EXPLORATION OF THE UNBURDENING PROCESS: AS EXPERIENCED AND EXPRESSED BY THE FAMILY CAREGIVING SPOUSE AFTER THE PATIENTS DEATH

by

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ABSTRACT

EXPLORATION OF THE UNBURDENING PROCESS: AS EXPERIENCED AND EXPRESSED BY THE FAMILY CAREGIVING SPOUSE AFTER THE PATIENTS DEATH

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This research study is designed to explore the phenomenon of unburdening as experienced by the family caregiver spouse. The study is being conducted to better understand the perceptions of spouses who have sustained a significant life transition through caregiving and bereavement. For purposes of this study, unburdening is defined as the extent to which caregivers' perceive an alteration in their physical, social, financial, emotional, mental, and spiritual domains as a result of the spouse's death.

Indepth interviews were carried out at one, and two months following the death of the family member who needed care. The purpose of this study was to qualitatively describe patterns of unburdening for a small number of individuals. The specific focus was to collect descriptive data about unburdening phenomenon from the subjects frame of reference. The range of dimensions of unburdening including the commonalities and differences among participants was discussed. Also described are changes in sub-constructs over time and the factors accounting for the changes at one and two months of bereavement. Based on observation and interview data, the resulting themes or patterns offered explanations of the behaviors of the individual participants which were unique to caregiving bereavement.

To my mother, Christine Donner Vollman, and
in memory of my father, Charles Vollman
and
Ken, Jennifer and Jeffrey.

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Introduction

It is generally well accepted that home care is more beneficial to the chronically ill patient and the caregiver than institutionalization. Furthermore, the majority of families, in this country, prefer to care for their debilitated relatives at home, and as a result the family is recognized for its critical role in making home care possible (Crossman, 1985). Studies have shown that the distinguishing characteristic of those individuals cared for in the home versus those cared for in institutions is the availability of family members to provide care and not the extent of physiological or emotional symptoms (Crossman, 1985; Archbold, 1982).

Unfortunately measures of burden experienced by caregivers can lead to exhaustion, depression, or physical illness for the caregiver (Kahan,1985; Robinson, 1979). Moreover, with the death of an older family member needing care, associated increased rates of physical and mental illness and an increase in the caregiver mortality rate has been cited in the literature (Parkes,1970; Bennett,1983).

Accounts of reaction to the death of a family member have been published in the literature dating back to Lindemann's 1944 classic account of the reaction of one hundred and one subjects to the death of a close friend or relative (Lindemann,1944). Clinicians agree that there is substantial individual variation within the grieving process in terms of specific manifestations and the speed with which one moves through the process (Diamond,1981). However, little has been written about the unburdening process as experienced by a caregiver of a chronically ill family member who has died. The literature does support the impact of caregiving and grieving on the health status of the older adult (Crossman, 1981; Parkes, 1971).

In this explorative, qualitative study the researcher will examine dimensions of the unburdening experience through in depth interviews conducted by the researcher at one and two months following the death of the care recipient with three individual spouses.

Background of the problem

There has been an interest in "*caregiving* " as a focus for study in recent years. A number of researchers have described the relationship between physical and mental states of patients confined to the home due to chronic illness (Baines, 1984; Zarit, 1980). Additionally, research relating to the burden and involvement experienced by their caregivers is wide spread in the literature (Brody, 1985; Zarit, 1985, 1980; Turner, 1982; Campbell & Brody, 1984; Clark, 1983). Nevertheless, family caregivers of disabled older adults have been ignored by health professionals even though they are the hub around which the future of the patient revolves (Sanford, 1975). Studies have not followed caregivers beyond the point at which the caregivers' burden is lifted or the event marking the death of the care recipient, to examine the process of unburdening as perceived by the caregiver. Equally important, there are increasing numbers of older people, and many of them will experience chronic debilitating diseases requiring long term assistance (Baines,1984).

Since the mid 1960's researchers on aging have demonstrated that many elderly individuals are neither isolated from their families in the community nor abandoned by them in nursing homes (Shanas, 1979). Families are the first line of defense against institutionalization as many elderly care recipients reside in homes. Regardless of the strength of the bonding linking the caregiver and care receiver, some emotional stress or physical strain is inevitable in caregiving (Eggert,1977). Over time, caregivers become less able to carry out the caregiving role, resulting in an increased burden. Consequently, caregivers become vulnerable to guilt, anger, resentment, and bitterness which may override the caregiving relationship and further intensify the strains of care. (Robinson,1979)

While previous studies have explored relationships between family caregivers and their patients, this study will explore qualitatively the unburdening experience as defined by the spouse caregiver following the death of the patient. Dimensions of caregiver burden will include the social and psychological impact of increasing involvement in caregiving upon the ability of the caregiver to cope with this role. It is believed that as caregivers become more involved in caregiving they withdraw from other social roles and will be at greater risk for functional deterioration themselves. A burdensome life style then may be perceived by the caregiver due to social isolation, exhaustion, and physical illness (Archbold, 1982; Sanford, 1975).

Patterns of unburdening following the death of the care recipient will address how changes in caregiver perceptions of releasing burdens influences the emotional, physical, social, mental, and spiritual states. Using the nursing conceptual model as proposed by Martha Rogers (1981), with the broader concepts of holistic man, environment, pattern and organization, the caregiver who is unburdening as a result of the death of a family member is a whole being as reflected in differences and uniqueness from other individuals. This person is continuously exchanging energy with environment and this interchange serves as the basis for growth and behavior (Rogers, 1981).

Statement of the problem

The problem under study is to explore the process of *unburdening* as experienced and expressed by the recently bereaved family caregiver of a chronically ill spouse. This will be carried out at one and two months following the death of the family member who needed care. To determine themes which prevail over time, the interviewer will explore and learn about the course of the unburdening experience, by seeking the social, emotional, physical, mental, and spiritual factors that facilitate or impede that process.

Purpose of the study

There is evidence in the literature to substantiate the relationship of the patients functional, social, and mental limitations to the family caregivers involvement in caregiving and the perceptions of burden this care imposes upon them (Zarit,1986; George & Gwyther, 1984; Archbold, 1982; Baines, 1984). There is minimal data, however within the literature that describes/explores the experience of family caregiver unburdening following the death of the patient. The purpose of this study is to describe patterns of unburdening for a small number of individuals. The specific focus of this research is to collect descriptive data about the perceptions of the unburdening process that facilitate or impede the release of caregiver burden one to two months following the death of the patient.

Importance of the study

An in depth exploration with the family member of the unburdening process following the death of a family member who needed home care due to debilitation is a significant area for nursing investigation. In particular, recent literature supports the physical, emotional, social, and spiritual cost of home care on the care giver (Zarit,1980). Attending to an ill elderly person at home is a considerable burden which is largely a womans' responsibility (Brody, 1984). Studies have shown that about 85% of caregivers are women who are wives, daughters, or daughters-in-law. These individuals shoulder the tasks of feeding, dressing, toileting, and comforting the patient. Men make up 15%, or less, of the caregiving population (Brody, 1984; Sommers, 1985). Additionally, the caregiver sometimes carries out medical and nursing tasks as well. Many elderly spouses are attempting to care for their ailing mates at home. If the caregiver is personally experiencing declining health, the load may indeed be a heavy one.

In the bereavement literature, it is well recognized that death of a spouse is ranked as an emotionally devastating event (Holmes & Rahe,1967). Even among those past middle age, conjugal bereavement can no longer be considered untimely. Even when the death is preceded by chronic illness, family members generally do not engage in anticipatory grieving and withdraw from the dying partner. On the contrary, there may be an intensifying of attachment and a reaffirmation of commitment and loyalty (Osterweiss, 1984). The crisis of spousal loss in the elderly as having severe implications on the physical and mental health of the surviving spouse is described in recent literature (Richter, 1984; Kaprio ,1987).

In conjugal bereavement there may be changes in sense of self and purpose and meaning in life which may impact the grieving and unburdening process. The fact that bereavement and other losses can lead to positive and negative outcomes makes it important to understand the intermediate variables that precede these outcomes and identify individuals at risk (Parkes, 1985, 1981; Raphael, 1977).

The nurse is in a unique position to assist an individual in the processing dimensions of burden and unburdening. The model of unburdening utilized in this study has unknown outcomes. Nevertheless, an individual who is on a post caregiving health continuum has growth potential. If research supports that the process of caregiving for a chronically ill spouse is indeed associated with the experience of caregiver burden, and that the crisis of mate loss in the elderly can impact health, the nurse is then in a position to design and implement a plan of care to assist the individual in adjusting to this life cycle transition. To facilitate needs and resources, and thus enhance growth within the individual who experiences the losses of caregiver bereavement is indeed an important role of the nurse in advanced practice.

Conceptual Definitions

The model used in this study contains the concepts of:

Burden

Prior to describing unburdening as utilized in the problem statement, the writer will first define burden. Burden as stated in Webster's Dictionary (1985), is something difficult to bear, something carried, a load, or a task. Funk and Wagnall's Standard Desk Dictionary (1980), describes burden as something that weighs heavily, as responsibility or anxiety. Caregiver burden is the realm of human experiences that predisposes the caregiver to perceptions of physical and mental states, views of elderly care requirements, the period of time caregiving, role relationships with other family members, and associated financial responsibilities. Zarit (1985) defines burden as "the extent to which caregivers perceived their emotional or physical health, social life, and financial status suffering as a result of caring for their relative" (Zarit, 1985, p. 261). Caring for a chronically ill person in the home can become an overwhelming burden and produce excessive stress in family members (Deimling, 1985; Baines, 1984).

Furthermore, with the death of the chronically ill family member, mourning becomes a subset of burden. Grieving is a natural and normal reaction to loss. The death of a spouse, or partner in an adult bonded relationship has great impact because of the intensity with which the relationship was held. The marital dyad of closely interwoven lives may be intensified through caregiving so that loss of one partner may erase the very meaning of the others' existence (Raphael, 1983). Schneider (1984) assumes grieving to be a holistic process which affects people physically, emotionally, and spiritually. Moreover, grief is represented in our thoughts, perceptions, and behaviors. Therefore, some aspects of grief are not observable and consequently are not apparent to others, while others are directly observable by resource support (Schneider, 1984).

The nature, quality, and type of relationship lost, influences the reactions of the survivor since each type of relationship has its' own personal and social meaning (Martocchio, 1984). On the scale of life events, loss of a spouse is ranked as the most stressful of all losses and can be emotionally devastating to the surviving mate (Martocchio, 1984). While response of loss of a parent to death is contradictory, Horowitz, (1984) cites death of a parent as a serious life event leading to a measure of symptomatic distress. Weiss (1983) suggests that death of a mother is more difficult than that of a father, perhaps due to customary maternal nurturing. Owen (1983) however, describes death of a parent in adulthood as the least disruptive and thus causing the least intensive grief responses.

Indeed, one's reactions to loss is an individual and highly variable phenomenon. Responses range from the most stressful and disruptive of ones' life patterns such as the death of a spouse due to the intertwining nature of the relationship, to the death of a parent in adulthood which manifests lesser mourning reactions. Nevertheless, response to grief covers a range of expected and unanticipated feelings, emotions and behaviors.

Unburdening

Unburdening is defined as the process of removal or release from the state or quality of burden, or sometimes even an intensification of the impact of burden. Patterns of unburdening may be observed in a trajectory over time as the person who was formerly caregiving begins to explore perceptions which predisposed him to burdens associated with the caregiving role and the reaction to the loss of the mate. For the purposes of this study, unburdening is the extent to which caregivers' perceive an alteration in their emotional, physical, social, financial, mental, and spiritual dimensions as a result of giving up their caregiving role.

During the course of a relationship the marital dyad gradually changes undergoing peaks and valleys in everyday living. Marriage is many things to many people: it is stability and change; pain and sorrow; intimacy and distance; and love and excitement. When the partnership changes with illness and subsequent death, the meanings and memories of marriage are altered (Raphael, 1983).

It is well established that loss is a common occurrence among the elderly population with the death of a spouse being one of the most profound of all losses. While loss is a frequent and predicable event for an older adult, little is known about the mourning process or resolution of grief among the elderly (Dimond,1981). Accordingly, restructuring and repatterning of behaviors of the bereaved spouse predictably begins at the time of the death of the marital partner.

Therefore, the process of mourning involves a review of many aspects of the lost relationship. With time, the bonds that attached the marital dyad may gradually be relinquished freeing the emotional investment for ongoing life and growth (Raphael, 1983). As the transition continues, the bereaved person may begin to see himself as one rather than two. With repatterning and restructuring, new choices and decisions may begin to appear as the one continues to unburden. One choice may be to decide to relinquish the need to be responsible for the needs of another person. With unburdening the individual has an opportunity to move forward along the life process as he/she begins to perceive and experience alterations in varying dimensions of being.

Family caregivers

Family caregivers as defined for this study are primarily spouses, or other family members who provide most of the assistance or supervision needed to attend to a dependent, ill person in the home. People who traditionally have been assigned to caregiving roles are specific women in the family. Middle aged married or unmarried women have been caught in this middle generation (Brody,1984). Furthermore, women are in the middle between their parents and their children as well as careers and personal lives. This role conflict can cause self-confirmed and/ or socially imposed expectations, often unrealistic for this family member (Turner, 1982).

At least one half of the home care of older dependent adults is provided by spouses, who themselves are elderly and disease prone. Consequently, middle aged and older women now carry the main burden of responsibility for continuous home care for their aged parents and spouses (Haug,1985). Several reports on the aged bereaved suggest that older persons experience the death of a spouse in ways which are different from younger persons, possibly due to concurrent losses and inadequate supportive networks. Interestingly, bereaved elderly males may be at greater risk for physical and mental deterioration than women (Hogstel,1985; Dimond, 1981).

Chronic illness

Chronic illness is defined as the occurrence of sickness with resultant impairments or deviations from the norm leaving residual disability, caused by pathological alternations, and requiring rehabilitation and care from family members or other caregivers (Baines, 1984; Zarit et al. 1980). Chronic illness is Americas' number one health problem and requires great palliative efforts and a variety of services if patients are to be cared for properly (Strauss, 1984).

Loss through death

Loss is a natural part of existence. A physical or tangible loss can be described as having a friend or relative die. Further, loss is a common occurrence among the elderly, and one of the most profound losses is the death of ones' spouse (Dimond,1981). Loss always results in some kind of deprivation (Rando,1984). Loss is any change in a person's situation that affects the probability of achieving goals. The significance of loss can depend upon the number of related losses, and the extent to which daily routines or habits are disrupted (Schneider, 1984). The importance of loss will vary according to its' meaning to the specific individual (Rando, 1984). In any event, failure of grief to resolve itself keeps energy bound to the past and to the loss (Schneider,1984).

Assumptions

In this study the researcher is making the following assumptions:

1. Bereaved family caregiver of the ill relative experienced burdens and rewards for caregiving.

2. Death of a significant person will result in the process of grieving, loss, and adjustment.

3. With participant observation and guided open-ended questions, patterns of unburdening may begin to evolve within the holistic dimensions probed.

4. Former caregivers are able to identify and express their feelings.

Limitations

The following are limitations acknowledged in this study:

1. Unburdening in adult bereaved caregivers has not been studied, but it is possible that time frames selected for interviews may miss significant aspects of the process and were selected only for a short time frame.

2. Utilizing an interview approach for a search for themes may lead to interviewer bias. The subject's responses can be affected by the interviewer/respondent interaction.

3. Sampling size is voluntary rather than random, therefore generalization of the conclusions is questionable.

4. Sampling selection of three bereaved caregivers is small.
5. Exploratory process may miss relevant themes.

Overview of Chapters

This research study is presented in six chapters. In Chapter I the introduction of the study, the background of the problem, the statement of the problem, the purpose and importance of the study, conceptual definitions, assumptions and limitations of the study are presented. Within Chapter II, the conceptual framework is presented, the concepts of unburdening themes are developed within the holistic dimensions of physical, social, mental, and spiritual domains and the adult caregiver who experienced the loss of a chronically ill family member. The relationships of Roger's Theory to the person who is unburdening the experiences and losses associated with caregiving is explored. Chapter III holds pertinent literature and research studies in the problem area described.

In Chapter IV, research methodology and data collection procedures are described. The development of interview guidelines is presented. In Chapter V, data is presented, analyzed, and discussed. In Chapter VI, the research findings are summarized and nursing implications are discussed.

CHAPTER II

CONCEPTUAL FRAMEWORK

Introduction

In this chapter the relationship of the unburdening process to nursing theory in explaining the manner in which nurses could intervene and assist the surviving spouse in this life cycle transition will be presented. The discussion will begin with a conceptual system proposed by Martha Rogers (1981). Rogers uses a dialectic method of reasoning in which nursing is explained by referring to broader principles that explain man. (Rogers uses the term "man" in reference to human beings.) Rogers' conceptual framework provides a basis for associating the major concepts of unitary man and environment which is the basis for this chapter. Therefore, utilizing nursing theory, the process of unburdening following the death of a chronically ill spouse will be described.

According to Rogers, "Nursing practice focuses on human beings, on man in his entirety and wholeness" (Rogers, 1981, p. 127). Rogers views nursing from a global perspective utilizing knowledge gained from astronomy, religion, sociology, philosophy, history, anthropology, and mythology. Rogers perceives this background to be a necessary foundation for an understanding of nursing and the evolving theory and principles that must guide nursing practice (George, 1980). Rogers sees nursing as an humanitarian science which exists to serve people with a direct and overriding responsibility to society. Further, nursings' body of scientific knowledge seeks to describe, explain, and predict about human beings" (Rogers, 1981 p. 3). Therefore, Martha Rogers bases her theory on certain assumptions about man. Five basic assumptions are proposed by the theorist:

1. The human being is a unified whole, possessing individual integrity and manifesting characteristics that are more than and different from the sum of the parts. Because of the uniqueness of the whole person the life process of the individual is a dynamic course that is creative, continuous, evolutionary, and uncertain.

2. Man and the environment are constantly exchanging energy and matter with one another. Thus, this relationship is one of mutual interaction and mutual change and serves as a basis for growth and behavior. Consequently, man and environment are perceived simultaneously and are not to be separated. Rogers views this relationship as portending the future and not man adapting to his environment (Rogers, 1981).

3. The life process of human beings evolves irreversibly and unidirectionally along a space-time continuum. The space-time concept can be explained as a process consisting of a series of constantly unfolding changes in which past experiences are integrated and creative new patterns emerge, thus involving evolution of man and environment. The individual can never go backward as life exhibits a forward, one way trend (Rogers, 1980).

4. One's life pattern and organization identifies individuals and reflects their innovative wholeness. As man moves through life, the pattern is changed by interaction with the environment. Man's capacity for thought and decision making allows choices in selecting some environmental components. It is through these choices that an individual can influence his/her pattern and repattern. In this way life can be experienced as harmonious rather than discordant (Rogers,1983). Implications for this study are conceivable as knowledge about the process of unburdening following a significant loss by death can influence how an individual makes

a life transition change and moves forward toward maximum health potential.

5. Human beings are characterized by their capacity for abstraction, imagery, language and thought, sensation and emotion. These qualities are viewed as positive, integrative forces which can open new pathways of understanding and perceiving. This allows the individual to make changes along the health continuum (Rogers,1981). In brief, these assumptions about human beings are the basis for a conceptual system which helps guide the nurse in practice.

In discussing her theory of Unitary Man, Rogers explores man and his relationship to the environment and the uniqueness of the life process itself. The conceptual framework provides a basis for examining the process of unburdening. The researcher will examine in common themes or patterns which prevail over time, and across subjects, their similarities and differences. In particular, how the caregivers' emotional, physical, social,financial, mental, and spiritual states of health are influenced by perceptions of the burdens and rewards of caregiving will be described by study informants. Equally important, the researcher will describe unburdening through expressions of grief responses and alterations which may occur as the result of the death of the respondent's family member.

Rogers' (1981) concepts provide the foundation for understanding the life cycle transition experienced by the bereaved caregiver. Using Rogers five assumptions and principles as a foundation, the life process becomes one of potential growth and creative change. According to Rogers, man clearly can affect change in his future. He need not adapt to environmental influences which have impacted his past experiences. Rogers definitions of man, health, and nursing in relation to the spouse who is experiencing unburdening will be explored in the following sections. These definitions will lend further rationale for the use of Roger's theory for this study.

Man

Roger's definition of man as whole and unique, holds relevance for this study as spouses experience unburdening after caring for their chronically ill mates who subsequently died. Rogers' (1981) identifies man as having the capacity to search for meaning in life and death, and to maintain himself while undergoing change, because man is a sentient, thinking being, and is capable of thought, feeling, and sensation. Further, man is identified by pattern and organization. Therefore, as man moves through life, the pattern is changed by interaction with environment. Mans' capacity to think and make decisions allows choices such as choosing to express feelings of guilt and self-recrimination, that his marital partner still suffered and died even though he did all that could be done. Through this process man influences the repattern of his energy field as past experiences are incorporated and new patterns emerge.

The variety of choices available to the individual who is unburdening has implications for this study. As cited in a study by Malone, et al.(1985) the majority of caregivers of family members with senile dementia did not engage in any grieving prior to the patients' death. These caregivers stated that they were too occupied with getting through the daily stresses related to caring for the patient to dwell on the impending death. While the caregivers reported acceptance of the chronic illness and its' progressive deterioration, they reported feeling unprepared for the sense of loss they actually experienced after the patient died. Nevertheless, most bereaved individuals, do evolve through the period of loss, generally within a two year period (Gallaher, et al. 1983).

Other researchers argue that bereavement becomes a significantly more complicated process for persons whose spouses died after an illness of greater than six months (Gerber, et al. 1975). In the concept of Roger's, variations and changes occur as man moves forward through stages of development with this potentially growth enhancing experience of caregiving and unburdening (Rogers, 1981). In particular, the nurse who supports the spouse utilizing holistic perceptions of the life process can assist the individual in organizing a continuous repatterning in explaining the creativity of life despite a significant life cycle transition.

Environment

Roger's defines environment as encompassing all that is outside of mans energy field extending to infinity. Environment has no boundaries. The human field is dynamic and continuously interactive with environment. This interchange serves as the basis for mans' growth and behavior. Environment may include visible matter such as another person, an article of clothing, or an abstract invisible quality such as a perception, a value, or a belief. Any of these could extend out into the environment or move into mans inner world to be integrated by the individual (Rogers, 1981).

The continuous man/environment interaction is a major concept in Rogers (1981) theory. The relationship is one of mutual interaction and mutual change. It is this man/environment process which portends the future and not man adjusting to his environmental change. It is well known that families are responsible caregiving agents who provide substantial physical, emotional, social, and economic support to their chronically ill relatives (Brody, et al. 1985; Day, 1985). Interestingly, in a study by

Sexton, spouses of men with chronic lung diseases relied on children, relatives, physicians, and neighbors as sources of support. These individuals have the potential for becoming integral components in the caregivers' environment evolving with the caregiving spouse in this complex phenomenon of caregiving and unburdening (Sexton,1985).

Rogers theory further supports the mutuality of the man/environment interaction through nurse facilitated supportive interviews. The nurse enters the environment of the caregiver to assist in open discussion and sharing of the caregiving and unburdening experience (Rogers,1981). North described the caregiving phenomenon as private and hopeless. However, bitterness and frustration potentially can be replaced with new perspectives and a willingness to look at life differently (North,1985).

Therefore, Rogers concept of the mutuality of man-environment is supported and enhanced with the caregiving and unburdening phenomenon. Thus, the constant interaction between man and environment serves as a basis for man's becoming (Rogers,1981).

Health

The word health is used by Rogers, but is not specifically described. Health is assumed to be a value which can only be defined individually (Rogers, 1981). Furthermore, the health goal of achieving ones' maximum health potential is implied in this study by the mutual nurse-client exploration of the unburdening process.

Slow lingering illnesses have inherent stresses. George and Gwyther (1984) cited changes which impact caregiver well being over time as caregivers provide care for chronically ill relatives. These changes were measured in the four dimensions of physical health, mental health, financial resources, and social activities. Those caregivers who provided continuous in home care experienced different patterns then those who had institutionalized the patient. Caregivers who lived with the patient had decreased states of health, and diminished satisfaction with social and recreational activities and life satisfaction. Caregivers who provided home care for their chronically ill mate endured significant levels of burden relating to caregiving responsibilities often extending over twenty four hours per day (Archbold, 1982).

Nevertheless, in support of Rogers theory, Raphael (1983) described, that despite the ambivalence that certain debilitating illnesses and personality changes may bring, the complexities of illness and death will also have meaning in terms of each individuals' past experiences and feelings attached to them. With the integration of those past experiences into the present, the individual has a phenomenal capacity to self-maintain and actively participate in determining the patterning of his field. As a result of these changes, the individual is capable of looking to the future and may consider alternative solutions to complex problems such as how to bring meaning to his life without his spouse. Therefore, with the dynamic growth process of man/environment new patterns emerge as past experiences are integrated into new developments within the life process.

Nursing

According to Rogers, the goal of nursing is to promote a symphonic interaction between man and environment. The focus of nursing is compassionate concern for maintaining and promoting health (Rogers, 1981). Rogers views health promotion and health maintenance as a nation's first line of defense in building a healthy society. A conceptual system of nursing provides a means of viewing man and envisioning his developmental transition. Rogers hemodynamic principle of helicy reflects man and environmental change as continuously innovative, diversely rhythmic, and problematic. These rhythms are goal oriented by helping people to achieve positive health.

While this study has no stated health goal, the process of exploration of the phenomenon of unburdening is a positive health measure that is directed toward determining individual differences. Thus, the unburdening process will also assist people during bereavement in developing patterns of living that coordinate with their environmental changes rather than conflict with them (Rogers, 1981).

In explaining the assumptions of continuous repatterning in achieving maximum health, Rogers principles of resonancy proposes the nature of change occurring between man and environment. Resonancy describes change in pattern and organization of man and environmental fields as waves moving from lower frequency longer waves to higher frequency, shorter waves. In accordance with Rogers' theory, this process is a result of energy exchange between man and environment. Rogers views resonancy as the basis for explaining the creativity of man in moving forward through difficult life transitions.

Rogers principle of integrality sets forth the view that the interaction between man and environment is continuous, simultaneous, and mutual resulting from an inability to separate the two fields. Since change is continuous in Rogers theory, the study of man encompasses the multiplicity of events that may take place along the continuum of life through death. In this study, the nurse looks at health and illness as part of the same continuum and not dichotomous conditions. (Rogers, 1981). The process of unfolding that occurs after an experience such as caregiving and unburdening influences the health continuum of the individual and accounts for the dynamic complexity of the life process (Rogers,1981). Therefore, Rogers principles and assumptions provides a scientific framework for understanding the unburdening process as experienced by the older bereaved spouse.

The relationship between the spouse caregiver who is experiencing unburdening and the nursing exploration of this process is described in Figure 1. The spouse going through unburdening could be conceptualized as a rhythmic pattern within a pattern. The caregiving, unburdening process is a significant life cycle transition phenomenon which reflects individual differences and complexities of maturing and growing with change.

The meaning of this life cycle transition to the spouse and the feelings about it are influenced by many human and environmental characteristics. Human characteristics such as age, race, and ethnic status, past and present state of health, past experience with caregiving, and self care and self concept needs are integral when discussing variations of the life process. Certain environmental factors such as the number and ages of children, financial resources, and barriers of social isolation and family support may also impact the sequence stages of growth through which the individual passes.

The general guidelines utilized by the nurse in examining the caregiving experience and unburdening process are: What is it like being a family caregiver? What is it like now that you are not caregiving for your spouse? How are you taking care of yourself following the death of the spouse? An awareness of these and other characteristics provides a foundation upon which the nurse-client interaction will be built. As described in Figure 2,

Figure 1: Rogers' Man-environment interaction

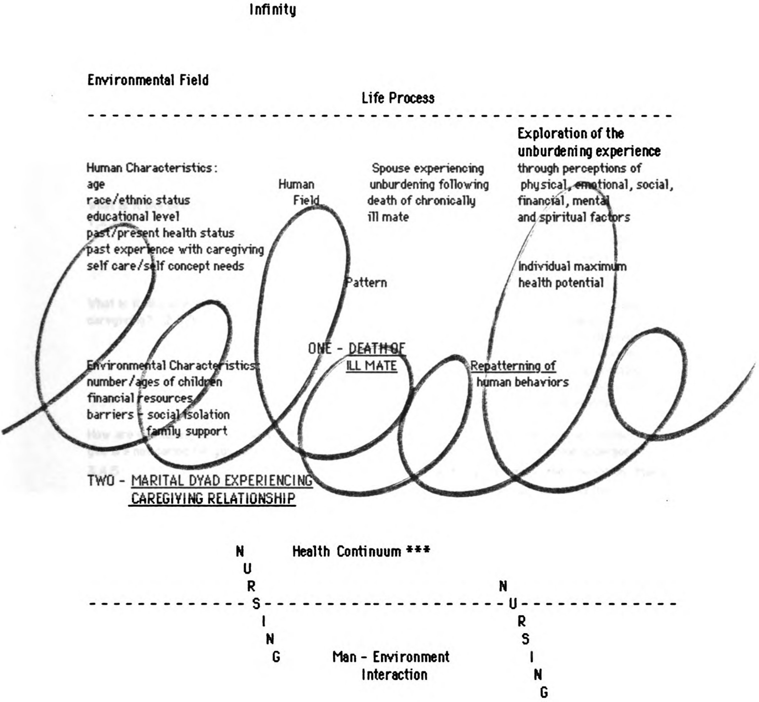

Figure 2: Rogers' Concepts/Interviewer Guidelines

Relationship Map

GUIDELINES	ROGER'S CONCEPTS
	1. Man is a unified whole, possessing integrity, has characteristics more than and different from sum of the parts. Man's life is a dynamic, evolutionary creative course.
What is it like being a family caregiver? 1,2,3,5.	2.Man and environment are constantly interacting with each other and continually affecting each other and this serves as a basis for man's becoming.
What is it like now that you are not caregiving? 2,3,5.	3. Life process evolves irreversibly and unidirectionally - a one way trend. From conception to death man moves through stages of development with observable attributes associated with each stage. Past experiences are integrated, new patterns emerge.
How are you taking care of yourself now that you are not caring for your spouse? 3,4,5	4. Pattern identifies man and reflects his wholeness. Patterning undergoes continuous revision and innovation. Man's self regulating ability allows him to maintain himself while changing, thus increasing man's complexity and diversity.
	5. Man is a sentient, thinking being. Man has capacity for feeling, imaging, and abstracting. Man seeks to organize his world and mans humaneness is identified.

these guidelines flow from Rogers concepts found in the five assumptions (Rogers,1981) and are used by the interviewer to describe the unburdening experience:

Guideline number one, What is it like being a family caregiver ? This guideline taps the concept of wholeness of the individual, by viewing the caregiver as one who possesses uniqueness and integrity. The life process of the individual which includes caregiving, is dynamic and evolutionary. The individual affects and is affected by the world around him as he/she moves through a sequence of stages of development which are observable from birth through death. This process reflects his capacity to contemplate past, present, and future. The concept of mans' capacity for thought, sensation, and emotion is shown in ones desire to explore the past experience of caregiving and the current reactions to significant losses. Some open-ended questions relating to this guideline and concepts are: Did the caregiving experience alter your relationships with other family members? Are you feeling closer or more distant with certain family members because of your caregiving experience ? Can you describe the bond between you and your spouse while you were caregiving?

Guideline number two, What is it like now that you are no longer caring for your spouse ? This guideline taps the concept of man and environment constantly interacting and continuously affecting each other. This interplay is viewed as an indication of the individual being affected by the world around him and the events occurring at any given point in time such as the caregiving experience and loss through death of a spouse. The life process is a one way trend where past experiences such as caregiving are integrated and creative new patterns of living emerge. The concept of sentient human being finds expression in joy and sorrow such as through the explorations of the person's desire to work through the grieving process. Reflections of the present experience are based on the caregiver's capacity for abstraction and imagery, where new pathways of understanding may emerge. Questions focusing on this guideline and concepts are: What is a typical day like now that you are no longer caregiving? What kind of support are you getting from family and friends? Are your support persons helpful? Where do you wish to go now having experienced your losses?

Guideline number three: How are you taking care of yourself now that you are not caring for your spouse? This question looks at the concept of man's capacity for the emergence of new patterns of self care based on integrated past experiences of caregiving and other life processes. The individual who is unburdening as an extension of the caregiving experience has the capacity to self regulate and maintain self despite a significant life transition phenomenon. Because of the unique capacity for sentience and thought the individual has the capacity to search for meaning and makes sense out of his/her life. Questions and concepts addressing this guideline are : How are you finding meaning and purpose in your life now? If you could do anything, go anywhere having no limitations, what would it be and where would you go? Describe your spiritual philosophy.

The life process of man is central to nursings' conceptual system. "As the life process of man is better understood, nursing is further enabled to initiate and implement positive measures directed toward achieving well being for people" (Rogers, 1981, p. 120). Through the use of probes which support the unburdening process, the interviewer is exploring concepts put forth by Rogers in her assumptions about unitary man (Rogers, 1981).

In summary, using Rogers conceptual framework, this study is an exploration of the unburdening phenomenon and includes restructuring and repatterning of behaviors as perceived by three bereaved spouses. Utilizing Rogers theory, direction is provided for an understanding of the inherent emotional, physical, social, mental, and spiritual factors which are a part of the bereaved caregiver and his/her environment. The caregiver has the capacity to knowingly rearrange his/her environment and actively make choices to repattern in a harmonious pattern.

Summary

Accordingly, Rogers conceptual framework clearly identifies man as the focus of nursing. In this study, the nurse seeks to understand the phenomenon of unburdening which is a central concern to each individual experiencing it. The nurse develops this awareness utilizing certain assumptions about man. It is assumed that man is whole, unique, evolving, and has the capacity for thought, emotion and active participation along his health continuum. Patterns of family functioning that impede and facilitate the process of unburdening will be explored. Therefore, Rogers theory provides a basis through which the nurse can assist the client toward reaching his maximum health potential. In the next chapter the review of the literature relevant to caregiving and bereavement will be explored.

CHAPTER III

LITERATURE REVIEW

Introduction

The scope of this literature review will include research studies and papers relevant to the unburdening process and its' impact on the spouse caregiver following the death of the chronically ill mate. Major research findings and opinions of authors relative to this life transition experience will be discussed. Thus, for the purpose of this study the literature review will be presented in three sections. To understand the experience of unburdening, the reader will become aware of the process of caregiver burden which includes the rewards and stresses inherent in the caregiving role. First to be discussed is the caregiving process with a description of caregiver and family involvement; secondly, caregiving burden within, emotional, physical, social, cognitive, and spiritual dimensions; and thirdly, caregiver unburdening which includes grieving related to the loss by death of the caregivers' spouse.

Despite the wealth of information within the literature about the process of caregiving and caregiver burden, relatively little is known about the phenomenon of unburdening. These three sections will comprise the range of literature contributing to the understanding of dimensions of this life transition referred to as unburdening.

The Caregiving Process

The caregiving process has been described in a number of previous studies as the provision of necessary daily services, assistance, and supervision that is needed to maintain a chronically ill family member at home (Campbell & Brody, 1985; Crossman, 1981; Archbold, 1982). Tasks most frequently cited in the literature as being associated with caregiving involvement fall into four categories:

1. Direct care, such as activities of daily living.
2. Personal tasks and concerns such as the impact of caregiving on finances.
3. Interpersonal ties with other relatives such as balancing of assistance and responsibilities to other family members.
4. The broader societal tasks of interactions with the health and service system.

As a result of the continuous provision of services to a disabled family member, caregiving can be an all consuming activity (Clark, 1983; Deimling & Poulshock, 1985; Crossman, 1985). When caregiving responsibilities are incorporated into the life process of the caregiver, life satisfaction, level of perceived stress, personal freedom, career, and personal relationships can be impacted (George & Gwyther, 1984; Archbold, 1982; Haug, 1985).

Caregiving is affected by many factors which include the chronic illness of the family member and the dynamic course of the process itself. The reality is that caregiving affects varying aspects of the caregivers' family relationships, sense of self, and freedom. The cumulative effects of caregiving over time places great demands on the increasingly limited energy level of the caregiver (George & Gwyther, 1984; Archbold,1982). To begin to understand caregiving and its' impact on the caregivers and their family, a cognitive awareness and a flexible open approach in exploring the caregivers' perspective will provide the foundation for examining a critical issue which affects many Americans today.

Montgomery (1985) clearly describes that the need for home care for the elderly is increasing at a time when social change is threatening to undermine the major source of care, which is provided by the family. Additionally, recent demographic trends show that the population of elderly individuals is increasing with more Americans living past their 85th birthday. Day (1985) reports that the 85 plus age group is the fastest growing segment of the United States population. Furthermore, this aging group is most likely to develop disabling impairments which will require some kind of health care in the home.

In 1985, 5.2 million elderly American persons lived in the community with disabilities that left them in need of assistance with day to day tasks. These daily activities consisted of meal preparation, dressing, bathing, and other functions of daily living. The number of disabled older Americans is expected to double by the year 2020. Trends in life expectancy, the age make up of the United States population and delayed child bearing will put pressure on the ability of the family to provide care in the future. Meanwhile, the offspring of the past 85 age group is decreasing and will continue to shrink in the 1990's. As a result, the likelihood of families caring for a disabled relative is increasing (Day, 1985).

Most elderly individuals reside at home either alone or with their spouses. These people live with the help of ordinary services and assistance that families typically give to and receive from one another over time. Elderly people are generally part of family networks where the flow of support is a two way system until the onset of extreme disability. At this time greater assistance is needed by the elder person requiring care. The myth that families negate their elderly is dispelled by the family network philosophy, which does not terminate with illness.

Todays families do not abandon their disabled elderly (Day, 1985). The results of a 1982 National Long Term Care Survey indicates that 80% of care received by chronically ill elderly in the home is provided by relatives (Manton, 1984). Moreover, most of the family caregivers are women, with spouses most frequently filling the caregiver role for their chronically ill mates (Crossman, 1981). Generally, however the caregiving role is assumed without an understanding of the consequences (Archbold,1982).

In the nursing literature, Archbold (1982) completed an exploratory study of the impact of parent caring on the lives of thirty women. Archbold (1982) asserted that parent carers represent a large and increasing group of women in American society. Caregiving, as described in most caregiver literature, is a care provider role. Archbold (1982) identified two caregiving roles, which consisted of care provision and care management roles. The care provider (mean age 57 years) identified the services required by the care recipient and personally provided services to the patient. Regularly performed activities which may extend over twenty-four hours each day included daily provision of tasks such as bathing, toileting, lifting, transferring, and feeding; and daily provision of food preparation, home maintenance, and housekeeping. The care manager, (mean age 51 years) identified and managed service provision through others by obtaining professional and non-professional services for those tasks they did not wish to do or were unable to do themselves. The mean age for all of the parents was 82 years.

Archbold (1982) drew attention to the differences by discussing factors such as socioeconomic status which influenced the assumption of the care provider or care manager role. Importantly, the care provider role was assumed rather than chosen when limited financial resources prevented the option of care management. The author concluded that activities which were restrictive of caregiver freedom were more predictive of burden. In general, care providers reported loss of freedom due to the fact they were more likely to live with their patients. Furthermore, care providers had fewer social supports compared to care managers which further limited ease of access to the social system and knowledge of options. The benefits of caregiving were identified primarily by the care manager group, associated with finding personal meaning and feeling a purpose within the caregiving experience.

According to Archbold (1982), only one half of the care providers found benefits of caregiving. Others expressed feelings of being trapped in a situation of great physical and emotional duress, increasing costs, and continuation of their present life situation. The problems encountered by providers and managers of care differed substantially. Providers identified and delivered direct patient care requiring assessment of function skills and implementation of methods to assist the disabled elder. Managers on the other hand, asssessed their patient's needs, and then identified others who would perform those services. Thus, the manager must also have the ability to negotiate the social system. The implication was that strategies developed by caregivers impacted their lives, the lives of the care recipients, and their families, the later of whom generally played a secondary role in the caregiving process.

Equally relevant, the importance of patient-caregiver relationships was highlighted in a Model of the Caregiving Process (Pearson, et al.,1986). In this model, it was reported that many parent caregivers' complaints about their caregiving relationships with their parents were rooted in earlier parent-child relationships. Moreover, Robinson and Thurner (1979) described relationships between adult children and their debilitated parent as becoming increasingly more negative during a five year study.

In spouse caregiving, it would seem that caregiver strain is related to the intensity of the bond between caregiver and care recipient. Indeed, the greater the emotional investment, the greater the frustration associated with caregiving (Cantor,1983). In a study which focused on the particular needs and concerns of the elderly caregiving spouse, some of the frustrations of wives who scored low in morale were such problems as isolation, loneliness, economic hardship, and role overload. For instance, Cantor (1983) described elderly spouses compared to other caregivers to be at greater risk for strain as a result of caregiving.

Within the caregiving literature, there is little evidence to support reasons why family members decided to caregive. The decision is based on complex factors which were influenced by the individual characteristics of the patient and caregiver, the patient-caregiver relationship, and situational factors unique to each patient-caregiver setting (Pearson, et al. 1986).

Ory (1985) supported previous literature findings, reporting that the bulk of caregiving falls principally upon female spouses, since women typically live longer than their mates. Therefore, the decision to caregive may relate to role obligation as a factor resulting in assumption of the caregiving role. Furthermore, genuine concern for the welfare of the patient alluding to the mutuality of concern shared between patient-caregiver was suggested by Hirschfield (1983). Nevertheless, little is known about emotional bondedness, love, and affection as key factors impacting the decision to caregive. Financial survival is believed to be an important factor particularly among aged women, who may not have worked outside the home, perhaps not even accruing social security benefits. Therefore, alternate forms of economic support necessary to pay for caregiving outside the home are not realistic alternatives (Pearson, et al. 1986).

Indeed, the majority of home care is provided by the family (Day,1985; Baines,1984). At least half of the home care of the older dependent adults is provided by spouses who are themselves old and vulnerable to disease (Bennett,1983). More research is necessary to focus on the internal and external forces that result in the decision to caregive and sustaining the caregiving role over time .

Clearly, limitations in the literature are the lack of focus on elderly spouses, including marital dyad norms which would enable one to examine how caregiving affects marital relationships (Cantor,1983). While a fair amount of research has focused on the incapacitated member of the family, the impact of illness on the spouse, and the special needs and problems of the aged spouse caregiver is extremely limited in the literature (Fengler,1979).

In summary, within the literature, the caregiving process during chronic illness of the older adult is a dynamic and increasingly diverse phenomenon. The reasons for assumption of the caregiving role are not clearly delineated in the literature. Consequently, more empirical data is needed which focuses on decisions to caregive and sustaining that role along the life continuum. Indeed, caregiving can result in varying dimensions of rewards and reactions which can impact the emotional, physical, social, mental, and spiritual realms of the life processes, particularly within the caregiver. The second section of the literature review will address caregiver burden as an extension of the caregiving process.

Caregiving Burden

The role of family and informal support plays a major role in helping a disabled person maintain himself in the home and community. Society benefits from the often full time caregiving responsibilities which are generally viewed as a deterrent to institutionalization (Kahan, 1985). However, the consequences of caregiving on the informal support system is currently a major concern as the population of elderly and the likelihood of manifesting chronic illnesses increases (Ory, 1985).

Currently most older people with physical, emotional, or social limitations live at home and receive care from spouses or younger family caregivers (Brody, 1985). Ory (1985) and Sommers (1985) described the behavior and characteristics of those individuals who provide care. The bulk of care was provided by a single caregiver, generally a woman, and was typically not shared among all family members. The role of the aged female spouse, the major caregiver, has been under reported. Further, the role of caregiver as performed by older males for their impaired wives was virtually unnoticed in the literature.

There is some controversy in the literature about the health consequences of specific caregiving behaviors for elderly individuals needing care. Podgorski and Williams (1982) reported generally positive health effects in caregivers unless "over zealous caregiving" promoted dependent behaviors among elderly care recipients. On the contrary, Cantor (1983) reported that elderly spouses were more likely to be stressed due to their own advancing age, poor health, and low economic status.

In particular, few studies of older women caring for disabled spouses have been addressed in the literature. Because the life expectancy of women is longer that that of men, and because men generally marry younger women, most of the caregiving literature has focused on women, not necessarily spouses, who care for disabled family members (Brody,1981; Shanas,1980).

A unique explorative study by Fengler (1979) involved examination of the special problems of elderly wives caring for their disabled husbands. Fengler (1979) examined other literature focusing on the social factors associated with caregiving. Men and their wives in the study were administered life satisfaction scales (Neugarten, 1961), and a series of social and health indicators. Fifteen of the men were married, and their wives were interviewed to determine the differences in morale after workshop participation. The limitations of the study was the small sample size (n=34) and the absence of a retrospective measurement of life satisfaction before the husbands' disabling condition occurred. Therefore, it was not known if or how wives' life satisfaction scores were affected by her husbands' illness. Nevertheless, wives with the lowest scores were married to the husbands' with low scores and the wives' with high scores were married to the highest scoring spouses.

According to Fengler (1979), knowing about the husband and wife relationship prior to the beginning of the caregiving role would have been helpful in understanding how wives were able to cope with their husbands disability. A sense of isolation, resulting from lack of intimacy, lack of social support, financial hardship, and role overload were problems distinguishing high and low morale groups. Fengler (1979) described the morale of wives of disabled men as fairly low overall, and higher when they perceived their incomes as adequate, and not necessitating employment outside the home. As proposed in the study, wives needed help and support as much as their spouses. Moreover, the inability to communicate due to aphasia within the patient, particularly a spouse, may have been a more significant morale factor than the loss of physical mobility. Since morale scores of husbands and wives were associated, it was concluded that helping the wife caregiver would indirectly help her disabled husband (Fengler,1979).

Indeed, as a result of investigations of caregiving, this life transition experience becomes a potential area for the nurse in primary care. Fengler (1979) pointed out the likelihood that caregivers of cognitively impaired patients may have been receiving less support from family and friends who chose not to be around the patient. The caregiver experienced further social isolation as a result of the situation. Additionally, patients with cognitive impairment may have been more burdensome for the caregiver than patients with physical disabilities, as the later may have provided companionship and support, and perhaps required less direct surveillance from the caregiver (Zarit,1986). Therefore, the nurse in advanced practice needs to examine the challenge facing the caregiver as the caregiver integrates past experiences such as personal coping strategies into the patient- caregiving relationship.

Recently, literature has focused on the potential for negative consequences of caregiving personally experienced by the caregiver in the form of objective and subjective burden. Objective burdens refer to actual burden or alterations and disruptions in the life process of the caregivers as a result of the demands of caregiving. Subjective burden refers to perceptions, feelings and attitudes about the caregiving phenomenon (Zarit,1986; Ory,1984; George & Gwyther, 1984).

George & Gwyther (1984) completed a longitudinal study of 389 caregivers made up of 54% spouses, 32% adult children, and 14% other relatives. Seventy-one percent of the sample were women. The aim of the study was an examination of the dynamics of caregiver burden, that is how the caregiving patterns and the well-being of caregivers of demented patients changed over time. Caregivers were surveyed on two occasions, a year apart. At the time of the initial interview, the patient was being cared for at home, therefore all of the caregivers had direct responsibility for providing care to their patients with Alzheimers' disease or related disorders at the first test date. Subsequent nursing home placement was strongly associated with the caregivers perceived burden, rather that objective indicators of the severity of the illness of the patient (George & Gwyther, 1984).

Caregiver well-being was measured in four dimensions:

1. Financial resources.
2. Physical health.
3. Mental health, such as stress related symptoms and/or use of antipsychotic drugs.
4. Time spent in social-recreational activities.

These four dimensions of well-being were expected to be potentially sensitive to the demands of caregiving. The dimensions were all measured using valid and reliable instruments. Particularly interesting in this study was that institutionalization of the patient during the year between test dates did not show that caregiver well-being increased. On the contrary, evidence of significant deterioration on several well-being indicators was evident. These surprising findings challenged previous assumptions that institutionalization of the patient alleviated caregiver burden. The data showed evidence that caregivers had not taken the time to make the adjustment from the demands of caring by transferring those feelings of responsibility to the institution. Thus, caregivers may not have relinquished their caregiving role.

Interestingly, bereaved caregivers reflected improved well-being in four of the fourteen well- being indicators. While death of the patient allayed the basic sense of chronic stress associated with caregiving for a disabled family member, the caregiver also experienced a complete relinquishment of the caregiving role. Nevertheless, loss of a loved one was expected to be grief producing regardless of the impairment within the care recipient.

As reported by George & Gwyther (1984), bereaved caregivers grieved and mourned their loss, yet well-being changes suggested that loss of the caregiving role had resulted in almost immediate improvement in certain dimensions of quality of life. Positive dimensions were noted in increased participation in voluntary organizations, decreased use of psycotropic drugs, increased involvement in social and recreational activities, and decreased levels of stress related psychiatric symptoms (George & Gwyther, 1984). All of these dimensions were positive health behaviors despite a major life transition experience.

The long term care and aging literature has drawn attention to the question of the ability of the family to provide prolonged care and to the commitment and consequences of providing care. The literature supports that while other family members may support the caregiving activity, caregiving is generally not an activity that involves many family members. Furthermore, the more cognitively impaired a patient becomes the greater the chances of caregiving being carried out as a single person activity (Bennett,1983). While several studies (Crossman,1985; Fengler,1979) have reported that spouses are the primary sources of informal support to married elders of both sexes, the role of males as primary caregivers has been relatively unexplored in the literature (Vinek,1984).

Nevertheless, speculation about sex differences suggests that male caregivers were less likely to institutionalize their patients and exhibited less burden, particularly in areas of mental health. The reasons for these differences, based upon empirical support was that male caregivers received more social support from friends and family than female caregivers (George & Gwyther, 1984). Other reasons for gender differences were that men may not attempt to do everything, thus are less involved in the caregiving role. Accordingly, male spouse caregivers may view their role as productive use of time formerly provided through paid employment. Moreover, Zarit, et al. (1986) suggests the importance of exploring and understanding the dynamics of caregiving as a foundation for designing well planned and timely interventions. These strategies may relieve some of the burden experienced by caregivers.

In a study by Crossman, (1985) a high risk group of caregivers, who were older women caring for disabled spouses was described. Crossman addressed the issues and special problems faced by this unique group of women wherein the emotional and physical demands of caregiving were superimposed upon the womens' own aging process. The importance of a multi-service support program for caregivers of disabled husbands in the home was portrayed as successful use of a support and respite model. The motivation for utilizing this health service intervention through a wives support group evolved from the author's personal experience. The author provided care for her stroke disabled husband for seventeen years. During this process she learned about a number of spouse caregivers who died as reported by their widowed husbands who subsequently were placed in nursing homes. One hundred and one wives have participated in this group since its' inception. Issues discussed were societal expectations which reinforce the "mother" as caregiver throughout her lifetime, and emotional and social isolation resulting from caregiving.

Equally important, subjects addressed by the support group were role ambiguity, loss of closeness and affective needs, anger and frustration with the myth of the "golden years". Sharing of common experiences and exploration of alternative methods of coping and problem solving were strategies used to create change within caregivers. The authors postulated that the wives respite project was the result of action on the part of a group of older women who gained strength from one another, and became advocates for each other during this phase of the life process (Crossman, et al. 1981).

Meanwhile, male caregivers reportedly tended to minimize the hardships that they had faced, yet recalled feeling isolated and tied down. It would have been interesting to know how responsive men would have been to formal supports such as group discussion and educational meetings which had been successful among female caregivers of disabled husbands (Vinek,1984).

It is well accepted that society benefits from caregiving for disabled family members in the home (Day,1985; Ory, 1985). The family is seen as a major variable in determining whether or not an elderly person will remain in the community, or will be institutionalized (Deimling & Poulshock, 1985). The positive intended and unintended consequences of caregiving burden is now being addressed in the literature. Having primary responsibility for an elderly spouse or older family member with one or more functional disabilities can potentially impact the caregivers' health and well-being (George & Gwyther, 1984; Zarit, et al. 1980, 1986; Ory, 1985). Perceptions of burden, however are not always correlated with the extent or severity of a care recipients' state of health. Many factors can impact objective and subjective burden causing a dissolving of the informal caregiving arrangements, leading to the institutionalization of the care recipient and ill health within the care giver (Gwyther & George,1984; Fengler, 1979). It is postulated that families and friends can potentially draw together and face special caregiving problems despite diverse life transition experiences (Haug, 1985; Crossman, 1981; Zarit, 1986; Vinek, 1984).

Little is known about male spouse caregivers, beyond the knowledge that such men do exist. In general, there is a need for research and attention to the roles of men in old age. Meanwhile, since the majority of caregivers are female, elderly, financially strained, and likely to have deteriorating health themselves, caregiver burden becomes a major concern among all elderly individuals and their families. It is not likely that a caregiver will institutionalize his/her family member without having experienced a degree of subjective or objective burden or external pressure. Nevertheless, continued research is necessary to determine what factors impact caregiving and care withdrawing decisions.

The nurse in advanced practice has an opportunity to function in mutuality with the caregiver at varying points along the caregivers' health continuum toward maximum health potential. Little is known about the phenomenon of unburdening. Nevertheless, the range of literature which contributes to an understanding of alterations in role transition from caregiver of ones' spouse to caregiver of oneself, following the death of the mate, will be explored.

Caregiving Unburdening

For purposes of this study, unburdening is defined as the extent to which recently bereaved caregivers perceived an alteration in their emotional, physical, social, financial, mental, and spiritual dimensions as a result of the death of their spouse. The process of unburdening is the release of, or yielding to, or holding onto that quality or state of burden when the actual force of the responsibility of caregiving is no longer present. Furthermore, with the death of the ill spouse, the intensity of the burden may be accentuated. At the same time the surviving mate moves forward reappraising patterns which previously may have provided meaning and purpose within the life of the caregiver.

The death of a spouse is viewed as an emotionally devastating event and is recognized as a source of intense emotional stress. It is ranked high on life event scales and may be the most severe stress an older adult may encounter (Martocchio, 1984; Breckenridge, et al. 1986). According to the literature on loss and emotional disorders, normal grief can be differentiated from pathological depression (Dimond, 1981; Parkes,1965, Breckenridge,1986). The current diagnostic and statistical manual (DSM III) of the American Psychiatric Association (1980) regards a pathological bereavement reaction indicator as a preoccupation with worthlessness. According to DSM III, normal signs of grief include such somatic depressive features as weight loss, poor appetite, and sleep disturbances.

Glick, et al. (1974) described the normal grieving process in three phases. The onset of the initial response begins at the time of death and usually lasts several weeks post burial of the deceased. During this period, feelings of numbness, emptiness, profound sorrow, and disbelief are characterized. The intermediate phase of normal grief is characterized by the need to review the death, search for meaning of the death, and occasionally searching for the deceased. Within several months, functional stability is reattained and behaviors are directed towards reorganization of lifes' goals. The recovery or third phase of bereavement is distinguished by social reinvolvement and an acquiring of competence of skill with the beginning of the second year post bereavement.

Following the death of the spouse, the degree of the loss is related to the nature and quality of the bond between the surviving spouse and the deceased individual. For example, the level of dependence and the role in the family may have been altered between the marital dyad due to the illness of the spouse, resulting in varying levels of felt burden and rewards within the surviving mate. Consequently, while the death may have been anticipated, the void that comes with the death was not expected (Pollack, 1978).

In a study by Breckenridge, et al. (1986), profiles of 21 self reported depression symptoms from recently bereaved elders (n=196; males=92, females=104) with a mean age of 67 years were compared with those of 145 control participants (males=80, females=65). The later subjects were married or single and had not lost a spouse to death or divorce in the past five years. The mean age of the later group was 70 years. Responses from bereaved subjects were recorded approximately two months following the loss of the spouse. A one hour structured home interview was utilized to probe bereavement reactions. In addition, participants returned by mail a set of self report measures consisting of the Beck Depression Inventory. Bereaved participants were significantly more likely to report symptoms typical of depression such as dysphoria, self dissatisfaction, and somatic disturbances, even when variations for age, sex, number of years married, and educational and occupational status were considered.

It was suggested by Gerber, et al. (1975) that bereaved older adults who lost a spouse due to lengthy chronic illness were impacted by a greater prevalence of grief reactions than those whose spouses died suddenly. Moreover, anticipatory grief responses during the course of the spouses chronic illness were significantly associated with depressive symptoms in the initial months of bereavement (Clayton,1973). In the Gerber study (1973), many participants stated they did not expect their spouses death yet were reporting serious chronic illness in their spouse. The apparent difference was that subjects did not perceive the death to be eminent. Interestingly, both Gerber (1973) and Clayton (1973) classified participants based on length of the spouses chronic illness and not on subjective report of expectations. Possibly, subjective report of expectations is a more accurate way to view this phenomenon because people tend to adapt to what they can foresee as a negative event in their lives. In any event, the topic of bereavement reactions in the elderly presents a need for further research about the impact of anticipated death on elderly survivors.

In a prospective study of 95,647 Finnish widowed persons during 1972-1976, Kaprio, et al. (1987) revealed that widows and widowers have a higher mortality risk than married persons. The principle excess mortality rate was found during the first week, month, and half-year after bereavement particularly related to ischemic heart disease. Speculation as to heart disease being the cause of death may relate to grief and emotional distress which may induce sleep disturbances predisposing to arrythmias, thus leading to cardiac mortality. Also, sleeplessness after bereavement may be a predisposing factor in a reactive psychosis which may predispose the individual to suicide. It is speculated that guilt feelings may be induced by loss of the spouse, leading to depression and self neglect. Consequently, mortality from suicides was greater than expected during the first years of widowhood. In addition, the study supports sex differences in health risks of the widowed male subjects (Kaprio, et al.1987).

Moreover, Helsing et al. (1981) reports support by other persons living with the bereaved person during the grief reaction was an important determinant of mortality. Furthermore, adults lacking social and community ties had a 2.3 to 2.8 fold risk of death, independent of variables of physical health status, socioeconomic status, use of alcohol, smoking, physical activity, obesity, and use of health promotive services (Berkman & Syme, 1979).

As reported by Werner & Beland (1984) there is a need for longitudinal studies of individuals who sustained gradual losses following long term illness of their spouses. The individual attempts to gain information over time and thereby evaluates his life situation as a result of the caregiving and bereavement experience. Components to the grieving process the person considers may include :

1. Prior stressful life events which have occurred.
2. Coping strategies employed in response to previous losses.
3. Social supports utilized.
4. Significant lifestyle modifications needed to be made.
5. General methods utilized to make these modifications.

As a part of the resolution of loss the individual explores past experiences to determine what has been lost, and the consequences of the loss. Future life style modifications can be repatterned through this process (Werner & Beland,1980; Thompson, et al. 1984).

Thompson, et al. (1984) reported on the effects of bereavement on self-perceptions of physical health in elderly widows and widowers two months following their spouses death. The researchers found that bereavement of a spouse is a significant stressor that may adversely affect the physical health status of survivors. Stress was manifested in an increased likelihood of the development of new health conditions, or the worsening of pre-existing conditions not evident in the non-bereaved counterparts. Thompson (1984) also found an increased use of previously prescribed medications or new medication usage. These findings were not supported in a study by Parkes (1972) who followed younger widow and widowers than the age group consisting of fifty-five to eighty-three year old subjects reported in the Thompson (1984) study (Parkes,1972; Thompson,1984).

Furthermore, Silverman (1972) cited that contemporary traditions and patterns of behavior have supported people and their reluctance to face death and the impact on family life. Verbal discussions of the concerns of widowhood rarely occurred, even when the spouse was seriously ill and death was eminent. However, silent consideration may have been occurring as people observed and experienced deaths of friends who became widowed (Silverman, 1972).

In the 1980's many bereavement related health services rely on self referral, assuming that people who need help will ask for it. This assumption is based on the premise that people who need help are aware of the need, and that they are willing and able to seek help. Unfortunately, many people are not physically, financially, emotionally, or spiritually prepared to seek help (Parkes,1981).

Surprisingly, there have been few reports of controlled intervention studies in the literature with conjugally bereaved persons. Gerber, et al. (1975) reported a longitudinal study that offered brief therapy to aged bereaved individuals. A group (n=169) of non patient elderly (over age 65) persons from a Health Maintenance Organization whose spouses died from either cancers or cardiovascular diseases were studied. Participants were assigned randomly to an intervention group (n=116) or control group (n=53) and were followed a minimum of three years. Weekly meetings or phone contacts with a psychiatric nurse or social worker were offered for the first six months of bereavement to the intervention group and their family members who were part of the same household. Therapy focused on moral support, grief work, and environmental manipulation. Interestingly, only medical indicators were reported to document the bereaved persons' medical, psychologic, and social adjustment initially, and at two, five, eight, and fifteen months post bereavement.

Results showed that during and shortly after the intervention, the supported persons reported less drug use, had fewer illnesses, and utilized fewer doctor visits than the control group. However, at fifteen months following bereavement, there were few significant differences in these measures and no significant differences in major illnesses. In conclusion, the authors reported those who benefited most from the intervention were physically healthy at the time of bereavement. Furthermore, it has been suggested by Gramlich (1968), that elderly bereaved persons face loss with greater cognitive acceptance, therefore most manifestations of grief are less prominent. On the other hand somatic symptoms and illusionary experiences involving the deceased person are thought to be more notable among the aged.

It is well described in the literature that the death of a spouse is a stressful process in terms of the intensity and duration of the mourning period which involves complex readjustments in life roles (Windholz, et al.

1985; Dimond,1981). Bowlby (1961) described the sequence of mourning the loss of a loved one, first as a subjective grief experience beginning with anxiety and anger, moving through pain and despair, and ideally ending with hope.

The course is not necessarily smooth, as yearning and rage, alternating with feelings of despair are reported. Therefore, mourning is a diverse psychological process beginning with angry efforts to recover the past, such as regaining purpose and meaning in ones' life again. Moving through apathy and disorganized behavior to the beginnings of reorganization is notable as mourning progresses. Further, mourning can take different courses, one which ultimately leads to relating positively to new objects through the pursuit of more constructive and satisfying activities, and another in which the individual experiences an altered course with increased depression and decreased socialization (Bowlby, 1961; Paul, 1966).

Malone, et al. (1985) completed an exploratory project in examining the effects of bereavement on the caregiver whose family member was affected by senile dementia. Malone (1985) recognized bereavement as a major life stressor and emphasized that conjugal bereavement was associated with physical and mental health decline, increased mortality, and a higher suicide rate. Further, despite the risk, most bereaved individuals adjust to the loss of a spouse. However, following lengthy illness, bereaved caregiver stressors do not end when the patient dies. Malone (1985) described the complex process through which bereaved caregivers of Alzheimers' patients' journey.

In the Malone study, data were collected from forty-two caregivers with a mean age of 56 years. Twenty one individuals were caregivers at the time of the study, and twenty one subjects were bereaved caregivers of

Alzheimers' patients. Caregivers were adult daughters (45%), spouses (40%), and other family members (14%). Study participants responded to questionnaires reflecting life satisfaction, depression, and social support. Bereaved caregivers also completed grief and coping inventories. Each bereaved participant was interviewed with questions addressing the patients' health care needs, caregiver attitudes about patient care, stresses experienced before and after the death, and methods used to cope with these stresses.

The Malone (1985) study showed that the stresses experienced by caregivers of Alzheimers' patients did not necessarily end with death of the patient. Bereaved caregivers in the study reported depression levels and life satisfaction scores similar to those found in the caregivers' sample. Further, bereaved caregivers of demented patients expressed ambivalence when discussing their loss. For example, they stated they had accepted the illness, but were unprepared for the sense of loss actually experienced about the patient's death. In both samples, caregivers and bereaved caregivers were mildly depressed even though the bereaved group had been bereaved an average of three years.

The limitations of the Malone (1985) study were the small sample size and an exploratory approach which inhibited drawing definite conclusions about physical and mental health, increased mortality and morbidity, and a higher suicide rate based on the single study. Nevertheless, the Malone (1985) paper illustrated the need for further empirical data and holistic interventions which focuses on the special needs of bereaved caregivers throughout the total experience of caregiving and the death of a family member.

In the psychiatric literature, Parkes(1970) completed a longitudinal study of widows in the first year of bereavement. Participants were recent widows who had visited their physicians during the first month of bereavement. The average age of participants was 48.8 years, with a range of 26 -65 years. All informants were willing to be interviewed by the writer with information systematically obtained about the process of grief and responses to bereavement over time. Employing a longitudinal technique, Parkes (1970) utilized standardized questions with each widow at one, three, six, nine, and thirteen months after bereavement. An empathic rapport was established early in the interview process with general questions which encouraged each subject to describe her experiences relating to bereavement. Only when the individual was finished verbalizing were additional questions asked to cover the scale areas. At thirteen months, 27% of the twenty two participants reported that their health was definitely worse, and none responded that they were clearly healthier.

Further, Parkes (1970) reported that the adjustment for widows who had multiple stressful life events in the two years prior to the death of their spouses was poorer than those widows who did not have such stresses. Typical complaints reported were headaches, digestive disturbances, and aching limbs. Parkes (1970) suggests that the loss of a spouse created a significant challenge in adaptation for the remaining spouse who had previously experienced multiple stresses. Furthermore, findings from this study included a failure of most respondents to accept warnings of the impending death of their spouses despite being told of the seriousness of their husbands conditions. The most prevalent cause of death of the spouse was cancer and cardiovascular disease. With the passage of time and because of the release of a great deal of affective information, the bereaved person gradually works through the grieving process. Nevertheless, most participants viewed their project involvement as helpful to themselves.

The responses made by the widows in this study confirmed Bowlby (1961) and Parkes (1970) belief that grief is a sequential process. The grieving persons gradually examined their situation from a new perspective. In the course of grieving, transitions from one phase of grief to another were not distinct, and aspects of one phase were integrated into the next phase. Numbness often took place first, followed by yearning and protest as one attempted to achieve that which was lost. At the end of four weeks of bereavement, tearfulness declined. Over the first year preoccupation with the memories of the lost spouse, irritability, and tension gradually declined. Simultaneously, despite psychological pain, anxiety, intertwining periods of depression, and loss of purpose and meaningful activity, widows began to redefine new roles and function effectively again after the death of their husbands (Parkes,1970).

Parkes (1970) concluded that a significant loss lead to painful review of ones' assumptions about self and a restructuring of the presupposition of the world to include a new view of ones' self. Therefore, the effectiveness of life review depended on the individuals' willingness to reappraise the meaning of life, purposes and beliefs she had about herself following a life transition experience.

In a quantitative prospective study, Bornstein, et al. (1973) explored the natural history of the depression of widowhood. A group of randomly selected widows and widowers (average age 62 years) were interviewed shortly after the death of their spouses. Members of the group (n=92) were reinterviewed from approximately one year to seventeen months of the death. All of the subjects met the following criteria for diagnosis at the time of the interview. Depression was defined as subjective report of low mood characterized by feeling depressed, sad, feeling despondent and blue, or any other low mood terms such as lost or numb. Additionally, four of eight of the following symptoms required were:

1. Loss of appetite or weight.
2. Sleep disturbances.
3. Fatigue.
4. Feeling restless.
5. Loss of interest.
6. Difficulty concentrating.
7. Feelings of guilt.
8. Suicidal thoughts.

This cluster had to be present at the time of the interview. The study used the Chi Square to determine significance. The focus of interest in this study was how the subjects fared psychologically over a year following the spouses' death. At follow-up, 17% of the subjects were depressed when measured by consistent and systematic criteria.

The Bornstein (1973) findings correlated with Parkes (1970) study of twenty-two London widows which described psychological states of 14% of study subjects as poorly adjusted, depressed and still grieving at thirteen months following the death of their spouses. Data confirmed that the strongest predictor of depression symptoms at thirteen months was the presence of depression at one month ($p<.01$). Factors which may have contributed to prolonged depression were lack of supports such as financial and religious (Bornstein, 1973). Furthermore, Parkes (1983) suggested that lack of a close supportive family network perpetuated social withdrawal as the bereaved widow was unable to displace emotional needs which commonly resulted from ill directed expressions of anger during the grief process. Bornstein (1973) cites that prior losses may have strengthened the ability of the spouse to cope with losses in later life.

These previous studies did not focus on the elderly bereaved, however the older adult may be particularly vulnerable following the loss of a spouse. The older bereaved person may have outlived both friends and relatives. Moreover, remaining significant other persons may themselves be in a precarious health state producing a sense of apprehension about their well-being. Additionally, elderly individuals are likely to experience other kinds of losses such as loss of a home or neighborhood due to a necessary change in residence to accommodate the deteriorating health status of the family member. Further, physical losses, such as loss of physical function, loss of hearing or vision associated with chronic illness may produce gradual losses of the self over time. Kastenbaum (1969) referred to the accumulation of losses in the elderly as "bereavement overload" producing a different pattern of grief with the additional loss of a spouse, than the grief displayed in a younger population (Dimond, 1981).

The conclusion of the Bornstein (1973) study cited that while some subjects experienced depressive symptoms, none were called psychotic. Therefore, normal depression of widowhood should be considered as separate from studies of affective disorders in psychiatric patients. A disadvantage of the study was that when grieving is viewed from a physical or psychological perspective alone, reports such as weakness, fatigue, physical emptiness, and pain may not be recognized as significant symptoms of grief. Thus, the need to restructure patterns within the bereaved individual may not be made apparent.

In bereavement following the caregiving experience, losses have occurred as a part of the process of caregiving such as loss of a marital relationship, loss of intimacy and sexuality. Loss of an occupation, and role, loss of social supports, loss of finances, and loss of purpose and meaning in ones life are also reported. Therefore, while not cognitively aware of the magnitude of the loss, the caregiver moves into widowhood with a history and foundation for making the transition from the role of the wife to widowhood (Silverman, 1972). Nevertheless, in the United States, despite the extent of the losses, a bereaved persons' period of mourning is expected to be of short duration and often ends before the new widow or widower knows how a new role as a single person will impact his/her life (Silverman, 1972).

It is clear in the existing literature that the loss of a spouse creates a major adaptive challenge for the bereaved spouse. The resolution of grief, establishing a new identity as a single person, and repatterning ones' life into the social structure are complex tasks which require resources and time (Dimond, 1981).

However significant this adjustment to bereavement, little has been done empirically to describe grieving following caregiving in the elderly population. Nevertheless, Dimond (1981, p. 469) proposes that "a logical and integral part of nursing care to the dying person is bereavement care for the spouse." Accordingly, utilizing the concept of unburdening to assess and identify clients at risk, a role of the CNS in primary care is to provide a source of continuity of care for the caregiver. Further, the nurse is able to mutually assist bereaved individuals as they move to redefine their lives and form the pattern of trajectory of adjustment to the loss of a spouse following caregiving. The nurse is the only professional in a position to provide continuous care (Rigdon,1987). Therefore, in the process of helping the spouse reestablish and restructure his/her life, the CNS has an opportunity to facilitate evolvement through this period of multidimensional transition (Rogers, 1981).

Silvermans' (1972) widow to widow program teaches individuals to care for themselves, then move into the caregiving role of helping one another, thus the helping person is being helped. Help comes from really understanding, based on knowledge and experience and having alternatives available to assist the widowed individual. A cycle of giving and receiving is achieved where the potential for healing and health is maximized.

Similarly, within the nursing literature, Rigdon, et al. (1987) conducted a study to generate a theory of helpfulness for the bereaved elderly. The study was a part of a larger descriptive, longitudinal study of elderly bereaved individuals. Thirty bereaved persons were interviewed in their homes, six times during a two year period, post death of the spouse. The initial interview occurred approximately four weeks following the death, then at two, and six months, one year, eighteen months, and two years. Interviews were tape recorded. Three questions were asked:

1. Is there any advise you would give someone else who has lost a spouse ?
2. Have others been helpful to you during the past few weeks ?
3. What have they done ?

Using content analysis a search was made for data that recurred repeatedly, thus representing patterns or themes that could be clustered into categories.

The frequency of recurring data throughout the interviews was used to determine that the data represented patterns or themes. Examples of categories that described behavior of others, that elderly bereaved perceived as helpful were; "being available, expressing concern, keeping in touch, extending social invitations, providing transportation, providing legal and financial assistance, and giving "care packages", and providing physical help" (Rigdon, 1987, p. 39). The seven categories were expressed in two unidimensional and mutually exclusive categories, which were described as "be there and do something" (Rigdon,1987, p. 41).

Researchers found that to be helpful, the bereaved person needed a call and a response from self to self, and from others to the self. In essence, older bereaved persons had the primary responsibility to invite themselves to a new life, after the death of a spouse, by being an individual and by being involved with others. Additionally, researchers found that others must invite the bereaved person to become a part of their lives by being there and by doing something for or with them. Without an invitation from others, the new life of the bereaved was diminished and the invitation was only partial. Further, the bereaved were able to give to others in response to the question, "what advise would you give to someone else who lost a spouse" (Rigdon,1987, p.36). For example, bereaved respondents answered by advising others to be an individual because grief is unique for each person, and to communicate with others.

Unburdening potentially could occur when participants actively communicated advice to others, to assist them in coping with a significant loss. It would appear that by coming to the assistance of someone else, the possibility of resolution of ones' own problems becomes clarified. The process seems to progress when perspective is altered by reaching out to another person.

According to Rigdon (1987), an invitation to a new life for the bereaved meant giving and receiving. This theory of helpfulness during bereavement was primarily crisis oriented. Intuitively, nurses realize that bereaved persons need care and concern from others. Less commonly realized is the fact that bereaved elders also want and need to help others. Nurses are in a unique position to intervene to facilitate healing and growth following bereavement by encouraging family and friends to allow widows and widowers to not only receive help but to give it. Furthermore, continuing help for a longer period of time is a more credible approach for elderly bereaved persons (Rigdon,1987).

Further, in an opinion article within the nursing literature, Hogstel (1985) identified older widowers as a small group of bereaved individuals who were more likely to experience loneliness and depression then widows. This phenomenon of widowhood occurred in part because of their advanced age. Most widowers were eighty years and older, and at this age they made up a small population of individuals. Furthermore, women tend to out live men by almost a decade in this age group. The age factor often prohibits cultivating new social contacts or maintaining old friendships made in previous associations with the spouse. Loss of a spouse and companion for numerous years is devastating to many men. The significance of this loss may account for the statistic that places white males in their eighties as having the highest suicide rate in the United States (Hogstel, 1985).

Interestingly, some of the unique concerns experienced by widowers related to their inability to evolve through the grief process as satisfactorily as widows, as many men in American society did not learn to express their emotions openly. Further, men in their late years may be physically and emotionally unwilling to learn new skills which were formally considered the "wives tasks", such as cooking and keeping house (Hogstel, 1985). Moreover, widowers have more difficulty adjusting to alternate living arrangements such as living with adult children. Therefore, loss of independence that may be associated with ill health, and loss of usefulness and role in the family may be threatening to the well-being of the widower (Hogstel, 1985).

Raphael (1983) cites that bereaved widows and widowers have a number of tasks to negotiate for longer term adaptation to life without their spouses. There is a need to find new sources of adult to adult relationships that will meet needs now unfulfilled with the loss of the spouse. As described by the author, the needs within these adult interactions include attachment, nurturing, guidance and reassurance, social interaction, and alliances. Outlets for meeting these needs must be individually planned and mutually negotiated. Indeed the nurse is in a key position in a primary care setting where the needs of the elderly can be assessed and addressed. Moreover, the bereaved spouses sense of worth may have been intimately bound to the roles and identity that the marital relationship prized (Hogstel,1985; Raphael,1983). Therefore, an awareness of patterns of adaptation to loss in the elderly widower is health promotive and can be incorporated into unburdening management by the nurse in advanced practice.

Importantly, researchers preparing empirical data and other caregiving research have concurred that the consequences and implications associated with loss of a spouse following a long term illness of the mate is distressful and can impact the health status of the aged survivor (Parkes, 1970; Vinek, 1984; Bowlby, 1970; Malone, et al. 1985; Hogstel, 1985). Accordingly, knowledge and understanding of caregiving burdens and grieving following the death of a spouse can lead to new insights in helping bereaved caregivers as they release their burdens.

As cited by Schneider (1984), the spiritual dimension of grieving involves the process by which an individual finds meaning and purpose in life following loss. After experiencing a significant loss, a persons value system, his goals, and beliefs are altered. Therefore, an individual may need to redefine and integrate a life purpose that no longer is dependent upon what was lost. The unburdening process within spiritual dimensions depends upon grieving themes which include confronting ones' belief system, ones' goals in life, and a reappraisal of lifes' purposes (Schneider, 1984; Parkes, 1970).

Summary

In summary, the literature supports repatterning and growth with the concept that as resolution of loss occurs, the body recovers and depleted energy stores are renewed (Glick,1974; Schneider,1984; Parkes,1970). Nevertheless, limitations in the literature in the area of unburdening and bereavement are clearly evident. Bereavement among the elderly is an under researched area. Most studies of bereavement included only widows in spite of evidence linking an increased risk of physical and emotional deterioration greater for bereaved men than for bereaved women.

Furthermore, Maddison and Viola (1968) reported the failure to include widows of men over the age of sixty years was deliberate to avoid the possibility of contamination of the sequence of bereavement with the consequences of the normal aging process. For such uninsightful reasoning, there is little knowledge of the bereavement process in older age males and females. Additionally, the use of cross-sectional design with good and bad bereavement outcomes determined on the basis of recall of health-illness symptoms over the past year produces a criticism of the validity of findings based on recall (Dimond,1981). Furthermore, Thompson (1984) reported that while economic factors may be important moderators of the impact of bereavement on elderly adults, few studies have examined the differential effects of socioeconomic status. Consequently, complex interactions among age, sex, socio-demographic factors have not been explored well in the literature.

