient's belongings.	1	2	3	4
65. Felt unable to recall the patient's image when I was alone.	1	2	3	4
66. Felt I would welcome death.	1	2	3	4
67. Felt afraid of losing control of my emotions.	1	2	3	4

PRETEST INTERVIEW GUIDE

Initials: \_\_\_\_\_ Date \_\_\_\_\_

Date of Birth: \_\_\_\_\_  
                  day           month           year

Pretest Interview Guide

Introduction to the interview guide:

I'm going to be asking you a few questions about your family and \_\_\_\_\_ current illness. Please feel free to answer only the questions you are comfortable with and to let me know if you are getting tired. Feel free to stop the interview at any time.

1. Could you tell me a little bit about yourself and your family?

2. How long have been coping with \_\_\_\_\_ present illness?

Could you tell me a little bit more about it?  
(distressing symptoms)

How much difficulty would you say your are having coping with the illness?

How would you describe your relationship with \_\_\_\_\_?

3. Do you think others (family, friends, health care workers) understand what you are going through or feeling?

family:

friends:

health care workers:

Is there someone you can talk to, and share your thoughts and feelings?

Do you feel supported by family/friends/health care workers?

How many people do you feel you can turn to for support?



4. Many people talk about the changes they experience in their lives when there is an illness in the family. Do you feel your life has changed in any way since \_\_\_\_\_ illness?

How do you feel about these changes?

How do you feel you are coping with these changes?

5. Are there any other aspects of your life that are causing you stress or anxiety at this time? (work/retirement, family, other losses)

I'm finished with my questions at this time. Is there anything else you would like to discuss?

Are there any questions you would like to ask of me?

How did you find this interview. Were there any questions that were particularly stressful for you?

I'd like to thank-you for your time and your willingness to participate in the study.

BEREAVEMENT INTERVIEW GUIDE

Initials: \_\_\_\_\_ Date \_\_\_\_\_

Date of Birth: \_\_\_\_\_  
                  day        month        year

Bereavement Interview Guide

Introduction to the interview guide:

What I would like to do now is to ask you a few questions about your current situation and the circumstances surrounding \_\_\_\_\_ death. Please feel free to answer only the questions you are comfortable with and to let me know if you are becoming tired. Please feel free to stop the interview at any time.

1. Can you tell me about the circumstance surrounding \_\_\_\_\_ death?

Were you and he/she able to talk about his/her impending death?

How long was \_\_\_\_\_ in the hospital before he/she died?

How prepared did you feel for \_\_\_\_\_ death?

2. Can you tell me a little bit about the funeral?

3. Do you think others (family, friends, health care workers) understand what you are going through or feeling?

family:

friends:

health care workers:

Is there someone you feel you can talk to?

Do you feel supported by family, friends or health care workers?

How many people do you feel you can turn to for support?

4. Many people talk about the changes they experience in their lives when there has been a death in the family. Do you feel your life has changed in any way?

How do you feel about these changes?

How do you feel you are coping with these changes?

5. Are there any other aspects of your life that are currently stressful for you? (work/retirement, family, other losses)

I'm finished with my questions. Are there any other concerns you would like to tell me about?

Do you have any questions you would like to ask of me?

How has this interview been for you? Are there any questions which were particularly stressful?

I would like to thank-you for your time and your willingness to participate in the study.

CONSUMER EVALUATION

Initials: \_\_\_\_\_ Date \_\_\_\_\_

Date of Birth: \_\_\_\_\_  
                  day           month           year

Consumer Evaluation

The following questions relate directly to the bereavement followup program of the Palliative Care Unit of the St. Boniface General Hospital. Please answer only the questions you feel comfortable with.

1. How would you describe your experience with the bereavement program?

2. Comment on how you felt about each of the following:  
the bereavement card:

a telephone call from the bereavement visitor:

home visits from the bereavement visitor:

the bereavement social evening:

3. Did you feel the bereavement visitor understood what you were going through? Why did you feel this way?

4. Would you have preferred to be contacted by someone who was not affiliated with the palliative care unit. Please explain.

5. What would you identify as the major strength of the bereavement program?

6. What would you identify as the major weakness of the bereavement program?

7. What suggestions can you make that would improve the bereavement program for you?

8. If you had the opportunity to make the choice of becoming involved in the bereavement program again, would you do so? Why or why not?

9. Would you recommend the bereavement program to another individual who had gone through a similar experience? Why or why not?

Additional Comments: