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THE LIVED EXPERIENCE OF DAUGHTERS WHO CARE FOR FRAIL, ELDERLY PARENTS IN THE PARENTS' HOME

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In the College of Nursing and Health

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ABSTRACT

The Lived experience of Daughters Who Care for Frail, Elderly Parents in the Parents’ Home

The care of frail, elderly parents is becoming an issue of rising concern as the number of aged people in the population increases. It is estimated that over 22 million people currently provide support to elderly family and friends in this country. Caregivers often provide services at great physical, emotional, and financial cost to themselves. Evidence indicates that the majority of informal caregivers are daughters caring for their parents. Abundant research is available on family caregiving, however, the greatest focus has been on the concepts of caregiver burden and strain. Little investigation into the needs of daughters as a specific group has been conducted. The purpose of this study was to examine the lived experience of daughters who care for their frail, elderly parents in the parents’ home. The philosophical underpinnings and nature of phenomenological research were examined as the context for application of van Manen’s design. Data were collected from interviews with seven daughters who were currently in the caregiving role. Support for the themes was gleaned from artistic sources. Ten essential themes were elicited. These themes were that caring for frail, elderly parents in the parents’ home is: (1) being torn between worlds; (2) embracing the wholeness of commitment; (3) a crucible of individual human effort; (4) a means of self-discovery; (5) a thread that can weave a family together or cause it to pull apart; (6) an experience of reciprocity; (7) a doorway to intimacy; (8) the attempt to maintain the autonomy of the parent; (9) grieving the decline of the parent; and (10) making the best use of the time left with a parent. The ten themes were used to compose a narrative of the daughters’ experiences of caring for their frail, elderly parent in the parent's home. The findings were examined in light of Bowlby's Attachment Theory and Kristen Swanson's Theory of Caring. Congruence of the findings with Attachment Theory and partial congruence with the Theory of Caring were found. Implications for research, practice, and education were discussed.

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Chapter 1: The Phenomenon

Good my lord,
You have begot me, bred me, loved me: I
Return those duties as are right fit,
Obey you, love you, and most honor you.
William Shakespeare (1963, p. 17)

Introduction

Human beings have many things in common. Perhaps one of the most significant similarities is that all humans have parents. Unless a parent dies or is absent from a person's life, one is faced with the reality of the parent eventually aging and becoming frail. When parents no longer are able to care for themselves independently, their adult children are faced with the question of how to help them cope. This chapter presents the phenomenon of family caregiving for frail, elderly parents in the 21st century. The purpose and significance of the current study are presented, as well as the specific research question and definition of terms in the question.

Nature of the Phenomenon

The care of frail elderly parents is becoming an issue of rising concern as the number of aged people in the population increases. The United States Administration on Aging (2003) estimates that more than 22.4 million people in this country currently provide support to elderly family and friends. This number reflects the fact that only 20% of all long term care in the United States occurs in nursing homes, while 80% of such care occurs in the home (Administration on Aging [AOA] 1999). Data from AOA (2001) also indicate that of all elders who live in the community and require assistance, 95% have family involved.

While the scope of the informal caregiving network has been and is currently extensive, the need for such family support will increase in the future. The actual number of people requiring assistance can be expected to rise significantly in the first half of the 21st. century as the baby boom generation ages. The enormity of this projected increase is evidenced in data provided by the Federal Interagency Forum on Aging-Related Statistics. It is estimated that 3 million people over the age of 65 were alive in 1900. By 2000 this number had risen to 35 million. When the first “baby boomers” begin to turn 65 in the year 2011, it is estimated that 20% of the population will be age 65 or older. By the year 2030, the number of those over the age of 65 is expected to have reached 70 million (Federal Interagency Forum on Aging-Related Statistics, 2000). The trend of increased life expectancy carries with it particular problems. As people live longer their risk for developing chronic illness and disability increases. In 1998, 28.8% of people aged 65 to 74 years reported limitations caused by chronic health problems, while at the same time, 50.6% of those aged 75 years and older reported such limitations (AOA, 2001). These changing demographics of an aging population will put additional strains on the caregiving network as it exists today.

The current pattern of family caregiving in the United States has remained stable over the past decade (AOA, 2001), despite the changing demographics of American family life. The 2002 birthrate in the United States decreased to 13.9 per 1000 population, the lowest level recorded since national data have been available (U. S. Department of Health and Human Services, 2003). This decline will eventually lead to fewer numbers of adult children available to care for aging parents. The national divorce rate has increased to 43% of first time marriages (Centers for Disease Control and Prevention, 2002), thereby decreasing the availability of spousal caregivers in the future. A final strain on the informal caregiving system is the increasing number of adult women who hold jobs outside the home. The data suggest that while caregivers currently face great challenges in rendering their services, those challenges can only be expected to increase in the future.

One of the most consistent findings in the demographic research on caregivers is that the majority of people fulfilling this role are female (Brody, Litvin, Hoffman, & Kleban, 1992; Miller & Cafasso, 1992; Stone, Cafferata, & Sangle, 1987). Women provide 67% of all spousal care giving and 80-90% of all parental care giving (Miller & Cafasso, 1992). The average age of caregivers is 57.3 years (Stone et al., 1987) and the average amount of time given to this role is 20 hours per week (AOA, 2001).

Family members who take on the role of caregiver to elderly parents or spouses provide a largely invisible network of services that greatly benefit both the elderly and the society as a whole. The AOA (2003) estimates that the cost to society, if family caregivers did not provide their services, would average approximately $257 billion dollars per year. However, family caregiving is not without potential and actual cost to the individuals in the role. Issues confronted by family caregivers include threats to their emotional well-being (Beach, 1993; Boykin & Winland-Brown, 1995; Bull, 1990), risks to their physical health (Schulz & Beach, 1999) and economic disadvantage caused by missed work (Robinson, 1997; Ward, 1990). These liabilities can negatively impact not only the life quality of family caregivers themselves, but also that of their spouses, their children, and eventually, through association, the lives of those for whom they care.

Purpose of the Study

The purpose of this study is to describe the experience of daughters caring for a frail, elderly parent or parents in the parents' home. By increasing understanding of the family care-giving experience, sensitivity to, and conceptualization of this often invisible role can be increased. Women who find themselves caring simultaneously for their children and their aging parents, often while being employed full-time outside the home, face multiple and frequently conflicting issues. The potential for burden, stress, and role overload is present; however the possibility of living out one's values and sense of commitment is also present in the role. Examination of the phenomenon of family caregiving as it is experienced by those currently in the role can provide insight into the meaning of the caregiving experience for those people.

Significance

The uniqueness of the current study is that it went directly to the caregivers themselves to give voice to their informed perspective of the experience. Insight into the lived experiences of the caregivers provides an accurate foundation of understanding for health care providers. Of further significance is the fact that the current study dealt with a unique population of caregivers. Spousal caregiving was not included, only the caregiving provided by daughters to their parents. Identification of the unique perspective of those people who provide the greatest amount of caregiving in the United States further clarifies understanding of their experience.

An ample body of research exists on family caregiving. However, the focus of much of this research is quantitative investigation into the concepts of burden, strain, and stress. Abel posits “this preoccupation with stress has denied us a full understanding of the experience of caregiving” (1991, p.8). Similarly, much of the caregiving literature deals with the care of family members with specific diseases such as Alzheimer's disease, cancer or heart disease (Biegel, Sales, & Schulz, 1991). These authors also discuss the need for investigation of caregiving as an experience that transcends specific disease processes.

Insight into the lived experiences of daughters who care for their frail, elderly parents can clarify specific ways health care providers can be of assistance and support to the caregivers. Increased understanding can lead to better support services to the caregivers themselves and thus, indirectly, lead to better care for the elderly. Greater theoretical understanding also can be gained about the concept of caregiving, adding to the body of nursing knowledge. Such theoretical understanding will be essential as members of the nursing profession strive to understand the full meaning of the caregiving experience for family caregivers and the ramifications of the experience for those individuals. Finally, such research can identify areas for further investigation in both the practical and theoretical domains.

This phenomenological investigation elicited the voices of those persons who are living the caregiving experience. As family caregivers continue to support so much of elder care in America, their perspective is one that society can ill afford to ignore.

The Research Question

The research question was: What is the lived experience of caring for a frail, elderly parent or parents in the parents’ home? As a phenomenological investigation, the study aimed to arrive at an answer to this question from the perspective of daughters who currently were living the caregiving experience.

Definitions

The aim of the study was to elicit the perceptions of female informal caregivers who were caring for a frail, elderly parent or parents in the parents' home. In order to achieve this aim, a convenience or volunteer sample was used. The goal in sampling was to have participants who were currently living the experience of caring for a frail, elderly parent or parents and who had done so for at least a six month period. For the purpose of this study, a caregiver was defined as either a biological or adoptive daughter of at least 18 years of age who currently was giving a frail, elderly parent or parents physical and/or emotional support for fifteen hours or more per week in the parents' home, and who had done so for at least six months. A frail, elderly parent was defined as a biological or adoptive parent who was at least 65 years old and who would not have been able to remain living in his or her home without the support of the caregiver or some other person.

Summary

Family caregiving is a significant phenomenon in American society. It affects the caregivers, their families, the care recipients, and the larger society. Much research has been done on family caregiving, however, much of that research has focused on the negative aspects of the role. The current study was undertaken to give voice to women currently providing such care. A phenomenological research approach was chosen as the most appropriate means of achieving that goal. A greater understanding of the phenomenon can lead to advances in both the practical and theoretical dimensions of nursing.

Chapter 2: The Researcher's Perspective

…the I is assured of itself through its
self-consciousness, that strong golden thread
on which the many-colored circumstances are strung.
Martin Buber, 1937, p. 84

Introduction

Van Manen (1984) informs us that all phenomenological investigation begins with the real life experiences of the investigator. As one stands "in the middle of life," experiences begin to act upon the person, fostering the educational development of that individual. Knowledge of a phenomenon is not something that the researcher objectively sets out to accrue; rather it grows as an integral part of the person. This process has its fruition in what Oiler Boyd (1999) called the researcher-as-instrument. The research conducted is the product of a particular person who comes from a particular perspective.

My interest in family caregiving had its beginnings in my professional life as a nurse and came to fruition in the many years of personal caregiving I provided for both of my parents in the latter years of their lives. The evolution was non-linear and intuitive in many ways. This chapter explores that evolution through examination of my professional development, my experiential development, and a brief review of the current literature on family caregiving.

Professional Development

Among the factors that help create a person's worldview is the professional education he or she receives. The assumptions and values of the profession are transmitted through the educational process and through the socialization process. In this way members of a profession gain a perspective that is consistent with the values of the profession. Meleis (1997) identified four characteristics of the nursing discipline that influence the perspective of its members. She identified these characteristics as the presence of a human science epistemology, the practice aspects of nursing, the caring relationships between nurses and patients, and a health and wellness focus (Meleis, 1997).

In identifying nursing as a human science, it is important to differentiate between the philosophy of humanism and human science. Humanism as a philosophy had its beginnings in the 16th century European Renaissance and has continued to evolve since that time. Some of the key tenants of humanism are that all forms of supernatural beliefs are myth, that no conscious survival exists after death, that humans are responsible and capable of solving their own problems, that human happiness is its own justification in life, and that humans have the intelligence and creativity to create a peaceful and balanced life on this earth (Lamont, 1965).

Human science on the other hand, is defined by Cohen, Kahn, and Steeves (2000) as a term evolving from the German word "geisteswissenschaften." The 19th Century German philosopher Wilhelm Dilthy was one of the earliest proponents of the use of this term to differentiate those branches of science that did not fall appropriately into the category of the natural sciences. The areas with which he was primarily concerned were those sciences that dealt with humans, history, and society (Dilthey, 1989). Dilthey based the distinction between the natural and human sciences on the fact that "man (sic) finds within his self-consciousness a sovereignty of the will, a responsibility for actions, a capacity for subjecting everything to thought and for resisting, from within the stronghold of his personal freedom, any and every encroachment" (Dilthey, 1989, p. 58). One of the differences between the natural sciences and the human sciences is that the human sciences reflect the unique capacities brought about by the presence of human self-consciousness.

Meleis (1997) summarized the characteristics of the human sciences. Among these characteristics are the belief that humans are regarded as whole and unique entities and that the focus of human science is the understanding of experiences as they are lived. Other characteristics are that meaning is unique to the individual and that interaction with human beings is the source of information appropriate for the human sciences. Although the term human science was not in popular usage at the time of my early nursing education in the late 1960’s, the underlying assumptions I received were clearly based on nursing as a human science rather than nursing as humanistic philosophy or nursing as a purely empirical science. I was taught to respect humans as autonomous and unique beings who are ultimately responsible for their own decisions and that, as human beings, they have their own unique views of the world and of reality. I was taught that I should not make assumptions or generalize about people. I was taught that in order to be present to a person I must listen to the reality of that person. In short, I was taught to interact with people as one would within a human science framework.

Meleis (1997) identified the second characteristic of nursing as a human science to be its practice aspects. I chose the area of maternal-child health as my professional practice area. I was interested in the phenomenon of human attachment and how nurses are best able to foster this process in new parents. As my career progressed I began to wonder about the role of attachment over the human life span. While caring for my elderly parents, I wondered about the role of attachment in that process.

The third characteristic of the nursing human science perspective cited by Meleis (1997) is its caring component. Whether talking about the care rendered by a bedside nurse to individual patients, or discussing nursing theorists at the highest level of abstraction, to be a nurse is to be involved with the care of others. I spent many years as a bedside nurse and many more as a nursing faculty member engaged in the education and socialization of nurses. I have spent my entire professional career involved in the care of other human beings.

Finally, Meleis (1997) cited a health orientation as one of the characteristics that comprise the nursing human science perspective. The concept of health as part of the nursing domain was identified by authors such as Yura and Torres (1975), Fawcett (1984), and Meleis (1997). As one of the key concepts within the nursing domain, a focus on health is recognized as being central to the practice, research, and theoretical endeavors of the discipline. Coming from the perspective of the nursing discipline, I have been educated to be concerned about the health of human beings, and I have spent my career dealing with issues pertaining to health.

Thus as a nurse I bring a particular perspective with me to the investigation of family caregiving. I operate from within the framework of the human sciences. I have spent my entire professional career in a practice profession that focuses through caring relationships on the health needs of human beings.

Experiential Development

In addition to my professional grounding I also bring life experiences as a family caregiver to the research endeavor. Approximately two years were spent caring for my terminally ill mother in my parents’ home until she died of ovarian cancer in 1985. Another seven to eight years were spent, along with my brothers and sister, caring for our frail, elderly father until his death in 1997.

These experiences sensitized me to the significance of the care-giving role as an issue for women in American society and throughout the world. As my siblings and I took care of our mother over the months and years, the strain of trying to balance the demands of full-time employment, caring for my own children and husband, as well as caring for a dying parent became almost intolerable at times. No matter how difficult it became, however, I only knew what I was experiencing as an individual. I had no idea that anyone else was doing the same thing or that there was a name for the experience. That perception changed for me on a summer day in 1985, however, as I sat on my front porch reading a *Newsweek* magazine that had come in the mail that day. The cover story was about caregiving and the sandwich generation. I sat on my porch and cried as I read the article. Those tears came simply because someone had named my experience. It was as though having a name for it and knowing that it was a national phenomenon gave it more meaning. It was no longer just me doing what felt like an almost impossible job on my own. Other people understood the pressures I was feeling. I felt validated.

The first-hand experiences of caring for my parents in their home caused me to wonder about caregiving as a phenomenon. I wanted to know more and I wanted to participate in the generation of more knowledge about the topic. I felt driven to bring into clearer focus the experience that many women face in relative isolation. This interest eventually led to my doctoral studies and to my choice of family caregiving as my area of concentration.

The Literature

As my academic investigation of the phenomenon proceeded, I found that both the nursing and social science literatures contained a substantial body of research on family caregiving. Much of the early work was quantitative and focused primarily on the negative aspects of the caregiver role, particularly caregiver burden and caregiver strain. Baille, Norbeck, and Barnes (1988) found that caregivers who cared for mentally impaired elders for extended time periods with little social support, were at risk for psychological impairment. A study by Bull (1990) supported the hypothesis that increased burden was associated with increased presence of eventual depression in family caregivers.

Movement away from studying only the negative outcomes associated with the caregiver role has occurred. Researchers have investigated the existence of possible positive outcomes for individuals in the role. A study by Picot (1995) included perceived rewards as one of her independent variables along with other variables such as caregiving demands and perceived costs.

As the trend toward appraisal of positive outcomes continued, efforts were made to measure these outcomes more accurately. Carruth, Tate, Moffett, and Hill (1997) conducted a study of the effects of reciprocity, emotional well being, and family functioning as factors affecting satisfaction among caregivers. Picot, Youngblut, and Zeller (1997) developed and tested a measure of perceived rewards in caregivers. Research into the conceptualization and measurement of “doing family caregiving well” was conducted by Schumacher, Stewart, and Archbold in 1998.

While movement toward the investigation of the positive rewards of caregiving has occured, a heavy emphasis on negative outcomes is still reflected in the literature. Studies of the burden and psychological strain of caregiving have been conducted by many investigators. England and Roberts (1996) sought to develop an instrument with which to measure caregiver strain. The quantitative study conducted by Faison, Faria, and Frank (1999) into the perceived burden of informal caregivers found that increased caregiver burden was related to increased direct and indirect care activities. Jepson, McCorkle, Adler, Nuamah, and Lusk (1999) investigated the relationship between characteristics of the caregiver and a home intervention on the caregivers' psychological status and found that informal caregivers for cancer patients who had physical problems themselves were at greater risk for emotional problems than caregivers without physical problems.

Recent investigations have also been conducted into the physical consequences of care giving. Picot, Zauszniewski, Debanne, and Holston (1999) studied the relationship between mood and blood pressure in caregivers and non-caregivers and found that lower levels of expressed anger in caregivers was associated with higher blood pressure. Another study provided revealing results about the risk of mortality associated with informal caregiving. In their study of 392 elderly caregivers and 427 non-caregivers, Schulz and Beach (1999) found that for elderly caregivers who experienced strain in the role, the risk of mortality within a four-year period was 63% higher than for members of the non-caregiver control group. Thus even though the trend in the research is toward consideration of the benefits associated with the role, the presence of strain and its associated consequences cannot be overlooked.

The quantitative research on family caregiving is extensive. The problem, however, is that quantitative research by virtue of its nature, can deal only with parts of the caregiving experience. The experience is broken down into specific variables that can be tested, but the results can measure only those things the researcher originally sets out to investigate. What of the caregivers themselves? What do they perceive to be of significance within the experience? Is their perception primarily of burden or stress or do they find meaning and reward in the role? Perhaps caregivers experience all of these things and perhaps they experience none of them. Only the caregivers can describe the total perspective of what it means to be a family caregiver.

Qualitative studies elucidating the lived experience of family caregivers are evident in the literature. Four studies used a grounded theory method to uncover the basic social processes within the care-giving experience. Beach (1993) identified three categories of experience including role strain, sense of self, and problem solving. Boland and Sims (1996) described caregiving as a solitary journey. The concepts of burden, responsibility, isolation, and commitment were identified as components of the caregiving experience. Carmack (1997) gained insight into the beneficial outcomes for caregivers who are able to effectively balance engagement and detachment in their caregiving roles. McCarty (1996) identified an emerging theory involving the beliefs, perceptions, and transactions of caregivers.

Six studies of family caregiving employing a phenomenological approach were identified. Thibodeau (1993) used a phenomenological method to investigate the experience of adult children caring for elderly parents who had moved into the child's home. The gender of the children was not identified. Boykin and Winland-Brown (1995) used a phenomenological method to describe the experience of being a family caregiver living with a relative with Alzheimer's disease. The relationships in this study included both male and female spouses, daughters and daughter-in-laws. A study by Parsons (1997) used a phenomenological methodology in attempting to describe the experience of male informal caregivers. The sample included both sons and husbands, some of whom lived with the care recipient and some who did not. Australian researchers Kellett and Mannion (1999) used an ontological-hermeneutic approach to gain understanding of the human experience of family caregiving at home. It is not clear if the caregiver and care recipient resided in the same home. The gender of the participants in this study also was not identified, nor was the nature of their relationship to the care recipient. Gates (2000) conducted a phenomenological investigation into the meaning of caring for an elderly relative. The sample consisted of spouses, daughters, and nieces of the care recipients. The gender of the spouses was not identified. Several of the care recipients lived in institutions. The residences of the other care recipients were not identified. Vellone, Sansone, and Cohen (2003) conducted a hermeneutic phenomenological investigation of caring for a family member with Alzheimer's disease. The sample consisted of male and female caregivers who were either spouses or children of the care recipient. It is not clear if the caregivers and recipients lived in the same home or not. The findings of these six studies will be examined in Chapter 3.

Despite the number of qualitative studies present in the literature, none of them specifically address the experience of daughters caring for frail, elderly parents in the parents' home through a hermeneutical phenomenological perspective. One unpublished doctoral dissertation was found that used a phenomenological method to examine the experience of family caregiving from a female perspective. McDowell (1996) used a sample of daughters and wives who cared for either frail parents or spouses. No distinction was made in the sample as to whether the cared for person lived in his or her own home or with the caregiver in her home. This study was found to have limitations, particularly in regard to premature closure in the findings.

Because of the limitations of the current literature, a qualitative study dealing specifically with the experiences of daughters who care for frail elderly parents was conducted. This endeavor was validated by the current prevalence of the family caregiving phenomenon in our society and the projected increase of need as our population ages.

Although many male children do provide care for their parents, the focus in this study on female caregivers was appropriate since the vast majority of family caregivers are female.

Summary

An assumption of qualitative research is that the person conducting the research is the instrument. As such, the researcher brings a certain perspective that is the product of his or her evolution as a person. This chapter examined my evolution as a researcher from my professional and experiential perspectives and from my understanding of the current literature.

Chapter 3: Method

Perceptions of reality are man's (sic) main food.
Jean Toomer, 1999, p. LXII

Introduction

Method in a research endeavor is not randomly chosen. Rather, the method reflects the researcher's philosophical beliefs about the nature of reality. Method is situated in and flows from one's world-view and the nature of the question being researched. This chapter explores the nature of paradigms as the foundation of the present study. Qualitative research and the assumptions on which it are based are examined, as are phenomenological research and van Manen's design. The philosophic underpinnings of phenomenological research are examined through consideration of the work of Brentano, Husserl, and Heidegger.

Paradigms

The philosopher Thomas Kuhn offered a twofold definition of the term "paradigm." First, it was defined as "the entire constellation of beliefs, values, techniques, and so on shared by the members of a given community" (1970, p.157). A second definition of the term offered by Kuhn was that "it denotes one sort of element in that constellation, the concept puzzle solution employed as models or examples" (1970, p. 175). Thus Kuhn's definition of a paradigm implies that a community's system of beliefs and values will give rise to particular ways of approaching puzzles, or problems. Stated in another way, one's assumptions will give rise to one's epistemology, and one's epistemology will give rise to a method.

Polit and Hungler (1997, p. 451) define assumptions as the "basic principles that are accepted as being true on the basis of logic or reason, without proof or verification." Assumptions are the givens with which one encounters life. Meleis (1997) further posits that assumptions arise from within one’s philosophical underpinnings. Munhall (1999) differentiates the assumptions of two primary philosophical paradigms, realism and idealism. These schools of thought serve respectively as the foundations for quantitative and qualitative research.

From the viewpoint of philosophical realism, reality is accepted as that which can be experienced through the senses. Reality is fixed and exists outside of the human person. The social world is accepted as given in its physical manifestation (Munhall, 1999). Conversely, while philosophical idealists do not deny that objective reality exists, proponents of this philosophical perspective believe that human consciousness mediates experience to create a perception of reality. For those operating from this standpoint, reality is conceived of as fluid and relative to each person depending upon his or her perception of the world (Munhall, 1999).

Thus from a philosophical perspective, two views of reality are presented. One view is of objective reality as experienced through the senses. The other view is of reality as perceived by the individual human being through the power of consciousness. Both realities exist. Much in life does indeed possess spatio-temporal reality. However, no less real is the human consciousness of that reality, that is, the human consciousness that exists outside of spatio-temporal reality.

Kuhn’s definitions indicate that besides providing assumptions or beliefs, a paradigm also leads to the problem solving practices of a group. These problem solving practices are the way the particular community produces knowledge, or in other words, the group’s epistemology. Epistemology is the branch of philosophy that deals with the theory of knowledge. As a philosophical framework, epistemology guides a person in defining what one knows and how it is that one knows. The significance of epistemology is evident in the fact that it guides an individual's or group's approach to their accepted standard of what it means to know. If a person adheres to one epistemological view, he or she will accept a particular way of knowing as appropriate. If a different epistemological view is accepted, the person will follow a different path. The nature of what is accepted as knowledge is thus defined by the means used to arrive at that knowledge.

The philosophical assumptions of realism lead to an epistemology based on acceptance of empirical evidence. Munhall (1999) describes the characteristics of this received view as being akin to objectivity and quantification. Conversely, the philosophical assumptions of idealism lead to a way of knowing identified as the non-received view. In this epistemologic style, the focus is on subjectivity and interpretation.

Two distinct views of how knowledge is gained are identified. The received view reflects a belief about the world as a fixed, externally objective reality. As such, this world may be dissected. The parts may be pulled apart and examined in isolation from one another. The world is seen to exist in complete separation from the person who is learning about it. The learner may be in the world without affecting it and without being affected by it. On the other hand, the non-received view identifies a world that exists in conjunction with the way in which it is known. This view of the world holds that reality exists as it is perceived, it exists as a whole, and therefore it cannot be reduced. These differing epistemological views have lead to two primary research paradigms accepted within the nursing discipline. These are the quantitative and the qualitative research paradigms.

Creswell (1994) offers a comparison of the underlying assumptions of each research paradigm. Those underlying the quantitative paradigm are that reality is objective and that it exists outside of the researcher. Only one reality is believed to exist and it can be measured objectively. Because of an objective reality existing outside of those involved in the research, it becomes the researcher's goal to separate all bias from that reality. Practices such as random sampling and introduction of a control group become imperative in the process. In a similar way, the researcher operating within the quantitative paradigm attempts to keep personal values outside of the process and to deal only with objective facts. Thus the rhetoric considered appropriate within the quantitative paradigm is formal, empirical, and based on pre-determined definitions. Finally, the methodological assumptions of this paradigm reflect deductive reasoning with its emphasis on testing theories and hypotheses in cause and effect relationships. The purpose of the investigation is to develop generalizations leading to prediction, explanation, and control.

The assumptions underlying the qualitative paradigm as described by Creswell (1994) are vastly different from those of the quantitative approach. Unlike the quantitative view of reality, the qualitative view is that reality exists as constructed by the persons involved in the research project. Different realities therefore may exist for the researcher, those being studied, and those reading the results. The way of knowing in the qualitative paradigm implies that researchers attempt to decrease the distance between themselves and those being studied. An axiological assumption in the qualitative approach is that the researcher's values and those embedded in the study are acknowledged. The assumption about the rhetoric within the qualitative paradigm is that the language is personal, informal, and evolutionary throughout the study. The methodology called for in the qualitative paradigm is characterized by an inductive approach. Categories and patterns of information arise from within the context of interviews, rather than being determined a priori by the researcher.

Thus based on the differing assumptions underlying each paradigm, one can easily understand that, depending on which tradition the researcher chooses, the perspective of the study will be quite different. These differences are evidenced in the types of designs that flow from the respective paradigms.

Description of Phenomenological Research

Phenomenology is one research tradition that flows from the qualitative paradigm. As a method, phenomenological research attempts to explicate phenomena as they are lived by human beings. Omry (1983) described the method as an inductive, descriptive research method, the goal of which is to “describe the total systematic structure of lived experience, including the meaning that these experiences had for the individuals who participated in them” (p. 50).

The full significance of this definition is easy to overlook. The emphasis is not simply on the meaning attributed by human beings, but rather on “the total systematic structure” of the phenomenon. The goal in phenomenological research is to reveal the phenomenon for what it is, beyond what our everyday, culturally determined understanding of it is. The method challenges the researcher to look not outside the box perhaps, but rather to look deeply within the box. The researcher is challenged to strip away the layers of the box to see what ultimately and primordially remains. The goal is to elucidate what remains of the phenomenon when one’s preconceived ideas of it have been removed.

Characteristics of the phenomenological method facilitate the researcher’s attempts to dig beneath that which superficially presents itself about the phenomenon. Theory testing is not done, nor are any operational definitions used. Data collection is not based on empirical data; rather, the participants' subjective experiences are examined. All data are accepted as they are experienced and reported by the participants. The goal of phenomenological research, however, does not end with the evocation of shared descriptions and meanings. Instead, the phenomenological researcher attempts to interpret those shared meanings (Crotty, 1996).

Van Manen (1984) offers five characteristics of phenomenological research. He identifies it first as the study of lived experience. By this phrase he means that the researcher investigates an aspect of human existence as human beings experience it. The key word in the definition is “experience,” for the researcher aims to describe a phenomenon as it is experienced, not as it is conceptualized or mentally processed.

Phenomenological research is further described as the study of essences (van Manen, 1984). In attempting to get to the heart of the human experience, the researcher attempts to identify “that which makes a ‘thing’ what it is (and without which it could not be what it is)” (van Manen, 1984, p. 38). The researcher conveys the essence of the phenomenon in the writing of the investigation. If the researcher's language and content evoke in the reader an awareness and deeper understanding of the meaning of the phenomenon, then the essence has been revealed.

The third characteristic of phenomenological research described by van Manen (1984, p. 38) is that it is “the attentive practice of thoughtfulness.” The researcher attends to the phenomenon at hand with inquisitiveness, sensitivity, and persistence. All aspects are considered, no matter how mundane or insignificant they may seem, for it is in the every-day-ness of the phenomenon that the essence will be discovered.

Van Manen identifies the fourth characteristic of phenomenological research as "a search for what it means to be human" (1984, p. 38). By pulling forth into consciousness the meaning of a particular human endeavor, deeper insight and understanding into the fullness of human nature is gained. Increased understanding of the complexity of that nature enables one to become a more fully human person. Thus van Manen identifies the ultimate aim of phenomenological research to be the fulfillment of human nature, enabling people to "become more fully who we are" (1984, p.38).

Finally, phenomenological research is identified as a poetizing activity. The author draws similarities between the activities of the research process and the creation of poetry. The poet and the researcher see the world through their own eyes and attempt to convey the essence of an experience in words. The words themselves are the results or, said in a different way, there are no results outside of the words the researcher uses to describe and interpret the phenomenon. There are no other results, no conclusion, no summary—only the written descriptions and interpretations (van Manen, 1984).

Description of van Manen's Design

In order to best achieve the characteristics of solid phenomenological research, van Manen's (1997) research design was used. Van Manen's conception of phenomenological research is based on hermeneutic phenomenology. In defining phenomenology as "pure description of lived experience" (van Manen, 1997, p. 25), the author is drawing upon the notion of phenomenology developed by Edmund Husserl in the early 20th century, that is, phenomenology as a descriptive endeavor. Hermeneutics on the other hand, defined as the "interpretation of experience via some 'text' or via some symbolic form" (van Manen, 1997, p. 25) evolves from the work of Martin Heidegger. Hermeneutic phenomenology differs from pure phenomenology in that the researcher attempts, through interpretation rather than solely by description, to strip away everyday understandings in order to reveal the essence of a phenomenon.

The design proposed by van Manen is not to be confused with a method. While the original founders of phenomenology, Edmund Husserl (1967) and Martin Heidegger (1962), considered phenomenology to be a method, they were describing a method of doing philosophy. In contrast to the method of phenomenological philosophizing, phenomenological research is characterized by the noticeable absence of a method (van Manen, 1997).

Van Manen differentiated between a research method and a research methodology. A method is defined as a "set of investigative procedures that one can master relatively quickly" (van Manen, 1997, p. 29), while a methodology is understood to be "the philosophic framework, the fundamental assumptions and characteristics of a human science perspective" (van Manen, 1997, p. 27). Thus while van Manen espouses a methodology, he, like other phenomenologists, does not propose a specific or rigidly fixed method (van Manen, 1997). What he proposes instead, are six methodological themes that offer a general guide to the researcher. These themes reflect the essentials of the phenomenological tradition. Consequently, a suppositionless approach to research is proposed; that is, no predetermined procedures or techniques are espoused (van Manen, 1997). The methodological themes merely provide a pathway the researcher may follow into the phenomenological world view.

The six themes currently identified by van Manen (1997) began as what he earlier had identified as "four procedural activities" (van Manen, 1984). These activities were not to be taken as linear steps to be followed by the researcher, but rather as processes that were interwoven and that built upon each other. The four activities were further broken down by van Manen into eleven slightly more specific procedures. With the publication of his book in 1990, van Manen had expanded the four activities into six methodological themes. These six themes and the original eleven procedural steps will be identified.

The first theme of the phenomenological study, according to van Manen (1984) is to turn to the nature of a lived experience. In doing so, the researcher becomes oriented toward that which is to be studied. The research question arises from the process of wondering about the true nature of the experience of someone living the phenomenon. In order to be more fully open to the true nature of the lived experience, the researcher is encouraged to identify his or her assumptions and pre-understandings of the phenomenon (van Manen, 1984). It is only through the acknowledgement of one’s biases and presumptions that these beliefs can be dealt with effectively. By bracketing such pre-existing beliefs, one is able to identify their existence in order to move beyond them.

The second theme in doing phenomenological research is the existential investigation (van Manen, 1984). As the researcher begins to generate data, understanding of the phenomenon is deepened in several ways. A person’s own experiences are drawn upon to possibly provide clues for how to orient to the phenomenon. The etymological source of key words associated with the phenomenon are traced so that the researcher gains a reconnection with the original meaning of the words, as they existed before they began to be taken for granted in everyday use. Similarly, a search for idiomatic phrases associated with the phenomenon is conducted as a source of insight into the nature of the phenomenon. A primary means of deepening one’s understanding of the phenomenon is to interview others who have or who are living the experience. Another part of the existential investigation is for the researcher to examine literature and art for particularly sensitive reflections of the phenomenon.

Van Manen (1984) describes the third theme of the research design as phenomenological reflection. The researcher conducts thematic analysis to determine the structures of which the experience is composed. The search for themes and the isolation of thematic statements provide the researcher with a means for continuing the exploration of the phenomenon. The isolation of thematic statements is done by examining transcribed data on a line-by-line basis, watching for the emergence of commonalities among the various descriptions (van Manen, 1984). Once themes and thematic statements have been identified, the researcher attempts to develop them into paragraphs. A similar process is conducted with the artistic works that reflect the phenomenon. A final part of phenomenological reflection is to determine the essential themes of the phenomenon (van Manen, (1984). In order to do this, the researcher engages in conversation with the participants to determine if indeed the researcher’s descriptions accurately reflect the participants’ experiences.

The fourth theme of the phenomenological investigation described by van Manen (1984), is the writing. In attempting to be true to the phenomenological process, the researcher attends to the subtle undertones of what was said. Significant examples of what the participants said are gathered to make visible the essence of their experience. The actual writing is done in a way that makes sense of the essential structure of the phenomenon under investigation. Rewriting is a final process that allows the researcher to think and rethink the phenomenon, until he or she is confident the work is an accurate reflection of the phenomenon.

These four themes and the ensuing narrative constitute the framework provided by van Manen in 1984. The two additional themes of “maintaining a strong and oriented relation” and “balancing the research context by considering parts and the whole” were eventually added (van Manen, 1997).

These methodological themes are not to be considered a procedural prescription. Van Manen is emphatic in his reminders that phenomenological research does not follow formulaic methods. Instead, it always reflects the work of a given person in a given time, someone who feels compelled to make sense of some aspect of human existence (van Manen, 1984). These themes and activities are summarized in Table 1.

Table 1

Van Manen's six methodological themes and associated activities

Themes	Activities
1. Turning to the nature of lived experience	1. Orienting to the phenomenon 2. Formulating the phenomenological question 3. Explicating assumptions and pre-understandings
2. The existential investigation	4. Exploring the phenomenon: generating data a. Using personal experience as a starting point b. Tracing etymological sources c. Searching idiomatic phrases d. Obtaining experiential descriptions from subjects e. Locating experiential descriptions in literature, art, etc. 5. Consulting phenomenological literature
3. Phenomenological reflection	6. Conducting thematic analysis a. Uncovering thematic aspects in lifeworld descriptions b. Isolating thematic statements c. Composing linguistic transformations d. Gleaning thematic descriptions from artistic sources 7. Determining essential themes
4. Phenomenological writing	8. Attending to the speaking of language 9. Varying the examples 10. Writing 11. Rewriting
5. Maintaining a strong and oriented relation	
6. Balancing the research context by considering parts and whole	

Table adapted from "Practicing Phenomenological Writing", M. van Manen, (1984), Phenomenology & Pedagogy, 2(1), P. 42 and Researching Lived Experience: Human Science for an Action Sensitive Pedagogy, M. van Manen, (1997), p. 33.

Philosophical Underpinnings of the Method

Understanding a research method must be differentiated from understanding the philosophy from which the method arose. The importance of differentiating between phenomenology as a philosophical movement and as a research method was identified by Omery (1983) and Crotty (1996). These authors stressed that failure to make this necessary distinction leads to lack of clarity in one's purpose and methods. Phenomenology as espoused by Husserl and Heidegger guides the research method, but it is not identical to it. Husserl and Heidegger describe methods of conducting philosophic inquiry; van Manen describes a method of conducting qualitative research in a human science domain. The philosophy provides a foundational framework for the research.