A review of the current and classical literature has been presented in the following areas; the caregiving process, caregiving burden, and caregiving unburdening including grieving following the death of the caregivers' mate. A great body of literature has been focused on these areas with the exception of caregiving unburdening. Critical points will be summarized as follows; grief can be conceptualized in several ways, each accompanied by a slightly different set of bereavement behaviors; little is reported in the literature about the response of elderly individuals to the loss of a spouse, and widowers are virtually excluded from the literature. Further, differences relating to the manner older persons experience the death of a spouse from younger persons was not found in the grief literature. Some significant contributions have been made within the grieving literature relating to the first year of bereavement.

Minimum attention has been given to caregiver unburdening following spouse bereavement. A powerful predictor of adaptation to widowhood is past experience. The competencies and skills utilized in previous difficult situations probably continue to be used to cope and survive losses such as the changes related to chronic illness and the death of a spouse. Empirical data to support this area is lacking, yet it is reasonable to assume that successful coping in one stressful event is potentially transferable to another.

In general, there is a need for research and attention to the experience of grieving and unburdening within spouses following the loss by death of their chronically ill mates. There is a need to explore over time resultant physical and mental problems, spiritual concerns, family relationships, financial sequela, social isolation, self care as well as the positive implications following the loss by death of a significant family member. The researcher attempted to find data on the concept of *unburdening* but none was available.

Thus, in conclusion, the literature findings would suggest that the process of unburdening may well be related to a number of different factors:

1) Factors concerning the caregiver/care recipient process such as the duration of caregiving, prior relationship, health status, social supports available, and financial constraints.

2) Factors relating to the bereaved caregiver such as age, level of physical or mental impairment, well being, previous coping strategies, and prior stressful life events.

Therefore, the extent and rapidity of unburdening will depend upon these factors which can best be ascertained by examining the interview guidelines and outcomes. In the next chapter, the methodology used for the collection and interpretation of data within this study will be described.

CHAPTER IV

METHODOLOGY AND PROCEDURES

Overview

This research study was designed to explore the process of unburdening as experienced and expressed by the former spouse caregiver following the death of the chronically ill mate. In depth open ended interviews were carried out at one and two months following the death of the former caregivers' spouse. Within this chapter, the research approach, the criteria for inclusion, the method, and human subjects protection will be described. Also discussed is the development of the interview schedule, socio-demographics, data collection procedure, and instrument formulation. Data analysis plans are identified.

The Research Approach

A qualitative research approach was chosen to explore unburdening within physical, emotional, mental, social, financial, and spiritual dimensions in former caregivers following the deaths of their chronically ill spouses. Ethnographic field work was used to explore the general area of unburdening, a phenomenon about which little is known. A qualitative type of research refers to the methods and techniques of observing, documenting, analyzing, and interpreting attributes, patterns, characteristics, and meanings of the cultures of individuals experiencing caregiver unburdening (Spradley,1980; Munhall,1986). Culture is defined as acquired knowledge that people use to interpret experience and generate social behavior (Spradley, 1980).

The researcher documented and described the major features of the events, situations, and experiences of spouse unburdening following the death of the family member. The goal of this qualitative study was to analyze and describe the unburdening phenomenon from the subjects point of reference. Further, verbatim statements, thoughts and behaviors were studied in depth to discover common patterns and themes from informants within the individual, actual life setting, their homes.

A quasi-grounded theory approach of data analysis was utilized (Field & Morse,1985). An inductive, from ground up method, is guided by the assumption that people do, in fact, make sense out of their human field and environment despite the seeming appearance of disorder or chaos to the observer (Munhall,1986). The researcher has chosen a subject area where the knowledge base is sparse. Based on observations and interview data, the resulting findings may assist in understanding holistic dimensions of the study participants who have experienced caregiving and the death of their spouses. The resulting data may provide a foundation from which timely nursing interventions may be identified as well as, social planning and problem solving in this increasing human social problem in todays society, as the size of the older population increases.

Criteria For Inclusion

The study subjects consisted of recent widows or widowers, who were willing to be interviewed one and two months following the death of their chronically ill spouses. A convenience sample of three spouses was utilized for the study. The participants were admitted initially to the study through a telephone interview. Spouses of care recipients, who died approximately one month prior to the phone screening, were asked to participate in interviews exploring their caregiving and unburdening experiences.

Criteria for qualifying participants for the study included:

1. Former spouses 65 years of age or older.
2. Ability to speak English.
3. Bereaved spouses who are mentally alert.
4. Consent in writing, for two audio taped, one hour, interviews at one month intervals.
5. Willingness to be interviewed in their homes.
6. Individuals who cared for their spouses for a minimum of two years, or more.

Methodology

In this study, the researcher used ethnography as a means of factually describing, exploring, and analyzing aspects of a way of life of individuals experiencing caregiving unburdening following the deaths of their spouses. The essential method used was participant observation, field work, and intensive interviewing with interviewer participation within the subculture. The purpose of the methodology was to contribute descriptive and exploratory findings of the subjective meanings about the phenomenon of unburdening involving three bereaved spouses (Spradley,1980; Munhall, 1986).

The in-depth interview portion of the research was carried out in the homes of the participants. Using open ended interview questions and observation methods, the researcher explored the subculture with the informant moving from concrete to higher levels of generalization. As a result, patterns and themes were derived from the data which served to communicate meanings of a subculture.

Additionally, there was search for commonalities, and differences in unburdening constructs across informants and changes occurring over time. As a result of the interview content, and interpretation of data, new dimensions and insights, and could shed light on unburdening as a viable process.

As the interview was audio-taped, the informant was fully aware of the main components of informed consent, as follows:

1. Freedom to refuse to answer any questions at any time during the interview.

2. Permission to stop the interview or withdraw from the study at any time.

3. Understanding that names were not associated with the material.

4. The preliminary interview was utilized for the purpose of getting acquainted, arranging, and scheduling the subsequent interview. Further, the interviewer then proceeded with questions that related to a typical day when caregiving and current reactions which developed since the death of the spouse.

The researcher entered the respondents field as a stranger and learned about the environment by asking questions and obtaining explanations from informants. All respondents were asked the same questions. Nevertheless, the process of getting information required the interviewer to listen for implicit and explicit meanings in the explanations and responses to questions provided by the informant. The interviewer probed for additional data, building on the previous interview in a cumulative process over two consecutive interactions with a month interval between interviews.

By means of participant observation, the researcher constructed a description of the subculture as the informant reported it. The researcher observed the activities of people, the physical characteristics of the social situation, cultural artifacts, and what it felt like being a part of the participants' world (Spradley,1980). Further, in making the ethnographic record, the researcher took field notes and recorded observations to obtain a broad overview of the social situation. Open ended interviews were utilized. The interviews were considered formal as they were held at appointed times and resulted from a specific request from the interviewer to hold the interview. The recordings served to build a bridge between observing and analyzing which lead to more questions for further insights and ideas. As a result of this methodology, findings which identified strategies applicable in primary health care in working with unburdening clients became apparent.

During the initial interaction, the interviewer obtained a broad overview of the situation with non-threatening questions about a typical days' activities. Building a trusting rapport was essential during this period. The researcher anticipated that informants' may respond in a reserved and guarded fashion during this period and that this reaction would resolve as the interviewer was accepted into the subjects' environment. After the initial half of the first interview, the researcher asked questions leading to more focused observations in the search for patterns or themes, dimensions and insights into the meaning of caregiving unburdening.

In the final phase of data collection, role disengagement was incorporated. During this time there was a termination of relationships built over a period of two months. At the conclusion of the last open-ended question the interviewer turned off the tape recorder. The researcher asked each participant to evaluate the experience. Participants were asked if they shared their personal thoughts and feelings relating to caregiving and unburdening with anyone else. Equally important, participants were asked if they would recommend this type of experience for someone who shared a similar life transition phenomenon.

Each informant was thanked for participating in the study and praised for helping others to understand the human experience called unburdening. Additionally, respondents were given a typewritten summary of the recent literature on caregiving and unburdening (see Appendix A). Participant observation activities provided ongoing data to fill the gaps through objective notes of what was happening in the informants environment. Field notes were made to obtain a broad overview of the situation such as characteristics of the people, what goes on in the environment and how the people act. Also noted were cultural artifacts, and physical and spatial characteristics of the environment. A gift of flowers was then sent to the home of the individual participants at the conclusion of the final interview.

Informed Consent

The researcher contacted Barbara Given, R.N. Ph.D., Professor of Nursing, Graduate College of Nursing, and Charles Given, Ph.D., Professor, Department of Family Practice, Michigan State University. The purpose was to request permission for initial contact of potential research participants through a National Institute of Aging funded study entitled " Caregiver responses to managing elderly patients at home", currently coauthored and conducted by the above researchers at Michigan State University. Following approval, recently bereaved caregivers were contacted by telephone, by data collectors, for the above study. Bereaved caregivers were asked if they would be willing to participate in an in-depth study exploring varying reactions following the death of their chronically ill spouse. Individuals who agreed to be part of this study were contacted by phone by the researcher, seeking criteria affirmation and initial consent for participation. (see Appendix B) Approval for the research study was requested of the Michigan State University Committee Involving Human Subjects (UCRIHS).

Approval was received on 2-2-87, per Henry E. Bredick, Ph.D., Chairman of UCRIHS (see Appendix C). Following Institutional and UCRIHS approval, the researcher contacted each participant by telephone to verify their current interest in participation in a research study. The data collection process was conducted in the following manner:

1. Introduction of self by name, title, and association as a graduate nursing student at Michigan State University.

2. Explanation of the nature and purpose of the study and the criteria for being a part of the study.

3. Determination of interest in the study by willingness to sign consent form.

4. Explanation of what was expected in participation and an estimation of the amount of time needed to participate. What the participant could gain from involvement in the study was discussed. Assurance that a potential subject could withdraw from the study at any time and that withdrawal would in no way effect the care received from their physician or formal agency.

5. Assurance of confidentiality, including protocols of privacy and ethics of interviewing. Understanding that names would not be associated with study material.

6. Request for participation.

If the individual agreed to participate in the study, a time was scheduled for the first visit at the informants' convenience. At the first interview, the informed consent procedure was discussed (see Appendix D). The participant was asked to read and sign the consent form (see Appendix E). The consent form provided an explanation of the study, the benefits, and human rights protection information, the right to privacy and confidentiality. Each participant had the right to deny responding to any portion of the interviews. Subjects could refuse to participate at any time without experiencing any form of loss. If an individual refused involvement or continued participation in the study, he/she would have been thanked, supported, and assured that regular care would not be interrupted. Informants who agreed to continued participation mutually established dates and times for the second interview to take place. A consent form letter describing involvement in the study and signed by the researcher was given to each participant (see Appendix F).

Interview Schedule

The instrument utilized followed an open ended, in depth interview format. A process of intensive interviewing and participant observation was utilized to explore caregiving and unburdening perspectives with the informant. The standardized interview schedule was designed to collect the same categories of data from all study participants. Therefore, the answers of respondents are comparable and classifiable (Spradley,1980).

The interview format utilized for this study specified topic areas to be explored and probes used for each question (see Appendix G). Questions within this instrument were concepts based upon Rogers' (1980) theory of unitary man (see Figure 2). The literature review of grieving theory following chronic illness and death of ones' mate and the application of selected concepts to the older adult also served as a basis for questions.

The topic areas were organized so that they progressed through related issues from a non threatening topic area of a typical day now, followed by a comparison to the time when the respondent was caregiving. The subject areas moved through physical, emotional, mental, social, financial, and spiritual spheres with probes eliciting related information. The progression of questioning left the more sensitive topic areas for later in the interview when trust and rapport had been established. An example of a more sensitive question was, "if you could talk to someone who is in the same situation as you were, just two months ago, what would you like to tell them?" The socio-demographic instrument was administered at the conclusion of the taped interviews (see Appendix H).

Operationalization of Concepts

The concepts operationalized included unburdening, family spouse caregivers, loss through death, and changes occurring because of the death. The concepts of caregiving and unburdening were operationalized by observing, listening, and responding to participants' responses to open ended questions related to each of Rogers (1980) concepts developed by the researcher. Through open ended questions the informants were provided an opportunity to express themselves as whole, unique individuals who integrated past experiences into new patterns of living. Physical, social, financial, emotional, mental, and spiritual assets and limitations were observed and recorded by the interviewer.

The concepts of caregiving and bereavement, following spousal caregiving, were operationalized separately by listening and exploring, utilizing the following basic questions. Informants were asked to describe a typical day now, as opposed to when they were caregiving. Consideration was given to such activities as food and fluid intake, exercise, daily activities, and sleep and rest, i.e. 1) Could you describe a typical day now ? [measured unburdening] 2) How is this different from then? [measured caregiving] In-depth, probing questions were utilized such as "How is your energy level not, compared to when you were caregiving?"

Further probing questions guided interactions which explored the impact of caregiving and bereavement on the whole person. Questions were aimed at describing how the participant felt physically, emotionally, mentally, socially, and spiritually now as opposed to when he/she was caregiving. With these questions the interviewer encouraged the respondent to compare and contrast now versus then. [measured caregiving/unburdening].

In the search for further patterns and common themes across participants, the second interview sought to explore reasons for caregiving, reappraisal of purpose and meaning in life, and self care goals. The participants were asked if they could do anything, go anywhere, without any limits, how would they view themselves? The latter questions were designed to operationalize unburdening. Probing questions were utilized during the interview process were designed to assist informants in verbalizing their caregiving and bereavement experiences with the interviewer.

A description of the bereaved caregivers age, race/ethnic background, highest level of education, occupation, financial status, current health status, number of years of caregiving, and family and social supports operationalized the extent and nature of human and environmental variables. This data described the man and environmental factors which may impact the sequence stage of growth through which the respondent passes during caregiving and bereavement. Therefore, the major goal of participant observation was to record and describe what was seen and heard, in the language used by the informant, thus identifying cultural meanings within the subculture itself.

Piloting

The initial data collection phase included piloting of the interview with one individual who was similar to the proposed sample informants, with the following exceptions, the pilot participant was an adult child, bereaved caregiver who was 55 years of age and had cared for her mother in law for a period of five years in her home. During the pilot interview, understanding of the questions was established to determine if questions were clearly understood by the informant. Also verified was the informants capacity to communicate feelings of reactions to caregiving and loss associated with the death of a significant family member. The piloting verified the appropriateness of the questions and the sequence of evolving through the life cycle transition.

Because of the piloting, further development of the interview questions and instructions to the study participants was completed. A socio-demographic open ended questionnaire was added to the study to provide an additional dimension which would verify sample criteria and add clarity to the conceptual framework. Organization and expansion of interview questions for ease of transition between conceptual guidelines occurred as a result of the piloting. The piloting process demonstrated the effectiveness of the interview format in eliciting responses.

Post Interview Schedule

At the completion of each interview, the interviewer informed the respondent that the interview had formally ended. At that time the tape recorder was turned off. The socio-demographic instrument was self administered in the presence of the interviewer. The interviewer asked each participant to evaluate their interview experience. If there was a difference between the participant's description of his/her experience and the verbal responses during the interview process, a discussion of the differences was initiated by the interviewer. Discrepancies were noted in the field notes to be discussed in Chapter 6. Further, a debriefing was completed at the conclusion of the interview process for the purpose of providing the individual with an opportunity for free verbal expression. At the conclusion of the final interview, each participant was supported, thanked, and assured that what they contributed during this interview process will help others who are unburdening.

Data Collection Procedure

In this study the researcher utilized a process of open-ended, guided interview to explore a significant life transition experience with each participant. During the process of participant observation, it was the interviewers role to guide the interaction and keep it on topic. In order to minimize wandering off track, several open-ended questions were asked beginning with concrete questions about specific events of every day life and moving toward more in-depth, generalized focus about the caregiving and unburdening experience. On initial interaction, the interviewer established a rapport with the informant and the latter decided if the process was meaningful and the if interviewer could be trusted. Trust and rapport are essential components for field work validity and reliability (Leininger, 1985).

The interview process was enhanced in a quiet atmosphere which was free of interruptions and required a non judgemental attitude of the interviewer. In obtaining information, the researcher listened to the implicit and explicit meanings in descriptions, explanations, and non verbal cues provided by the informant. Where areas of communication were superficial, additional meanings were sought through effective use of silence, acknowledging with "hmmm" or could you expand on that?", thus giving permission for the informant to continue (Field, et al. 1985).

The use of a tape recorder may have increased the level of anxiety experienced by the respondent. However, by placing the tape recorder out of sight, and utilizing an invisible microphone the informant was able to forget about the tape recording machine. The interviews were considered guided as some knowledge about the structure of the topic was known out of the caregiving and grief literature, but responses could not be anticipated. Between the interviews the researcher evaluated the quality of the interviews by listening to the transcribed recordings. From the verbatim interviews and through selective observations of the environment, themes and patterns of burden and unburdening began to emerge.

If secret information was passed onto the researcher in the course of a trust which developed, the interviewers' primary responsibility was to the informant. The informant had the option of retracting any requested information at any time. The researcher respected these wishes at all times during the course of the interview process. If an informant gave information to the researcher that was of an ethical nature, such as suicide threats, the researcher would have advised the informant that a risk to his/her life was the concern. The researcher would have faced the issue of violation of confidence openly by trying to persuade the informant to seek help with the interviewer in accompaniment.

To improve the researchers understanding of the phenomena of unburdening, the setting was described through the use of explicit field notes. In addition, the researcher jotted down objective descriptions of the environment, such as other people involved and significant physical things that were present. Subjective impressions of nonverbal communications such as general impressions of emotional status or state of distress in an observed interaction and the interviewers reactions to the process supplemented the taped interview. Additionally, for each interview session, field notes included a record of the date, time, and place of the interview and who was involved in the interaction (Field, et al. 1985).

Data Analysis

For data analysis within this study, the researcher examined the content of the interviews of three participants beginning with the dimensions of the unburdening concepts consisting of physical, emotional, social, financial, mental, spiritual, as well as mourning, and growth. In the analysis each interview was coded according to these concepts considering the possibility that each interview may not have all concepts. For example, under the concept of physical unburdening, three to five short statements representing evidence of unburdening at a physical level were identified. Verbatim quotes were extracted from the transcripts which summarized the physical status of the subject. A short narrative statement summarily described the extent of physical burden or unburdening and some insight into the causes was presented. Utilizing these pages of data, the researcher prepared for the interpretation of themes and patterns section by taking each concept under unburdening and summarizing it as follows:

1. What was the range of physical or other construct of unburdening across all respondents ?
2. Did changes occur in each construct from interview time one to interview time two ?
3. What accounted for the differences in each construct of unburdening across all participants ?
4. What accounted for the changes from interview time one to time two ?

The researcher developed a format where the unburdening themes and patterns evolved from physical, emotional, mental, social, and spiritual domains. The process of unburdening was broadly impacted by perceptions of one or more of these categories as a result of caregiving and the death of the spouse. Qualitative content analysis served as the research approach to inductively derive cultural patterns or dominant themes from the data which focused on verbatim, typewritten transcripts from the interviews, observed behavior, and artifacts in the subjects environment. Themes or patterns were identified after comparing, contrasting, and examining the data for a themes' presence or absence, as well as changes and differences in each construct across time. The occurrence of a theme could be positive or negative.

As a result, subjective meanings derived from descriptive data provided through participant observation and all other data sources served as a basis for drawing cultural inferences. Themes were developed as a result of recurrent patterns typically described by all study participants. From the data, unburdening themes and meanings within holistic dimensions emerged and were used to formulate the written perspective presented.

Summary

The research approach, criteria for inclusion in the study, methodology, human subjects, interview schedule development, operationalism of concepts, socio-demographics, data collection procedures, and plans for data analysis were identified within this chapter. In Chapter 5 the data will be presented and summarized.

CHAPTER V

DATA PRESENTATION AND ANALYSIS

Overview

The data presented in this chapter describe the study population and caregiver unburdening, by older adult individuals within holistic domains. Participants were interviewed at one and two months after the death of their spouses. Data are presented about the unburdening process with concepts consisting of physical, emotional, mental, social, financial, spiritual, mourning, and growth. A discussion of the findings within the verbatim transcripts and field notes with analysis and summary of the findings is presented within this chapter.

The following study questions presented to respondents followed a guided, open-ended interview format:

1. Please describe a typical day now in contrast to a typical day when you were caregiving.

2. How do you feel physically, emotionally, mentally, socially, and spiritually now as opposed to when you were caring for your spouse ?

3. What would a typical day be like if you could do anything you wanted to do ?

4. If you could talk with someone who is in the same situation as you were in just two months ago, what would you like to tell him/her ?

5. Each subject was offered the opportunity to respond to the question, "Is there something else you would like to talk about ?"

The analysis of the data began with an examination of the socio-demographic variables which provided an added dimension of person/environmental factors and provided a frame of reference in the analysis of the unburdening process. Further, typewritten transcripts and field notes from the interviews were analyzed for the presence of unburdening constructs with verbatim quotations noted, which represented evidence of the presence of that construct. Following this process, a short summary was written describing the extent of the level of construct burden or unburdening with some insight into the causes on each subject and each interview. In the summarization process, the range of construct unburdening across all respondents, and changes in sub-constructs from interview one to interview two were described. Also included were factors accounting for the differences in each category, and factors accounting for changes between interview times. A discussion of the study with an analysis and interpretation of the study results is presented.

Description of Study Sample Findings

The sample for this study consisted of three individuals, two females and one male. All subjects, upon the initial interview had been caregiving for their spouses a minimum of two years. Each person had been bereaved for approximately one month at the first interview. The population was obtained from the State of Michigan, two subjects had participated in the Family Caregiving Study, and one subject was referred from a primary care provider in the Lansing area.

Socio-demographic Variables

Socio-demographic variables utilized in this study were age, race/ethnic background, educational level, occupation (when employed), total family income per year, medical/health insurance, and state of health. Additional data collected were present state of health, number of years as caregiver for spouse, number and ages of living children, and children living at home. Other data collected were, children living away from home, the number of miles away, frequency of visits outside of the home, and participation in outside activities (see Table 1).

The age of the study informants were from 65 to 68, with a mean age of 66.6 years. Racially, all subjects were Caucasian, with educational levels ranging from 11th grade in two participants to graduate education in one subject. Former occupations of the study participants included factory work, bar maid, and math school teacher. All subjects were retired. Total family income included the categories of: $4,000 - $9,999; $10,000 - $19,999; and $30,000 - $39,999.

Subjects were covered by Medicare A & B, with two participants utilizing other medical insurances to supplement Medicare. Two subjects (67%) indicated adequacy of insurance coverage. One subject (33%), who utilized Medicare A & B exclusively, indicated medical insurance was not adequate. On a four point scale ranging from excellent to poor two subjects rated their present state of health as good, and one rated her health state as excellent.

Two participants had been caring for their spouses for a period of two to three years, while one subject had been a caregiver for her spouse for five or more years.

The number of living children ranged from three to five with a mean of 4.0. All study subjects have grown children who live within a fifteen mile range of their homes. All study participants indicated that they visited people in their homes, with two indicating outside visits. One indicated frequency of outside visits was less than once a month. The other two

Table 1

Sociodemographic characteristics of informants

	n	%		n	%
AGE			OCCUPATION		
60 - 65	1	33	Teacher	1	33
65 - 70	2	66	Bar Maid	1	33
	3	100	Factory	1	33
				3	100
RACIAL/ETHNIC BACKGROUND			SEX		
White	3	100	Male	1	33
			Female	2	66
				3	100
TOTAL FAMILY INCOME			EDUCATIONAL LEVEL Highest Grade Completed		
$4,000 - $9,999	1	33			
$10,000 - $19,999	1	33	6 - 12 grades	2	66
$30,000 - $39,999	1	33	Masters Degree	1	33
	3	100		3	100
STATE OF HEALTH			YEARS CAREGIVING		
Excellent	1	33	2-3 years	2	66
Good	2	66	3-4 years	0	00
Fair	0	00	5 or more years	1	33
Poor	0	00		3	100
	3	100			
NUMBER OF CHILDREN			CHILDREN LIVING AT HOME		
Three	1	33	None	2	66
Four	1	33	One	1	33
Five	1	33		3	100
	3	100			

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stated their outside visits were more than once a week.

Data was collected on activity participation outside of the home. All subjects indicated neighborhood activities, two marked church participation and one noted club participation. The entire group of respondents listed involvement in at least two categories of outside activities.

This is a sample of older adult Caucasian widows, and widower, who followed patterns of American growth and development. All went to school, were employed, got married, had children, and retired. All subjects have recently experienced caregiving and bereavement of their spouses.

Presentation of Findings

In the following section the researcher will identify by code, each of the three subjects. Under the various construct headings, the researcher will:

1. Number and list each statement which represents unburdening at the construct level.

2. List verbatim quotes which summarize the construct status of the subject, coded in brackets [ ] to match the appropriate construct statement.

3. Construct development will be presented on each of the two interviews, by subject. Both interviews will be summarized together and will include the status of the burdening/unburdening process.

Subject #1 Interview #1

Physical Unburdening

1. Schedule revolved around tasks.
2. Positive or negative health perceptions.
3. Self care practices.

Quotes:

"I was busy all the time, I'd have to get up and turn him over ever two or three hours, or help him to the bathroom." [1]

"I was up and down with him so much, the last year."[1]

"I go to sleep for about - fairly sound - then I'll have these light dreams - just come and go and wake me at night. Most of the time I'm rested when I wake up." [1]

" I think I'm pretty healthy."[2]

"I've got a bad back."[2]

"I go to a Chiropractor once a month for an adjustment."[3]

" I take motrin for my arthritis and I'm on a blood pressure pill."[3]

"I've been on them for about two years." [3]

(My back problem) - "at that time taking care of him - lifting on him and turnin' him so much that - kept my back tore up."[2]

Subject #1 Interview #2

Physical Unburdening

1. Schedule revolved around tasks.
2. Positive or negative health perceptions.
3. Self care practices.

Quotes:

"I just hope that I can go when I'm 90 years old like she (neighbor) does. She still drives a car - works in her garden."[2]

"I just go down there and set with them (elderly neighbors) - if she has any dishes - I did her dishes up."[1]

"I usually go out and do my shoppin' early in the mornin' before it gets too hot." [3]

Summary:

While caregiving, physical care was organized around a busy schedule of functionally related tasks such as lifting and turning. Her schedule still revolves around caregiving tasks, as if they still existed. Wishes for long life filled with ambitions and hard work, however initiates little self care. Researcher sees little progress in physical unburdening between interviews. This subject is not physically unburdening.

