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TOWARD A THEORY OF THE TRANSFORMATIVE POTENTIAL
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FOR BEREAVED YOUNG ADULTS
FOLLOWING LOSS OF A PARENT TO CANCER

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TOWARD A THEORY OF THE TRANSFORMATIVE POTENTIAL OF GRIEF: PERCEIVED SOURCES OF SUPPORT FOR BEREAVED YOUNG ADULTS FOLLOWING LOSS OF A PARENT TO CANCER

By

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ABSTRACT

TOWARD A THEORY OF THE TRANSFORMATIVE POTENTIAL OF GRIEF: PERCEIVED SOURCES OF SUPPORT FOR BEREAVED YOUNG ADULTS FOLLOWING LOSS OF A PARENT TO CANCER

By

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This study was designed to explore the young adult's grief experience following the death of a parent to cancer, with a focus on discovering what constituted helpful supports for the bereaved in this stage of the life cycle. Growth potential from grief was assessed based upon a transformative theory of grief. Research design was qualitative and data collection consisted of in-depth, semi-structured interviews of 12 adults between the ages of 23 and 43 years, recruited from a Hospice database. Time since death was varied at 13 and 24 month intervals; within two groups of six participants, three had utilized formal grief support services, three had not. Four professionals involved in the provision of grief services also were interviewed. Comparisons were made to clarify misperceptions about useful grief supports. Major findings revealed that all of the participants at 1 year were actively grieving, and lingering sadness continued for those in the 2 year group. Growth from grief was difficult to assess. In addition, formal support assessed as useful was primarily in the form of support groups or classes. Themes that emerged from the data were the role of friendship in the lives of grieving young adults, and other developmental loss issues implying special needs for resolution of loss at this stage in life. Hypotheses were generated that will serve as useful guidelines for further exploration in areas such as friendships and the family system as a form of support for grieving young adults. Suggestions for future research include examining the effects of bereavement at different developmental/life cycle stages, and exploring the role of friendship as a source of support for the grieving young adult, especially in the absence of a functional family system. Suggestions for revision within Hospice bereavement programs were provided, with a recommendation that evaluation studies be conducted to examine the effectiveness of group support and to better understand the determinants of the decision to seek support.

DEDICATION

This dissertation is dedicated to the memory of my father, Irving Dale Rhoades, who died as a result of colon cancer at the age of 50. I was 26 years old, in the midst of graduate study. His advice to me then, as he left this world was to strike a balance between structure and flexibility (he thought I worked too hard). His death has taught me about how to live life fully. After eight years, I still grieve, although the hurt is for different reasons and less intense. He will never see me graduate, or meet my husband, or know and love the children we want to have. Those are the developmental losses that will always sting just a little, and which the bereaved in this study also identified as ongoing losses. After eight years I also celebrate his memory, and the gifts he gave to me, which were many -- above all, he taught me to laugh, and to love people without judgment. I continue on the transformative journey myself, as I question what my life means, and what contributions I am supposed to make while I live. Losing my father in young adulthood changed my life and my direction forever, and it is because of the loss that I pursued this topic for study. So this dissertation is also dedicated to the bereaved in the world who need help and seek it without shame. Always my father's daughter, I will continue to strive toward loving people and helping those that need help. I plan to contribute to the development of effective grief supports and promote grief education in society. This dissertation is my launching pad, as I work as a human ecologist, promoting the health of individuals and families in society.

ACKNOWLEDGEMENTS

It is often the case that major accomplishments in life are done with the encouragement and assistance of others. This dissertation is a major accomplishment for me. I have many people in my life whose support and encouragement need recognition. I would like to begin by thanking my family of origin: My mother, Thora Stefnisdottir Rhoades, for the transgenerational gift of Icelandic tenacity. It helped me to endure this process. I hope to grow into the wisdom that she possesses. My sister, Kathleen Lou Rhoades who by example taught me to strive for academic excellence. She was there for me when I needed someone to show me the way. My brother, Kevin Rhoades whose wit and humor maintain connection to the Rhoades family legacy. He reminds me not to take life so seriously, as did our father and grandfather. We all continue to heal. I feel so fortunate for the loving support of my husband Jeffrey David. He gave me the greatest gift anyone has ever given me -- the freedom and the time to completely focus on this research for one full year. His love, silent strength, and encouragement are between the lines. I would like to express appreciation to my doctoral committee: To Dr. Linda Nelson, the Chairperson of my committee. She truly is a committed academician whose priorities lie with her students. Her attention to detail in the seemingly endless rounds of revisions helped me to write clearly and concisely. Her energy kept me going when I was weary. To Dr. Barbara Ames who was instrumental in starting my graduate school experience by offering me a teaching assistantship 9 years ago. She provided invaluable guidance in the writing of this dissertation. To Dr. Lillian Phenice whose class in death and dying introduced me to the Hospice movement and made it okay for me to grieve. She encouraged me to pursue my goals at my own pace. To Dr. John Schneider whose life's work and theory about the grieving process are at the base of this study. It was in his class that I learned about the importance of receiving and giving validation in the journey through grief. I am eternally grateful to the Hospice of Muskegon County and the Executive Director Mary Anne Gorman for supporting this research and believing in its value. Thank you to the entire Hospice staff for all their support and encouragement during this project. I am especially grateful to the participants, without whom this study could not have taken place. I felt privileged to be a part of their journey. Many thanks go to the support of my beautiful friends. I am blessed. I would like to offer a special note of gratitude to my kindred spirit Anita Louise. She believed in me when I didn't believe in myself, and taught me the meaning of perseverance.

TABLE OF CONTENTS

LIST OF TABLES

CHAPTER I. INTRODUCTION

Statement of the Problem

Every year 11.6 million adults, 5% of the U.S. population, lose a parent. Yet the number of research studies on parent death in adulthood is limited (Becker, 1992). Furthermore, although the death of a parent may be one of the most critical events in adult development, and the literature on death awareness is rapidly expanding, information on the effects of parent death is almost nonexistent (Douglas, 1991; Malinak, Hoyt, & Patterson, 1979). Overall, there has been extensive growth in the literature in the area of grief and bereavement, particularly in light of the earlier works of what we would now consider to be "classic" studies (e.g., Bowlby, 1969; Kubler-Ross, 1969; Parkes, 1972). But there still exists an information gap in the area of parent death (Becker). To help fill the gap, Becker's book focuses primarily on adjusting to the idea that a parent is dying, with less focus on the grieving process. Since proposing this study, the researcher discovered more recently published books in the popular literature on parent death, one of which does focus more on healing (Kennedy, 1991). However, little information is available about the effects of parent death on young adult development.

Douglas (1991) attempted to explain this gap by stating that, "a review of the literature on parent death reveals little information, although there is a considerable body of research that focuses on related areas" (p. 124). Related areas range from studies that examine caring for and losing an elderly or aging parent as an adult in "mid-life," aged 35-55, (Douglas, 1991; Myers, 1988) to coping with separation and loss as a young adult, aged 17-24 (LaGrand, 1986). There is also a mass of information on early childhood loss and later life development (Denes-Raj & Ehrlichman, 1991; Finkelstein, 1988; Tennant, 1988) as well as the effects of parental death on children (Grollman, 1967; LeShan, 1988; Wolfeldt, 1983). Yet there appears to be very little written about the experiences of grief and bereavement for parent death in adults, and especially for adults 25 to 40 years of age. The decision to complete a qualitative study with a focus on this age group came about because of an interest in young adult development and after a review of the literature revealed that very little had been written about the experiences of grief and bereavement for parent death in a young adult's life.

Background Information

The researcher's personal interest in identifying supports for the bereaved, and specifically for young adults who have lost a parent began with the loss of her father as a young adult (age 26). Professional interest began after taking a doctoral course in death and dying, where the researcher learned about the Hospice movement (one year following the loss of her father), and subsequently accepted a position as a bereavement coordinator within a Hospice. In addition and as part of ongoing doctoral study, the researcher enrolled in a series of courses about grief and loss. Information and knowledge about grief and bereavement on a theoretical level became accessible through course work. The researcher continued learning about the grieving process through hands-on experiences at Hospice. It was useful to combine theoretical knowledge with real life experience, witnessing the healing power of "validation" (Schneider & Olson, 1990). The orientation received in the Department of Family and

Child Ecology, specifically, the human ecological perspective (Bubolz & Sontag, 1993), dovetailed with the holistic and interdisciplinary team approach within Hospice. Valuable experience was gained while teaching the Hospice Grief Recovery Class and conducting in-home assessment visits with the Hospice families. The ideas for this study developed from this work, from continued scholarly commitment to learning about the complexity involved in the grieving process, and from the researcher's own experience with grief and loss.

Hospice Bereavement Paradox

Hospice bereavement services need support and validation of their importance. There is a lack of funding, lack of clarity in program goals, and lack of resources overall to provide for sustainment of competent bereavement staff, and ongoing, quality program development (Beresford, 1986; Lattanzi-Licht, 1988). In short, Hospice bereavement services are not reimbursed by Medicare, yet to be a licensed, certified Hospice, the program must make provision for bereavement follow-up for all Hospice families (information about Hospice licensure, certification, and accreditation is in Appendix A). Hospice is no longer a "movement" but rather an ongoing aspect of the health care system (Hayslip & Leon, 1992). Attention of the industry has shifted from starting programs to regulating them (Blum & Robbins, 1985, cited in Hayslip & Leon, p. 34). As the Hospice movement grew from a philosophy of care to an ongoing part of the health care system, the National Hospice Organization (NHO), established in 1977, sought public recognition and public and private funding for Hospice services. Issues of quality of care also arose across insurance providers, and the NHO was instrumental in developing guiding principles underlying Hospice care. The Medicare Hospice benefit became law in August of 1982, and in 1986, legislation made the benefit permanent (Hayslip & Leon). Bereavement services were not included as part of this Medicare benefit for reimbursement, yet provision of such services was still required if a Hospice wanted to become licensed. This is still the case presently (M. Gorman, Hospice Executive Director, personal communication, March 4, 1993).

Beresford (1987) has written repeatedly about Hospice management issues, and particularly about evaluating bereavement services. He states that:

> Offering bereavement follow-up support for survivors is a basic tenet of the hospice philosophy, and is in fact required under the Medicare Hospice benefit. However, Hospice Bereavement program planners often may be hard-pressed to offer scientific justifications for such services or even to specify what these services are intended to accomplish. As a result, bereavement care may be among the most vaguely defined and administratively neglected services offered by some Hospices (p. 2).

The researcher's postdoctoral career goals include involvement in Hospice bereavement evaluation studies, in part, as a way to justify the value of bereavement services. As a Bereavement Coordinator and a teacher of Grief Recovery classes, the researcher observed the value of and developed "hunches" about the usefulness of grief education and counseling. Yet only 6% of Hospices conduct any type of research, and even fewer conduct evaluation of bereavement services (Lattanzi-Licht, personal communication, March 2, 1989). Furthermore, Hospice bereavement programs, due to lack of reimbursement, rely primarily on outside sources for funding, such as allocations from the United Way, and in-house fundraising. Lattanzi-Licht (1988) states that "the majority of bereavement follow-up is done in the shadow of budgetary and staff time constraints . . . consistency in bereavement services would allow for a clearer, more accurate answer to the question of what bereavement services achieve" (p. 82).

One final issue related to Hospice bereavement services involves a misperception that exists in the field about just what it is that helps people grieve. Observation in classrooms of grieving people led to the working hypothesis that grief education facilitates movement through the grieving process. But there is some documentation about differences between what the professional views as being supportive to the bereaveds' needs, and what the bereaved identify as being useful supports during bereavement (Conway, Hayslip, & Tandy, 1991; Corr & Wass, 1991; Levy & Derby, 1992; Stylianos & Vachon, 1993). A national study of bereavement done by the National Academy of Science (Osterweis, Solomon, & Green, 1984) failed to uncover conclusive evidence of measurable benefits from Hospice bereavement programs. It seems there is a great deal to learn about provision of services for the grieving person. "Why are we doing bereavement?" asks one Director of a Hospice (Tscheu, as cited in Beresford, 1987, p. 2). He states that answering this question will help us to become aware of our assumptions about bereavement and grief, and presents the idea that as professionals we might be doing what we are doing in bereavement care to justify the (Hospice) philosophy.

Parkes (1988), however, completed a 10 year survey on research in bereavement and, although he credits Osterweis et al. (1984), he states that:

> We are now beginning to realize that we cannot over-simplify the problem of bereavement, and to recognize that, although our first task may be to foster and strengthen the neighborhood supports and mutual

> help that have always been available to the bereaved, there is a substantial number of people for whom this help will not be enough (p. 373).

In this review of literature, Parkes cited research on grief and bereavement which demonstrates the many negative consequences suffered from the death of a loved one, such as: physical health problems, higher rates of mortality than those who did not suffer death of a loved one, hospitalization, mental disturbance, and suicide. He summarized by stating that we have a great deal to learn about the complexities of bereavement.

In summary, an obvious discrepancy exists between the findings of bereavement research, the perceptions of professionals, and the services offered by Hospice bereavement programs. Beresford (1987) surmised, once again, that it may be related to program goals. Thus it is a return to Tscheu's (as cited in Beresford, 1987) question: why are we doing bereavement and what are the assumptions we are taking into program development? The crux of the issue, according to the findings of Osterweis et al. (1984) is that Hospices need help determining whether their services are intended simply to offer modest efforts to their bereaved families, consisting of a home visit, letters, and occasional (but timed) telephone calls, social gatherings, support groups and referral. Or is the goal to offer intervention services? Who is truly at risk? If a survivor is at risk emotionally, or physically, then how far does Hospice reach? Should an in-house psychologist or therapist be part of the Hospice disciplinary team? The range of services and the intensity of follow-up do vary widely among individual Hospice programs (Osterweis, et al.). Beresford reduces this complex dilemma by asking two simple questions: "Are the benefits of Hospice Bereavement services therapeutic or humanitarian?" and "How does the Hospice insure that the few who are at risk are properly identified?" (p. 2).

It should be evident by now that clarity on the goals of bereavement services has become more urgent as Hospices continue to expand and confront the financial pressures of the competitive health care system of the 1990s. Perhaps there will come a day when this component of Hospice will be reimbursed and given more attention. Perhaps it will truly become an integrated part of the services that Hospices offer.

Significance of the Study

The focus of this study was on a smaller scale and served as a precursor to the long term goal of conducting evaluation research among Hospice programs. The primary purpose for conducting this study was to begin to assess "what helps people grieve?" with specific concerns for what helps young adults grieve. A second purpose was to explore the transformative potential of grief (Schneider, 1989). An attempt was made to learn more about the formal and informal sources of support that the bereaved identify as helpful to them in their grief process, and to clarify misperceptions about provision of grief support services.

Objectives

The short-term objectives were:

1. To understand the young adult's experiences following the death of a parent to cancer.
2. To identify formal and informal sources of grief support.
3. To clarify misperceptions about provision of grief support services.
4. To build upon Schneider's (1989) theory about the transformative power of grief.

The long-term objectives are:

1. To generate guiding hypotheses for further inquiry into the grieving process.
2. To complete Hospice bereavement evaluation studies as a way to justify the value of bereavement services and to clarify program goals.
3. To test and utilize the Response to Loss (RTL) Inventory developed by Schneider and other colleagues (Schneider, Deutsch, McGovern, & Morgan, 1992).

Research Questions

The general research questions that led to the design of this qualitative study are:

1. What helps people, specifically young adults, grieve following the loss of a loved one?
2. What do young adults find supportive in their grieving process?
3. How do people find the strength and courage to move through the grieving process and transform grief?

Conceptual Definitions

The Hospice bereavement program, specifically the Hospice Grief Recovery Seminar, provides education and formal support to the grieving individual in a way that facilitates the grieving process and helps one move beyond the intensity of grief and into living again. The conceptual definitions that follow are those that relate to the research objectives, research questions, and developing theory. Some are used in the next chapter within the review of the literature.

1. Hospice: refers not to an institution, but rather to a program of care for the terminally ill and their families. This program emphasizes control and palliation of symptoms rather than cure of disease (where palliation means management of pain and symptoms of a life threatening illness, and the focus of care is on comfort, not cure). Also emphasized is the concept of care given at home or in a home-like environment, where patient autonomy is maintained about decisions of care (autonomy means the patient has the freedom to make decisions in his or her best interest, based on personal values). In addition, dimensions of patient needs such as emotional, social, spiritual, and physical reflect the holistic approach to patient care. "Emotional" refers to the patient's feelings; "social" refers to the life and relations of the patient and the people he or she comes into contact with each day; "spiritual" refers to the person's moral or religious beliefs and sense of hope; and "physical" refers to the bodily functions that, due to the disease, require medical and/or nursing care. Because the patient and his family are considered to be the unit of care, support is provided both before and after the death (ideas from Osterweis et al., 1984).

2. Bereavement: refers to a state involving loss. In fact, to "bereave" means to take away from (Kalish, 1985, p. 181-182).

3. Bereaved: refers to those individuals who have incurred the loss of a loved one through death. Individuals may be related. The bereaved in this study refers to adults, aged 25 to 40 years, who have lost a parent to cancer, or those persons who completed the Hospice bereavement support questionnaires.

4. Young adult development: refers to movement over time of a young adult (age 25 to 40 years) through life events, observing self and environmental changes as adjustments to transitions and challenges occur.

5. Loss: refers to the death of a loved one.

6. Hospice bereavement support services: refers to a program developed for family members of Hospice patients and also for others in the community who are mourning the death of someone close. Such a program is designed to facilitate the bereaveds' grief process with a focus that is educational and supportive, promoting well-being. Services are provided for both adults and children.

7. Grief: refers to the feelings of sorrow, anger, guilt, and confusion that can arise when one has suffered a loss or is bereaved (Kalish, 1985, p. 182).

8. Grieving process: refers to the movement through the feelings of grief that one must experience in order to transform the loss.

9. Transform: refers to an individual's capacity to move beyond grief into a newly defined sense of living. (Transformative: a variation of transform; ideas from Cochran & Claspell, 1987).

10. Transformative potential:

> the transformations which result from grieving significant losses and are often characterized by a shift from a focus on limits to an exploration of opportunities. Transforming loss can allow us to discover new ways to relate, understand, create and commit oneself to an ongoing process of renewal and discovery. Loss, grief and the potential for transformation are all part of the cycle and celebration of life (Schneider, 1989, p. 31).

11. Hospice Grief Recovery: refers to a six week class offered through Hospice that emphasizes how to manage one's feelings of grief and provides instruction on how to move through the grieving process by accomplishing certain identified "grief tasks." Such a class is based on an educational

versus therapeutic approach to managing grief. The tasks of grief are (a) believing that the loss really happened, (b) facing the pain of grief, (c) adjusting to the environment without the person who died, and (d) reinvesting in a new way of life, and in new relationships. The six week course is based on Worden's identified tasks of grief (Worden, 1982). Instruction about Worden's tasks and other grief models is provided within the classroom setting.

12. Recovery: refers to the extent to which a grieving individual learns to manage his or her grief by gaining knowledge about the grieving process and having a willingness to transform loss.

One of the objectives of this study was to identify formal and informal sources of grief support. Formal support has been defined in relation to structured programs, while informal support was defined by the bereaved during the interviews.

13. Formal support refers to programs, counseling services, ongoing groups, or classes that are available within the bereaveds' local community that function in a manner to provide instruction and assistance to the bereaved, and more specifically, refers to the educational, structured support that Hospice Grief Recovery Class provides, or a one-on-one counseling or therapy situation that the bereaved attend.

14. Informal support refers to what the bereaved in this study defined as friendships, family, significant others, church/faith.

Theoretical Models of Grief

One of the short term goals of this research was to build upon Schneider's transformative theory about the grieving process. In addition, Worden's tasks of grief were conceptually defined as the theory at the base of the Hospice Grief Recovery Seminar, used as an educational tool for helping bereaved persons. These two models of grief are discussed below, followed by other related theories that support this research.

Schneider's Holistic Model of Grief

Schneider (1984) developed a model of grieving that is holistic in nature, and includes multiple levels of experiencing: emotional, cognitive, behavioral, spiritual, physical. Whereas Kubler-Ross (1969) examines more the attitudes about death and dying, providing a starting point for theorizing about the grieving process, Schneider examines multiple levels of responses to grief, thus permitting a more comprehensive understanding of the grieving process. His model assumes a more optimistic stance, whereby he believes the experiences of grief are not all painful and filled with despair. One can grow from and integrate a loss, and perhaps find new meaning in life, with a greater sense of self-awareness and priorities. The model has three themes, under which various phases are described. The complexity of this model is perhaps best described according to the themes.

Theme one: What is lost? Schneider describes the person's ability to maintain some level of functioning while preparing to deal with the reality of the loss. The person experiences two phases: In the first phase, **initiating awareness (shock)**, one might ask: How is it possible that this has happened? The person attempts to limit awareness by engaging in coping mechanisms whereby he or she is holding on or letting go. **Holding on** is exemplified by thinking, I don't have to face this loss if I keep busy, try harder, or am overly optimistic. **Letting go** can be exemplified by diminishing the true significance of the loss or attempting to escape from the loss. This may be destructive, and often is a time to just "pull back from" life for awhile (p. 69). The next phase, **awareness**, is what most people commonly refer to as active grieving. The person has literally exhausted ways of avoiding the loss, and is facing reality.

Theme two: What is left? The person begins to enter into a time of healing, recognizing limits, and identifying supports. Increased self-awareness and search for meaning of life and reorganization of priorities may occur. In the **healing** phase one might ask, what keeps me going? Who gives me strength? The next phase, **perspective**, the person asks, what remains? What is the best and worst of this experience? The person may gain a new sense of living in the moment, vowing never to forget the loss, but to move into living again. And finally, in the next phase, **restoring/regeneration**, one might ask: Can I trust myself? The person begins to accept the loss, perhaps passively at first, but begins to really accept with time, that life will never be the same. Bereaved persons detach themselves from those aspects of their lives that were meaningful, and move into a new pathway and self-definition. Schneider states that a person, at this phase, may choose to continue limiting awareness, and may not choose to move ahead into defining a new life. This is a critical point in the grieving process.

Theme three: What is possible? The person begins to integrate the loss -- mind, body, and spirit -- and may ask if forgiveness is possible. What must be done to get on with my life? How does this loss fit into the rest of my life? The person enters into the **reformulation** phase, where the focus moves to one's potential. Are there other ways to look at this loss? What is now possible for me in this life? Reformulation extends the self-trust and self-awareness that emerge from grief; the person may take risks he or she has never before taken. Major life decisions and changes may take place with energy renewal and the focus is on growth, and discovering of potential rather than limits. The last phase, **transforming the loss,** happens when individuals discover that the reformulation process is a trustworthy one. They have accepted a new sense of identity, becoming less self-focused and more focused on being open to all experiences. Transforming the loss involves the person placing the loss in a context of growth, and he or she may ask, how have I grown from this loss? How has my view of the world changed? How much can I live? In this phase the person integrates the emotional, physical, behavioral, cognitive, and spiritual aspects of him/herself in order to gain higher levels of understanding and acceptance of the loss (Schneider, 1984).

Schneider summarizes by pointing out the holistic, growth-oriented nature of this model, which is based on observations and experiences from a variety of settings (e.g, clinical; educational). The model consists of the following phases: initiating awareness; limiting awareness (coping); awareness (active grieving); gaining perspective; integrating loss, reformulating and transforming the loss.

Based on this theory, Schneider (1989) has conducted research and written extensively about the grieving process as a way to promote understanding of the nature of grief as a transformative process. In addition, the Response to Loss (RTL) Inventory has been developed as a clinical and research tool (Schneider, Deutsch, McGovern, & Morgan, 1992). It is a self-assessment tool based on the model (Schneider, 1984) of the grieving process outlined above. This researcher is particularly intrigued by how some people grow from their losses and others do not. This study was based on this interest, building upon Schneider's ideas about the transformative potential of grief, and discovering how transformation takes place. The holistic, comprehensive theory outlined above is the primary theoretical base of this study, out of which came the general research question, "what helps people grieve?"