Although Edmund Husserl is usually credited as being the founder of the phenomenological movement within the discipline of philosophy, the term was in existence prior to his use of it. The word itself was coined by an 18th century mathematician named J.H. Lambert, to describe a science of appearances (Scruton, 1995). The philosopher Hegel used the term to describe a form of investigation different than that espoused by Husserl. Spiegelberg (1965), a historian of the phenomenological movement, compared the development of phenomenology to a stream that has several parallel currents. The currents are related but not identical; likewise they each travel at their own pace, not necessarily moving toward the same destination. The branches of the phenomenological movement that eventually led to the phenomenological research method are those of Franz Brentano, Edmund Husserl, and Martin Heidegger.

Franz Brentano

The 19th century philosopher Brentano is considered by many to be the founder of the phenomenological movement. This designation results from his contributions to the origins of the movement, particularly his drive to make philosophy a rigorous science (Scruton, 1995). His belief in the need for a renewal of philosophy resulted from his recognition that the discipline had become bogged down in skepticism and practical concerns, abandoning its ultimate goal of the quest for wisdom.

Brentan's other contribution to the development of phenomenology was his investigation into the concept of intentionality. Briefly stated, the concept of intentionality means that a distinction exists between the material and the intentional objects of a mental state. The material object is that which exists in space and time. The intentional object is that which presents itself to a person's human consciousness. Correspondence between the two objects does not, nor need not, necessarily exist.

Edmund Husserl

While Brentano initiated the inquiry into phenomenology, his pupil Edmund Husserl brought discussion of the topic to the center of philosophical debate. Like Brentano, Husserl was driven to bring philosophy to the level of a rigorous science. What was needed, according to Husserl (1950 / 1967, p. 3), was "a radical reconstruction which will satisfy the ideal of philosophy as being the universal unity of knowledge by means of a unitary and absolutely rational foundation." His efforts in this reconstruction were guided by the works of Descartes "to such an extent that phenomenology might almost be called a new, a twentieth century, Cartesianism" (Husserl, 1950 / 1967, p. 3). Following the Cartesian method, Husserl sought an absolute foundation to philosophical science by questioning the giveness of all knowledge. Instead of relying on what was theorized as knowledge, Husserl called for proof "*by reference to the things and facts themselves, as these are given in actual experience and intuition*" (Husserl, 1950 / 1967, p.6).

Each of us lives in the "natural" world. Husserl posited that as humans we tend to accept the natural world about us as being reality. At the same time we are in the natural world, however, we also possess within ourselves a transcendent ego that is able to step back and consider the fact that we are thinking about the natural world. Thus two realities are available to us: the immanent experience of the objective world and the transcendent experience of the conscious world. Husserl held that by a change of consciousness, a person is able to pass from one attitude to the other, that is, one is able to pass from being "in" the world to thinking about being in the world (Husserl, 1917 / 1981). Unlike the natural scientists, however, who deal solely with " naïve objectivism," Husserl, like Descartes, considered the human consciousness of the things and the facts, or a transcendental subjectivity, to be the final basis for knowing (Husserl, 1950 / 1967). He defined transcendence as "*an immanent mode of being, that is, one that constitutes itself within the ego*" (Husserl, 1950 / 1967, p. 32). As such, transcendence encompasses every possible meaning, everything thinkable. The universe of true being does not exist outside the universe of possible consciousness. "Essentially both belong together; and what belongs together essentially is a concrete unity, one in absolute concretion: that of *transcendental subjectivity*" (Husserl, 1950 / 1967, p. 32-33). In other words, consciousness is always conscious of some thing. Similarly, no thing exists of which consciousness cannot be aware. The two exist in union with one another. Thus Husserl carried forward and developed more fully Brentano's concept of intentionality.

In order to fully grasp Husserl's understanding of phenomenology, one must first comprehend the manner in which the philosopher used various terms. The first of these is Husserl's use of the term "phenomenon." What exactly did Husserl include in his understanding of this term? Increasingly inclusive definitions are presented in his writing. Initially he stated that "at the lowest cognitive level, they are processes of experiencing, or, to speak more generally, processes of intuiting that grasp the object in the original" (Husserl, 1917 / 1981, P. 11). Again he stated " 'phenomenon' signifies a certain content that intrinsically inhabits the intuitive consciousness in question and is the substrate for its actuality (sic) valuation" (Husserl, 1917 / 1981, p. 11). Thus not only does a mental image of the object exist, it also is seen as reality. Husserl (1917 / 1981) further expanded the meaning of "phenomena" to include the "continuously changing perspectival (sic) looks of a real object" (p.11). And finally, he expanded the meaning to include the myriad ways that the experience can be known. It becomes the task of the phenomenologist "to investigate how something perceived, something remembered, something phantasied (sic), something pictorially represented, something symbolized looks as such, *i.e.*, to investigate how it looks by virtue of that bestowal of sense and of characteristics which is carried out intrinsically by the perceiving the remembering, the phantasying (sic), the pictorial representing, etc., itself" (Husserl, 1917 / 1981, p. 12). Thus it is not just one's immediate experience that leads to phenomenon, but rather the entire realm of ways in which one can experience.

In his explication of the term "phenomenon," Husserl often used the word "intuit." How are we to understand his meaning of this term? He stated that the original use of the term was " 'seeing,' that is, the perceiving of visual objects"(Husserl, 1894 / 1981, p. 130). He moved beyond this understanding of the word to define intuition as a "presentation in a more authentic sense, namely, a presentation which actually sets its object down before us, so that it itself is the substratum of the psychic activity" (Husserl, 1894 / 1981, p. 131). This process moved beyond only perceptual presentations to also include phantasy (sic) presentations. This intuition arises from attention to the things themselves and not any intervening theories or suppositions. The role of intuition is key in understanding Husserl's philosophy. He identified intuition as "*a source of authority (Rechtsquelle) for knowledge, that whatever presents itself in 'intuition' in primordial form* (as it were in bodily reality), *is simply to be accepted as it gives itself out to be*, though *only within the limits in which it then presents itself*" (Husserl, 1913 / 1931, p. 92). Thus intuiting becomes the primary way of knowing phenomena.

The goal of this intuiting is realization of the essence of the phenomenon. Husserl described "essence" in various ways. First, he indicated that essence is " that which in the intimate self-being of an individual discloses to us '*what*' it is" (Husserl, 1913 / 1931, p. 54). This insight occurs when individual intuition is transformed into essential insight, or ideation. The object of this insight is the pure essence, or eidos, of the phenomenon. Husserl stated that "the Eidos, the *pure essence*, can be exemplified intuitively in the data of the experience, data of perception, memory, and so forth, but just as readily *also in the mere data of fancy (Phantasie*) (sic)" (Husserl, 1913 / 1931, p. 57). The essence of a phenomenon is the primal data of our consciousness concerning a phenomenon.

The heart of Husserl's phenomenology lies in understanding how it is that one elicits the essence of a phenomenon. According to Husserl, this goal is achieved through use of the phenomenological reduction and epoche. He stated that the method of phenomenological reduction to the pure phenomenon, or in other words, to the purely conscious, consists of two processes. These processes include the methodological and consistent “epoche” of all objective knowing in the psychic sphere, and in the methodically practiced describing of the multiple “appearances” as appearances of their objective units and also of the meanings accrued to them (Husserl, 1913 / 1931). The reduction involves the epoche, which is Greek for bracketing. The simple understanding of bracketing is that one sets aside previously known data, knowledge, or theories. This understanding, however, makes bracketing into something that is seemingly impossible to do. How can one set aside what he or she already knows? How can something be un-known? This problem is clarified with a deeper understanding of what bracketing actually entails. Schmitt (1967) explains that the term “bracketing” is a metaphorical term carried forward from Husserl’s background as a mathematician. In mathematics, to bracket something is to assign it a different value, or in other words, to give it a different meaning. We do not un-learn the material, nor does it cease to exist. Rather, through a change of attitude, we assign it a different meaning. We step back from the active engagement with the phenomenon in space and time and observe it from a distance, that is, from within our consciousness. We experience it as a psychical activity rather than an eminent activity. It is through repetitive phenomenological reductions and bracketing that one discerns the essence of the phenomenon.

Although Husserl’s writings are complex, understanding his use of the concepts of intentionality, phenomenon, intuiting, essence, and reduction yields insight into his view of phenomenology as a philosophical method.

Martin Heidegger

If the earlier analogy of phenomenology as a stream is to be continued, the question arises if Martin Heidegger is part of the branch begun by Husserl, or if he represents a completely different current. That Heidegger's conception of phenomenology initially flowed from that of Husserl is a given. In writing about his own work, Heidegger stated that his work "would not have been possible if the ground had not been prepared by Edmund Husserl, with whose *Logische Untersuchungen* phenomenology first emerged" (Heidegger, 1927 / 1962, p. 62). As Heidegger's work evolved, however, differences between the two philosophers' understanding of phenomenology emerged. Investigation into the ways Heidegger's use of the primary concepts of phenomenology differed from Husserl's use will bring these differences to light.

In order to discuss the concept of intentionality in terms of Heidegger's work, one must first consider his use of the term "dasein." It is within this term that the eventual differences between Hussel's and Heidegger's thinking can first be elicited. Instead of using the more common terms of "man" or "human being," Heidegger employs the term "dasein." Explication of the German word's root components, "da" and "sein" indicate that the general meaning of the term "dasein" is being "da," that is, being there. Thus a person is characterized by being in some place. The emphasis in "human being" shifts from human being as a noun to a human who is in the process of "being." The being-ness of the human becomes the focus of Heidegger's interest. "It is peculiar to this entity that with and through its Being, this Being is disclosed to it. *Understanding of Being is itself a definite characteristic of Dasein's Being*. Desein is ontologically distinctive in that it *is* ontological." (Hedegger, 1927 / 1962, p.32). The focus of Heidegger's work was clearly the study of being, whereas for Husserl, the focus is the study of meaning as construed by consciousness. Consequently, the significance of intentionality varied with the two philosophers. The concept is central to Husserl's phenomenology, while Heidegger rarely mentions the word.

Heidegger was not interested in phenomena as they present themselves to consciousness, but rather as they present themselves in themselves. “Being lies in the fact that something is, and in its Being as it is; in Reality; in presence-at-hand; in subsistence; in validity; in Dasein; in the ‘there is’” (Heidegger, 1927 / 1962, p. 26).

Heidegger’s use of the term “phenomenon” also differed from the use made by Husserl. For Heidegger, a phenomenon is “*that which shows itself in itself*, the manifest” (Heidegger, 1927 / 1962, p.51). It is not what shows itself to one’s consciousness; it is what shows itself in person. As such, the manifestation of a phenomenon can be elusive and hidden. According to Heidegger, the work of the phenomenological method is to interpret and to call forth the true being of the phenomenon. Thus, another major difference between Husserl’s phenomenology and that of Heidegger begins to emerge. For Husserl, phenomenology is descriptive; for Heidegger it is interpretive. “Our investigation itself will show that the meaning of phenomenological description as a method lies in *interpretation* (Heidegger, 1927 / 1962, p. 61).

The interpretation that Heidegger called for was the hermeneutical approach. Described as “interpretive” or “explanatory” (The American Heritage Dictionary, 1985, p. 607), a hermeneutic approach moved beyond description. Heidegger described several purposes of a hermeneutic approach, one of which was “this business of interpreting” (Heidegger, 1927 / 1962, p. 62). Heidegger viewed interpretation as an active process. Phenomena become hidden behind their everydayness. We see things as we are conditioned to see them with our everyday eyes; that is, through the cultural and contextual framework to which we are accustomed. The job of the philosopher, however, is to break through the veil of the everyday. “Thus the very *point of departure* [*Ausgang*] for our analysis requires that it be secured by the proper method, just as much as does our *access* [*Zugang]* to the phenomenon, or our *passage* [*Durchgang*] through whatever is prevalently covering it up. The idea of grasping and explicating phenomena in a way which is 'original' and 'intuitive' ['originaeren' und 'intuitiven'] is directly opposed to the '*naivete*' of a haphazard, 'immediate' and unreflective 'beholding' ['Schauen']" (Heidegger, 1927 / 1962, p.61). Again he stated "Is it playing with words when we attempt to give head to this play of language and to hear what language really says when it speaks? If we succeed in hearing that, then it may happen--provided we proceed carefully--that we get more truly to the matter that is expressed in any telling and asking" (Heidegger 1954 / 1977, p. 365). Thus for Heidegger, language becomes a tool through which the essence of a phenomenon can be elicited.

Another tool Heidegger saw as being invaluable for breaking through the everydayness of a phenomenon is art. "*All art*, as the letting happen of the advent of the truth of beings, is as such, *in essence*, *poetry*. The essence of art, on which both the art work and the artist depend, is the setting-itself-into-work of truth. It is due to art's poetic essence that, in the midst of beings, art breaks open an open place, in whose openness everything is other than usual" (Heidegger, 1960 / 1977, p. 184). Consequently Heidegger views art, like language, as a most valuable tool in stripping away layers of the naive everyday appearance of phenomena, thus revealing their true being.

Heidegger's understanding of "essence" also differed from Husserl's understanding. For Husserl the essence of a phenomenon is that which makes the phenomenon what it is. It is the permanent and unchanging nature of the thing. For Heidegger, however, the concept of essence is more fluid. The essence of a phenomenon is that which lasts and endures, but also that about the phenomenon which evolves along the way. He agrees that “All essencing (sic) endures”, but goes on to ask “But is enduring only permanent enduring?” **(**Heidegger, 1954 / 1977, p. 312). Thus for Heidegger, that which endures is the essence of a thing, but that which endures does not have to be permanent. It may be fluid and changing. “And if we now ponder more carefully than we did before what it is that actually endures and perhaps alone endures, we may venture to say: *Only what is granted endures. What endures primally out of the earliest beginning is what grants”* (Heidegger, 1954 / 1977, p. 313).

Finally, the use of the phenomenological reduction by the two philosophers must be examined. For Husserl, the function of the reduction was to move away from actual being. He was interested in phenomena only as they were reflected by human consciousness. Thus for his purpose “winged horses, white ravens, golden mountains, and the like” (Husserl, 1950 / 1967, p. 310) were as appropriate for his philosophical method as were things in actual existence. The opposite was true for Heidegger. While Husserl’s reduction took him away from being, Heidegger’s reduction took him away from consciousness toward being. He stated “phenomenological reduction means leading phenomenological vision back from the apprehension of being …to the understanding of the being of this being” (Heidegger, 1982, p.21).

From examination of the key concepts of phenomenology from the perspective of these two main proponents, it can be seen that while Heidegger built upon the work of Husserl, he took the understanding of phenomenology into a new direction. The works of these two men are truly like branches of a stream. Their thinking originated in a common source, but they followed their own direction sometimes moving together, sometimes diverging.

The Dutch School

A later point of convergence occurred in the works of western European scholars of the mid 20th century. It was from within one locus of convergence that the educator, Max van Manen was to receive the training that evolved into his practice of phenomenological pedagogy.

The Utrecht School of the Netherlands was a center of phenomenological scholarship that arose within the university of that name. The primary figures came from diverse backgrounds including medicine, psychiatry, psychology, theology, philosophy, and education (van Manen, 1996). What drew these scholars together was an underlying phenomenological view of reality. Although their disciplines varied, they were united in their desire to better understand the human person in his or her lifeworld. Van Manen (1996) cited the experience of World War II as a motivating factor that drove scholars to a re-evaluation of human values and led them to search for sources of meaning, human relationship, and a sense of being situated in a place. It was within the descriptive phenomenology begun by Husserl and the hermeneutic phenomenology of Heidegger that these scholars found their intellectual home.

The central thrust of the movement developed under the rubric of phenomenological psychology. Among the key proponents were scholars such as Buytendijk, vanLennep, vandenBerg, Strasser and Linschoten. Although from science backgrounds, these individuals turned to hermeneutic phenomenology in attempts to better understand the world. In their embrace of hermeneutics, these thinkers turned toward the use of poetry and other art forms to achieve their goals. Use of these tools reflected the belief that art can be vital in helping one understand a phenomenon and consequently to understand what it means to be human (Kockelmans, 1987).

Van Manen’s involvement with the Utrecht School came through the discipline of education. He identified “phenomenological pedagogy” as the predominant approach to teacher education in the Netherlands during the 1960’s (van Manen, 1997). The movement reflected both the descriptive thrust of the “Fenomenologische Pedagogiek” of the Netherlands and the “Geisteswissenschaftliche Paedagogik” of Germany. Reflecting the union of these two schools of thought, phenomenological pedagogy was characterized by its union of descriptive and interpretive phenomenology, its use of the arts as a means of interpretation, and its lack of emphasis on method. Among the practitioners of this now combined stream of phenomenology were educators such as Langeveld, Beets, Vermeer, Perquin, Strasser, and vanManen (van Manen, 1997). While each of these scholars understand and implement phenomenology in slightly differing ways, they are, none-the-less, unified in their belief in phenomenology as a means of exploring the lived world.

Thus, what started as Husserl’s attempt to make philosophy into a pure science has been modified and developed into an epistemological tool for multiple and varied disciplines. For those who practice qualitative research based on phenomenological underpinnings, the common factor is the desire to understand better the lived world of human beings.

Summary

This chapter investigated the methodology of the study and the philosophic origins upon which it is based. The nature of paradigms as the genesis of the design was examined. Descriptions of qualitative research in general and phenomenology in particular were provided. The specifics of van Manen’s design were explicated. The philosophical underpinnings was traced from the work of Franz Brentano, Edmund Husserl, and Martin Heidegger. The application of these philosophical concepts in the work of the members of The Dutch School of Phenomenology was examined.

Methods used in qualitative research today are based on the work of philosophers, but are not identical to the philosophical methods. Understanding of the philosophical concepts, however, is necessary in order to properly apply them in current research methods.

Chapter 4: Implementation of the Design

In the first legend of the Grail, it is said that
the Grail…belongs to the first comer who asks the
guardian of the vessel, a king three quarters
paralyzed by the most painful wound, 'What
are you going through?'
Simone Weil, 1977, p. 51.

Introduction

Van Manen states "lived experience is the starting point and the end point of phenomenological research" (1997, p. 36). The research process begins with awareness of a phenomenon as it exists in the world. Through application of a research design, the attempt is made to convey the meaning of that phenomenon through a written text. If the design is used effectively, the text will reveal to the reader the essence of the phenomenon. This chapter explores the implementation of van Manen's research design. The processes of turning to the nature of the lived experience of caregiving, conducting the existential investigation, and undertaking phenomenological reflection are examined.

Turning to the Nature of Lived Experience

Lived experience is defined as "our immediate, pre-reflexive consciousness of life" (van Manen, 1997, p. 35). It is the life one leads when he or she is not thinking about the living of life, but rather simply experiencing it. The goal of phenomenological research is to arrive as closely as possible at an understanding of the lived, that is, the pre-reflexive, experience of the phenomenon under investigation. The way in which van Manen advocates achieving this goal is through orienting to the phenomenon, formulating the phenomenological question, and explicating one's assumptions and pre-understandings.

Orienting to the Phenomenon

Van Manen informs us that the orientating component of a study consists primarily in discovering what it is we feel most interested in and then identifying this experience as a true phenomenon, that is “an experience that human beings live through” (1984, p. 43). My interest in family caregiving began in 1985 during the process of caring for my mother as she died of ovarian cancer. The events and emotions encountered during those years of caregiving had a deep and lasting effect on me and eventually led to my choice of family caregiving as my phenomenon of interest while in graduate school. The specifics of that process have already been delineated in Chapter 2 of this study. My experiences and data from the Administration on Aging (1999) indicating millions of American daughters are in the caregiving role led me to believe family caregiving was an appropriate phenomenon for investigation.

Formulating the Phenomenological Question

Van Manen states that “to truly question something is to interrogate something from the heart of our existence, from the center of our being” (1984, p. 45). Working from a phenomenological perspective, the research question became “What is the lived experience of caring for a frail, elderly parent or parents in the parents’ home?” The question was aimed at opening up or uncovering the experience as it was being lived by individuals.

Explicating Assumptions and Pre-Understandings

By the time I began the current research study, I had completed over a decade of combined caregiving for both my mother and my father. What was to be done with all of the thoughts I had accrued in relation to those experiences? Van Manen indicates that it is best to explicate our mental processes about the phenomenon, not in order to erase them, but rather to identify them for what they are. This process was identified as bracketing by Edmund Husserl (1981) and was discussed in Chapter 3 of the study.

In an attempt to identify my pre-existing ideas about family caregiving, I kept a journal on the topic prior to beginning interviews with the study participants. The length of the journal was not determined by time put into it but rather by the extent of my thinking. Forty-four pages of writing were produced between April 13, 2002 and July 6, 2002. These pages genuinely represented my thinking about my caregiving experiences. The presence of my thoughts on the pages represented a step back from my original experiences. Initially I had lived the experiences, then I had experienced them in a different way, that is, by mentally processing them. They now took on a different meaning than they did in their natural existence. I was now at least one step removed from the original experiences.

Existential Investigation

The researcher is considered the instrument in qualitative research. As in any other research design, it is important that the instrument in a qualitative study be as effective as possible. Only with the use of an effective instrument can meaningful results be achieved in the study. The second process in van Manen’s design, the existential examination, aims to prepare the researcher as an effective instrument, that is, one who is prepared to examine the lived experience being studied.

Exploring the Phenomenon: Generating “Data”

Van Manen describes this element of the research design as the researcher’s efforts to become educated by continually searching for ways to deepen his or her understanding of the phenomenon. This process consists primarily of drawing upon one’s life experiences and one’s exposure to the arts. The genesis of one’s insights and understanding about reality result from the dynamic interplay of these seemingly disparate sources, for each informs the other (van Manen, 1984).

Using Personal Experience as a Starting Point

Van Manen asserts that the first source of investigation begins with one’s own experience. My experiences as a caregiver to my mother and my father occurred. They had become part of who I am. My perceptions of those experiences had been recorded. As such, they were one possible interpretation of the caregiving experience. While those experiences had been bracketed, they still informed my conduct of the research study. When I spoke with caregivers, I came from the perspective of one who had done caregiving. Since in the qualitative research tradition the researcher is recognized to be the research instrument, I was a different instrument having done caregiving than I would have been had I not done it. Although my own caregiving experiences would not be included in the data analysis process or results of the study, the existence of those experiences would be present in my ability to relate to the caregivers and in my thinking as I analyzed their interviews. The phenomenological investigation is the product of the person who undertakes it.

Tracing Etymological Sources

Words are the building blocks of language. They represent the accumulated understanding of reality as a group of people experience it. When a word first evolves to define a phenomenon, its use is vibrant and current. It conveys the immediacy of what is experienced. The meanings of words change over time, however, as societal needs and customs evolve. Words that originally meant one thing may assume a totally different meaning as the context of their usage changes.

Also, as words are used throughout time, the immediacy of their meaning may become clouded. A word like “love” can represent the strongest of emotions between human beings; on the other hand it also is used to describe one’s preferences in food or beverages. Words become diluted and weakened with use; they become taken for granted. Van Manen (1997) suggests they become “forgetful of their past power.” This same concept is expressed by Buddhist monk Tich Nhat Hahn (1998, p. 5) when he states “Words sometimes get sick and we have to heal them.” Tracing the etymological source of the words associated with caring for a frail elderly parent is an attempt to heal those words by reconnecting with the strength of their original meaning as experienced by human beings. The etymology of “daughter,” “mother,” “father,” “parent,” “frail,” “elderly,” “care,” “giving,” and “home” was examined.

The word “daughter” has been in use since prior to the 12th century (Merriam-Webster OnLine Dictionary, 2004). It developed from the Old English word “dohtor” and the Middle English word “doughter” and is defined as “a human female having the relation of child to parent” and “a female subject to the authority or love of a parent” (Webster’s Third New International Dictionary, 1993, p. 577). The word is also defined as “a female child of any age” (ARTFL Project: Webster Dictionary, 1913). The etymological origins may be traced to the Sanskrit word “duhitR,” meaning originally “the milker or drawing milk from her mother” (Cologne Digital Sanskrit Lexicon, 2004**)**. These definitions establish a relationship between the female and the parent. The female is the offspring of the parent; the parent was her source of origin. Furthermore, the daughter is responsible to the authority or love of her parents. No matter what her age, the daughter is always the child to the parent. The concept of “child” carries with it various connotations. On the one hand it implies the status of offspring, on the other it implies one who is not yet mature. Based on the Sanskrit definition, the daughter is also one who was intimately connected with her mother. This earliest definition focuses solely on the fact that the daughter derives her nurturance from her mother (Cologne Digital Sanskrit Lexicon, 2004**)**.

The word “mother” evolved from the Latin “mater,” Old English “mOder,” to the Middle English “moder” (Webster’s Third New International Dictionary, 1993, p. 1474). It has been in use since prior to the 12th century (Merriam-Webster OnLine Dictionary, 2004). Mother is defined as “a female parent,” “one to whom a filial affection and respect are due” and “a woman having authority or dignity like that of a mother”(Webster’s Third New International Dictionary, 1993, p. 1474). It is also defined as “that which has produced or nurtured anything; source of birth or origin; generatrix;” the root of the word is close in origin to that of mud, the stuff from which things are made (ARTFL Project: Webster Dictionary, 1913)**.** In addition to its definition as a noun, “mother” also serves as a verb. In this sense, the word means “to care for, cherish, or protect in the manner of a mother” (Webster’s Third New International Dictionary, 1993, p. 1474). Like “daughter,” the word “mother” implies a relationship. In the strictest sense, the relationship is that of woman to her child. In the larger sense the word implies a woman who creates someone or something. Implicit in the definition too is the sense that the status of mother carries with it the responsibility to provide for and to protect another. In each of these definitions, the mother is the one who initiates action. The mother produces, she creates, she nourishes, she protects. Both the noun and the verb “mother” are associated with output. There can be no mother unless she has produced or nourished. Whether a biologic or adoptive mother, the direction of energy is from the mother toward another. Noticeably absent from the definition is any reference to the mother receiving. However, because of her status, a mother is due filial affection and respect.

“Father” arose from the Latin “pater” to the Old English “foeder” to the Middle English “fader” (Webster’s Third New International Dictionary, 1993). The word has been in use since before the 12th century (Merriam-Webster OnLine Dictionary, 2004). It is defined as “a man who has begotten a child,” “a male parent,” “one that originates or institutes,” and like mother, “one to whom a filial affection and respect are due” (Webster’s Third New International Dictionary, 1993, p. 828). Another definition states that a father is “one who performs the offices of a parent by maintenance, affectionate care, counsel, or protection” (ARTFL Project: Webster Dictionary, 1913). Thus like “mother,” “father” carries with it an understanding of being the parent of a child and one who is responsible for providing for the well-being of the child. While the definitions of “father” imply relationship to a child, the nature of the relationship is slightly different than that between mother and child. The father is to provide “maintenance, affectionate care, counsel or protection” but the child is not defined as the “milker” of the father, only of the mother. Like the definitions of “mother,” those of “father” imply a direction of activity within the relationship. The father originates, he maintains, he protects. In return, he is due filial affection and respect.

“Parent” arose from the Latin “parens” and is similar to the Latin “parere” which means “to give birth to.” The word moved through the Middle French and Middle English to the word we know today (Webster’s Third New International Dictionary, 1993, p. 1641). It has been in use since the 15th century and is defined as “a person who cares for and brings up another” (Merriam-Webster OnLine Dictionary, 2004). It is defined as “one that begets or brings forth offspring” (Webster’s Third New International Dictionary, 1993, p. 1641). It is also defined as “cause; source; author; begetter” (ARTFL Project: Webster Dictionary, 1913). Thus like the gender specific terms of “mother” and “father,” the word “parent” implies a person who has begotten or given birth to a child and whose role as parent involves a responsibility to that child. In the larger sense, the word implies the source of things, whether a child or activities. The direction is from the parent, not to him or her.

The word “frail” arose from the Latin “frangere” and has been in use since the 14th century (Merriam-Webster OnLine Dictionary, 2004). It is defined as “easily broken: not firm or durable,” and “easily destroyed: likely to fail or die easily” (Webster’s Third New International Dictionary, 1993, p. 901). Another source defines frail as meaning “liable to fail and perish; easily destroyed; not tenacious of life; weak; infirm” (ARTFL Project: Webster Dictionary, 1913). In its current usage the word frail brings to mind a delicate balance. One thinks of old people, vulnerable but managing to maintain a necessary balance to survive. The original Latin word, however, implies a much different situation. “Frango” is defined as to “break,” “to shatter,” “to discourage, dispirit, humble,” “to strangle,” “to dash to pieces” (Cassell’s Latin Dictionary, 1959, p. 231). The image brought to mind is of the eminent end of a battle, one in which the frail person will not be victorious. The word connotes a downward trajectory of both a physical and emotional nature.

The etymological sources of “elderly” are not available, however, those of “elder” are. “Elder” developed from the Old English “elloern” through the Middle English “elder” and has been in use since before the 12th century (Merriam-Webster OnLine Dictionary, 2004). “Elderly” is defined as “somewhat old: rather advanced in years: past middle age” and “of, relating to, or characteristic of one past the prime of life” (Webster’s Third New International Dictionary, 1993, p. 730). Thus being elderly implies that one is past middle age but not necessarily aged. Perhaps it is a kind word implying one is on the verge of being old, but may not be quite there yet.

“Care” arose from the Latin “garrire” meaning “to chatter” or “babble,” through the Old High German “kara” meaning “to lament,” through the Old English “caru” to the Middle English “care” (Webster’s New Third International Dictionary, 1993, p. 338). The word has been in use since before the 12th century (Merriam-Webster OnLine Dictionary, 2004). Definitions include “suffering of mind,” “responsibility for or attention to safety and well-being,” “to feel trouble or anxiety,” “to feel interest, concern, or solicitude,” “to provide for or attend to needs or perform necessary personal service,” “to have a liking, fondness, or taste” (Webster’s New Third International Dictionary, 1993, p.338). Other definitions include “a burdensome sense of responsibility; trouble caused by onerous duties; anxiety; concern; solicitude;” “charge, oversight, or management, implying responsibility for safety and prosperity: attention or heed; caution; regard; heedfulness; watchfulness;” and “the object of watchful attention or anxiety” (ARTFL Project: Webster Dictionary, 1913). Thus “care” is a word of complex meanings. On the one hand to care is to be burdened, to have onerous duties, anxieties and concerns. On the other hand, to care is to have a liking or attachment, to be concerned or interested in something or someone. It also means to be heedful and watchful and to assume responsibility. To care is a multidimensional undertaking.

“Give” evolved through Middle English “given” and is of Scandinavian origin. It is akin to the Old English “giefan” which meant to give. It is thought also to be akin to the Latin “habEre” which means to have or to hold (Webster’s New Third International Dictionary, 1993, p. 959). Today’s definitions include “to make a present of,” “to grant or bestow by or as if by formal action," "to put into the possession of another for his use," and "to contribute without compensation" (Webster's New Third International Dictionary, 1993, p. 959). Other definitions include "a conferring or imparting" and "a benefaction" (ARTFL Project: Webster Dictionary, 1913). The essence of the word implies a movement from one source to another. It is a word that implies an interaction between things or people. It has a positive connotation in its definitions. It is associated with gifts and benefactions.

"Home" evolved through the Middle English "hom," from the Old English "hAm," and has been in use since before the 12th century (Merriam-Webster OnLine Dictionary, 2004). The earliest origins are from the Sanskrit "kshma" meaning "abode, place of rest, security" (ARTFL Project: Webster Dictionary, 1913). Current definitions include "one's principal place of residence" and "the family environment to which one is emotionally attached; focus of domestic affection" (Webster's New Third International Dictionary, 1993, p.1082). Other definitions are "one's own dwelling place; the house in which one lives; esp., the house in which one lives with his family," "one's native land," the abiding place of the affections, especially the domestic affections" (ARTFL Project: Webster Dictionary, 1913). Home is full of positive connotations. It is a place of affection, a place of family, a place of security. Under normal circumstances it is a place one wants to be.

Examination of the words associated with caring for a frail elderly parent revealed a subject matter that is primal in nature. Words like "mother," "father," "parent," and "daughter" are used so often it is easy to think of them only as words and not as the phenomena they are. These are words that imply deep filial connection. "Care" and "give" are words that confound by the complexity of their meanings, while "frail" and "elderly" reveal a state of great vulnerability. Finally, “home,” that place so often taken for granted, is revealed as the source of security and comfort that it ideally is.

Searching Idiomatic Phrases

Van Manen encourages a similar process with idiomatic phrases. The American Heritage Dictionary (1985, p. 639) defines an idiom as “a speech form or expression of a given language that is particular to itself grammatically or that cannot be understood from the individual meanings of its elements.” Van Manen indicates such phrases can teach us about the phenomenon under investigation. The reason for the informative nature of idiomatic phrases is that they usually have arisen phenomenologically, that is, they have arisen from the lived experiences of people (van Manen, 1997).

One such phrase associated with the care of aging parents is “sandwich generation.” Having arisen in the latter half of the 20th century, the term refers to individuals who are “sandwiched” between caring for their own children and caring for their aging parents. While this phenomenon is not unique to the 20th century, the demographics of this era have made it much more common. Women are choosing to have their children later in life, thus leading to the inclusion of the child-rearing role later in women’s lives. At the same time, advances in medical technology are enabling the elderly to live longer. While evidence indicates adult children in the United States have been fairly consistent in caring for their aging parents (AOA, 1999), the phenomenon of doing so while still caring for one’s own dependent children is new. As this pattern emerged through the latter part of the 20th century, the lived experience of middle-aged adults was that they found themselves in the middle. They were being enveloped by caregiving activities involving both ends of the life spectrum.

In its most basic meaning, a sandwich is “two or more slices of bread with a filling such as meat or cheese placed between them” (American Heritage Dictionary, 1985, p.1089). It also means “ to insert [one thing] tightly between two other things of differing character or quality” and “to make room or time for” (American Heritage Dictionary, 1985, p.1089). Tradition holds that the Earl of Sandwich created the sandwich for the sake of convenience. His gambling habit was so extensive he needed a way to eat his meat without disrupting his game (Encyclopedia Americana, 1994).

Thus reflection on the term “sandwich generation” yields several levels of meaning. Primarily, a sandwich is food. It is a source of nourishment for another. By providing content squeezed between two sides, it becomes a convenient source of that nourishment. However, in the process of providing nourishment to another, it is consumed. Use of the idiomatic phrase “sandwich generation” to denote those caregivers caught between the needs of a younger and an older generation is so common and widespread, the term runs the risk of losing some of its significance. As van Manen states, it has perhaps become “silted, crusted, or fossilized in such a way that the original contact with our primordial experiences is broken (van Manen, 1997). For while a sandwich is something wedged between two sides, the more basic meaning of a thing consumed in order to give nourishment to another is also subliminally present.

Obtaining Experiential Descriptions from Participants

Another aspect of the phenomenological investigation is to obtain experiential descriptions from other persons. By examining the experiences of other people the researcher is able to come to a deeper and richer understanding of the phenomenon. The researcher is able, as van Manen (1984) states, to become more experienced.

Sample. In order to achieve this aim, a convenience or volunteer sample was used. The goal in sampling was to have participants who were currently living the experience of caring for a frail, elderly parent and who had done so for at least a six month period. For the purpose of this study, a caregiver was defined as either a biological or adoptive daughter of at least 18 years of age who currently was giving a frail, elderly parent or parents physical or emotional support for fifteen hours or more per week in the parents' home, and who had done so for at least six months. A frail, elderly parent was defined as a biological or adoptive parent who is at least 65 years old and who would not be able to remain living in his or her home without the support of the caregiver or some other person.

The decision was made to include only those daughters who cared for parents in the parents' home and not daughters who had parents living with them in their own home. This decision was based on my belief that different issues would be present in the two situations. A daughter who cares for parents in her home faces concerns about personal space and boundaries that would not be present to a caregiver with whom the care recipient does not live. Daughters who care for parents in the parents' home deal with different issues, for example, concerns for the well-being and safety of the parent when she is not there. Also, when the parents reside in their own home, issues of the caregiver's absence from her home and family arise. Although the families of the caregiver are affected in both situations, the effects can be different in nature. The decision was made to seek a consistency of living arrangements as much as possible.

It was also decided that only daughters who cared for frail, elderly parents and not those who cared for terminally ill parents would be included. I believed the issues in these two types of circumstances would be different. Daughters who care for frail, elderly parents do so without knowledge or anticipation of their parents' impending death. Although daughters who care for terminally ill parents ultimately do not know the time of their parents' death, they enter into the caregiving experience with a perceived end in sight. As with the issue of living arrangements, I wanted to keep consistency of circumstances as much as possible.

An exclusion criterion was caregivers who were deemed to be emotionally vulnerable as identified either by the researcher or the representative of a referring agency. An example of emotional vulnerability would be a caregiver who was experiencing multiple situations that she perceived to be of crisis proportion. The exclusion of such individuals was for the purpose of their protection. Also excluded were daughters-in-law who care for parents through marriage. These relationships involve attachment issues that may or may not be present with other parent-child relationships.

Volunteer participants were solicited through two physicians' offices, one church, and one adult day care agency in the Northern Kentucky area, as well as through word of mouth. An initial sample of ten participants had been anticipated, however this number decreased throughout the research process. The goal in sampling had been to find enough participants to ensure data saturation. Attainment of the goal was recognized when after interviewing seven participants no new information was being attained and redundancy in the themes was present.

Two local physicians were contacted by letter (see Appendix A) to ask their assistance in recruiting potential participants for the study. One of the physicians informed two caregivers about the study and asked their permission for me to contact them by letter (see Appendix B). Once the caregivers had consented, the physician provided me with the name, address, and telephone number of the potential participants. A letter was sent to the caregivers, informing them of the study. A follow-up phone call was made to these two caregivers to inquire if they were interested in participating. After talking with the women, however, it was determined that they did not meet the inclusion criteria.