Subject #1 Interview #1

Emotional Unburdening

1. Emotional response.
2. Positive or negative loneliness.
3. Resignation to commitment.

Quotes:

"He was a good man, a hard worker - he made a living for his family."[1]

"My family keeps track of me pretty good."[1]

"We were always pretty close."[1]

"I know we miss him."[2]

"Once in a while I'd get a little disgusted - he'd mess the floor or something and I'd get frustrated for a few minutes."[3]

"I did the best I could toward him."[3]

"He wanted to die here - and he did."[3]

" - feeling lonely and sad along towards the end."[2]

"I don't think that I felt any burden - and when I was taking care of him and now, course I worked after he had his first two heart attacks. I had to go to work and I worked for 20 years - and then my health got bad and he began to get worse and I had to quit."[3]

Subject #1 Interview #2

Emotional Unburdening

1. Emotional response.
2. Positive or negative loneliness.

Quotes

"Well, we were always pretty close as I say - we raised a family."[1]

"You don't think of it (bond of love and affection) at the time. You love the person and you feel it's your duty to look out after them."[1]

"When he got so bad that I had to quit work - I didn't have a lot to do around the house and that (caregiving) did give me something to do."[2]

"It gets awful lonesome here now. Course I've been goin' out a little more now and doing things."[2[

Summary

The emotional support network, for this subject, is supplied almost exclusively by her family. The inability to talk of love, such as using terms of endearment, i.e. loving, caring, for her spouse and others probably relates to her learned patterns of communication. The bond of love and affection is at a level of commitment. She promised to take care of her husband, so that he could die at home, and she did her duty. The respondent is lonely but initiates very little to resolve this feeling. The subject was less emotionally burdened at the second interview and is emotionally unburdening. Expectations for emotional support are minimal.

Subject #1 Interview #1

Social Unburdening

1. Social relationships.
2. Outside social activity limited.

Quotes

" My son's here and he tries to get me out of the house and of course he checks on me every day."[1]

"I can go now, if I want to, but I don't want to go."[2]

"The other boys check once a week, sometimes twice."[1]

"As far as social life - I don't have any."[2]

"We've (former boss) been out to lunch since ______ passed away."[2]

"I go to church once in a while."[2]

"I've been over to my daughters once since ______ passed away."[2]

Subject #1 Interview #2

Social Unburdening

1. Social involvement almost exclusively remains inside family.
2. Socialization - caregiving.

Quotes

"The kids been trying to find places for me to go and things to do."[1]

"I'll go and color my hair - make him (son) happy."[1]

"I was down there last night and she's got two ladies that she takes care of - runs a Foster Care Home - and I went down there and set with them. It gives me something instead of watchin' television all the time."[2]

Summary

Social relationships are primarily with the respondents family. Outside social contacts are minimal and, for the most part, are not self initiated. She has the option of going out socially now but does not choose to participate unless the activity is work related.

The respondent shows little change between interviews. The researcher believes again that this is due to her inability to initiate activity. She is slowly unburdening but the process may be a long one.

Subject #1 Interview #1

Financial Unburdening

1. Financial stability/instability.

Quotes

"- - all I'll have is Social Security and I don't think that will amount to much - - so I don't know what I'm going to do from now on."[1]

"When he was alive our income was right around $900.00 a month." [1]

"My Social Security will be $255.00 a month and that's not very much to live on."[1]

"I can't understand it - I'm just going to have to wait and see."[1]

"No, I don't know much about that stuff." (finding out answers to questions through the system) [1]

"- - his life insurance through the shop - where he retired from - why they raised that life insurance up to five thousand - -." [1]

Subject #1 Interview #2

Financial Unburdening

1. Financial stability/instability.

Quotes

"We couldn't afford anything else."[1]

"There's one thing that bothers me - I haven't got any hospitalization insurance - as yet."[1]

"I'm still getting bills from up there." (spouse in Nursing Home for two and half days prior to death) [1]

"I never took care of bills or anything up until he got sick. When he got sick it was really hard for me - because I had to learn all that."[1]

Summary

The respondent has been severely impacted by a reduction in her monthly income since the death of her spouse. Further financial burden will result when life insurance benefits are exhausted. Poor prior planning has resulted in a sense of hopelessness . Again, she is unable to initiate change and her financial status continues to deteriorate to its' present poverty level. The change between interviews indicates future financial burdening.

Subject #1 Interview #1

Mental Unburdening

1. Copes with problems via religion.
2. Duty describes specific coping behaviors.
3. Denial of problems.

Quotes

"I just sit down and have a talk with the Lord and kinda forget about it." (problems) [1]

"I just get the Bible out and start reading it." [1]

"I thought it was my duty to care - - "[2]

"He'd be howlering for me and I'd be outdoors mowing and I come in and check on him."[2]

"Because he was always a very clean person - I knew he wouldn't do things like that if he could control it - so I just had to calm down."[2]

Subject #1 Interview #2

Mental Unburdening

1. Talk of decision/nondecision to provide care for spouse.
2. Coping methods.

Quotes

"He asked me not to put him in a Home unless I absolutely had to - and I told him I wouldn't. I didn't want to put him into a Nursing Home anyway - because I wanted to be there - - ."[1]

"Seems to me like if I have to do something - I don't always enjoy it."[2]

"I was always told if you made just a little bit (money) - you managed to get by on it. I've got to where I believe that."[2]

Summary

The respondent copes out of a sense of duty and commitment. She relies on advice and input from others, including the Lord, to make decisions, or to avoid making them. There was no change in mental unburdening between interviews. The coping method of avoiding and religious practices supports never reaching the real issues, thus leads to the recurrence of similar problems.

Subject #1 Interview #1

Spiritual Unburdening

1. Purpose and meaning of life - not stated.
2. Talks of God, Bible, and PTL Club as spiritual resources in critical moments.

Quotes:

"I just live each day as it comes and let each day take care of itself."[1]

"So the past is gone and we can't do anything about that - and again we can't do anything about tomorrow."[1]

"In the critical moments I'd just get the Bible out and start reading it."[2]

"At nine o'clock I turn on the TV and watch the PTL Club and the 700 Club."[2]

Subject #1 Interview #2

Spiritual Unburdening

1. Purpose and meaning in life stated.

Quotes

"I had an idea that - that (purpose and meaning) had something to do with it." (the decision to care for her spouse)[1]

"I didn't have an awful lot to do around the house and that (caregiving) did give me something to do."[1]

"All my life it's all I've been doing is taking care of somebody. I'm still doing that - I set for Mrs. __________ (neighbor) in fact I was down there last night."[1]

Summary

Purpose and meaning in life has been fulfilled through caring for other people. Caregiving has been a part of the entire life of this respondent. She utilizes religion as a spiritual shelter in critical moments. In the context of this individual. There were no changes in the spiritual unburdening construct from interview one to two.

Subject #1 Interview #1

Mourning

1. Experiencing sleep disturbances as a part of the grieving process.
2. Tearfulness expressed.

Quotes

"I still hear him howlering for me during the night."[1]

"I sit up in bed - then it dawns on me - he isn't here."[1]

"It still hurts to talk about it (her husbands death)."[2]

"We've been here for 30 - 38 years - lived at this place."[2]

Subject #1 Interview #2

Mourning

1. Talks of spouse as if he is still there. Saving spouses bed.
2. Tearfulness absent.

3. Reminiscing.

Quotes

"I find myself seein' and if he's there - cause he slept in that room there and I have to go through to get to the bathroom."[1]

"I thought I'd just keep it up - if we have company - well, they can sleep in the bed - it's a nice bed."[1]

"I don't still wake up in the night and hear him callin'."[3]

"We've been here for 30 - 38 years, lived at this place - -." [3]

Summary

The subject is experiencing characteristics of mourning throughout the interviews. Sleep disturbances and tearfulness described and expressed in interview one were diminished in interview two. The attachment to the room and bed where care was administered to her spouse was still evident in the second interview. Reminiscence is beginning to play a role at interview two in the mourning process. The greatest amount of change between interviews occurred within this construct. The mourning process is clearly changing with a decline in tearfulness and increase in reminiscing apparent at the second interview.

Subject #1 Interview #1

Growth

1. Reaching out to future.
2. Contrasting past/future in discussions.

Quotes

"I don't know - you never can tell you know. I might even take on a job of caring for someone."[1]

"I look forward to evenings when I can turn television on and relax and watch the news - watch all the trouble around the world."[1]

"I think I can understand more about people when they're sick, because I have taken care of elderly people years back." [2]

Subject #1 Interview #2

Growth

1. Reaching out to future.
2. Contrasting past/future in discussions.

Quotes:

"It gets awful lonesome here now, course I've been going out a little ever now and then & doin' things."[1] (adult sitting for neighbors foster patients).

" ____________ (her former husband) and I was always pretty close."[2]

"Oh, sometimes I think I'd like to take a trip to California and visit with my son out there - and I may do it - - later on."[2]

" - you never can tell you know. I might even take on a job of caring for someone - if I can find 'em close enough."[2]

Summary:

Evidence of growth is limited. She speaks of going out and doing things, and has taken steps to do so in the contest of caregiving. She talks of past and future in relating to caregiving. She views the future with doubt and hesitation. Some change was noted between interviews as she reaches out to the future as a caregiver.

Subject #2 Interview #1

Physical Unburdening

1. Schedule extremely busy.
2. Positive/negative health perceptions.
3. Self care practices.

Quotes

"I never feel there are enough hours in the day for me to get all the things done I would like to do."[1]

"Now there is no one here to monitor or to coordinate with on when I get up, when I go to bed."[1]

"I had to direct him (spouse) to where the bathroom was and he would wet the floors."[1]

"A year before he died he was having nightmares and I would be awakened because he would be grabbing me and shaking me."[1]

"The worst thing is finding - going to bed - in this bed."[1]

"I tell myself, you need to go to bed. Instead I'll get up or I'll have a cup of tea or I'll have a snack and I'm wide awake."[2]

"I intend to live to be 120."[2]

"I just passed a flight medical. I'm in fantastic health."[2]

"I tried to make sure that we had three simple, balanced meals that were low in calories and highly nutritional."[3]

"I try to get - I should get eight glasses (water) a day."[3]

"I've been almost over obsessive toward it (chocolate). So I am able to say no you don't need chocolate, but before (spouses death) there was no way

I could say no."[3]

"I've been trying to get with the lady next door and continue my walking because I know it will be good for my heart and good for my waist."[3]

"Age to me - you know - that's just like a number. What does 68 mean ? I feel just like I did when I was 38 and I love all the same things."[3]

Subject #2 Interview #2

Physical Unburdening

1. Self care practices.

Quotes:

(as a way of helping others) "try to maintain your own sense of dignity and sense of humor."[1]

Summary:

While caregiving, the respondents schedule demanded constant vigilance and attendance. While no longer providing care her daily activities continue to be busy with social invitations and getting things done. Her sleep patterns are altered due to the impact of her spouses illness and perhaps the memory that he died in the bed she currently uses. The respondent is positive about perceptions of health and is futuristic in her self image as a healthy, older person. Little change was noted between interviews. She uses humor and self care as a means of maintaining her sense of dignity.

Subject #2 Interview #1

Emotional Unburdening

1. Emotional response.
2. Positive or negative loneliness.

Quotes:

"I will call my daughter, and she & I will talk or call _____ (son), in Europe, more often than I used to."[1]

"He's (son in town), sweet and helpful." [1]

"My friends have been wonderful to me."[1]

"You've lived with and loved someone for 46 years and you just don't stop when they become ill."[2]

"I knew the things he was doing that were very hurtful to me - was not the man who loved me or that I had loved. This was a sick man."[1]

"He didn't like it (flying) as much as I did, but I thought - he (spouse) must have loved me because he would always give me a flight for my birthday."[1]

"I think I learned patience (associated with caregiving) and a different meaning and depth of love - and a new belief in myself."[1]

"I think people love me."[1]

"I was too busy to sit and mope about most things."[2]

"I'm alone - but I'm rarely lonely."[2]

"What else to do (but be positive) ?"[2]

"You still feel a wash of melancholy but my feeling is -that's over now and I have to get on with my life."[2]

Subject #2 Interview #2

Emotional Unburdening

1. Emotional response.

Quotes:

"When you've lived with someone for 46 years and you loved and cared for each other - - - - -"[1]

"Love is respect and tenderness and caring, concern, empathy, and you know - a multifaceted, many colored thing."[1]

"I'm grateful that he died so peacefully."[1]

"Try to preserve and add to the sense of dignity of the person that you are caring for."[1]

Summary:

The respondents emotional support network is broad, including family and friends, and extending throughout the caregiving and bereavement periods. Relationships reflect in-depth expressions of love, caring, and growth. A quality of patience was described in context of her relationship with her spouse. Statements of a loving relationship with spouse and support persons increased at the second interview, while tearfulness declined. Feelings of loneliness clearly do not occupy her mind despite the hurtful experiences that her spouses illness fostered. Emotionally unburdening was evident between interview one and two.

Subject #2 Interview #1

Social Unburdening

1. Social relationships.
2. Outside social activity.

Quotes:

"I went over and had dinner with him (son) last night and he said - you must be going all the time."[1]

"I fly by myself, but I have a friend that enjoys flying and he can't get his license renewed because of a heart condition and he loves to fly - so I will ask him to come out and fly with me."[2]

"- - -getting ready for this trip to Italy - I want to see and do everything."[2]

"I have friends who ask me out to dinner. I have more invitations than I ought to accept, I ought to start saying no."[2]

"I have a friend who is also a Psychiatrist and I have consulted with him - he operated as both Doctor and friend."[2]

"I have as many men friends as I have women friends."[1]

Summary:

Over the years the respondent and her spouse had established a solid network of social relationships, both in and outside the family. Those relationships and those independent of her spouse remain intact. The respondent is socially active to the extent that she is accepting invitations from family and friends. There was no change between interviews.

Subject #2 Interview #1

Financial Unburdening

1. Financial stability/instability.

Quotes:

"This is not one of the problems - it could be a problem for anyone who does not plan ahead."[1]

"I have sufficient income for my needs and to live very comfortably and very well."[1]

"Everyone should think of the worst possible scenario and do something - make things good for themselves."[1]

"We both had good retirement plans and he had been a wise investor - and I was able to get these things in order."[1]

"My big problem now is to get all those bills sent in so that I can get the money back from the insurance, because I paid all our Doctor bills."[1]

"We had good financial advisors, had a good lawyer and CPA."[1]

Summary:

Due to pre-planning and consideration for financial contingencies, finances are not considered a problem. The only exception is the reimbursement for Doctors bills paid prior to submission to the insurance company. The respondent made use of financial advisors and reports satisfaction with income that meets her wants and needs. There were no changes in the financial construct between interviews.

Subject *2 Interview *1

Mental Unburdening

1. Copes via problem solving.
2. Uses support network.

Quotes

"Have someone you can go and pour out these feelings and get them out and have someone who can help you look at them objectively."[1]

"I've so many years in my science training and math training - Okay - - you're faced with a problem, what do you do ? What are the possible outcomes and how can you reach them ?"[1]

"What end do you wish to achieve and how are you going to go about it ?" [1]

"All of my wonderful friends - I've gotten so much support from them."[2]

"Do what you have to do - don't sit and mope."[1]

Subject *2 Interview *2

Mental Unburdening

1. Talks of decision to provide care for spouse.
2. Uses broad religious beliefs.

Quotes:

"You don't make that kind of decision - it's made for you."[1]

"If it wasn't a husband I suppose you could say - this man is getting impossible - I'm going to leave this situation."[1]

"It's not really a conscious decision - you don't just step aside."[1]

"And I need to make decisions about what I'm going to do with this house - it's not a pressing thing."[1]

"You're doing the best that you can do - don't blame yourself, you didn't cause it."[2]

Summary:

The respondent has relied on coping strategies such as problem solving techniques utilized in her professional life. She utilizes support persons to ventilate her feelings. She believes in herself and respects others emanating from a foundation learned in childhood. She talks of regaining control of her life as she contemplates future decisions. There were no changes in the mental unburdening construct between interviews.

Subject #2 Interview #1

Spiritual Unburdening

1. Meaning and purpose of life stated.
2. Broad religious beliefs.

Quotes

"We were brought up to go to whatever church was nearest or that our friends were going to - because they felt we should have a religious background."[2]

"I grew up with a great respect for everyone's religion."[2]

"My father brought us up to feel we needed to make up our own minds."[1]

(former student said): What you taught me has been so helpful all these years. "I get this same experience (from former students) over and over - I feel the same thing about him (her spouse) - that's what eternity and infinity means - it's something very practical."[1]

Subject *2 Interview *2

Spiritual Unburdening

1. Meaning and purpose of life stated.

Quotes

"And so - it's over for him and it's over for me - and it's good."[1]

Summary

The informant utilized learned attitudes and outlooks to form a philosophy to support her spiritual needs. There was no evidence of changes in the spiritual domain between interviews. The illness had a beginning and an end, and it's over for both - it had meaning.

Subject *2 Interview *1

Mourning

1. Experiences altered sleep patterns.
2. Tearful and sad.
3. Reminiscing.

Quotes:

"He was having nightmares and was waking up at night - I would be awakened."[1]

"He went to bed and never woke up again." [3]

"I'm talking to myself - all right I'll go to bed in just a few minutes, let me just listen to this tape one more time. Then, before I know it - it's two. it's three and it isn't unusually four like it was last night."[1]

"I think I've put in enough tears over the last couple of years."[2]

"I never spend much time, anymore, crying."[2]

"I think that it's time to tell you about fixing the light bulb." [3]

Summary:

The respondent is mourning the loss of her spouse. While she verbalizes that she has shed enough tears over the past years, tears come as she remembers and reminisces about the sadness she empathically felt for her husband and the caring experience. Reminiscing increased and tearfulness was diminished at the second interview. Evidence of unburdening was evident with the changes noted between interviews.

Subject #2 Interview #1

Growth

1. Reaching out to the future.
2. Contrasting past/future discussions.

Quotes:

"I grew up with a father who was a very strong person and I think that has been a real source of strength for me."[2]

"We (she and husband) had done a lot of wonderful things together."[2]

"I know I'm going to go, go, go, and when I get there I want to see and do everything."[2]

"Someone said, there is no excuse for growing old just because you live a long time - - and I thought - that's for me."[1]

"I couldn't feel that this tore me apart and left me in shreds - I had to keep all those pieces together and weave something new."[2]

"You make a new collage and the pieces are arranged differently and lets hope more beautifully and that the whole weaving is stronger."[1]

Subject #2 Interview #2

Growth

1. Reaching out to the future.
2. Contrasting past/future discussions.

Quotes:

"I've learned two things - whatever is happening: 1) nothing is important if it isn't life threatening or earth moving; 2) what difference is this going to make in a year, ten years, in a life time - no one will know or care - - forget it."[2]

"I'm going to see Rome and Florence - it's just going to be a happy time."[1]

Summary

The respondent is clearly growing and at interview two was talking of a holiday in Europe with her son. She is able to discuss her future with joy and enthusiasm, yet recalls the memorable past with her husband. During both interviews she reaches out by sharing her personal philosophies with others. Changes between interviews indicated growth and further unburdening within this construct.

Subject #3 Interview #1

Physical Unburdening

1. Schedule.
2. Positive or negative health perceptions.
3. Self care practices.

Quotes:

"When I was caring for her she was taking medication, it was every three hours, a 24 hour project."[1]

"Now I go to bed from 10:30 to 11:00 and I usually get up at 7 or 7:30, I feel relaxed then."[1]

"Medication and care had to be precise and on schedule. I kept a record of everything."[1]

"This is about all I do - read or - - I do house work, dishes, mow the lawn and different things around the house."[1]

"I've got good health - as long as you watch your intake of food."[3]

"I'm in pretty good shape, from what they tell me."[2]

"I have high cholesterol."[2]

"I've been watching my cholesterol for several years. I'm not a coffee drinker - I drink quite a lot of water."[3]

"I try to eat a balanced diet."[3]

"I really don't get much exercise."[3]

Subject #3 Interview #2

Physical Unburdening

1. Schedule.
2. Positive/negative health perceptions.

Quotes:

"As far as I know I've got good health."[2]

"I could do about anything I wanted to do - I don't feel that - I just don't want to - - -."[2]

"I just don't do nothin'." [1]

Summary:

While caregiving his schedule centered around caring for his spouse, and administering medications around the clock. Activities now center around housework and lawn work. He feels rested and energized, but is not physically active. Self care is related to diet. His state of grief is probably impacting his energy level and self care activities. There was little change noted between interviews, and the respondent remains physically burdened.

Subject #3 Interview #1

Emotional Unburdening

1. Emotional response.
2. Positive or negative loneliness.

Quotes:

"I don't see too much of 'em (children and families) they've all got jobs - come around once in a while, not too often."[1]

"We never had words. We didn't have any problems. She never was a burden."[1]

"Loneliness is something you can't run from. You just can't hide from it. Loneliness is what hurts you."[2] (tearful)

"We had a good relationship."[1]

"We agreed pretty good."[1]

"When you go through all this - watchin' your mate just gradually go - I'd say it was a pretty bad experience."[1] (tearful)

Subject #3 Interview #2

Emotional Unburdening

1. Emotional response.
2. Positive or negative loneliness.

Quotes

"Why I figured we'd be together more."[1]

"We've always been close."[1]

"The only one I've talked to would be my sister-in-law."[1]

"She's a lonely woman and I feel for her. I knew her feelings, and I think she kinda understands mine."[1]

"The worst part of it - the loneliness."[2]

"I never gave it much thought - anticipating loneliness."[2]

Summary:

Expressions of affection for the deceased mate were noted when describing decision to caregive at interview two. The respondent does not dwell on family relationships however, he does show concern for a relative who is experiencing similar reactions to loss. The respondent was able to express feelings of loneliness and concern for others at the second interview. Tearfulness had diminished at two months of bereavement. Changes between interviews indicate the process of emotionally unburdening.

Subject #3 Interview #1

Social Unburdening

1. Social relationships.
2. Socialization - institution.

Quotes

"We had a lot of friends that would come. We couldn't go to them."[1]

"I don't see too much of 'em (family) - course they never did really - - they've all got their jobs - they stop in - come around once in a while, but not too often."[1]

"Nothing other than church."[2]

"Wednesday nights - Sunday, and go shopping once in a while."[2]

"We never did socialize that much."[2]

"Now I don't get many calls. I don't get many visitors."[1]

"Instead of coming to me, why I could go to them but - - - -."[1]

Summary:

The respondent appears socially burdened. During caregiving friends and family would visit, however since the death there has been a drastic reduction in visitations. The respondent seems to have been more socially active during caregiving than now. He is experiencing acute grieving and an inability to mobilize himself except to go to church and shop for food. There has been little change between interviews.

Subject #3 Interview #1

Financial Unburdening

1. Financial stability/instability.

Quotes:

"Money has never been a problem, because she was a good manager."[1]

"I've always had a good job."[1]

"I had a lot of loose ends - I had to pick up - the arrangements you have to make in your incomes, property and insurance, etc."[1]

"She paid - she handled - I didn't -- I never did believe two people handling the pay -and she always taken care of it - the utilities and so on."[1]

"This is no problem now. Health care needs just call the phone number through Health Central - that's not a problem."[1]

Subject #3 Interview #2

Financial Unburdening

1. Financial stability/instability.

Quotes

"We got a good insurance policy, which helped a lot, through General Motors."[1]

"As far as finances are concerned we're not rich - but I could do about anything I wanted to do. I just don't want to do nothin'."[1]

Summary:

The respondent describes no financial burden due to ample insurance benefits, and prior planning. He indicates he could afford to travel but chooses not to do so. There were no changes evident between interviews.

Subject #3 Interview #1

Mental Unburdening

1. Copes via religion.
2. Coping methods.

Quotes:

"I try not to dwell on problems too much."[2]

"I just kind of wipe it out of my mind as much as I possibly can."[2]

"No use creatin' problems until they occur."[2]

"I'd be a pretty sad case (without the Lord)."[1]

"The Bible is a source of support, I still read the Bible and see what it says - you know, the counsel of it."[1]

Summary:

The respondent appears to be mentally burdened. He has learned a method of handling his anxiety through the use of denial. By not talking about his loss, he holds it away from his awareness. The Bible and his church provide a source of shelter and counsel for him. There were no apparent changes within the cognitive construct at one and two months of bereavement.

Subject #3 Interview #2

Mental Unburdening

1. Decision to caregive.

Quotes:

"This is what she wanted - she didn't want it - or go to a Nursing Home - so we taken the responsibility on ourselves." [1]

Subject #3 Interview #1

Spiritual Unburdening

1. Purpose and meaning in life not stated.
2. Talks of God or Bible as resources.

Quotes:

"The purpose in life - you don't know what it is - that's up to the Lord."[2]

"I don't know and of course you feel kind of low sometimes."[1]

"Maybe, that you're not beneficial to the world, but I guess you are - some way or other."[1]

Subject #3 Interview #2

Spiritual Unburdening

1. Purpose and meaning in life not stated.

Quotes:

"You never know from one day to the next what you're going to do."[1]

"How do I know what I'm going to do ?"[1]

Summary:

The respondent reflects his purpose in life as being in the hands of the Lord, and describes some ambivalence in his grief state relating to purpose and meaning in his life. He seems to be awaiting direction. There was no change in this construct between interviews.