Worden's Tasks of Grief

Worden (1982) identifies one assumption of his theoretical model wherein he describes four "tasks" of grief. This assumption is that to grieve seems necessary to effective functioning, or that grief requires some form of expression (as described by Kalish, 1985). Kalish supports this assumption by stating that:

> Whether this happens early in the bereavement or later, with great initial intensity or spread out over time, through public display of tears, or through private sorrowing by means of overt behavioral expressions of grief or by means of physiological changes, grief will virtually always be expressed in some fashion (p. 183).

The four tasks of grief as outlined by Worden (1982) are succinctly summarized in a textbook written by Kalish (1985, p. 183). Therefore, this summary was utilized for description of Worden's model.

Task 1: The grieving person must believe that the loss really happened, and accept the reality of the loss -- that the death is real. Denial of the death may lead to prolonged and unhealthy grief (perhaps pathological in some cases).

Task 2: The grieving person must accept that grief is painful, i.e., must face the pain of grief. People may cope with the pain by attempting to avoid it or dull it with the use of alcohol, drugs (including tranquilizers), or by overworking or denial of the intensity of feelings (e.g., anger, deep sadness). In reference to task two, Yeagley (1984) states that "pain must be experienced if healing is to occur. Pain must be expressed if growth and new life are to result" (p. 24).

Task 3: The grieving person needs to adjust to the environment that no longer includes the person who died. This may mean many new adjustments, such as taking on tasks that the deceased once did, or doing things solo.

Task 4: The grieving person, over time, needs to withdraw the emotional energy once invested in the relationship with the deceased, and begin to reinvest in other relationships. This may mean developing healthy, new relationships, or reaffirming the closeness with loved ones.

It may be obvious with this overview of two different theoretical models that grief is indeed a process. Qualitative research is useful in the study of processes, therefore, it was selected as the focal method for this study. Initial interest was in the individual's perception of and experiences with loss and healing, noting events as they unfold. This design proved most useful in answering the question, "what helps people grieve?" and helped to develop a better understanding of the young adult's experience of grief.

Family Development Perspective

The family development perspective has been a mainstay in studying family relationships, and an important tool for understanding how the family changes over time. Family theorists have various versions of the stages of the family life cycle, the most common being the seven-stage model that entails looking at family development in terms of successive stages with developmental tasks characteristic at each stage (Aldous, 1978; Mattessich & Hill, 1987). This life cycle model represents linear movement of the family through a set of stages over time, and has been criticized for its assumptive conventional patterns (Is there a "typical family form" in society?), and its white, middle-class biases (Hogan, 1985 as cited in

Lamanna & Riedmann, 1994). However, family developmental theorists argue that this perspective is useful because it can sensitize us to transitions and challenges that families encounter through the life cycle.

A transitional time in a young adult's life may be following the loss of a parent. It has been speculated that "off time" events (Neugarten, 1976) will influence the development of a young adult, disrupting the timetable for when people are expected to accomplish major tasks of adult life, such as getting married, having children, or establishing themselves in a career path. Furthermore, Schneider (1994) has defined disruptive losses, and specifically identified parent death as a loss that takes from the person sources of support and safety. Sheehy (1974) believes that the most traumatic transition time in life is between young adulthood and middle adulthood, the midlife crisis. Further discussion about loss of a parent and the affect this may have on young adult development is included in the literature review (Chapter II).

Human Ecological Perspective

According to Herrin and Wright (1988) there is a growing interest in using an ecological perspective within home economics, family studies, family therapy, and human development. They have attempted to connect the principles of an ecological perspective to the study of family life, establishing an historical legacy of the ecological perspective as it is used in the natural and social/behavioral sciences. Central to these principles is the assumption that ecology is concerned with the interrelationships among organisms and their environment (Bubolz & Sontag, 1993; Wright & Herrin, 1988). Application of the ecological perspective provides one way to examine these interrelationships within families, with an ultimate goal of improving the quality of life of family members and society (Bubolz & Sontag, 1988).

The human ecological perspective is useful in the study of processes, particularly at the interface of the individual and family. Grief is a process. Measuring and assessing bereavement reactions is complex due to the nature and intensity of the symptoms of grief that can vary over time. Furthermore, any research or clinical assessment related to grief and healing calls for a multidimensional approach (Hansson, Carpenter, & Fairchild, 1993). The human ecological perspective assists in meeting this goal, as integrating it into empirical studies aids in understanding the complexity of interactions among people and their environment (Wright & Herrin, 1988). Ecological research is used "to identify patterns of relationships between systems and their environments, especially noting what happens at the interface" (Andrews, Bubolz, & Paolucci, 1980, p. 47). Bubolz and Sontag (1993) note that the ecological perspective emphasizes process and complex human-environment interactions using a holistic approach. This makes it ideal in addressing certain problems that cannot adequately be studied by using other theories with a more limited scope.

Family Ecology

Family ecology has been defined as "representing and describing an interdisciplinary ecological perspective for studying the dynamic interrelationships among families and their environments and contexts" (Wright & Herrin, 1988, p. 259). Family ecosystems are assumed to contain cybernetic processes such as feedback and homeostasis, i.e, regulatory mechanisms that help maintain balance in the system (Wright & Herrin). As part of the interview in this study, participants were asked about the quality of parent-child relationships and the changes in the family system just previous to and after the parent died. The death of a family member may disrupt homeostasis; change results as family members adapt to and reorganize around the missing member (Lavee, McCubbin, & Olson, 1987). Adjusting to a loss involves a delicate interplay between the individual and the family.

Family Communication and Boundaries

Sometimes people have difficulty carrying out their grief work within the family and have to seek outside help (Rosenblatt et al., 1991). Do family members share their grief or cope with it individually, i.e, is the system open or closed in terms of communication patterns? In addition, boundaries within a family system represent a limitation upon interaction and activity between a family and its environment. The limitations established by a family will determine what is allowed inside and outside of that system (Minuchin, 1974). The boundaries in a family may also define the family rules. A family rule might discourage a member from sharing information outside the family, disregarding individual needs. Rosenblatt (1993) describes family systems as possessing both implicit and explicit rules (Ford, 1983 as cited in Rosenblatt, 1993) including rules that monitor emotional expression. Depending upon the functioning of family rules, a family may or may not be helpful in processing grief. One could assume that open communication in the family about the death of a loved one might have a positive effect on the family's ability to transform loss. However, not all families possess a comfort level that allows for discussion of uncomfortable or sad feelings such as those experienced in grief.

As regulatory mechanisms, family boundaries and communication patterns determine how its members express grief. Some individuals may not be coping well with the loss, and grief may be interfering with daily functioning. Such a dynamic affects the family structure and function, and, ultimately, what family members can contribute to society. Every family member grieves differently, and perhaps those with impermeable boundaries or within closed family systems may actually distance from one another at a time when closeness and supportive behaviors would be more desirable (Rosenblatt et al.). In sum, individual grief influences family functioning, which in turn affects what one person or one family can contribute to the larger environment. Within the human ecological perspective, the interaction between people and their environment is of central importance.

CHAPTER II. REVIEW OF RELATED LITERATURE

This preliminary review of the literature contains information on some of the pertinent issues presented in Chapter I including: (a) the grief experience for young adults following the death of a parent, couched within a developmental perspective, (b) identifying formal and informal sources of grief support, (c) the Hospice bereavement paradox, and (d) Schneider's holistic model of grief (1984). Following data analysis, after emerging themes were identified, a second review of the literature was completed in search of information that would assist in integration of these themes and major concepts with the developing theory (Glaser & Strauss, 1967). An integrated summary can be found in Chapter IV.

Young Adult Development

Much of the work of the adult life cycle theorists has been based on the classic work of Erikson (1966) and his eight stages of adult development. Most notably, the young adult experiences certain "seasons" (Levinson, 1978) or "passages" (Sheehy, 1974) in development. He or she may experience change or transition ranging from being in the crux of a major upheaval or quietly reflecting on growth from changes that have occurred. The most applicable "stages" for the adults in this study appear to be (a) entering the adult world, (b) the age 30 transition, and (c) settling down (Levinson; Sheehy). In addition, Gould (1978) describes adult developmental theory by linking childhood consciousness to adult consciousness. Nemiroff and Colarusso (1990) summarize Gould's "landmark contribution to adult developmental theory" (p. 367) in response to Gould's clinical application of his initial theoretical framework (Gould, 1990). They succinctly summarize this stage theory by describing the developmental steps toward achievement of adult consciousness. This can only happen when one understands and overcomes the irrational fears from childhood. If not acknowledged, these fears can carry into one's adult life, interfering with developmental progression. One must confront and release these irrational fears on the way to becoming an independent adult. Gould (1978) describes the protective devices in part as false assumptions used by people as they attempt to preserve childhood illusions of safety. Abandonment of these false assumptions and redefinition of self must occur if one is to progress into adult consciousness. Stage theorists are compared in the following paragraphs as a way to understand the existing and varying conceptualizations of young adult development.

Just previous to entering the adult world, the early adulthood transitions usually occur between the ages of 17 and 22 years. Developmental tasks during this time involve differentiating from the parent, establishing an adult identity, and forming close intimate adult relationships outside of one's family. The young adult at this stage is attempting to balance the part of self that is still dependent on the family and the part of self that is striving for autonomy. As a person establishes new relationships outside of family, loyalty conflicts may arise. Gould (1978) describes the inner tugs one often feels when attempting to balance the need to have friends and love relationships outside the family with the need to feel connected to the family. The young adult explores other relationships as a way to support newly developing beliefs and changing views of the world. Simultaneously, the very nature of "family" calls for "lifelong loyalty" (Gould, p. 62). As one shifts the feelings of family to other groups of people who are important to the newly developing sense of self, one may encounter these loyalty conflicts. If a person does not "separate" and develop his or her own sense of self, it is theorized that successive mastery of tasks at subsequent "stages" may not occur. For example, one may realize the many challenges of establishing significant other relationships because unresolved conflicts with a parent enter into these new attempts at developing intimacy (Gould; Sheehy, 1974).

What then are the implications of parent loss at this stage of development? Harris (1991) studied adolescent bereavement and stated that loss of a parent in adolescence comes at a time when separation and individuation are central developmental tasks. Such a loss can be disruptive to this task because the parent is no longer available for working through of this stage, and the adolescent may have difficulty accepting the finality of the loss.

In the next stage of adult development, as outlined by Levinson (1978), a young person enters the adult world (ages 22-28). He or she may be testing the goals set up in an earlier time. The chief task according to Levinson is twofold and conflicting. The person must shift from being a child in one's family of origin to becoming a novice adult with a vast array of choices. Decisions are tested around issues of career, love relationships, friendships, values and life style. Tension is often experienced due to ambiguity between exploration and commitment, and finding a balance between the two tasks can be simultaneously exciting and confusing. The young adult is laying the groundwork for the future, creating a life structure for him or herself.

Gould (1978) describes this stage (ages 22-28) of development in terms of false assumptions that need to be challenged and redefined if one is to truly define oneself as a responsible adult. There is continued movement away from one's parents' viewpoint and toward one's own viewpoint. It is a time for building self-confidence, developing competency, assuming responsibility for one's life and one's choices, and achieving independence. Like Levinson's (1978) conceptualization of this stage, Gould describes the vacillation between the desire to enter into this new phase of adulthood and the desire to remain dependent and protected within the secure place called home.

Little research has focused on loss of a parent at this stage, which marks the beginnings of the age parameters selected for this study. It is an issue that needs further study. However, Schneider's (1994) examination of disruptive losses reveals that such losses challenge one's beliefs, and people are often faced with two main issues of midlife: (a) we have limitations, one being our own mortality and (b) relationships do not last forever. Schwartzberg & Janoff-Bulman (1991) explored assumptions about meaning in life following death of a parent for adolescents and young adults. They found that the bereaved had not only lost a parent, but many had lost the comfortable way of making sense of their world. Attempts were made to minimize the disruption to their assumptive beliefs, and 30% of the bereaved mentioned that the experience had called into question the belief in personal immortality. Levinson (1978) states that whether it is a fear of death or a desire to transcend it, preoccupation with death is common in all adult transitional stages "since the process of termination-initiation evokes the imagery of death and rebirth" (p. 51). What does differ from one transition to another are the meanings of death and the kinds of developmental work to be done. How death affects development at each stage is unclear. However, it seems that losing a parent at this stage of development would create an upheaval, not easily assimilated when the young adult is approaching a time in life where establishing intimate relationships and preparing for a career are usually the focus. Levinson points out that a developmental crisis occurs when one has difficulty mastering appropriate tasks and it seems that transition takes a more stressful form in the next stage of development: the age 30 transition.

If young adults do choose to follow the developmental trajectories within the stage theories, making commitments usually continues as the focus in their 30s. This can be demonstrated by decisions to marry or divorce, have children, establish a sense of home/family, and overall, fulfilling those "on time" events (Neugarten, 1976). Death of a parent at this stage may be considered "off time" as one of the tasks in the family life cycle theory involves childbearing -- providing grandchildren as one's parents become grandparents. Neugarten believes that "social clocks" guide our lives, and if we are "out of sync" with them, life may seem more stressful than it is for those who are "on schedule." Schneider (1994) outlines assumptions that aid the age 30 transition, assumptions that replace those from earlier life stages and serve as guidelines for a newly emerging life style. Levinson (1978) describes the age 30 transition as a time for changing the first life structure that was established in one's 20s. A moderate or severe crisis may be common during this period, e.g., one may find the present life structure intolerable, yet struggle to form a better one. In severe times of crisis one may experience a threat to life itself and loss of hope for the future.

The first three periods of young adult development described thus far: (a) early adult transition, (b) entering the adult world, and (c) the age 30 transition focus on a person's movement through life between the ages of 17 and 33. According to Levinson (1978) they represent the "preparatory, 'novice' phase" of adulthood" (p. 59). He maintains that the next phase, settling down (ages 33-40) is crucial as one reaffirms old choices or creates a second life structure by making new choices.

The second life structure entails a firming up of what has been established thus far, perhaps enjoying some stability. It may also be that at this stage, complacency or dissatisfaction with life choices thus far signal restructuring. The task in this stage is to become a full-fledged adult, graduating from the novice stage in early adult development as described by Levinson (1978). This is a time for coming into one's own which is strengthened as one approaches the late 30s and into the 40s.

Gould (1978) conceptualizes the midlife decade (ages 35-45) with five false assumptions that are challenged at this stage, two of which are especially pertinent to the current study: (a) the illusion of safety can last forever and (b) death can't happen to me or my loved ones. Similar to the work of Levinson (1978) and Schneider (1994), Gould maintains that during this stage one is confronted with the reality of becoming a full-fledged adult. One is losing the sense of having the parents' protection, and assuming final authority over the conduct of one's own life. One is feeling that former sense of safety slipping away, while simultaneously confronting one's own mortality. The latter is especially true if one's parent is diagnosed with a life threatening illness or dies. Gould vividly describes what it is like for a young person to challenge this assumption is the following passage:

> The safe feeling that 'it is only a dream' is lost forever. Life's limited time slams us in the face like a steel door, and the limitation of our powers is never so pitifully clear as when time temporarily becomes the only reality (p. 227).

One may vacillate between denial and grief during a parent's illness and death, attempting to restore the sense of safety one felt under the assumption that things like this cannot happen.

Sheehy (1974) describes the middle of one's 30s as being the midpoint of life. Similar to the conceptualizations of previously mentioned theorists (Gould, 1978; Levinson, 1978; Schneider, 1994), Sheehy describes this stage as a time when one begins to notice the first signs of growing older, acknowledging one's own mortality, and as "a sudden change in the proportion of safety and danger" (p. 351). This is a time when a person experiences a change in the sense of time, shifting from time already lived to time left to live. The developmental task according to Sheehy is to acknowledge the change in one's sense of time, and to do that which one has always wanted to do. The paradox as she sees it is that "as death becomes personalized, a life force becomes energized" (p. 356). Similarly, Gould states that "the pain of remembering...what can no longer be destroys any hope of cheating death -- and it thereby keeps us open and alive" (p. 228).

Depending upon one's situation, resources to handle the death of a parent at this settling down stage could vary greatly. For example, if one is in a place of stability and contentment with one's choices and current life style, perhaps the upheaval of losing a parent would be less disrupting. Whereas if one is in a state of restructuring such as making a career change or experiencing divorce, then the loss of parent could present one with overwhelming life changes. These ideas are mere speculation, and testing these stage theories via empirical study is recommended.

Rosenfeld and Stark (1987) question the common patterns presented in the age and stage related theories, as they may not be reliable indicators of what people will be like at various points in life. It may not be possible to conceptualize a "timetable" for adult development due to the complexities in today's world, such as the varying social expectations based on age-group cohorts. Young adults today have a different perspective on life when compared to those born during the depression, or the optimistic 1950s (Neugarten, as cited in Rosenfeld and Stark). Nonetheless, people move through certain identifiable and similar patterns or events in life, and family development theory and life stage theories assist in understanding this movement over time, by indicating how individuals and families may process change.

Attitudes about Death and Dying in America

Death is a part of life, and loss is universal. Confronting feelings around the experience of grief can be frightening and even overwhelming. This is especially true in a society that denies the reality of death and the intensity of grief. The American way of dealing with a death is to not deal with it openly (Becker, 1992). For example, as little as 3 years ago, with an effort at promoting education in death and dying, the researcher was involved with a Hospice team that selected a lesson plan on death and dying for the 4th grade. It was rejected by a state employee responsible for curriculum development in elementary school systems in Michigan because it had the word "dead" in it. Children are exposed to violence in the media via television and perhaps within their own neighborhoods and schools, yet there is still a taboo about talking about "death." As a culture this situation is improving, especially where children are concerned because there is finally an awareness that children grieve too (Linn, 1990; Wolfeldt, 1983). Since 1980, there has been an increased social recognition of the issues of death and dying (Rognlie, 1989). Since Kubler-Ross's (1969) book On Death and Dying, and the founding of the Hospice movement by Cicely Saunders (1967), American culture has at least begun to include realistic thoughts and talk about death and dying (Becker, 1992). Raphael (1983) completed a survey of bereavement research that included more than 400 published works. Progress has been made culturally and empirically, with the attention given to grief and bereavement research.

Even though the research in the area of bereavement is blossoming, as identified previously, the number of research studies on parent death is very few. Kalish (1985) states that:

> Our society offers no clearly defined roles for adult children of dying parents, so each family develops its own way of functioning. Nonetheless, the loss still has a profound effect on the survivors, and among other changes it produces, parental death leaves the child a little more aware that his or her own death is now a real possibility (p. 246).

Because this loss involves confrontation of one's own mortality, it may be one of the most critical events in adult development, and still, information on the effects of parent death is almost nonexistent (Douglas, 1991; Malinak, Hoyt, & Patterson, 1979). Moreover, one may still be sheltered from death within one's family. For most people, the idea of discussing a parent's death is not exactly a pleasant topic. Confrontation usually does not occur until it absolutely has to be faced and then one may not know how to begin to confront such a stark reality.

Hospice and the Reshaping of American Attitudes

At Hospice, life and death represent a delicate weave. Death is a final act of living, and not something to avoid or deny. Hospice enables the dying person to enter into the final stages of life with dignity, and as free from physical pain as is humanly possible. Perhaps most importantly, a person can die with his or her family members at the bedside, within the familiar surroundings of where their lives were joined, at home. One does not have to die alone or in an institution. Bereavement follow-up is part of the holistic approach to patient care. "Bereavement follow-up is a primary characteristic of Hospice and it sets Hospice apart from other types of health care for dying persons and their families" (Hayslip & Leon, 1992, p. 180). But, the National Academy of Sciences' study of bereavement (Osterweis et. al, 1984) concluded that the range of services and the degree of follow-up among Hospice bereavement programs varies greatly, and this investigation failed to uncover any real measurable benefits from such services.

Developing Hospice Bereavement Programs

Given the findings about the lack of measurable benefits of Hospice bereavement services (Osterweis et. al, 1984), Beresford (1987) suggested that perhaps the questioning about the value of such services is related to the philosophical goals of Hospice:

> Are their services intended simply to offer balm to the majority of survivors -- who are expected to experience a "normal" grief process...or is the goal to intervene and prevent serious harm to those grieving survivors who are truly at risk of serious physical or psychological harm? (p. 2).

Since there is little clarity in program goals, there is very little research evaluating these programs. Lattanzi-Licht (1988) stated that this question of whether bereavement follow-up achieves anything underlines the deficit of research and evaluation of these services. She called for consistency and reframed the boundaries of Hospice Bereavement in the following statement:

> Bereavement follow-up can serve as a transitional support... (it is) not the antidote for the pain and adaptation of grief. A range of services needs to be offered, with the realization that only a small

> percentage of family members will avail themselves of group meetings or memorial services (p. 82).

Group meetings may be enough for those seeking transitional support. But what about those who do need more? It appears that Hospices need help with clarity in program goals, i.e, deciding upon the type and magnitude of services offered.

Related issues in provision of adequate grief supports have to do with grief reactions of the bereaved. Parkes (1988) completed a decade review of the literature to examine bereavement reactions. He identified the types of bereavement interventions that go beyond "mutual support resources in the neighborhood and community" (p. 365). He explored the latest research on several levels within bereavement, such as the physical effects of bereavement, the effects on one's mental health, and gender differences in bereavement. Parkes also listed factors affecting bereavement outcome, such as age at time of loss, cultural factors (e.g., mourning rituals, expression of grief), type of bereavement (relationship of deceased to living), anticipatory versus sudden losses, social and psychological factors, and treating pathological grief. Overall, in this summary, Parkes (1988) suggested that the problem of bereavement cannot be oversimplified. Service providers need to recognize that for many people, moderate grief supports are not adequate.

Hospice offers some form grief support to all its grieving families, such as an educational letter series about the grieving process, phone calls and letters acknowledging an anniversary date, or an assessment visit with referral to an ongoing support group. However, this may not be sufficient for those bereaved who do develop physical health problems or psychological/emotional disturbances following the loss of a loved one. In addition, there exists a delineation between "normal" grief and "pathological" grief. Though one might think of parent death as a natural and expected event in adult life, when it actually happens one's emotional reactions vary greatly, depending on many factors, such as who died (mother or grandfather) and how they died (sudden death or chronic illness) (Parkes, 1988). A person's existing coping mechanisms also seem to play a part in how one would cope with loss.

Bereavement Reactions and the Death of a Parent

One study looked at initial psychological responses to parental death (Horowitz, Krupnick et al., 1981), while a follow-up study examined reactions to the death of a parent (Horowitz, Weiss et al., 1984). Both of these studies focused on a clinical adult population, i.e., comparing patients and nonpatients, or those adults seeking therapy to help cope with the loss of a parent versus those not seeking therapy but whom the researchers identified as having lost a parent to death. They found that the patient group had significantly higher levels of distress 2 months after the death than did the controls. They also found that the primary differences included such variables as capacity to tolerate the intensity of feelings and ability to move forward into the acceptance of the death. Parent death was found to be a serious life event for both patient and control groups, and the levels of distress did decline in both groups over time. Overall results were useful in identifying those "other factors" that might contribute to the stress of bereavement in parent death. A discussion of these factors follows.

Other Factors to Consider

1. Meaning of attachment: refers to who died, or the relationship of the bereaved to the person who died. Parkes (1988) calls this "type of bereavement."

2. Cause of death: refers to how the person died -- was it a sudden death or was death a result of a long term, chronic illness (Parkes, 1988).

3. Learned coping strategies: refers to individual responses to stress or crises. These will vary depending upon how a person has learned to cope with hardship (Malinak et al., 1979).

4. Grief reactions: refer to the way in which an individual responds to the loss of a loved one, usually expressed in a variety of different ways, and unique to that person, having to do with feelings and emotions. Grief reactions may vary among family members (Horowitz, Weiss et al., 1984).

5. Complicated or pathological grief: a pathologic reaction, by definition, exceeds the capacity of the person to self-correct the condition. Intervention of some sort is necessary -- often for survival (Schneider, 1984, p. 261).

6. Time since loss: refers to how much time has elapsed since the loved one died. This can either impede or enhance the grief process, since people vary on how much time they need to sort through a loved one's death. For example, for some it takes 2 years to begin to grieve; for others, the loss may be integrated after 2 years. There is no predictable time table for grieving. Time since loss plays a key role in the bereavement program design in Hospices.