The same process was followed with word of mouth contacts. When someone informed me of a potential participant, the contact person asked the individual's permission for me to contact her. When permission was granted, the contact person provided me with the name, address, and telephone number of the caregiver. A follow-up phone call was made to see if the individuals were interested in participating in the study after having read the explanatory letter**.** Participation was completely voluntary and no recruitment incentives were used. Word of mouth proved to be the most effective means of recruiting participants. Twelve caregivers were referred by this process. Of these twelve women, four did not meet the criteria and one did not wish to participate.

A request for referrals was made to the administrator of an adult day care center in the Northern Kentucky area (see Appendix A). By the time this request was made, however, the seven word of mouth participants had already been located. When these interviews were completed, data saturation and redundancy of the findings were already evident. Thus no referrals were taken from this agency.

All seven of the participants were Caucasian. Efforts were made to recruit African American participants, but these efforts were unsuccessful. Permission was asked of the pastoral administrator of a local African American church to place a flyer in the church announcing the study (see Appendix C). She stated a verbal announcement from her to the members would be more effective so the flyer was not posted. No participants were elicited in this way. Contact was made with one African American caregiver through a word of mouth referral. A letter was sent to this woman and the phone call was made. Although the caregiver was willing to participate, her mother was in and out of a rehabilitation center over a several month period. Phone contact was maintained with the caregiver over this time, but ultimately her mother was placed in a nursing home, thus rendering her daughter ineligible for the study. I also had planned to recruit volunteers from a local African American community center by use of the flyer, however this center was closed due to internal administrative problems.

The final sample consisted of seven women who ranged in age from approximately thirty to sixty years of age. All resided in Kentucky, within a twenty-mile radius of the Northern Kentucky area. Most lived in suburban areas; one lived in an urban setting and one in a rural setting. As evidenced by their homes, most appeared to be of a middle socio-economic class with some variation up and down from the middle. One home was not seen at the participant's request. The women were mixed in their educational backgrounds. All were employed outside of the home, some of them full-time and some of them part time. The nature of their occupations ranged from that of laborer to professional positions. All of the women were married. All but two still had children living in their homes.

Setting. A time and place for the initial interview with caregivers were decided upon during the initial phone call. The time and location of the interviews were determined at the convenience of the participants. Five of the initial interviews were conducted in the participants' homes, one was conducted in my home, and one was conducted at a diner in a small rural community. Each of the second interviews with the seven participants was conducted in the same location as the first one had been.

Informed consent. Upon meeting with each participant the first time, social conversation was pursued until the participant appeared to be comfortable and rapport had been established. The participants were given time to read and ask questions about the Informed Consent Statement (see Appendix D). Informed consent was obtained after the participants were given time to carefully read the consent form and to ask any questions they had before signing it. As stated in the form, participants were free to refuse participation or to discontinue their participation at any point. I refrained from any subtle manipulation or incentives aimed at keeping participants involved in the study if they did not wish to do so. The participants were given a copy of the consent form after signing it and one was retained by me.

The initial interviews were conducted face-to-face and were audio-tape recorded. Most of the interviews lasted sixty to seventy-five minutes. An interview guide was used during the interview (see Appendix E). After each interview, I took notes in order to document my impressions of the meeting and to record non-verbal cues the participant demonstrated. Each audio-tape was transcribed verbatim by a paid transcriptionist and each transcription was checked for accuracy by me against the original audio-tape. Data from the transcribed interviews were used for analysis. A second face-to-face interview was conducted to allow the participant to review the data from the first interview, to make any changes or revisions, and to elicit any additional data the participant wished to contribute. The second interview occurred within approximately six weeks after the initial interview had occurred. Data from the second interviews were analyzed in the same manner as the first interview. Additional data, clarifications, and revisions obtained in the second interview were considered equally with data from the first interview. This process continued with all seven participants; data analysis was ongoing as the interview process progressed.

Confidentiality. Appropriate measures were taken to ensure the confidentiality of the participants and included the following steps. The names of the participants were equated with a pseudonym chosen by the participant. No list was constructed to connect participants to the pseudonym. All audio-tapes, field notes, and typed transcriptions were identified only by use of the pseudonym. The tapes will be destroyed after the successful defense of the dissertation. These materials will be kept until that time in case revisions or clarifications are necessary. The transcripts will be kept indefinitely as stated in the informed consent agreement, for purposes of future publications. The transcriptionist signed a confidentiality statement (see Appendix F) and all identifiers within the text of the research report were eliminated or changed to protect confidentiality.

Descriptions from Artistic Sources

Another means of exploring the phenomenon was an investigation of literature and art for experiential descriptions of the caregiving experience. Van Manen (1984) describes this process as one that widens the researcher’s perspective, allowing vicarious experience of the scenes presented by the author or the artist. The following works of literature were examined for the study: Anna Quindlen’s novel *One True Thing* and the children’s book *Love You Forever* by Robert Munsch and Sheila McGraw. An example of photographic art by photographer Burk Uzzle was also examined. The results of these investigations are included with the data analysis.

Consulting Phenomenological Literature

Van Manen (1997) identifies the researcher's consultation of phenomenological literature as the final part of the existential investigation. He identifies four benefits that such consultation can render in the research process. First, the phenomenological literature may already address the topic in which the researcher is interested. It is the researcher's responsibility to become familiar with these materials in order to be aware of what has already been done with particular topics. An additional advantage to be derived from this process is that such consultation gives the researcher a framework with which to interact intellectually. By knowing what others have found and written about the topic, one has touch points on which to base one's own thinking. A third benefit of consulting the phenomenological literature identified by van Manen (1997) is that the process enables the researcher "to reflect more deeply on the way we tend to make interpretive sense of lived experience" (p. 75). As the researcher becomes more familiar with the phenomenological tradition through examination of the works of others, one is better able to determine to what degree he or she wishes to follow their lead or pursue a unique interpretation of the phenomenological method. A final benefit to examination of the phenomenological literature is that it helps the researcher identify and stretch beyond the limits of his or her personal interpretive abilities.

Nine pieces of phenomenological writing were examined for this study. Six of these pieces were phenomenological studies of family caregiving taken from the nursing literature and three were investigations undertaken by representative members of the Dutch School of phenomenological psychology. Review of the six nursing studies was undertaken primarily to achieve the first benefit cited by van Manen, that is, to be aware of what has already been written about the topic. In undertaking this activity, however, the other three goals were achieved. These works became a source of intellectual dialogue and as such, they facilitated my recognition of how I tend to interpret the lived experience of caregiving. Finally, they helped me see the limits of my own interpretive abilities and defined my desire to transcend those abilities and those of the authors I had read. Review of these content-related articles was conducted after data collection and data analysis of the current study had been conducted. The purpose of the review of these studies was not so much to examine their results as to examine the implementation of the phenomenological approach to research. The topics of the six nursing studies were closely related but not identical to the current study.

The other three phenomenological investigations were chosen because they were authors cited by van Manen (1997) as being expert representatives of phenomenology as practiced in the Dutch School, the source of van Manen's own education in the doing of phenomenology. Review of these three pieces revealed the wide variation in approaches to phenomenological writing within the Dutch School and certainly between the writers of the Dutch School and the nursing researchers.

One example from the nursing literature was Thibodeau's (1993) hermeneutic phenomenological investigation into the experience of caring for a live-in parent, that is, when the parent has moved into the child's home. The author cited the use of Alfred Schutz' theoretical framework of phenomenology of the social world and Spiegelburg's method of implementation (1993). The steps of this method included bracketing, intuiting, analyzing, and describing. The author defined bracketing as the researcher suspending what one thinks about the experience, and intuiting was described as the researcher becoming "immersed in the world of the subject's experience" (Thibodeau, 1993, p. 16). Analysis was described as the identification of the ingredients of the phenomenon and how they relate to one another. Finally Thibodeau defined the process of describing as the use of “negation, analogy, and metaphor” (1993, p. 17). These processes were used in the analysis of interviews with the members of ten families. Comparative analyses were made of the data from individual family members with the data of the family unit. Finally, data from individual families were compared and contrasted with data from other families. The recurrent themes of time, space, and energy were identified through this process. Exemplar or paradigm cases were then chosen to represent these themes (Thibodeau, 1993). No mention of identifying the essence of the phenomenon was made.

Another study from the nursing literature was Boykin and Winland-Brown’s (1995) phenomenological investigation into the experience of being a caregiver for a relative with Alzheimer’s disease. Colaizzi’s method was used to analyze audio-tape recorded interviews with five relatives who were caring for a loved one in the home. The purposive sample consisted of two husbands, one wife, one daughter and one daughter-in-law. Four themes were identified, including: “the progression of the disease results in feelings of frustration and sacrifice of self” (p.14), “caregivers find courage to continue through sharing and living in the moment” (p.15), “altered perceptions of reality and time result in the need for constant supervision” (p.16), and “caregivers struggle with guilt as they try to be authentically ‘with’ and to retain respect and dignity of loved ones” (p.16). The last step of Colaizzi’s method involved incorporating the results into a final description of the phenomenon. This process yielded the finding of “the human experience of unending care and the paradoxical struggles of love and frustration” (p.16).

Another example of a phenomenological investigation from within the nursing literature is Parsons' (1997) study of the male experience of caring for a family member with Alzheimer's disease. The researcher used van Manen's methodology. Eight men who were either spouses or sons of the family members were interviewed. No distinction was made among caregivers who had given care in the past and those who were doing so currently. Neither was any distinction made between caregivers who lived with the care recipient and those who did not. The following themes were identified: enduring, vigilance, a sense of loss, aloneness and loneliness, taking away, searching to discover, the need for assistance, reciprocity, and for those caregivers who were sons of the recipient, overstepping the normal boundaries. Following van Manen's approach, the researcher sought to identify the essence of the caregiving experience. Interestingly, the author identified the disease itself and the effect it had on the care recipients as the essence of the phenomenon.

Kellett and Mannion (1999) conducted an ontological-hermeneutic study into family caregiving at home. Seven caregivers who cared for an older family member at home were interviewed twice. Thematic analysis of these interviews was conducted using the NUD*IST 3.0 data analysis system. Seven themes of meaning were identified. These themes included the sense of family life past, sense of change, sense of engaged involvement, sense of worth, sense of concern, and sense of continuity. No further analysis of the data was conducted and no mention was made of discovering the essence of the phenomenon.

Gates (2000) conducted a phenomenological study of caring for a loved one. Nine participants who were spouses, daughters, or nieces of the care recipient were interviewed. The gender of the spouses was not identified. The author modified van Kaam's method by interviewing the participants rather than having them write about their experiences.

Transcripts of the interviews were analyzed using van Kaam’s method in order to elicit meaning from the data. The findings were presented in terms of Parse’s theory of human becoming. The definition that emerged from the study included the elements of poignant remembering; dogged continuing; nurturant giving and confirmatory receiving; swells of enjoyment and tides of sorrow; and uplifting togetherness and valleys of aloneness.

The final study from the nursing literature to be examined was that of Vellone, Sansoni, and Cohen (2002). These authors conducted a hermeneutic phenomenological investigation into the experience of Italians caring for family members with Alzheimer’s disease. Twenty-six participants were interviewed. The sample consisted of both male and female participants. The participants were either the spouses or children of the person with Alzheimer’s disease. The authors describe their method of data analysis simply as the use of an approach based on the Utrecht School of phenomenology. Transcripts of the interviews were assessed for themes that were then grouped with similar themes. The result was the emergence of the following six themes: change in relationships, changes in lifestyle, difficulties in caring, hopes and fears for the future, family duty, and respectful treatment. No attempt was made to identify the essence of the experience.

These six nursing studies were different in many ways. Some of the studies were identified as being phenomenological, or descriptive in nature, while others portended to be hermeneutical-phenomenological, that is, to involve both description and linguistic interpretation. Each researcher identified a different method of data analysis. The results of some of the studies involved identification of the essence of the phenomenon while others did not. One study produced exemplar cases while others did not. Although the particulars of the processes differed, all of the studies were similar, however, in that they involved interviews with purposively selected participants. The interviews in each study were audio-tape recorded and the transcribed results were subjected to some form of analysis. This pattern differed greatly from the investigations conducted by representatives from the Dutch School of phenomenology.

In the first work considered, Buytendijk (1977) undertook a phenomenological investigation of the problem of feelings and emotions. Although very difficult for the non-philosopher to penetrate, careful study of the work reveals the method of the Dutch School phenomenologist. The author began with an introductory description of his intended purpose. Through his years of studying animal behavior, he had learned that the characteristics and significance of both animal and human behavior exist in relationship to their respective essences and to their situated selves. The behavior of animals makes sense only in light of the fact that they are animals; behavior of humans makes sense only in light of their humanity. Buytendijk’s method is based on the phenomenology of Edmund Husserl, particularly his concept of intentionality, that is, that consciousness is of necessity conscious of something, a reference that assumes a meaning. In order to understand the meaning of the reference, one would seek out the subjective opinions of those who experience the particular phenomenon. This process is possible only when a person stands outside of the situation and views himself as experiencing the phenomenon, in this case the phenomenon of feelings.

Given this introduction, Buytendjik then proceeded to provide an essay in which he analyzed feelings and emotions. He began with the beginnings of the affective life that arise with the emergence of consciousness itself. He discussed differences and similarities in the nature of feeling and emotions. Linguistic considerations used in the explication of both phenomena were examined. The author identified modes of being he believes are associated with types of feelings. The characteristics of happiness were differentiated from those of shame. Although he did not employ the work of artists in this essay, Buytendijk indicated that art is often an appropriate and powerful tool in achieving an appropriate phenomenological description. Through these subtle investigations Buytendijk presented a description of happiness in which he attempted to describe the essential structure of the phenomenon of happiness. The goal was to elicit insight into the nature of experience, in this case the experience of happiness. How does one know after such an endeavor, that the results are anything more than subjective opinion? Buytendijk contended that the proof comes when the description presented is affirmed by everyone who considers the phenomenon under investigation.

In the "Eidetic of the Experience of Termination," Strasser (1977) investigated the nature of happiness. As an eidetic undertaking the work is descriptive in nature, but descriptive in a purely philosophical sense. The nature of happiness was first examined and found to be a type of termination, the end result of some process. Differences and similarities between happiness and simply reaching any type of positive result were investigated. Happiness was found to be possible at the termination of only certain levels of human activity, but since no laws exist that determine what these levels are, the author concluded that the existence of levels of happiness-producing activities was relative to one's existential situation. The author then attempted to examine some phenomena that might engender happiness. In doing so, he first compared and contrasted the characteristics of enjoyment to those of pleasure. The representation of enjoyment by various artists was described. The characteristics of enjoyment were then differentiated from those of happiness. In like manner, the nature of joy was contrasted with that of enjoyment, and serenity was contrasted with joy. Finally the essential features of happiness were identified through comparison and contrast with each of the above phenomena. The description of happiness was arrived at by purely cognitive analyses.

Jan Linschoten (1977) undertook a phenomenological investigation of the phenomenon of falling asleep. His stated goal was to understand the essential structure of the experience. He painstakingly differentiated between the pre-reflexive and reflexive nature of the experience in order to establish how the goal is achievable. He also indicated that in doing a phenomenological investigation of the phenomenon, it is crucial that he lay aside everything he knew of the physiology of falling asleep. Likewise, he could not use the data produced by other persons in studying the same phenomenon, because their method of investigation had already impacted the nature of their outcomes. Instead, Linschoten stated that in order to get to the essence of the phenomenon, he must go to those directly engaged in the experience, namely himself and others who had written descriptions of the experience. Drawing upon these sources, the author examined various characteristics of the phenomenon, for example, that “sleep is a meditation of the body” (Linschoten, 1977, p. 105) and “falling asleep means abandoning one’s attitude” (Linschoten, 1977, p. 108). Comparison and contrast were used to determine those characteristics that are essential to the phenomenon and those that are not. The author used quotations from artistic sources to support his descriptions.

The investigations conducted by the three representative members of the Dutch School of Phenomenology had much in common with one another in terms of method and style. Each author identified a phenomenon to be investigated. They then attempted to set aside what was generally accepted to be known scientifically about the phenomena. Instead they went to the works of authors who had written about the respective phenomena from either a phenomenological or artistic perspective. The themes identified either by the author or the other writers were then examined to see if they were essential to the phenomenon. The narrative in which the author discussed the essential themes of the work constituted the phenomenological investigation.

The Dutch process is different than the phenomenological studies conducted by the nurse researchers. However, this comparison of the representative works from the two groups gives a clue into how the work of the original phenomenological writers was adapted by nursing and other modern social science researchers. The seed of the original writers is present in the modern studies, but the blossom is of a slightly different variety.

Both groups of writers begin with a question about a phenomenon and both attempt to set aside their preconceived notions. The point of greatest departure is the source from which the authors elicit themes about the phenomenon. The members of the Dutch School draw predominantly from other writers. The nurse researchers, as well as other social scientists, draw not from people who have written about the experience, but rather from people who are living the experience. This variation is appropriate for disciplines whose purpose is not merely to understand the phenomenon, but also to support people in their various lived roles.

Another dissimilarity between the two groups is their presentation of the essence of the phenomenon. Writers of the Dutch School studies consider the narrative description of the phenomenon to be the essence. The reader recognizes the essence if the narrative rings true. Authors of the nursing studies present the themes as being the essence. These studies are presented in professional journals, however, and not in the form of the original research. Thus it is not possible to know the format of the original studies. For purpose of this investigation, the decision was made to follow the lead of the writers from the Dutch School. This decision was thought to be most congruent with the design set forth by van Manen.

Comparison of these two groups of authors was instrumental in allowing me to achieve certain goals. Primary among these goals were two set forth by van Manen (1997), that is, being better prepared to decide how one wishes to interpret the use of the phenomenological method and to establish a base by which to compare one's own interpretive abilities.

Phenomenological Reflection

Van Manen defines the purpose of phenomenological reflection as the attempt "to grasp the essential meaning of something" (1997, p. 77). The researcher attemps to make explicit that which was implicit in the collected data. Two main endeavors constitute this process. These include the undertaking of a thematic analysis of the data and the determination of essential themes.

Conducting Thematic Analysis

What is searched for in thematic analysis? What are the themes being analysed? Van Manen defines phenomenological themes as the "structures of experience" (1997, p. 79). They are the units of meaning that recur in a person's description of an experience. Van Manen is careful to clarify, however, that themes are not categorical in nature, nor are they formulaic. Themes reflect the concerns of particular people examined through the guise of a more universal understanding. Van Manen further describes themes as being the "point" of an anecdote, an inadequate "simplification" of the experience, and a "form of capturing the phenomenon one tries to understand;" a theme is not something "one encounters at certain points or moments in the text" (1997, p. 87). The theme is not an objective thing one locates, rather it is something one creates through self-reflection on what is presented in the data. A theme is a “process of insightful invention, discovery, disclosure” that is “given” to the researcher from within the lived experience of the phenomenon (van Manen, 1997, p. 88).

The process of uncovering thematic aspects began in the current research study when the interviews were conducted with daughters living the experience of caring for a frail elderly parent. Questions used on the interview guide (see appendix E) were formulated to enable the participant to move from their direct involvement in the caregiving experience to a more cognitive consideration of the experience. Husserl would define this transition as a movement from the eminent to the transcendental experience of caregiving. The movement is from the experience of caregiving to the meaning of the caregiving experience. Questions were also constructed to facilitate the participants’ movement away from their preconceived notions of caregiving to what presented itself to them on an intuitive and visceral level. When the interviews were completed, I wrote memos in which my impressions and thoughts about the interview were recorded. I referred to these memos periodically during the data analysis process to refresh my memory of the particular interview.

Van Manen describes three approaches to uncovering the themes from a text. These include the wholistic or sententious approach, in which the fundamental meaning of the text as a whole is considered; the selective or highlighting approach, in which statements or phrases that seem particularly insightful into the phenomenon are identified; and the detailed or line-by-line approach, in which every sentence is examined for its relevance to the phenomenon (van Manen, 1977).

The selective or highlighting approach was implemented in this study. The transcription of each interview was read while listening to the audio-tape in order to insure the accuracy of the transcription. Any deviations from the original recording were corrected in the transcription in the attempt to insure the greatest accuracy possible. Each transcription was then read carefully and all phrases and sentences relevant to the phenomenon were highlighted for further consideration. The highlighted parts of the interview were examined for the themes contained within them. Following van Manen's (1997) lead, the themes were the meaning I was able to discern from the interview. Through sensitivity to the lived experience of the participant as reported in the transcripts, I developed a dialogue with what was being said. The resulting themes were the interpretive product of that interaction. The themes were what was revealed to me in my interaction with the transcript.

Van Manen offers a guide to examining the data for essential themes. He posits that all phenomenological human science research is an examination of the lived world as experienced in the everyday events of life, and that because of this fact, certain fundamental themes are relevant to all human beings, regardless of their particular situation in life (van Manen, 1997). He identifies these themes as "existentials" in order to differentiate them from more particular themes one may discover. Four of these existentials are proposed as guides to the reflective process, and consist of the themes of "lived space (spatiality), lived body (corporeality), lived time (temporality), and lived human relation (relationality or communality)" (van Manen, 1997, p.101). Van Manen contends that these four themes are common to all living people, albeit to different degrees at different times in one's life.

Once the themes of the various transcripts were identified, I composed linguistic transformations of them. In this hermeneutic activity, I attempted to interpret the text and to move the language to a more universal level of abstraction while at the same time remaining faithful to the participant's lived experience.

A slight modification of van Manen’s design was implemented at this point in the study. Van Manen indicates that works of literature and art are to be examined as a source of increased understanding of the phenomenon, and in his design this process occurs before the essential themes of the participants are identified. In this study it was believed that the themes of the participants were of greatest significance, and an attempt was made to maintain the integrity of those themes. For this reason, the pieces of literature and art were examined after the essential themes of the participants had been identified. The literary and artistic pieces were examined for the support they lent to the themes identified by the participants rather than for the identification of new themes. I believed this modification was allowable since van Manen identifies his process as one that is flexible and able to be used differently by different researchers.

Determining Essential Themes

The final component in the process of the phenomenological reflection is determining which of the themes are essential to the phenomenon and which are incidental. Van Manen defines universal, or essential, themes as those that “make a phenomenon what it is and without which it cannot be what it is” (1997, p. 107). Since the essential themes are those around which the phenomenological description will be constructed, the quality of the description will depend largely on the accuracy of the themes. If the phenomenological description is to “ring true” to those who have lived this experience, or who currently are living the experience, the foundational themes upon which the description is based must first be accurate. In order to delineate between the essential and the incidental themes, van Manen recommends the method of “free imaginative variation” (1997, p. 107). In this process the researcher asks if the phenomenon would be the same without this theme or would it be fundamentally altered? By carefully considering each of the emergent themes in this manner, the researcher winnows out the themes until only those that are essential to the understanding of the phenomenon remain. It is upon these remaining themes that the phenomenological narrative is constructed. This process was carried out with the themes elicited from the participants of the current study.

SUMMARY

This chapter presented a thorough investigation into the implementation of van Manen’s research design. Explication of the specific ways in which the processes of turning to the nature of the lived experience, the existential investigation, and the phenomenological reflection were carried out in the present study was presented. The modification made in van Manen’s design was identified and the rational for the change was stated.

Chapter 5: Data Analysis

Given a choice, I preferred someone
to understand my situation, even though she was
helpless to fix it rather, than the other way around.
But that's just me. (Kidd, 2002, p. 258).

Introduction

The purpose of phenomenological reflection is to elicit the essential meaning of a phenomenon. Van Manen states that this is a process of "reflectively appropriating, of clarifying, and of making explicit the structure of meaning of the lived experience' (1997, p. 77). This process involves the conducting of thematic analysis, uncovering thematic aspects, isolating thematic statements, composing linguistic transformations, gathering thematic descriptions from artistic sources, and differentiating between incidental and essential themes (van Manen, 1997). Van Manen's design as explicated in Chapter 3 was used. A selective or highlighting approach was used to examine the transcribed interviews of the seven participants. The responses of each participant that revealed her perceptions of her caregiving experience were highlighted. The responses within an interview were examined for commonalities pointing at a theme for that participant. As the next interview was analyzed, the responses were analyzed in light of those of the previous interviews for comparative analysis. This process continued until all of the interviews had been analyzed and a list of themes from all of the participants had been elicited. This chapter presents the results of the thematic analyses, isolation of thematic statements, composition of linguistic transformations, and the differentiation of incidental and essential themes. Thematic descriptions from artistic sources are also presented.

Experiential Descriptions from Participants

Participant 1: Jackie

"I would have died without my Mother"

Jackie has been caring for her parents for several years. They are frail and elderly, but not bed ridden or senile. They live in their own home. Jackie's mother would like to move into an assisted living facility, but her father refuses to leave the home. Jackie shares the caregiving role with her sister. They have a brother who has recently returned to the area and who is gradually assuming some caregiving responsibilities with the parents.

Analysis of the initial interview with Jackie revealed sixteen themes.

1. Caregiving doesn't make me a good person; you would do it too if your parents were still alive.

You know my friend has said to me before, 'you know, you really do take care of your parents.' I don't want them to think I'm really good. I just want them to know that you would do the same thing if your mother or father was still living.

I mean, I'm not a bad person but I mean it doesn't make me a wonderful person because I'm doing this. I mean, it's just something that I think everybody would care for someone they loved. And maybe somebody that they didn't even love, you know, if it was helping them---helping that person--- it's helping the person.

2. I have responsibilities beyond my parents.

The constantly being on call twenty-four hours a day and even though I have a life of my own. It's like I have to two lives now. I'm like---they depend on me for everything, one hundred percent.

3. I try to encourage my parents' independence.

I don't like to make their decisions. And, I might encourage them to say well, what do you really think? You know, but I sometimes just sit and make them.

I don't mind going to the grocery for them. Sometimes Mom wants to go along and that's a long trip to the grocery store. She is so slow but she doesn't get out so much so this is an outing. But, whatever needs to be picked up, we can pick it up in the meantime but she still likes to go.

I just, I want people to know that, I guess even though my Dad is so sure he wants to live in the house---that's OK if he wants to and I'll help them if that's what they want to do. Even though I don't agree with it, I'll help them…

But, then we sit down and my sister and I talk about it and say that, 'Well, if he goes out there and he thinks he has to sweep the sidewalk off when it snows and he has a heart attack. It was his decision not ours.'

4. I don't want to be like my parents are.

…somedays its like I don't want to be like they are. I don't want to live to be so that I can't take care of myself.

But, I just kind of don't want to be that way and I don't want my children to have to---I don't want to be one hundred percent dependent on my children. I think I've learned maybe, if they think I need to go to assisted living, maybe I will. I've learned that it's OK and it's hard to turn, except you don't, just don't want to ever do anything to turn lose of everything or give up your independence. But, I think I've learned that maybe it would be OK to do that, and I've seen both sides of assisted living versus living in your private home. It's a lot easier on the person and the family if you have some little step down from the home.

I think Mom feels probably worse about it than anybody and I feel bad for her and I've told her a million times. 'Mom, it's OK, don't worry about it. I don't ever mind. Call me anytime, I'll be over if you need whatever. If you want to make another doctor's appointment well make it or whatever.' I mean she sat there one time with a kidney infection because she didn't want to call and make an appointment because we had just been there the week before. And, my heart goes out to her. So, I think maybe I've learned that I might just make it easier on my kids or the caregiver…

5. I worry about my parents' safety versus their right to be independent.

…just like Dad knows he's not supposed to be out shoveling snow and raking leaves but he does it anyway. He has a terrible heart. But it's like 'Well alls we can do is tell you.' I'll call Mom the day that I think I know where he is, out there in the yard, but Mom just will say 'I can't do anything with him. I don't know how you're going to do anything with him.' So, you know, we just let him go but he's totally---he's ---it's so frustrating. I would feel horrible if he was out there raking leaves and died. But my Mom said, 'Well it's something that he really wants to do. And, if he dies doing it, that's his choice, he enjoys doing that.' But, it upsets me. 'Cause I think, you know, it could be prevented---just like I get upset with Mom when she goes down the basement steps without anybody around. That's like…you've already been at the bottom of the steps twice now; she has fallen. If she breaks something, she won't have a choice. She won't be able to stay in the house. I mean she's already crippled up with her Parkinson's and that. And that, really, really upsets me, you know, you hate to yell at your parents but you're really trying to be stern and point out all of the negative things that you know. 'You can go down the steps, but once you fall, then what's

going to happen?' She goes, 'I know, I know.' But, she'll do it anyway. It's like, what are you going to do---I guess if I live to be eighty-six, I'll have such a mind of my own too, I'll do exactly what they're doing.

I've just truly worried about my mother and father in their home. Mom---she thinks she can go out in the kitchen and do things and I've gone in there and I said, 'Mom, what's that pan in the sink?' And, it'll be totally burnt.

6. It's difficult for me to see my parents struggle.

She has Parkinson's and she is crippled and she's got her walker and she has her seat on her walker that she carries her dishes---it breaks my heart to see her carry the dishes from the counter to the table on her little walker seat you know. But, you know, it's not fair, but that's the way it is.

And sometimes it's depressing and you see how they are and how dependent and you hate to see them that way.

7. Caregiving would be easier if I had more control over them.

Both Mom and Dad have their minds one hundred percent, which is good but then it's not great sometimes because you can't tell them what to do like you'd like to sometimes.

8. We want to take care of our own.

You know, Mom says, what about Meals on Wheels? Well, that's a good program but it's like Mom, we can really do it, you don't need Meals on Wheels. We can get enough stuff in here so you don't have to depend on Meals on Wheels.

9. I've gotten much closer to my parents since I've been caring for them.

We've become closer. I mean we always were kind of close but now I mean we're really, really close. I mean just like before I was the caregiver, we talked maybe a couple of times a week but now it's everyday. I see them five times more a week than I did. And, we've definitely become closer and probably Mom has shared more with me about her past life, you know, eighty-five years in the last two years than I ever--- we never sat down and had a big conversation. Everybody I guess was so busy. And, in fact that's kind of neat. And, I loved to hear my Dad talk about his war stories. And, he never really talked about it at all---the war. And, just lately he's started to talk and open up and even my kids find it fascinating.

…I think everybody, the family has been closer. Just like my daughter, she really likes to hear her grandpa talk and it's good for the whole family probably. But we had a closer relationship with him giving him care. I guess that's maybe that's how they help us out. You know, what I'm saying…

I mean, you know like since we spend a lot more time with them, I'll even ask Mom different things or Dad and all's you do is ask them and they'll tell you anything but it's neat, it makes you feel, you know, what went on when you were little and before you were born what they did and you know like how my Mom and Dad met. It's really neat. That part is really---I think that's really a plus. It's real satisfying that---gosh you know it really turned me --- yeah, it is.

I just learned that, you know, they're your parents but they grew up and just like us and they had the same feelings and went through so much more than we ever dreamt---what they sacrificed to give for us. I mean what they went through. I've learned that my Mom was a very strong, strong person and all my life I thought Dad was the boss. But, she really is. You know, maybe sometimes, maybe that was the era too where the wife was always serving her husband but she really was like the glue that held the family together. You know, I've learned that about Mom. She was just, she is just a very strong person. But, ah I have probably learned a lot about them. I've learned that I've said more in these past two years about them than I did in my lifetime than when living with them. That's kind of neat.

It's kind of neat. It's like sometimes they tell you the same thing three times and you never heard that your whole life till the last---it's like maybe they want to tell us everything too before they go and they're making up for lost time.

10. My parents need and want so much attention.

Every doctor bill that comes in, my Father can't pay them without me totally reviewing the whole thing. You know as soon as the mail comes. I get a phone call no matter what's in the mail. He has to read it to me. It's like, 'Well tell me about today what you know.' 'Well, I have three bills, well two of them aren't bills it's an issue with benefits or something.' But, he knows they're not bills but he still, you know, wants you to you know, but I think when they get older like that and they really can't do what they've been used to doing their whole life---they need more attention. My Mother is not demanding and she hates to depend on my sister and myself for everything. But, she can't help it. She has to depend on us.

The constantly being on call twenty-four hours a day…I'm like---they depend on me for everything, one hundred percent.

11. My parents and I have a reciprocal relationship.

…you know your parents have given you so much your whole life and you feel like, it's no really big deal. If I cook sometimes I cook on Sunday for three meals. You know, and it's like I'm cooking anyway, so I'll just cook extra. So, you know, I don't mind it at all.

…they depend on me, not 100% but they ask my opinion now where I used to ask their opinion. And, it probably does make you feel like 'Yeah, it's OK, you know.'

…I mean I just really appreciate that my parents took care of me and raised me and if I can just give them back a little bit, I'll do it.

12. I have grown to know myself better through this experience.

I guess if I live to be eighty-six, I'll have such a mind of my own too; I'll do exactly what they're doing.

I probably learned that I haven't really learned anything. But, I probably feel like I learned that I didn't have a ton of patience. You know, sometimes---that's not good but you hate to not have patience and then you feel guilty for not having it. It's kind of making me a better person to know that, you know.

It's something that's OK. I mean, that it's really not a burden and that I just feel like, don't let anybody ever pity me because I don't, you know---I think first of all, God only gives you what you can handle. And He wouldn't have given me this to do if I couldn't do it; I think it's making me a better person. It makes me appreciate more in life. I think it gives me---I think it just gives me compassion for other people too. Um, I don't know, it just makes me just appreciate life more in the fact that we accept…our parents set the groundwork, I mean if it wasn't for them, where would our values…where would really, you know, our character and everything.

13. Caregiving is evidence of love.

I know when I was in high school, I was in a terrible automobile accident. I was a Senior. And, I always felt like, you know, I had a younger sister and brother and I always felt like Mom really didn't have time for me because she so busy with the younger kids but she, I know I didn't die and she held my hand for three straight days while I was in a coma. The fact that I'll miss them---I would have died without my Mother. If I can just do this much to help her I would---but, I just feel like she kept me alive. She was there. She did not leave my side. I feel like I could be at her side now.

I just---like I said, sometimes a parent, they don't have to tell you they love you everyday of your life, you just know it. And, they show it by what they do. It's like I didn't tell Mom and Dad I love them everyday. I probably don't ever tell them I love them, but they know I do and I know they always loved me. But, I never realized it until that day, over that period, you know, when I had this horrible accident. No, I don't feel like I've ever lost anything.

14. My siblings are involved in the caregiving.

But you know, I am lucky I have help. I am not the sole person taking care of them. My brother shares the doctors' appointments, you know, with me. He'll take Dad and I'll take Mom. My sister is so helpful. She'll, you know, be there in a pinch if anything is needed.

15. Caregiving gives me a purpose in life.

Well, I feel like sometimes I have a purpose in life here. But, God probably put me on earth---you know how sometimes---that I really don't have any talents. I'm not an artist, I'm not a *singer and---but I feel like God put me here for some reason and maybe this is what I'm supposed to be doing here on earth. And, so that makes me feel probably a little good about myself that, you know, I can really help them and be there for them and all kind of---glad they depend on me, not 100% but they ask my opinion now where I used to ask their opinion. And, it probably does make you feel like 'Yeah, it's OK, you know.'*

16. Caregiving involves contradictory feelings.

I guess basically it's been a total role reversal. But, it's been very---sometimes it's very even depressing for me. I come home and cry after I leave their house. But it's, it's I can't explain it. I don't mind it at all. I want to help them. I want to do whatever I can for them, but then some days it's like I don't want to be like they are. I don't want to live to be so that I can't take care of myself---but I would do anything for them. I mean any time any day of the---you know, week or---but sometimes it is overwhelming.

…it's almost like it's a fulfilling experience but it's frustrating at the same time. And it's just I never really thought about it until you asked the question. I guess you just do it everyday and I'd have to say sometimes it's not that you get tired but you think, 'Oh please,'---just like I said it's frustrating sometimes. And sometimes it's depressing and you see how they are and how dependent and you hate to see them that way. And, but then you get home from their house and five minutes later the phone's ringing and, 'Oh I forgot to tell you,' you know, then I don't get so depressed; I think this is OK

Discussion:

In going over the data several times, it seemed to me that # 3, 5, and 7 were touching on the same topic, that is, supporting the autonomy of the parents. The issue of safety was seen as a subset or a variation of the topic. I watched to see how this played out in the future.

I try to encourage my parents' independence.
I worry about my parents' safety versus their right to be independent.
Caregiving would be easier if I had more control over my parents.

When Jackie talked about how difficult it is to watch her mother struggle, is she grieving the decline and gradual loss of her mother? I waited to see if other participants discussed this issue.

The topic of reciprocity recurred many times: my parents cared for me so now I will care for them. The separate topic I identified as "evidence of my love" possibly belongs with the topic of reciprocity. I think they may be getting at the same thing.

My parent s and I have a reciprocal relationship.
Caregiving is evidence of love.

I had originally thought Jackie was saying she was trying to keep her parents alive through her caregiving. Careful analysis of the transcript, however, revealed that she had not actually said this. In the second interview Jackie verified that she had not said it, so this was not included as a theme.

Jackie spoke often of what she has learned about herself and how she has grown. I think the topic of giving her a purpose in life is part of this. Not everything is positive in nature, but all have to do with how she has developed and what she has realized about herself. Realizing she does not want to be like her parents when she is their age is part of this. I think numbers 4, 12, and 15 are all part of Jackie's self-actualization as a person.

I don't want to be like my parents are.
I have grown to know myself better through the caregiving experience.
Caregiving gives me a purpose in life.