Subject #3 Interview #1

Mourning

1. Experiences altered sleep patterns.
2. Tearfulness expressed.

Quotes

"She was taking medication - so it was every three hours -- ."[1]

"You usually have to get up a time or two at night."[1]

"You're at a standstill - -." (tearful)[2]

Subject #3 Interview #2

Mourning

1. Reminiscing.
2. Tearfulness diminishing.

Quotes:

"It's just something you gotta go through and each person puts out a little different."[2]

"No, I wouldn't try to advise anybody."[2]

"We traveled quite a bit - a few years back." [1]

Summary:

With tearfulness and difficulty in affective expression, the respondent describes life at a standstill. The respondent is clearly mourning, however tearfulness has diminished. between interviews. He is beginning to reminisce in his reflection of past experiences at the second interview. The respondent is reflecting unburdening within the construct of mourning.

Subject #3 Interview #2

Growth

1. Reaching out to future.
2. Contrasting past/future discussions.

Quotes

"I was talking to a woman the other day that I've known for a few years, and she had lost her husband and she told me - - -."[1]

"We've got one (a widow) over here - she lost her husband - - she's been living alone but I don't know - - - evidently there's not companionship they're looking for."[1]

"I figure probably people get up in their latter years - don't look forward to a remarriage - but a younger person - why I would say that they might - - -."[2]

"We (subject and sister-in-law) talk back and forth quite a bit. I knew her feelings and I think she kinda understands mine."[1]

Summary:

The respondent is showing signs of growth. He speaks of interactions with a neighbor and a family member who all have common experiences of loss. The word remarriage has been safely mentioned in the context of a younger person. However, this may be an indicator of possible growth. When urged, the respondent is able to give advise to other males who may be faced with similar circumstances. There was a slight increase in the unburdening process within the domain of growth from the first interview to the second.

Summary of Data

Physical Unburdening

All subjects were concerned with their health, however one subject, who was the most active, gave information indicating she felt great and indeed felt half her age. The remaining respondents stated they "guessed" they were in fairly good health, based on information from other people. One informant was involved in her physical well-being through physical activity and diet, while the others described being somewhat concerned with their diets or food. No change was detected from interview one to interview two, in all respondents therefore there was no evidence to report physical unburdening had occurred.

Physical alterations following caregiving and loss are predictable, to a point, by the characteristics of the former caregivers' personalities. While no longer constricted by their caregiver schedule, two respondents continue the same life style. This may be a continuation of perceptions related to the grieving process. These two respondents have not transferred their caregiving energies to self care energies. The one exception, of this group, is now actively pursuing outside physical involvement, because she sees herself as vital, dynamic, youthful, and purposeful, while the others may not.

Emotional Unburdening

Being alone is a common trait expressed by all participants, however one participant reports not having time to experience the loneliness. The other two participants dwell on loneliness as if it is a natural state at this transition point in their lives. The researcher got the distinct feeling from these two subjects that loneliness was a part of their duty or obligation to their former spouse. These perceptions were unchanged between interviews.

Two of the three respondents were unable to affectively describe any emotional bonding, including words such as love, caring, or even using the name of their former spouse, although there was a sense of the presence of a loving experience based on commitment and togetherness. One respondent utilized a broad vocabulary which described a wide range of emotional expressions. This subject is by far the best educated, and therefore appears to be better equipped to deal with emotional and other issues generic to the caregiving and loss.

All respondents were better able to express feelings of loneliness, and and their own descriptions of a loving relationship, which were more easily verbalized at the second interview. In all three respondents tearfulness diminished significantly from interview one to interview two. Time is obviously a coping and healing mechanism which affects all aspects of the unburdening process and enables one to look at the past, while their spouse was still with them. Unburdening at the emotional level was apparent at the second month of bereavement.

Social Unburdening

Social relationships ranged from broad to nearly none. One participant was so busy socially with male and female friends that she did not have time to be socially burdened. Another subject has had limited social involvement, and the third has had almost no social activities, except when initiated by another person. This process holds true with family relationships, because it seemed strongly indicated that the personalities and environments of each individual participant determined their social activities. Two, of the three in the group, had time on their hands while the other respondent had too little time to accomplish all of the things that she needed and wanted to do.

There were no apparent differences in perceptions from interview one to interview two. Two subjects appeared to confine themselves to their homes, much like they were when caregiving, and the third was preparing to leave for Europe. There was no change in social perceptions, which determined no change in activity, therefore no change in the social unburdening process.

Financial Unburdening

All of those in the research group had adequate incomes to live on, at this time. Two of the respondents will probably have no financial problems in their lifetimes, as a result of financial planning. The third respondent will undoubtedly be experiencing serious financial problems within six months, due to poor financial preparation. One participants' social economic status would be considered middle-upper income, one lower-middle, and one below the poverty level. While all of their spouses were ill for a long period of time, one did nothing to prepare for financial contingencies associated with the illness and death of her spouse. Another not only planned, but worked with professional advisors to plan for the financial unburdening process.

The time frame involved between interviews reflected no furtherance, or change in the financial process therefore, financial unburdening was not apparent but may occur for one respondent in the future. The lack of change is probably due to the relatively short time span between interviews.

All participants have resources, some have planned for the use of those resources and others have not, just as some have planned for their futures, some have not. Some are making their lives happen, and some are waiting to see what will happen to their lives. This researcher saw this to be true in nearly every category examined thus far.

Mental Unburdening

The differences in dealing with the mental construct varied widely in this small group of subjects. One respondent confronted issues, used problem solving strategies, networking, and made decisions based upon fact and reappraisal of past events. The other two participants responded by putting their problems in the hands of the Lord, thereby appearing to avoid reaching the real issues. This leads to problems not being addressed, and the same decisions having to be remade as problems continue to resurface. Again, in the area of unburdening there was no apparent change between interviews.

One participant was been trained as a problem solver and believed she could effect change, and as a result was successful in creating change. The other two subjects had not described problem solving techniques. They tended to utilize religion and denial as coping methods. This perhaps was an attempt to regain control and cope with the multiple losses currently experienced.

Spiritual Unburdening

One participant used a non-religion specific philosophy to provide meaning and purpose to her life. This philosophy encompassed a broad spiritual view of knowing that who you are and what you do impacts who others are and what they do. Two participants held to a rather narrow spiritual religious philosophy which was utilized in the critical moments and was seen primarily as self comforting. Caregiving for their spouses provided meaningful activity and role responsibility. Therefore, without caregiving life seemed to hold no meaning for them. The most pronounced difference was the absolute reinforcement of purpose and meaning in life, in one respondent, while two respondents express little or no meaning in life without caring for their spouses.

The second interview revealed no discernible change in spiritual repatterning. The differences in the spiritual aspects of these respondents seemed to vary according to their formal education, spiritual or religious teachings, and their life experiences.

Mourning

In examining the mourning process, the respondents again represented both ends of the spectrum, while sharing a few common characteristics. All respondents showed the common behavior of tearfulness at various times during the interviews. This characteristic however, was somewhat diminished in the second interview for all participants. All respondents were using reminiscence in interview two as they attempted to bring order and meaning into their lives which became more apparent in interview two. Another commonality in the mourning process among all respondents was continued disrupted sleep patterns, which for the most part were similar to when they were caregiving.

The most apparent change in the first and second interviews was the decrease in tearfulness and the increase in reminiscence displayed by all respondents. It was indicated to the researcher that the mourning process begins to distance the former caregivers from their loss. Of all the constructs of unburdening, more similarities among respondents were noted in mourning than any other domain. This would indicate that mourning is so basic to the unburdening process that it presents fewer variables in behavior.

Growth

The concept of growth was clearly familiar with one respondent. The other two respondents found it most difficult to view themselves as "in process" of change. During the interviews a question was asked that stated, "what would you do if you could do anything you wanted, with no restrictions ?" One knew exactly what she would do. The other two subjects had difficulty conceptualizing the question and did not know what they would do. The latter two subjects were still living "caregiving style" lives and were seeking ways to maintain their identities as caring persons but in alternate ways. The process of change has impact on the growth process, and seems to be a choice of life style at this time. All of the respondents were able to talk of the past and future in the context of caregiving notable at the second interview.

Growth was identified at the second interviews, when one subject had spoken to a relative and neighbor, both of whom had similar loss experiences. That was a big step for this subject as he had not spoken of his feelings to anyone at the time of the first interview. The same respondent began to explore the concept of remarriage, but safely limited that possibility for "younger" people. The researcher believes this may be an indication of growth.

Changes were taking place within the three individuals in uniquely different ways. One respondent was expanding geographic limitations and interacting, freely with others. Another respondent seemed to be headed toward resuming a caregiving role. While the other was just waiting to see what was going to happen. One loves life and will probably grow to fill it with as much joy, excitement, and adventure as possible. She has learned that life is full of possibilities and choices. The other two respondents do not seem to be in charge of their lives, at this time, and are not looking forward to whatever may be in store for them. The latter circumstance is perhaps related to the need for role fulfillment.

Summary

In Chapter V, data were presented that described the study sample of three individuals and burdening and unburdening within holistic domains following caregiving and bereavement. All study respondents had unique patterns, strengths, and styles from which they reacted or responded based on previous learned behaviors, personality patterns, and outlooks on life.

The range of dimensions of unburdening including the commonalities and differences among participants was discussed. Also described were the changes in sub-constructs over time and the factors accounting for the changes between interview times. Additionally, proposals accounting for the differences in each unburdening construct across all participants was included.

CHAPTER VI

SUMMARY AND IMPLICATIONS

Overview

A research study was designed to describe patterns of unburdening for a small number of older bereaved individuals who have cared for their chronically ill spouses at home. The focus of the study was to describe perceptions of the caregiving bereavement process from the respondents frame of reference. These perceptions may facilitate or impede the process called *unburdening* at one and two months following the death of the mate. Contained in this chapter is a summary of the research, a summary of the findings, and strengths and the limitations of the study. Also included are implications for nursing practice and education, and recommendations for further research.

Summary of the Research

An in-depth exploration of the process called *unburdening* was completed to better understand the feelings, perceptions, and reactions of older adult spouses who have sustained a significant life transition while caregiving and mourning the death of their spouses. Despite the health care implications associated with the increasing size of the older population, this subject area has received little empirical attention. Further, the literature indicates that the death of a spouse causes a significant bereavement reaction in the elderly necessitating crisis resolution (Gerber, 1975; Glick, et al. 1974). Martha Roger's (1981) conceptual framework provided a structure to describe repatterning within holistic dimensions. Using Rogers' assumptions and principles, the theory was used as a vehicle for understanding how individuals' continuously repattern their lives despite seemingly devastating experiences. Roger's (1981) framework provided a basis through which the CNS could intervene within the client/environment in exploration of patterns which impede and/or facilitate resolution of a major life transition.

To better understand the experience of caregiving and bereavement, a literature review was completed of the caregiving process, caregiver burden within holistic domains, and grieving losses relating to the death of the spouse who was ill and needed care in the home. A number of different factors within the caregiving process may be related to a phenomenon called *unburdening* Those factors concerning the caregiver/patient relationship may relate to support network and financial stability. Other factors which also may impact the bereaved caregiver include role alterations, previous coping methods, and health status.

An open ended in depth interview format was developed to explore the life transition experience within physical, emotional, social, financial, mental, and spiritual constructs. Those constructs were chosen because a holistic approach from multiple dimensions provided a comprehensive body of information about the unexplored subject area of caregiver bereavement among elderly spouses. From this foundation, the potential for timely, appropriate, and sufficient care could be generated. A qualitative research approach was selected to explore the subject area with three individuals. Study respondents were caregivers bereaved approximately a month prior to the first interview.

Data were obtained from content analysis of the interview material. Through the process of coding the interviews, for multi-dimensional constructs with verbatim citations, the presence of that construct within each interview was identified. After summarizing the extent of unburdening, and the possible cause for each respondent at each interview, a summary of the findings was completed. The range and changes of construct *unburdening*, as well as factors accounting for differences and changes were identified.

Commonalities or differences, within each construct across participants and changes over time was determined. In interpreting the data, patterns or themes, which were either positive or negative, were developed as a result of their recurrence in all three participants. Changes occurring within construct domains from month one to two months of bereavement were termed *unburdening* within the domain area. The socio-demographic variables verified portions of the interview content.

Interpretation of Findings

The defining characteristics of *unburdening* within holistic dimensions were reported by respondents and presented in Table 2. The study sample consisted of three respondents, all Caucasian, two females and one male. The study respondents were between 65 and 68 years of age. All of the participants were recently widowed, and all were retired from former employment. Socio-economic status ranged from the poverty level (Michigan Department of Social Services, 1987) to upper middle income.

In previous studies of grieving among the elderly, sex and age range does not include widows or widowers over the age of sixty despite the increased risk of physical and emotional dysfunction in this bereaved age group (Gerber, et al. 1975; Maddison, 1968). Further, few studies have addressed the effects of socio-economic status as factors impacting the bereavement process (Thompson, 1984).

All respondents in this study utilized federally subsidized health

Table 2

Unburdening Constructs

INTERVIEW #1

Physical Unburdening	Subjects Number		
Schedule	1	2	3
Positive or negative health perceptions.	1	2	3
Self care practices	1	2	3

INTERVIEW #1

Emotional Unburdening	Subjects Number		
Emotional response.	1	2	3
Positive or negative loneliness.	1	2	3

INTERVIEW #1

Social Unburdening	Subjects Number		
Social relationships.	1	2	3
Socialization - institutions			3

INTERVIEW #2

Social Unburdening	Subjects Number		
Socialization - caregiving.	1		

INTERVIEW #1

Financial Unburdening	Subjects Number		
Financial stability/instability.	1	2	3

INTERVIEW #2

Financial Unburdening	Subjects Number		
Financial stability/instability.	1		

INTERVIEW #1

Mental Unburdening	Subjects Number		
Copes via religion.	1		3
Copes via problem solving.		2	
Uses support network.		2	

INTERVIEW #2

Mental Unburdening	Subjects Number		
Talk of decision/non-decision to provide care for spouse.	1	2	3
Coping methods.	1	2	3

INTERVIEW #1

Spiritual Unburdening	Subjects Number		
Purpose and meaning in life - stated.		2	
No purpose and meaning in life - stated.	1		3
Use of God, Bible or PTL Club as resources.	1		3
Broad religious beliefs.		2	

INTERVIEW #2

Spiritual Unburdening	Subjects Number		
Purpose and meaning of life - stated.	1	2	
Purpose and meaning of life - not stated.			3
Purpose and meaning in life - beyond control.			3

INTERVIEW #1

Mourning	Subjects Number		
Experiencing sleep disturbances as a part of the grieving process.	1	2	3
Tearfulness expressed.	1	2	3
Reminiscing.		2	3

INTERVIEW #2

Mourning	Subjects Number		
Sleep disturbances.	1	2	3
Reminiscing.	1	2	3
Tearfulness diminished.			3

INTERVIEW #1

Growth	Subjects Number		
Reaching out to the future.	1	2	3
Contrasting past/future discussions.	1	2	3

INTERVIEW #2

Growth	Subjects Number		
Reaching out to future.	1	2	3
Contrasting past/future in discussions.	1	2	3

insurance (Medicare), and two subjects had supplemental health insurance. One informant indicated inadequacy of insurance coverage and had an income at the poverty level since the reduction of Social Security benefits at the time of her spouse's death. All respondents had living adult children and all had at least one child living within a fifteen mile range of home. None had children who were involved in direct caregiving. This finding lends support to the literature that the elderly are a part of family networks and live within a half hour's journey to at least one child. Further, most of the caregivers are female spouses and want to live independently as long as possible (Day, 1985).

All participants indicated visitation outside of their homes with two visiting outside in the "more than once a week" category and one reporting outside visitations of "less than once a month". All three subjects participated in at least two activities outside the home such as church or community. The frequency of outside activities occurred after the death of the respondents' spouse.

Supportive network resources are described in the literature as accounting for some of the variation in adaptation among elderly bereaved individuals (Dimond,1981). Thompson (1984) found that spouse bereavement has an adverse impact on the physical health state of survivors. However, in this study, at one and two months following bereavement, all respondents rated their health status as good or excellent despite having been the primary care provider for a minimum of two years, with one subject caregiving for her spouse for more than five years (see Appendix H).

All study respondents had unique patterns, strengths, and styles from which they responded to the open ended interview questions. Participant's responses and reactions seemed to be based on previously learned cognitive and behavioral strategies, former coping methods, and social networks. Personality characteristics, self worth, financial resources, perceptions of purpose and meaning in life, mourning and growth also impacted individual responses.

Interpretation of Constructs

In this section, each domain construct with an assessment of the subconstructs and changes unique to unburdening within the participants will be presented.

Physical domain

All respondents seemed to indicate that the physical strains of caregiving had lessened following the death of their spouses. Nevertheless, survivors continued a schedule of activities at one and two months of bereavement that appeared to fill the time previously spent with caregiving activities. The literature related to elderly spouse caregivers is limited, however, George & Gwyther (1984) cite the cumulative effects of caregiver strain over time which places greater demands on the energy level of the older caregiver. Further, the health status of the caregiver may already be strained due to advancing age and poor health (Cantor,1983).

In this study, all subjects indicated that they tried to take care of themselves by some minor health practices such as diet and physical activity. All respondents made a statement that they were in good health, one was more positive. While respondents were no longer constricted by their caregiving schedule, it would appear that they have not transferred their caregiving energies to self care energies. One respondent was actively pursuing outside activities, but was still struggling with sleep alterations at two months following the death of her spouse. The other two respondents were continuing a caregiving life-style. Since there did not appear to be a significant change in physical status during caregiving and following the death at one and two months, it may be hypothesized that unburdening within the physical domain did not occur.

Emotional domain

Emotional expressions were related to the individual's perception of self as feeling valued and worthy and expressing such feelings as love, fear, or loneliness. All respondents experienced and tearfully related their own unique expressions of love and loneliness during caregiving and at one and two months post bereavement. One respondent openly expressed love and feelings of being nurtured by others. Two respondents made statements about commitment and togetherness that reflected a sense of a loving experience. Tearfulness, in expression of feelings, declined at two months in all participants, while ease of verbalizing increased at two months post death of the spouse. Pollack (1978) cites the degree of the loss is related to the nature and quality of the bond between the surviving spouse and the deceased individual. The greater the emotional investment, the greater the frustration associated with caregiving (Cantor,1983). Unless an individual has unusually strong psychological resources or particularly sensitive confidents, the bereaved spouse may absorb more losses than can be accommodated (Dimond,1981).

In two of the three respondents, their introverted personality characteristics and feelings of self worth probably have impacted their ability to express themselves as needing support during caregiving and bereavement. Consequently, perceptions of loss and feelings of loneliness have affected their emotional and social resource availability. The third, apparently extroverted respondent did not experience emotional withdrawal, as bereavement was filled with social and emotional support from family and friends to the extent that feelings of loneliness did not occupy her mind.

Additionally, Hogstel (1985) cites that bereaved males may have more difficulty expressing emotions openly, thereby increasing the likelihood that gender differences may be a factor in obtaining emotional and social support. This gender characteristic was supported in this small study which consisted of one male and two female participants.

Tearful expressions of feelings declined at two months and ease of verbalization increased from interview one to interview two. Therefore, within the emotional construct, it is suggested that unburdening on an emotional level did occur within two months following the death of the spouse.

Social domain

All respondents seemed to socialize with family and friends but in different ways. Respondent number two displayed extroverted characteristics and was actively involved socially with males and females. Additionally, this respondent appeared to be a practical, logical individual who socialized independently and with her husband during the caregiving process, thereby having a broad social network. There did not appear to be a social void for her following the death of her spouse. The other two respondents' social and emotional ties were related almost exclusively to their spouse and family. Both respondents appeared more introverted or reserved in describing their rather limited social experiences. Despite having access to appropriate resources such as church and social services, the latter respondents continued to remain socially isolated following the deaths of their spouses. However, this isolation seemed to provide them with a kind of comfort to withdraw within themselves as they coped with their losses.

Social isolation is documented in the literature as a common factor resulting from caregiving (Crossman, 1981). Further, Dimond (1981) cites that the question of why some older individuals manage the stress of bereavement more successfully than others is not only accessibility to adequate and appropriate resources, such as that provided by family members, but perceptions of the network as being supportive.

All respondents socially repatterned in their own characteristic manner. The study participants had access to family members but used family support in different ways. One respondent appeared to see herself as dynamic and outgoing and seemed to have no void in companionship during the caregiving and bereavement period. The other two respondents seemed shy and non assertive and may have viewed themselves as socially non-interesting and thus experienced limited social support. Therefore, personality characteristics of extrovert and introvert, and learned social behaviors appeared to play a role in the extent and quickness of adapting socially and to new roles following significant losses.

Further, the aging theory of continuity (Havighurst,1968) serves as a element in understanding reactions and responses to losses as bereaved spouses are faced with addressing social competency and flexibility in adaptation to new roles with personalities remaining relatively consistent with age. Within this construct it may again be hypothesized that unburdening in the social domain did not occur within two months following the spouse's death.

Financial domain

The financial burden of caregiving was indeed reflected by financial stability and prior planning. One respondent experienced a reduction in monthly income at one month post bereavement, while the other two respondents did not experience a change in financial status during caregiving and at one or two months following the death of their spouses. With two respondents, no apparent financial strain was evident, while one respondent found herself in a situation where she appeared to be victimized due to the lack of preparation for potential catastrophic events. This may have related to the passive personality trait of this respondent, creating a helplessness whereby she was out of control of the sequence of events in her life.

Cantor (1983) describes a relationship of low morale scores of caregiver spouses and the problem of economic hardship. Further, Fengler (1979) cites that low income elderly are more isolated with less access to confidants and resources than higher income elderly individuals. The latter respondent needed guidance and support to help her repattern financially. Nevertheless, this individual may choose not to repattern in this construct area due to feelings of self worth, past coping methods, and a submissive personality characteristic. The other two respondents did not require financial guidance as they prepared well for financial contingencies.

There appeared to be an interrelationship between social, emotional, and mental constructs which overlaped into the financial domain. While the interview format was not designed to measure financial change between interviews, there appeared to be little change occurring at one and two months of bereavement. During caregiving and at one and two months bereavement, a common characteristic was that no serious financial problems had been encountered. Therefore, it may be suggested that there has been no unburdening in the financial domain. However, it would appear that unburdening will occur sometime in the future for one respondent.

Mental domain

All respondents described the use of coping methods to overcome stresses such as problem-solving, denial, compliance, and seeking support from family and friends. According to Dimond (1981) the ability to cope is determined by a number of specific cognitive and behavioral strategies, previous experiences, and personality characteristics. Some of the mental processes which reduce threats are ignoring, denial, selective attention, and rationalization. The behavioral plan of keeping busy, was reflected in all participants during caregiving and at one and two months post death of their spouses. Behavioral strategies such as flexibility in participating in activities, farsightedness, and doing something new was reflected in one respondent throughout the caregiving process and in the two months following the death of her spouse.

Respondents shared that indeed they all used some form of decision-making behaviors which appeared to be related to assertive or non-assertive personality characteristics. In support of the continuity theory of aging, there is no sharp discontinuance of personality over time, suggesting increasing consistency with age. Therefore, while problem-solving behaviors did not appear to be indicators of unburdening during caregiving and at one and two months of bereavement, these behaviors were probably influenced by personality type. Personality type is described in the continuity theory as the extent to which one is able to integrate the thinking components of the personality with the emotional elements (Burbank,1986).

In this study, the decision whether to caregive or not to caregive for a spouse is probably interdependent on multiple factors such as feelings of commitment and obligation, need for purpose and meaningful activity, social acceptability, and the strength of the bond or relationship within the dyad. There were no commonalities noted on interview one, however interview two reflected commonalities in decision making and coping methods. This was attributed to the interview format which focused on decisions to caregive during interview two. Since no change was apparent during caregiving and at one and two months following the death of the spouse, it may be supposed that unburdening in the mental domain did not occur.

Spiritual domain

Degrees of spirituality were difficult to measure. What spirituality was to one man or woman may reflect traditional religious values to another. Ebersole (1981) cites that understanding spiritual elements of meaning in a client's life provides data concerning the generation of hope and the way one gives meaning to uncontrollable events. Using Rogers (1981) model, one conceptualizes man as having the capacity to search for meaning in life and death. Two respondents described experiences which reflected traditional religious ethical attitudes which provided comfort during a significant life transition experience. The third respondent professed a philosophy which appeared to be an Eastern spiritual view. While undergoing change this philosophy served to give permission to move forward and not to dwell on the caregiving and death experience. Therefore, her spouse's illness had a beginning, and an end, and at the end the experience provided meaning.

In all subjects there seemed to be a relationship between spiritual beliefs and level of function. Two respondents appeared to experience a void and a kind of immobility resulting from the absence of or ambivalence in relinquishing the caregiving role, or perhaps searching for meaning in life. The third subject did not seem to experience incapacitation or uncertainty, as purpose and meaning in life probably did not relate exclusively to the caregiving role.

Spiritual beliefs seemed to provide a source of the individual's strength and hope. Perceptions of self again played a role in spiritual repatterning. It is the researchers belief that those who viewed themselves as having value at an early age perceived themselves as having value regardless of what they did. Those who did not exhibit self worth tended to gravitate submissively toward a self help idea that satisfied their need and helped them to feel valued.

The lack of commonalities or changes between interview one and two, reflected a wide range of individual spiritual or religious beliefs and capacities to maintain self identity while undergoing changes in the life process. Since no change was evident during caregiving and at one and two months post death, it may be suggested that unburdening on a spiritual domain did not occur.

Mourning

The concept of mourning was not a clear and separate notion, but flowed and overlapped with other dimensions of the whole being during loss. Ebersole (1981) reports losses occurring throughout a lifetime, but the cumulative effects may be felt acutely among the elderly. Gerber (1975) reports that elderly individuals who are bereaved following a lengthy illness within their spouses are impacted by a greater intensity of grief reactions than those whose spouses died suddenly. Further, if purpose and meaning in life was generated by the caregiving role, the vacuum created by that loss of meaningful role activity and role relationship, may help differentiate unburdening from mourning.