7. Gender differences in grief: Men and women are socialized differently in our society in terms of expression of feelings. Malinak et al. (1979) suggested inclusion of comparisons of men's and women's reaction to

loss, and specifically, reactions to the loss of a father versus the loss of a mother. Parkes (1988) in his review also suggested further study regarding gender and grief reactions.

8. Multiple losses: refers to other losses that the bereaved may have had, enduring a stressful time or a time of upheaval in addition to the loss of the parent. For example, another death of a family member or friend may have occurred simultaneous to or around the same time as the death of a parent. Or other significant losses or changes (e.g, job loss or change, divorce, or birth of a child) may have occurred at about the same time or just before the death of a parent. Inclusion of a "life line" activity during interviewing was suggested by Douglas (1991) and Robbins (1990) as a way to assess multiple loss factors.

9. Pre-existing psychological disturbance: Parkes (1988) lends insight to the effects that bereavement may have on mental health by stating that "since some people come through the stress of bereavement and emerge stronger and more mature than they were, while others suffer lasting psychological damage, it is important for us to identify factors which affect vulnerability" (p. 368). There is controversy in findings in this area, as it is difficult to measure (e.g, differentiating between depression and normal grief, Schneider, 1980).

Continuing with Parkes' (1988) suggestions, Rando (1992) cautions caregivers in the field of thanatology to be aware of "pitfalls" in assessing complicated mourning. Rando notes several problems that are inherent in the field of thanatology and may actually be contributing to complicated mourning. Among others, she acknowledges that caregivers are not always adequately trained to assess complicated grief. All mourners are not alike and caregivers must recognize and respond to the differences inherent in different loss situations, e.g., loss of a child versus loss of a spouse; sudden versus anticipated loss. Such insight is particularly helpful in relationship to the reframing of Hospice bereavement service boundaries, and to the issue of misperceptions about what professionals deem to be helpful grief supports and what the bereaved may identify as helpful. There is much to learn about the complex sequences of events which lead to such disturbances, to specify interventions that are needed, and to test out their effectiveness (Parkes, 1988).

Another study, preliminary in nature, explored adults' reactions to the death of a parent (Malinak et al., 1979). In-depth interviews were completed with 14 people whose mean age was 32.4. They discovered several factors influencing reactions to loss of a parent, called categories or themes, which were as follows: importance of the last meeting with the parent and events at the time of death; initial responses to the death and clinical significance of the absence of grief; what the adult child's identification was with the deceased (their self-image); idealizing the deceased parent; having ambivalent feelings about the deceased, e.g., anger or guilt; coping resources of the bereaved, and favorable, growth-oriented aspects. The authors were careful to cite limitations due to the preliminary nature of this study, yet inclusion of these factors provided a guideline for ideas about development of interview content and other research design and methodology concerns for the current study. Most notably, these authors concluded that a future study might want to address issues of gender and bereavement, early and recent parent-child relationships, death of first or second parent, and the effects of the death on the family system. All of their suggestions were noted and these areas were explored within the current study.

Finally, Moss and Moss (1983) looked at the effect of parental death on middle aged children (approximately 35-55 years old), noting the paucity of literature dealing with this issue. Some of the reasons given are: intense grief may seem to be absent, or denied because of its severity; parent death may actually be a relief and hence, a release; it is difficult to quantify "grief" due to large individual differences in expression. These were merely suggestions, not data based findings. The authors were quick to list limitations of their study which, once again, did provide insight while conceptualizing the present study design. Those limitations were lengthy, yet worth including in this review. They are (a) whether the death is of the first or second parent, (b) the quality and circumstance of the relationship over the life cycle, (c) the degree, intensity and quality of the parent child interaction, especially toward the end of the parent's life, (d) the circumstances and timing of the illness and death of the parent, (e) social supports and the life situation of the surviving child, (f) financial resources of parent; of child; did they live in the same household?, (g) gender of the parent; gender of the child. (h) cultural, ethnic and religious characteristics of the family, (i) personality of the parent and of the child, and (j) the broader family and intergenerational implications of the loss.

The studies reviewed thus far have dealt specifically with death of a parent, yet the samples consisted mainly of "midlife" adults with an age range of 35-55 years. Only the preliminary study by Malinak et al. (1979) addressed the age group that was the focus of this study (age range 25-40 years). In the study referred to previously about young adult development (Schwartzberg & Janoff-Bulman, 1991), the mean age of bereaved subjects was 19.8 years. These authors also noted the paucity of literature examining young adult bereavement. The researcher was not aware of any other study that attempted to explore or examine grief and bereavement reactions of this specified group of people. However, a return to the literature following data analysis, in search of supportive evidence for the majority findings in this study, revealed resources in the form of doctoral dissertations that address parent loss and the implications this loss has for adult children (Staggs, 1989; Wheeler, 1991).

The other research discussed in this review address other concerns that are of equal importance, and in summary are as follows: (a) our death denying society and the potential inhibiting affect this has on free expression of feelings during grief, (b) the Hospice philosophy is growing and so, too, is the continued ambiguity within bereavement programs and outreach, and (c) since 1980 there has been an admirable surge of scholarly effort within bereavement studies, however, there still remains a gap in the literature regarding bereavement reactions and the death of a parent for young adults.

CHAPTER III. RESEARCH METHODOLOGY

Qualitative research methods have become increasingly important modes of inquiry for the social sciences (Marshall & Rossman, 1989). Perhaps this is especially true within Human Ecology, where researchers attempt to capture the complexities of human interactions at the family and societal interfaces (Bobbitt, 1990). Qualitative methods have to do with discovery, exploration and observation. The researcher becomes the research instrument (Wolcott, 1988). Having defined a general research question or problem, the researcher, through observation and interaction with a select group of people, begins to make discoveries about the phenomenon of interest. He or she conducts a detailed analysis, attempting to produce valuable explanations about processes. Bobbitt states that to choose qualitative design, one assumes that phenomena can be understood from the individual's perception of the situation. She writes:

> Its purpose is to understand the perceptions and perspectives of the people involved in the situation with emphasis on the larger picture and the relationships of the micro- and macro-cultural systems. (It) does not impose an a priori research design...but notes events as they unfold (p. 3).

Furthermore, Bubolz (1991) describes qualitative methodology within the interpretive or hermeneutic mode of science as best suited for an exploratory study, where explanation comes through understanding of intentions, motives, and reasons behind actions and responses. Marshall and Rossman (1989) also describe valuing participants' perspectives on their worlds, viewing inquiry as "an interactive process between the researcher and the participants...that is primarily descriptive and relies on people's words as the primary data" (p. 11). In sum, the qualitative researcher studies processes, capturing depth and richness in the research findings. Qualitative methods are a search for general statements about relationships among categories of data, and they can build grounded theory and allow for generation of hypotheses that can be tested empirically.

The above stated logic and rationale provide support for the decision to utilize qualitative methods in this study, which was designed to explore what helps people in their grieving process following the loss of a loved one. Approval of the data collection procedures used in this research was obtained at Michigan State University by the University Committee on Research Involving Human Subjects (UCRIHS) on June 21, 1993. The primary data collection technique involved in-depth, semi-structured interviews with young adults. Other techniques involved interviewing grief support providers and analysis of selected documents. This chapter contains a discussion of how participants were selected, descriptive data on participants, data collection techniques, data analysis procedures, validity and reliability, and limitations of this study.

Selection of Participants

This researcher served as a bereavement coordinator in a Hospice for nearly three years, from 1988-1990. The position provided opportunities to teach Grief Recovery seminars, run grief support groups for different segments of the population, and conduct in-home assessments for grieving individuals and families. This experience clearly influenced some of the decisions made about the design and implementation of the study. This Hospice graciously supported the research efforts here, serving as the main site for recruitment of participants.

Indepth interviews were conducted with 12 adults between the ages of 23 and 43 years of age who had lost a parent to cancer. For comparison, two criteria in addition to age were selected, (a) time since death was 13 months or 24 months, and (b) use or nonuse of formal grief support services. Each of the two groups consisted of six participants and within the two groups of six persons, three utilized formal grief support services (FGS) and three did not (NoFGS), as seen in Table 1.

Table 1: Participant Groups (N=12)

Time Since Death	Use/Nonuse Support	No. of Participants
13 Months	FGS	3
13 Months	NoFGS	3
24 Months	FGS	3
24 Months	NoFGS	3

Participants were obtained through the bereavement database at Hospice of Muskegon County in West Michigan. Initial recruitment began by collaborating with the Hospice clerical staff, identifying via computer database those participants who met the specific criteria outlined. Not all participants fell exactly on the 13 month or 24 month mark, thus a range was established for both groups where the actual time since death could vary by 1 month on either side of the ideal. Therefore, the 13 month group could be 12 to 14 months since the death, and the 24 month group could be 23 to 25 months since the death. Two separate computer listings were generated with 66 names on the 13 month list and 73 names on the 24 month list with a total of 139 names. Each list contained the patient's file number, patient's name, date of death, and primary diagnosis. Then for each name on the list the researcher had to manually examine the "face sheet" within the patient files which provides overall information about a patient and the family. This process was necessary for identifying whether there were adult children in the family that met the age criteria of the study. From this process, two final lists resulted in 25 names for the 13 month group and 17 names for the 24 month group, reducing the original number of potential participants to 42.

Potential participants were further screened for other appropriate criteria. For example, since the study design included division of the 13 month and 24 month groups by use and nonuse of bereavement support services, participants needed to be screened over the telephone regarding this information as it was not readily available in the Hospice family files. The bereavement coordinator kept records for everyone who had enrolled in the seminars and groups through their agency. Contained within those records were the names of both those who had utilized Hospice services and those non-Hospice families or "community referrals." Consultation with the bereavement coordinator resulted in identification of 10 more potential participants in the formal grief support (FGS) listings, six names in the 13 month group and four names in the 24 month group. The contact information necessary for the non-Hospice families was provided by the class or group rosters or a local telephone directory as needed. Finally, since the pool of potential participants was obviously much slimmer for those who had sought some form of grief support, contacts were also made to two other local grief support providers, a hospital and a funeral home, one of which was able to provide one more participant who met the stated criteria.

The next phase of participant selection involved mailing letters to the identified potential participants on Hospice letterhead, introducing the study and asking them to participate (Appendix B). In this letter, potential participants were told they would be contacted by phone within approximately two weeks to inquire about interest in being part of the study. Not everyone receiving a letter received a phone call, because there was a greater number of potential participants generated than was actually needed (especially among the two NoFGS groups). Therefore, there was no procedure for selecting who on the final lists would be contacted, although extra efforts were aimed at recruiting male participants, to no avail. The researcher called potential participants as they were ordered on the list, until a positive response was obtained from 12 people.

At the time of the call, the final screening was completed regarding the selected criteria. If the person indicated interest, more detailed information was provided about the study and an interview was scheduled in his or her home or in the Hospice office. It should be noted that during this initial phone contact, only three participants, two of whom were male, directly refused to be a part of the study. There also were those who expressed an interest in the study, but had concerns over potential emotional reactions that might occur during the interview. The researcher reassured persons with this type of response by normalizing feelings, and disclosing personal information about her own responses to the loss of a parent, and professional experiences with other bereaved persons. For some people, this initial time on the phone resulted in rapport building and sharing of feelings about their grief. In the case of a potential participant's refusal to be part of the study, the researcher also normalized this type of response, and thanked them for their time and consideration.

Every attempt was made to schedule interviews in an intentional order, beginning with the 13 month FGS group and moving into the 13 month NoFGS group, the 24 month FGS group and the 24 month NoFGS group. However, circumstances dictated a need to reschedule some of those in the 13 month group, and in reality, this ordered succession did not occur exactly as intended. In addition, a brother/sister team from the 13 month group cancelled their scheduled interviews after some of the 24 month FGS already had confirmed a time. Therefore, the researcher opted to schedule interviews on an as available basis until all 12 were completed. Eight of 12 bereaved participants in this study were recruited as a result of an affiliation with Hospice.

After each interview was scheduled, consent forms (Appendix C) were mailed with a second letter (Appendix B), thanking them for their willingness to participate, and asking them to complete and save the consent form until the scheduled interview. After the interviews were completed, all 12 participants received a follow-up letter (Appendix B) thanking them for participating, and reminding them of available support services.

In addition to the 12 participants described above, four interviews took place with the following professional grief support providers: the Hospice executive director, a clergy person who works with the bereaved in that community, the Hospice bereavement coordinator, and an oncology social worker from a hospital in that community. These interviews were a supplemental data collection technique used for exploration of what is/is not being reinforced between gatekeepers and the bereaved in terms of grief support services. Interviews with the professionals took place after all interviews with the bereaved were completed. These interviews were arranged with one telephone call, at which time the study was briefly described and a request for an interview was made. All four responded favorably, and a mutually convenient time was scheduled for the interview. A separate consent form (Appendix C) was provided for the professional participants and was signed just before proceeding with the scheduled interview.

Descriptive Data on Participants

Interviews were completed between September 14 and October 29, 1993 with 12 young adults, all caucasian, 11 females and 1 male, ranging in age from 23 to 43 years old. The average age was 34 years. Eight participants were married, three were single, and one was divorced. Six had children and six did not. All but one participant resided within or nearby the same town as the dying parent. All participants completed high school, most had some college experience, with two having completed associates degrees, and one a Master's degree. Total annual incomes for participants ranged from under $5,000 to over $50,000.

It was proposed that every effort would be made to contain participants' ages within the specified range of 25 to 40 years, with flexibility over this exact range pending circumstances. There are two reasons for inclusion of the 23 year old participant in this study. First, she had attended the Hospice Grief Recovery Seminar just after her father's death two years previously, and was still attending the ongoing bimonthly support group which she entered right after the seminar. Recruitment of participants for the FGS group proved more challenging than those for the NoFGS group, and especially within the two year FGS group. Since she met two of the three specified criteria, it was decided to interview her. The second reason for inclusion was that at that point in the study, there were fewer participants in their 20s, (average age was 34), thus her inclusion provided more balance in the age of participants. The decision to include the 43 year old participant was based on the fact that he was the only male participant that responded favorably to taking part in this study. Other males were asked, but declined. It should also be noted that this participant turned 43 between the time of the telephone screening and the scheduled interview.

The procedure for recruitment of participants was designed with the intent of obtaining equal distribution of males and females in the criterion groups, even though it was anticipated that this would be unlikely. The researcher's experience as a former bereavement coordinator was that seminars and grief support groups were predominately attended by females.

It also was decided to attempt to recruit siblings, perhaps male/female pairs, or simply interviewing two same sex siblings for a perspective on family grief. At one point, recruitment of a brother and sister team was arranged, however both participants cancelled their interviews. Recruitment of participants from the same family did not occur.

Rationale for Research Design Decisions

Varying the time since loss at 13 and 24 month intervals was not arbitrary, but based on the desire to compare grief reactions over time, and to follow the design of the Hospice bereavement services time line where the bereaved are followed for 13 months after the death of a loved one.

Choosing to interview young adults whose parent had died from cancer or a long term chronic illness was based on the differing grief reactions that people have when death is expected versus sudden. In addition, this study was supported by a Hospice, and one of the long term goals of this study addresses the need for evaluation of Hospice bereavement programs. Thus completion of the work within this setting was mutually beneficial. The majority of Hospice patients are admitted with a diagnosis of cancer. All but one participant in this study had a parent die from cancer. One participant's father died from chronic heart disease, after an illness of nearly 10 years.

Three of the 12 participants had had both parents die: the first had a father die from cancer in 1984, and had lost her mother in 1992; the second had just lost her mother to cancer in 1990 and six weeks later her father (with a history of mental illness) committed suicide; and the third lost both parents to cancer just 2 1/2 months apart. Clearly, grief reactions may be more intense when both parents die, and indeed this variable could be treated as a confounding variable in a traditional positivist design. It was decided to include these participants in this study because the focus was to explore what helps people grieve and the transformative potential of grief, whether there was one loss or multiple losses. It is interesting to note that three of the four criterion groups contained one participant who had lost both parents, thus there was almost equal distribution. Overall, five participants experienced death of a father, four experienced death of a mother, and three experienced loss of both parents.

Data Collection Techniques

For primary data collection, in-depth interviewing was utilized with the bereaved in the four criterion groups. Supplemental data collection techniques included elite interviewing and analysis of available documents. A description of these techniques follows.

Primary Techniques

The researcher used semi-structured, in-depth interviewing as the primary method of data collection. Each interview was audio-taped and lasted on average of just under two hours, ranging from 1 1/2 hours to 2 1/2 hours. Each participant was asked to choose the preferred location of the interview. Eight chose in-home settings and four chose the Hospice office.

Each interview began with reassurance about confidentiality, collection of the consent forms, and a request to complete the background information sheet as a way to obtain demographic information for all participants. Some initial conversation usually occurred, as an attempt on the part of the researcher to establish rapport. The interview then proceeded with the use of a "life line activity" (Appendix D) which asked participants to list the significant events in their lives on a life line, i.e., a vertical line on a blank paper marked off by years from birth to age 40. Instructions for completion of the activity were provided, followed by clarification about the meaning of "significant events." Examples were provided for each participant about what constitutes significant life events, such as a death, a birth, marriage, job loss, graduation, moving, or major life achievements. The objective for including such an activity was to aid in gaining information about events preceding or following a parent's death. Especially important was the intent to capture the richness inherent in changes within one person's lifetime, particularly as they related to the grieving process. The completed activity also proved useful during the analysis of interviews by serving as a quick reference and a guide accompanying the data.

Based on the literature review, an interview guide was developed (Appendix E), containing the content areas of interest for exploration about grief support. After completing the background information sheet and the life line activity, the researcher provided a brief set of instructions about the actual interview content. Each participant was told that level of disclosure was at their own discretion based on their comfort level, and that the researcher would be making notes on the interview guide as the interview progressed as part of data collection.

Ordering of the questions was intentional, beginning with some general information questions, and then moving into the more emotional laden areas about their grief experiences. Length of responses varied with each participant, some providing in-depth, detailed descriptions, and some providing shorter answers. In the latter case, probes were made by the researcher when it appeared the bereaved would be receptive to such probes, however, individual levels of disclosure were respected. An effort was made to ask all of the questions, in order, on the guide. Sometimes participants answered questions before they could be asked. If this was the case, a statement was made by the researcher indicating that a particular area had already been sufficiently covered.

Each interview was transcribed verbatim from the cassette tapes as soon as possible following the interview. The researcher chose to transcribe all interviews herself as a way to begin immersion in the data, and formulate ideas for direction in the analysis. This proved very time consuming, but very helpful. Tapes containing interviews were destroyed immediately after transcription. Observations made during the interviews were recorded both during and after the sessions on a specially designed "notetaking" form dividing description and interpretation (Appendix D). Reflections about experiences were kept in a research journal throughout the entire data collection period, and a separate journal was kept documenting any personal events that may have influenced the researcher's objectivity or abilities.

Supplemental Techniques

Two supplemental data collection techniques were used: elite interviewing and documentary analysis. "Elite" interviewing consists of interviewing those respondents that are considered to be the influential, prominent, and well-informed people in an organization or community (Marshall & Rossman, 1989, p. 94). Elites are selected for interviews based on their expertise in areas relevant to the research. For this research, all the elites were professional people whose work entailed provision of grief support services. An interview guide (Appendix E) was developed based on the issues within related literature and professional experiences. This guide was used during the professional interviews, with primary interest in their responses to what they viewed as helpful to grieving persons. All the questions on the guide were asked, as well as additional questions that surfaced depending upon the participant's area of expertise.

Three of these interviews took place within the participants' professional environment, and one opted to conduct the interview in her home to avoid interruptions. Interviews averaged about 1 hour and 15 minutes. Consistent with the bereaved interviews, all of the professional interviews were audio-taped and transcribed verbatim by the researcher. All tapes were destroyed following transcription.

Observations were made and notations were recorded directly on the interview guide during the interview. Reflections about the interview were written in the previously described personal journal. Journaling was an invaluable tool to the researcher during both the data collection and data analysis stages of the research process. Having such detailed documentation allowed the researcher to return to an interview and recapture moments, remembering even what participants had worn, the setting, or the weather. The journal and the notetaking form also provided a quick reference to help frame a particular interview transcript when that was necessary. The personal journal that the researcher kept during the research process provided a means to monitor and vent emotions that were present after leaving an interview. After debriefing a participant, journaling of feelings helped the researcher in her own attempts at debriefing.

The second supplemental data collection technique utilized was documentary analysis. Hospices routinely request that the bereaved complete a "bereavement support questionnaire" as a form of closure and as a way to evaluate Hospice services following participation in the 13 month bereavement support program (Appendix F). The researcher tabulated responses for these questionnaires collected over the past six years, 1987 to 1992 (N=205). For purposes of perspective and comparison, the researcher obtained historical data about the successful increase in number of patient/family units served each year for these six years. The decision to include this analysis as part of data collection was to provide triangulation, thus lending to the generalizability of the study, and to encourage the Hospice to utilize valuable, existing data that may be useful to them in future planning.

Managing and Recording Data

Following transcription of all 12 of the bereaved interviews, each numbered interview (P1-P12) was placed in a three-ring binder in order by criterion group, i.e, by use, non-use of supports and time since death. Since the interviews were not conducted in any particular order, but rather on an "as available" basis, each had to be given a new number, and was re-ordered, for purposes of clarity and ease in description of each group. Assignment of participant's identifying number and ordering of criterion groups is clearly seen in Table 2.

Table 2: System of Numbering and Ordering of Criterion Groups for Data Analysis

Participant No.	Time Since Death	Use/Nonuse Support
1-3	13 Months	FGS
4-6	13 Months	NoFGS
7-9	24 Months	FGS
10-12	24 Months	NoFGS

Once the groups had been assigned a number for data analysis, and placed in order in the binder, the researcher began to develop a strategy to systematically compare the content in the 193 pages of transcribed interviews. The decision was made initially to concentrate only on the content within the bereaved transcripts. When this was completed, the researcher began analysis of the 61 pages of professional transcripts.

Originally, it was proposed to color code emerging categories and themes directly on the observation notes, however, these notes as well as the life line activity proved most useful as guides to the interviews, and color coding was not necessary. Highlighting the data with different colors representing emerging themes and categories did prove very useful in both the preliminary and final analyses of the data. It also was proposed to number the pages in the data, and keep note cards connecting themes, categories, and similarities and differences. However, it proved most efficient to make these notations in the margins of the transcribed interviews, and on the backside (blank) of each preceding page, adjacent to the text. This seemed more efficient than keeping them separate on notecards, saving the step of having to cross reference the material with page numbers. When a passage in the data appeared to be supportive of a theme in the developing theory or if it represented what the majority of the participants were saying, then actual quotation marks were used in the notation of the material for ease in locating the content, and only the actual passages used in the final analyses were highlighted directly within the raw data. Different colors were chosen to represent emerging themes and developing categories and other information, such as that which would be used for demographic description. This same procedure was utilized for the analysis of the four transcribed interviews of professionals.

The initial managing of the data began with transcribing the interviews from the cassette tapes, and continued as the researcher began to develop a more systematic procedure to further condense the huge volume of information within the raw data. The researcher was able to meet the original goal of devising an intricate system of organizing and managing the data to promote ease of retrieval for the final analysis.