Both positive and negative feelings were expressed about the caregiving experience. It is contradiction and it is paradox, the yin and the yang of loving someone. The fact that her parents want and need so much attention probably is part of this contradiction.

Caregiving involves contradictory feelings.
My parents need and want so much attention.

After looking at the content this way, the themes evolved as the following:

1. Caregiving doesn't make me a good person; you would do it too.
2. I have responsibilities beyond my parents.
3. I try to encourage my parents' independence.
    a. issues of safety v. independence
    b. easier if I had more control
4. It's difficult to see them struggle.
5. We take care of our own.
6. I've gotten much closer to my parents since I've been caring for them.
7. My parents and I have a reciprocal relationship.
    a. evidence of love

    b. keeping the other alive (not supported and later dropped)
8. I've grown to know myself better through this experience.
    a. I don't want to be like them
    b. Caregiving gives me a purpose in life
9. My siblings are involved in the caregiving.
10. Caregiving involves contradictory feelings.
    a. My parents need/want attention

Participant 2: Mary

"Oh my God, what's wrong now?"

The second participant was Mary. She has been caring for her parents for approximately ten years. Both of her parents lived together in their own home until her mother, who has Alzheimer's disease, was moved to a nursing home. Since that time she has continued to care for her frail, elderly father in his home. Mary works five days a week outside of her home.

The interview with Mary revealed the following fourteen themes. The title of the theme in the participant's own words is stated first. The title by which the theme was tracked is stated in parentheses following the participant's words.

1. I feel torn in different directions when I'm taking care of my parents (Conflicting responsibilities).

…it really got nerve wracking and stressing plus at the same time, my husband got transferred to Michigan. He was in Michigan for seven years---right when this first happened in '93. My mother gets a brain tumor and my husband gets transferred to Michigan. I had to stay here. You know, I didn't want to leave them. They needed me; I just couldn't do it. He went up there and commuted back and forth.

So it was just like commuting back and forth, trying to run this house and trying to do the jobs that he normally did and it was just getting overwhelming.

…when he(my Father) had the last bout and he had to go to the hospital, he was really bad. He has a bladder infection and he bleeds. You know at that time, they had him on coumadin. He was running like a faucet. I was really scared and I got him out there and then I had to get somebody to stay with her and then come back and stay with her and then go to work and I would have to get somebody to stay there then and then come back and stay with her. At the same time, I was trying to get things here and they were trying to do something. But

they're kind of like, 'Well, you know, you know, what should we do?' So it's like your house kind of slacks and your family kind of slacks, you know. They'd come second and then they don't like that sometimes you know. They're kind of, 'You're always up there, you're always up there.'

That was one of the most stressful times in my life I think that was. I had her with the brain tumor, I had him going up there and I knew I couldn't go and had to stay here because they totally needed me. I was going through menopause at that time. And I had all those things and I just became very depressed and I would just cry all the time.

2. I don't get as much help as I need from my family (Siblings/support).

Yeah, they were older kids and so they helped, you know, but not tremendously because I think I spoiled them all. But, you know, my son would cut the grass…

…it's hard because I know kind of how they were feeling but yet I was kind of wanting them to be more understanding and pitch in, you know, and everything like that. And I don't think that they were as understanding as I think they could have been.

That was bad, you know. That part of it was rough, you know---and then he's up there and I'd call him and say, 'Well, I don't know what I should do about this.' And he's say, well he couldn't help me. So I don't know, sometimes he'd try to tell me and he'd say, 'Well try and handle it the best you can because I can't be there for you.' And, I'm thinking I'm calling you because I don't know what to do, you know. I had a lot of good friends at work truly, real good friends that helped me though a lot of stuff during that, you know. But that part was---I was pretty depressed.

…I think my husband's getting better now because he's kind of having to turn into a little bit of a care giver for his parents. And, I think he's getting a better understanding. A lot of times when I kind of say things, he wouldn't believe it. He'd think like: 'Oh well that's not true. They're just saying that.' Or that isn't true, that isn't really happening and now he's finding out. He's coming back and telling me the same thing about his parents and I say, 'Ah, huh. Yeah, ah, huh. You want me to turn around and say well your father is not telling the truth of his life. You're finding out now, aren't you?' At least I think he's getting a lot better on the deal now because now he's really figuring it out too. So, it's been good for him to be a care giver, you know. And he's learning how much it involves

Sometimes I might get a little tired and maybe a little frustrated and think well maybe I need to get away for a little bit you know, go out, and see too, I have a way to take it. I have the girls I work with; we go out to dinner which was a cut from the action and a break, you know. And working is an outlet and so I just I don't know, I don't really think about it.

1. I've become closer to my parents through caregiving (Learning more about the parent).

…now I think I've really become a lot closer with my Dad than I maybe might have been before and maybe not as close with my Mom because of her being there, you know.

…but we've become real close, really. Not that Mom and I---we're still you know, but Dad and I have become a lot closer.

4. I try to keep my Dad active mentally and physically (Supporting the independence of the parent).

I like to try to keep him as independent as he can be because the more he can think, the more he keeps his brain going.

If he sees things on television, then we talk about it and we discuss it and things like that just to keep him thinking and keep him as independent as he can be so he can be in his house, which he wants to do. He doesn't want to go to a nursing home, you know. So just to try to keep him as-- you know, current as he can.

…but just anything to keep him active and then he sweeps a little bit and different things like that, you know.

But anything that I can keep him moving, you know, and keep him thinking.

5. I help my parents with the things they can't do anymore (Helping the parent compensate).

And, she might say, 'Oh, I'm so hot.' When she means she's cold. See. So, and I'm really---even my Dad has a hard time understanding her. He'll always say to me, 'Can you understand what she wants?' And, Mom and I have always been not just mother and daughter but best friends, you know. And, that's, you know, I can understand what she wants. You know, and now I could help people, you know, understand what she's talking about.

She's eighty-nine and he's eighty-six and they were in their eighties when this all happened and he couldn't do it all. So, I mean I'd go up there and clean the house and do the yard work and different things like that. And, I could see him declining. You know, he couldn't do it anymore.

…I'm still up there just about the same---because Dad---I know he gets lonely and he loves to have somebody to talk to and he just, I got to keep in mind that he doesn't want to cook anything. So, I always make him some supper and I was making him supper then too but not as much. But, now I make him more supper. Because I don't trust him, I'm afraid he's not eating, you know. And I do his housework and I don't cut the grass but I do a lot of the trimming and yard work and everything like that for him.

Like I grew up---I'll do basics---the cleaning since he doesn't do bathrooms. So I do bathrooms. He doesn't do dusting, so I do dusting. He only sweeps, so I do a lot of the other stuff.

…going up cleaning their house or taking care of this or taking care of---you know, bathing them or something like that. Yeah, that's expected, you know I kind of figured that out.

6. Safety versus independence

I'm having trouble with him because he wants to shovel snow. I don't want him to shovel snow, you know, and stuff like that…

7. Caregiving means worrying about what's coming next in life (Issues of control versus the unknown).

But it did get stressful because of that fear that when that phone rang and they would say, 'Oh, it's Grandpa' or 'It's Dad', or something I could feel it going through my chest. Oh, my God, what's wrong now. What is it? What can I do and then when I'd get up there and it was an emergency and you had to make a decision what to do. Should I take him out? Should I do that? Because then my Dad had stroke, just a mini one. And, trying to get him to go to the hospital because he---my Dad's never been like that and he became combative. You know and it was like a total shock, because my Dad---what are you doing, you've never been--- was like this before, you know.

It's the mood swings and the difference like that. That's what I think is harder for me than just going up and knowing that I might have to clean the house today or do this or do that. It was the actual meeting with the different mood swing-- changes and hospital things all the time and trying to decide what she's got now on this or who's got what now or something like that---that kind of stuff was more than I guess I was thinking, the other stuff I figured normal, I got to do that here, you know. But, trying to understand where they're coming from and that kind of stuff I think and, you know, what's going on with them at that age and some of that was rough.

8. I learned how to take care of my parents through earlier life experiences (How I learned).

You know I was brought up with elderly. I was an only child. I had my great, great grandmother and grandfather alive while I was living. I had my grandfather. I had my great, great aunt. I was around elderly all the time. And, my mother had to take care of all that. So, I saw what she did and how she took care of things and she was real kind and understanding and everything like that of the older people. So I kind of developed a, you know, feeling of how you act and understand and, you know.

I think I've become more mild and mellowed and I think I maybe don't think as much about myself maybe as I used to. I'm more the last guy on the totem pole, which doesn't bother me. You know, probably something like that because like I said, I had a great teacher. You know, *and she was always like that and I just follow the way she is and I kind of don't like think about me or my needs and all this kind of stuff as much, you know, I'm more interested to see what they need and, you know, stuff like that.*

But now I watched my Mother and everything like that and I think that's what it was.

9. It's difficult to watch my parents change with age (Being sad about the decline of the parent).

…I've told my husband, I said that it really makes me feel bad and it happens to everybody is that they feel useless. You know, they're not needed. They're not---my Dad said to me, 'I don't know why I'm still living. I'm not worth anything. I'm not, you know, I should just go ahead and die.' You know and that really made me feel bad because and my Mom and two others in my family lost their independence. It's traumatic, you know, it's really traumatic, so…

So that was real upsetting to me too because I never saw my Dad act like that before and it was just really upset--- you--- and everything like that and just to see them go down like that was, when you knew how they were, you know, that really was---that was hard, that was hard.

Because Mom and I were so close and we used to talk about things all the time. Like everything like buddies and girlfriends and then I didn't have that any more…

Well, in a way you feel bad because that's the parent, you know and they always told you what to do. And, now it's turned around and it's like they're the child and I have to tell them what to do, you know.

That's hard, you know, that's kind of hard because like I said, they always told me what to do. I just feel bad you know telling them what to do. I feel like it's not my place, it's not my right, that I shouldn't---you know I shouldn't be doing that. But, you have to you know because the comprehension isn't as good as it was and different things and their judgment is not as good as it was and things like that. So I mean you have to do it but it really makes you feel kind of funny and strange cause you just—you really don't want to do that, you know.

…it's just kind of funny because one day you're the child and they're telling you things and they have all the knowledge of any kind of an answer like you might need. And, then the next day, it seems like they forgot all the answers, you know. And, then you have to tell them. And, I feel really bad.

…like I said, it's selfish---I just don't want nothin' to happen to them but yet I can see that they're just going down. I don't like that. I wish there was some way I could do something but there's nothing. You know, I realize that…

10. I have learned a lot about myself because of caregiving (Self-discovery).

I just think I've learned to be more considerate of others. I try to be more understanding of others and like I said put myself in somebody's place and try to understand where that person's coming from, you know, before I judge them. You know or anything like that, I just think it helps you being more around it and understand other people's needs and things like that, you know. I just---I really do.

You know, so I just really think that it's really helped me be a lot more understanding and considerate and trying to find out where the other person is coming from, you know. But with everybody, I mean not just with an older person. It's everybody, you know---your family, kids, people you work with—anything, you know.

I think I've become more mild and mellowed and I think I, you know, maybe don't think as much about myself maybe as I used to. I'm more the last guy on the totem pole, which doesn't bother me. You know, probably something like that because like I said, I had a great teacher. You know, and she was always like that and I just follow the way she is and I kind of don't like think about me or my needs and all this kind of stuff as much, you know, I'm more interested to see what they need and, you know, stuff like that. So, I don't know. Maybe that's it.

I thought that I've really learned a lot. Sometimes I think I can go to the nursing homes and do their jobs better than they could because you know, I just feel like I understand them. I just feel like I've learned a lot about the elderly.

11. It's easy for me to help my parents because they have always been so good to me (Reciprocity).

It really doesn't bother me, you know, doing for them because I just sit back and I had a wonderful childhood. And they were great to me and they were wonderful parents so, you know, if I can do back you know, it's fine with me. And, I enjoy talking to them. I always did.

Mom always was, you know, she always would teach me. We always would do things and everything was a learning experience, you know. We'd learned things and we'd learn how to do gardening and we'd do this and we did crafts and we did music and just everything. You know and she was always teaching me and now it's like I've got to turn around and teach her but it really---it's not bad, I try to think of all different little things. Like I used to do flash cards with her and help her with her words and do little books and I would have phrases that she could read like touch her hair and stuff like that just to help her comprehend.

Well, I don't know they've just always been very independent people. Dad's a good ol' boy, you know, he tries and tried and tried. He really, you know, he would not give up on trying. You had to tell him and Mom--- I don't know, they're just people that would always try and not give up so I knew that working with them wasn't going to be terribly bad. You know, they've just always been caring and understanding people.

I feel that I've got a chance to help them and give back to them all the stuff that they've even though a lot of times they don't want me to because they feel like they're putting me out. You know, but they're not and I just feel that now's my chance to give back to them all the things that they've done and everything for me, you know, all my life and everything like that. It means a chance to help them and see that, you know, their old ages is nice and not rough or hard or anything like that and that I can be there to make sure that that's the way it is, you know.

But, it's just I can give back to them and do for them everything they did for me and try to make their life happy and more comfortable and everything like that.

Why do I do it? I really don't know. I just, you know I just do it. It's not that I feel like I have to or I'm forced to do anything, although I know that they need me and they really need my help. Dad couldn't do it without me and, you know, and I know that but I enjoy my parents.

They're my Mom and Dad and I could not leave them and say, 'Well, here take care of yourself. I don't have time for you.' I just couldn't do that. Not with the childhood I had and growing up the way we all did and the closeness and everything like that. So, I said it makes me feel so good that I can help them. You know, anything I can do.

12. I still treat my parents with respect (How I treat them).

I always try to put myself in their spot, you know, I think that really helps me to put myself in their spot. You know, how are they feeling, you know, if I'm old and my joints are achin' and do I want to move or, you know, how bad does that hurt when I move because I could feel my poor Mom when I help her up, I heard all this cracking, you know. And, you know, my knees, you know. I know, I'm getting arthritis myself now so I can double that and I think that helps me a lot being around the elderly all the time. And, then I think I kind of put myself in their spot---to feel what they feel.

Like I said, I grew up with a bunch of elderly that maybe I didn't know things then because I was a child, you know. But now I watched my mother and everything like that and I think that's what it was. I mean one time she made a statement to me, because I knew she had all the elderly and she got really down and depressed and everything and it hurt her bad when she had to put her grandmother into a nursing home and everything like that and she told me, she said---and I just always thought about this and she said, 'You know, you try to do all this stuff but she says there'll come a day when you'll wish that they would pass on.' And, she always said that to me and so far that day hasn't come to me, you know.

But, she said that to me and I always thought about that and thought how could she think something like that but then I can see a lot of the stuff that you go through and a lot of stress and anxiety and frustration and everything like that and I could see maybe where she might think that thing being as she had so many but that day's never come for me, you know. And, I know that they're getting old and I may come to feel that. But, it hasn't come for me but it always made me think when she said that you know. How could you say that? I guess it's *just because, I said, 'Oh no, Mom. That will never happen.' And she says, 'You don't know.' She says, there'll come a day she says, you don't know how people change and they're not the same person, you know, and you just don't know--- they're not the same person. They're not the person you grew up with and everything like that. It's a different person that sometimes comes out there and then of course my mother has dementia. And, I said, 'Well, I don't think I'll do that.' I don't think--- well I haven't before. Like I said, I enjoy talking with them, you know. I really do.*

It's just---it really doesn't bother me, you know, I don't get stressed over it if they don't do every thing in a hurry, you know, all that kind of stuff. I mean because I'm enjoying the time with them.

Like I can't just go and say, 'Well Dad you've got to do this.' Or, 'Mom, you've got to do this. This is the way it is you do it.' It kind of helps you to get around but in a different way and in an easy way and make suggestions to them and, you know, things like that so that then they'll say, 'Oh, yeah, that's a good idea maybe I'll do it,' because if you come up to somebody and say, 'Do it,' then, there's going to be resistance or you know they might not want to do it. But if you can talk in a circle and talk about it and the pro's and con's and things like that, you get it across to them that way. Then I don't have as much trouble, you know.

That's hard, you know, that's kind of hard because like I said, they always told me what to do. I just feel bad, you know, telling them what to do. I feel like it's not my place, it's not my right, that I shouldn't---you know, I shouldn't be doing that. But, you have to, you know, because the comprehension isn't as good as it was and different things and their judgment is not as good as it was and things like that.

…it's just kind of funny because one day you're the child and they're telling you things and they have all the knowledge of any kind of an answer like you might need. And, then the next day, it seems like they forgot all the answers, you know. And, then you have to tell them. And, I feel really bad. I have to try to go around it someway, because I don't want to make them feel dumb or something like that, you know, so you've got to try to get around it a certain way and not make them feel, you know, like that.

13. My parents and I have always been close.

And, Mom and I have always been not just mother and daughter but best friends, you know.

You know it wasn't necessarily that I didn't like to do it because, you know, like I said, Mom and I and Dad have always been so close.

It really doesn't bother me, you know, doing for them because I just sit back and I had a wonderful childhood. And they were great to me and they were wonderful parents so, 'You know if I can do back you know, it's fine with me.' You know. And, I enjoy talking to them. I always did.

…I've just been with them so long since as a child I mean, you know, it just was like I said, it wasn't like parenting with parents involved, we were friends. You know and I've got to know them so well from all---from being so involved with their life all the time and everything, you know. But I mean I went on their anniversary dinners with them. We were just always really close, you know. So---

The kids were up there all the time and everything like that. And, I just really enjoy them, you know, I enjoy talking to them. My husband would say, 'Doesn't it drive you crazy going up there with your Dad everyday and everyday and or your Mom or something like that? Why do you do that?' Well he came from maybe---poor---I don't know, maybe it wasn't the same but I've always enjoyed going up there and having a good time and fun and everything. We talked about stuff, we did this, we did all kinds of stuff so it's, I just always enjoyed it and it's no different now. You know I like going up and talk to my Dad. I know I planted his Morning Glories and we discuss his Morning Glories all the time and how many blooms he's got, you know and things like that. I just always enjoyed it, you know. So, it's just like that, you know, we were just always just a close family.

14. Caregiving can be very difficult, but it has good parts too (Paradox).

In the beginning it was really rough and actually it was pretty rough up until Mom went into the nursing home which was only March. You know it wasn't necessarily that I didn't like to do it because you know like I said Mom and I and Dad have always been so close. So, I didn't mind doing it. It's just---it took a lot of time.

You know because then when that phone call came when Mom was still home, Dad would call me for everything.

So, he was calling me for everything. You know, it just---it really got nerve wracking and stressing plus at the same time, my husband got transferred to Michigan. He was in Michigan for seven years---right when this first happened in '93.

You know, I couldn't keep up with things and it was really getting hard, very stressful and everything and I had to go to the doctor and get some medication, you know and everything like that.

So, it was really ---that part was really hard you know when something happened to him and he had to---and I just busted and I said, 'This can't keep going on.' Because I knew they're going to keep getting problems and probably go into the hospital, you know.

Maybe I've become more---I don't know how to say it, scatter brained or something with so many jobs to do. You know, I just might not do something as well as I could because I'm hurrying to get this thing done and that thing done.

So, I just think that kind of stuff because elderly can be really, really difficult I think to work with and deal with and it can be real frustrating and real tiring and, you know, sometimes I think that's why people get irritated with them and don't want to try or something like that.

Because it can get rough. It can get real rough and hard, you know, dealing with them, you know 'cause you want to help them hurry up and do it a lot of times, you know, and things like that. So it can get really tough like that.

…like I said at that time I don't know if I was starting to go into menopause or if just all this at one time threw me into it but, you know, but I was going through that and I had all this other stuff going on and I thought, 'Hmm, man I'm just really totally depressed.' Like I told my husband, I said I will never go through a depression like that again, never not one thought. I refuse---I'll take any pill that they give me because I---that was horrible.

And, I had all those things and I just became very depressed and I would just cry all the time, you know. And, so that was really rough.
I was pretty depressed.

…because the elderly are also kind of impatient. They want their thing done right now. And, it's like you're trying to say, 'You know, let me go to work first. Then after I do that, I don't want to be putting you on the backburner but I've got these other things that I have to do.' And I think they kind of forget what it was like when they worked and they would come home and my Dad like he had to take care of my great Grandmother and when I left home, my Mom and him both and I try to say, 'Did you forget what that's like?'

…it's had its stressful times, but it's not really to me like I said--- maybe if I was a twenty-four hour care giver but I've always enjoyed going up there, you know. Like I said I'm a person that likes to try to work with people. So, I've been so close to my parents, so to me it's had highs and lows, has its stresses and it's worry but mostly it's been rewarding because, you know, you learn, you learn a lot, you know. I thought that I've really learned a lot.

Discussion:

After reading this interview several times, I found that fourteen themes were present. Many of these were similar to those of the first interview; however, several had new components to them. Several new themes were also identified.

The topic of supporting the autonomy of the other was significant in both interviews. Two sub-topics surfaced in this interview. These were issues of control versus the unknown in the caregiving role and in life in general, and helping the parent compensate. This idea of helping the parent compensate is what I think the original theme of "we take care of our own" is about.

Reciprocity was also a topic that was significant in both interviews. After this second interview, however, a few sub-sets emerged that, again, I wanted to keep my eye on. These were that the daughter and the parents had always been close, and ideas about how the daughter treats her parents.

The topic of “siblings” now seemed to be part of a larger topic that had to do with “support”. Husbands, children, and friends were discussed in this interview along with siblings as a source of support or a lack thereof. The original theme of “taking care of our own” was now seen as a new subset of supporting the parents’ independence. Specifically, it was identified as “helping the parent compensate.” A new topic was present, that is, how the daughter learned to be a caregiver.

The following is a track of the themes from both interviews with the new ones bolded. Evidence from the first interview to support the new themes is included after the list of themes.

1. Caregiving doesn’t make me a good person. (Caregiving is a normal experience)
    a. (not present in this interview)
2. Caregiving means having conflicting responsibilities.
3. Caregiving is supporting the independence of the parent (similar, but some new sub-sets emerged)
    a. Issues of safety v. independence
    b. Easier if I had more control
    c. Issues of control versus the unknown
    d. Helping the parent compensate
4. Caregiving is being sad about the decline of the parent.
5. Caregiving is learning more about the parent.
6. Reciprocity (similar, but some new sub-sets emerged)
    a. Evidence of love
    b. We’ve always been close
    c. How I treat them
7. I’ve grown to now myself better through this experience. (Self-discovery)
    a. I don’t want to bek like them
    b. Caregiving gives me a purpose in life
8. Siblings/**Support**
9. Caregiving involves contradictory feelings (Paradox)

a. My parents need/want so much attention

10. How I learned

Theme: Issues of control versus the unknown.

This theme was not present in the first interview.

Theme: Helping the parent compensate:

I just, I want people to know that, I guess even though my Dad is so sure he wants to live in the house...that's OK if he wants to and I'll help them if that's what they want to do. Even though I don't agree with it, I'll help them…(Interview 1, Jackie)

You know, Mom says, what about Meals on Wheels? Well, that's a good program but it's like Mom, we can really do it, you don't need Meals on Wheels. We can get enough stuff in here so you don't have to depend on Meals on Wheels. (Interview1, Jackie)

Every doctor bill that comes in, my father can't pay them without me totally reviewing the whole thing. (Interview 1, Jackie)

If I cook sometimes I cook on Sunday for three meals. You know and it's like I'm cooking anyway, so I'll just cook extra. (Interview 1, Jackie)

I feel like I could be at her side now. (Interview 1, Jackie)

…but I would do anything for them. (Interview 1, Jackie)

Theme: We've always been close.

I mean we always were kind of close. (Interview 1, Jackie)

Theme: How I treat them.

I don't like to make their decisions. And, I might encourage them to say well, what do you really think? (Interview 1, Jackie)

…my heart goes out to her (Interview 1, Jackie)

…like I get upset with Mom when she goes down the basement steps without anybody around. That's like---you've already been at the bottom of the steps twice now---she has fallen. If she breaks something, she won't have a choice. She won't be able to stay in the house. I mean she's already crippled up with her Parkinson's and that. And that, really, really upsets me, you know you hate to yell at your parents but you're really trying to be stern and point out all of the negative things that you know. 'You can go down the steps, but once you fall, then what's going to happen?' She goes, 'I know, I know.' But, she'll do it anyway. It's like,

what are you going to do---I guess if I live to be eighty-six, I'll have such a mind of my own too, I'll do exactly what they're doing. (Interview 1, Jackie)

I mean I just really appreciate that my parents took care of me and raised me and if I can just give them back a little bit. I'll do it. (Interview 1, Jackie)

I want to help them. I want to do whatever I can for them…(Interview 1, Jackie)

We let them---we let them do what they want to do and we're not enablers but we help them because that's---they really are mentally alert. I mean---and they---and we can't argue with them about it because we just, maybe it's because they're our parents and we can't ---I don't know. But, we let them do what they want to do and we help them do it. (Interview 1, Jackie)

I guess it's because---we do it because they're our--- even though they didn't let us do everything when we were growing up, it's like we feel like we have to let them do it. It's like maybe it's their last hoorah. And it's like we don't want them to be unhappy and I guess that's why we do it. Otherwise---I can't explain it otherwise. (Interview , Jackie)

Theme: Support

I have a very supportive husband. He is wonderful and you go and do what you have to do. And so, of that I'm also fortunate and my two children are wonderful. Sometimes if I'm at work and just can't get away or if my car's not there…if they're not working, they'll go for me. So, I have to say my family's learned it well enough to support my other obligations.

I mean she (my daughter) helps me when she can. I mean she offers, which is good. I don't have to ask her. That's a big help.

Theme: How I learned.

…our parents set the groundwork, I mean if it wasn't for them, where would our values---where would really, you know, our character and everything.

Participant 3: Linda:

"Things will work out"

Linda's father is deceased and her frail, elderly mother lives in an apartment on the grounds of a care center. Her mother is not in assisted living however, and Linda is her sole means of support. Linda has been caring for her mother in some way for approximately twenty years; however the caregiving role has increased during the past three years when her mother began to experience memory loss.

The interview with Linda revealed eighteen themes.

1. I can't do everything for everybody (Conflicting responsibilities).

And, that's you know what I've committed to do to the point that I'm thinking about cutting back my work hours this coming year because I really need to be there three times a week.

I've always been a person who tried to do everything. And, I've always had really responsible jobs and I've always been in charge of a lot of people and a lot of money and, you know whatever, and I've always felt like I need to be the person who could take care of everything and do everything. I can't and I've learned I can't and I've learned to make the choice now that I can't do all this and also take care of my Mom and also be (my husband's) wife and also be (my daughter's) Mom and you know there's a limit to what you can do.

Because I can't work everyday and go out there in the evenings and I tried that and I can't do it, so---it's hard to do these things. I learned that I can't do everything.

2. I wish I had more support in caring for Mom (Support).

…well there's certainly days I feel somewhat put upon because I'm the eldest of four children and none of the other children live here. I'm the only sibling here. And while my two brothers and my sister are concerned and when they're here they're wonderful and are attentive to Mom and stay with her while they're here when they do come to town. For the most part, they don't deal with any of the day-to-day issues related to taking care of Mom. My sister is very attentive. She talks to my mother every weekend and I talk to my sister every weekend, which may not be about Mom, but always there's something about Mom that we discuss. My brothers, on the other hand, are attentive but they're not as---you know, they don't talk to her every week like my sister does. So, there are times I feel put upon when I wish they were here or they could help share a little bit with her care.

I feel alone sometimes in that regard. My husband is very good at doing anything to help care for Mom. He'll take her to the grocery. He'll go pick her up. Like recently, I was sick; I had a bronchitis and I never want to be around her when I'm ill because I'm afraid I'll give it to her and she is frail. I mean she's very active but health wise she has some concerns with heart disease and she gets colds and things very easily. So, he'll just, you know, go take her to the store and go see her or do whatever. Ah, but still I usually have to ask that that be done and it would be nice not to have to ask---to just have someone.

…there are times I worry. Realizing that worrying is a stupid thing to do because it doesn't get you anywhere but sometimes I feel anxious and worried about her. And, that's certainly part of care giving. But, that's not overwhelming. Usually I can deal with it. I talk with either (my husband) or whatever, you know, it works out OK.

Very often if I need support I just have to make a doctor's appointment. Because my Mother grew up in a time when doctors were God and whatever the doctor says, that's what you do.

And so, if Dr. (___) says to her, 'Now listen Mrs. (___), you have to eat dinner every night.' Then she will do that---as best she can remember.

3. I've learned more about my Mom through caregiving (Learning more about the parent).

I think one of the things I gained was a real appreciation for the total life of who someone is.

I would have to say my care giving has made my Mom and I closer. I mean I think we're closer than we've ever been before. I think Mom knows she can tell me whatever she needs to tell and it's going to be OK.

...it's interesting, to me at leas,t my own experience has been when I was growing up my Mom was not a person I would tell my deepest most intimate thoughts to and I don't really remember my Mom ever giving me like any incredible advise that was just the perfect thing at the time.

And then as I have gotten older, I've become way more appreciative of who my Mom is and how who she is---is connected to who I am.

I've had the opportunity and the advantage over my brothers and sisters that Mom and I are closely connected. Because I'm the first born in the family and because I'm the one's who's here and the one who has the wonderful opportunity to see her and be with her all the time and they don't have that.

And, it's made me a better person. A less selfish person, a more caring person, more insightful, more kind of real about who my Mom is and who I am and what things are important. And um, really given me the opportunity to think about her and who she is and how that helps me to understand who I am.

I would like people to know that caring for somebody you love or caring for anybody could be a joyful thing. That there's great opportunity for enrichment and opportunity to know someone in ways you've never known the person before. And that it can be a wonderful thing to do and it isn't related to or dependent on the physical aspects of it. You know, there's really a soulful part of it, there's really a spiritual part of it. And, that we need to spend more time respecting the wiseness of elderly people--- of learning about their lives and why they did what they do and how they did those things and how they----

But, there's this whole piece of it that people are ignoring that's related to the view of the relationship you develop when you're really supporting someone for whatever reason, for illness or being old or whatever it is.

4. I'm going to help my Mom stay independent for as long as she can be (Supporting the independence of the parent).

I'm going to do whatever I can do to support her living independently because that's what's really important to her. As independently as she can.

…so we just problem solve the best we can so she can continue to be as independent as she can be.

Having been really involved in the care for my---an aunt of mine who was my father's sister who died about, oh gee, I think she died maybe ten years ago, um and having kind of seen what happened when they were made to move out of their house because neither one of them could manage it anymore and then how fast the decline was.

She tells me all the time how much she loves living where she lives. And, she does that in part because she is afraid when these memory things happen--- which she's well aware they happen--- that I'm going to insist she do something else, you know. And, I know that and she knows that. But, it's just this kind of a game we play where she tells me how much she likes to live there and I reaffirm that I'm going to help her live there, you know. And, she just needs to know that I'm going to do that.

I also asked him two times ago when we were at the doctor I was worried because she was losing weight. And even though she denied it, I could see it. And, he affirmed that she was losing weight and gave her a little speech about eating. And, that helps a lot.

5. I do things now to help my Mom get by (Helping the parent compensate).

I need to be there like every other day just to check on her and be sure she's eating well. Well, you know, I do that by taking her grocery shopping and then checking her freezer and seeing what she's doing. She doesn't really cook all that much anymore. We buy Healthy Start meals and things she can fix easily in the microwave. And, again I don't worry so much about the stove. And, sometimes I fix things--- she's here usually once a week to eat and then she takes things home with her.

And then the other challenges of taking care of Mom and other things that I've been concerned about---she takes a fair amount of medicine. She takes about five different things everyday---actually six with the vitamin pill she takes. And she was messing up her medication, which really concerned me and so we go to a pharmacy where there's an automatic refill and they call her and let her know when the prescriptions are ready. And then, she calls me and I take her. But, usually what happens is one of her friends takes her and she picks up her prescriptions. And, we use a pillbox and she puts her pills in everyday. And, I check on her pills all the time to make sure that she's taking them right.

…we moved Mom in March to a one bedroom apartment from the two bedroom apartment where she and (my father-in-law) had lived, in part because the rent kept raising and this would help her save a little money and in part because it's a smaller and more compact apartment. Everything is new there. She has her own laundry. She doesn't have to go down the way to do her laundry. She has a dishwasher. This goes along with it, you just keep problem solving. I don't try to get concerned about the fact that every time I was there I'd

get dishes out of the cabinet to use and they'd be far from clean. Even though she had 'cleaned them' quote, unquote. So, when this became available, we looked at it and she liked it and we made our joint decision it would be a better thing to do.

6. Mom's safety is important to me, but so is her quality of life.

But I know there are some people who would say that she is at the point now where you should put her in some more assisted care than she is in. But, having seen what happened to my aunt and uncle and how horrible it was when they were forced to do something that they didn't want to do, um I'm not going to do that. I'm ready to live with the guilt of helping my Mom being as independent as possible if something would happen to her. Because to me, it's the better choice and to my Mom it's the better choice.

She also has a high cholesterol. And, she promises me she eats regular. Of course, she doesn't. She loves sweet things and she and her friends have cokes and crackers and stuff every night when they play cards. And, I just said, OK, the hell with it. You know, I don't care. I mean she takes a cholesterol medication and she does the best she can do and at eighty years old, I'm certainly not going to be on this woman. I was initially---I tried to get her on skimmed milk and all this stuff and she just won't do it. And, I'm not going to be the police, you know.

7. I fear what I can't control (Issues of control v. the unknown).

I was just angry that, you know, she was losing her---and I think I was angry because I was scared.

But, I think the reason I was so angry is because I was so fearful. I have a really hard time imagining my mother not being here and so it makes me angry when I realize that's going to happen and I want that to happen in a really dignified way. I mean, everybody wants this.

And I said---I was able to say, and that was the first time I ever admitted it, 'I'm angry 'cause I don't want this to happen.' You know, that's what I'm really angry about. I'm not really angry at Mother, I'm just angry that this is happening and I don't want it to happen and I can't stop it.

I am afraid of what's coming next but to just know that it's going to be OK. I mean it will work out and just to stay the course, you know.

But to me the worst fear is that three o'clock in the morning fear when you worry about and you're just terrified because everything is happening that you can't control and can't do anything about. And, I've really learned to deal with that and I've really learned that I'm prone to three o'clock in the morning fear and I can manage it or it will overtake me.

You just don't like---I don't like what I can't control. Of course, we're never really in control of anything but we pretend we are and this is something which you just see changing all the time, you know. Like what Mom could do last year, she can't do this year. And what *she can do today, you know, could change tomorrow. And, so it kind of gives you that sense that things are moving on and things changing and you have to accept that that's OK, it's going to be that way…*

That really strikes home now that I find myself in a health condition of my own, you know, it's just more that same kind of thing that you can't control it but you just have to learn to deal with it and stay positive and keep going or you're going to end up in a place you don't want to be.

8. I'm learning how to face life better (Self-discovery).

…one of my significant strengths is bravery. And, that's from my Mom. I mean my mother is a brave person. She, when my father lost his business and could never recover from it due to his disability---Mother just went to work. She went to school. She learned to type, she learned to drive and she just went to work and supported the family. Now, that's the kind of person she is and she does that---I honestly can say I've never heard my mother complain about anything other than the weather.

And, so I've learned that from her, that this sense of what you do in life is you preserver. And you put one foot in front of the other and things will work out. You know, you just keep moving forward and things will work out. Even when you don't think they will, they will. That's from my mother and that's a great part in my adult life since I can provide and care for my Mom and before that care for my aunt. So, I think I've learned those things from her and from this experience of being a caregiver.

And, I've learned that from my Mom too. I mean if it wasn't for her ability to deal with this the best she can, I wouldn't be willing to do this.

She's taught me patience, she's taught me, you know, my sense of humor comes from my Mom and my Dad but more recently from my Mom. Because we can laugh about these things you know, they're not funny things. I mean it isn't funny when you don't know what's going on. But we've made it OK to laugh about that. So, she's taught me that at my age I wouldn't know that if it wasn't for my Mom. I wouldn't be able to do that with anybody else.

…and also I guess not take it too seriously, I mean we're not the only people who have ever dealt with this. Many, many people have way more serious things to deal with than we do. You know, I really do think people take life too seriously. They do all the time, you know. They get so bogged down like we're the only people in the world that ever had to deal with whatever it is. But if you just let it overtake us and consume us and um, we try not to do that. So, if I'm sick like I was a few weeks ago, I really can't be with my Mom. I do the best I can to make sure that (my husband) or somebody else is checking in with her. But, I don't sit around and worry about it and be guilty about it. Cause, you know, that's just life. That's the way it is and I learned that from my Mom, too.

And as I have gotten older, I've become way more appreciative of who my Mom is and how who she is---is connected to who I am. So, it's become really important to me to know her as *well as I can know her before she dies. And part of that's selfish. Part of that is because I know that in knowing her, I'm going to know me better.*

But, um, it's changed over time, I mean it's---my Mother doesn't irritate me any more. She used to when I was a younger person. You know, you kind of want your parents to be the way you think your parents should be rather than who they are. And, I mean never seriously, I mean Mother never---I mean I never would seriously ever go defy her. But there would be times when I would go, 'Oh my gosh, why can't Mom do this, that or the other thing? Why doesn't she take responsibility for this or whatever it was?' And, I don't ever feel like that anymore. It just not there anymore. So, it has changed things.