All respondents experienced sleep alterations at one and two months of bereavement. One respondent's husband died in her bed. After the death, she had difficulty sleeping until she was very tired, sometimes three or four o'clock in the morning. Her sleeplessness was a physical discomfort. She had difficulty consciously placing herself in her husbands death bed. Since her commitment to living was strong, it was contrary to put herself consciously in a situation where someone she loved had experienced the end of life.

The other two respondents experienced mourning as a time of restlessness, sleeplessness, tearfulness, and appeared to reflect a sense of uselessness, with feelings of abandonment. The latter respondents seemed to derive their meaningful activity from the caregiving role experience, thereby appearing to sustain greater difficulty in relinquishing the caregiving role for their spouses. One respondent in particular may be unable to adapt to a life without the meaningful activity that caregiving provided and was involving herself in a caregiving role for elderly patients within two months of her spouse's death.

Mourning represented the greatest change between interviews one and two. Tearfulness diminished in all respondents at the second interview. However, according to Glick, (1974) among other physical and emotional symptoms, tearfulness was present in bereaved spouses under the age of 45 years at three and eight weeks, and 13 months post bereavement. While age differences may be a factor, the presence of two or three major losses within a 2 year period, may distort the mourning process. Therefore, older individuals who have experienced the multiple losses associated with caregiving and spousal bereavement, and other concurrent losses may be particularly vulnerable and at risk for prolonged grieving and/or compromised emotional health (Schneider,1984).

Reminiscing increased in one respondent and was evident in all respondents at the second interview, perhaps as a mechanism of reconciling conflicts and disappointments associated with the lost role and relationship. Therefore, since changes occurred at one and two months after the death of the spouse in the areas of grieving such as searching for meaningful activity, decline in tearfulness, and reminiscence it may be hypothesized that unburdening within the mourning process did occur.

Growth

Growth is an individual experience. It comes and goes according to the desires of the person who expresses a need to move or expand emotionally, socially, physically, mentally, or spiritually. The aged individual's adaptability to a crisis, such as the death of a spouse, depends on perceptions of self worth, personality traits, social network, and the amount of functional ability remaining (Dimond,1981; Ebersole,1981). Growth was demonstrated in cognitive areas. It has been observed in clinical settings and imagined in ethical dilemmas. Growth has been magnified in philosophical debate. Growth occurs through crisis if the process is recognized and supported (Schneider,1984).

One respondent in this study, throughout the interviews revealed an inner sense of peace and self worth bonded with her own value system that served to provide her with the needed support when her husband died. She was a part of him, but not of him. She shared, she supported but she did not obligate herself to personal and physical deprivation. She walked with her partner through his experience offering guidance and support while retaining enough strength for herself to walk ahead after he had fallen behind. She was 68 years old. She was a pilot. She saw the sky and knew her future.

Two respondents appeared to keep themselves secure and safe within the only world they knew and trusted. It seemed to be a world directed, defined, and dominated by the only person they trusted - themselves. Their need for control and autonomy kept them safe within themselves as they demonstrated physical care, spiritual support, and emotional understanding in the only way they knew. They performed their duties well. While these respondents appeared quiet, sad, and lonely, each individual was beginning to reach out to the future in his/her own characteristic ways. The latter two individuals seemed to experience a greater sense of loneliness, and thus perhaps developed an awareness and empathy for the loneliness of others, which when experienced with someone provided growth to both.

It appeared that unburdening did occur between one and two months following the death of the spouse within the growth dimension of this life transition experience. Each respondent seemed to be reaching out to the future in their own individual ways. At two months post death of their spouses, one respondent talked of resuming a caregiving role, one spoke of sharing with another individual who had experienced similar losses, and other was planning a holiday with her son. It appeared that some growth at the second interview was common to all three respondents at two months of bereavement.

Utilizing Roger's (1981) theory, the nurse researcher enters the individual's field with the assumption that man is whole, unrepeatable, evolving and has the capacity for thoughts, feelings, and active participation along his health continuum. While becoming a part of the person/environment, the participant observer can not help but take something unique and special away about the interaction. A lesson learned by the interviewer from a study of bereaved caregivers is that a good caregiver follows the lead, open always to needs, wants, and desires, never judging, never resolving, just being there, for being there is enough. All of the respondents reflected their uniqueness as a part of this life transition experience and hopefully derived a greater appreciation for themselves.

In summary, as a result of this small study, it may be hypothesized that a change did occur in the emotional construct relating to commonalities in ease in verbalizing of feelings such as expressions of a loving relationship and loneliness which became apparent at two months post death of the patient. Further, the mourning and growth processes at two months following the death of the spouses appeared to reflect change. During the process of mourning, respondents were experiencing a searching for meaningful activity, tearfulness had declined, and reminiscing was apparent at two months following the death. However, due to the overlap in study constructs, it seemed apparent that growth was directly related to the process of grieving and manner in which the individual began to heal the scars of what was missing in his/her lives. It takes time and energy to search, examine, and experience the impact of the multiple losses associated with caregiving and the death of one's marital partner. Nevertheless, each participant appeared to have initiated the process of reaching out to the future in their own individual way at two months of bereavement. The changes in constructs which became apparent at two months of the death of the spouse are termed *unburdening*

Strengths and Limitations of the Study

The purpose of this paper has been to describe processes of *unburdening* utilizing holistic constructs in a small sample of bereaved, older adult spouses. The strengths and limitations of the study are:

Strengths

A strength in the qualitative, grounded theory approach is the appropriateness in tapping the under researched area of caregiver bereavement among the elderly population. The method allows individuals to describe their own experiences in a semi-guided manner. From the results, a body of information can be explored longitudinally and/or incorporated with structural studies for comparison. Therefore, qualitative studies in this subject area would describe dimensions of caregiving and loss which are difficult to identify and measure quantitatively.

Burns (1987) cites that the findings of ethnographic study are not usually generalizable from one culture or subculture to another. Nevertheless, a case may be made for some level of generalization to other groups of individuals who shared similar knowledge and experiences resulting from caregiving bereavement. The study may be criticized due it the small sample size, but the depth of information gathered over time may be generative of insights in a human experience of caregiver bereavement which is generally not addressed in the community or in traditional health care settings.

In the clinical setting, nurses become emeshed in real life dramas and complex social issues. The use of qualitative research in primary care settings can yield insights useful for addressing a range of human problems such as the timing of appropriate interventions, which address the multiple changes and losses associated with caregiving over time. Implications of qualitative study of bereaved caregivers seem evident. A risk profile of individuals who are in need of help and are missed by the health care system may be teased out through qualitative study. Some elderly bereaved individuals are unable to adjust to the complex task of adapting to life as a single person, perhaps through an inability to relinquish their caregiving role and reintegrate into social life. Therefore, utilization of a theoretical base is applicable for the CNS in clinical practice. The nurse identifies problems and intervenes in mutuality with the client/family in individually determined alterations or impediments associated with the caregiving bereavement process.

As a result of the participant observation approach, patterns of resolution are potentially facilitated, and the mourning and the healing process may indeed be accelerated. Utley (1987), a nurse practitioner, described that some older individuals may object to discussing their losses spontaneously, but may relay their own feelings of loss through incidents involving friends or family. An individual may look for help in dealing with his/her "friends" loss. Here the facilitator has the opportunity to discuss listening and supporting as the individual works through his/her own resolution process. This example of similar sharing was evident in study findings, as the male participant began to reach out to a healthy adaptation to loss in the context of another person, yet could not overtly express his own feelings.

Another strength in utilizing a small sample of individuals who have experienced similar life transition relating to the timing of the death, is that the experience of individuals at a certain point in the recovery process is explored and described. Study results can be compared with other studies of bereaved caregivers at the same point in the bereavement process to establish validity and reliability of the subject area.

The literature indicates that the death of a spouse causes a significant grief reaction in elderly individuals necessitating resolution of that crisis. Parkes (1970) describes bereavement in spouses during the first month. It is reported as a sequential process where yearning, numbness, and tearfulness declines at the end of the first four weeks. Further, loss of purpose and meaningful activity gradually gives way to a redefinition of new roles again over the first year of bereavement (Parkes, 1970). However, study findings indicate that individuals seem to be searching for meaningful activity at one and two months post bereavement. Further study is indicated to explore the differences in grieving for elderly bereaved spouse caregivers versus elderly bereaved spouses. Resultant findings may provide insight into appropriate and timely interventions unique to individuals experiencing multiple losses of caregiving and bereavement.

Therefore, replication of the study may provide a predictive profile of the impact of spouse caregiving bereavement on the health of elderly individuals. If commonalities of factors occur as a result of the caregiving bereavement experience over a variety of people, then intervention can target those domains areas. If shared meanings are not evident, an eclectic approach to nursing care may be more appropriate.

Limitations

Limitations of this study are:

1. The concepts of *unburdening* representing the area of interest are

in the fundamental stages of development and in fact may be relevant only to the losses associated with the abrupt termination of the caregiving role due to the death of a spouse. Some questions emerging from the data were: How does *unburdening* differ from the grieving process or spiritual patterns following loss in older adult bereaved spouses? Is *unburdening* a viable concept? Implications for further study seem indicated to document with greater clarity if indeed, *unburdening* exists as a process. In further studies describing *unburdening*, it would be helpful to know how burdened caregivers were prior to the deaths of their spouses. Further explorations into the perceptions of loss of meaningful activity, and the impact of re-focusing of energies into alternative activities needs to be done to determine dimensions of *unburdening* constructs.

Due to the exploratory nature of the study, with a range of individuals, concept development may lack the clarity to represent the phenomenon of caregiving unburdening. Therefore, repeated descriptions of the *unburdening* constructs, with small samples of bereaved caregivers, may lead to a more systematic and clarified description of the area of interest.

2. According to Dimond (1981), little is known about the response of the elderly to loss, since most of the grieving literature has focused on younger adult individuals, and few studies have included widowers. It is possible that the interview format may have included terminology which was perceived as vague, abstract, or inappropriate to respondents. The semi-structured interview may have limited data since some responses were superficial. The format structure does not give the interviewer an opportunity for true indepth exploration in the time frame requested of participants. For example, less structured open-ended questions such as "tell me how you felt about your losses while you were caregiving" and

"how do you feel about your losses now---"may provide more indepth responses about the impact of of the losses unique to caregiver *unburdening*

3. In this under researched area of caregiving bereavement, the pain of grief and the mourning process may be so intense that it obscures the ability of the individual to respond to the concepts of grief, loss, and *unburdening* Also, the time intervals between interviews may have been inaccurately represented the process of mourning.

Because respondents were mourning so heavily at the first interview, other responses to the *unburdening* concepts may have been clouded. From the Gerber (1975) study of elderly bereaved spouses, it was evident that the physical and psychological effects of bereavement (reports of illness and psychotropic drugs) were sometimes not evident until six months post death of the spouse. Therefore, consideration for two to three month, six, and twelve month post bereavement interviews should be investigated to provide longer term exploration of the caregiving bereavement process in elderly adult spouses.

4. Threats to validity, such as the participant observation effect altering the behavior within the subject's environment and the length of time necessary for the interviewer to become a familiar part of the environment were factors that could only be measured with study replication. Additionally, the interviewer may have pushed too hard for descriptive data within the time frame planned for the interview with the older individual, therefore the data may have been limited or inaccurate. In addition, utilizing a panel in determining if committee members would come to similar conclusions from data findings would help establish accuracy in descriptions of the observed reality and it's portrayal in the study findings.

5. A further limitation of the interview is that the interaction of the

participant observer and respondent may introduce interviewer bias. Utilizing Roger's (1981) theory, the nurse investigator enters the participant's field, and immediately becomes a part of the environment, and thus bias is introduced. Nevertheless, to reduce interviewer bias and increase reliability of the interview, an interview format was utilized with each respondent with probes that facilitated verbalization of responses. Further, the interview was conducted with the same order of topics and the wording remained basically the same with each respondent. The interview itself was guided by procedures developed for uniform interview behavior.

In summary, limitations within concept development or wording of questions to tap the caregiving and bereavement experience may have resulted in inaccuracy or participant reluctance to disclose the requested information. Modifying the time span between interviews needs evaluation. Consideration for follow up interviews may be indicated to explore and describe the subject area longitudinally in this under researched population of elderly persons.

With these considerations in mind the following suggestions are offered as implications for nursing practice, education, and research.

Nursing Implications for Practice

The implications for nursing practice will be presented from the perspective of the Clinical Nurse Specialist in the primary care setting. The CNS bases nursing practice on nursing and other appropriate theories drawn from allied disciplines. Martha Rogers' theory of unitary man was deemed applicable in explaining the manner in which the CNS could intervene in the life cycle transition of caregiver bereavement.

The CNS is concerned with health alterations and developmental transition points that must be accomplished so that an individual is better equipped to move on to the next phase of development. These health related components can arise as a result of caregiving and grieving as a response to multiple losses. As the life process is continuous, man has the capacity to knowingly rearrange his environment and actively make choices to repattern with increased competency and achievement of well being (Rogers,1981).

To conceptualize unburdening from Rogers' perspective, the system of a single human field is much like a wave traveling across a mighty ocean. Often the wave will meet obstacles or rip tides and become disrupted, just as a human being may meet adversity, and a great deal of upheaval and destruction may occur. But, the wave and the human will survive, in some form, to move forward, to swell and grow as a wave again, or to ripple unnoticed through time.

The nurse in advanced practice works to assist client's in meeting alterations in the life process. Once a pattern is recognized, mutual decisions are made as to how the client will respond to burdens or alterations that can impede growth. The harmonious interaction promoted by Roger's places the nurse in the role of promoting the interaction between person and environment. Therefore, from Rogers'(1981) perspective, the evolving process of caregiving bereavement may consist of pattern that can impede and/or facilitate that process of achieving maximum health potential. Those patterns which impede the caregiving and bereavement process can be viewed as part of a larger pattern within the life process of individuals.

The research described was not designed as an intervention study. Nevertheless, the CNS in a primary care setting is in a unique position to develop nursing interventions which are directed toward repatterning of the client/environment for more effective fulfillment of the client's individual capabilities. The design of a nursing system to meet the ongoing needs of the client and family emerges as the nurse and client interact over time.

Ideally, in a primary care setting it is appropriate to intervene during the caregiving process prior to the death of the family member, and then to follow the client intermittently through out the mourning process. The CNS is in a unique position to provide anticipatory guidance and education to the client and family members about health needs during the caregiving process and as a response to losses associated with the grieving process.

The nursing process is defined as systematic observational and problem solving techniques to identify problems and appropriate strategies and the evaluation of the effectiveness of the interventions (Carpenito, 1983). The steps in the nursing process taken to assist the client are to:

1. Gather data.
2. Assess data and formulate nursing diagnosis.
3. Determine short and long term health goals in mutuality with the client.
4. Implement nursing intervention.
5. Evaluate outcomes for effectiveness.

The first step in the nursing process is to gather appropriate data. For the older bereaved client, who is mourning following spousal caregiving, several kinds of data are gathered as a part of ongoing health care. In addition to a health history, information concerning the holistic dimensions of the individual relative to caregiving and bereavement are obtained. Gathering and recording data could be accomplished by the use of an assessment tool, such as Bereaved Caregiver Assessment Instrument, (see

Appendix I) which was specifically designed for this purpose.

According to recent literature, caregivers tend to minimize the hardships they faced and are preoccupied with the tasks of daily care which result in reports of denial of grieving losses prior to the deaths of the family member (Vinek,1984; Malone,1985). Nevertheless, it is appropriate for the CNS to anticipate a discounting of self care needs. By focusing on the caregiver, rather than exclusively on the care recipient during an encounter, those discounted self-care needs may be addressed. The nurse must support the client and caregiver from a knowledge base and seek to resolve and/or prevent the accumulation of unresolved grief. The chances for the older person and patient coping appropriately with the inevitable losses they face are increased.

The information obtained relating to person and environmental factors, assists in identifying a pattern. For example, intermittent assessment of financial changes that potentially can result from caregiving and loss of a family member may alter or even prevent secondary losses. Therefore, assessment of the objective and subjective characteristics of changes within the client/environment must be accomplished on an ongoing basis to determine actual and potential losses or disharmonies.

The second step in the nursing process is the nursing diagnosis. In this phase, the CNS formulates conclusions about the client based on the collected data. Any discordant variations in patterns related to caregiving and losses, which may impact health goals are identified. From these conclusions, planning and implementing of nursing intervention is provided. An example of a nursing diagnosis may be, altered sleep patterns resulting from the caregiving and mourning process.

Step three in the nursing process is determining short and long term goals. Another role of the CNS as planner is to collaborate with the client in establishing health oriented goals. The goals are established mutually with the client, considering such factors as; his/her right to choose, values and beliefs, personality characteristics, past coping methods, life style, and support system availability. Further, goals mutually accomplished with the client/family would play a role in the client's achievement of them. An example of goals set by the individual who is post caregiving and mourning may include:

1. Identifying environmental factors which may impede resolution of losses associated with the loss of caregiving role and death of one's spouse.
2. Determining patterns of symptoms relating to the mourning process.
3. Seeking a means of altering coping mechanisms previously used to cope with loss.

Utilizing study guidelines, short term goals may be identified as the subconstructs under the appropriate construct domain, and long term goals are the specific construct domain. For example, short term goals under the physical domain could include:

1. To identify discordant patterns in the daily schedule.
2. To identify health perceptions.
3. To determine environmental factors which impact self care.

The long terms goal is to seek appropriate repatterning and redirection of physical domain for achievement of maximum health potential as defined by the individual client.

The fourth step in the nursing process is intervention. The interventions are actions taken to achieve identified goals and thus are directed toward repatterning of the person and environment in fulfillment of the client's capabilities. One role of the CNS is to provide emotional support and counsel as the client disengages himself from the losses. The nurse seeks to facilitate confrontation of the difficult issues associated with the mourning process. Assurance that feelings are normal and necessary to resolve the grief may facilitate "moving on".

Interventions selected will depend upon the problems identified and the mutual goals established by the client and nurse. The choice of interventions must consider caregiver bereavement versus the unexpected loss of one's spouse. The changes associated with gradual, physical deterioration due to the strain of caregiving, social isolation resulting from caregiving over time, and the loss of the busy schedule associated with caregiving tasks can result in an accumulation of losses. Thus, patterns of grief displayed may differ for caregiving bereaved spouses and non-caregiving bereaved spouses.

Gaining perspective as a part of the grieving process is not easy nor is it reached quickly (Schneider,1984). Therefore, considering the multiple loss issue, the bereaved person needs an opportunity to describe his/her experience to a caring, understanding person. The CNS encourages a discussion of caregiving events, the importance of the caregiving role/activity, the loss of the relationship with ones' spouse, the scope of which encompasses a large area of the person and environment.

The loss of caregiving activity and role associated with caregiving bereavement challenges the nurse to mutually assist the client in the re-focusing of energies into meaningful alternatives. The nurse can aid the client in reviewing, strengthening, or developing existing resources for purposeful activity and appropriate sources of social support. The CNS in a primary care setting is in a position to assist the client/family by encouraging communication about the difficult and/or unresolved issues associated with caregiving and bereavement, such as guilt or feelings of abandonment. Further, the nurse can help the bereaved caregiving family in the identification and establishing realistic expectations for the future. As a result, the CNS assists in repatterning and redirecting of energies and making sense out of the losses.

The fifth, and final, step in the nursing process is the evaluation of outcomes for effectiveness. Outcomes may be evaluated by the following methods:

1. Utilization of caregiver bereavement instrument.
2. Recording goals, interventions and expected outcomes.
3. Revision and reformulation of interventions while moving toward maximum health potential.

In using Rogers' (1981) framework as a focus for nursing, mans' relationship to his environment, and the importance of this relationship across the life continuum is described. The CNS uses the nursing process to assist the grieving client in meeting mutually established goals. Interventions are chosen to pattern and repattern the client/environment to achieve maximum well-being within the individual's capability. Evaluation provides the opportunity to continually reappraise the caregiving bereavement process, identify new patterns or obstacles, and set new goals and interventions, in the primary care system.

In addition to <u>assessor</u> another role of the CNS in working with bereaved caregivers is that of <u>counselor</u>. According to Schneider (1984), the grieving process begins by respecting the process of healing and growth in another individual. Despite the fact that the bereaved person may choose not to accept what the helper may recommend, including stopping, dying, or not growing, the person continues to need help and understanding. Support for the survivor/family requires a helping relationship, which is continuous, accessible, and affordable. Grief work cannot be rushed. The nature of bereavement however, is that the intensity of the loss and the energy required to mourn are minimized with time (Whelan, 1985).

The CNS continues to recognize the client's capacity to think, feel, and make decisions as he/she moves through a seemingly chaotic life transition. The implication is that choices are made along the life continuum impacts the life process of man. Choices made from a knowledge base about caregiving bereavement can influence pattern and repattern so that life can be experienced as harmonious rather than discordant. Therefore, the individual client/nurse interaction will influence reaching maximum health potential.

Ideally, the nurse in advanced practice must seek to address the facilitation of the bereavement process prior to the death of the patient through anticipatory guidance. The first CNS/client contact may be during the caregiving process. The caregiver may be entering the health system because of a health problem related to his/her spouse. At this point in the health continuum, anticipating future problems and needs of the spouse caregiver may have it's origin.

Behavioral strategies such as a diary, where the non bereaved or bereaved caregiver takes a few minutes out of each day to log his/her thoughts and feelings about caregiving and loss could become part of the management plan. This process may give permission to the client, whereby release of burdened feelings such as anger, blaming, resentment and others reactions to loss are transferred onto the pages of the log. Sharing these feelings with a supportive person helps the client explore the impact of the caregiving and the meaning of the caregiving role for the individual. Rogers

(1981) believes that the diverse and dynamic nature of the life process calls for continuous revision of the measures used for intervention.

As nurse counselor, an assessment of the level of vulnerability to loss is indicated to determine whether the bereaved individual is experiencing depression or normal grief. Schneider (1984) cites that depression is suggested in individuals who have suffered more than the usual number of losses and exits from the social field, which the nurse might anticipate as a result of caregiving bereavement. Therefore, the nurse must be aware of signs of depression that indicate a need for treatment and/or referral such as severe insomnia, persistent feelings of worthlessness, loss of gratification from usual roles, suicidal thoughts and feelings, or persistent restrictions of pleasure (Schneider,1987)

Diminishing pangs of awareness of the loss may indicate the beginning of the healing process (Schneider,1984). At this time the client can begin to process the decision of whether to carry the burden of grief through life, and thus may move from the awareness of the extent of what was lost and gain perspective of discovering what remains (Schneider,1984). Throughout the process of grieving, and the client mourns the losses associated with caregiving and the death of the mate. The need for an ongoing, supportive network is of particular importance. The accessibility of these supportive resources is a factor in which the individual maintains social identity and emotional support.

The CNS provides stabilizing support, encourages expression of concerns and facilitates coping behaviors, having judged the client's capacity and/or desire to accept the counsel. Having established a trusting rapport, and utilizing a knowledge base, the CNS may facilitate repatterning of self care as she motivates the client to begin to reach out and to give help to others, not just receive it. It is common for nurses to realize that bereaved persons need care and concern, but it is also known that these same individuals may also want and need to help others (Rigdon, 1987).

In order for families to be supportive, they must be sensitive to the needs of the bereaved family member, and seek ways to provide help and assistance. In so doing the client maintains identity and balance. From a knowledge base, the CNS counsels and educates family members in the grieving process. Family members can play an important role in easing the process of mourning within the client and themselves through self help practices such as attending support groups. The CNS may serve as a counselor on a one to one basis with the client and for family members, or serve as a facilitator for support groups of bereaved caregivers.

The nurse in advance practice has a responsibility not only as an assessor and counselor for clients and families who are undergoing life transitions. As a client advocate, the CNS works in mutuality with the client in promoting a transfer of responsibility for improving self care and health promotive activities, and bringing about positive alterations in health behaviors. It is suggested by the researcher that the process of *unburdening* has been with each human being since life began. It is not just in illness or death of a loved one where burdens and changes are brought to bear. With each alteration on the health/illness continuum the individual is challenged with an opportunity to learn, to change, and to grow. The role of the CNS is to mutually facilitate that change.

Understanding the way in which bereaved individuals cope with stresses, losses, and change and restores a state of balance will depend upon person/environment resources that come into play. The CNS becomes aware of these factors and works with them to enhance growth and positive change with the client. Further, it is not always outside forces which bring burdens into the clients' environment. The client must first recognize a pattern in order for it to have an effect. Once recognized, decisions are made as to how to react or respond to that alteration. In the primary care setting, the CNS advocate assists the client toward exercising his/her rights, thus allowing the client to assume responsibility for choices based on their own quality of life expectations.

The CNS acts as a consultant and collaborator with other members of the interdisciplinary team in seeking assistance with planning care that will address the ongoing needs of the clients and families. As a consultant the CNS may provide advise and information to other team members, or lay groups, relating to an area of gerontological expertise such as caregiver bereavement in the elderly. In this role the nurse assists in broadening the scope of health care awareness and planning.

In summary, the CNS in primary care brings forth numerous roles, which assist in serving man in his entirety. The nurse seeks to promote harmony between man and environment, while strengthening the integrity of the human field. Interventions are directed toward patterning and repatterning of the field toward awareness of maximum health potential within the capability of each individual. To reach that goal, the CNS uses the nursing process to determine individual differences in assisting people to develop patterns which coordinate rather than conflict, with environmental changes. The bereaved caregiver instrument is part of a means of assessing the person/environment and variables, thereby planning ongoing care in mutuality with the client.

The need for human support from a knowledge base, enables the nurse counselor to facilitate the grieving process and identify behaviors that are motivating in helping the client achieve appropriate goals. Finally, it is emphasized that the CNS is in a unique position to contribute to the education of the caregiving bereavement process of family members, lay groups, and other members of the interdisciplinary team.