Data Analysis Strategies

The process of condensing interview data to make it systematically comparable by applying an objective coding scheme is called "content analysis" (Berg, 1989). Holsti (as cited by Berg) broadly defines content analysis as "any technique for making inferences by systematic and objective identifying of special characteristics of messages" (p. 106). Furthermore, Berg points out that a decision must be made about which levels or units of analysis will be counted when using content analysis. He lists seven major elements in written messages that are commonly counted in content analysis, two of which were adopted for analysis in this study: "items" and "paragraphs" (p. 112-113). The researcher made the decision to use as the content unit a combination of both in-depth interviews ("item") and selected "paragraphs." For example, in the attempt to condense responses from the subjective listings of "what helped you grieve?" the researcher summarized the content of paragraphs from the responses in each in-depth interview transcript, and made notations on the adjacent pages. Actual quotations were written after certain content areas began to emerge repeatedly. It was speculated that such material might be useful later in analysis, and some of it was actually highlighted in text, as described previously. The decision rule was made to consider "majority" (at least two-thirds of a criterion group) responses necessary in order to count it as a category. Therefore, if four of six (two-thirds) 13 month participants in response to the question, "what helped you in your grief?" said that "someone to listen and understand me" was helpful, then it was counted as a major emerging category, and included in final analysis. Further comparisons were then made by comparing responses within and between the 13 month groups, and then following with comparison between and within the 24 month groups. Finally, an overall comparison of participant responses was done between the 13 month and the 24 month groups. Each consecutive step in the data analysis is summarized in the following section:

1. Utilized content analysis with established units (item, paragraph) and began coding the data by writing marginal notations and selecting quotations from the text of the 13 month FGS group.

2. Repeated same for 13 month NoFGS group.

3. In a spiral bound notebook, developed columns for each participant, first for the 13 month FGS group, and then for the 13 month NoFGS group. These columns contained paragraph summaries of every question on the interview guide, as well as themes that emerged.

4. From the column summaries, data were further condensed by color coding majority responses, first for the 13 month FGS group, and then for the 13 month NoFGS group.

5. Generated one list of summary statements about majority findings by comparing responses from both the 13 month FGS and NoFGS groups.

6. This entire procedure was replicated for the two 24 month FGS and NoFGS groups.

7. Compared the lists of summary statements from the 13 month group and the 24 month group about majority findings by producing one enlarged version of columns.

8. Finally, after generation and comparison of these final two majority lists, categories emerged that could be attributed to groups of questions on the interview guide. These questions were collapsed and an outline was developed, matching the grouping of questions with the stated short term objectives of the study.

9. Participants' verbal responses to the questions were again reviewed within the data, and passages were color coded for use in the final report.

10. Three separate "themes" emerged, defined as majority responses that were not the result of direct questions from the interview guide. These were color coded in the columns and also in the data.

11. Professional responses relating to selected areas of interest from the literature were compared to the responses of the bereaved, and an integrated summary of findings was reported.

Categories must be grounded in the data in which they emerge, hence the term "grounded theory" (Glaser & Strauss, 1967). Qualitative methods provide a means to search for general statements about the relationships among categories of data and help to build grounded theory. Marshall and Rossman (1989) state that "in qualitative studies, data collection and analysis go hand in hand to promote the emergence of substantive theory grounded in empirical data" (p. 113). The researcher is guided by initial concepts and guiding hypotheses, but shifts or discards them as data are collected and analyzed (Glaser & Strauss, as cited in Marshall & Rossman). In an attempt to build upon Schneider's (1989) theory about the transformative power of grief, and to discover from bereaved persons just what helps them in their grief, this researcher based data analysis decisions on the previous work of the scholars discussed above, and on one more qualitative research study (Robbins, 1990) that explored grief responses to loss of a parent. The researcher was able to incorporate many of Robbins' steps or "phases" about data analysis. For example, in phase one, Robbins examined interview texts for themes, issues, and categories, and phase two of her analysis consisted of a systematic comparison of major themes and categories between and among all texts, which led to integration of findings. The previously described data analysis procedures used in this study were modeled after Robbins. Data analysis for this study also models a "classic" approach called the "constant comparative method" by Glaser and Strauss (1967) which is often used by qualitative researchers in developing grounded theory. This method utilizes an inductive approach to data analysis and also is concerned with generating categories, themes, and hypotheses following a four-stage analysis that includes: (a) comparing incidents applicable to each category, i.e., coding the data, (b) integrating categories and their properties, (c) delimiting the theory, and (d) writing the theory. The purpose in using the constant comparative method is "to generate theory that is integrated, consistent, plausible, and close to the data" (Glaser & Strauss, p. 103). During the interviews, "transformative" questions were asked such as, "Which things will never be the same?" and "Did you grow or gain in any way because of this loss?" These questions were most useful in the researcher's attempt to build upon Schneider's (1989) theory of the transformative potential of grief.

Search for Negative Instances

After data analysis was completed, the researcher returned to the transcripts and searched for negative instances pertaining to developing concepts, themes, and their relationship to the theory. Particular attention was given to the hypotheses that emerged during data analysis, searching for examples in the data that did not fit the hypothesized relationship of concepts and themes. A decision rule was made that at least three separate instances had to occur in order for the researcher to discard or reformulate the hypothesis. There was not sufficient negative evidence in the data that led to a discarding of any of the formulated hypotheses that had emerged. However, negative instances were highlighted within the transcripts, and a list was generated summarizing these areas. Further discussion of the use of negative instances in data synthesis can be found in the next section about the validity and reliability of this study.

Once the final data analysis was completed, there was a return to the literature in search of supportive evidence for emerging categories, themes, and generated hypotheses about the transformative potential of grief, as is customary in qualitative research. This information is integrated with the reporting of findings in Chapter IV.

Validity and Reliability

One of the most common criticisms of qualitative study is the issue of generalization, or external validity. Every bit as problematic, especially in the eyes of the traditional positivist, are the issues of internal validity, reliability, and objectivity. Lincoln and Guba (cited in Marshall and Rossman, 1989) have matched these positivistic terms with terms that more appropriately reflect the assumptions of qualitative research (p. 145-147). This matching can be seen in Table 3.

Table 3: Matching Qualitative and Quantitative Terminology for Validity and Reliability

Quantitative Terms	**Qualitative Terms**
Internal Validity	Credibility
External Validity	Transferability
Reliability	Dependability
Objectivity	Confirmability

Perhaps this matching makes sense in the search for truth, but it may still seem odd to assign the same criterion for a "sound study" to two very different, yet compatible research methodologies. The following discussion addresses some of the concerns about validity, reliability, and issues of objectivity/subjectivity that some traditional positivist researchers have about qualitative research design.

1. Credibility: The goal is to demonstrate that the inquiry will be conducted in such a way as to ensure that the subject or topic is accurately identified and described. In positivism, this is internal validity, and it is concerned with how truthful particular findings are of a study, and asks by what criteria can one judge research findings of a study? Within the interpretive mode of research, "an in-depth description showing the complexities of variables and interactions will be so embedded with data derived from the setting that it cannot help but be valid" (Marshall & Rossman, 1989, p. 145). A qualitative researcher must adequately state, then, the parameters of the research setting, of the population, and of the theoretical framework. Every effort was made to do just that in the current study. The very strength of qualitative study is its validity, in that it aims to explore a process or pattern of interaction.

2. Transferability: This is perhaps one of the most problematic areas of qualitative research, especially in the eye of the positivist who recognizes this construct as generalizability or external validity. Such a weakness can be dealt with in a qualitative study in several ways. The first is to refer back to the original theoretical framework to show how data collection and analysis will be guided by concepts and models. The theoretical parameters of the research are stated, clearly and concisely, so a determination can be made, within these parameters, by policy makers

whether or not the cases in a given study could be generalized for the making of new policy, and transferred to other settings. For example, Hospice policy makers (National Hospice Organization or insurance companies), after careful review of the theoretical base, the concepts and ultimately the findings of the current study may decide that such information can be generalized or "transferred" to the grieving population, in general. Perhaps bereavement program planning will become more seriously considered. The researcher did not expect reimbursement of bereavement services to become a reality because of the efforts within this study, however, some discoveries were made that helped generate hypotheses for future studies. Further research and theory testing could build upon and help bridge the currently existing grief models presented within this study.

One other way of enhancing generalizability is to utilize triangulation as a way of collecting data. This entails collecting data from more than one source, in more than one way, but still addressing one research point or question. Wolcott (1988) describes the process by stating that:

> the researcher himself is the research instrument, but in his information gathering, he utilizes observations made through an extended period of time, from multiple sources of data, and employing multiple techniques for finding out, for cross checking or for ferreting out varying perspectives on complex issues and events. The strength of fieldwork lies in triangulation (p. 192).

Triangulation addresses a study's research question in a way that helps to expand upon it or illuminate it (Rossman & Wilson, 1985 as cited in Marshall & Rossman, 1989), thus making it more useful for other settings. This strategy was utilized in the current study and is described in Chapter III on research methodology.

3. Dependability: is commonly known in quantitative research as reliability, addressing the issue of replication of a research study. This is a problem in qualitative inquiry -- period. The entire assumption underlying indepth, rich data gathering is to study the process of change. The researcher purposefully avoids controlling the research conditions and concentrates on recording the complexity of situational contexts and interrelations as they occur. A flexible research design allows for attainment of the goal of discovering the complexities that are part of the processes being studied. Replicability will not be possible, nor sensible given qualitative design. However, a research journal can be kept and was kept in this study. It was used to record any changes in design decisions as needed, and for documenting any changes or significant events in the life of the researcher -- the research instrument. Dependability of this study was enhanced by keeping data well organized and in a format that allowed ease in retrieval of information from the huge volume of raw data. Preservation of data also was made a priority, by taking extra precautions to make back-up copies of diskettes, and appropriate written materials.

4. Finally, the fourth construct used to assess the soundness of a qualitative study is confirmability, or objectivity in positivistic terms. It is possible that as a researcher, one's own subjectivity may shape the research, particularly with a topic that is close to the heart. But in qualitative study, this subjective stance is actually a strength, because it is precisely the researcher's understanding of the grieving process, and familiarity with the feelings of grief that provided entry into the world of the bereaved. Marshall and Rossman (1989) stated that the researcher's insights increase the likelihood that she will be able to describe the complex social system being researched. However, they caution that the researcher

must also provide controls for bias in interpretation, and offer several ways to help curb such a bias. They suggested (a) having a research partner or a person to play devil's advocate when reviewing analyses, (b) maintaining a constant search for negative instances (Glaser & Strauss, 1967) to disprove the developing theory, (c) checking and rechecking the data and purposeful testing of possible rival hypotheses, and (d) outlining a useful notetaking technique that will facilitate analysis. The researcher utilized three of four of these suggestions in the current work. A constant search for negative instances was done during data analysis, looking for examples in the data that might refute Schneider's theory. In addition, the researcher presented the preliminary results of this study to a group of people interested in grief as a topic for research. Feedback was solicited by the researcher regarding generation of hypotheses, and/or rival hypotheses, and overall insights from the group about the results. Lastly, in a doctoral course on qualitative methodology, the researcher practiced notetaking with a form that was developed for recording, separately, factual observations and interpretations of facts (Appendix D). Allowing for creativity or interpreting of observation may prove to be useful for more formal analysis, although that was not the case in this study. Observation notes were used as a guide to accompany the transcribed interviews, and did serve as another way to check the credibility of the raw data. Wolcott (1988) summarized the value of this exercise as follows:

> Description and interpretation need not be so dramatically separated in the final account, but I think it a valuable exercise for someone new to descriptive writing to begin by preparing an "objective" account as free as possible from one's own inferences and preferences (p. 201).

In addition to issues of validity and reliability, of utmost concern was the conduction of ethical research that preserved the rights and dignity of the participants. The following section includes a discussion of the protection of human subjects, and the cost/benefit ratio of conducting the research.

Protection of Human Subjects

As Wolcott (1988) stated, the researcher in qualitative research becomes the research instrument. The researcher, through observation and interactions with a select group of people, begins to make discoveries about the phenomenon of interest. Because of the key role the researcher plays in data collection, an awareness of how one may be influencing an interview must always be kept forefront. Careful thought was given during study design to the managing and recording of data. A research journal was maintained to record any thoughts, feelings, reactions, reflections, or changes in the researcher's life situation as a way to indicate how events in one's personal life might influence data collection. In addition, observations during the interview were written immediately after the meeting on the notetaking form (described in Chapter III; see Appendix D). Thus a conscious, thorough monitoring of self was maintained during interaction with participants.

In addition, the consent form (Appendix C) for bereaved in this study was designed with careful thought about the ethical treatment of participants in this study. This was especially true given the nature of this study where asking participants about their grief experiences represented a delicate area. Time was devoted both before and after interviews with all participants, the former for development of rapport and the latter for a time of debriefing. The researcher made sure participants were in a comfortable place emotionally before leaving an interview, and provided all participants with information about a contact person at Hospice if they found they required assistance after the interview. Permission to call the Hospice office and ask directly for the researcher was also given, however, a need for follow-up did not occur for any of the subjects, either in the form of a request to speak to a Hospice staff person, or the researcher. Conducting the interviews required a particular sensitivity on the part of the researcher, who had previous experience to develop specific skills and abilities.

1. Conducted 32 in-home interviews as part of a research project, within the Department of Family and Child Ecology (1986-87).

2. Served as bereavement coordinator at a Hospice from 1988-1990, where duties included conducting in-home assessment of grieving individuals. During the interviews, the researcher was cognizant of conducting an interview, not an assessment.

3. Taught Hospice Grief Recovery Seminars, led annual Memorial Services for Hospice families, and conducted Holiday Seminars for assisting bereaved with grief during the holidays.

4. Completed courses in marriage and family therapy, and gained experience as an intern counseling individuals, couples, and families.

5. Completed pertinent doctoral course work in areas such as: death and dying, grief and loss, qualitative research methods, quantitative research methods, statistics, marriage and family therapy, communication and crises, assessment, and interviewing.

All of the above experiences, combined with the researcher's own experience of parent loss in young adulthood, integrated the past with the present and provided a special sensitivity for capturing the richness and depth that interviews can provide. This background seemed sufficient to avert any difficulties that may have occurred, as interviews were conducted without apparent harm to the participants. In fact, some participants began disclosing about grief experiences during the initial phone call which was designed only for screening and establishing interest in the study. All 12 participants expressed that the interview itself served a form of support and that they viewed it as a positive experience, despite some initial apprehension.

Data collection procedures used in this research were approved at Michigan State University by the University Committee on Research Involving Human Subjects (UCRIHS) on June 21, 1993. Confidentiality was reassured at the beginning of each interview, and maintained by assignment of a code number selected by the researcher. As outlined in the proposal for this study, interviews were audio-taped with the permission of the participants, and were erased immediately after transcription. All notes, memos, and cassette tapes were identified only by the assigned number, and were kept in individual files, in a box, in the locked trunk of the car during times of transporting. Files and other materials were retrieved as needed for data collection, and then stored in the researcher's home office after data collection was completed. The names and addresses of the participants were obtained and are on file currently only for purposes of offering summary results to those who indicated an interest. And finally, any publication or presentation of this data will not include information that could identify the participants of this study.

Cost/Benefit Ratio

As stated previously, the participants found the interview experience to be supportive in itself, expressing gratitude for the opportunity to have been able to tell their story to someone who wanted to listen. The short term benefits to individual participants and society as a result of this study include a greater understanding of the grieving process, hence the opportunity to provide clarity and efficiency in program planning and provision of grief support services. Continued program development within Hospice includes provision of a children's grief support group with a family component. This type of service is both educational and therapeutic, with one long term benefit of making a systemic change in attitude that makes the expression of grief normal versus something to be avoided. Other long term benefits include potential justification of Hospice bereavement services which will enable reimbursement from Medicare and other insurance companies. Ultimately, this action will benefit individuals and families in that they will be able to obtain adequate and affordable grief support services as needed. Promotion of grief as a normal response to loss occurs through education about the grieving process. Participants who attended grief educational seminars in this study reported them as valuable in part because of the validation received and normalizing of feelings. What participants learn about the grief process and tasks of grief may circumvent later physical, emotional, or psychological upset. Furthermore, sometimes moderate grief supports are not adequate; for example, for those who do develop physical health problems or psychological/emotional disturbances following the loss of a loved one, outside assistance can be costly on many levels (Parkes, 1988).

Limitations

There are several limitations of this study. A discussion of them follows.

1. Participant groups were small in number and homogeneous in nature in that recruitment occurred primarily through Hospice, consisting of almost all caucasian females. Stroebe (1993) examined cross-cultural evidence that revealed that not all cultures subscribe to the "grief work hypothesis," stating that there is "not always a working through of a loss to achieve detachment from a deceased person" (p. 29). Furthermore, "suppression of memories is prescribed in certain cultures, just as the notion that one must work through grief is prescribed in our own" (p. 30). "Cultures vary considerably in the meanings assigned to loss, and in the nature of grief and its expression" (Hansson, Carpenter, & Fairchild, 1993, p. 72). Clearly, the groups did not reflect cross-cultural differences in expression of grief, thus any majority findings need to be placed within this context. This lack of cultural diversity in selection of participants may stem from the fact that the Hospice from which participants were recruited serves only a very small percentage of minority families. Such a fact may reflect geographic region and/or the diverse attitudes that exist in cultures about death and dying, and the value one places on cathartic grief expression, i.e, the Hospice philosophy promotes open expression of feelings around issues of death and dying, grief and loss, and individuals whose cultural values promote suppression of expression may not subscribe to the concepts purported by Hospice.

2. Participants' reports were retrospective, and based on one-time interviews. Ideally, a second interview could have provided the opportunity to administer the RTL Inventory (Schneider, Deutsch et al.,

1992), giving more support to the finding that participants in this study had not reached a reflective point in their grief where self-empowerment and transformative processes occur.

3. Every effort was made to promote gender equality within and across groups, to no avail. Clearly, it was not feasible to discuss gender differences in relationship to grief expression, as attempts at recruiting males participants failed. Given the socialization process that exists in this culture, it was not surprising to the researcher that male participants were reluctant to grant an interview, especially to a female interviewer. This is not meant to be a judgment, but rather a statement of fact, and maybe a male researcher/interviewer could pursue study of men's grief in the future.

4. Inquiry about different grief experiences as those related to loss of a mother versus loss of father did not surface as an important theme, nor did the researcher ask directly about these differences. Participants were directly asked about whether they had lost one or both parents, but the researcher failed to probe as to whether the death of a mother or father affected their grief experiences. There were three participants who had lost both parents, and a search for contradictory or dissimilar responses to those who had lost just one parent revealed that, particularly for two of the three, active grieving seemed to be just beginning following the first year of the losses. In other words, limiting awareness and simply coping from day to day seemed to be more characteristic of these two participants who lost both parents. Further study on the effects of multiple loss on adjustment is recommended. In addition, perhaps another study could explore gender differences in grief reactions, comparing differences by whether one has lost a mother or a father.

5. Some research has been completed on who is likely to attend grief support groups (Levy & Derby, 1992). Many factors affect one person's grief expression and the option to seek formal support (see subheading entitled, "Other Factors to Consider" under section "Bereavement Reactions and Death of a Parent," Chapter II). It was assumed that those who seek formal sources of support believe that it will be helpful to them. Part of the difficulty in conceptualizing and studying the grieving process and grief support is that grief is a unique experience for people, and formal support is evaluated as it is perceived by the receiver, i.e., what works for one person may not work for another. In addition, most people survive the grieving process without the help of a professional (Schneider, 1984; Worden, 1982). Therefore, the researcher assumed that persons seeking grief support believe in advance that it will be helpful and that they need it. Thus self-reports about the usefulness of grief seminars and groups may be inherently biased.

6. The results from analysis of the Hospice "Bereavement Support Questionnaires" (Appendix F) were compared with the responses of participants in this study. It was proposed that the only questionnaires that would be used for analysis were those returned by young adults meeting the specified criterion outlined for bereaved participants in the study. However, because the overall response rate for questionnaires returned over 6 years was a mere 16.5%, the decision was made to compile a summary report for all questionnaires (N=205). In addition, demographic information was not part of the questionnaire, thus it was not possible to identify time since loss or age of a participant. Summary results were compared with responses from bereaved in this study about the usefulness of formal supports, lending insight about the effectiveness of selected

Hospice bereavement services. Ideally, a comparison of same age young adults would have been more informative from the developmental perspective, but this simply was not feasible. Lastly, the analysis of the documents proved useful to the Hospice in the long run, as these questionnaires had not been summarized.

CHAPTER IV. MAJOR FINDINGS: CONCEPTS, THEMES, AND DEVELOPING THEORY

Losing a parent in adulthood may deal a significant blow to one's emotional and physical equilibrium (Moss & Moss, 1983). Although loss of a parent may be a critical event influencing adult development, little research exists in this area (Douglas, 1991), and even less attention has been paid to the bereavement experience in life course stages (Perkins & Harris, 1990; Scharlach & Fredriksen, 1993). Data analysis of interviews from the 12 young adults in this study revealed that after 1 and 2 years following the loss of one or both parents, lingering sadness and mood swings were still present. All of the participants in the 13 month group considered themselves to be actively grieving. The following sections represent concepts and themes that emerged from the interview transcripts, and their relationship to the transformative potential of grief (Schneider, 1989). Differences existed between the 13 month and 24 month groups, and responses varied depending upon whether a person had or had not sought formal grief supports. Therefore, majority findings have been reported noting these differences.

The Young Adult's Grief Experience

To develop the concept of young adult development and how development is influenced by the death of a parent to cancer, two questions were collapsed from the interview guide. These questions were:

1. Can you describe to me what your grief was like? A prompt was given stating that they could begin with the time of diagnosis or after the death. Most began describing their grief as it began with the diagnosis of the cancer.

2. What were the circumstances of the death?

Describing Diagnosis, Illness, Treatment, and Death

A theme was defined as something that consistently appeared in the data in at least two-thirds of participants' responses, and for which a direct question did not exist. This was information that the participants supplied that reoccurred without the researcher asking about it directly. For example, in the 13 month group, all six described the initial diagnosis, illness, and treatment procedures experienced by the parent and within the family. The majority of the participants chose not to describe the actual moment of death, with only one vividly describing the experience of being at her father's bedside as he died. In the 24 month group, two-thirds of participants provided detailed descriptions of initial diagnosis, illness, and treatment procedures with the other one-third describing this, but focusing more on what their grief was like after the death. Only one in this group described the actual moment of death, and did so as the researcher was leaving the participant's home, so this was not audio-taped.

The descriptions of the gradual loss and deterioration of the dying parent were vivid and sometimes very lengthy accounts, containing recollections of specific dates, times about when chemotherapy or radiation treatments began, or what it was like to be in the waiting room at the hospital as the parent was receiving initial surgery confirming the presence of cancer. The gradual physical deterioration of the parent seemed to parallel acceptance of the reality that this was really happening, as described by one participant in the 24 month group:

> And I think when we found out it was cancer, I mean, I think everybody just started right then. You know, she's not gonna be around much longer...actually, when she died I think I had a lot more relief. There's some guilt in there too. And -- because it was so hard

> to look at her. Because she looked so deathly ill. She looked like a concentration camp survivor. She started getting a bed sore on her one heel, and — it was just a relief, I really think that's the biggest -- I think that's how we all felt. We really felt bad, but we thought, she's not suffering anymore (P12).

Or as described by another participant in the 13 month group:

> It did begin with the diagnosis. It was like someone pulled a rug out from under me...I felt like I was a squirrel, you know, wandering around, spending time with my mother I was doing the same thing a squirrel would do before the winter comes, okay, hiding away... um... memories, and times to look back on and moments and things that I could never be able to have again (P1).

Such descriptions seem to indicate that a person's grief very likely begins at the time of diagnosis. The researcher did not directly ask participants to describe the initial diagnosis, but rather offered a prompt about how the diagnosis affected the family within the question about what grief was like for them. It was the participants' consistently detailed descriptions that emerged in the data that brought about this theme.

What Was Your Grief Like?

To develop the concept of grief and to understand more fully the grief experiences of young adults, responses from three more questions were collapsed and analyzed for emerging themes:

1. Do you consider yourself to be grieving right now?
2. How would you describe yourself today?
3. How would you rate your grief adjustment?

All six participants in the 13 month group said that they were grieving right now, with some differences in the FGS and NoFGS groups. In the FGS group, all three reported feeling better, but having much more work to do to reach acceptance of the loss:

> I'm wondering...my target date was one year. I thought, things will start feeling better in one year. At least a year. But I'm wondering, is it ever going to feel better?...It's still fresh ...a year is still fresh. She's in every fiber in my being it seems like.

> Sometimes I think she's here with me, within my body and soul. And I wonder if that's just because I'm part of her (P1).