I've learned what I mentioned earlier is, I really needed to deal with the anger piece, and figure out why I was angry about something that was nobody's fault. You know, that you can't do anything about. And, so I guess you could say I learned anger management in some ways. This was not something to be angry with my Mother about. And, um, I guess I also learned to deal with fear in some ways and to me the most serious fear is not that kind of fear, which I have experienced too, where you're in some horrible situation and something is going to happen if you don't get out of it. But to me the worst fear is that three o'clock in the morning fear when you worry about and you're just terrified because everything is happening that you can't control and can't do anything about. And, I've really learned to deal with that and I've really learned that I'm prone to three o'clock in the morning fear and I can manage it or it will overtake me. And I think part of what I had to do with my Mom has taught me that.

Well, it (the caregiving experience) means that I myself am maturing and getting older and have to face a lot of realities based on that. And, I think in one way that's really helpful. I think it means this closer relationship that I've talked about which is really important. It means it reshapes in a lot of ways how I would try to set my life as I get older, so that, because we have an only child, neither of us want her to be in the position that she has take care of us, even though she will, we're not worried that she's going to walk away from us. But, I want to do exactly what my Mom did, which was divest of stuff before the end of her life. Live in a place where I don't worry about her all the time. I mean, those are some of the ways that it's really impacted me is to think about these things related to my own life. And, it's made me a better person. A less selfish person, a more caring person, more insightful, more kind of real about who my Mom is and who I am and what things are important. And really given me the opportunity to think about her life and who she is and how that helps me to understand who I am.

And, so our daughter became really interested in who Mother was and said, 'I want to go see where Grandma grew up.' Which she has never been interested in doing and I offered many times. Why didn't she go---so, I see this really wonderful opportunity to impart this kind of family history and this thread of who we are and I think that's really important for people to understand who they are.

There are stresses. But all things considered, I can honestly say I'm glad for this opportunity and I'm the one who is with my Mom and that I'm here---that she's where she is---and that I have this opportunity to be with her so much and help with her care.

And, thinking about the fact that if my Dad, you know, that my Dad is looking down saying that he's glad that I'm able to do this in a different way than my Mom was (for him).

9. I was angry, but now I'm just sad that my mother is declining (Being sad about the decline of the parent).

More than anything else--- because my kind of overwhelming emotion about it all is I don't want---since she is dealing with a short-term memory problem I don't want it to be happening. I don't want---I don't like seeing my mother become frail and older. I don't like the fact that she can't remember things. I don't like the fact that she has osteoporosis and I worry about her falling.

I have a really hard time imagining my mother not being here. And, it so it makes me angry when I realize that's going to happen and I want that to happen in a really dignified way.

And I said---I was able to say, and that was the first time I ever admitted it, 'I'm angry 'cause I don't want this to happen.' You know, that's what I'm really angry about. I'm not really angry at Mother, I'm just angry that this is happening and I don't want it to happen and I can't stop it.

So, I'm not---I don't really feel that angry about it anymore, I just feel sad about it.

So, we just laugh and go on with it. But, it probably makes me sad. I'd rather it wasn't that way, you know.

10. Caregiving has helped me recognize my priorities.

I've also learned how to use my time better and what's really important. I mean I'm fortunate that I'm in a position that I can cut back on work and I don't need to worry about that financially.

---it has also taught me that I can't do everything. I've always been a person who tried to do everything. And, I've always had really responsible jobs and I've always been in charge of a lot of people and a lot of money and um, you know whatever and I've always felt like I need to be the person who could take care of everything and do everything. I can't and I've learned I can't and I've learned to make the choice now that I can't do all this and also take care of my Mom and also be(my husband's) wife and also be(my daughter's) Mom and you know there's a limit to what you can do. And, in large part that's been aging on my part, I mean dealing with my own issues but it's been the realization that my time with my Mom is limited and that's really the important thing. And, so I've learned you can't do everything. I just have to deal with that as best I can. So, to me, I'm a better person for that because my identity is no longer connected to I have to do everything. It's connected to I'm going to do

these things and this is a big part of what I'm going to do this care giving thing with my Mom and whatever that brings that's what I'm going to do and that's going to be way up there on the list. That's probably the biggest change this has personally made to me.

But, (my husband) and I have probably been talking for the last year about me not working as much and having more time to be with my Mom. Because I can't work everyday and go out there in the evenings and I tried that and I can't do it…so---it's hard to do these things. I learned that I can't do everything.

And, it's made me a better person. A less selfish person, a more caring person, more insightful, more kind of real about who my Mom is and who I am and what things are important.

> 11. I take care of my mother because I love her; I've never considered not doing it (Reciprocity).

And, if she doesn't remember everything and is somewhat doughty and whatever…so what, I mean it doesn't really change who she is. It's just---it's just the way it is now. But, it doesn't really change the soul of who this person is and she's been, you know she's a great Mom. And, if I were in a similar situation, she'd be standing by me, you know.

My mother is still my mother and she still has things to teach me and I still have things to learn from her. What I'm doing in my mind, is just I'm being a good daughter. I'm doing what I should do for my Mom because I love my Mom. And because she is deserving of someone taking care of her.

I mean if it wasn't for her ability to deal with this the best she can, I wouldn't be willing to do this. Now if she changes and becomes a mean, angry person you know because of her physical condition, I don't really think that's going to change how I approach this because she is still the soul she's always been. I mean, it doesn't really matter how she appears on the outside or what happens to her, she is still this brave, strong person who's my Mom, you know.

…well because she's my Mom. You know, because I love her and also because I'm the one who's here. I mean, I'm the person who is here. If I was not here, if it was my sister who was here, I would hope my sister would be taking care of my Mom. I just, I never thought about not taking care of my Mom. It's just what I do. Before I took care of my Mom, my mother-in-law lived with us seventeen years.

It just never occurred to me not to, you know. I want to, I love her, she's a great Mom. Now if she was a terrible Mom would I? Probably---because it's just what I do. You know, I take care of my sister, I take care of my brothers, you know, it's just what I do. I don't know if she was a terrible Mom would I take care of her, I don't know. I probably would. But, I just never thought of doing anything else.

I think a testimony to her strength and probably also to the way I view caring for her or helping with her care is when the family doctor told her, you know, this is full out---told us---this is dementia and your short term memory is effected and there's probably not a whole lot we can do about it and it's probably going to get worse over time. Mother said, 'Well, when you get older you just have to expect these things and learn to live with it.' And, that's pretty much her attitude about everything. You know, whatever happens she'll just deal with it and learn to live with it.

Well the truth of the matter is you learn way more and you become a much enriched person through the work than anything you could ever give back.

She's very appreciative and nice to me, you know and really does appreciate what I do and that all helps.

12. I love and respect my Mother even though she is changing (How I treat them).

I have a really hard time imagining my mother not being here. And, it so it makes me angry when I realize that's going to happen and I want that to happen in a really dignified way. I mean, everybody wants this. This isn't anything different than anybody else wants. And so, I'm going to do whatever I can do to support her living independently because that's what's really importantly to her.

I've really been able for the most part to take this really, um kind of attitude that I'm fortunate to still have my Mom here but I want to spend the time with her I can. And, if she doesn't remember everything and is somewhat doughty, whatever…so what, I mean it doesn't really change who she is. It's just---it's just the way it is now. But, it doesn't really change the soul of who this person is and she's been, you know she's a great Mom.

But, we have a lot of fun together. We really enjoy being together and we laugh a lot and we you know just have a good time.

You know that I don't find that I have that feeling that I hear some people talk about when their parents are older, which is, "I'm the parent now. And they're the child." I don't feel that way. My mother is still my mother and she still has things to teach me and I still have things to learn from her. What I'm doing in my mind, is just I'm being a good daughter. I'm doing what I should do for my Mom because I love my Mom. And because she is deserving of someone taking care of her.

And then as I have gotten older, I've become way more appreciative of who my Mom is and how who she is---is connected to who I am. So, it's become really important to me to know her as well as I can know her before she dies.

(I care for my Mom) because she's my Mom. You know, because I love her and also because I'm the one who's here.

It just never occurred to me not to, you know. I want to, I love her, she's a great Mom.

You know, there's really a soulful part of it, there's really a spiritual part of it. And, that we need to spend more time respecting the wiseness of elderly people--- of learning about their lives and why they did what they do and how they did those things and how they----
One of the most fun people to be with right now, I always enjoy being with my Mom. Well, not always sometimes you know, we aggravate each other but usually we really love being together. And, it's more fun now than it ever has been because Mom can't exactly remember what's wrong with me from time to time. So, she doesn't want to discuss it like everybody else does, you know. So, we can just be together, have a good time and I don't have to go through all this stuff that's going on with me and it's just fun, you know.

13. I have always had a good relationship with my mother.

…my Mom and I have always a good relationship and we really like each other, which helps a whole lot. And, she's been very open in letting me be part of her healthcare.

14. Caregiving is full of contradictions (Paradox).

I guess the overwhelming emotion to me is one of sadness more than anything else.

I was kind of complaining to her (my sister) about, you know, like the thing that happened today where we go to an appointment it isn't there and I had taken off work this one day and was really inconvenienced and I had taken Mother to an appointment that didn't exist. And, I was really angry about it. Not at Mother, I dealt with that with Mom like, 'Oh, it's OK Mom.' But it was one of those things where you're kind of biting your tongue and you're really irritated, you know.

…well, there are times I'd rather do something other than go see my Mom and take her where she needs to go. Sometimes it's not convenient. But, for the most part, that's not an issue. Um, there are times I worry. Realizing that worrying is a stupid thing to do because it doesn't get you anywhere but sometimes I feel anxious and worried about her. And, that's certainly part of care giving.

So---you know, in most ways, it's really enriched my life and made my life better even though it's sad in some ways.

There are stresses. But all things considered, I can honestly say I'm glad for this opportunity and I'm the one who is with my Mom and that I'm here, that she's where she is, and that I have this opportunity to be with her so much and help with her care.

I would like people to know that caring for somebody you love or caring for anybody could be a joyful thing. That there's great opportunity for enrichment and opportunity to know someone in ways you've never known the person before. And that it can be a wonderful thing to do and it isn't related to or dependent on the physical aspects of it. You know, there's really a soulful part of it, there's really a spiritual part of it.

…I would just like people to consider there is this whole---there is this strain of it, you know, all the things people talk about caregivers needing support and all that. That's all true. But, there's this whole piece of it that people are ignoring that's related to the view of the relationship you develop when you're really supporting someone for whatever reason, for illness or being old or whatever it is. Um and I guess that's why I would like people to spend more time trying to learn or figure out or look for and not just look at it as a burden or um, 'Oh, my God, I have to do this,' or however people see it in a negative sense. Because I do think there's this whole positive side.

Well the truth of the matter is you learn way more and you become a much enriched person through the work than anything you could ever give back.

15. Caregiving is a normal human behavior.

And also I guess not take it too seriously, I mean we're not the only people who have ever dealt with this. Many, many people have way more serious things to deal with than we do. You know, I really do think people take life too seriously. They do all the time, you know. They get so bogged down like we're the only people in the world that ever had to deal with whatever it is.

I just, I never thought about not taking care of my Mom. It's just what I do.

It just never occurred to me not to, you know.

You know, I take care of my sister, I take care of my brothers, you know, it's just what I do.

…I just never thought of doing anything else.

You know, it was just without second thought that (my husband) said, 'Can Mom come live with us?' And we just do that. And I said, 'Yes.' And, we did that for seventeen years. And, so it's just what you do, I mean I just think it's what you do.

And the other thing I guess I would like people to know is that it would be wonderful if sometime when people learn that I take of my Mom and what we do and how that all works out, sometimes I hear people say, 'Oh, my God, you're so wonderful for doing for that.' I would like somebody to say, 'Well, what's it like to do that?' or 'Do you like doing that?' or you know anything other than this, 'Oh, my God, you're so wonderful for doing that.' It's the same kind of response I've gotten all the years of my life working with people with disabilities. 'Oh, my God, you're such an angel for doing that.' Well the truth of the matter is you learn way more and you become a much enriched person through the work than anything you could ever give back.

I mean, it's really true and that comment that people make puts you in a condescending type of place you don't want to be. It's just you can't---nobody can respond to 'Oh, my God, you're such a great person.' You know, nobody can respond to that in any real way. So, I like people not to do that. I like people to just get real about it. I think that would be very *healthy for everybody. Instead of admiring you because you are doing something that everybody can do and most people do do and just deal with it as a real life experience, you know. I think that would be nice and it would be very humanizing for all of us if people could deal with it in that kind of way.*

16. My caregiving role evolved gradually.

The real care giving for my Mom probably started when my Dad died and that's when my daughter was three years old. And, that was the first time my Mom really needed me to help her. And, I went and stayed with her the day my Dad died. Stayed over night and then helped clean up the house. Helped sell the house. Helped do all those things. And, that was really the first time that I felt like a caregiver for my Mom because she really depended on me heavily through those years.

It wasn't a role that just started three years ago. That's when what I call care giving really started in that there's been a more significant amount of my time and my energy and my thoughts and all that's gone into it. The things I did before that were much more just in the stride, what needed to be done and what Mom needed me to do. But, it did evolve. I mean, I don't think it is possible I wouldn't feel the way I do if it hadn't been for some of those earlier experiences with Mom. You know, that we sort of got though a lot of these things together, like cleaning out all Dad's clothes and all that stuff. And, really sharing all that, you know, being closely connected through all that.

17. Caregiving is evidence of love.

(I care for my Mom) because she's my Mom. You know, because I love her and also because I'm the one who's here.

It just never occurred to me not to, you know. I want to, I love her, she's a great Mom.

18. Caregiving gives continuity to the life of our family.

And, it's made me a better person. A less selfish person, a more caring person, more insightful, more kind of real about who my Mom is and who I am and what things are important. And um, really given me the opportunity to think about her and who she is and how that helps me to understand who I am.

And as I have gotten older, I've become way more appreciative of who my Mom is and how who she is---is connected to who I am. So, it's become really important to me to know her as well as I can know her before she dies. And part of that's selfish. Part of that is because I know that in knowing her, I'm going to know me better.

…and really given me the opportunity to think about her life and who she is and how that helps me to understand who I am. And a really wonderful thing happened recently in that we have this family history on my Mom's side of the family which was a collection of family letters and poems and remembrances that people in the family have written. It is primarily all

written by my grandfather who was a newspaperman, who was kind of a renaissance man. He did a little bit of everything and he lived in a small town and was very well regarded in that town, the town that Mom grew up in. And my youngest---Mother's youngest brother, my uncle, he's not that many years old than I am, he collected all this some years ago. He got all the letters from all the family and put them together in a book that he gave all his brothers and sisters these books.

And, so our daughter became really interested in who Mother was and said, 'I want to go see where Grandma grew up.' Which she has never been interested in doing and I offered many times. Why didn't she go…so, I see this really wonderful opportunity to impart this kind of family history and this thread of who we are and I think that's really important for people to understand who they are.

My mother is still my mother and she still has things to teach me and I still have things to learn from her. What I'm doing in my mind, is just I'm being a good daughter.

Discussion:

Caregiving as evidence of love was back in this interview. While I thought this may be a component of reciprocity, it may not have been. I kept it separate but put it under reciprocity until I saw how it evolved.

A new idea came up in this interview, that is, that caregiving has helped Linda identify her priorities in life. At this point I put this as an elaboration or variation of the theme of self-discovery.

A new theme emerged in this interview. Linda had much to say about the fact that caregiving gives a sense of continuity her family. She learns more about herself by caring for her mother, and her daughter has also become more interested in the family. At this point I added this theme and called it "Caregiving gives continuity to the life of our family." A review of the first two interviews gave evidence that this theme was there also. This evidence is cited at the end of the following list of themes.

Another new theme was that for Linda, the caregiving role evolved gradually. Although this theme was not present in the first two interviews, I decided to watch for its presence in future interviews.

The following is a complete summary of the themes as they had emerged thus far. New themes are bolded. Data from the first two interviews lending support for the inclusion of the new themes follow the summary.

1. Caregiving is a normal experience.
2. Caregiving means having conflicting responsibilities.
3. Supporting the autonomy of the parent (theme revised from supporting independence)
    a. Issues of safety versus independence
    b. Easier if I had more control
    c. Issues of control versus the unknown
    d. Helping the parent compensate
    e. Her safety is important, but so is her quality of life.
4. Caregiving is being sad about the parent's decline
5. Caregiving is learning more about the parent.
6. Reciprocity
    a. We've always had a good relationship.
    b. How I treat them
    c. Caregiving is evidence of love
7. Self-discovery/actualization
    a. I don't want to be like they are.
    b. Caregiving has given me a purpose in life.
    c. Caregiving helped me recognize my priorities
8. Support
9. Caregiving is embracing the wholeness of love (theme revised from paradox)
10. **The caregiving role happened gradually**
11. How I learned
12. Cargiving gives continuity to the life of our family.

Theme: Her safety is important, but so is her quality of life.

…just like Dad knows he's not supposed to be out shoveling snow and raking leaves but he does it anyway. He has a terrible heart. But it's like 'Well alls we can do is tell you.' I'll call Mom the day that I think I know where he is, out there in the yard but Mom just will say 'I can't do anything with him. I don't know how you're going to do anything with him.' So, you know, we just let him go but he's totally---he's ---it's so frustrating. I would feel horrible if he was out there raking leaves and died. But my mom said, 'Well it's something that he really wants to do. And, if he dies doing it, that's his choice, he enjoys doing that.' (Interview 1, Jackie)

But, then we sit down and my sister and I talk about it and say that, 'Well, if he goes out there and he thinks he has to sweep the sidewalk off when it snows and he has a heart attack. It was his decision not ours.' (Interview 1, Jackie)

Theme: Caregiving has helped me recognize my priorities.

…but I feel like God put me here for some reason and maybe this is what I'm supposed to be doing here on earth. (Interview 1, Jackie)

Theme: The caregiving role happened gradually.

This theme was not present in the first two interviews.

Theme: Caregiving gives continuity to the life of our family.

…we've definitely become closer and probably Mom has shared more with me about her past life, you know, eighty-five years in the last two years than I ever--- we never sat down and had a big conversation. Everybody I guess was so busy. And, in fact that's kind of neat. And, I loved to hear my Dad talk about his war stories. And, he never really talked about it at all---the war. And, just lately he's started to talk and open up and even my kids find it fascinating. (Interview 1, Jackie)

It's kind of neat. It's like sometimes they tell you the same three times and you never heard that your whole life till the last---it's like maybe they want to tell us everything too before they go and they're making up for lost time. (Interview 1, Jackie)

…I think everybody, the family has been closer. Just like my daughter, she really likes to hear her grandpa talk and it's good for the whole family probably. But we had a closer relationship with him giving him care. I guess that's maybe that's how they help us out. You know, what I'm saying…(Interview 1, Mary)

…maybe it wasn't the same but I've always enjoyed going up there and having a good time and fun and everything. We talked about stuff, we did this, we did all kinds of stuff so it's, I just always enjoyed it and it's no different now (Interview2, Mary)

Participant 4: Sally

"This is going to go until it goes"

Sally cares for her mother who has Alzheimer's disease. The mother still lives in her own home, but Sally and her sister provide and oversee care 24 hours a day, seven days a week for her in the home. They have been doing this for approximately three years. Prior to this, they had cared for their father for four years before he passed away.

The interview with Sally revealed the following themes.

1. Sometimes it's difficult to try to juggle all of the responsibilities I have to people (Conflicting responsibilities).

It's difficult at times. Trying to juggle everything---between my home, my husband, my children, my grandchild, my daycare center and my mom. My other mother-in-law and my other side of the family--- it's just sometimes mind-boggling.

Sometimes you feel like you're letting other people down. Sometimes I feel like I'm putting my Mom before my husband, which, you know, I don't think you should do that but this is a different circumstance and I think he understands. If it was his Mom, I would understand. I think he knows that.

But then there's times I wonder am I doing a good job at work you know, am I leaning too much on my other two people at work? You know, because I'm tired or I have too many phone calls about my Mom and I'm worried or you know cause when you take care of kids, you have to be whole. Because that's what it takes to take care of kids. And so, you know, you have to put things on the shelf while you're with kids until they're napping or their parents pick them up because it would be dangerous not to. And, so that's hard to do but I can do that. But, sometimes I wonder if let down the other two employees, you know. And I always hope I don't.

2. I get by with help from a lot of different people (Support).

Most of the time I handle it well. There's times that I don't and when I don't I tell my husband I'm not handling it well and he tries to be understanding. And, you know, sometimes I just cry and I get that out and that helps. Or just talk to him--- about it with him.

But, I told him I said, 'You know, sometimes it's therapy for me.' You know, messing with my house. Sometimes it's just things I have to get done, I don't have a choice. But I do enjoy, you know, I try to read, I try to keep a book going just to relax.

Because all my friends they know where I'm at, I keep in touch with them and they know where I'm at. My husband, bless his heart, you know is a saint, you know, if I need help over there, he's there. He'll help in the daycare. I mean that's just the way he is. I'm very fortunate. Yes, he is a very wonderful man.

My kids are very, very supportive. My daughter, you know, if she can work a shift, she will. Or if she can do anything in turn, she does it. I even put my mother-in-law and my sister-in-law to work sometimes; everyone's very supportive.

I think you learn a lot about yourself, and your friends, and your family and---there's lots of support out there---because my sister and I went to the Alzheimer's support group over on Linn Street.

And we went to four different sessions and a wealth of information---it was unbelievable---not only from the people they brought in to talk to us but from the people that were there that are dealing with the same thing you are. You can call them anytime and if they don't know the answer, they will find it and they'll call you back. They will send you a little newspaper. I don't know if it's once a month or once every three months but it's just all kind of stuff in it. It will tell you all about the websites that you can download and the newest information as far as research, just anything new---which is really neat just to get the new stuff, so you're not repeating that road.

There's a lot of support groups out there. You know then when you ask people around you, you know, I say 'if you say, no, it won't hurt my feelings. If you say, yes, it'll help; I promise you that it will not---I will understand.' And I asked them if they wanted to help and they said ' yeah.' Well, I'm going to take them up on it. Because you know if me and (my sister) get sick, I need them to take care of mom, you know. So we have to keep our health up and so we both, you know, watch each other to make sure neither one of us is getting sick.

It's hard, you know, when you've got things---like I love gardening and I'm gonna have to figure out how I'm gonna do that, you know, it's little things like that you think, you know, you can't really let that go. It's either has to be done or it's not done. Or maybe you're gonna have to turn it into grass, you know, because I used to have a lot of flower beds, and that. That's to me, that's therapy, I love doing that. So there's some things I'm not going to give up. You know, you look around and say I'm not going to give that up because it's good for me and I like it---there's just some things gonna keep doing. But there's other things I do give up and I figure I---just do it. And, I'm sure there were things Mom wanted to do but couldn't do when we were little so she gave it up, so. You know, you gotta look at it that way.

You need a lot of help, a lot of support. It's little things like people saying, 'You know I could come over for an hour here and there, you know.' That really helps. That's an hour to do something at your house or just sit and read a book. Just a lot of support. You need to look into the support groups. A lot of people it seems like they're afraid of support groups, but man, I highly recommend them, the one me and my sister went to.

There was a big talk of Alzheimer's and a support thing, and I would highly recommend it to anybody who is taking care of the elderly because it really helps. I would recommend reading as much as you can about whatever the other parent is dealing with---whether it's dementia or another kind of illness. I would elicit a lot of help and not try to do it all yourself. That's what we did at first; you can't do it. You can't do it yourself. Then you also have to be able to trust people. You can't go behind and do it over or what's the sense of having them. You have to be able to give up, you know, some of that authority to someone else, you have to delegate and that's real hard to do.

…you just really have to find ways to relax and get the help you want, social support groups---even if you go to church, if you---well we belong to a church but even if you don't belong to church, you can call on (another person) and put their names on prayer lines. People from church will come over if you call them. Even if they don't know who they are, they, you know, they know it's someone's who's interested in them who's come to visit them.

As far as (my sister) helping with mom, um you know, she helps a lot. I feel that (she) does as much as I do. Other people say, you know, they think I do more. I say, well, if we're going to get into that, than it'll just tear us apart. I don't want to do that because we've always got along good. There's been times I've had to call her and say (__)---and have it out with her. About, you know, different ways that, you know, she didn't get the care giver in when she said she would and it was her turn and stuff like that, and I said '(__) we've got to do this evenly or it's just not going to work.' But I would say all and all, we're as close or probably not closer. If there was more people in the family, it'd be even easier I'm sure because then we would have more to divide it up. But, then if you didn't get along with them, I don't know how it would work. But I would say me and (__), we get along good, you know. We're probably closer than we have been and I've seen a big change in her definitely. Definitely good.

But we (my sister and I) have had many, you know, we've had, you know, a lot of difficulties over this and my main goal is to get through this and us not hurt our relationship. So, you know, that's real important to me. So, we have had problems and we have worked them out. But, it hasn't always been easy. But, I've got a feeling that she has the same goals.

That's what really helps most---it is---I'll just cry and then I'll just, you know, I'll tell him (her husband), you know, I have no problem telling him, you know, I'm not doing well at all. And, he knows that I need him to be understanding and maybe help do some other things, you know, without even having to spell it out. That's how I do. I've got to get it out.

I think you need to take advantage of anyone who offers help. I think a lot of people shy away from that but I do, I take advantage of---you know, my mother-in-law, friends, the girl that does my hair, you know, if I call them and they can't do it, I say, 'fine.' But I mean they offered, so I take them up on it if I really need it. I think people…I think they should do that. You can't do things all by yourself. And people don't say that unless they mean it. So, I truly believe that, you know, the help is there. You've just got to be able to ask.

3. I've learned a lot about my Mom through the caregiving experience (Learning more about the other person).

I'm not saying that I wasn't close to my Mom but not as close as I am now. And, she can remember things long term more than short term, so we get to kind of, you know, go back in time sometimes and talk about things, which is nice. You know---good memories.

Yes, definitely closer. Definitely closer, no doubt about it. I don't know if it's because we're together more. She's always been pretty congenial. So, I mean we've always had, you know, a pretty good relationship.

But, yeah, I definitely think we're closer because I'm, you know, I'm really taking care of her, you know, spiritually, and mentally and, you know, physically--- and I don't see how you could do that and not get close to someone.

I think it's confirmed a lot of things that I suspected about Mom as far as fears---her fears and what she really wanted out of life and what really made her happy. Because she's talked about a lot of things in the past and cause she doesn't really remember things now. But we've had some really pretty good conversations, even though, someone says 'How do you do that, if she's got Alzheimer's?' Well, what she remembers, she remembers and we just keep talking about it. What she doesn't, I say 'That's fine Mom, don't worry about it then---no big deal.' But---so we have talked about a lot of things---her sisters and brothers and her mom. How she grew up. Her relationship with my dad.

Yeah I am, I am definitely am closer to my Mom. My Mom, she was never, I can't say real involved with what we did. She knew what we did and, you know, we knew what our rules were but like, you know, I don't think she's ever, ever was at school once the whole twelve years I was there. She probably wouldn't know any of my teachers. That just wasn't Mom. She wasn't a people person, never was. But, you know, she knew what was going on and made sure, you know, we didn't get in trouble---the more I have done this with both of my parents, the closer I got to them plus understanding maybe why they were the way they were.

4. We do what we can to help Mom to stay in her home (Supporting the independence of the parent).

You know, a lot of times, like a little kid. She's scared of what's going to happen. You know she'll start thinking, 'Well, am I going to get to stay here? You're not going to put me in a nursing home are you?' And, I'll say, 'No, Mom, not unless a doctor would say we have to---no, we're not going to.'

You've got to really watch her. We had to child-proof the house. We can't let her cook. She microwaved her girdle---it had the metal things in it---we had to childproof the whole house. All the medicine has to be put up. We have to have someone twenty-four hours so she doesn't try to leave cause she will try to get back to her own home. She still doesn't recognize the house. So, you have to really be careful with things like that.

5. We try to help her with what she can't do (Helping the parent compensate).

So, little things like that, you know, I try to help her through.

But, you know, with Mom, you know, I have to bathe her, that's kind of difficult---you know having to bathe your Mom. It's not really too bad. But at first it was, it was, you know---difficult. I didn't want to do that to my Mom. And, she wears Depends and--- make sure she gets changed and is clean and everything. And, that was kind of hard at first, but I had to do that for Dad too.

6. I feel so responsible for her safety (Safety versus independence).

It's a big responsibility cause, you know, if anything happened to Mom, and you know it was something we could have prevented, you'd feel so bad. That's when we first had to start childproofing the house. That was really hard. We had to check everything. Is there anything, you know, have we locked this or, you know, have we safeguarded this, done that, you know, just things like that, you know. But actually during the twenty-four hours, I probably don't worry as much, even though my husband thinks that---he said, 'I think you still do.' Well, I don't really feel like I do. I feel like I'm more relaxed knowing someone's there all the time.

1. I saw my Dad's family care for their Mom when I was young (How I learned).

…but I will say, my Dad's family took care of his Mom. She lived with different brothers and sisters---for so long then she moved on. So, I guess I did see that and they took very good care. And, I always thought that was neat that they did that for her instead of sticking her someplace and going to visit her um until she got bad. And, she lived to be ninety-six. I guess in the back of my mind, I thought that was pretty neat how they did that. So, that probably gave me the basis of, you know, what you do for someone that needs help in the family.

Oh, sure yeah, it's harder. Yeah, it's---And, I figure unless you do it, you can't realize, you know, how hard it is because one thing, it takes a lot of time, a lot of patience. Um, you have to be able to give up stuff. So, yeah, I don't think I ever realized---cause my Mom and Dad never had Grandma at their house, I mean she was always at someone else's house; mom did never really do it. The other ones had like a bigger house or more room, or more people there that could, you know, if some had to go out, someone was always there. We didn't have that in our house so I never saw that…

I mean I've always taken care of children. I've done that my whole life. I started when I was about eleven babysitting and it's just been something that I love to do. But I've never, ever, ever taken care of an adult or anyone elderly in my entire life, so I had a lot to learn. And, you know, I think you learn by just doing and, you know, finding out what works and what doesn't. I don't think anyone can tell you, 'This is what you should do.' I don't think the same things work for everybody. Everybody is an individual person. Some things might relate to every elderly person but not generally---I think it really has to be an individual thing for every elderly person, what works for them and what doesn't.

My Mom's Mom was taken care of by my Mom's one brother and my Dad's Mom lived with his one sister until she died and they, all the brothers and sisters would go there to that one person's house to visit her and take things, take things to the person taking care to help them out there, monetarily wise without actually giving them money, you know. Take over hams or desserts or things like that and they did the same thing with my Mom's Mom. So, you know I saw that---I always thought that was really neat that they did that.

2. I saw how miserable my Dad was on dialysis (Being sad about the parent's decline).

I told him not to worry; it was his time to go and I said 'you go.' It was time. He was so tired of dialysis. And one reason he kept doing it was because Mom was still alive. So, 'if Mom wasn't there, I would take myself off it and die within two weeks', you know. You know if Mom hadn't been living and Dad had made that decision I would have backed him up. Because I had taken him there and brought him home and saw how miserable he was.

3. I've learned to do more than I ever thought I could (Self-discovery).

Well, see I took care of my Dad first because he was on dialysis for four years. So, we were there constantly for Dad, and, then Mom for about three years now. So, we just have to kind of, we just have to kind of put things on hold. I just can't do the same things. I'm a real stickler with, you know, I have to have the house a certain way. So, I've had to, you know, change myself---my home here, yeah, I had to change myself. I had to let some things go.

And, it makes you feel good that you're doing something for someone else. I've always felt that way.

I think you learn a lot about yourself.

It's hard, you know, when you've got things---like I love gardening and I'm gonna have to figure out how I'm gonna do that, you know, it's little things like that you think, you know, you can't really let that go. It's either has to be done or it's not done. Or maybe you're gonna have to turn it into grass, you know, because I used to have a lot of flower beds, and that. That's to me, that's therapy, I love doing that. So there's some things I'm not going to give up. You know, you look around and say I'm not going to give that up because it's good for me and I like it---there's just some things gonna keep doing. But there's other things I do give up and I figure I---just do it. And, I'm sure there were things Mom wanted to do but couldn't do when we were little so she gave it up, so. You know, you gotta look at it that way.

…you just really have to find ways to relax…

Oh, sure yeah, it's harder. Yeah, it's…and, I figure unless you do it, you can't realize, you know, how hard it is because one thing, it takes a lot of time, a lot of patience. Um, you have to be able to give up stuff.

You can do---you can take a lot more than you ever thought you could. Like you say, my plate is full. And there's times I think that if it got any fuller, I don't know what I'd do. We went on our cruise just recently. I got all the bases covered. Everything—working—and my husband said, we need to get away because my husband, he is a fire chief—a very stressful job and we went away for a week and it was great—unbelievable it was so wonderful—read books, relaxed. But my daughter picked us up at the airport and I knew something was wrong and I said 'What's wrong?' and she said 'Mom, your sump pump stopped working when you were gone and your whole basement's destroyed.' Well, we got home and I went downstairs and as soon as I saw it I started crying—I mean everything we had to pull up all the carpet, *everything's in the middle, the whole basement is ruined. And I was pretty upset. I cried that night and part of the next day and I told my husband 'I have to do this, I have to get it out of my system' and he said 'It's just a basement.' I said 'I know. I know we'll fix it up. I just don't need anything else on my plate right now.' But then after I got done crying I was fine and we've already had it painted and it'll be fine but it was just one more thing that is going to put you over the edge but it doesn't. But it's just one more thing to deal with and you go on. So I think it's made me stronger. Yeah, as far as being able to deal with things.*

I think you find out you have more inner strength than you ever thought you had. And I think you really find out what's important---and what's not. It's easier to give up things that you were so used to doing than you thought you would be able to do.

I think you realize you can give up more things. And, things aren't as important. And then I also, I think you're more aware of other people's distresses---that you don't really, there's always someone who's got it worse---always. And, so those kind of things kind of, you know, pop up all the time.

10. Caregiving has taught me what is important in life (Recognizing priorities).

Yet I think another thing that it teaches you what's important and what's not. I think that's real important.

And I think you really find out what's important---and what's not.

I think you realize you can give up more things. And, things aren't as important.

11. I tell Mom we're all in this together (Reciprocity).

So, Mom, luckily she is very easy to get along with. She's pretty up most of the time. She said 'I could just go tomorrow and I'd be OK.' And, I said that I understand that Mom but it's just not in my power. But, um, so that makes it easier, you know, to have Mom be that way. If she was real difficult---Some people say their parents get mean---Mom's never done that. And I don't know what I'd do if she did. I guess we would be doing the same thing, it just would be really harder.

But, you know, being with Mom is not hard because she's just pleasant. Actually she's always has been. So, that way she hasn't changed too much.

But then like I said, she's very congenial, so that helps too. My Dad needed to go and he was so worried about Mom, we promised him we would take care of her when he passed on, you know, now we're gonna keep that promise.

And, Mom, she said many times to me, 'I'm ready to go be with your Dad.' And, I said, 'Well, I don't blame you, but can't help you there you know.' I said, 'There must be a reason, I don't know what it is but I guess we still need you here. You've just got to put up with us.'

So, she's always saying, 'Oh thank you for everything. I hate that you have to---' I said, 'Mom,' I said, 'Don't worry about it.' I said, 'We're in this together,' You know, I don't want her to feel guilty. But, I don't think she does too much because of the Alzheimer's. I'm not real sure she knows what's going on sometimes. But, every once in awhile she says, 'You know, I really appreciate what you do.' I say, 'Mom, don't worry about it. We're all in this together.' So, I think she's pretty comforted by that.

…she is easy to---you know, to be around, you know, and want to make happy. Because she's not really happy. If I had Alzheimer's and arthritis in my back and I wouldn't be happy either. So, when she's not, when she's down, I said, 'Mom, you have every right to be down. But, it's not going to get you anywheres, you might as well get it out and get back up.' So, she usually does. She's pretty positive. She's pretty cool.

You're a gift to them and they're a gift to you. You gotta reciprocate.

…she'll say, 'You spend all this time,'---she said, 'I feel so bad'---I says, 'Mom, you took care of me for nineteen years until I moved out.' I said 'I'm not taking care of you hardly at all. Not compared'... So I said, 'You've got to quit worrying about that'.. I said, 'If I didn't want to be here, I wouldn't be here. So you've got to quit worrying about that…'

But there's other things I do give up and I figure I---just do it. And, I'm sure there were things Mom wanted to do but couldn't do when we were little so she gave it up, so. You know, you gotta look at it that way.

Like when you are taking care of her and she'll look up at you and she'll smile and she'll say, 'I really appreciate all you do for me.' You know and sometimes when, you know, you're at your wits end. You're trying to juggle and you're thinking, 'I don't know, I can't do this. How much longer can I do this?'---what you're doing at the time. And, you're saying how much longer can I do this and then she'll, you know, she'll hold your hand and she'll say, 'I really, I really appreciate all you do, that you've been doing.' You can't put a time limit on it.

12. I still treat my Mother with respect (How I treat them).

I think because I've always worked with children, I think of mom now as a child. Where it's easier for me than my sister. My sister just gets impatient with her. But, I don't because, you know, I've worked with kids for twenty-two years. And, you have to be patient with kids so to me Mom's real child-like now. So, you know, I can be really patient with her. And, I have---it doesn't---nothing that she does actually really bothers me because I relate that to all the kids at the daycare.

To me you respect your parents to the day they die. That's just the way I think it should be.