Nursing Implications for Education

The purpose of this study is to describe and explore the experiences of the spouse family caregiver following the death of his/her mate. The researcher found there was literature to support how the patients' functional, social, and mental limitations are related to perceptions of caregiver burden. The nature of grief and bereavement among younger adults and widows is described in various studies (Parkes,1971; Glick,1974). However, little is understood about older adult bereaved caregivers.

Nurses in advanced practice have a responsibility for envisioning and initiating health services directed toward an unknown future. It is known that trends in life expectancy indicate that families provide the bulk of care for elderly Americans. These increasing numbers of elderly are a new phenomenon with little known consequences (Day, 1985). Therefore, during the educational process, the nurse must develop a knowledge base about the aging trends, aging theories, and the magnitude and complexity of providing care for the aged and its' impact on caregivers and their families. In addition, the CNS must understand and educate others in and out of the health care system of needed health care policy changes and programs that support home care for the elderly.

Further, while grieving and loss theories are part of undergraduate and graduate curriculums, the theoretical basis often is related to bereavement. Within the older population, past experience is a predictor of adaptation to widowhood. Therefore, knowledge of those skills and competence utilized throughout life to cope with loss, needs to be recognized and assessed. The nurse must be educated to systematically assess prior losses, and previous coping patterns, and the impact of patterns of health care alterations at any point in time, on an ongoing basis. The meaning of loss and the perception of the transition experience effects goal achievement.

Nurses who are planning to specialize in gerontology must have incorporated within their educational curriculums advanced knowledge of the normal aging process and variations of this process. This knowledge helps differentiate normal aging changes from grieving responses, and symptoms of illness. Further, in working with individuals who are grieving the losses associated with caregiving and bereavement, an understanding of the response to multiple losses is essential. With a theoretical foundation, the nurse will be able to recognize alterations or patterns attached to the life process of the client. The educated nurse will be prepared to facilitate resolution of symptoms of unresolved loss within a clients and families.

In working with clients who may have complex multidimensional problems associated with caregiver bereavement, the CNS needs an educational foundation where creative interpersonal strategies, problem solving skills, and other communication skills, such as active listening are readily available and appropriately timed and implemented as a part of a management plan. Based on sound theory the CNS creates a climate where the client becomes responsible for deciding his/her own quality of life.

Implications for Research

There are several implications for further research derived from a study of the process of *unburdening* Some suggestions are as follows:

1. Clarify and further refine caregiving bereavement constructs. The interview questions relating to emotional and spiritual domains, mourning, and growth concepts were perceived as abstract and unclear to some respondents.

2. Describe a study to explore the styles in problem solving. For example, locus of control is the extent to which one perceives himself capable of determining his own destiny referred to as internal locus of control, or whether an outer force such as luck, chance or God controls it known as external locus of control (Rotter,1966). There are few studies in the area of locus of control among widowed, older persons (Dimond, 1981). The relationship of locus of control to predict responses such as adaptation to widowhood among bereaved caregivers, could be integrated and clarified in a modified replication of the present study.

3. To further evaluate the interview format, and to describe ways in which varying groups of individuals experience caregiver bereavement, administer it to small groups of individuals experiencing caregiver bereavement, such as male bereaved caregivers versus female bereaved caregivers; non-caregiving bereaved and bereaved caregivers; age group comparisons, such as 50 to 60 year old group versus 60 to 70 year old group versus 70 to 80 year old groups; and selected socio-economic groups.

4. Conduct a longitudinal design which captures the sequence of caregiving bereavement at one, three, six, and twelve months, post death of the mate. This design could identify the nature of bereaved caregiver patterns among the elderly, as well as clues to long term resolution or non resolution of multiple losses.

5. An open-ended, guided interview approach allows participants to describe their experiences in a holistic manner. Using a combination of

qualitative methodology along with selected structural measures for comparison, would assist in understanding the extent of the caregiving bereavement phenomenon among elderly individuals. Further, questions may be developed from all constructs using this comprehensive approach. Adding the following question at the end of each interview session may add an extra dimension missed by the guided interview approach. That question is: "Is there any thing else that we haven't mentioned ?"

6. Much of the research that has been done with older adults examines the process of spouse bereavement (Dimond,1981). Another area for study is the loss, by death, of friends who live in close proximity, which may result in significant bereavement responses. This group of individuals who concurrently are experiencing multiple losses due to age and the life process, may be in need of primary health promotion and disease prevention, possibly having been missed by the health system.

Summary

In Chapter V1, a summary and interpretation of the study findings in relation to the problem area was discussed. The major contribution of the study has been to describe a process termed *unburdening* from a holistic perspective as expressed by recently bereaved caregivers. The results of the study showed that respondents were experiencing emotional, mourning, and growth changes which became apparent at two months following the death of the patient. These changes may be unique to the caregiver bereavement process and thus have been termed *unburdening*

All respondents seemed to be searching for meaningful activity within eight weeks following the deaths of their spouses, perhaps a reflection of the process of relinquishing the former caregiving role and/or reaching out for meaning in life. All respondents were able to express individual feelings of love and loneliness as well as reminisce about the lost role and relationship at two months following the death. Another commonality among study participants was the decline in tearfulness which may be a protective mechanism which allows the bereaved individual to limit his/her vulnerability having experienced multiple losses of caregiving and death of a spouse. Variation in responses to *unburdening* constructs may have related to one's physical capacity, and perception of the number and extent of previous losses. Further factors accounting for differences seemed to encompass financial stability, gender, learned coping methods, perceptions of purpose in life, perceptions of supportive resources, and personality characteristics.

Another contribution of the study was to demonstrate the use of of the qualitative approach in studying the under researched area of caregiver bereavement among elderly spouses. The individuals studied are quite possibly a large group of persons who are missed by the health care system, following the deaths of their spouses. The study results of the extent of *unburdening* can be utilized to further develop and refine the construct domains to be used for further research, education and nursing practice.

APPENDIX A

Caregiver Information

APPENDIX A

Caregiver Information

While a wealth of information has been written about the general problems of caregiving for elderly family members in the community, very little is reported on how caregivers evolve through the experience of death of the caregivers' spouse. The literature clearly describes the need for home care for the elderly is increasing. It has been reported that the population of older individuals is increasing with more Americans living past their 85th birthday. In fact, in 1985, 5.2 million elderly persons lived in communities with disabilities that left them in need of assistance with such day to day tasks as meal preparation, dressing, and bathing. Furthermore, the likelihood of families caring for a disabled relative is increasing.

Recent literature emphasizes the burdens and stresses of the caregiving role. Despite these strains, family caregivers continue caring for their elderly spouses or parents. Interestingly, while other family members may support the caregiving activity, caregiving is primarily a single person role. In spouse caregiving, it would seem that caregiver strain is related to the intensity of the bond between caregiver and care recipient. Indeed, the greater the emotional investment, the greater the frustration associated with caregiving.

The death of a spouse is viewed as an emotionally devastating event. Following the death of the spouse, the degree of the loss may be related to the nature and quality of the bond between the surviving spouse and the deceased individual. Nevertheless, while the death may have been anticipated due to a chronic illness affecting the patient, the void that comes with death was not expected. Further, the caregiver may not have allowed time to experience what life would be like without his/her spouse.

The literature supports the concept that the bereaved widow or widower has a number of tasks to negotiate for longer term adaptation to life without their spouse. As one "unburdens", one releases or holds onto for a time the state of burden when the actual force of the responsibility of caregiving is no longer present. The process of thinking about, feeling, and verbalizing the experience of caregiving, compared to how one thinks and feels after the death, has the potential of opening the door to appraising a life purpose that is no longer dependent upon what was lost.

APPENDIX B

Initial Study Contact

APPENDIX B

Initial Study Contact

Exploration of the Unburdening Process

In __________ of last year, you participated in the first part of a study about family members who provide care for older adults. As you may recall, this study is being conducted by the Michigan State University College of Human Medicine and College of Nursing. Recently, you told us about the death of your spouse. When did he/she die ? (If death occurred within the past one to two months, proceed with the interview. If death occurred greater that two months ago, support the individual in their loss, as a follow up to previous participation in the Family Caregiving Study.)

I'm calling today to talk with you about participation in a study about the unburdening process, as experienced by caregivers for their spouses. Would this be a convenient time to talk with me about this study ? (If "No", schedule a more convenient time for the phone interview) This study is being done to better understand the feelings, perceptions, and needs of spouses who have experienced varying reactions to caregiving and the death of their mate.

Indepth interviews will be carried out at one and two months following the death of the family member who needed care. The study is being conducted as part of my work for a Masters Degree in Nursing at Michigan State University. Participation in this study will take approximately one hour on each of two sequential appointments, at your convenience. The interviews will take place in your home. During these interviews, questions will be asked regarding your feelings about caregiving and your perceptions following the death of your spouse.

Please be assured that all of your responses will remain confidential. Are you be willing to participate in this study ? (If "No" - thank them for their previous participation). (If "Yes" - schedule a time for first home visit and obtain directions to the home). Inform the participant that the appointment will be confirmed again, the day before the visit by phone.

APPENDIX C

Approval Letter UCRIHS

APPENDIX C

MICHIGAN STATE UNIVERSITY

UNIVERSITY COMMITTEE ON RESEARCH INVOLVING
HUMAN SUBJECTS (UCRIHS)
238 ADMINISTRATION BUILDING
(517) 355-2186

EAST LANSING • MICHIGAN • 48824-1046

February 3, 1987

Ms. Margery L. Taylor
College of Nursing

Dear Ms. Taylor:

Subject: Proposal Entitled, "An Exploration of the Unburdening Process as Experienced and Expressed by the Family Caregiver Spouse Following the Death of the Chronically Ill Mate"

UCRIHS' review of the above referenced project has now been completed. I am pleased to advise that the rights and welfare of the human subjects appear to be adequately protected and the Committee, therefore, approved this project at its meeting on February 2, 1987.

You are reminded that UCRIHS approval is valid for one calendar year. If you plan to continue this project beyond one year, please make provisions for obtaining appropriate UCRIHS approval prior to February 2, 1988.

Any changes in procedures involving human subjects must be reviewed by the UCRIHS prior to initiation of the change. UCRIHS must also be notified promptly of any problems (unexpected side effects, complaints, etc.) involving human subjects during the course of the work.

Thank you for bringing this project to our attention. If we can be of any future help, please do not hesitate to let us know.

Sincerely,

Henry E. Bredeck, Ph.D.
Chairman, UCRIHS

jms

cc: Dr. Barbara Given

APPENDIX D

Informed Consent Procedure

Appendix D
Informed Consent Procedure

Before we get started today, I would like to take some time to explain what will be involved in taking part in this study and to answer questions you may have about participating.

Over the course of two months there will be two home visits arranged at your convenience.

There are just a few things that are important for me to discuss with you relating to your involvement in the study. The interviews will be tape recorded permitting the interviewer time to focus on the interview with you.

Your participation in the study will not result in immediate benefits personally, however your insights may add to the understanding of health care professionals of the experiences and reactions to caregiving and the death of ones spouse. Your insights can contribute to a body of knowledge which may help another who is faced with a similar circumstance.

Taking part in the study will not change the health care or services that you are now receiving. The study does not provide any services and cannot arrange for services for you.

It is important for you to know that all of your responses during the course of the study are anonymous and confidential. Your name and anything which would identify you personally will be kept separate from your responses. Neither your name nor the name of your family member will be given out to anyone else or used in any written reports of the study at any time.

I wish to reinforce for you that taking part in the study is voluntary and you are free to withdraw from the study at any time without consequence.

Do you have any questions about taking part in the study?

IF THE PARTICIPANT DOES NOT WISH TO SIGN THE CONSENT FORM, LEAVE THEM A COPY AND PROCEED WITH THE INTERVIEW. LEAVE A COPY OF THE PARTICIPANT INTERVIEW SCHEDULE AND CONSENT FORM WITH ALL INFORMANTS.

APPENDIX E

Consent Form

APPENDIX E

Consent Form

The study has been described and explained to me and I agree to take part in the study. I understand what my participation will involve:

1. I voluntarily consent to participate in this research study.

2. I have had an opportunity to ask questions.

3. If I change my mind and wish to not participate in the study before the study is completed, I may do so.

4. I give permission to utilize the taped interviews and questionnaire for the purpose of exploring and understanding caregiver unburdening following the death of my spouse.

5. I understand that the results of the study will be held in strict confidence and should they be published, my name will remain anonymous. I understand that names will not be associated with study material. I understand that within these restrictions, results can be made available by me upon request.

6. I understand that the tapes will be erased at the completion of the study and that all of my responses are confidential.

7. I understand that no immediate benefits will result from taking part in the study, but am aware that my responses may add to the understanding of health care professionals of the experiences and reactions to caregiving and the death of ones spouse.

Signature: ________________________________ Date:__________

Signature of Interviewer: ______________________ Date:__________

APPENDIX F

Consent Form Letter

APPENDIX F

MICHIGAN STATE UNIVERSITY
College of Nursing
Consent Form Letter

Investigator: Margery L. Taylor, RN, MSN Student
Gerontology Clinical Nurse Specialist Program
Michigan State University
(517) 353-0852

Date

Dear ____________________,

The study in which you are to participate is designed to explore the process of unburdening as experienced by the family caregiver spouse. In order to help others, this study is being done to better understand the feelings, perceptions, and needs of spouses who have experienced varying reactions to caregiving and the death of their mate. In depth interviews will be carried out at one and two month intervals following the death of the family member who needed care. The study is being conducted by myself as a part of the requirements for a Masters Degree of Science in Nursing.

Participation in the study should take approximately one hour of your time at each of the two sequential scheduled appointments, at your convenience. The interviews will take place in your home and will be tape recorded. During these interviews questions will be asked regarding your feelings about caregiving and your perceptions following the death of your spouse. Please be assured that your responses will remain confidential. There will be no identifying information on the tape, questionnaire or within the report of the study material.

The tapes of the interviews will be erased following the completion of the study. In addition, you are free to deny responses to specific questions on the interview or questionnaire. You may withdraw from the study at any time should you so choose and that withdrawal will in no way effect the care you may be receiving from your physician or formal agency.

If you have any questions, please call the researcher at any time. I would be privileged to send you a summary of the study results at its completion if you so desire.

If you are willing to participate, please read and sign the attached consent form.

Thank you very much for your generous gift of time and effort.

Sincerely,

Margery L. Taylor, RN
Gerontology Clinical Nurse
Specialist Program

APPENDIX G

Interview Format

APPENDIX G

Interview Format

To explore the phenomenon of unburdening the following open-ended questions will be utilized to guide interactions:

INTERVIEW I

I would like you to describe a typical day now, as opposed to when you were caregiving. Please consider such activities as food/fluid intake, exercise, daily activities, sleep/rest, etc.

1. Could you describe a typical day now ?

2. How is this different from then?

PROBES

(1) Can you describe your sleep habits ? Do you wake up at night ? How do you feel at the end of your sleep? How is your energy level?

(2) What kind of food and fluids do you usually eat for breakfast ?

(3) What do you do for the remainder of the morning activities,exercise, shopping, etc. Do you read, watch TV, listen to the radio, on a typical day ?

(4.) Can you describe the form of transportation you use ?

(5) At lunch time, what is the typical menu ?

(6) How do you spend your afternoon ?

(7)What about daytime naps ?

(8) What do you do if you feel lonely or sad ?

(9) Can you describe how satisfying your life is ?

(10) Please describe any social activities as a part of your typical day.

(11) At dinner, what do you typically eat and drink? Any alcoholic beverages consumed on a typical day ?

(12)Whatfamily/friends relationships take place on a typical day? (Frequency and Quality)

(13) How busy is your typical day ?

(14) How do you relax on a typical day ?

	(15) How do you unwind at the end of a typical day ? Any habits that you use ?
Caring for a chronically ill family member over time and then experiencing the death of that person can affect the caregiver in many ways.	
A. 1. Could you tell me how you feel physically now ? 2. How is this different from when you were caregiving ?	(1) Can you describe your health status ? (2) Are you taking any medications ? (3) Can you describe health care problems that need medical attention ? (4) How are you taking care of yourself ?
B. Some people express changes in their mental outlook as a result of caregiving and subsequent letting go of the former caregiving role. 1. Could you tell me about your mental outlook now ? 2. How is this different now as opposed to then ?	(1) What do you view your next role to be ? (2) How do you cope with your problems ?
C. Some people express varying emotional reactions in stressful or difficult situations. 1. Could you describe how you are feeling emotionally now ?	(1) Describe the bond (relationship) between you and your spouse. before caregiving ? (2) Describe the bond while you were caregiving ? (3) Please describe your feelings about the relationship with your spouse since his/her death. (4) What kind of burdens and rewards (personal gratification/satisfactions) do you feel ?
2. How are these feelings different from the feelings you experienced as a caregiver ?	(5) Can you describe feeling frustrated or angry ? (6) Do you feel you are a better person because of caregiving ?

	(7) Do you have difficulty saying no to people ? When you do say no, do you feel guilty ? (8) Have you had concerns about someone saying you are not a good person ? (9) Do you miss the daily activities associated with caregiving ? (10)What was the earliest you remember taking care of people ? (11) How did you view the person who was dying ? (12) When it was at its worst, what was it like? When it was at its best, what was it like ?
D. Some people say that their social relationships are altered during the caregiving experience.	
1. Please tell me about your social situation now ?	(1) Can you describe feelings of being isolated from people or the outside world ?
2. How is this different from when you were caregiving ?	(2) Did you feel you were in the care giving situation alone ?
	(3) What kind of support do you get from family/friends ? Is it helpful ?
E. Some people report changes in their financial status as a result of the caregiving role.	
1. How do you view your financial situation now ?	(1) Who handled the finances in the family? Is this a problem?
2. How is this different from when you were caregiving ?	(2) The older you get, do you become more fearful of not having enough financial resources; knowing how to negotiate the system ?
F. Some people say that they have experienced changes in their spiritual outlook, such as changes in meaning and purpose for life, as a result of loss the caregiving role and death of their mate.	

1. How do you find meaning and purpose in your life?

2. How is this different from when you were caregiving?

(1) How is your spiritual outlook or philosophy helping you?

(2) How do you find purpose and meaning in your life?
(3) Who do you turn to in the critical moments?
(4) Is there anything that is especially frightening or meaningful to you?

INTERVIEW II

People decide to provide care for their family member for many different reasons. Would you please describe the primary reason you decided to care for your spouse?
(If children) What about the children? Did they influence your decision?

Some people decide to provide care because they view caregiving as their duty. Did a sense of duty affect your decision?

Other individuals caregive out of feelings of love and affection. Was the bond of love and affection a factor influencing your decision to caregive?

Some decide to care for their spouses because caregiving provided purpose and meaning in their life. Was the sense of purpose and meaning a factor?

Others believed their spouse always depended on their being there for him/her. Did this sense of always being there affect your decision?

Some say "I began caregiving, found myself doing it, and even though I wanted to, I couldn't say no." Did the belief that you couldn't say "no", affect your decision?

Others say, "I just couldn't afford to do otherwise." Were financial concerns a factor in your decision to caregive?

If you could do anything you wanted to do (you have no limits):
1. Describe to me what you would do on this day.

2. Help me to see what you are seeing on this day.

3. If you could talk to someone who is in the same situation that you were in, just two months ago, what would you like to tell them?

(1) Where would you be? What do you see yourself doing?

(2) Who or what would make you happier?

In our final few minutes together, I am going to give you a poem written by a person named "Louise". What does this mean to you in terms of caregiving?

> ...I'm doing what I should
> have done years ago, which
> is finding out who I am and
> what I want. I want to have
> a choice. And when I make
> decisions through choice,
> not duty, it has to be better
> for me and for the people
> who love me and the
> people I love.

Is there anything else you would like to talk about?

The tape recorder is turned off. At this time I want to thank you for your participation in this study. What you have contributed during the interview process will add to an understanding by health care professionals of the impact of experiences/reactions to caregiving and the death of ones spouse. Your insights may help another person faced with a similar circumstance.

APPENDIX H

Sociodemographics

APPENDIX H

Socio-demographics

The socio-demographics tool is utilized to elicit descriptive information about the participants under study for the purpose of verifying sample criteria for participation. Knowledge of the socio-demographic data adds meaning for understanding an individual undergoing a life cycle transition. Socio-demographic data collected will include age, racial/ethnic background, educational level, occupation, financial resources, present state of health, past experiences with caregiving, number and ages of children living at home, distance from home of other children, family and other support.

<u>Socio-demographic Questionnaire</u> Code# _____

1. What is your age ? _______ (Write in number)
2. What is your racial or ethnic background ? (Please check all that apply) (Optional)

________ Black
________ White
________ Asian American
________ Hispanic
________ American Indian
________ Other (please specify)

3. How much schooling have you had ? (Please check highest grade completed): K-3: ______ 3-6: ______ 6-12: ______
College: Associate Degree: ______
Bachelors Degree: _____
Masters Degree: ______
Doctoral: ______
Other Professional Degree: ______

4. What is (or was) your primary occupation ? ______________________
Are you currently working ? Yes ______
(If yes, how many hours per week ?): ______
No ______

5. What is your total family income per year ? (Check one)
______ Between 0 and $3,999.00
______ $4,000 and $9,999.00
______ $10,000 and $19,999.00
______ $20,000 and $29,999.00
______ $30,000 and $39,999.00
______ $40,000 and over

6. Do you have health or medical insurance ? Yes: ______ No: ______
(Check all that apply)
Medicaid : ______
Medicare A: ______
Medicare B: ______
Blue Cross: ______
Other: ______

7. If yes to #6, is your coverage adequate ? Yes ______ No ______
8. How is your present state of health ?
(Please check one) ______ Excellent
______ Good
______ Fair
______ Poor

9. How many years have you been a caregiver for your spouse ?
(Please check one) ______ 2 to 3 years
______ 3 to 4 years
______ 5 or more years

10. Do you have any children ? Yes ______ No Children ______
Any Children Deceased ? Yes ______ No ______

11. If you have children, what are their ages ? ______ ______
______ ______ ______ ______ ______ .

12. Do you have children living at home ? Yes ______ No ______
If yes, how many ? ______ (write in number)
If yes, was this person(s) involved in caregiving ? Yes ______ No _____
Was this helpful ? Yes ______ No ______

13. If you have children living away from home, approximately how many miles away do they live ? Child 1 ______ Child 2 ______ Child 3____
Is there anyone else living in the household ? Yes _____ No _____

14. Do you visit people outside your home ? Yes ______ No ______
(Check one)

15. If your answer to #14 was yes, how often do you visit outside your home ?

______ More than once a week
______ Once a week
______ 2 - 3 times per month
______ Less than once a month

16. Do you participate in activities outside of home ?
(Please check all that apply)

______ Church
______ Work Related
______ Neighborhood
______ Community
______ Clubs
______ Political

APPENDIX I

Caregiver Assessment

Appendix I
Bereaved Caregiver Assessment Instrument.

Years of caregiving ____
Relationship to client ________________________________
Why did you decide to caregive ? ________________________________
Date of care recipient death __________

I. PHYSICAL	CURRENT STATUS	STATUS WHILE CAREGIVING
A. Diet: typical day (include caffeine, alcohol)	______ ______ ______ ______ ______ ______	______ ______ ______ ______ ______ ______
B. Medications/ Reason for:	______ ______ ______ ______ ______ ______	______ ______ ______ ______ ______ ______
C. Activity/Frequency:	______ ______ ______ ______	______ ______ ______ ______
D. Perceived State of Health: (Excellent, Good, Fair, Poor)	______	______

II. SOCIAL	CURRENT STATUS	STATUS WHILE CAREGIVING
A. Leisure Activities:	______ ______ ______	______ ______ ______
B. Social Activities Outside of Home/Frequency: (Clubs, Community, Church, etc.)	______ ______ ______	______ ______ ______
C. Family Contact/Frequency:	______ ______ ______	______ ______ ______

III. FINANCES	CURRENT STATUS	STATUS WHILE CAREGIVING
A. Adequate: (yes/no)		
B. Inadequate: (describe area's of need)		
C. Health Insurance: (yes/no)		
1. Adequate: (yes/no)		
2. Inadequate: (describe)		

IV. EMOTIONAL	CURRENT STATUS	STATUS WHILE CAREGIVING
A. Felt About Caregiving:		
B. Felt About Your Loss or Anticipated Loss:		
C. How were/are your Intimacy needs met ?:		

V. MENTAL	CURRENT STATUS	STATUS WHILE CAREGIVING
Usual Method of Coping With Problems (note all that apply):		
A. Cognitive:		
Problem Solving:		
Use of Supports:		
Coping with previous losses:		
Denial (avoid conflict):		
Other (write in):		
B. Behavioral:		
Keeping Busy:		
Religious Practices:		
Doing Something New:		
Other (write in):		

VI. SPIRITUAL (Describe)	CURRENT STATUS	STATUS WHILE CAREGIVING
A. Clients Purpose and Meaning in Life:		
B. Use of Religion:		

MOURNING [Person-Role] (Check if appropriate)	CURRENT STATUS	STATUS WHILE CAREGIVING
A. Tearfulness:		
B. Periods of Depression:		
C. Periods of Fatigue:		
D. Loss of Energy:		
*E. Loss of Interest in Usual Roles:		
F. Loss of Appetite:		
*G. Persistent Sleep Alterations:		
H. Body Weight Changes:		
I. Difficulty in Concentrating:		
J. Loss of Purpose/With Person:		
K. Loss of Meaningful Role - Activity:		
L. Feelings of Ambivalence Toward Lost Person:		
*M. Feelings of Worthlessness:		
*N. Suicidal Ideation:		

(Note: - If [*] present consider referral)

GROWTH (Briefly describe)	CURRENT STATUS	STATUS WHILE CAREGIVING
A. Positive Anticipation of Future (Statements of):		
B. Ability to discuss Past/Future:		

	CURRENT STATUS
A. Pertinent Physical Findings:	
B. Nursing Diagnosis:	

C. Plan:

1. Diagnostic: ______________________________

2. Treatment: ______________________________

3. Education and Counseling: ______________________________

4. Expected outcomes: ______________________________

(Note: Update briefly on subsequent visits, as needed)

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