> I think I'm a lot better now than I was six months ago. I think I'm a little bit better now than I was three months ago. The increments though, are very small I think, but I think I'm headed in that direction ... You know, I think I hurt as bad today as I did the day of his death, but I think I hurt in a different way, or I handle it differently. It's still a tremendous loss, but I'm beginning to be able to accept it in the overall perspective of things. And I guess time has allowed me to do that (P2).

Two of the three in this same group described their grief as it occurred in "sections" or "quadrants," as exemplified in the following passages from the data:

> The grief came in sections...so if she would lose sections of her physical strength, or if her hands or feet went numb from the drugs...when these things started limiting her, it was hard for her but it was harder for me to accept my mom's limitations, because my mom had always been able to do everything. So I would grieve my mom in little pieces (P1).

> A part of me is submerged I guess. I've pictured myself...actually as being divided into quarters and when I, when I see this picture of myself, actually the top right quadrant is ah, is you know -- is gone. I'm split basically into fours, and that piece is just gone. For some reason that image is very vivid to me (P2).

In the NoFGS group, two of the three expressed surprise that tears and sadness were still so sharp, even at the one year point in their grief. The third participant in this group stated, "I would say it's affecting me more now than it ever has" (P4). One other NoFGS participant who had lost both parents to cancer just 2 1/2 months apart expressed that:

> I'll probably be grieving the rest of my life. I don't think you ever stop...grieving to me is just missing someone so bad...I don't think you ever stop missing them. I think it gets easier, because it has. Even though it's only been one year, it has. But it's still fresh in my mind (P5).

Two-thirds of the participants in the 24 month group stated that they were grieving "some", although all six also reported feeling movement in their grief, and that the feelings were not as intense as the first year of grief. One participant rated her movement in grief on a scale from 1 to 10, going from a 6 1/2 to an 8 1/2 after two years (P9). There were no notable differences in the FGS/NoFGS groups in their descriptions of what grief was like, and how they felt they were doing. Overall, most reported feeling a lingering sadness, especially over little things such as certain events or reminders of the deceased:

> Well, I think any time I really sit down and really think about Mom and really talk about her...I still grieve her. But um... not really actively grieving. Just when the situation comes up, or...you know there's days that are hard. You know little things like that will make you feel sad...and bring up the feelings. There's a lot of ups and downs. If you were going to chart it, it was a real zig zag kind of a thing on a daily basis. Some days would be really up and some down, and it just went from that, to peaks and valleys to where it's pretty much a straight line now (P11).
>
> I mean you have your days. I thought about it this morning. I don't know if it was because I knew you were coming over or what (laughing). On my way to work...I'm driving down the road and my mind is wandering, and my eyes get kind of misty (P7).

In sum, those in the 13 month group appeared to be actively grieving, with some differences in those that sought formal support versus those that did not. In the 24 month group, both the FGS and NoFGS groups reported movement in their grief, and less intensity into the second year, but still a sense of loss and lingering sadness.

Formal and Informal Sources of Support

To develop the concept of support, and specifically formal and informal sources of support, six questions from the interview guide were collapsed and the data analyzed to promote a better understanding of what helps young adults grieve. These questions were:

1. What did you find helpful in your grieving process?

2. Did you find that some things were not helpful? If yes, what were these things?

3. Describe your social supports.

4. Did you attend any grief support groups, a class or a group or both? Any personal counseling or therapy to help you cope with this loss?

5. If you had to list one aspect, the thing that helped you the most in your grieving process, what would this be?

6. What has this interview been like for you today/tonight?

Formal Supports

In the 13 month FGS group, two of three attended the Hospice Grief Recovery Seminar, with one describing it as helpful and one stating that it was interesting, finding the class useful upon reflection:

> It was interesting from the standpoint of knowing that I was not alone. I personally don't think I got a lot out of the class...I could sympathize and empathize with those people who did discuss what they were feeling. I guess one of the things that bothers me is that in certain situations there's just nothing you can do (P2).

The participant that did find the seminar useful stated that:

> Uh... I guess validation. That the things that I was experiencing were normal, if you want to use the word normal. That it was okay that I didn't know what the heck I went to the grocery store for. That I didn't feel like eating. That I couldn't sleep or that I wanted to sleep all the time...it ran the gambit. I think the class helped me to stop running, and gave me permission to cry...I needed to cry and I hadn't done a lot of that (P1).

In addition to the class, two of the three in the FGS group found personal counseling valuable in processing the loss. One described needing a more private forum for expressing grief, and felt that this was due to the fact that she had had a miscarriage just 12 days prior to her father's death. Therefore, she felt overwhelmed by a group setting. The other participant who sought counseling for assistance with her grief felt that it helped her in addition to the seminar, because:

> It helped me to get more focused on what didn't work in my life. It helps you deal with a lot of different things in a more healthy way, and grief is one of them (P1).

No one from the 24 month group had sought personal counseling, not even the FGS group, for help with processing feelings about the loss.

In the 24 month FGS group, all three participants reported that the Hospice Grief Recovery Seminar was helpful, providing this information as a response to "what did you find helpful?" All three found the class useful to them in their grieving process because:

> You felt, boy when other people were talking about their experience, you'd sit there, and wow, I can really relate to them. These people understand...understand what I'm going through, and what we're going through. Also to understand that people do grieve in different ways. There's no right or wrong way to grieve (P7).

> I went through the grief recovery class and that helped some. It helped me understand a lot about what I was going through. And what I realized from that was the grief for my mother started the minute I learned that she had the cancer. All the symptoms, um... emotional ups and downs and everything like that started then. So that helped me to understand what was going on (P8).

> It was helpful because I grew up in the kind of family where you can't talk about how you feel. I was finally able to let them out after my dad died, because of the group. It helped me learn that I'm not the only one in this situation. Everyone has similar experiences, and somehow that helps. You can remember good things with these people...you can talk to grieving people about your memories and they know what that means (P9).

Only one in the six FGS participants had attended an ongoing grief support group and still attended at the time of the interview. The most valuable aspect of this experience for her was making friends who also had loss experiences because she did not feel as alone in her grief (P9).

Informal Supports

Other useful grief supports identified by all the bereaved in this study were classified as "informal" supports, assisting in further development of the concept "informal" support. Stylianos & Vachon (1993) state that it is difficult to measure exact helpfulness of a specific support attempt. Shumaker & Brownell (1984 as cited in Stylianos and Vachon) view social supports as individual properties, interventions that must be seen as helpful by the person receiving them in order to be supportive.

In the 13 month group all six expressed that friends were valuable sources of support, in terms of their ability to listen and try to understand feelings. The NoFGS group especially spoke about "select" friends as meaning those who had experienced loss and grief and could better understand without judgment the bereaveds' process. The following excerpts from the data exemplify the value of friendship as an informal source of support during the first year of bereavement, taken from both the FGS and NoFGS transcripts as indicated:

> I appreciate a friend who is just letting me be...just be where I'm at. And for the most part, that has been my experience. But there's the offhand comment, or you know, something that devalues my feelings. And I'm really alert to stuff like that (P1, FGS).
>
> Well, I honestly don't know if there is anything that is helpful...but I am comforted in the fact that there are people that I am close to, whether they be family or whether they be friends, who understand how I feel and are willing to listen (P2, FGS).
>
> My best friends, oh geez, there's like three of them, three really close friends I could let my hair down with (P3, FGS).
>
> I had lost all my friends, telling 'em that I had to take care of my mother, which made it hard to keep in contact, I just wasn't real good at that. Really nothin' was helpful, not even friends. I mean I could talk, but people are sick and tired of hearing, you know... they get tired of listening to you talk (P4, NoFGS).
>
> But I, I, I, remember just feeling so much guilt, so much hurt, so much sadness all at once, I felt I was losing my mind one time (crying). I called up this other friend...I started bawling hysterically, and I said, "I think I'm losing my mind." She prayed with me, over the phone and I remember feeling better...and that's when it hit me all of a sudden that day and I had to run out of the room and call that friend. Sometimes I just needed to connect, sometimes they would just listen and cry with me...she had lost a lot of people too, so she knew what I was going through. I mean the others understood and tried, but they couldn't

> understand totally, because they had never gone through that (P5, NoFGS).

> ...some select friends. Because not everyone can deal with this. I have a neighbor across the street from us...she has been an extreme, extreme, source of strength for me during all of this. Extremely. And she still is. She will sit and listen. She does not appear to be uncomfortable. I can sit and say anything I wanted about this to her. Cry -- um -- and she handles it very well. Also, one of the older ladies there (at work), she's 50 and she's lost both her parents. So she can sympathize. She's gone through the same thing...so I think that that was definitely a factor in them being helpful to me (P6, NoFGS).

In addition to describing the role of friendship as a source of support, two-thirds of the 13 month and one in the 24 month group also noted that "cliches" and "insensitive things that people say" were unhelpful aspects of support coming from friends and/or co-workers. One participant's father was well known in the community because of a career position. She found it difficult to be anywhere in public for quite some time because of the well meaning comments from administrators and staff. For example:

> Things that didn't help were things that people said, but they didn't know what to say, and I don't blame them. I found that when people offer solutions, it's almost undermining to what you actually have ...These are people that never had anyone -- die. Day to day, dealing with cancer, a close family member. These were administrators, other (staff), it's just really -- they just didn't know what to say. Um...things regarding Dad -- a very simple, "I'm sorry" or direct eye contact, or giving them a hug, things like that...that would be very helpful (P2).

The reader will recall that when the 24 month FGS group was asked about useful grief supports, they all responded by describing the Hospice Grief Recovery Seminar. When probed further for identification of informal supports, there were no clear majority findings as was the case in the 13 month group. In the 24 month group, however, two-thirds of the NoFGS participants reported that it was especially helpful to talk to someone who listens, and understands. All three spoke of friendships:

> My best friend --my neighbor and my lifeline (names friend). She's good. She really is (P10, NoFGS).
>
> I talk a lot...and I talked a lot about my mom. And my friends were real good about listening to it. I have two very close girlfriends, one that I've had since like 7th grade, and the other one it's just been kind of childraising years kind of friendship. But they were both real good about listening to me (P11, NoFGS).
>
> It was nice to know that I had more friends than I thought I did. It's important to know that you're not alone. There are three women in the office that I would talk to. They are close friends. And we all do that for each other. And it helps, so you're not bottling it all up inside (P12, NoFGS).

Two-thirds of the participants in this group also reported that sharing fond memories of the deceased was helpful, especially noting that it felt good to be getting beyond the memories related to the parent's illness and treatment. Participants in the 13 month group were not as likely to share fond memories about the parent as were those in the 24 month group. It seemed that the greater the amount of time that had passed since the parent's death, the more likely participants were to describe fond memories of the parent before the illness:

> Well, we're trying to grow a garden. My dad was a very good gardener. Things like that make me feel good. Ya know.. so I try to talk about him in a tense like that...I have a garden now, and that helps. It's something Dad loved to do...and somehow I feel I'm with him when I'm doin' that, too (P10).
>
> We include Mom in our life. Still very much. My kids have lots of memories, you know, things will come up, and we do things like...you know I always wanted to keep her alive to them...we talk about her a lot, you know. We catch a fish, and we say, "Nah, Nana would say it's too small. Throw it back." And we believe that when you see the sun's rays coming down, that that's people looking down from heaven...So we include her. And sometimes it will make them cry, and that's okay, I still cry sometimes too (P11).
>
> I think trying to remember the good things we've done. Vacations we've gone on...thinking about those things, and thinking about what good parents they were. That helps me the most (P12).
>
> ...after the death it felt for so long that every memory of her was (crying) being sick. All the bad things. And I did feel for a

> long time that that would never go away, that I'd never get past that (P6).

When describing social supports, the most frequent responses from participants in the 13 month group were family of origin and procreation and faith including church, God, prayer, church community. Some felt the support of family and the strength derived from their faith were invaluable to them, although these were not majority findings. However in the 24 month group, all but one participant stated that a significant other, i.e., husband/boyfriend and their own children were the most valuable "social supports." Some examples:

> It wasn't hard to go on with my daily routines and things like that. (Husband) was so supportive...when I think back on it I don't even know what I did with (son) all those months (P7).
>
> My family. My immediate family. My husband and my children (P8).
>
> My mom is the main support in my life. My boyfriend. Also a friend who lives downstairs. Being with my boyfriend has changed. We're a lot alike, and we used to argue. Now we get along better. I think we help each other. My attitude is more positive (P9).

The other most common source of support given from this group was "friends" which was discussed previously. It is also noteworthy that two of three in the NoFGS found the Hospice mailings useful. Typically, the NoFGS participants described themselves as "not a group person," thus an indirect service such as a mailing seems to make sense for this group. Only one participant in the 13 month group mentioned the mailings as helpful. It was not a direct questionnaire item as it was assumed that all Hospice families received the monthly mailings.

Identifying Other Sources of Support

When asked to list "one" aspect that helped them the most in their grief, no majority responses surfaced in any of the groups, however a brief listing is included because these responses may lend additional insight to concept development and assist in answering the question, "What helps people grieve?" The following responses, then, are from the 13 month group: (a) can't give you just one answer, (b) time, for healing, reflection, and perspective, (c) my faith, (c) my father taught me how not to be afraid to die, (d) my strength in the Lord, therefore my ability to reach out to others, (e) the support of what I feel are the people closest to me, and (f) talking, having someone to listen. The 24 month group indicated: (a) isn't just one thing, (b) friends (c) husband/boyfriend, family, (d) myself, (e) being open and talking about it, and (f) being present at the dying parents bedside; caregiving.

Finally, when participants were asked what the interview had been like for them, all 12 participants reported that the interview had been a positive experience, in spite of initial apprehension. Some expressed appreciation for having had the opportunity to share their feelings, even some feelings they perhaps had not shared previously. Common responses were, "It's been a godsend;" "Someone to talk to, to be able to put it into words again;" "The pain is brought back, but so are all the good memories, it was helpful;" "It's been great to actually sit here and cry, to be myself and to have someone listen, it's reassuring;" "Better than I thought;" "Feels lighter, reflected on myself and my growth;" "Helpful to talk about Dad and remember him." Two-thirds expressed feelings about how doing the interview may also be useful to help the researcher to help other grieving persons, and that this was their motivation for taking part in the study.

In sum, it appears that the formal grief support services -- the Hospice Grief Recovery Seminar, the ongoing support group and personal counseling -- were valuable to those who sought them. Friendship appears to be a major source of informal support for the bereaved (9 of 12 participants discussed), and especially for those in the 13 month NoFGS group, "select" friends were the most desired form of support. Because friendship was consistently reported as being an important support for the bereaved, the implication is that such friends may need to be available to their bereaved friends especially during that first year of bereavement, and know how to be supportive. Because of this finding, the role of friendship in the grieving young adult is discussed further as a theme in the next section.

Role of Friendship in the Grieving Young Adult

Rubin (1985) has written about friendship, primarily based upon in-depth interviews conducted with people in every stage of life about the role of friendship. She states that "friends are central actors in the continuing developmental drama of our adulthood" (p. 11). Furthermore, as a central thesis to her book Rubin describes friendships and the developing sense of self as an interplay, each influencing the other. Friends provide a reference outside the family against which to measure ourselves. Friends help us move through key rites of passage. In terms of the young adult, they help with that process known as separation and individuation, assisting in the development of new rules, and adaptation to new roles. Friends help heal the hurts and provide a haven for healing that perhaps a family cannot provide for whatever reason. At the same time, Rubin cautions, "friends choose to do what kin are obliged to do" (p. 22). Therefore a certain maintenance is expected in friendship, because it does not have the element of permanence that a family holds.

The young adult who has experienced the death of a parent often reaches out to friends for support during the grief and subsequent transitions to the loss, as expressed by Crenshaw (1990):

> Friends are extremely important at any stage of the life cycle, but they play a special role during the early adult years in terms of providing support as young adults attempt to establish themselves into a secure pattern of adult life (p. 137).

Crenshaw discusses grief of the young adult for any significant loss in life, but emphasizes spouse and child deaths. He does note the importance of other significant losses, such as the loss of a parent or a friend, and only briefly offers insights about grieving when a parent dies. He does make note of the grieving young adult who may find him or herself lacking a supportive network of family and friends, and discusses community based grief support groups as being useful supports during bereavement. Even the most understanding families can be difficult to lean on when one of its members has died, as there may be a tendency to "hurry along the process of grief so as to shorten the period of agony and pain. Those who have experienced it will appreciate that you cannot go around grief but rather you have to go through it" (Crenshaw, 1990, p. 126).

In the current study, it was pointed out that friendship played a vital supportive role in the lives of the young adults who had experienced the death of a parent. In light of what Crenshaw surmised about lack of family support or inability to grieve openly because of family coping styles, it would appear that friendship would be a most important avenue of support, as well as formal grief supports:

> I wish family would be more supportive...I have to go to a grief support group to talk about this. They just don't want anything to do with it. It's not okay to bring up the subject. I can talk to my mom about dad, now, but not early on (P9).

And there are those who for their own reasons just cannot attend a grief support group or class, and for whom family members are not open to talking about the loss, either:

> ...our family has never been one where we discussed our feelings a lot...we knew it was there but we didn't know how to talk about it...We haven't talked about my mom, my sister and I. I think we both think about her, but it's something that we really don't say much about. So to have somebody actually say, "tell me what you're feeling" is really different (laughs). My sister went to a Grief Recovery class. It didn't really hit me, anyway, until the second Christmas. I think it's just our family. We don't get that emotional. We all tend to hold that side of us in. I think I'm doing good, like I say, I miss my mom, but I think a lot of my friends have taken up some of that, and my dad a little bit ...although he doesn't talk about a lot of his feelings (P12).

For this participant, friendships provided the major source of support for her in her grief. Rosenblatt and Elde (1990) maintain that where parent loss is concerned, relationships with siblings are an important source of support for "shared reminiscence" (p.206) about the deceased parent's life. However if siblings have minimal interaction, or are cut off from one another, an alternative source of support may be necessary for coming to terms with the loss. Clearly, friendship may serve as a "surrogate sibling" role.

Rubin (1985) cites Winnicott's concept of friendship as "transitional objects -- people who join us in the journey toward maturity, who facilitate our separation from the family and encourage our developing individuality by providing the contact and comfort needed for the transition from child-in-the-family to person-in-the-world" (p. 34). She summarizes by stating that friends are not simply replacements for deficits in family life, but they are crucial to one's well-being as negotiating life's transitions would be much harder without friends.

Based on the developmental stage theories of young adults (Erikson, 1966; Levinson, 1978), Tokuno (1983) reported that friends play a major role in the resolution of developmental issues facing young adults, and completed a subsequent study (Tokuno, 1986) to determine specific processes by which that support is delivered. Outside of his work, it appears that little research has been done on the role of friendship as support for bereaved young adults. Based on the emerging theme in this study that friendships appear to serve as an informal source of support during grief, it is recommended that future inquiry be directed in this area.

Developmental Loss: What is Lost and What is Left?

The period of young adult life from about age 20 to 45 is seen as a time for movement away from one's family of origin and into formation of intimate ties with others (Crenshaw, 1990; Erikson, 1966). The upheaval and pain of losing a parent at this time can perhaps be understood more clearly within the developmental framework, i.e., just when a person is beginning to separate from the family, a loss occurs within that family resulting in many painful emotions and subsequent adjustments (Schwartzberg & Janoff-Bulman, 1991). Crenshaw maintains that this loss hits hard, because in the midst of decision making for establishing a secure pattern of life, a young adult may still desire the support and encouragement of parents. Feeling understood and cared for by significant others, such as close friends and family, appears to be central to the young adult's ability to cope with life (Winefield, Winefield, & Tiggemann, 1992).

Changing Relationship with a Parent

The situation is further complicated as many young adults may be working through potential unresolved issues with a parent (Kaltreider & Mendelson, 1985). The death of the parent may occur just as resolution of these issues is taking form and redefining of the relationship with one's parent is possible, as expressed by many of the participants in this study:

> She was probably my best friend...even though she was my mother, it was almost like we viewed each other as close friends, then the mother-daughter relationship came in second. I don't know if that makes sense. We spent a lot of time together, and did a lot of stuff together. So it was not only losing a parent, it was a major loss for me as a friend, and a big part of my life (P6).
>
> ...she was my best friend. She was the person I turned to when things got really wild, and to me, seeming out of control, like there's so much going on, and people are being a real pain in the rear, and you could just go home, and you could get a hug, and you could sit and talk to mom or not talk to mom. Just be in the same room...You know, just to say, "it's okay, I understand. I love you anyway"...she gave me a lot of unconditional love and acceptance (P1).
>
> My mother isn't there for me to tell her about the good things happening to me, or for her advice (laughs). I was really, I think, dependent on my parents, a lot. And I'm still dependent on my dad...It has dawned on me how much my mom and dad meant to me... And my mother, I'm sure she thought some of things her kids did were dumb (laughs). But she didn't tell you that. She tried to be there for you, and help you decide (P12).
>
> Mom and I had this real good friendship. It wasn't always a mother-daughter relationship, it was a friendship kind of a thing. And I could always call her...we could talk about everything and anything. And all of a sudden the person I could always turn to was not there anymore ...I couldn't call Mom up and say, "Well what do you think?" (P11).
>
> But it seemed like she was old enough to be my grandmother. She was 36 when I was born. There seemed always to be a generation gap there really...I wished I'd had a mother around that could really understand me. Now she's gone. And it's like when I got to my 30's, and I really felt I could communicate and have a real friendship with her, really understanding her more, she was gone (P8).

Loss of Opportunities

Crenshaw (1990) also points out that in addition to this incredible sense of personal loss, the young adult may also mourn the loss of opportunities. A theme emerged in the present study that was termed "developmental losses," the most prominent being the participants' descriptions of what the parent will never witness in their children's lives, such as marriage or birth of a child. Over and over participants spoke about the sadness they felt because their children would not have the influence of their parent as a grandparent. One-half of the participants in the study had children, and this group tended to focus on family memories from times gone by involving the deceased parent. They also spoke of the effect the death had and would continue to have on their children. Those that did not have children felt sadness because the parent would not be present at the births of children they might be having, and of the three single participants, one expressed sorrow over the fact that her mother could not be there to help her pick out a wedding dress. Some of the following passages from the data exemplify these lost opportunities:

> Even at the ripe old age of 32, I can still feel like an orphan. ...I've wanted children since I was a child. I mean I wanted to be a mom, and I guess I wanted to be a mom because I had one of the best mom's there ever was. And we were looking into fertility treatments and so forth right around the time of the diagnosis. I couldn't bring myself to...further pursue it because at that time it stood right smack between me and what I wanted -- it was like this baby will never know my mother (P1).
>
> I just got to thinkin' you know how she was at my brother's wedding. She was at my sister's wedding. She'd never be at mine (crying). She won't even be there to help me plan it, or pick out the dress, or anything like that (crying). Or if I ever have kids, she won't even see them (P4).
>
> (upon hearing the diagnosis)...Then he dropped, and the first thing he said was, "I won't be able to see (name) go to kindergarten." These two were more like a father and a daughter. A grandparent and a grandchild. They were very close. They were bonded like you wouldn't believe (P3).
>
> Dad didn't talk about...he accepted death as far as he wasn't afraid to die, but he wasn't ready to die because um...(name) was his only grandchild. And that part is still hard for my husband and I sometimes because boy, (name)'s gettin' to the age where he can do so much, and things that Dad always said, "Oh I hope I'm around to see"...And he'd say, "But I'm not ready to die, because I want to see (name) grow up" (P7).
>
> The thing that's the hardest is that my kids will have no grandma. They only have one grandpa (P8).

> She didn't get to meet him. Well she'll never get to sit on grandpa's lap. He always had nicknames for his grandkids...And he didn't even know I was pregnant. He did get to come to my wedding and see that. He wasn't too healthy, but he was there (P10).

> ...and I couldn't have children...and she was always, she felt bad about that. She wanted a granddaughter. And I could tell, I think that she was a little more upset when I had...my hysterectomy than I was. She wanted to have those grandchildren. I miss her for that. I can't talk to her about it (P12).