Now when you look at someone who doesn't know where's she at and she's really got arthritis in her back---and scared. You know, a lot of times, like a little kid. She's scared of *what's going to happen. You know, she'll start thinking, 'Well, am I going to get to stay here? You're not going to put me in a nursing home are you?' And, I'll say, 'No, Mom, not unless a doctor would say we have to---no, we're not going to.' Or she'll get scared, she'll say, 'Do I have enough money? How will I live?' I'll say, 'Mom, you've got plenty of money. You don't have to worry about that.' You can see she's just like a like little kid and you never want kids to be afraid, you know. You just always want to, you know, I don't want a child's life to be, you know, everything done for them and their life never has any bumps. But I don't want a child to be afraid.*

I've told my kids this, I said, 'You know, my Mother is seventy-nine years old and she has Alzheimer's. And, to this day, I would not talk back to my Mom. I would not say anything mean to her.' I said 'To this day, I still know, even though I'm taking care of her, she's my Mom and you respect your parents---no matter what. That's just the way I was brought up.' And, I believed it. …I think my daughter smarted off about something one day and I said, 'I tell you what,' I said, 'To this day, you know, my Mom might not even know that I'm doing it or not, I wouldn't do that, cause to me that's just not acceptable behavior'…but, I truly believe that. To me you respect your parents to the day they die. That's just the way I think it should be.

You know, because even though we do have the twenty-four hour care, I'm not there twenty-four hours so I have to be really able to trust these people that come in there. I have to kind of do drop-in visits, unannounced visits---and really keep my eyes and ears open to make sure that everyone is treating Mom the way they should. And if I find out that they're not, you know, we've had to take some of the caregivers aside and just very gently say, you know, 'Is there a miscommunication about this, or this, or this?' And if there was, let's find out because you know there's certain things we expect done when they're there. Because we cannot do it all. When you're here, you know, if this wasn't agreeable then let me know because this is what we expect.

Well, because we made a promise to Dad but even if we hadn't made the promise to Dad, my Mom would get care. She's just pleasant to handle. Now I know that sounds unrealistic. But my Dad worked very hard to save money in case something like this happened. So, the money is there. So, we're going to use the money to keep her home as long as we can because I know that's what Dad would have wanted. And, I know how hard he worked and how hard he saved.

But, Dad always said, you know, 'If something happens to me, I really---I want you to put me in a nice place.' I always told Dad I would. And then, you know, when he was worried about Mom and I told him I would take care of her. But even if he hadn't said, if Dad had passed away before he talked about that with us, like if he died accidentally or something, me and my sister both knew how hard my Dad worked---we knew that that money was not to just be spent frivolously just to put Mom in a nursing home because we didn't take time with her.

I figure another thing that when you're at the house, you know, you can see a million things to do, but there's times I just sit down with Mom and we just watch TV together or I'll just *talk to her or I'll give her a backrub instead of doing all these other things. And, I'm a little bit anal.*

I have to make myself not do things at Mom's and just sit there and just sit by her while I'm reading my book or just sit by her and she likes 'I Love Lucy' so we bought her the 'I Love Lucy' reruns. I sit there and watch stuff like that with her instead of getting up---because then you're not really with them you know, that makes mom nervous too. Because, she has to sit and why are you just running around, you know, why don't you sit down. So, you know, now I make myself do that, just sit down and relax with her. Cause she does sleep a lot, so when she's not sleeping you really should just be with her. And, sometimes she doesn't say anything; sometimes she'll just hold your hand. Or sometimes she'll laugh at something funny and that makes you feel good to know that something's cheering her up.

I think the only vision I had of care giving was, you know, just try to be kind to someone who needed care giving, just try to make their life more meaningful.

That's what my husband said too. He said, 'You know, that was just a silly thing that you said to your father when he was, you know, passing away.' And I said, 'Well, I said it and when I said it I meant it and I said it to ease his mind.' I said it but that's not what it's about. You know, it's about that----like when I give my Mom a shower and she's yelling and screaming and slapping at me and stuff. I'm very patient and I don't do anything. I just do what I have to do. I'm thinking in a nursing home? Are they just not going to do her bath or are they going to be mean, you know, and yell? Or when, you know, it's little things like that, how would they deal with it? And, when she's really, really scared, are they going to try to reassure her or just ignore her and hope she stops. You know, stuff like that I'm thinking, 'I just don't know. I don't know what they would do.' And, I don't know that I'd want to take that chance until we have to. So, we're not.

13. My husband and I have always been close to our families (Always had a good relationship).

But my husband and I---we're really---we're very family-oriented. We always spent a lot of time with my parents, with my kids, his mom, his sister, whatever. You know, it got to a point where, we didn't want to be divided so we just started inviting both of the sides of the family here. So, that way you don't have to go to one person's house and go to another person's on the holidays. So, we've done that forever. So, we always did spend a lot of time with the family. So, that's not really different.

I mean we've always had, you know, a pretty good relationship.

Because me and my Mom were not always close but we always had a good relationship.

14. Caregiving is very challenging; I have had to give up some things in my life because of it (Paradox).

You know you try to make schedules---I do the medicine and the bills and my sister does the groceries. And, you know, I have to be organized to the tenth degree or it'll be a mess. So, you know, I have lots of notes, lots of calendars and lots of schedules and I just try to stay really, really scheduled. But, it's very difficult.

So we have---we have to work twenty-four hour shifts. So, we have my mother-in-law takes a little shift---my sister in law. We have a lady who comes in the daytime. We have a home care company that will send out caregivers then my sister will pick up the slack. A lady comes in to clean. And but, it's hard when you've got to go to work the next day and I have to come to my mom's house.

…it gets very difficult at times because you just feel really bogged down. You have to change your life. You have to change it. You have to give up things. A friend of mine called me today, two of my friends called me today and said come on we're going to Silverlake Recreation, you're got to join with us. We're going to start working out and swimming. And, I called them---I was at my Mom's, I said, 'Guys, I don't have extra time to do anything and I would love to do it. I appreciate you thinking of me, but I can't do it.' There are a lot of things I have to just not do now. I just can't do the same things I used to do.

So, we just have to kind of, we just have to kind of put things on hold. I just can't do the same things. I'm a real stickler with, you know, I have to have the house a certain way. So, I've had to, you know, change myself…my home here, yeah, I had to change myself. I have to let some things go.

I'm used to a busy schedule. I like being busy. Um, but you know, I like being busy with things I choose; I really didn't choose this. But, I feel like it's my responsibility and I'm going to do it. But, I'm used to a busy schedule but, you know, when you choose to be busy it's different than when you have to be busy. And this right now in my life, I have to be busy.

I'm not saying that I wasn't close to my Mom but not as close as I am now. And, she can remember things long term more than short term, so we get to go back in time sometimes and talk about things, which is nice. You know---good memories. And, it makes you feel good that you're doing something for someone else. I've always felt that way.

So, you know, I really like doing that, you know, like I said, you know, when you choose to do it and you say, 'Well, I've had enough, I'm going to stop now.' With this, I can't say I've had enough. This is going to go until it goes. So, there's a difference there.

I guess the only thing you lose really is time. You know, because you have to put a lot of time in. Not only the shifts that you run, you know, it takes me a long time to do her bills and banking, a long time to---all the medicine has to be in. Most---I'd say ninety-five percent of the medicine has to be ordered through a company. It's very, very---um, not organized. So, you know, by the time you get through, you know, all the phone calls you make to get her medicine and sometimes you… we have to get it from the pharmacies, so you know, you lose a lot of time that you probably would, you know, do something else.

But, you know, with Mom, you know, I have to bathe her, that's kind of difficult---you know having to bathe your Mom. It's not really too bad. But at first it was, it was you know---difficult. I didn't want to do that to my Mom. And, she wears Depends and--- make sure she gets changed and is clean and everything. And, that was kind of hard at first, but I had to do that for Dad too.

Nobody wants someone to have to help put Depends on, give them their own bathes, you know, do that kind of stuff. Clean them up when they're messy. Nobody wants that. But, I'd rather it be us than a total stranger that doesn't really care, you know. I think most people that work in a nursing home, hopefully are there because they like doing that job but there's no way, those jobs can be anything but stressful. So even in stress, you know, even if you really like your job and you really care about people, if you're really stressed, you're not going to be as good to them as their own family members. So, as long as we, you know, and I've just heard horror stories about nursing homes that, you know, I just don't want to do it unless we have to.

But I guess I never realized, you know, the extent of what you have to do. You know, I mean they're not really taking care of themselves, you've got to cover all the bases. If you don't know what the bases are, you know, I didn't know anything about how to do my Mom's medicines. I didn't know anything about how or where you could get help. I didn't know anything about childproofing a house. So, you know, I asked a lot of questions. Talked to a lot of people. Read a lot of stuff, you know, you just gotta do all that---and still hope that you haven't missed something. Yea, I don't think I had a clue what was all involved. I don't know of anyone that does who doesn't actually do it.

You know, we had to put up rails on my Dad's bed---we hired someone to come do that. And before he died, we had to go to Rothert's and get the potty on the wheels and um for my Mom we had to get certain kinds of canes and walkers and, you know, I didn't know---we didn't know anything about any of that kind of stuff until we started doing it. And, I never, my husband does all the bills---does all the bills …so, I had to learn to do all that. I still can't balance her check book; I just call the bank to give me a number. So, I had to learn a lot how to do all that kind of stuff. You know, I didn't know any of that stuff. So, um I guess I'm getting an education at the same time. I'm learning things I couldn't do before.

A lot of responsibility---a lot of responsibility. Sometimes I don't feel---I think cause we're just with her so much now that for a long time I felt burdened. I felt, 'Gosh, am I ever going to have to not worry about you know Mom and doing all her stuff.' And then I think, 'No, you're not, you're always going to have to. You took on that role, you told Dad--- you gotta do it, you just gotta get used to it.' And, I think I'm pretty well used to it now. I don't really feel like it's a burden now, but I do feel like it's a big responsibility.

It's hard, you know, when you've got things---like I love gardening and I'm gonna have to figure out how I'm gonna do that, you know, it's little things like that you think, you know, you can't really let that go. It either has to be done or it's not done. Or maybe you're gonna have to turn it into grass, you know, because I used to have a lot of flower beds, and that. That's to me, that's therapy, I love doing that. So there's some things I'm not going to give *up. You know you look around and say I'm not going to give that up because it's good for me and I like it---there's just some things I'm gonna keep doing. But there's other things I do give up and I figure I---just do it. And, I'm sure there were things Mom wanted to do but couldn't do when we were little so she gave it up, so. You know, you gotta look at it that way.*

But as far as, you know, simple things like medications and bookkeeping, you know, I didn't do that. So, I just don't think anyone would have clue unless---even my friends, they'll say, 'Can you do something?' I say, 'No, I've got to go to Mom's tonight.' I'm sure they don't have a clue, they probably think I'm just going to sit with Mom. Yeah, they don't have a clue what I do. You know, because we do make sure she has on her pajamas, gets a bath, gets her medication, her snack, you know, make sure, you know, make sure she gets in bed OK. You know, and make sure that when she gets up over night that she doesn't fall. The cat comes into her face---it's just things like that so there's just a lot to it. You know, there's a whole lot to it.

It's a commitment you make and try your best to, you know, do your best by them without harming yourself or the people around you. Keeping yourself whole and healthy and, you know, a productive individual. There have been a couple of times when I felt that I wasn't sure if I could continue it because I felt like it was hurting me, physically, mentally and the people around me. But it would pass and I would get by whatever that obstacle was at that time and I'm sure my sister's gone through the same thing.

15. We've helped Mom in many ways over the years (Role evolved gradually).

And, my Mom, my Mom was never what you call a strong person, physically or mentally. But it really surprises me because she was always really very weak physically and she was a waitress for--- until she retired at seventy. But, she never did anything physical at the house. And, she really couldn't do anything physical for Dad, so we had to do all that. So, we had a lot those four years--- you know when he had the dialysis. And, you know, she never did anything physical. You know, once Dad couldn't do it, everything in the house or outside the house in the yard had to be done by us.

…she just never did it so she couldn't do it because she's always been a very weak person. But mentally too, I mean, you know, Mom can't handle a lot, she never could. Not a lot of disruption or upset or anything like that. So, she was always kind of frail inside and out and we always knew that and so we took care of her.

…we had to do a lot at the house because Dad couldn't do it and Mom had never done it before. And Mom had never put up mini-blinds. She had never used a screwdriver. She had never cut the grass. She had never got gas in the car. I mean, she just wasn't even driving at that point, you know. She had never done any of those things. Where I have always done that around here because my husband's always had a job where, you know, he's not---can't always be here. And, so we had to jump in right then and it's just continued.

16. Caregiving gives continuity to our family.

My kids are very, very supportive. My daughter, you know, if she can work a shift, she will. Or if she can do anything in turn, she does it. I even put my mother-in-law and my sister-in-law to work sometimes; everyone's very supportive.

There's been times I've had to call her (my sister) and say (__)---and have it out with her. About, you know, different ways that, you know, she didn't get the care giver in when she said she would and it was her turn and stuff like that, and I said '(__) we've got to do this evenly or it's just not going to work.' But I would say all and all, we're as close or probably not closer.

…so we have talked about a lot of things---her sisters and brothers and her Mom. How she grew up. Her relationship with my dad.

…but I will say, my Dad's family took care of his Mom. She lived with different brothers and sisters---for so long then she moved on. So, I guess I did see that and they took very good care. And, I always thought that was neat that they did that for her instead of sticking her someplace and going to visit her um until she got bad. And, she lived to be ninety-six. I guess in the back of my mind, I thought that was pretty neat how they did that. So, that probably gave me the basis of, you know, what you do for someone that needs help in the family.

But then like I said she's very congenial, so that helps too. My Dad needed to go and he was so worried about Mom, we promised him we would take care of her when he passed on, you know, now we're gonna keep that promise.

Well, because we made a promise to Dad but even if we hadn't made the promise to Dad, my Mom would get care.

17. My parent has certain characteristics that make me want to care for her.

She's always been pretty congenial

So, Mom, luckily she is very easy to get along with. She's pretty up most of the time. She said 'I could just go tomorrow and I'd be OK.' And, I said that I understand that Mom but it's just not in my power. But, um, so that makes it easier, you know, to have Mom be that way. If she was real difficult---some people say their parents get mean---Mom's never done that. And I don't know what I'd do if she did. I guess we would be doing the same thing, it just would be really harder.

But, you know, being with Mom is not hard because she's just pleasant. Actually she always has been. So, that way she hasn't changed too much.

But then like I said she's very congenial, so that helps too.

So, she's always saying, 'Oh thank you for everything. I hate that you have to...' I said, 'Mom,' I said, 'Don't worry about it.' I said, 'We're in this together,'

But, every once in awhile she says, 'You know, I really appreciate what you do.' I say, 'Mom, don't worry about it. We're all in this together.'

…she is easy to---you know, to be around you know and want to make happy.

She's pretty positive. She's pretty cool.

She's just pleasant to handle.

Like when you are taking care of her and she'll look up at you and she'll smile and she'll say, 'I really appreciate all you do for me.' You know, and sometimes when, you know, you're at your wits end. You're trying to juggle and you're thinking, 'I don't know, I can't do this. How much longer can I do this?'…what you're doing at the time. And, you're saying how much longer can I do this and then she'll, you know, she'll hold your hand and she'll say, 'I really, I really appreciate all you do, that you've been doing.' You can't put a time limit on it.

Discussion:

Many of the themes were similar in this interview but some of the previous ones were not present this time. In the area of supporting the independence of the parents, many of the more subtle variations were absent, specifically the desire for more control, issues of control versus the unknown, helping the parent compensate, and the quality of life issues. The absence of these more subtle issues makes sense given the parent's condition. Because of the presence of Alzheimer's disease, the parent is completely dependent upon her caregivers. All of their actions are aimed at protecting her. While the caregivers still do everything they can to protect her dignity, they cannot protect her independence in many significant ways other than by their ultimate attempt to do so by keeping her in her home.

A new theme emerged: the parent has characteristics that make the daughter want to care for her. Evidence from the previous three interviews to lend support to the inclusion of this theme is included after the summary of the themes thus far. The new theme is bolded.

1. Caregiving is a normal experience. (Not present in this interview).
2. Caregiving means having conflicting responsibilities.
3. Supporting the autonomy of the other
    a. Issues of safety versus independence
    b. Easier if I had more control
    c. Issues of control versus the unknown
    d. Helping the parent compensate
    e. Her safety is important, but so is her quality of life.
4. Caregiving is being sad about the other person's decline
5. Caregiving is learning more about the other person.
6. Reciprocity
    a. We've always had a good relationship.
    b. How I treat them
    c. Caregiving is evidence of love
7. Self-discovery
    a. I don't want to be like them.
    b. Caregiving gives me a purpose in life.
    c. Caregiving helped me recognize my priorities
9. Support.
10. Wholeness of love/Paradox
11. The caregiving role happened gradually
12. How I learned
13. Cargiving gives continuity to the life of our family.
14. **Mom has certain characteristics that make me want to care for her**.

Theme: Mom has certain characteristics that make me want to care for her.

And sometimes it's depressing and you see how they are and how dependent and you hate to see them that way. And, but then you get home from their house and five minutes later the phone's ringing and, 'Oh I forgot to tell you,' you know, then I don't get so depressed; I think this is OK (Interview 1, Jackie)

Well, I don't know, they've just always been very independent people. Dad's a good ol' boy, you know, he tries and tried and tried. He really, you know, he would not give up on trying. You had to tell him and Mom--- I don't know, they're just people that would always try and not give up so I knew that working with them wasn't going to be terribly bad. You know, they've just always been caring and understanding people. (Interview 2, Mary)

I mean if it wasn't for her ability to deal with this the best she can, I wouldn't be willing to do this. Now if she changes and becomes a mean, angry person, you know, because of her physical condition, I don't really think that's going to change how I approach this because she is still the soul she's always been. I mean, it doesn't really matter how she appears on the outside or what happens to her, she is still this brave, strong person who's my Mom, you know. (Interview 3, Linda).

She's very appreciative and nice to me, you know, and really does appreciate what I do and that all helps. (Interview 3, Linda)

But, we have a lot of fun together. We really enjoy being together and we laugh a lot and we, you know, just have a good time. (Interview 3, Linda)

Participant 5: Rosie

"It's that bond."

Rosie has been caring for her mother for approximately fourteen years. Her mother has multiple chronic health problems but is able to live in her own home with Rosie's help. Rosie lives in the city and works full time. She chose to come to the researcher's home for both interviews.

The interview produced the following sixteen themes.

1. I have to choose among my responsibilities (Conflicting responsibilities).

It's like you know, if I've got something to do during the day and I've got my Saturday all planned. We're going to go to the zoo, or we're going to go the park or my husband and I are going to go out to eat and we're going to go to a movie, if I go visit my Mom, and she's sick and she needs me, that's my top priority. You know, it has to be---and sometimes---well a lot of times my husband doesn't understand that.

2. I wonder why my siblings don't help Mom more (Support).

None of my other brothers and sisters, except for one even come around very much. My one sister comes around on Sunday to take her out to lunch and that's it.

So, it's kind of like all during life you grow up and your Mom teaches you all these things and you learn them you know. And, where all my other brothers and sisters went I don't know during that process. But, I guess I was the one under her wing more than I really realized.

When I see my brothers and sisters, I wonder what happened to them, why they don't have that special---that they want to do something with my Mom or they want to just be there. You know, it's kind of like, I wonder, am I a weird person for wanting to be there while all my other brothers and sisters, yeah, they have their own little families, their own little jobs, their own little world but look, this is your Mother, you know. It's the person that put you here. I guess that's just the part that irritates me more than anything.

3. I get quality time with my Mom now (Learning more about the other person).

I mean I don't gain any money or any prestige or anything like that, no. It's just the thought that I was there when she needed me. That's all I need. I gained those little laughs that we have with each other. And, I think that we're closer because of it.

This woman's made of stone, whatever. She is rock hard but then she has feelings like everybody else. She gets lonely like everybody else. She laughs like everybody else. She's not that person that I thought of as God kind of growing up. You know, that hard rock of stone.

Little stories that she brings out that come out and parts of little songs that she remembers from back in the twenties or thirties or forties, you know. Different things that go on in life and history that I didn't remember that she remembers. Things that you learn all the time.

She was the Rock of Gibraltar. She, you know, held the family together. Everybody thought my Dad was the one that held everybody together but No, Mom was the definite one. She was the one wh---that told Dad when to get up and go to the work. And, she'd fix his breakfast and she'd get all of us kids ready for school. You know, everything was, Mom did everything but you didn't realize it at the time.

4. I try to get her to take care of herself (Supporting the independence of the parent).

...I have to be stern with her about you need to eat, you need to drink, you need to take care of yourself, you need to do these things for you not just I need to clean the house or I need to do this.

She tends to look out for everybody else right now even the fact that she's got dogs that she takes care of and she'll feed the dogs but then she won't feed herself. And, you know, I can take her---I go and take her breakfast in the morning before I go to work and pack a lunch for her.

5. How I learned

But, um, growing up, it's like she (my Mom) would make the priority list that morning and in her head it was like who needed me the most?

So, it's kind of like all during life you grow up and your Mom teaches you all these things and you learn them you know.

…I guess when I was maybe five or six, my Grandpa on my Mom's side was sick. And, she would go up there and take care of him but I was never around when she took care of him.

…it was always family-oriented. Every Friday night, no matter what, we all got in our old station wagon and we went out and got a sack of White Castles, went to the drive-in, had a good time but it was that moment when you knew you were family. The whole world could go by but on the weekend, it was our night to rock, you know. It was family. And Christmas it

was the same way. So, I always grew up with that idea that family stuck together, that you always took care of your kind.

6. I'm sad that I know my Mom will die sometime (Being sad about the parent's decline).

I just know that my Mom's toward the final end of her life right now. And, I know someday soon, I'm not going to have her. So, that's where the tears are kind of welling up.

I mean when you've lost one parent and the other parent's just barely hanging on, it's kind of like, you know, you grasp every part, every moment of that life that you can get.

7. I've learned things about myself through caregiving (Self-discovery).

I think it's made me a better person, you know. Even when I go into the hospital and the way I treat my patients, my Mom always told me growing up, 'You always treat everybody like you would want to be treated.' And even when I look at a patient, it's not, 'Hey Mr. So and So or Miss So and So.' You know, 'Hi, how are you doing'? You know, I want to be addressed like a person not a patient or a number there--- and, I think in that respect, it's helped a lot.

I've learned I'm stronger than what I would ever thought I could be.

Well, the fact that I could rearrange anything at the drop of a hat. I could do more things than I ever thought I ever knew. You know, my Mom complained one time that the shingles were coming off of her house. So, I went out and got a ladder and climbed the top of the house and repaired her shingles on the roof, you just learn to do things.

Oh, sometimes I've learned I'm kind of a doormat that my Mom knows which way to get me to do what she wants. And, I really don't want to do. You know, she has little tricks sometimes. Like if she's feeling lonely or something, she refuses to answer her phone. You know, she's got an answering machine there so she knows who's going to be on it. And, then she knows if I call and I don't get her, I call back and I still don't get her then I'm going to come over and check on her.

Maybe it's just the thought that what is my purpose on earth was to take care of people. I'm a very people-minded person. Even when I'm out on my own, I'm watching everything going around me, all the people and how people take care of people and things like that…

8. Reciprocity

She's my Mother and I wouldn't do it any other way.

Sure, it's hard for me to get up every morning and fix her breakfast and go see about her and check on her. But, on the other hand, some of things that she comes out with, some of the experiences she's had in life---it's all worthwhile because when she's gone my brothers and *sisters aren't going to have that. I'm going to have those memories that they're not going to have. And, to me, you know, it's almost like she brought me into the world yes, I owe her that but on the other hand, she's my mother and I love her. So, it doesn't take much to go do things.*

I mean I don't gain any money or any prestige or anything like that, no. It's just the thought that I was there when she needed me. That's all I need. I gained those little laughs that we have with each other. And, I think that we're closer because of it.

It's kind of like the role's reversed. You know, I was a child, she took care of me. Gave me everything I need and now on the other hand I'm kind of like the mother. She's kind of like the child and I give her whatever she needs.

…it's more like I get the opportunity to be with her to realize that I'm going through her life with her where they're outsiders. They really are and they're going to miss a lot by not being there with her that I'm getting, you know. Just day-to-day moments that we have. Funny little things that happen.

I don't know, maybe if I didn't take care of her I would lose out on a lot---a lot of things that she grew up with; I mean when people get older, they forget a lot of things but they start remembering back to the days when they were bringing up. You know, things with their Mom and Dad. I never knew my grandmothers on either side of the family. But, I feel I know them, because my Mom used to tell me different things that they would do or say or show me their pictures or, you know, all kinds of things then she would tell me sometimes, well you were just like my Mother when you did that.

So, I always grew up with that idea that family stuck together, that you always took care of your kind.

9. I treat my Mom like a friend (How I treat them).

I really don't think of it as care. I think of it as, she is my companion and I'm her companion. She's my Mother and I wouldn't do it any other way.

…it's like today---every Tuesday's Mom's night out. She goes anywhere she wants to go, does whatever she wants to do. We do it together but it's not as mother-daughter and we even say that. We're not mother-daughter today, we're girlfriend-girlfriend.

And, you know, she's like, 'Well, you need to go out with your girlfriends.' I said, 'Mom, you can go with me and my girlfriends because you're my girlfriend.' You know, it's not a problem for me.

On the other hand I've got to understand she is by herself. And, it only takes a couple of minutes to drop in and say, 'Hey, Mom, how are you doing? Here's a hug,' you know. And, I always begin the day with a hug and a kiss on the forehead because she's shorter than I am, you know and I always end my visit with her like that, you know.

And, you know, I can take her---I go and take her breakfast in the morning before I go to work and pack a lunch for her. And, I pack a lunch for me. So, that we both have the same lunches, and that way she'll say, 'Well, I'll sit down around 12:30 when my shows come on and I'll think you're gonna sit down too. And, it's like, you're going to be here with me watching the show.' I said 'So you let me know what happens on the show and I'll let you know what happens at work.' But that way she pretends like she's got somebody there sitting to eat with. And, then I go up after I get off work and she has supper then.

10. We've always had a good relationship.

I think it's always been good as far as the relationship, mother-daughter type thing. But, as we were growing up I, you know, I felt I was a number of eight kids in the family. You know, and Mom always shared with everybody. But you didn't get that ideal time that I'm getting now.

We've always got along with each other.

She's my Mom. She's my girlfriend. She's the best person I ever know, you know, and she needs that. She needs me and I need her. It's like that bond. You know they talk about it when you have babies at the hospital, breastfeeding makes everybody closer. I was a bottle fed baby and I shouldn't be saying this because I'm lactation consultant but, you know, there's no greater bond than my Mom and I have. You know I can't see ---any difference. It wouldn't be any different I don't think if I was an adopted child. You know, it's just how you perceive life and family and the way everybody interacts.

11. Sometimes caregiving is hard, sometimes it's not (Paradox).

I think sometimes, it's hard. Sometimes it's easy. You know, it's just like anything else you put your mind to, you can do it.

There's other opportune times that I would go to the mall and shop or go out with my girlfriends or do this and that and the other…

You know, and her idea of order in the house is not order, it's kind of like, she grew up around the depression era, so she saves everything. You know, little napkins, little tops of cans or bottles and I find myself with little boxes everywhere and she has to---that part is really irritating…

That it's not always a burden. There's more to life than, you know, you know, I don't know how you say it. It's kind of like you always have to work harder to get something that's worthwhile. You know, if it's handed to you on a silver platter, it's not worthwhile.

12. The Caregiving Role Happened Gradually

Just being there at the time of need---and you're not actually giving any care as such---you're just being there a little bit more at the time when the need arises. You know, and eventually that need gets bigger and bigger and bigger and then there you are a full-fledged caregiver.

13. Normal experience.

She's my Mother and I wouldn't do it any other way.

So, I always grew up with that idea that family stuck together. That you always took care of your kind.

14. Gives continuity to the life of our family.

But, on the other hand, some of things that she comes out with, some of the experiences she's had in life---it's all worthwhile because when she's gone my brothers and sisters aren't going to have that. I'm going to have those memories that they're not going to have.

…it's more like I get the opportunity to be with her to realize that I'm going through her life with her where they're outsiders. They really are and they're going to miss a lot by not being there with her that I'm getting, you know. Just day to day moments that we have. Funny little things that happen.

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I don't know, maybe if I didn't take care of her I would lose out on a lot---a lot of things that she grew up with; I mean when people get older, they forget a lot of things but they start remembering back to the days when they were bringing up. You know, things with their Mom and Dad. I never knew my grandmothers on either side of the family. But, I feel I know them, because my Mom used to tell me different things that they would do or say or show me their pictures or, you know, all kinds of things then she would tell me sometimes, well you were just like my Mother when you did that.

And she brought this picture out one time of my Grandma and Grandpa, their marriage picture and it was really a wild looking outfit, kind of looked like Queen Elizabeth in her hat. I always laugh at that, you know, but you know those are treasures that you get that other people don't get.

15. Mom has certain characteristics that make me want to care for her.

Sure, it's hard for me to get up every morning and fix her breakfast and go see about her and check on her. But, on the other hand, some of things that she comes out with, some of the experiences she's had in life---it's all worthwhile because when she's gone my brothers and sisters aren't going to have that.

16. Using the time that's left.

I just know that my mom's toward the final end of her life right now. And, I know someday soon, I'm not going to have her. So, that's where the tears are kind of welling up.

I mean when you've lost one parent and the other parent's just barely hanging on, it's kind of like, you know, you grasp every part, every moment of that life that you can get.

It's just like when you lose both your parents, something inside of you is gone and it's gone forever. In a sense, I mean they're always still with you---part of them. But you've lost that grasp of---just going up and hugging them or telling them you love them or they're there to tell you the same thing. That's all the part that keeps you going.

You take care of things that you have to work for to get. And it's like a relationship---if you have to work harder to get it, once you've got it, you want to hold onto it and keep it. You work harder to keep it.

Discussion:

Much of what Rosie had to say supported the themes identified in the previous four interviews. While her statements about her relationship with her Mother were stronger than in the previous interviews, I found this to be a difference in degree and not in content. I did believe, however, that a new theme was present in this interview, that is, that Rosie is making the best use of the time she has left with her parent.

The following is the summary of the themes so far, with the new theme bolded. Evidence from the first four interviews to support inclusion of the new theme is given at the end.

1. Caregiving is a normal experience. (Not present in this interview).
2. Caregiving means having conflicting responsibilities.
3. Supporting the autonomy of the other
    a. Issues of safety versus independence
    b. Easier if I had more control
    c. Issues of control versus the unknown
    d. Helping the parent compensate
    e. Her safety is important, but so is her quality of life.
4. Caregiving is being sad about the other person's decline
5. Caregiving is learning more about the other person.
6. Reciprocity
    a. We've always had a good relationship.
    b. How I treat them

        c. Caregiving is evidence of love
6. Self-discovery
    a. I don’t want to be like them.
    b. Caregiving gives me a purpose in life.
    c. Caregiving helped me recognize my priorities
8. Support
9. Wholeness of love/Paradox
10. The caregiving role happened gradually.
11. How I learned
12. Cargiving gives continuity to the life of our family.
13. Mom has certain characteristics that make me want to care for her.
14. **I’m making the best use of the time I have left with my parent**

Theme: I’m making the best use of the time I have left with them.

The fact that I’ll miss them---I would have died without my Mother. If I can just do this much to help her I would---but, I just feel like she kept me alive. She was there. She did not leave my side. I feel like I could be at her side now. (Interview 1, Jackie)

It’s kind of neat. It’s like sometimes they tell you the same three times and you never heard that your whole life till the last---it’s like maybe they want to tell us everything too before they go and they’re making up for lost time. (Interview 1, Jackie).

It’s kind of neat. It’s like sometimes they tell you the same thing three times and you never heard that your whole life till the last---it’s like maybe they want to tell us everything too before they go and they’re making up for lost time. (Interview 1, Jackie)

It means a chance to help them and see that, you know, their old age is nice and not rough or hard or anything like that and that I can be there to make sure that that’s the way it is, you know. (Interview 2, Mary)

…sometimes my daughter says to me, ‘I just wish the Lord would take Grandma. She just is so sad and so many problems’---and this and that. And, I can see that. I can understand that but yet I still want her. I guess it’s selfish, you know. I just---I still want her and I still want him and because it’s like, I don’t know how to describe it. I guess from the closeness. It’s not the same as talking to your children or your husband. There’s something different there. And, you can go up and talk and say almost anything, you know, and talk with them and stuff like that. So, it’s just I kind of don’t want to lose that, even though I know sometimes like Mom doesn’t understand. (Interview 2, Mary)

…it’s just like the difference between children, you know, but if you tell your child this or you always tell you husband this or something like that, I don’t know. It’s just something different between a parent. You know, and it’s---like I said, it’s selfish; I just don’t want nothin’ to happen to them but yet I can see that they’re just going down. I don’t like that. I wish there was some way I could do something but there’s nothing. You know, I realize that, I know that. (Interview 2, Mary)

…sometimes I think, what am I'm going to do if they're not there to talk to. You know, what am I going to do? Even though I know that I really can't do anything and stuff like that but it's like, well what am I going to do, who am I going to go tell these things to, and who am I going to talk to about all different things? I guess it's kind of like I have my husband and our memories and our children's memories, but I had my Mom and Dad and that memory. You know, we have different memories---separate memories that are not the same and they're private and this and that. And, that's our memories and so I can share and communicate that kind of stuff with them but the rest of them might not understand how that might be special to me, you know, or somethin' like that. So, I mean I'm thinking to myself. Who am I going to talk to? Who am I going to share that with, you know, when they go, you know and that's hard. You know, that's hard. It is, it just really is. I mean who am I going to talk to? (Interview 2, Mary)

I have a really hard time imagining my mother not being here and so it makes me angry when I realize that's going to happen and I want that to happen in a really dignified way. (Interview 3, Linda)

So, it's become really important to me to know her as well as I can know her before she dies. And part of that's selfish. Part of that is because I know that in knowing her, I'm going to know me better. (Interview 3, Linda)

I've really been able for the most part to take this really, um kind of attitude that I'm fortunate to still have my Mom here but I want to spend the time with her I can. (Interview 3, Linda)

And then as I have gotten older, I've become way more appreciative of who my Mom is and how who she is---is connected to who I am. So, it's become really important to me to know her as well as I can know her before she dies. (Interview 3, Linda)

…recently Mom had started talking about the fact that she isn't going to be here forever. And, I think she's doing that for both of us. You know she's not just doing it for her or for me---she's doing it for both of us. And, it isn't that she's ill or anything---it's just that she's going to be eighty-one this year, you know, she realizes her limitations. She gets tired easier. She's just a realistic person. She's a realist. And she thinks the way you prepare for things is you talk about them. (Interview3, Linda)

…you want to have a relationship with them as long as you can. And, I think once they're in a nursing home you know you're just visiting. I don't know that that's a relationship. Because to me a relationship is you're doing with them and if you're just sitting there visiting I don't know that that's a relationship. And, I think that I don't want that until it has to be that way. I want---even though it's hard and there's time when they're---you know, I----but that's what I want. And I think that's important. So, it's what we're going to do until they tell us we can't do it anymore. (Interview 4, Sally).

Interview 6: Lynn

"…but I ain't singing."

Lynn works outside the home full-time. She has been caring for her parents for a number of years. Her mother has recently moved to a care facility, and her father now lives alone in his home. He is able to do this because of the help he receives from Lynn.

The interview with Lynn revealed nineteen themes.

1. Support

I guess it's become more obvious to me how isolated they chose to make themselves. They're not from this area. My father was from New England, New Hampshire and my Mother is from Alabama and they were both only children. So, there's not a wealth of relatives or friends and this area when we were growing up is very click oriented---I should say that people who live here have lived here a long time and they can trace their family back and they know people and my parents didn't have that so they were always feeling like the odd man out. And my Father's a very reserved person.

I would like for people to appreciate the fact that all us, if the good Lord gives us enough time on this earth are going to be in a position where we're all going to need assistance at some time or another. And if everybody would try to help---not just relatives---neighbors, friends, etc., the preponderance of the responsibility would not be on one single person. And, it takes a village to raise a child. It takes a village to take care for the elderly. I firmly believe that I would probably be doing more if I didn't feel like I was the only one doing anything.

I have a brother who lives almost as close as I do. And, I'm very resentful of the fact that for two weeks when I go on vacation and I ask him to take over my responsibilities of caring for my Mother and helping with Dad, he's bitter, he's busy. I work part-time therefore I have lots of free time. I'm a nurse, I know more about it than he does. Mom doesn't make sense when he goes to visit. You know, and I'm resentful of him. And, I don't like that feeling either. That, you know, why is one child seeing the need and doing it and the other child is fighting against doing it. It doesn't make sense. We came from the same family. So, it's not like we have a lot of relatives so that's the other thing you know. We should be closer but it's just he and I and it's just two different kinds of people so…

I know that he (her brother) is extraordinarily busy with things community wise that he is involved in but unfortunately I don't have the opportunity to get involved in other things because of my commitments to my family, which I feel are paramount to volunteering with the Boy Scouts. I mean it's nice to be able to do that if you can afford the time to do it.

Sometimes it helps just to be able to talk to somebody about this. It does, believe me. Especially, you know, you don't know whether there are other people that are doing the same thing and have the same feelings. There needs to be a resource for people who are in this situation. Who are caught between generations. Because I don't think we've experienced that too much. With people living longer, we're going to see more of it.

…you sometimes feel guilty for having feelings of anger, frustration, that you shouldn't feel that way and it helps a lot of know that I'm not alone in my thinking and it's not an abnormal or a poor response to the need.
…unfortunately being a nurse compounds the issue too because obviously you're not going to have an elderly person without health issues. Always, I don't care how healthy you've been born and raised. But, that re-enforces my brother's ability to allow---force me to be the primary responsible overall person. Because I'm the quote, 'nurse' unquote.