Return to the Holistic Model of Grief

It may be clear by the previous examples from the data pertaining to both the redefining of one's relationship with a parent and grieving the missed opportunities one may have had with the parent, that the focus seems to be on what has been lost and what remains. In relationship to Schneider's (1984) theory described in Chapter I, in the first phase of grief, the person may be coming out of the shock of grief and entering into active grieving, with an acceptance and awareness that this loss is really happening. They may ask: How is it possible that this has happened? There is a realization that the loved one really has died and is never coming back. Movement into the feelings resulting from this realization may bring about a variety of coping mechanisms by the grieving person. There may be an attempt to limit awareness as gradual confrontation of reality occurs. The person begins to absorb the fullness of what was lost. In the second phase, the person may begin to enter into a time of healing, gaining perspective on the loss. There is a recognition of personal limits and a need to identify supports. There is usually an increased self-awareness and a search for meaning in life. The grieving person might ask, what keeps me going? Who gives me strength? What remains? What is the best and the worst of this experience? There is movement toward acceptance of the loss, perhaps passively at first, but with time, one begins to accept that life will never be the same.

Based on all of the major findings of this study thus far, it appears that the data lend support to these first two phases of the grieving process as described by Schneider.

<u>Theme one: What is lost?</u> Participants were interviewed at approximately 1 and 2 years following the death of one or both parents. Most appeared to be in the phase of **initial awareness** (shock; believing that this was happening). All of the 1 year group and two-thirds of the 2 year group provided vivid descriptions of the diagnosis, the illness, and treatments. The 1 year group expressed that they were actively grieving and the 2 year group still had lingering sadness with certain memories and events triggering grief reactions. There were clear descriptions about experiencing difficulty believing the reality of the loss:

> Um...I felt numb for so long...and (crying) -- a disbelieving type of thing, like it wasn't real. And I think I have to say, even, can I say this -- it might sound stupid -- even being a year, I still have moments when I can't believe it really happened (crying). Still deny -- um, I don't know -- It was (pause) devastating. I guess the full impact of it didn't really sink in at first. I think it took awhile, even after the funeral type of thing, it was just, it was something like I never experienced before (P6).

> It's been a rollercoaster. I didn't figure I'd start this so soon (crying). When I found out that you know it was a long time before I could even say the word cancer...It was very difficult for me to accept and still is. I honestly believed that as bad as things were, that he was going to get better. I just wouldn't allow myself to think that ah -- you know, he was, this was my dad. He was immortal (voice cracking and crying hard). So the acceptance for me has been really difficult and still is (P2).

> And I went through right off the bat, it could be polyps, um, a bleeding ulcer, and then he got to cancer, and we both -- that's when I first felt it. I thought, no. It's that pulling back not wanting to face it...and scream NOOO (loudly) and holding my arms out and just you know, just push it all away. I was listening, but I couldn't hear

> him (the doctor). Down. Not a high and low. I kept pushing things away. Nope, this is not going to happen, we're going to beat it...It's so hard to accept this (P3).
>
> Actually, at the time, I really didn't even think about it. I mean I just put it on the back burner...Well, it clicked. I faced reality. I'm one of those kinds of persons who tries to do that really well. I knew in the back of my mind that she wasn't gonna make it anyways...cuz they kept having more cancer found (P4).
>
> Not that I live in the past so much, but I just kinda, my imagination runs wild sometimes. I think what they might be doing. People don't even have to look like them...somebody walking down the street and for a second -- then I realized you ding dong. I did this just the other day with my dad, I mean the guy didn't even look like Dad. I hear their voices. Sometimes I can just hear them calling me...I'm not hearing voices...I'm just picturing them. I know they died. But I don't, I didn't want to accept it at first (P5).
>
> I don't believe that he's dead. It's almost two years now. And it's rough...I still, sometimes, have a hard time believing that Dad's gone (P9).
>
> And after awhile, my dad just said, "okay this is it, I'm gonna die." And you know, it's like you try to tell him, no, no, no, you're not gonna die. Well you know, you don't have time to grieve. There's no time. You can't think of that. You can't. Your thoughts are you're gonna help him. I was concerned with getting him up and out of that hospital. He's coming home (P10).

In addition, the bereaved expressed examples of attempting to cope with the reality of the loss by holding on, e.g., keeping busy, trying harder, being overly optimistic:

> I would push it out of my mind a lot. I would keep busy. I would work (P5).
>
> And starting a new job. Maintaining. And believe me I was aware that I needed to maintain that job. It was almost like I had to stuff the feelings down, and the job almost kept me sane I think. Cuz I knew I had to pull it together from 9 to 5 or whatever time I was there (P1).
>
> ...sometimes it's hard to accept that when you are this devastated and have had a loss like this that life goes on. Everyone else is just doing their thing — and having kids at the age they are, involved in school and such, I was forced into having to keep up with it and do this type of thing. And it actually at the time was good for me, although it was hard to make myself be involved. I had moments where I couldn't just continually focus on how devastated I was feeling (P6).

> And you try to think positive during that whole time. And you, you try not to say anything that would be a real downer for him, or negative. So see, I don't really think that reality hits until after it's all over because you live in that kind of mode through all of that...after he's been diagnosed and so you know you didn't want to bring him down yet he's preoccupied (P7).

> I remember thinking, knock it off, you're being negative. Your dad is dying, you have to walk in there with maybe a happy face, once would be nice, and a hug and a kiss...(P3).

> ...my mother would tell me he has so long to live, you know. So then you kind of deal with that. You just (crying) you get up and you go to work. You — I don't know sometimes I'd put it on the back burner, and yet it's there. Ya know, and then you go visit him and you see him and you know that -- okay, this man is not gonna be here, maybe tomorrow. So then you leave again, to go to your family, and you just wonder okay, am I doing enough for my family? Maybe I shoulda said, "I love you" more today (P10)

> I keep busy. I'm always busy. I stay away from my mom's house, sometimes, still, it's just too hard to go there (P9).

And some demonstrated letting go by diminishing the true significance of the loss or attempting to escape or "pull back" from life:

> Basically I locked myself up in the house and I got an answering machine and if I didn't feel like answering the phone, I didn't answer it...My family doctor diagnosed me with depression...and I didn't feel like I was a person anymore. And emotions were like every which way, up and down. It's like I didn't know who I was anymore (P4).

> It's hard to get up in the morning. It's hard to laugh. There were times during all of this, that I just didn't want to keep going. I did because basically I'm a happy person, and I love people. And because of the children (she worked with children), I love children. The children kept me going (P5).

> As her death got closer, I guess I kind of pulled myself away. I found it hard to communicate...I guess the main symptom I have with the grief and this whole process is that I have very little tolerance for people anymore...If something rubs me the wrong way or gets on me I pull away from a lot of people. I kind of cocoon myself..." (P8).

Theme two: What is left? There were also clear examples in the data representing phase two of Schneider's theory, "What is Left?" One might prioritize differently, show an increase in self-awareness, and search for meaning in life:

> It's probably made me more mature in a way, and more independent. I think it's made me focus on really some of my priorities, what's important what isn't important, definitely, to me personally. And I think I've also found that -- just not to sweat the small stuff anymore, it just isn't important (P6).

> I really want to live life the way I want to live it. I don't want to have to do things I don't want to do. I want to delve into things I enjoy, things that make me happy...And there's things I'd love to do, but always been afraid to do them. And I've decided to forget it, I'm going to do it anyway. Try to keep on talking myself into following through, but... (P8).

> Myself. My own growth and confidence in myself has helped me. It's just that I have grown in that I have more self-control (P9).

> I think I'm a little less afraid to do things. And I don't know why that would be. I suppose maybe because you find out that you're stronger than you thought you were (P12).

> I am a little more relaxed. I mean I used to be one of those people, go, go, go. and I especially notice that I prioritize differently. I don't push myself, I don't push my husband as much as I used to...I am creeping back into it, now that it's the second year, I can feel my old self returning (laughs), but really, I do think some of it will stick with me (P7).

Theme three: What is possible? And finally, phase three of the theory asks the question, what is possible? The bereaved truly begin to integrate the loss, with a shift in focus from what was lost to what is now possible. There may be a discovery of personal potential versus limits to one's capabilities. Perhaps a renewal of energy occurs, with a focus on the growth that may have occurred from the loss. Transforming the loss involves the person placing the loss in a context of growth, with a focus on how he or she has grown, and achieving higher levels of understanding and acceptance of the loss (Schneider, 1984). The participants in this study did talk about how they had grown from the loss, however, truly transforming the loss, if it happens for an individual, appears to be something that occurs more than 2 years from the time of the major loss.

Building Upon the Transformative Potential of Grief

To develop the concept of transformation and to build upon Schneider's theory (1984; 1994) of the transformative potential of grief, the following questions were collapsed from the interview guide:

1. Which things will never be the same?
2. Do you feel like you have grown or gained in any way because of this loss? If so, can you talk about this growth? How specifically have you grown?

In the 13 month group, two-thirds reported that holidays will never be the same with the loss of family rituals and tradition. Other common responses were "I will never be the same" or "nothing will ever be the same" (two-thirds). Some differences existed between the FGS and NoFGS groups when asked if they had grown or gained in any way because of the loss. Specifically, the 13 month FGS group all spoke about growth in some way, expressing an increase in personal strength, in facing fears, and in just feeling more confident for having made it through the first year:

> I think facing two of the biggest fears in my life and coming to the other side of them, that I've gained some personal strengths and some inner strength. And some calmness...there's something about looking it all right in the face and realizing that there's not too much on my scale anyway that's going to come close to rocking my life and turning it upside down. Ah, I guess a lot of acceptance, a lot of growing up, I guess. And I've found out some things about myself that I didn't know were there...that I can take care of myself (P1, FGS).

> Oh yes. It's ah, you know it's an experience I wish had never happened. It's a bump in the road that you have to learn how to negotiate. It's taken me awhile...There will be some quiet times that I'll spend alone rather than being able to share it with him (father). And there are a number of significant things that have changed. I think one of the other things it's done is to sensitize me a little bit to some of what's going on in other people's lives. You know, ah, I'm reminded of John Dunn, that no man is an island. And don't ask for whom the bell tolls, it tolls for thee. And I understand what that means now...I think I see things a little bit differently now. And that someone's death,

> whether they are known to me or not does diminish me...that gives me a different perspective about the order of things, and the importance of things, and so on (P2, FGS).

> I didn't think I could get any more faith than I had before this happened, but I know I have. I've grown much more closer to God. And I thought I was already there...you get strength. I'm not afraid to die. And my dad taught me that...it was very reassuring...I'll never be the same. You realize we all have to grow, and I don't like change. That's part of life, it's part of growing up. I understand all of those sayings now. But a part of me is gone. That went with my dad. And that hurts...I feel like I have a part of him in me. You know he took a part of me with him (P3, FGS).

Participants in the 13 month NoFGS group had some difficulty understanding the question in terms of what was meant by "growth." This could be related to the finding that two of three in this same group were surprised that even after 1 year feelings of grief were still sharp. Furthermore, one participant in this NoFGS group was really just beginning to actively grieve, and the other one who had lost both parents just 2 1/2 months apart was overwhelmed by these questions. Perhaps "growth from grief" would seem odd, or at least further away for those who may be entering awareness:

> I'm not the same. I felt like I was this crazy person. I mean one minute I'm way out over here, and the next minute I'm there...(When asked if she has grown or gained:) Golly, I really don't know how to answer that one...(P4, NoFGS).

Another possible explanation is that for those not seeking grief education, i.e., formal support, perhaps the grieving process is less understood and "growth" may not be a familiar option to them. Still, two of three participants in the NoFGS group did express that they handled their feelings in grief better than they thought they would, and did experience some movement:

> My faith has grown, it is stronger. My self-confidence, because I can handle it better than I thought I could. (When asked about things that will never be the same, the participant could not answer the question. Appeared to be actively coping, and could not respond) (P5, NoFGS).

> (crying) Part of me wants to say everything. I mean it is so different without her...I don't think anything as far as holiday-wise in any respect will -- it will never be the same...I would have to say probably that I've gained in the respect as far as going back to my family situation -- that I feel now I can say what I want to my father without having to worry about this coming back onto my mother or any of that type of conflict (P6, NoFGS).

In the 24 month group, all but one reported that the holidays will never be the same with loss of family rituals and tradition. All but one participant (both FGS and NoFGS groups) reported a similar theme: they had grown more responsible for themselves and for their own lives. This included more independence in terms of letting go of dependence on parents in areas such as emotional or financial, and setting priorities differently. The following passages from the data exemplify this growth:

> Oh, I think responsible about a lot of things. My dad...was usually there to help us. And not that my husband -- we relied on him all the time for things, but...he was easy to have around as far as doing things for us and getting things done, and taking care of certain things. Or to go and ask questions. So as far as being responsible, we've had to take on that for ourselves...he's not here to do it, so we've had to do that now (P7, FGS).

> Not ever being able to call them up, or even visit them. I don't think I'll ever be the same (P8, FGS).

> On my own, yea. I've learned how to save money. I take care of myself. I pay the bills on time. I'm on my own and more responsible (P9, FGS).

> Not that I wanted to...I gotta do a lot of things myself. I can't depend -- I was the baby. I'm spoiled rotten. And my dad, it was a you know, now I'm not it. Whatever I wanted I basically got (P10, NoFGS).

> So yea, you grow up a lot when you lose a parent. Because you don't have that person to fall back on. You can't put things over on them anymore. You know, you can't take your problem and give it to them like you did all your life (laughing)...you're grown up. Figure it out, you know? You have to grow up. And I thought I was really grown up before she died (laughing). You know? I thought I was very grown up (P11, NoFGS).

> Holidays. Those were real important to us...just certain little rituals. And you miss that a lot. Holidays are the hardest...I really think I've even grown some...and I don't know if it's just that I'm more confident ...I don't know, I really don't know why (P12, NoFGS).

The above excerpts lend support to the first two phases of the theory, and perhaps show signs of movement into phase three -- **reformulating and transforming** the loss. However, examples were not as clear pertaining to how the bereaved may have integrated the loss, where they may be asking questions like, (a) what must be done to get on with my life?, (b) how does this loss fit into the rest of my life?, and (c) are there other ways to look at this loss? Schneider (1994) has described "reformulation" as a time of "self-empowerment" when the person begins to focus on his or her own potential, extending self-trust and self-awareness. A renewal of energy may emerge from the grief, resulting in taking risks and discovering things about oneself. Transforming the loss involves in part, even more growth, by accepting this new identity and extending oneself even more by being open to all new experiences. For example, the person may place the loss in a context of growth, having moved out the awareness phase, i.e., the intense feeling stage where the he or she is focused on coping, and may ask (a) how have I grown from this loss? and (b) how has my view of the world changed? The participants in this study were just 1 and 2 years past the loss, and particularly those in the 1 year group appeared to be in a coping phase, beginning to gain some perspective and acceptance on the reality of the loss. Schwartzberg and Janoff-Bulman (1991) examined grief and the search for meaning by adolescents and young adults at 3 years past the death of a parent, and found even at this point in their grief, those that had found a way to "explain" or "understand" the death of a parent did so by holding on to old assumptions and beliefs. Their study did not examine the growth potential of grief, and they concluded with a call for new directions and conceptual paradigms to aid in the understanding about grief. Therefore, with an effort to continue building upon the theory of the transformative potential of grief, further study is suggested, focusing perhaps on persons where time since loss may be 3, 4, even 5 years and beyond.

Overall, the participants in this study seemed to be moving into a stage of redefinition of self, and a realization of what life will be like without the familiar anchor points. They seemed to be almost surprised that they had made it through the last year or two, expressing that they were "doing okay, better than I thought I would be" (P1, 2, 5, 6; 7-12). At the same time and as stated, many observed a sense of feeling stronger and more competent, however, there was still a sense that the detachment from life as it once was and the realization that things will never be the same was still in process, even for those in the 24 month group. The participants appeared to be just moving into the next phase of the theory about "what's possible?" As Schneider has stated, transforming the loss involves the person integrating the emotional, physical, behavioral, cognitive, and spiritual aspects of him/herself in order to gain higher levels of understanding and acceptance of the loss. This holistic, growth-oriented model of the grieving process led to the development of the Response to Loss Inventory (RTL), an instrument where each concept in the model has been operationalized and is being subjected to construct validation as development of it continues (Schneider, Deutsch et al., 1992). The researcher made the decision not to administer this inventory to participants in this study because follow-up work is sometimes necessary. Nonetheless, it would have provided insight in terms of assessing just where the participants are with viewing the loss as impetus for growth. Clearly the RTL Inventory would be useful both in research and clinical settings to continue building upon the transformative potential of grief, and to offer a long term evaluation of outcome for grieving persons.

Malinak, Hoyt and Patterson (1979) conducted a preliminary study about grief reactions of young adults whose mean age was 32.4, and time since loss was 3-20 months in which "favorable growth-oriented aspects" from loss emerged as a theme. All 14 of the participants in their study reported that the loss of a parent was painful, and half stated that they had realized some benefit or experienced growth from the loss. Similar to the findings in the current study, these gains included an increased sense of strength and self-reliance, as well as a greater caring for friends and loved ones, and a "deepening of their appreciation of existence" (p. 1155). In addition, more recent research has been conducted examining the potential growth aspects of bereavement (Calhoun & Tedeschi, 1990; Ulmer, Range, & Smith, 1991) and changes in life meaning following bereavement (Edmonds & Hooker, 1992; Schwartzberg & Janoff-Bulman, 1991). Overall, findings in the current research were supported by these studies, where positive changes were associated with bereavement, such as respondents' description of themselves as stronger, more competent, independent, and better able to face life crises. It appears that further research is needed to examine a person's sense of meaning and purpose in life as a positive outcome of bereavement. Also noteworthy is that not all persons "transform" grief positively. Some may choose to limit their awareness (coping phase), perhaps remaining there for a lifetime (Schneider, 1989).

CHAPTER V. MISPERCEPTIONS CLARIFIED

The researcher has described the misperceptions that exist in the field about useful grief support services (Chapter I). In short, there is documentation that perceptions do not always match what the professionals view as being supportive to the bereaved, and what the bereaved identify as being useful supports (Conway, Hayslip, & Tandy, 1991; Corr & Wass, 1991; Levy & Derby, 1992; Stylianos & Vachon, 1993). It will be recalled that a national study conducted by the National Academy of Science (Osterweis et al., 1984) failed to uncover conclusive evidence of measurable benefits from Hospice bereavement programs. Perhaps such a study was conducted too early in the Hospice movement, as bereavement programming particularly in many of the smaller Hospices has only begun to solidify and demonstrate consistency since the mid-1980s.

The researcher's professional experiences in Hospice as a facilitator within Grief Recovery Seminars provided the opportunity to personally witness "evidence of measurable benefits." However anecdotal evidence does not usually convince funding sources about program effectiveness. Defining program goals and designing effective programming requires evaluation of services. Are current offerings of Hospice grief services adequate and cost effective? Because of the increasing need to justify program expenses, a decision was made to include this "big picture" issue in this dissertation as a precursor to a long-term career goal of conducting bereavement evaluation research within Hospices. Two supplemental data collection techniques were utilized to obtain pertinent data that would lend insight into Hospice programming: interviewing professional grief service providers, and analyzing Hospice bereavement support questionnaires. Results from these analyses can be found in the following sections.

Matching Perceptions

Contrary to the reports in the literature, misperceptions did not exist in this study when comparisons were done between the professional grief service providers and the bereaved. The focal point for comparison was between professionals' and bereaveds' perceptions of useful grief supports. Overall, the professionals' viewpoints matched what the bereaved in this study had reported as helpful grief supports. The following is a summary of matching perceptions.

What Helps People in Their Grief?

All four professionals strongly advocated group support for the bereaved in need. The value of the group setting was described as the educational component of support that offers validation, normalizing of feelings and comfort to the bereaved in knowing they are not alone. Qualifiers were placed on bereaveds' utilization of group support by stating that group work is not for everyone and may not be enough for some people. It was seen by two professionals (E1, E2) as imperative to offer follow-up to the persons in groups, making available the help and the resources for those who do not find what they need in a group. The person with spiritual issues and concerns was provided as an example by three of four professionals (E1, E2, E3) as someone who would need one-on-one processing because such an issue was viewed as a highly personal concern, where shame might be attached for questioning one's faith. Such one-to-one processing was seen as something that could be done with a friend, a counselor, and/or a therapist. The point is that group work is not always appropriate for everyone. The FGS participants, both 13 month and 24 month groups, were previously quoted as saying that the Hospice Grief Recovery Seminar and other support groups were useful in terms of the provision of validation of feelings and identification with other grieving persons, thus perceptions matched (Chapter IV). Those in the NoFGS groups gave the following reasons for not attending the seminar or groups:

> There was none that I knew of. I wasn't even informed that anything was offered...I probably would have tried it...I'm not really into like my sister says, "having people picking your brain..." (P4).
>
> I've thought about it. I'm just not a person that can go and talk about my deep down feelings with a group of people. That's too scary. I've considered it though (P5).
>
> I did talk about the one (Grief Seminar). But since then, yes, I've thought about it, but I still think, ahhh -- I don't think so. I think back then the timing just wasn't right for me. And I'm just not a group person...I thought I might try a support group. I've heard it's a good program. But I felt it was not for me. Maybe the programs like that are very helpful for a lot of people. I think I'm not good as a group person -- sharing feelings in the group. I also think I'd feel isolated, or how can I say this -- so many people who go to these things are people who have lost a mate...not a parent, not a child. I would like to talk to people with the same loss as me (P6).
>
> No. Nope. I was big enough. No, I can do it...I guess I deal with my own things within myself...I just do things myself. You know, it's just much easier to do it that way. Why bring everybody else into it, you know?...Sometimes I have a hard time expressing what I want to say, and within a group, I wouldn't be able to -- I'd figure I'm taking up maybe too much of the time. Maybe somebody else has got something else...more to share that they need that. I just eh, if I need to get away I'll just take a walk out back in the woods...(P10).

One professional (E1) stated that it was particularly useful but not mandatory when the "listener" has processed a similar loss. What is most important, according to all four professionals, is that the bereaved are provided a forum in which to "tell their story" without judgment, to review the relationship with the deceased, and to be able to say farewell. And finally it was the suggestion of one professional (E1) to differentiate between "primary losses" and "secondary losses," the former of which represent the actual death of the person, and the latter representing those losses that are a result of the death, usually transitional issues that can inhibit movement through the grieving process. Those with the need for help in processing secondary losses may need additional, more focused support to "plummet the depths" of their grief, at their own pace. Specific techniques were recommended (E4) to help individuals and families cope as follows: (a) relaxation tapes; music, (b) videos about diseases, treatment options, grief and loss education, (c) humor, (d) aggressive release, and (e) journaling.

In sum, it was the consensus of all four professionals that grief education provides validation and normalizes feelings, which was also expressed by the bereaved who attended the seminars or groups. Groups were seen as most useful, but not for everybody, and sometimes one-on-one counseling may be more helpful depending on the type loss and adjustment issues. There needs to be flexibility in provision of grief support services in the form of groups, and for those desiring long term counseling and therapy. Sometimes both forms of support are needed, where group work is done in conjunction with private counseling (Rognlie, 1989).

Hospice Program Clarity: Existing Services and Future Directions

The reader will once again recall the study completed by the National Academy of Science (Osterweis et al., 1984), where, according to their findings, the crux of the issue within Hospice bereavement services seems to be about clarity in program goals. In an effort to gain clarity, Beresford (1987) reduced the issue to two simple questions:

1. Are the benefits of Hospice bereavement services therapeutic or humanitarian?
2. How does the Hospice insure that the few who are at risk are properly identified?

Following an analysis of the four interview transcripts of the professional grief support providers, a summary was compiled containing overall suggestions for revision in the current 13 month follow-up program in Hospice bereavement, as well as future directions for both Hospice based and community based grief support services.

Hospice Bereavement 13 Month Follow-up: Suggested Revisions

Existing services are functional and programming decisions have been based on that, with continuity in service offerings over the last 5 years. However, there is always room for growth, for improvement. There needs to be flexibility in provision of grief services.

Three of four professionals suggested extending the 13 month follow-up to those who need continued connection. Some bereaved are prematurely "dropped" from the mailings, and lose that sense of connection from Hospice. Others may be at a place where termination of service feels right, but for those who are not, an extension of service should be an option. One suggestion entailed reframing the last "milestone" mailing that goes to grieving individuals and families just after the one year anniversary date of the death of the loved one. Perhaps making it an optional termination would be preferable.

In addition it was suggested that the initial staff assessment visit to bereaved families be offered more frequently and later in the grieving process (it is now offered at 4 weeks past the death). For instance, personal contacts could be offered routinely every 3 months throughout the year, versus just that first time call and visit where a staff member leaves with the message, "call us if you need anything." Grieving persons often do not ask for help. It was also pointed out that the staff person doing the assessment visits would have to have adequate assessment skills to detect those bereaved who are classified "high risk." Of the four professionals interviewed, two believed that the role of bereavement coordinator could be filled by a person with at least a bachelor's level education in human services, and training in the grieving process. All four believed that if a programming decision were made to go beyond assessment services, for example, hiring of an in-house therapist, then at least a Master's degree with clinical training would be mandatory job requirements.

There was a return to the age-old question about whether Hospices should offer community referral/community services or just work toward supporting their own bereaved families. Working within a bereavement team was one suggestion for addressing this issue, where each professional realizes the value of self-care and what his/her limitations are as a care provider. It was suggested that services offered match available staff for provision of such services.

Is there an "interdisciplinary team concept" within Hospice? It may be just that, a concept. Is it a reality? Are Hospice staff persons working as a team? Hospice bereavement services should not be billed as an "after death" service, but rather based on the assumption that grief begins with the diagnosis. It was suggested that Hospice staff positions be interchangeable as much as possible, with equal emphasis placed on every component in Hospice. Currently there continues to be a separation of bereavement services and spiritual care, in which these areas are "over there" and the patient care aspects are "over here." One goal might be to continue to work at integration within Hospice, making a commitment to truly creating an interdisciplinary team approach to patient/family care.

Whatever decisions are made about community outreach, there appears to be a consensus for the need to prioritize offerings, and aim efforts at educating children. This could happen perhaps most efficiently within schools and was viewed by the professionals as a preventative effort. One long range goal would be injecting at an early age the idea that grief is a normal process, a response to a loss, and that it is okay to feel, okay to cry, and to talk about those feelings. Such programs would not only teach children how to process feelings of grief, but such a focus would begin to bring into the picture the parents and families, as well as the teachers. This systemic perspective has another long range goal of making a societal level change with lasting affects.

Future Directions

All four professionals envisioned a "Grief Center" -- two supported a hospital based center and two supported a Hospice based center. This "Grief Center" would be a comprehensive center, catering to the needs of both Hospice families, if Hospice based, and community service referrals. These services would be offered by a team of professionals trained to work with the grieving people, and they in turn would continue empowering a strong core of interested volunteers, teaching them about peer support. In addition, outreach would continue in terms of empowering church congregations by training members about how to help a grieving friend. Empowering other professionals by continuing education efforts about the grieving process would also be a component of the center. In-house counseling and therapy would be included as part of the services, as well. And finally, as discussed previously, programming in the schools would permit grief education to be delivered directly to children, injecting at an early age the idea that feelings are okay, and grief is a normal process. Ongoing children's grief support groups within schools, where parents are involved, would also be designed and implemented by staff at the center. These ideas were presented to the researcher by all four professionals envisioning the ideal for provision of grief services. Having a "Grief Center" would consolidate current grief services in communities where redundancy and overlap sometimes occurs. It was speculated that offering services under just one roof would be less confusing to grieving people as well.

In sum, the perceptions about just what it is that helps people in their grief seemed congruent between professionals and bereaved persons. Professionals in one community believed that current Hospice bereavement services are adequate, as demonstrated by continuity over time, however, the consensus about revision within specific areas of bereavement programming may indicate the need for program evaluation. Future directions implied the need to consolidate grief support services, perhaps by creating a community grief center. The following section offers further evidence that Hospice bereavement follow-up services are effective.

Documentary Analysis: Bereavement Support Questionnaire

Following the death of a loved one, the Hospice bereavement coordinator routinely contacts surviving family members, explaining available bereavement services. These support services include in part, placement on a monthly mailing list whereby letters and accompanying articles containing information about the grieving process are mailed to the bereaved. In addition, during the initial telephone contact an in-home assessment visit is offered and available bereavement services are explained, such as the Grief Recovery Seminar or the annual Memorial Service. This follow-up program continues for 13 months after the loved one has died. At the termination of services, the bereaved are asked to complete a "Bereavement Support Questionnaire (Appendix F). Souter and Moore (1990) completed an evaluation of a bereavement support program for survivors of cancer deaths and found that the program was beneficial to survivors and very much appreciated. Similar procedures were followed for this analysis.

The Hospice supporting this research has seen a steady increase in service from 1987 to 1992, with an average of 181 patient/family units served annually. Following data collection for this study, an analysis was completed for the 205 questionnaires returned over this 6 year period, showing a response rate of 16.5 percent. Because the response rate was so low, a decision was made to include all questionnaires in the analysis, regardless of age, type of loss, or time since death. Results from this analysis follow.

Monthly Mailings: Letters and Articles

The first section of the questionnaire asked the bereaved to evaluate the monthly mailings and articles. Participants were asked about the usefulness of the letters and articles following the death of a family member, and whether this information helped them to cope with their loss. Respondents overwhelmingly indicated that such material was helpful. A summary of responses can be found in Table 4. Some respondents chose not to answer certain items, thus a code of 0 was given for missing data (M.D.).

Table 4: Bereavement Support Questionnaire: Evaluation of Hospice Monthly Letters and Articles

Usefulness of Letters/Articles	Responses	Assistance with Coping	Responses
Very Helpful	166	A Great Deal	132
Somewhat Helpful	35	Somewhat	61
Not Very Helpful	2	Very Little	2
M.D.	2	M.D.	10
TOTALS	205	TOTALS	205

The next section of the questionnaire asked respondents to identify any mailings that may have been especially helpful. Categories were developed from the responses (M.D.=105) and can be seen in Table 5.

Table 5: Bereavement Support Questionnaire: Specific Hospice Mailings Identified as Helpful

Mailing	Responses
All Mailings Helpful	61
Feelings	10
Grief Experience	9
Anniversary Letters /Birthday Cards	7
Getting Through Holidays	7
"Like hearing from a friend"	6
M.D.	105
TOTALS	205

Few responded to the question about whether any of the mailings were nonhelpful (M.D.=151). Those who did reply simply gave a "no" and only four gave specific reasons about why they disliked the mailings. Only one from that group stated that the mailings "reminded them of the death." Overall it appears that the bereaved found the monthly mailings helpful.

Selected Hospice Services

The next section of the questionnaire asked about the usefulness of selected Hospice services, using a Likert-type scale to obtain this information (5=outstanding; 1=poor). Missing data were coded in the same manner when this was possible, i.e., the questionnaire composition made missing data difficult to assess, as not all respondents utilized all services. Among those who did respond, greater numbers reported that the monthly letters and monthly articles were "very helpful," with the next highest response reported as "outstanding" (Table 6). All of the other services included in this section of the questionnaire were rated most often as "outstanding," with the exception of volunteer contact in which "very helpful" and "outstanding" were reported equally.

Inquiry about Additional Services

The final sections of the questionnaire inquired whether bereaved wished to receive additional services, or if they would like a call or a visit. For those who responded (N=141), 131 did not wish to receive any additional services, and only 10 wanted to continue receiving the mailings. As far as receiving a phone call or visit (N=164), 127 responded no, 32 indicated they would like another visit, and 5 said they would like to receive a phone call. Overall, it appears that these bereaved were at a point in their grieving process after the 13 month follow-up where additional services from Hospice were not desired. Most gave a positive evaluation, and expressed no need for further service.

Table 6: Bereavement Support Questionnaire: Usefulness of Selected Hospice Services

	Response Scale					
Type of Service	Out-standing	Very Helpful	Average	Somewhat Helpful	Poor	M.D.
Monthly Letters (N=172)	65	73	32	2	0	33
Monthly Articles (N=163)	59	71	29	4	0	42
Other Printed Material (N=118)	58	42	15	2	1	n/a*
Grief Recovery Seminar (N=65)	34	24	6	1	0	n/a*
Memorial Service (N=45)	24	14	5	0	2	n/a*
Staff Visit (N=90)	60	25	4	1	0	n/a*
Volunteer Contact (N=65)	28	28	5	3	1	n/a*

*Bereaved did not attend/receive this service.

Written Comments by the Bereaved

Many respondents provided written statements about the usefulness of Hospice services, some of which are quoted as follows: "I have nothing but praise for Hospice of Muskegon." "Sometimes certain things came to mind, I thought I was crazy. But after reading your letters I understood those things were normal." "They reminded me that how I feel was normal, that time heals, and pain will fade." "I wish the article on how to write a journal would have come sooner." "The very fact that you didn't forget me on my birthday, on Bud's birthday, and on our anniversary and Christmas, and today, it's just one year." "The timing was perfect! The letters helped me understand my grief process and support it." "It was helpful to know that the feelings I was having were not unusual. The programs and books were very informative." "When I started receiving things from Hospice, I found them very hard to read and they just made me feel uncomfortable. I felt I had to grieve in my own way, in my own time, and I had to do it -- nobody could help me." "I knew your letters helped me a great deal this past year, but I think I'm just beginning to realize how much." There were many such written comments by the bereaved, most of which were in support of the follow-up services at Hospice. Those responding negatively provide clues for service revision as well.

Summary of Questionnaire Results

In summary, it appears that the majority of those responding to the questionnaire did find Hospice bereavement support services useful following the death of a family member. A pattern of responses developed when respondents were asked to rate the usefulness of specific services, with the majority of respondents rating them as "outstanding" or "very helpful," and only a small number reporting "poor." Most written comments provided by the bereaved offered praise for the program services.

Comparing Questionnaire Results to Participants' Responses

One major objective of this study was to explore formal and informal sources of support for grieving persons, in part by asking them, "What helped you in your grief?" It seems that the responses of the bereaved in this study parallel those responses of the Hospice bereaved families who evaluated bereavement services over the past 6 years. For this comparison, the researcher has decided to focus primarily on the Hospice

Grief Recovery Seminar, since the majority of the FGS groups in this study described this particular Hospice service as helpful. A brief discussion will also follow about the Hospice monthly mailings.

Hospice grief recovery seminar. The analysis of the questionnaires revealed that those who took the Hospice Grief Recovery Seminar found it outstanding or very helpful to them as a source of formal support. The bereaved who took the Hospice Grief Recovery Seminar in this study (in the 13 and 24 month FGS groups, 5 of 6 attended) also reported that it was very helpful. It should be noted that the ongoing bimonthly support group that Hospice currently offers was not being offered during the time these evaluations were completed. It is a new service at this Hospice.

Hospice monthly mailings. Families utilizing Hospice services are automatically included in bereavement follow-up services, a part of which involves receiving the monthly letters and articles. These mailings are a major part of that follow-up support, regardless of whether the bereaved seek formal supports. Therefore, it was decided not to count the mailings as formal support, because all Hospice families receive them unless they indicate otherwise, and very few do so. The researcher has decided to include the summary results about the monthly mailings, because over half of the questionnaire itself focuses on evaluation of these mailings. As noted previously, the bereaved overwhelmingly reported that these mailings were useful to them during their grieving process. In this study, when asked what helped them grieve, one-half, i.e., three of six of the FGS participants who had received the mailings mentioned them as helpful. This was not a direct question during the in-depth interviews, however, findings were consistent with the questionnaire results in that the bereaved seem to find the monthly mailings very useful in their grief.

Comparing Questionnaire Results to Professionals' Responses

Another major objective of this study was to explore potential misperceptions between the professionals and the bereaved about just what constitutes helpful grief support services. Part of this exploration involved asking professionals about programming goals and future directions in Hospice bereavement services. Overall, the professional group indicated that the Hospice 13 month follow-up services are effective, but need revision. Contrawise, the bereaved responding to the questionnaires seemed satisfied with the program services, and the majority stated that they did not wish to receive any further services at the end of the first year. The bereaveds' evaluation supported the current Hospice follow-up program.

One particular area where revision appears to be needed is around the issue of termination of services. The professional group seemed to be concerned with premature "dropping" of the bereaved after the first year following the death of a loved one. This problem could be addressed by offering options to the bereaved to continue with further service if they so desired. As it is, a closure letter is sent referring to a "major milestone" having been reached. Perhaps some bereaved persons are only just beginning to grieve after the first year, and such a letter would be discounting to their feelings. There is certainly room for growth, especially around the content and appropriateness of the monthly mailings. This concern, however, did not surface in the analysis of the questionnaires.

Summarizing the Comparisons

The general research question in this study was, "What helps people in their grief?" The researcher chose to compare the responses of the bereaved in the study to those bereaved reporting via the questionnaires about what helped them grieve. In addition, the professional group responses were compared to the bereaved reporting via the questionnaires, to explore and clarify misperceptions about what constitutes helpful grief support. The researcher included analysis of the questionnaires as a way to further explore the general research question with more than just the majority findings from the in-depth interviews. Comparing the interview data with the results from the questionnaires further lends credibility (validity) and transferability (generalizability) to the study. Overall, bereaved persons in this study and those responding via questionnaire reported that Hospice bereavement services were helpful to them in their grief. Although professional participants had some suggestions for revision, as outlined in the previous section, support for services was also evident.

CHAPTER VI. SUMMARY AND CONCLUSIONS

This chapter contains a summary of this study, recommendations for future research, suggestions for improvement within Hospice bereavement programs, refining of conceptual definitions, and concluding remarks.

Summary

This qualitative study was designed to explore the young adult's grief experience following the death of a parent to cancer, with a focus on discovering what constituted helpful supports for the bereaved in this stage of the life cycle. The primary purpose for conducting this study was to begin to assess "what helps people grieve?" with specific concerns for what helps young adult's grieve. A second purpose was to explore the transformative potential of grief (Schneider, 1989). An attempt was made to learn more about the formal and informal sources of support that the bereaved identify as helpful to them in their grief process, and to clarify potential misperceptions about provision of grief support services.

Data collection consisted of in-depth, semi-structured interviews of 12 adults, all caucasian, 11 females and 1 male, ranging in age from 23 to 43 years old. The average age was 34 years. Participants were recruited from a Hospice database in Western Michigan. Interviews were completed between September 14 and October 29, 1993. Time since death was varied at 13 and 24 month intervals; within two groups of six participants, three had utilized formal grief support services, three had not. As a supplemental data collection technique, four professionals involved in the provision of grief support services were also interviewed as a way to explore what is/is not being reinforced between gatekeepers and the bereaved in terms of grief support services. Documentary analysis was also used as a supplemental data collection technique by tabulating responses for bereavement support questionnaires collected by the Hospice providing support for this study. This analysis was completed in part, as a way to encourage this Hospice to utilize valuable, existing data that could prove useful to them in planning and developing future bereavement support services.

Major findings revealed insight about the grieving experiences of young adults. All of the participants in the 13 month group reported that they were actively grieving, while lingering sadness continued for those in the 24 month group. Since the majority of participants were seemingly in the coping stages of grief, assessing the growth potential from loss of a parent was difficult. It appeared that more time was needed to fully reflect on how one may have grown or gained from such a loss. In addition, formal support assessed as useful was primarily in the form of support groups or seminars. Themes that emerged from the data were the role of friendship in the lives of grieving young adults, and other developmental loss issues unique to young adults, such as the changing relationship with a parent as one matures and the loss of opportunities such as witnessing the birth of a child. Such themes imply special needs for resolution of loss at this stage in life. Future research directions are discussed in the next section.

Contributions to the Theory of the Transformative Potential of Grief

By utilizing an inductive approach in the continuing effort to build upon the theory of the transformative potential of grief, four hypotheses emerged from the data. A discussion about their relationship to the theory and suggestions for future research follows.

Hypotheses Generated from the Data

1. **The gradual physical deterioration of the parent parallels acceptance of the reality that the parent is going to die.** A theme emerged about diagnosis, illness, and treatment as they related to one's grief experiences. Most notably, it appeared that grief started with the diagnosis of the cancer. Participants and their families witnessed the limitations that disease gradually introduced into their lives. A once vibrant, healthy, and energetic parent is now bedridden, unable to perform daily self-care activities. Perhaps the parent is unable to communicate due to the effects of the disease. These related losses, or "secondary losses" as described by one professional (E1), appeared to be very real, occurring before the actual death of the parent. According to another professional (E3), bereavement services have been typically billed as "after death" services within Hospice. Perhaps the Hospice team needs to be aware of the deep sense of loss a family member may be feeling before a patient actually dies. The Hospice team, particularly the nurses and social workers, need to have knowledge of the grieving process, implying that Hospice truly does function as an interdisciplinary team. In turn, bereavement coordinators may be able to visit patients and family members before a death occurs, offering grief support and education prior to death. This sense of loss that family members may be experiencing is often referred to as "anticipatory grief" and according to Buckingham (1983) "grief over the anticipated loss of a loved one may begin as soon as the diagnosis is confirmed and prognosis revealed" (p. 167-68). In terms of theory building, this hypothesis clearly implies that the young adult would be actively grieving (phase one), coping with the reality of the impending loss of the parent. It appears that grief begins at the time of diagnosis and

that the survivors gradually adjust to the reality of losing the parent during the course of the illness. These concerns could be addressed in future evaluation research of Hospice services that involve both the patient and survivors.

2. **Grief education promotes healing.** Persons who utilized formal grief support services seemed to understand the intense feelings of grief, particularly when comparing those in the 13 month FGS to those in the NoFGS. For example, in the NoFGS group, those still surprised by their sharp feelings at one year were also somewhat uncertain about what the researcher meant by "growth" from grief. If there is no knowledge about the grief process, such as the concept of validation or normalizing feelings, then it may be less likely that "growth from grief" would be understood as an option, as the person may be feeling confused about the range of emotional reactions that occurs during grief. Perhaps grief education facilitates movement through the grieving process. Future research suggestions include continued evaluation studies of the effectiveness of support groups, and determinants of an individual's decision to seek support (Levy & Derby, 1992). In addition, interviewing participants at 3 to 5 years and beyond their loss may provide greater insight about the growth potential from grief.

3. **Following the loss of a parent, friendship provides support for the grieving young adult, especially during the first year of bereavement.** Of the participants, all six in the 13 month group and three in the 24 month group expressed the value of friendship as an informal grief support. In cases where family support may be lacking, or if a particular coping style of a family discourages open expression of feelings, then it may be that friendship provides a nonjudgmental forum for expression of feelings.

Especially noteworthy was the finding that it was preferable for some to share only with "select" friends who had also experienced a similar loss. Death of a parent seemingly robs one of a sense of security and forces a facing one's own mortality (Kennedy, 1991; Schneider, 1994). Since certain adjustment issues may occur prematurely or "off time" for the young adult, friends who have not experienced similar losses may be uncomfortable listening to the grieving friend (LaGrand, 1985). Stylianos and Vachon (1993) describe the support of family and friends as a "naturally occurring intervention," if it is done sensitively:

> Family and friends should be encouraged to allow the bereaved to express his or her feelings rather than shutting them off in attempts to avoid the helper's own feelings of impotence or insecurity, which arise if the helper feels unable to act, help, or "do something" to make the bereaved person well...Potential helpers might be assisted to gain insight into how their own grief, needs, and desires might cause them to become too invested in the victim's recovery...they might be advised to listen to the bereaved without feeling obliged to make comments or offer advice (p. 406).

In terms of the developing theory, it appears that supportive friendships could facilitate growth from grief. Suggestions for research include exploring the effects of bereavement at different developmental/life cycle stages, particularly for those in the young adult stage, and the role of friendship as an informal grief support for the grieving young adult (Tokuno, 1983; 1986).

4. **Family support promotes healing.** In light of the fact that five of six participants in the 24 month group, regardless of whether formal support was sought, stated that husband/boyfriend and/or children were supportive to them, it would seem feasible to investigate which family variables assist in grief recovery. Initial data analysis in this study suggested that open communication promotes movement through grief, however, the pattern that emerged in the first three participants started

and ended there. No commonalities or majority findings emerged about how families might be supportive to each other beyond mention of a significant other. In fact, some of the research reviewed suggests that bereavement may have a detrimental effect on and cause additional strain within family and/or marital functioning (Guttman, 1991; Lavee, McCubbin, & Olson, 1987; Vess, Moreland, & Schwebel, 1985). Future research about how family members cope with bereavement might be conducted utilizing family ecology, family development, family stress and crises, and/or family communication theories. For example, it would be of interest to examine family coping strategies, e.g., open or closed communication and their relationship to healing. Clearly movement into phase three of the transformative theory, "what is possible?" could be facilitated or inhibited by family members, all of whom grieve uniquely.

In sum, the hypotheses that emerged from the data will serve as useful guides for further inquiry into (a) the young adult's grief experience following the loss of a parent during this stage of development, (b) identification and development of formal grief support services for the young adult following loss of a parent, (c) the importance of friendship as a source of informal support for bereaved young adults, and (d) family as a source of support for bereaved young adults.

Additional Research Ideas

Suggestions from previous researchers were incorporated into the current study by including in the interviews questions in the following areas (as recommended by Malinak et al., 1979; and Moss & Moss, 1983): (a) early and recent parent-child relationships, (b) the effects of death on the family system, (c) changes in relationship with parent just prior to death, (d) loss of a mother versus loss of a father (e) social supports and the life situation of the participant (i.e., did they live with the parent), and (f) personality of the parent. Inclusion of these recommended content areas did not reveal majority findings or produce common themes in the current study. However, suggestions for future research include the effects of death on the family system, and particularly how families may or may not assist one another in the grieving process.

Because demographic statistics indicate an increase in the frequency of divorce throughout most of the 20th century (Lamanna & Riedmann, 1994), future studies might address how death of a parent influences adult development when the parents are divorced. This situation could further complicate the adult child's grieving process. An increasing number of adult children will be confronting this reality in the future, especially if the current divorce rate remains stable.

Lastly, although it was not a majority finding, some of the participants in this study spoke about the importance of their faith in God and how this helped them in their grief. Some spoke of faith as their saving grace, feeling that it was the most important support that helped them to endure the grief. Future research could address the spiritual aspects of grieving both in terms of support for the bereaved and training issues for the clergy who are often called upon to provide support services.

Suggestions for revision within Hospice bereavement programs were also provided, with a recommendation that evaluation studies be conducted to examine the effectiveness of group support, and the determinants of the decision to seek support. As a result of the review of literature, other suggestions for future research became evident in areas related to this study, such as gender differences and grief reactions, the effects of multiple loss on grief adjustment, and examination of a person's sense of meaning and purpose in life as a positive outcome of bereavement.

A return to the data in search for negative instances occurred repeatedly. The decision was made to discard a hypothesis if three or more instances could be found that negated it. This search did not produce examples that may have warranted discarding of any of these emerging hypotheses. Ideally, an independent reviewer could also be asked to search for such instances, a common practice in qualitative methodology. The researcher chose not to enlist an independent reader for the scope of the dissertation, as a thorough search for negative instances was done both during analysis and while writing the content. It is recommended that the hypotheses be utilized as guidelines for future inquiry in the area of parent loss and young adult development, as well as in evaluation of Hospice bereavement services.

Suggestions for Hospice Bereavement Services

Recommendations emerged about clarity in program goals and development of effective grief support services with Hospices:

1. To extend the 13 month follow-up for those bereaved who indicate that further service is desired, versus automatic termination at a specified point.

2. To offer more frequent follow-up in the form of personal contacts, beyond the initial staff assessment visit or phone call.

3. To insure high risk bereaved are recognized as such, specify appropriate training for Hospice bereavement staff, differentiating between assessment skills and therapeutic skills, or offering a "balm" versus an intervention.

4. Increase bereavement staff to service ratio as decisions are made to expand services. Exercise self-care and recognize limitations as a care provider.

5. Work at integration within Hospice making a commitment to truly creating and maintaining an interdisciplinary team approach to patient and family care.