I think this is a wonderful idea and I think that in senior programs maybe there should be some sort of support group for caregivers. There may be out there and I'm just ignorant to the fact but I guess unless someone identifies you as a caregiver you don't really see yourself in that role. You see yourself as a daughter.

1. It's tough to have to choose between responsibilities (Conflicting responsibilities).

It's a tough transition---I was talking with my husband and I said I resent the place in our life, it feels like our energy should be focused on the generations to come, our grandchildren. And, I've found myself having to refuse watching my grandchildren so that I can give care to my parents. And, I know that my children understand it to a point, but it feels like I'm letting them down but I can only do one thing at a time. I can't take a five-year old and a ten-month old to clean a house so and I wouldn't, believe me.

And, I'm not that much of a strategist that I can take care of my house, my work, my children, cause see I have three, and two grandchildren and two parents, and my husband is out of town a lot. So, I'm like the single Mom and I have been for years because of his job---which is fine, you know, I've gotten used to that now that the kids are older. But, I guess I've been used to being very self-sufficient and I guess it's just a kind of an expectation that since I work part-time, I have lots of time with nothing to do.

There needs to be a resource for people who are in this situation. Who are caught between generations.

I'm what gives for me because I'm at the bottom of that list of people that need to be taken care of--- it feels like a lot of the time.

3. My relationship with my Dad has not always been what I wanted.

It's not that I'm grieving a close relationship because my father's never had close relationships, sorry to say. He's not been an open, sharing person or someone that you could go to with a problem or concern. He was---he's very closed off about things like that--

-always has been. So, it's not that our relationship from him being a nurturing, caring, giving, supportive father even though he is all those things in his own way, it's not your typical 'Ozzie and Harriet' father.

... we've always been on speaking terms. You know we've never severed any ties of any kind. But, so far as close, as in what my perception of what having a close relationship like I have with my daughter, no.

so far as closeness of the relationship, I've got to say that since I got married and moved out and grew up more, maybe, and realized the world was not about me and what I want, we've gotten along much better---much better. I mean, it's always been cordial. I feel so sorry for both of them in their situations but unfortunately I can't change that for them. I can only try to give them something that I've always wanted to and---

4. I've learned what my Dad is really like (Learning more about the other person).

…I told you he's your typical fifties husband, who in the fifties, the husbands didn't lift a finger, they made the money and came home and got the respect and went back to work the next day and that was it. So, before Mom went to the nursing home, he had not done a dish, cooked a meal, run a vacuum, changed a bed and probably still hasn't. So, he's not evolved. He has discovered the cooking channel on TV and faithfully watches it. He has flipped from a sports fanatic to a cooking fanatic.

My kids call me a sucker---I sometimes, I sometimes feel like I've been manipulated into the situation. A round about ways that my Father has of asking me and while I'm doing them, I realize that he's smarter than I gave him credit for because I'm doing it and resenting it and then realizing, 'Well, he knew that all along.' He knew that, but he's an extremely intelligent man…

No, because in care giving I had thought at some point my Father being given the clues of how to do little things around the house would catch on as to how to do it because he'd never been instructed. And, I was wrong, I was wrong. He assumes---I felt like my Mother, that when she would do the dishes, his job would be to get out of her way. So rather than staying and talking to me, he leaves the room and goes and turns on the TV and stays out of my way until---and doesn't talk to me while I'm doing chores until I'm finished because he doesn't want to interrupt for fear that that's the end of it. She's not going to change the bed now. I don't know if that's his motivation or whether he's just---I don't know, I've never really thought about it. But I had thought that there would come a point in time where it'd be easier but the more time goes by, the more care he needs because his resources physically are diminishing and the more he's coming to rely on people, my brother and I specifically for everything. Even to taking the garbage out of kitchen to the back door.

I know that my Father has always been very rigid in his mindset. He is not an open person. He does not share, would never share feelings---as a child growing up other than, 'I'm mad at you,' directed toward me. Those feelings were never discussed, shared or mentioned and that's not changed for him.

I've heard him yell but my Father was such a stern person that he didn't usually even need to raise his voice, he could slay you with a look---just one look and whatever you were doing, ceased. I mean it wasn't abusive physically at all, I don't remember him ever, you know, spanking or hitting us but it didn't need to be because the fear was always there and I guess that's where the---he felt like respect came through fear----from the authority so---it was a little hard to get close to that. So, that part---he has eased off now because I think he's finally accepted that I am an adult. And, sometimes I even know some things---more than he does. So---that's actually, my parents and I are closer now than we ever have been.

5. I try to get my Dad to do more for himself (Supporting independence).

And, so for my children, I've learned that I don't want them----I hope that I have the faculty to appreciate where I am with my capabilities and that I can make my own decisions, which is what I've been encouraging my Father to do. Please make decisions that you want for yourself now while you still can. Before I make a decision for you that I don't know whether you want or not.

I mean I try to get him to get up and, you know, if you do nothing else, get up and get a shower, have your breakfast and then find something to do that day. One thing, just one thing to give you a reason to do something and unfortunately his routine is not that and I expect too much from him…

I don't know that I'm helping him by---I've been trying to wean myself back from doing the little running to Kroger's, the store things because I know that would give him the exercise and just the social outlet of just getting out of the house. That if I don't say, 'Hey, I'm going to Kroger's, do you need something?' If I say--- if I don't offer, maybe he would be forced to go. So in trying to do that I'm hoping that I'm motivating him a little bit. I don't know that that's happening. But, I don't---I love them and I want to help them and I can only do so much---granted.

I mean, he needs more work done on that house. My husband and I have offered to run a Rumpke thing but he feels that everything there has personal momentos. Everything, even broken crystal, when I try to put it in the garbage, 'Oh, no, no, no. That's good, you know that's a good piece.' 'But, it's broken Dad, it's worthless.' 'No, no, no, no, you can superglue it'----and he does. I don't understand. I mean he's got his father's clothes that are probably a hundred years old but are no good to anybody but he will not get rid of---call the Salvation Army, put it in the garbage because I guess of the attachment that he's not an emotional person at all.

I did get him out of the house last week…which was good…he actually went and---
I had told him that I had gotten him the doctor's note from doctor (___) to say 'OK, you're eligible now for the parking.' But, he had to go to the courthouse to get it. So, I said, 'Here it is. You follow through with it if this is what you want.' So he goes, 'Well, OK, I'm going to do that.' I started, 'What are you going to do today?' after I dropped off the groceries, 'Now what are you going to do?' 'Well, I was going to do this, that and, I was going to go

see Mom.' 'Oh, she would love that, Dad. She's missed you.' So, that made him think, 'Well, maybe I really should do it, even though I wasn't going to do it.' So, he did actually leave and I made a big deal---'How was your day? Didn't you have fun? It was beautiful weather, it wasn't too hot.' And he said, 'Oh, yeah, I did have a good time. I'm exhausted.' So, I said, 'But it's a good tired? Right? You got something done.' 'Well, yeah it is. But, I am just so tired.' 'Whatever, you got out of the house. You needed it to expose yourself to something.' Of course, the next day he needed something else. 'You've got the car key now, Dad. Use it.'

But he did hear me when I said, a few weeks ago, 'Even if you just washed one dish each time you eat off it, it will always be clean for you.' So, when I saw the dishes were clean in the sink the other day, I didn't want to bring that to his attention that I was proud of him because that would not have been good for me to acknowledge that. But, it was a pleasant surprise shall we say.

But, trying to get him to be autonomous because---and he did actually do a load of dishes in the sink. I was very impressed with that.

6. I do things to help him live on his own (Helping the parent compensate).

But just the refrigerator because his sense of smell has deteriorated. I don't know whether it's a natural sign of aging or not, but it frightens me that he can't tell when something has gone bad in the refrigerator or not. I've encouraged him to look at dates and, you know, after a week goes by, if it's still in there, throw it out but it doesn't occur to him to do that and I worry that he's going to get food poisoning. I mean something as simple as that that you wouldn't think of, it's frightening. Because I know that he's waiting for a catastrophic event you know, I mean that's the only thing that's going to change his situation. Because he's fine the way he is, he thinks.

He doesn't touch base with me but I call him daily---just to make sure that he can answer the phone and that he's---that something hasn't happened. And, I see him frequently. I mean even, you know, stoppin' by to do the dishes, change the bed, do the wash, because the laundry is on the lower level and in speaking with you before, I told you he's your typical fifties husband.

But it does---I try to--- I try to envision what their days are like and I try to make the time that I'm with each of them something that at least is a good point of the day. Even if it's just taking a pork chop to my Dad. He loves pork chops, you know. 'Here I've got dinner.' You know, you take over the occasional meal and you try to infuse a little life where you can and just to break up the monotony of the day for him because I can only image how horrible it is.

The only other thing I can add is, I do feel better about myself when I've accomplished something over there. I know I've done it and that at least for a while, you know, he can make it another day. He can eat a decent meal. I feel better having done that but that seems pretty shallow.

Well, I had told you---I told my father at one point, I'd said like after I'd cleaned and spent quite a few hours over there trying to right the things that needed to be done. I told him, I said, 'I don't know whether I'm truly helping you, but I feel like I'm just buying you just a little more time in your house.' He goes, 'I know that and I appreciate it.' So that made it worthwhile. So, OK, I'll keep doing it. Buy a little more time each week.

…because I do **care** *for my parents. That's why---I love them and without someone helping them, my father---even though there are resources out there to tap into for seniors, and he's well aware of them, he chooses not to.*

7. I worry about what will happen to my Father (Control versus the unknown).

I feel---I hate to say that you dread the thought of opening a door but when I drive by the house and his drapes are still shut at 11:00 in the morning, that means he's still asleep. When I see them still shut at noon time when I come back from the grocery store, my first thought is, 'Is today going to be the day that I find him dead? Is this what I'm walking into?' So, I have to steel myself every time to go into the house not knowing what I'm going to find. So, in the sense, I dread going in because I don't know what it's going to be. And, I dread my reaction to my impatience with him.

---distance wise, I think we're about three miles apart from where our houses are. So, in the night because there are frequent sirens up and down (__) Road, my first thought when I hear it, it's not for my children anymore, it's is it my Father? Is this the one that's going for my Father?

He doesn't touch base with me but I call him daily---just to make sure that he can answer the phone and that he's---that something hasn't happened.

I obviously can't control anything that goes on over there.

…to allow him as much independence if that what he wants to call it for as long as he is able to make those kinds of decisions. I'm willing to--- I hate to say it but I have no other choice but I've had to resign in my own head that no matter what happens, this is what he wanted.

8. My Dad's health is important, but so is his quality of life.

I have learned that even though he's a diabetic I still buy him his Hershey's with almond kisses every week. But, the compromise is his blood sugars have always been OK. So, he's within his guidelines of where the doctor wants the blood sugar. And, obviously the Hershey's Kisses are not impacting it that much and I'm not going to deprive that man of that pleasure that he derives from that piece of candy. Because, as a nurse, knowing this is something that he should not be eating---especially with the weight gain issues that he has now too but that's a compromise that we've both made.

And the compromise has been all with my ways of handling it. Not with what I'm doing there differently but just how I can justify in my own head. And the only way that I have been able *to do that for myself is just say that, 'That this is what he wants, in as much as a living will indicates what the person wants. This is what he wants.' And, not that I'm allowing it, but I'm willing to tolerate some of his---his decision-making or lack of decision-making because this ultimately is what he wants for himself. And he must be content or else he would be making noises about wanting to change.*

9. I'm not sure why I'm the one who cares for him (How I learned).

I don't know why he's---well I hate to say that the male-female thing. Whether it's always been even when I was a child, there was this take care of things and that's why I always wanted to be a nurse. I don't know whether I'm overly aggressive in seeing a need and taking care of it right now, whether than waiting for somebody else to see the glass of milk is spilled and cleaning it up.

…my Mother was an alcoholic and my Father was blind-eyed to it through my whole growing up years. He was---if you don't acknowledge it, it's not happening. If you don't talk about it, it can't be real. Well, I wasn't like that so I would…when the situations would get bad at home, I would pretty much try to lance the boil and get people to talk about it and got absolutely nothing, no cooperation from anybody wanting to deal with things. So, it was until, you know, people were in the hospital and he was on the golf course and he won't come to the hospital because he's been too many times with her and here I am a sixteen-year old kid, trying to make healthcare decisions for my Mother, because my Dad won't come in until he finishes his eighteenth because he's been through too much.

My grandmother, my mother's mother, lived with us my whole life. And, my mother---having two adult women in a household with small children, it's a continuous source of friction. Because who was actually the caregiver? Which one did you mind? Which one was the mother?

So, over the course of the years, my Mother made me promise that when and if the time ever came that she reached a point like my grandmother, that I would not take her into my home because she knew how it made her feel. That she did not want that for me. Yes, it was not good.

10. How the caregiving role evolved.

It was ah---when my Mother first was hospitalized with a nervous breakdown---I don't know what they called it, four year ago. It was like immediate. Because my Father even with as minimal of the chores that she was able to do at home, my Father was lost.

11. My Dad just doesn't do the things he used to (Being sad about the parent's decline).

And then when, you know, you try to care for him---the same situations day in and day out frequently not bathing, shaving, dressing, doesn't do the dishes. I'm concerned about the health aspects not only for his---he has a cardiac condition. He has diabetes, he has arthritis and diabetic neuropathy with his legs so his legs hurt primarily.

You lose the---well, I feel like I have lost the---I still love my parents deeply but I've lost the role of being someone who looks forward to the phone call from Mom or Dad because it's never, 'Hi, how are you? What are you doing?' It's, 'I need.' 'I want.' My Father never calls me unless there's a chore at the end of it. He never calls to say Hi, to check on how you're doing, how are the kids? It's never about that. He doesn't touch base with me but I call him daily…

---he should have realized that to eat off of a clean dish is something that's just human nature. But, he doesn't---he just doesn't seem to act in that line.

And my Father's a very reserved person. Other than golf, he did not have really any social outlet and when he became unable to play golf, he just more or less stayed in the house and hibernated. So, he doesn't have that many friends and it became more obvious what a lonely existence that is. Not to have something or someone; I've seen that his other great enjoyment used to be doing the crossword puzzles and I don't know whether his attention span is just not along that line but he doesn't do them anymore. Which is sad because that was one thing he truly enjoyed doing. He didn't like talking on the phone. Now the TV is more of a substitute entertainment for him but without that it would be a nonexistence. We want so much for him but you can't make them want it for themselves.

You know, you take over the occasional meal and you try to infuse a little life where you can and just to break up the monotony of the day for him because I can only image how horrible it is.

You do learn----when you grieve, but you maybe learn how to open your eyes to---into your own soul to find out what his situation is telling me about myself. What in his situation hurts me so badly---and I think it's his aloneness. It's just deeply saddening to see just how utterly alone he is.

…the nurturing is on my side now. Which I guess is the way it should be but he's somewhat forgotten that he's still my Father and he still has grandchildren and great grandchildren and unfortunately doesn't seem inclined to even ask about them, which is sad.

It's not that I'm grieving a close relationship because my father's never had close relationships, sorry to say. He's not been an open, sharing person or someone that you could go to with a problem or concern. He was---he's very closed off about things like that---always has been. So, it's not that our relationship from him being a nurturing, caring, giving, supportive father even though he is all those things in his own way, it's not your typical 'Ozzie and Harriet' father. It's a grieving for something that I never really had and know now that as he's declining and I'm becoming more of a caregiver that I never will have. So, it's also a grieving of something that I thought at some point in my life I was going to develop this relationship and it's not ever materialized.

12. I've learned what I don't want through the caregiving experience (Self-discovery).

I've gained a lot of insight into what I don't want for my children. I know that this just goes way back to even when I was a child. My grandmother, my mother's mother, lived with us my whole life. And, my mother--- having two adult women in a household with small children, it's a continuous source of friction. Because who was actually the caregiver? Which one did you mind? Which one was the mother?

And, so for my children, I've learned that I don't want them----I hope that I have the faculty to appreciate where I am with my capabilities and that I can make my own decisions, which is what I've been encouraging my father to do. Please make decisions that you want for yourself now while you still can. Before I make a decision for you that I don't know whether you want or not. So my husband and I have talked that we want to have, you know, something set up for ourselves so that if and when the time comes, we can step into that transition and not make our children take on the responsibility of trying to assume what we want so, it's given us a lot of forward direction.

Right because in the course of life if we live a long life, and both of my grandmothers lived to be a hundred and two, there will come a point in time where you will need help and it's help that should be obtainable from one source of another but I don't know that it's the right thing to except it to come--- to expect it to come from your children. If that makes sense.

I think I've learned that I am more short---short on patience I guess when it comes to my Father as compared with say my children because these are things that should---

And, I dread my reaction to my impatience with him.

If I were a saint I would be doing this with a smile on my face and a song in my heart, but I ain't singing.'

You do learn----when you grieve, but you maybe learn how to open your eyes to---into your own soul to find out what his situation is telling me about myself. What in his situation hurts me so badly---and I think it's his aloneness. It's just deeply saddening to see just how utterly alone he is.

Well, he's not living the way he is to frustrate me. I mean my frustration is all on my part. It's my perception. He's not frustrated, which is even sadder for me. You know, I don't know whether I'm take charge or whatever, but I guess I am because I need to find out how to not be frustrated and just accept.

…unfortunately unless you feel within yourself that you're doing good things, you know, that you feel good about it. You can't see yourself through other people's eyes. I mean, I can't see myself in that light. I mean I know what I'm doing is helping but my frustration when I'm doing it totally detracts from my good feelings about it.

I'm a fighter. It's the fighter in me. I go in kicking and screaming and wanting to right the world in one day. You know…gosh I can do this, you know, and we can change the course of *the world and I can make you see the light, you know. I can't do it. Some people have such rigid walls around them. I mean I can't make her walk any more than I can make him want to do more. And, I have to accept that about me. And, I have to learn how to tone down those feelings you know of wanting to get more for them. Because they don't want that and I am pushy about what I want for him to do.*

13. Reciprocity

You lose the---well, I feel like I have lost the---I still love my parents deeply but I've lost the role of being someone who looks forward to the phone call from Mom or Dad because it's never, 'Hi, how are you? What are you doing?' It's, 'I need.' 'I want.' My Father never calls me unless there's a chore at the end of it. He never calls to say Hi, to check on how you're doing, how are the kids? It's never about that. He doesn't touch base with me but I call him daily…

…while it's still loving and giving, it's very pointed that my Father's never been very demonstrative in affection. But, he's now because I end every conversation with 'I love you.' So, he is at least reciprocating now where he didn't use to. He will say, 'I love you,' back…

…the nurturing is on my side now. Which I guess is the way it should be but he's somewhat forgotten that he's still my Father and he still has grandchildren and great grandchildren and unfortunately doesn't seem inclined to even ask about them, which is sad.

He knew that, but he's an extremely intelligent man and he did the very best he could with us in what his upbringing was. So, I guess I just love him and I want him to know that I do and if takes me washing a dish for him to know that, you can just say you love me so many times but you know, you still have to show that you can do with somebody, you know and spend some time with them.

Well, I had told you---I told my father at one point, I'd said like after I'd cleaned and spent quite a few hours over there trying to right the things that needed to be done. I told him, I said, 'I don't know whether I'm truly helping you, but I feel like I'm just buying you just a little more time in your house.' He goes, 'I know that and I appreciate it.' So that made it worthwhile. So, OK, I'll keep doing it. Buy a little more time each week.

He hasn't seen my kids in a long time. I mean and it's not because of geographical distance between them but he's never, he's never been an affectionate---or it's more critical with him. And, to mow grass, ' you missed a spot. You didn't weed eat. There's grass on the driveway,' to the point of where being when they were younger, it hurt them so badly, you know, 'I didn't do it well enough.' And they would come home in tears to the point of where I just started doing the grass myself rather than subjecting my children to--- unfortunately to their eyes was extremely ungrateful and critical but he frequently forgets to say 'Thank you.'

And, I'm thinking he knows that more by my actions. Although the words to him are almost painful for him---to see him say, 'I love you,' for the first few times was kind of painful, *because he wasn't used to saying that. And, it took a while for him. Now, it kind of rolls off the tongue for him. He's getting used to that too.*

14. I love my Father and accept who he is (How I treat them).

…while it's still loving and giving, it's very pointed that my Father's never been very demonstrative in affection. But, he's now, because I end every conversation with 'I love you.' So, he is at least reciprocating now where he didn't use to.

…it's not--- the nurturing is on my side now. Which I guess is the way it should be…

…because I do care for my parents. That's why---I love them and without someone helping them, my Father---even though there are resources out there to tap into for seniors, and he's well aware of them, he chooses not to.

…I've never seen my Father cry. I've never seen my Father---I've seen him mad. But, I've never seen him affectionate because he is of the Polish-New Englandish---New England background where you---emotions were not displayed period And, so he's got a different mindset. So, it's his pride probably prevents him from thinking that he needs anything. At least I know that and I accept that about him so I don't ask and I just step in and do it. That's why I do what I do.

Well it means I have less hours to pamper myself, ha, ha. But it does---I try to--- I try to envision what their days are like and I try to make the time that I'm with each of them something that at least is a good point of the day. Even if it's just taking a pork chop to my Dad. He loves pork chops, you know. 'Here I've got dinner.' You know, you take over the occasional meal and you try to infuse a little life where you can and just to break up the monotony of the day for him because I can only image how horrible it is.

Eskimos had a different idea ---about the elderly and that's not what you want but that's unfortunately what a lot of people's feelings seem to be. Why do you do all that? Well, they're my parents.

15. Caregiving is evidence of love.

So, I guess I just love him and I want him to know that I do and if takes me washing a dish for him to know that, you can just say you love me so many times but you know, you still have to show that you can do with somebody, you know and spend some time with them.

It needs to be done and I see the need, therefore I do it. I don't know whether it makes me too aggressive. Cause I could very easily turn around and walk out the door. But, he needs me to do something and I'm there. Even though he doesn't know he needs it, you know. I know it, so therefore I do it. I just, I love him, I want more for my Dad than he wants for himself right now. And, I guess that's the bottom line.

But, the big thing for me has been, you have to accept people for what they are, not what you want them to be. So, my display of love for them is my way of doing it. They have their own ways that maybe I'm just not interpreting of saying I love you to me, even though it's without words. And I'm still looking for where it is, what nuance, what look I've missed that tells me and I'm still looking. I know it's there somewhere I just haven't discovered which unspoken part it is. So, it's there. It's just a matter of finding it. That's all.

16. My Dad can be very frustrating to me (Paradox).

It's somewhat frustrating because of things that I want for him to do, he doesn't feel inclined to do. He has very limited energy. He's extremely depressed I guess about his situation but doesn't acknowledge that fact. That he's depressed. He is not motivated.

And, with Mom in a nursing home, he's not inclined to participate in his own care much. Now as far as his medications, he's very religious, very good about taking them. He just forgets sometimes to tell me that the medications are due today that I need to go pick them up for him today. Or, I've got my insulin but I have no syringes.

My father doesn't drive as much---probably self-imposed---that he doesn't visit her as much as he should I mean in my opinion. But, that's just my opinion.

Well, bless his heart, my Father doesn't really work on any assumptions. He's just waiting. He's not---he's not proactive. He waits for something to happen and for a while before he's motivated to do anything about it. He doesn't think ahead, plan ahead from day to day, let alone, you know, hour to hour.
…he's your typical fifties husband. Who in the fifties, the husbands didn't lift a finger, they made the money and came home and got the respect and went back to work the next day and that was it. So, before Mom went to the nursing home, he had not done a dish, cooked a meal, run a vacuum, changed a bed and probably still hasn't. So, he's not evolved.

I feel---I hate to say that you dread the thought of opening a door but when I drive by the house and his drapes are still shut at 11:00 in the morning, that means he's still asleep. When I see them still shut at noon time when I come back from the grocery store, my first thought is, 'Is today going to be the day that I find him dead? Is this what I'm walking into?' So, I have to steel myself every time to go into the house not knowing what I'm going to find. So, in the sense, I dread going in because I don't know what it's going to be. And, I dread my reaction to my impatience with him.

Well, I had told you--- I told my father at one point, I'd said like after I'd cleaned and spent quite a few hours over there trying to right the things that needed to be done. I told him, I said, 'I don't know whether I'm truly helping you, but I feel like I'm just buying you just a little more time in your house.' He goes, 'I know that and I appreciate it.' So that made it worthwhile. So, OK, I'll keep doing it. Buy a little more time each week.

17. Caregiving affects the strength of our family ties (Continuity to the life of our family).

I have a brother who lives almost as close as I do. And, I'm very resentful of the fact that for two weeks when I go on vacation and I ask him to take over my responsibilities of caring for my Mother and helping with Dad, he's bitter, he's busy. I work part-time therefore I have lots of free time. I'm a nurse, I know more about it than he does. Mom doesn't make sense when he goes to visit. You know and I'm resentful of him. And, I don't like that feeling either. That, you know, why is one child seeing the need and doing it and the other child is fighting against doing it. It doesn't make sense. We came from the same family. So, it's not like we have a lot of relatives so that's the other thing you know. We should be closer but it's just he and I and it's just two different kinds of people so---

I don't know why he's---well I hate to say that the male-female thing. Whether it's always been even when I was a child, there was this take care of things and that's why I always wanted to be a nurse. I don't know whether I'm overly aggressive in seeing a need and taking care of it right now, rather than waiting for somebody else to see the glasses of milk is spilled and cleaning it up. I don't know why the difference is. I know that he is extraordinarily busy with things community wise that he is involved in but unfortunately I don't have the opportunity to get involved in other things because of my commitments to my family, which I feel are paramount to volunteering with the Boy Scouts. I mean it's nice to be able to do that if you can afford the time to do it.

So, over the course of the years, my Mother made me promise that when and if the time ever came that she reached a point like my grandmother, that I would not take her into my home because she knew how it made her feel. That she did not want that for me. Yes, it was not good.

> 18. My Dad doesn't do things that I wish he would (My parent has certain characteristics that make me want to care for him).

You lose the---well, I feel like I have lost the---I still love my parents deeply but I've lost the role of being someone who looks forward to the phone call from Mom or Dad because it's never, 'Hi, how are you? What are you doing?' It's, 'I need.' 'I want.' My Father never calls me unless there's a chore at the end of it. He never calls to say Hi, to check on how you're doing, how are the kids? It's never about that. He doesn't touch base with me but I call him daily…

…the nurturing is on my side now. Which I guess is the way it should be but he's somewhat forgotten that he's still my Father and he still has grandchildren and great grandchildren and unfortunately doesn't seem inclined to even ask about them, which is sad.

I took him out to dinner last week and there's a sports TV on behind me and I was trying to make conversation. Of course, when you think about the conversation that you have, it's dealing with the experiences of the day and things. Well, his days are the same so he has no resource for conversation. And, as I'm trying to make conversation with him about everything I can think of, I see that he's not answering me and I keep looking at him and he's focusing above my head and I turn around and he's watching the TV, which is what his *pattern is at home. The TV is really his source of entertainment and I thought---I could just sit here and eat and not make conversation because he's entertained. So, I thought it was pretty funny. Yeah, bless his heart.*

Well, I had told you--- I told my father at one point, I'd said like after I'd cleaned and spent quite a few hours over there trying to right the things that needed to be done. I told him, I said, 'I don't know whether I'm truly helping you, but I feel like I'm just buying you just a little more time in your house.' He goes, 'I know that and I appreciate it.' So that made it worthwhile. So, OK, I'll keep doing it. Buy a little more time each week.

19. I'm making the best use of the time I have left with my parent.

So, I guess I just love him and I want him to know that I do and if takes me washing a dish for him to know that, you can just say you love me so many times but you know, you still have to show that you can do with somebody, you know and spend some time with them.

I know I've done it and that at least for a while, you know, he can make it another day. He can eat a decent meal. I feel better having done that but that seems pretty shallow.

Well, I had told you--- I told my father at one point, I'd said like after I'd cleaned and spent quite a few hours over there trying to right the things that needed to be done. I told him, I said, 'I don't know whether I'm truly helping you, but I feel like I'm just buying you just a little more time in your house.' He goes, 'I know that and I appreciate it.' So that made it worthwhile. So, OK, I'll keep doing it. Buy a little more time each week.

But, the big thing for me has been, you have to accept people for what they are, not what you want them to be. So, my display of love for them is my way of doing it. They have their own ways that maybe I'm just not interpreting of saying I love you to me, even though it's without words. And I'm still looking for where it is, what nuance, what look I've missed that tells me and I'm still looking. I know it's there somewhere I just haven't discovered which unspoken part it is. So, it's there. It's just a matter of finding it. That's all.

Discussion:

The interview with Lynn was very different in tone than those with the other women. While it was different in tone, the themes were not different. Lynn simply provided a greater breadth to the understanding of the themes. Things that were described as components of the caregiving experience by other participants were discussed by Lynn in terms of their absence. The area in which this was most noticeable was in her relationship with her father over the years. The other women had described their relationships as being good throughout the years. Although varying levels of closeness had been described, they all considered the relationships to have been positive. Lynn, however, moved the bar farther out as to the nature of the relationship. While she did not describe her relationship with her father as being bad, neither did she find it to be what she had wanted. It was evident from the interview, however, that the relationship was of great significance to her. No new themes were elicited in the interview. However the wording of one variation within the theme of reciprocity was changed to reflect the broader scope brought forth by Lynn. The variation of the daughter having always had a "good" relationship with her parent was changed to reflect the presence of a "significant" relationship.

The following list reflects the themes and variations at this point of the study.

1. Caregiving is a normal experience. (Not present in this interview).
2. Caregiving means having conflicting responsibilities.
3. Supporting the autonomyof the other
    a. Issues of safety versus independence
    b. Easier if I had more control
    c. Issues of control versus the unknown
    d. Helping the parent compensate
    e. Her safety is important, but so is her quality of life.
4. Caregiving is being sad about the other person's decline
5. Caregiving is learning more about the other person.
6. Reciprocity
    a. We've always had a significant relationship.
    b. How I treat them
    c. Caregiving is evidence of love
7. Self-discovery
    a. I don't want to be like them.
    b. Caregiving gives me a purpose in life.
    c. Caregiving helped me recognize my priorities
8. Support
9. Wholeness of love/Paradox
10. The caregiving role happened gradually
11. How I learned
12. Cargiving gives continuity to the life of our family.
13. Mom has certain characteristics that make me want to care for her.
14. I'm making the best use of the time I have left with my parent.

Participant 7: Victoria

“you can do what you can do”

Veronica is a young woman who has been caring for her parents all of her adult life. Her mother was recently placed in a rest home. Veronica continues to support her father who lives in his own home despite numerous serious medical problems. Veronica chose to meet the researcher at a local diner in her community for both interviews.

The interview with Veronica yielded the following fourteen themes. No new themes or variations were found.

1. I have a lot of different responsibilities (Conflicting responsibilities).

It’s fulfillment because I know that I can—He can stay in his home and he doesn’t have to go to a nursing home like we had to do with my mother. But, yet in the same breath it’s difficult because I also have two children I have to raise also. But it’s fulfilling but also aggravating and stressful at the same time. But we compensate for me taking away from my kids and having to do for him and we all get along fine. So, it works out.

And, you know, I had to put my mother into a nursing home, so I could take care of my father, because I couldn’t take care of them both. ‘Cause it’s really difficult to try to raise your own family on your own, being a single parent as I am and take care of another family in the process of it.

People need to know how hard it is. To---you know, give the effort and the time to your parental family, as well as your own family. And, it does get difficult, it does get hard, it gets time consuming but it’s rewarding to me.

Well, the kids always come first, OK. And, my parents, both of my parents know that my kids come first. And if something happens to where I can’t really be with them because I’m helping my Mother out, then they’ll go to Dad, and Dad will do something with them. And, you know, it used to be vice versa, because Mom’s in a resting home now. Resting home---I’m sorry, that’s what (___) calls it, my youngest---but that she’s in a rest home now, it’s kind of a little more difficult but the kids know that Mom and Dad are both ill and they do understand that Mom has to be here and Mom has to be there.

It’s hard because there’s not enough hours in the day to keep my home up, keep his home up, take care of my kids, take care of him and work and you know, my laundry, his laundry, my cooking, his cooking. That’s the hard part.

2. Support

But ever since I was a young child, both of my parents have been ill. So, when my older sister got married back in 1978, I've been the only one there to take care of them so…

I get my support from my family, my friends and a big deal of it from my church. I have been lucky enough that one of the elders in my church just happens to be my supervisor at work. And, they're also my second Mom and Dad. Their oldest daughter was my best friend all through our childhood years and they did things with me and took me places and stuff that my parents couldn't, because of their health issues. So, their family has supported me a 110%. They've seen all the tears. They've got the phone calls at 3:00 in the morning when I've been, 'Oh, no, what am I going to do?' And, just you know, anybody that will listen, basically is my support. And, I've come to find out if you do talk about it instead of being upset about it all the time, that it does help you deal with it on an emotional basis. And, that if you've got somebody that believes in you which I have friends that believe in me. My supervisor believes in me. Then you can conquer anything that God gives you.

…I've come to find out through a lot of hard times that you do need the fellowship of Christian people and of the church. And, the church has helped me out just going in there and being able to silently meditate and pray during our worship services every Sunday. I can feel the strength that God bestows on a person to deal with life's hardships.

3. I've learned a lot about both my parents through caregiving (Learning more about the other person).

It's made us closer. It's made us a lot closer. Yeah, we joke around more and tease each other a little bit more and I have a new found respect for him and he has a new respect for me that neither one of us has known before and I've taken legal guardianship with my Mother now. So, now it's like I do have that daughter that I never had. Because now I'm my Mother's parent, as well as my Dad's caregiver. So, yeah. Much closer.

Ah, yes, quite a bit. I know we're discussing my Father to be the one that lives at home. But, I've learned that I've never known my Mother because my Mother's been sick since way before I was born. And I did not realize this until seven months ago. That I don't even know who my Mother is. So I've realized that and I've realized the emotional stress and the physical stress that my Father has been put through having to care for my Mother when she was living at home.

I mean my Father had a stroke when he was twenty-seven, he's had four heart attacks, three open heart surgeries and he's now on peritoneal dialysis for his kidney. And, I've learned that my Father will not give up. He's not a quitter. And, if he would be a quitter then my children would not have a grandpa, and I wouldn't have a Dad. He's very strong willed. I think I might be able to get that from him during all this. Maybe, I don't know.

…but just being able to, you know, spend more time with him since I do have to go over there so much that, you know, I know his personality a little bit better.

4. I’ve always been close to my parents (Always been close).

We’ve always been close. I mean I’ve always been Daddy’s little girl…

I’ve always had a close relationship with my parents.

5. I try to keep my Dad able to live on his own (Supporting the parent’s independence).

I live in the same house that I was born in, I’ve been in the same house for thirty-four years. When it got too big for them, they moved next door and I continued to stay where I am so I can be close to them and take care of them.

Um, well it means that I can help him remain in his home. I mean he’s spent his entire life working for what he has now and why should he have to give that up because he needs help with certain things. He should be able to keep all that and you know enjoy what he’s worked for all his life and be able to keep it. And, if he would get to the point to where I couldn’t take care of him then he’s going to end up in a nursing home like my Mother and I can’t see him doing that because he’s too strong willed and tries to be too independent to be confined like this. This gives him his freedom. It gives him his freedom so he can still get up in the morning and make his coffee and get dressed and go to (his hobbies) and it gives him his freedom. And I want him to have his freedom because I know what he put up with when he had to care for my mother. And, it’s his time. It’s his time to have his freedom to be able to do what he wants to do and if I can continue to help him remain in his home to give him that freedom, I will.

6. I’ve had to care for my parents most of my life (How I learned).

Um, ever since I was thirteen years old and I’m thirty-four now but--- that was both parents until we recently put my mother into a nursing home. But ever since I was a young child, both of my parents have been ill. So, when my older sister got married back in 1978, I’ve been the only one there to take care of them so----

It’s all I’ve ever known. It’s all I’ve ever known since my sister got married when I was ten years old, I’ve cooked, cleaned, did laundry, you know, taken over the household duties. Because my Mother was ill, my Dad was ill. I had---when I was thirteen I had one in Lexington and one in Cincinnati at the same time in different hospitals. So, it’s---to me it’s nothing.

You just---you do it. Nobody is going to do it for you. You just---you know you have to do it. If you don’t do it, it’s not going to get done.

7. I’ve learned a lot about myself through caregiving (Self-discovery)

I’m a stronger person than what I thought I was. I can emotionally handle a lot of stress in my life that I never thought I’d be that strong willed to do that. But, I’ve proven to myself *that if I can make it through what I've made it though the past year, that I handle anything that God would happen to put in front of me.*

I mean my Father had a stroke when he was twenty-seven, he's had four heart attacks, three open heart surgeries and he's now on peritoneal dialysis for his kidney. And, I've learned that my Father will not give up. He's not a quitter. And, if he would be a quitter than my children would not have a grandpa, and I wouldn't have a Dad. He's very strong willed. I think I might be able to get that from him during all this. Maybe, I don't know.

You do what you have to do because your time will come. OK, I'm going to be, you know, sixty-eight years old and hopefully I'm going to be a little healthier than my father but nevertheless I'm going to be at that age, hopefully, God willing one of these days and my children are going to have the say so over the care that I get and I hope that they see me take care of my parents the best that I can and they're going to return that favor when I get that age and not discard me. I know, I used to work in a nursing home, I dispatched for a police department for five years, I know all about the elderly abuse and about how people do just discard them and forget about them and just leave them there and never go visit. And, I don't want that. And, I don't want that for either one of my parents, so---I guess that's about all I can give you on that answer.

I know I'm just like him, you know, I was always wondering which parent because usually your children end up being either their Mother or their Dad. And, I'm my Dad. You know, I've come to find that out.