6. Prioritize community outreach efforts, making children's bereavement services high on the list.

7. Ideally, work toward the vision of a comprehensive "Grief Center."

Such recommendations are directed toward professionals working within Hospice bereavement services, as well as policymakers, therapists, clergy, social workers, nurses, and other professional caregivers involved in the care of the dying and the bereaved. It was previously suggested and subsequently confirmed that evaluation of bereavement program effectiveness is needed within Hospices.

Reframing Concepts

Further development of key concepts occurred which aided in refining the meaning of formal and informal support and the value of such supports for bereaved young adults. The concepts of grief and loss in the context of young adult development emerged as a theme, alerting researchers and those who interface with bereaved young adults that loss of a parent at this stage in the life cycle may mean more than the devastation of the loss itself, presenting adjustment issues, recognized as "secondary losses" or "opportunities lost," e.g., one's child never knowing and loving a grandparent.

In addition, insights about the concept of transformative potential were gained, confirming that time since loss plays an important role in assessing the growth potential of grief. The participants in this study were approximately 1 and 2 years past the death of a parent, with the majority of them actively grieving and coping with the reality of the loss. Some showed movement into the third phase of grief as outlined by Schneider (1984) in the theory, however, examples of transformative growth did not surface in the data for persons at the 1 and 2 year points past a major loss. Future studies examining the concept of transformative potential need to consider time since loss as an important variable and include participants who are 3, 4, and 5 years past the loss. A longitudinal study design would be useful in which researchers and/or therapists repeatedly administer the RTL Inventory (Schneider, Deutsch et al., 1992) to clients within a specified age group. It might also be useful to include in such a design persons who have and have not utilized formal grief support services.

The researcher has speculated about why there was a lack of validation in the data for the third phase of Schneider's (1984) theory. Some of these reasons are:

1. Perhaps grief is not a transformative process. For some people, perhaps coping with the loss involves denying it or avoiding it for self-protection. Whether consciously or unconsciously the choice may be to remain in a coping stage for as long as possible. Denial does play an important role in coping with grief, offering protection when reality is overwhelming. Remaining in this stage, however, clearly inhibits movement into the other phases of grieving, such as reformulation and transformation.

2. "Growth" from grief may mean different things to different people. It may be a cultural bias to assume that one must "work through" certain stages of the grief process. Certain people may not ascribe to the "grief work hypothesis" (Stroebe, 1993). There are perceptual and cultural definitions implied when asking a grieving person about "growth" from their grief. The young adults in this study may not grow from their loss experiences in the way it was conceptually defined as "transformative potential."

3. Hospices utilize an adaptation or coping model of grief that theoretically empowers the bereaved to utilize their own resources to accept and cope with a loss. A risk assessment is completed on bereaved persons and if one is at high risk, an intervention or plan of follow-up care is completed. For example, those who cope by avoidance may need help in confronting and adjusting to the loss, while those who may be overwhelmed are encouraged to get away from their grief for awhile. The basis for use of this approach, as reported by Parkes (1993), is that "the right help given to the right people at the right time can reduce physical and mental symptoms and improve the quality of life before and after bereavement" (p. 99). What is neglected here is the positive side of grief, i.e, "What is possible?" or Schneider's third phase of the transformative theory. The data in this study, however, would validate this "preventive intervention" model where those who are at risk receive appropriate counseling and support. Therefore, although the data did not fully validate Schneider's three phase theory, they do support other existing models that would be useful in the development of grief support services.

4. Schneider, Deutsch et al. (1992) suggested that the RTL Inventory would be useful as a research tool for bereaveds' risk assessment and

growth potential from loss, as well as for offering clinical assistance to therapists as a long term evaluation of outcome for grieving persons. It became evident that greater insight could have been gained had the researcher utilized the RTL Inventory as a way to assess the growth potential from loss for the bereaved in this study. In future studies, an interviewer/researcher could ask more questions pertaining to the third phase of the theory that addresses the existential nadir of a grieving person. One could study the "Awareness" (coping) section of the current RTL Inventory and generate questions about existential issues. It should be noted that the participants in this study were interviewed just one time, thus it was difficult to ask certain indepth, probing sorts of questions without the safety to explore the answers. In addition, due to geographic distance, the researcher was not available for ongoing follow-up meetings with participants had that need arisen. A future study could address these issues by incorporating into the study design two interviews with each participant. More time together might allow for a greater sense of rapport to develop between the researcher and the participants. Follow-up work could be done more readily if the researcher's geographic location was near the research site. Living and working in a community where one has had the opportunity to network with other professional people, especially clinicians who work with the bereaved, would indeed be an asset to the researcher. One could be more certain about making referrals for participants should such a need arise.

5. Finally, this study explored the grief experiences of young adults within specific age parameters. Perhaps lack of support for phase three of the theory is embedded within the developmental or life cycle issues of young adults, i.e, it would seem that loss of a parent necessitates

movement into self-reliance. Some of the participants in this study reported that they felt more confident and more mature in terms of assuming adult responsibilities for themselves and their families. Yet most did not discuss existential issues such as changes in the meaning of life or a renewed focus on possibilities versus limitations. Perhaps the age of or stage in life of the participants reflects their lack of concern for or unfamiliarity with the transformative potential. Their focus may be more on attainment of age-appropriate tasks such as establishing relationships, attending to career goals, and meeting the needs within the family. One wonders about the responses that would come from an older sample, e.g., mid 50s to mid 60s, when asked about growth from losses. Such a group may be in a more reflective state, approaching retirement and encountering many different types of losses. Thus, age may influence one's ability to transform losses.

In sum, while speculating about the reasons why the third phase of the theory was not validated by the data more questions emerged: (a) Is grief a transformative process? (b) What is meant by "growth from grief?" Are perceptual and cultural biases inherent in the assumption that one must "grow from" or "work through" grief? (c) Does the familiar coping model (often used by Hospice bereavement programs) overlook the positive side of grief? Are current grief support services empowering the bereaved to "transform" loss, by considering "what is possible?" (d) In the context of the interview design, can researchers really safely address the existential, indepth questions that may open up even more issues for the bereaved? Is this ethical? (e) Does age influence one's ability to transform loss?

In spite of the questions that emerged, further clarification was obtained in defining the concept of transformative potential and building upon the transformative theory of grief. It appears that there are ample opportunities and ideas for future studies as the researcher's long term career goals will involve bereavement evaluation research and further testing and refinement of the RTL Inventory.

Concluding Remarks

It is because participants allowed the researcher to enter their world, relying on words and nuances in expression as primary data, that concepts and themes emerged and theory was further grounded. A select group of grieving young adults have assisted in contributing to the knowledge base by providing detailed descriptions about what grief feels like and what helps or does not help following the death of a parent. Objectives were met, so that the researcher now possesses not only a deeper understanding about the young adult's experiences of grief and an idea of what constitutes useful supports, but also greater clarity about bereavement program development within Hospice. Themes emerged about anticipatory grief, the support of friendship and developmental loss issues unique to young adults. For the researcher, whose current age is the average age of participants in this study, greater insights were gained about the special needs of the young adult who loses a parent. In particular, that loss of a parent can mean loss of a sense of safety, loss of opportunity, and loss of identity:

> The dying and death of a parent trigger a process of initiation, sometimes one that is long overdue. In the basic pattern that applies to all initiations, we feel tortured. We die over and over again as we have to let go of old beliefs, structures, and ways of being. We die to who we were...the death of a parent, in true initiatory fashion, shakes up the very foundations of our lives. Daily routines are disrupted, assumptions about life and death jolted, values challenged (Kennedy, 1991, p. 55-56).

Conducting interviews with same age bereaved was truly a profound experience both personally and professionally. With these concluding thoughts, the researcher as the "research instrument" would like to change roles and express in the first person how completing the interviews affected her. On a personal level, I was deeply moved by the articulation of thoughts and the heartfelt expression of feeling that was displayed so openly by the participants. This was particularly true because as the researcher/interviewer, I was only part of their lives for the duration of the interview. Listening to their stories caused a return to the pain of my own grief just after my father's death. At times it was difficult to remain in the role of researcher because I felt more like a comrade. As they shared their experiences, many commented that unlike most people, it was easy to talk about their grief with me, and that they welcomed the opportunity to share their stories with someone who understands. Such disclosure creates a bond that is special indeed. There need not be a history, for the common bond of losing a loved one provides a forum for trust. I felt privileged to be a part of their journey.

On a professional level, the interviews helped to validate my hunches about the need to continue educating society about grief. The urge to educate occurred during an interview every time one of the participants seemingly felt shame about and apologized for crying and showing emotion. I am even more motivated to strive for the long term goals stated within this study, continuing with the development of effective grief support services and educating society about grief as a normal reaction to loss versus something to overcome. I am also more aware of the developmental issues for young people beyond my own experience, with a deeper understanding of how losses may affect one's ability to move through the stages of living.

Losing a parent in one's 30s is different than losing a parent in one's 50s. Future research needs to include an examination of bereavement reactions at different developmental/life cycle stages.

Losing a parent may thrust a young person into an awareness of his or her own mortality that triggers a questioning of the very core of one's being. Schneider (1994) examines grief and loss by weaving together a developmental model and the transformative theory of grief; the effects of loss and the potential for growth are examined at every stage in the life cycle. Such a base includes a detailed description of the young adult's adjustment process, where a questioning of the value of old assumptions occurs, and new, more realistic assumptions about living emerge. Part of the process of healing involves accepting the reality of what is lost, and the need to rebuild what is left in a way that is meaningful. Schneider views loss and grief as universal experiences and, potentially, our most frequent path toward transformation and growth:

> When we are grieving, what is the catalyst that leads us to personal growth and transformation rather than to depression and stagnation? Obviously, having someone or something to believe in is a critical ingredient that holds us on the growth side of grief's chasm, even if only by the skin of our teeth. This someone or something, however, isn't just anyone or anything. Some people step on our fingers and cause us to lose our hold and our hope. Even well-intentioned friends and therapists can do that. Others would bring out in us strengths we didn't know we had. Who is it we find helpful? What is it they do or don't do? What are the factors which seem to help us find a transformative path through our grief? (1994).*

This study was, in part, designed to address these questions and to generate new ones, as a way to contribute to the body of knowledge that exists about the grieving process, and because of a scholarly commitment to the ever-evolving process of theory building, empirical research, and practice.

(* See next page).

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* The in press manuscript was used throughout the preparation of this dissertation. However, the actual book release is one day following the deadline date for this dissertation. The year is provided, but not the actual page numbers for this passage from the text.

APPENDICES

APPENDIX A

Explanation of Hospice Regulation Procedures in Michigan

Hospice is no longer a "movement" but rather an ongoing aspect of the health care system (Hayslip & Leon, 1992). Attention of the industry has shifted from starting programs to regulating them (Blum & Robbins, 1985, cited in Hayslip & Leon, p. 34). There are three distinct but related terms that will help one to understand the importance of regulation: licensure, certification, and accreditation. **Licensure** refers to "a legal process that ensures at least a minimum standard of quality. The requirements are established by a designated government agency, typically an aspect of the state health department" (Hayslip & Leon, p. 34). There are 15 states that have specific Hospice licensure laws and the remaining states operate under licensure categories covering hospitals, home health agencies, or nursing homes (Tehan, 1985, cited in Hayslip & Leon). In 1978, Michigan established specific Hospice licensure laws which were amended in 1984 (B. Kowalski, Hospice staff, personal communication, March 31, 1993). All public and most private insurance companies do require service providers to be licensed in order to be eligible for reimbursement.

The second issue of regulation, **certification**, is "a process that allows a provider to be reimbursed for rendered services under the Medicare and Medicaid health insurance programs" (Hayslip & Leon, 1992, p. 34). To become a certified Hospice and therefore to qualify for reimbursement under Medicare, the Hospice program must meet requirements established by the Health Care Financing Administration (HCFA) and the state level agency that oversees Medicare and Medicaid programs (Hayslip & Leon, 1992).

The third issue of regulation, accreditation is "a voluntary process established by the industry as a whole...it involves the comparison of service providers against established standards...the standards are established by professionals within the industry" (Hayslip & Leon, p. 35). As the Hospice movement grew from a philosophy of care to an ongoing part of the health care system, The National Hospice Organization (NHO), established in 1977, sought public recognition and public and private funding for hospice services. Issues of quality of care also arose across insurance providers, and the NHO was instrumental in developing guiding principles underlying Hospice care. The Medicare Hospice benefit became law in August of 1982 and in 1986 legislation made the benefit permanent. Bereavement services were not included as part of this Medicare benefit for reimbursement, yet provision of such services was still required if a Hospice wanted to become licensed. This is still the case presently (M. Gorman, Hospice Executive Director, personal communication, March 4, 1993).

APPENDIX B

Series of Three Letters Sent to Participants

Letter One (on Hospice Letterhead)

Date

Dear (Person's Name):

Hello. I am a graduate student in the Department of Family and Child Ecology at Michigan State University. I was formerly the Bereavement Coordinator at Hospice of Muskegon County. The Executive Director, Mary Anne Gorman, has given me permission to conduct research through this agency. I have an interest in understanding what helps grieving people. I have this interest, in part, because I know what grief is like. My father died of cancer in 1986. From my own experience I have some ideas about what helps. I would like to see what others have found.

I am writing to you to invite you to be a participant in a study that I am doing as part of the academic requirements for completion of my doctoral degree. I will be conducting interviews with young adults who meet the following criteria: (1) are between the ages of 25 and 40 years old, (2) have had a parent die of cancer or a long term illness, either one year or two years ago. I am especially interested in learning about those things that have or have not helped you in your healing process.

Since it appears that you meet the criterion, would you be willing to help me gain information about the grieving process? Those who have experienced grief can provide the most useful information about grief support. My goal is to help organizations like Hospice in the development of their grief support services. I want to know what helped you and what did not.

I will be calling you in about 2 weeks to see if you would like to know more about the study. At that time, I will give you details, and answer any questions you might have. Of course, I completely understand if participation in the study is something you just feel you cannot do at this time. I will be in touch.

(continued on next page)

Thank you so much for taking the time to consider this. I look forward to talking with you soon.

Sincerely,

Kelly Rhoades, M.A.
Doctoral Candidate
Michigan State University

Letter Two (on Hospice Letterhead)

Date

Dear (Person's Name):

Hello again! I really enjoyed talking with you on the phone today. I am so glad you would like to help me with this study! I do hope what I have told you so far, over the phone, has given you an accurate idea about what to expect. Remember, to complete the enclosed consent form. You may give it to me at the start of our interview on

____

Thanks again for your willingness to be a part of this study. Ultimately, your participation will help us learn more about the grieving process and grief support. I look forward to meeting you in person.

Sincerely,

Kelly Rhoades
Doctoral Candidate
Michigan State University

<u>Letter Three</u> (On Hospice Letterhead)

Date

Dear (Person's Name):

I would like to thank you for your willingness to be a part of my research study about grief support. I enjoyed the time we spent together and I learned so much from you. I feel privileged to have had the opportunity to meet, and I will send you summary results of this study if you are interested. Just check the box below indicating your preference.

I know it isn't always easy to share with others the pain of grief, especially with those you don't know very well. But I was touched by your openness and honesty, and I want to reassure you that nothing you shared will be identifiable in a way specifically attributable to you. Your contribution to this study has already helped in the development of adequate grief supports. I hope you found it worthwhile.

Remember, if you have any questions or concerns in this time following our interview, you may call Connie at Hospice of Muskegon (728-3442), and your message will be forwarded to me.

Sincerely,

Kelly Rhoades
Doctoral Candidate
Michigan State University

==

YES ___ NO ___ Please send me results of this study.
My name and address are listed below.

Name ____________________

Address__________________

APPENDIX C

Research Consent Forms

For Bereaved:

1. I have freely consented to take part in a study being conducted by Kelly Rhoades, a doctoral student at Michigan State University.
   Under the supervision of: Linda Nelson
   Academic Title: Professor, Family and Child Ecology

   This research involves me being interviewed and asked questions about my grieving process following the loss of my parent, and issues concerning grief support.

   Participation in this study usually takes approximately 90 minutes to 3 hours.

2. The study has been explained to me and I understand the explanation that has been given and what my participation will involve.

3. I understand that I am free to refuse to participate and to discontinue participation in this study at any time, and to choose NOT to answer any of the questions.

4. I understand that all details about my participation in the study are confidential.

5. I have given my permission to have this interview audio-taped with the understanding that my confidentiality will be maintained and that the interview will be erased as soon as it is transcribed. The interviewer will keep the tape in a locked automobile trunk while transporting it to the place where it will be transcribed. Transcriptions will be identified by code or by pseudonyms which I selected.

6. I understand that in any report of the research findings, information from all interviews will be included together, and that I will remain anonymous. Results of the study will be made available to me at my request.

(continued on next page)

7. I have been given the name and the phone number of a contact person, in case I have any questions or concerns after participating in the study.

Signed:____

Dated:______________________

For Professionals:

1. I have freely consented to take part in a study being conducted by Kelly Rhoades, a doctoral student at Michigan State University.
   Under the supervision of: Linda Nelson
   Academic Title: Professor, Family and Child Ecology

   This research involves me being interviewed and asked questions about grief services provided for bereaved individuals and families in my community.

   Participation in this study usually takes approximately 1 to 2 hours.

2. The study has been explained to me and I understand the explanation that has been given and what my participation will involve.

3. I understand that I am free to refuse to participate and to discontinue participation in this study at any time, and to choose NOT to answer any of the questions.

4. I understand that all details about my participation in the study are confidential.

5. I have given my permission to have this interview audio-taped with the understanding that my confidentiality will be maintained and that the interview will be erased as soon as it is transcribed. The interviewer will keep the tape in a locked automobile trunk while transporting it to the place where it will be transcribed. Transcriptions will be identified by code or by pseudonyms which I selected.

6. I understand that in any report of the research findings, information from all interviews will be included together, and that I will remain anonymous, unless otherwise indicated by me. This agency/organization will be referred to only in a generic sense, and not identifiable by name, unless permission is granted by me to use the agency/organization name. Otherwise findings will be reported anonymously (e.g., "According to one Hospice Bereavement Coordinator...," or "a hospital oncology Social Worker stated that ..."). Results of the study will be made available to me at my request.

(continued on next page)

7. I have been given the name and the phone number of a contact person, in case I have any questions or concerns after participating in the study.

Signed:____

Dated:___________________________

APPENDIX D

Data Collection Aids

YOUR LIFE LINE

On the life line below, place significant events in your life in sequence as you recall them, or by your age.

(birth)
1
2
3
4
5
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10
11
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14
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19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
(death)

Notetaking Form

DATE ________ BEGIN TIME ________ END TIME________ PAGE__

PARTICIPANT NO. ______ FGS ___ NO FGS ___ 13 Mo.___ 24 Mo.___

FACTS	INTERPRETATION

APPENDIX E

Interview Guides

<u>For Bereaved:</u>

PARTICIPANT NUMBER: ______ SETTING CHOSEN: ________________

13 month 24 month male female FGS NoFGS

(make observations to be recorded immediately following interview, on facts/interpretation form or in journal).

Reassure about confidentiality.

1. Complete background information sheet.

2. Draw your own life line indicating turning points or significant events. Okay to draw pictures. Paper, color pens and markers will be provided for participants. This time will serve as a period for rapport building with participant.

3. What was the geographic location of your parent at the time of death? What was your geographic location at the time of death?

4. Did you serve as a "caregiver" to your parent when they were ill?

5. I would like to understand as fully as I can, the experience of grief you had following the death of your parent. Can you describe to me what that was like? You may begin at the time of diagnosis of the illness, or following the death.

6. What did you find helpful in your grieving process?

7. Did you find that some things were NOT helpful in your grieving process? If yes, what were these things?

(trying to understand FORMAL and INFORMAL supports -- if participant should identify a formal support as the most helpful aspect of grief support, then I will probe further, for example by asking if any other supports were helpful to them?).

8. Do you consider yourself to be grieving right now?

9. (Transformative question): Which things will never be the same?

Do you feel like you have grown or gained in any way, because of this loss?

If so, can you talk about this growth? How specifically have you grown?

10. Is this your first or second parent to die?

11. What was your relationship like with your (deceased parent) mother/father?

as a child?

previous to his/her death?

any changes toward the end of life? (degree/quality of interaction)
describe your (deceased) mother's/father's overall personality?

12. What were the circumstances of the death -- e.g., when did you first learn of the cancer, and how was your mother/father cared for during the illness?

13. Describe your social supports.

14. Did you attend any grief support groups? a class or a group or both? attend personal counseling or therapy to help you cope with this loss?

If yes, what did you find useful about this experience?

If not, did you consider attending any grief support groups?
Did you find anything not so useful? If yes -- can you describe those things?

15. How would you describe yourself today? How are you doing? What has changed since the loss of your parent?

16. Have there been major changes in your marital and family life since your mother's/father's death?

17. (If attended GS) do you have any siblings that did not attend a grief support group or class? If YES, do you think he or she would be willing to grant an interview with me? May I have his/her name and phone number?

18. Any related stressors? (e.g, any physical problems? financial problems?)

19. Do you keep a journal? (if yes -- I will explore this)

20. How would you rate your grief adjustment?

21. If you had to list ONE aspect -- the thing that helped you the most in your grieving process -- what would this be?

22. Is there anything you would like to add?

23. What has it been like today?

Thank you.

For Professionals:

PARTICIPANT NUMBER: _________ SETTING CHOSEN: ________________

Male_____ Female______ Racial/ethnic group __________________

Educational level __________ Time worked on current job __________

Location of interview_____________________________________

Position/Title ____

What part of the population does your organization/agency serve?

Describe your job duties.

What credentials are required to obtain this position?

Describe, overall, this organization and how it operates.

BEREAVEMENT SUPPORT:

What do you think helps people in their grief?

How have these services grown over the last five years?

What do you see as the needs within bereavement (if any) ?

What is your perception about the future of bereavement services in this agency/organization?

What do you envision?

Do you think your agency/organization provides adequate service to meet the needs of the bereaved in your community?

yes no for the most part

Can you tell me, specifically, about some of these services? For example, how they got started, how they have sustained -- do you see these services as helpful or not helpful? as meeting the needs of the bereaved individuals and families?

Which of these services do you view as most helpful? Are there any you see as not very helpful? Why?

In what ways can service/support be improved?

Does this agency network/communicate with other agencies that provide bereavement services?

Anything else you would like to share about bereavement services?

If you had unlimited resources, and you could choose ONE area that you would like to develop within bereavement and grief support services, what would it be?

Have you lost a parent? If so, when? What was the cause of death? Did you utilize bereavement services? What kind?

Thank you.

APPENDIX F

Hospice Bereavement Support Questionnaire

PATIENT NAME:_______________ BEREAVED NAME:_________________

ADDRESS:_____________________________ PHONE:____________________

1. In general, were our letters and articles helpful to you following the death of your family member? Check One:

   _____ Very helpful _____ Somewhat helpful _____Not very helpful

   Please explain: ____
   ____
   ____

2. Did the mailings help you cope with your loss? Check one:

   _____ A great deal _____ Somewhat helpful _____ Very little

3. Were any mailings especially helpful? Explain:

4. Were any mailings especially non-helpful? Explain:

5. Please rate the usefulness of the following Hospice services. Circle your response.

   5=Outstanding 4=Very helpful 3=Average 2=Somewhat helpful 1=Poor

a) Monthly letters	5 4 3 2 1	Check one:	___ Rec'd.	___ Did not
b) Monthly articles	5 4 3 2 1	" "	___ "	___ " "
c) Bereavement Booklet "The Days Ahead"	5 4 3 2 1	" "	___ "	___ " "
d) Grief Recovery Course	5 4 3 2 1	" "	___ Att'd	___ " "
e) Memorial Service	5 4 3 2 1	" "	___ "	___ " "
f) Initial visit by staff member	5 4 3 2 1	" "	___ Rec'd.	___ " "
g) Contacts by bereavement volunteer	5 4 3 2 1	" "	___ "	___ " "

6. Do you wish to receive any additional services? ___ Yes ___ No

7. Would you like a phone call or visit? ___ Yes ___ No

Thank you for helping us in this way. Please return this form in the enclosed envelope to: Bereavement Coordinator, Hospice ------- (name and address of Hospice provided here).

BIBLIOGRAPHY

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