8. I want to pay my Dad back for everything he's given me (Reciprocity).

Yeah, I feel like I'm paying him back for everything he's done for me for my life. Because he's helped me out financially, he's helped me out emotionally, two marriages, two divorces, kids without a Dad, you know, he's help take over the role of being a male figure in my children's lives as well, being a PaPa. And, I feel like I owe him so much because he's given me so much. So, I feel like it's not my obligation but also my duty to take care of my parents.

Because I love him, you know, I mean I love both of my parents dearly and not to say that you know, everybody has problems with their parents throughout their years---but if it wasn't for my Mother and my Father, especially my Father because my Mom, you know, hasn't been, I guess healthy for a long, long time. So, it's mainly been my Dad that has taken care of me, you know, he raised me, not my Mother. My Dad raised me and I'm Daddy's little girl, I guess you could say and---you know, I owe him so much that it's just----it's my obligation and my duty to make sure he's taken care of. You know, I owe him that much for everything that they did for me.

And, I see the same appreciation in my Dad. If I go over, you know, be bop over about six o'clock, 'Hey, Daddy, I'm cooking supper. Do you want supper tonight or do you want to grab and sandwich or what do you want?' And you know, when he looks at me I can see that he appreciates me and he doesn't take me for granted. And, it---that makes it all OK, you know.

I've put my life on hold for them. And, I owe it to them. But you know as soon as---I don't want my parents to pass on but it's inevitable. You know, you're born for one reason and the reason you're born is so you can die. And, when they're gone, so am I. I'm packing up and I'm going do what I want to do and live where I want to live and so on and so forth. But until that day happens, I'm obligated to stay here and take care of them.

What would they have done for me? You know, I've got two great kids, I'm here, they gave me life. You know, they've helped me out. They helped me buy the home that I was born and raised in, you know. So, it's just I---you know, it's my responsibility.

Because he's given up so much for, you know, my Mom and the rest of us girls and everything. That it's his time to live his life and to do what he wants to do.

Yes, it's a payback. It's a payback for what they've given me.

9. I want my Dad to be happy (How I treat him)

It means that I can help him remain in his home. I mean he's spent his entire life working for what he has now and why should he have to give that up because he needs help with certain things. He should be able to keep all that and, you know, enjoy what he's worked for all his life and be able to keep it. And, if he would get to the point to where I couldn't take care of him then he's going to end up in a nursing home like my mother and I can't see him doing that because he's too strong willed and tries to be too independent to be confined like this. This gives him his freedom. It gives him his freedom so he can still get up in the morning and make his coffee and get dressed and go to (his hobbies) and it gives him his freedom. And I want him to have his freedom because I know what he put up with when he had to care for my mother. And, it's his time. It's his time to have his freedom to be able to do what he wants to do and if I can continue to help him remain in his home to give him that freedom, I will.

If they love their parents, they will do everything in their power to let their parents have their freedom when they get into their older years and not discard them or you know, 'Well, I've got a family. I don't have time to take care of you so therefore we're going to put you into a nursing home.' And, you know, I had to put my Mother into a nursing home, so I could take care of my Father, because I couldn't take care of them both. But, if you love your parents and you want to see your parents happy in their older years and you do what you can. You can do what you can do.

It's like, he's going to the movies tonight. He's been to three movies since I've taken over the care of my Mother as well. And, I think this is the first time he's actually been to the movies probably in twenty-five years. So, he's doing what he wants to do now and I feel like I've helped him be able to accomplish that.

Because there's a lot of people out there I think the only reason they are taking care of their parents is because they feel so guilty because they've never been there for their parents and *they've taken their parents for granted. And, you know I'm not that way. I've been there for my parents since day one.*

10. I give up things to help my Dad but I want to (Paradox)

It's fulfillment because I know that I can—He can stay in his home and he doesn't have to go to a nursing home like we had to do with my Mother. But, yet in the same breath it's difficult because I also have two children I have to raise also. But it's fulfilling but also aggravating and stressful at the same time. But we compensate for me taking away from my kids and having to do for him and we all get along fine. So, it works out.

Ah, yes there is. I want to move. I've been in Kentucky---I live in the same house that I was born in, I've been in the same house for thirty-four years. When it got too big for them, they moved next door and I continued to stay where I am so I can be close to them and take care of them. And I would like to get another job and move and, you know, go live my life. But until they're gone and passed away, I'm stuck where I'm at, which is fine---it's fine with me, you know, I don't want to leave them alone with not having anyone there.

It's all I've ever known. It's all I've ever known since my sister got married when I was ten years old, I've cooked, cleaned, did laundry, you know, taken over the household duties. Because my mother was ill, my dad was ill. I had---when I was thirteen I had one in Lexington and one in Cincinnati at the same time in different hospitals. So, it's---to me it's nothing. It's basically a breeze. It's just there's not enough hours in the day to get everything done I'd like to get done. But, other than that, it goes well. People need to know how hard it is. To---you know, give the effort and the time to your parental family, as well as your own family. And, it does get difficult, it does get hard, it gets time consuming but it's rewarding to me. It is so rewarding to be able to help him out so he can continue on with his life.

It does get raveling at some times.

…it just depends on what kind of day I'm having or what kind of day he's having. And if I've had a hard day, then it's going to be hard that day. If I'd had an easy day, it's going to be an easy day.

11. I can't stand to think about my dad not being here (Grieving the decline of the other).

Now, if something were to happen to my Dad, yeah, I'll probably be done for. I'll probably be done for--- I'm not even---I know it could be this afternoon but I'm not---don't even like to think about it. Don't even want to prepare for it, nothing like that. Not a thing; no way. It's kind of hard.

12. I can't control what happens (Issues of control versus the unknown).

But if I worry about what the future's going to hold and what I have to do in the future, than I can't make a good present. So, you know, if something were---if he were to have another heart attack next week. Then I'll deal with it next week. There's no sense in dealing with it today. Because you don't, you don't know what the future is going to be and so you just take it day by day and enjoy them while they're here…

You know, you've just got to do it day by day.

And, there's no sense in worrying about the future because nobody knows what the future holds. So, you take it day by day and if the waters would flood, then you'd cross the bridge when you get to it. You know---cause I would drive myself crazy worrying about what I'm going to do if something happens---if they get sicker or so on and so forth. So, just you deal with it as it comes.

13. Caregiving is what families do (Continuity of our family)

Well, I guess I have a story. Where we are sitting at right now, like I told you before, my cousin owns this place. And, it's my uncle (___)'s youngest daughter, my Dad's sister's husband, and he was diagnosed with kidney cancer, probably five years ago and he beat it. Now, his lung cancer's come back. He's got lung cancer now. And, I've watched a very virile, virile---however you say it, man that would pick me up and throw me over his shoulder like a sack of flour when he was seventy, turn into a very frail, very distraught man. And, I see what my cousin (___) and my cousin (___), which is his other daughter, and his wife, which is my aunt (___), I see the pain in their eyes, but only I see the pain in his as well because he knows that his days are numbered. And I also see the appreciation and the respect that he has for his family because he's still at home. You know, they didn't put him in a cancer treatment facility and say, "Well, you know, you're there to die. You know, we're going to take care of you as long as we possibly can take care of you." And, it's very, very hard on my aunt to take care of him. And, I see the same appreciation in my Dad. If I go over, you know, be bop over about six o'clock, "Hey, Daddy, I'm cooking supper. Do you want supper tonight or do you want to grab and sandwich or what do you want?" And you know, when he looks at me I can see that he appreciates me and he doesn't take me for granted. And, it---that makes it all OK, you know. So, that's about it.

And when they did put her in a rest home, they put her in a rest home up the street so we could still go in and see her and my Dad went twice a day religiously, like he does my Mom now. Which we've cut my Mom's visits down to once a day, but that's no problem.

And, when I was six and seven years old I was around people fifty and fifty-five, and that's all the time growing up I would hear, "Well, this daughter did this. And my son did this." And, so on and so forth and it's like how could you do something like that to your parents. How could you just, OK, I'm grown up, I'm married, I've got my own kids, I'm moving away to, you know, five states away and you're going to see me once every two or three years. You know, families aren't supposed to do that. Families are supposed to stick together. So, I'm selfish I guess, I don't know, but yea, I don't want to be like that.

14. Using the time we have left

If the information goes out to anybody, just that keep a hold of your parents as long as you can because they're not going to be around and when they're gone and you go to pick up the phone to call them because you need something or because you want to talk. And, they're not there, then it really puts in perspective---did I do everything that I could for them? And, I'm going to know when my parents are gone that I did everything possible that I could for them and I'm not going to have any guilt at their funeral. You know, the only thing I'm going to----you know, I'll have a lot of tears but I'm going to be one of the people up there that know that they're looking down on me with respect and not, 'Well, she should have done this for me. And, she should have done this for me.' I'm going to know in my heart that I did everything that I could to take care of both of them. So, that's it.

Because you don't, you don't know what the future is going to be and so you just take it day by day and enjoy them while they're here…

Discussion:

The interview with Victoria supported the themes as they existed at this point, and no new themes were identified. Because data saturation had occurred, no further interviews were conducted.

In considering the final list of themes, I determined additional changes were appropriate. Reciprocity had stood as an independent theme as had the fact that the parent's characteristics affected the caregiving relationship. Reciprocity, however, has gradations of meaning. A person may wish to help another individual in return for those things the individual has done for him or her in the past. For example, the daughter may wish to care for a parent in return for the care given to her by the parent in the past. Reciprocity, however, also can exist in the give and take of the current relationship. A human being may feel drawn to help another because of the ongoing characteristics and behaviors of the other person. In this case, the daughter may be drawn to care for the parent because of qualities in the parent or things the parent does. For this reason, the theme of parental characteristics was moved to be a variation of reciprocity.

Another change concerned the themes of how the caregiver learned and the fact that the caregiving role happened gradually. These two themes deal with how the daughter became a caregiver. These are part of the daughter's evolution as a person and as such were considered to be variations of that theme.

The final themes are as follows:

1. Caregiving is normal human behavior. (Not present in this interview).
2. Caregiving means having conflicting responsibilities.
3. Caregiving is supporting the independence of the other
    a. Issues of safety versus independence
    b. Easier if I had more control
    c. Issues of control versus the unknown
    d Helping the parent compensate
    e. Her safety is important, but so is her quality of life.
4. Caregiving is being sad about the other person's decline
5. Caregiving is learning more about the other person.
6. Reciprocity
    a. We've always had a significant relationship.
    b. How I treat them
    c. Caregiving is evidence of love.
    d. My parent's characteristics affect my desire to care for him.
7. Self-discovery
    a. Caregiving helped me recognize my priorities.
    b. The caregiving role evolved gradually.
    c. I evolved as a caregiver.
    d. How I learned.
8. Support
9. Wholeness of Love/Paradox
10. Cargiving affects the continuity of our family.
11. I'm making the best use of the time I have left with my parent.

Composing Linguistic Transformations

Van Manen (1997) states that as the themes emerge, the researcher should attempt to move the ideas to a level that is "more phenomenologically sensitive" (p. 95). This process builds on the methodological assumption that words have power. It is a hermeneutic activity that fosters the researcher's attempt to convey the depth of the human experience embodied in the theme. To achieve the linguistic transformation, van Manen (1997) indicates that the researcher should write her thoughts about the theme in order to discover the meaning entailed in it. This process was carried out with the final eleven themes.

The first theme evolved as the idea that caregiving is what people do. This implies that it is a human characteristic, something that all human beings would do. If it is a standard for human behavior then it could be called a normative behavior. The first theme identified was that caregiving is a normative human behavior.

Caregiving was described as a situation in which the caregiver has conflicting responsibilities. The women in this study described feeling torn between the responsibilities of caring for their aged parents while at the same time being present to their dependent children, their spouses, and their jobs. Each of these domains is integral to who the caregiver is. They are her lifeworld, areas from which she cannot simply extricate herself. While each area of responsibility is part of the woman's lifeworld, they do not always overlap, and they often conflict with one another. What the women described was the sense that caregiving is being torn between worlds.

The women in the study described having conflicting feelings about the caregiving experience. Many of the feelings were positive and many were negative. All of these feelings arose within the context of wanting to help their parents, a goal to which all of the women were committed. That sense of commitment enfolded the sometimes incongruent feelings the women experienced. Commitment is not simple. It is not always a positive experience. Sometimes it is difficult and sometimes it is overwhelming. But in a committed relationship, the people involved stay the course, even in the presence of difficulties. The daughters in this study were embracing the wholeness of commitment.

The women discussed the need for support. Although all of them tried individually to do the caregiving, they discovered that while the demands of caregiving were inexhaustible, they themselves were not. They discussed feeling challenged to the extreme and not being able to fulfill all of their roles without the help of others. What was described was caregiving as a crucible of individual human effort.

The women had much to say about their own development throughout the caregiving process. They discussed what they had learned about themselves, things that were both positive and negative. They discussed how they had grown and how they had come to recognize what was important to them in life. They described caregiving as a means of self-discovery.

The impact of caregiving on familial links across generations and within generations was an important aspect of the interviews. For most women, but not all, the caregiving experience was viewed as one that pulled the family closer together. Those for whom this was not the case discussed their realization that family bonds were being tested and strained. Caregiving was described as a thread that can weave a family together or cause it to pull apart.

Caregiving was described in terms of give and take, of fairness. The parents had cared for the daughters when they were in a dependent position and now the daughters would do the same for the parents. The journey through life was seen as one of mutual support. From a global life perspective, the parents had given to the relationship during the early part of the daughters' lives and the daughters were giving back to the relationship during their middle years. The give and take was not described as all or nothing, however. The parents were not viewed as now taking only, just as the daughters had not only taken during their youths. The process continued in both directions into the present, so that caregiving was described as an experience of reciprocity.

The relationships between the daughters and the parents for whom they cared were strengthened. Each of the daughters reported growing closer to her parents through the caregiving experience. Part of this increased closeness was a greater understanding of and appreciation for who the parent was as an individual. What these women described was, that for them, caregiving is a doorway to intimacy.

A significant aspect of caregiving was the daughters' attempts to support the independence of the parents. Although the degree of independence possible varied greatly, the effort to maintain it was present in each situation. The efforts of the daughters, however, seemed to be aimed at maintaining something more than independence for their parents. They attempted to let their parents function as themselves as much as possible. The focus was not so much on the parent being able to do things for the sake of the things themselves, but rather for the sake of the parents being themselves. The daughters were striving to maintain the parents' sense of identity as autonomous human beings. Caregiving was identified as the attempt to maintain the autonomy of the parent.

The relationships between the women of the study and their parents were long standing relationships. The role of being a child to the one for whom she is caring means the parent has been a significant factor in the caregiver's life, for all of her life. The relationships were not without problems and disappointments, nor were they all happy. What they had in common, however, was that they were significant. One's parent is central to one's life. When that parent begins to fail, it impacts the child, no matter what the child's age. The foreseen death of a parent is a central loss to a person, and for these daughters, caregiving involved grieving the decline of the parent.

The parents in this study were frail and elderly. The trajectory of their lives was toward conclusion rather than beginnings. The daughters expressed awareness that their parents would not always be with them; the finiteness of life was appreciated. Children often think of their parents as immortal. It is difficult to imagine one's parent no longer being present in life. We say the words but the reality often does not sink in easily. The daughters in this study had come to the emotional acceptance that their parents would not always be alive. Having accepted that reality, the daughters viewed their caretaking role as an opportunity to use the remaining time to its best advantage. What constituted the best advantage was different from daughter to daughter. For some it was to enjoy the parent; for some it was to respect the parent's wishes; for some it was to try to achieve a level of intimacy not yet achieved. But for all of the caregivers, the caregiving experience was an opportunity to make the best use of time left with a parent.

Determining Incidental and Essential Themes

Van Manen offers multiple definitions of themes, each getting at some aspect of what a theme is and what it does. Several of these get precisely at the heart of the matter. A theme is "the experience of focus, of meaning, of point;" it is "the form of capturing the phenomenon one tries to understand;" "it is the sense we are able to make of something;" and finally, "it is always a reduction of a notion" (van Manen, 1997, pp. 87 - 89). The themes elicited from the participants are the sense the researcher was able to make from the interviews. In the second interview with each participant, the women validated that the themes captured their experiences. However, in order to be considered an essential theme, the standard is higher. In order to be essential, a theme must “contain qualities that make a phenomenon what it is and without which the phenomenon could not be what it is” (van Manen, 1997, p.107).

Eleven themes were gleaned from the interviews, as well as thirteen variations of those themes. The variations need not be present in each interview. Instead the variations yield depth and dimension to the experience of the themes. However, to be essential, the themes should be present in some way in the experiences of each woman. This was true for all of the themes except one, that caregiving is a normative experience. While some women did express their belief that this was true, the topic did not emerge in several interviews, and some participants actively disagreed with the idea. Thus caregiving as a normative experience was dropped as an essential theme. The other ten themes, however, were found to be essential to the participants’ understanding of their caregiving experiences. The essential themes and their variations are presented in Table 2.

Table 2

Essential Themes and their Variations of Daughters Caring for their Frail, Elderly Parents in the Home

Themes	Variations
Caregiving is being torn between worlds.	
Caregiving is embracing the wholeness of commitment.	
Caregiving is a crucible of individual human effort.	
Caregiving is a means of self-discovery.	Recognition of priorities Evolution of the caregiving role Evolution as a caregiver How the caregiver learned
Caregiving is a thread that can weave a family together or cause it to pull apart.	
Caregiving is an experience of reciprocity	Presence of an ongoing significant relationship How I treat my parents Evidence of love Effect of parental characteristics on caregiving
Caregiving is a doorway to intimacy.	
Caregiving is the attempt to maintain the autonomy of the parent.	Issues of safety v. independence Perceived need for more control Issues of control v. the unknown Helping the parent compensate Issues of safety v. quality of life
Caregiving is grieving the decline of the parent.	
Caregiving is making the best use of the time left with a parent.	

Gleaning Thematic Descriptions from Artistic Sources

Art is a record of human experience. Through the various mediums of artistic expression, individuals are able to give form to any phenomena that human beings encounter. A truly gifted artist is able to portray his or her subject matter in such a way that those of us who come upon it say "Ah yes, this author understands how I feel. This author has captured my experience." Van Manen (1997) states that art is a means to increase our understanding of a lived experience and that as such, it is an appropriate resource for phenomenological reflection.

Three types of artistic expression were considered in this study: a novel, a children's book, and a photograph. These works were examined for the potential to support the themes identified in the participants' descriptions of their lived experiences.

Experiential Descriptions in Literature

The first piece to be examined was the novel *One True Thing*, written by Anna Quindlen. The book is a fictional account of the author's own life experience of caring for her mother who was dying at home of cancer. Unlike the caregivers in the study, the protagonist of the novel had moved in with her parents to provide the needed assistance. The researcher believed this difference was admissible since the protagonist was not a participant in the study. The work was examined solely to see if the author portrayed an experience that shed light onto the experience of the study participants. The work was analyzed in the same way the interviews were. The book was read and those parts dealing with the protagonist's, Ellen Gulden's, perceptions were highlighted. These sections were then typed and compared to the original work to ensure their accuracy. The experiences of Ellen Gulden were used not to discover themes, but merely to see if the work lent support to those expressed by the participants. The findings are presented in the framework of the themes elicited from the study participants.

1. Caregiving is being torn between worlds.

> *'Doctor, I can't predict the future, but I can tell you this. No hospice, no hospital. I had a good job in the city and a nice apartment and friends and places to go and people to see and I junked it to take care of my mother. And I'm going to take care of my mother. I will do what is required' (Quindlen, 1994, p. 79).*

> *I heard a shuffling sound and looked up to see my mother leaning on the doorjamb. She was wearing a pair of my old leggings and a shirt of my father's, its lower buttons pulling slightly over her distended belly. And for just a moment I thought to myself: you have ruined by my life. You have ruined my life with your damn selfishness, your damn accommodations, your damn illusions, your damn husband, and now your damn death (Quindlen, 1994, p. 115).*

2. Caregiving is embracing the wholeness of commitment.

> *I was tired to death of the sour smell of her body and the straw of her hair in the brush and the bedpan and the basin and the pills that kept her from crying out, from twisting and turning like the trout do on the banks of the Montgomery River when you've lifted them on the end of the sharp hook and their gills flare in mortal agitation.*
>
> *I tried to do it all without screaming, without shouting, 'I am dying with you' (Quindlen, 1994, p. 9-10).*

> *I did not break until the last one: 'I have the right to be cared for by caring, sensitive, knowledgeable people who will attempt to understand my needs and will be able to gain some satisfaction in helping me face my death.'*
>
> *'What satisfaction?' I sobbed, and the tears ran hot down my face and I cried into a pillow until my face was as swollen as I imagined my mother's stomach must be beneath my father's shirts (Quindlen, 1994, p. 121-122).*

> *'What the hell do you think I've been doing around here all this time?' I said. 'Who do you think runs the vacuum and does the laundry and makes all the meals? Who do you think shops and cleans and makes the beds?' My voice began to break and there were tears in my eyes. I stopped and turned away, back to the kitchen. 'Shit,' I heard Jeff say and my mother did not reprimand him (Quindlen, 1994, p. 147).*

3. Caregiving is a crucible of individual human effort.

> *'I'm just afraid'*

'I know you are. But when you come back here you will have done something really important.'
'If I come back.'
Jules squeezed my hand so hard I winced. 'This is not Peter Pan,' she said, 'Your brothers are not the Lost Boys. They can learn how to run a microwave. Your father can learn where the Goddamn drycleaner is' (Quindlen, 1994, p. 30).

I tried to tell Jonathan all this. Dr. Comb was right; I needed someone to talk to (Quindlen, 1994, p. 85).

'Everyone deals with bad stuff in their own way,' Jon added.
'Well, that's the point, isn't it, Jon,' I said. 'Whenever one of you guys says people deal with bad stuff in their own way, it means you don't deal with it at all. You just wait for it to go away. You don't help. You don't listen. You don't call. You don't write. WE deal with it in our own way. WE deal with it. We girls. We make the meals and clean up the messes and take the crap and listen to you talk about how you're dealing with it in your own way. What way? No way!' (Quindlen, 1994, p. 93).

4. Caregiving is a means of self-discovery.

'I'm scared shitless,' I said, putting my face in my hands.
'Of course you are,' Theresa said. 'You are doing all of the right things and that is the right thing now.'
'"I can't stand this much longer,' I said (Quindlen, 1994, p. 153).

Even when there's no love, it's so much more than anything else in your life. I did love my mother, but I didn't know how much until she was gone (Quindlen, 1994, p. 261).

5. Caregiving is a thread that can weave a family together or cause it to pull apart.

I pictured my mother marooned in the living room, some cheery woman in a white uniform making her tuna sandwiches and folding her under things, the house silent and a little dusty. But there was no story to go with that picture. When I'd written a false paragraph in a story, my friend Jules would say, 'This one just doesn't parse' (Quindlen, 1994, p. 24).

I spent the rest of that evening cleaning onions, peeling yams, making stuffing exactly as my mother directed, producing a great groaning board of dishes just as she always had. After Jonathan brought me home, as I stood in the kitchen in my nightgown slicing celery, I realized that I was doing it all for sake to stability, to make it seem as though this Thanksgiving was no different from any other. I was maintaining, abetting, creating a kind of elaborate fiction, just as my mother had, with gravy and pumpkin pie and heavy cream. The fiction that everything was fine, that life was simple and secure, that husbands did not stray and children grow, that the body did not decay and finally fail, that the axis of the earth passed dead center through the kitchen and the living world and the world kept spinning, our family, unchanging, safe and sound (Quindlen, 1994, p. 86-87).

'When your mother's gone, you've lost your past. It's so much more than love. Even when there's no love, it's so much more than anything else in your life (Quindlen, 1994, p. 261).

When I was in therapy as part of my training I told my therapist that since my mother had died I no longer knew who I was. I felt as though I had lost my connection to the past. The future seemed to me, as hers had been, the blink of an eye (Quindlen, 1994, p. 281).

6. Caregiving is an experience of reciprocity.

For despite the chemotherapy, and the days afterwards when I could hear her heaving pitiably in the master bedroom, despite the weekly blood tests and exams, I suspect that my mother would have said those were wonderful and full months for her. She and her daughter finally had the relationship she had always imagined would accompany the canopy she had made with a four-poster bed in the attic bedroom, the scrapbooks she kept of report cards and literary magazine poems, the hours she spent on birthday parties and care packages to college and camp (Quindlen, 1994, p. 63).

7. Caregiving is a doorway to intimacy.

I was frightened of this other Kate, this enraged and dessicated imposter. She was right about that; I did want that angry stranger gone. For so long I had wondered why she was not angrier at my father, at her lot in life, at the bargain she had made. But as I saw her rage, felt it like a black thing with teeth and claws, I blessed her tranquility and yearned for it (Quindlen, 1994, p. 85).

8. Caregiving is the attempt to maintain the autonomy of the parent.

'I just want you to be comfortable,' I said.
'You want me to be dead. You want me to die so you and your father can get on with your lives.'
She was wrong, I had hoped the wheelchair would give her back some of her dignity, not take it away. And I'd hoped I'd get her back, too, for a few weeks more, another book perhaps, another series of lessons in her old familiar domestic life (Quindlen, 1994, p. 85).

9. Caregiving is grieving the decline of the parent.

'I'm fine,' she said, but her smile was bleak, without light or warmth. And for the first time I thought of what it must be like to know that you're going to die, that the trees would bud, flower, leaf, dry, die, and you would not be there to see any of it. It was like standing too close to the fire; my mind leapt back (Quindlen, 1994, p. 35).

I had never before and have never since set about a task which required me so completely to act without thinking. My mother leaned her elbow on the edge of the tub and her head on her hand and wept as I toweled off her poor ravaged body. I took it piece by *piece, bit by bit, because I knew that if I allowed myself to really look at her, at what she had become, I would be done for (Quindlen, 1994, p. 162).*

10. Caregiving is making the best use of the time left with a parent.

'…and I'm watching this woman start to slowly disintegrate before my eyes, and all I can think is, this is my last chance to know her, to be her, to not kiss her off because she doesn't work or she didn't graduate from an Ivy League school or she doesn't think the world rises and falls on whether or not there really was a Dark Lady behind Shakespeare's sonnets (Quindlen, 1994, p. 85-86).

And I thought of how my mother had already read this book, and both the others, how she had formed the book club to break through the reserve of her own daughter, to find something that the two of us could talk about before it was too late for the two of us to ever talk again (Quindlen, 1994, p. 183).

These excerpts from *One True Thing* lend support to the themes identified by the participants. The fictional experiences of Ellen Gulden ring true to the lived experiences of the women who are currently engaged in caring for their parents.

The second piece of literature to be considered was the children's book *Love You Forever* by Canadian author Robert Munsch (1986) with illustrations by Sheila McGraw (1986). In this deceptively simple work, the theme of caregiving over the life span and across generations is examined. In the first scene a young mother joyfully accepts her new baby son. She holds him close to her and looks upon him lovingly in Figure 1.

Figure 1. Mother with her new son.

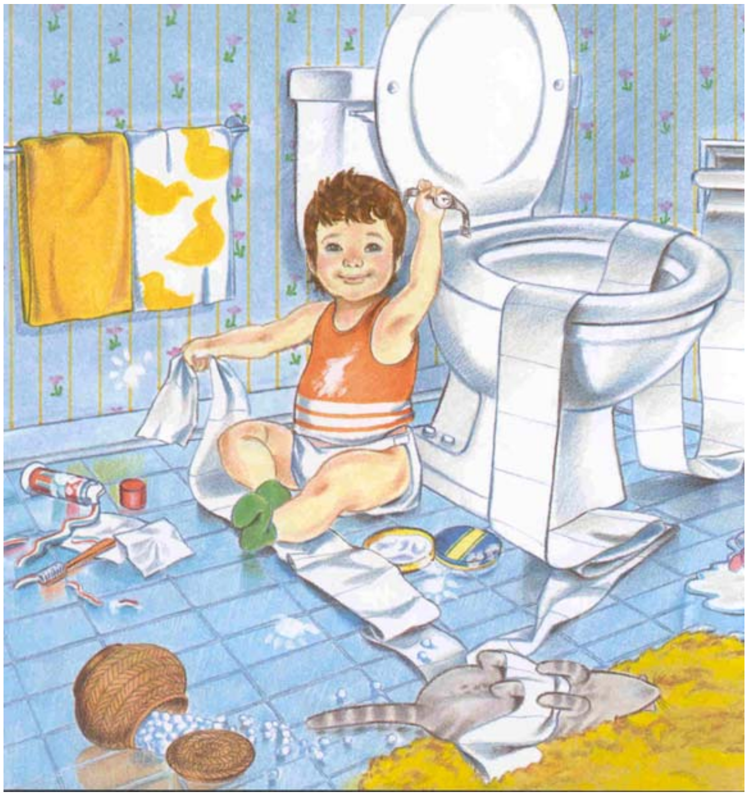
Picture from *Love You Forever* by R. Munsch, illustrations by S. McGraw, 1987. Copyright 1987 by Firefly Books. Reprinted with permission of the publisher.

The text reads:

A mother held her new baby and
very slowly rocked him back and forth,
back and forth, back and forth.
And while she held him, she sang:
I'll love you forever,
I'll like you for always,
As long as I'm living
My baby you'll be (Munsch, 1986).

Over time, however, she comes to realize the amount of work and frustration involved in her commitment to raise this son. When he is a toddler he gets into so much mischief and makes such a mess around the house as seen in Figure 2.

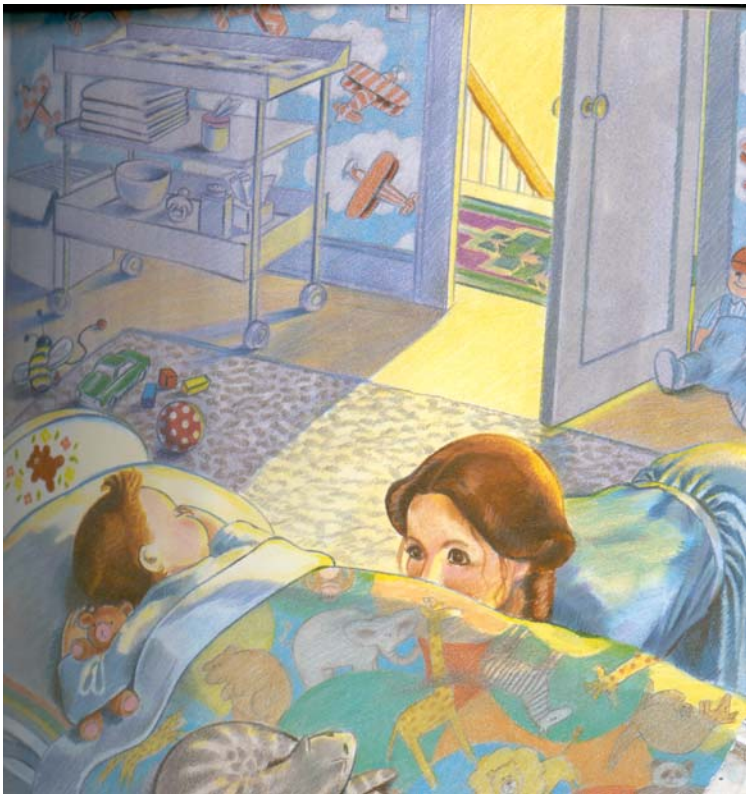
Figure 2. The toddler son makes life difficult.



Picture from *Love You Forever* by R. Munsch, illustrations by S. McGraw, 1987. Copyright 1987 by Firefly Books. Reprinted with permission of the publisher.

The picture reflects a child who is allowed to pursue his interests and be himself. As he explores his world as a typical toddler, he creates havoc for those around him. His mother admits that sometimes being his parent is driving her crazy because caring for the boy takes so much time and energy. Her love never fails for him, though, and she continues to express her commitment to him as seen in Figure 3.

Figure 3. Mom still loves her child no matter how much work he causes.

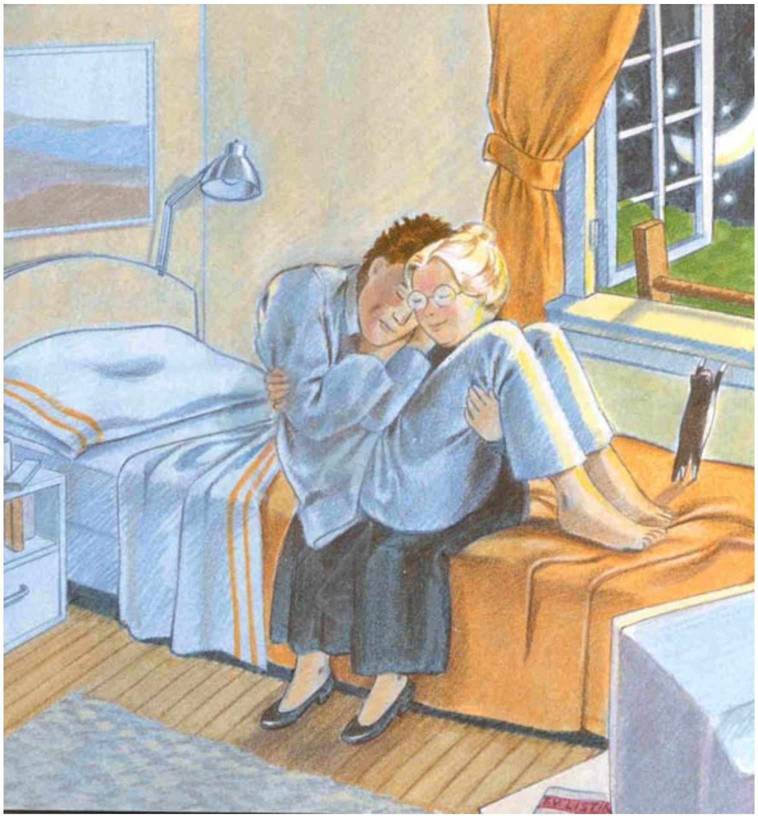


Picture from *Love You Forever* by R. Munsch, illustrations by S. McGraw, 1987. Copyright 1987 by Firefly Books. Reprinted with permission of the publisher.

But at night time, when that two-year-old was quiet, she opened the door to his room, crawled across the floor, looked up over the side of his bed; and if he was really asleep she picked him up and rocked him back and forth, back and forth, back and forth. While she rocked him she sang:
I'll love you forever,
I'll like you for always,
As long as I'm living
My baby you'll be (Munsch, 1986).

The son continues to grow and the frustrations become those of raising a preteen and then a teenager. No matter what his age and what the challenges, the mother continues to symbolically slip into his room at night to hold him, rock him, and sing him her song of commitment. This behavior continues even after the son is a grown man living in his own home across town as seen in Figure 4.

Figure 4. Mom's commitment to her son continues across the lifespan.

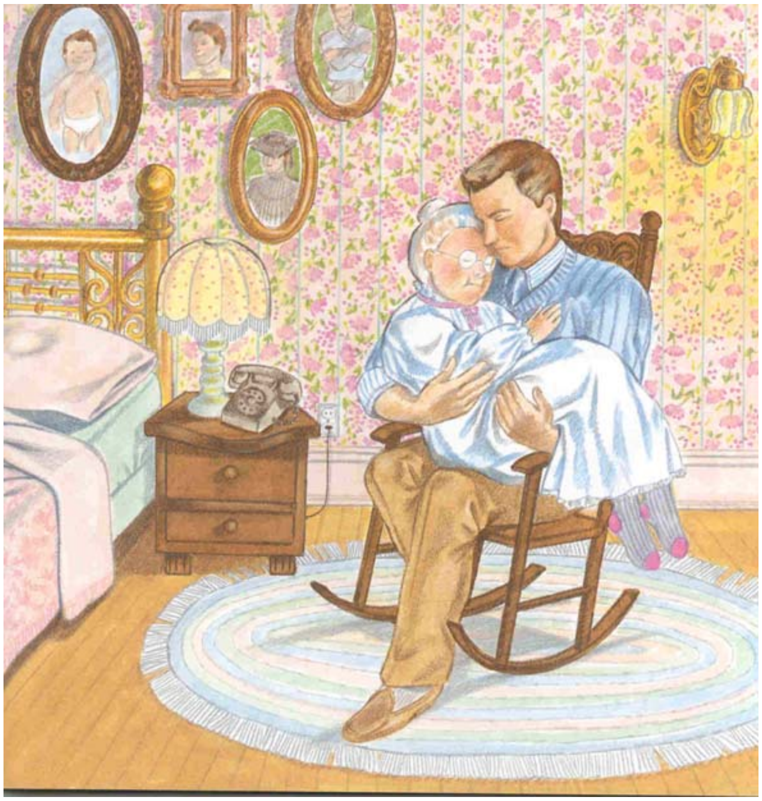


Picture from *Love You Forever* by R. Munsch, illustrations by S. McGraw, 1987. Copyright 1987 by Firefly Books. Reprinted with permission of the publisher.

If all the lights in her son's house were out, she opened his bedroom window, crawled across the floor, and looked up over the side of his bed. If that great big man was really asleep she picked him up and rocked him back and forth, back and fort, back and forth.
And while she rocked him she sang:
I'll love you forever,
I'll like you for always,
as long as I'm living
My baby you'll be (Munsch, 1986).

Over time the mother ages until one day she asks her son to come see her because she is old and sick. She tries to sing the song to him, but she is too frail to finish it. Instead the son responds to her in Figure 5. As he holds her one sees sorrow on his face. His smile is gone and his brow is furrowed as he holds her to him closely. Their arms embrace one another reflecting the intimacy between them.

Figure 5. The son reciprocates his mother's lifelong commitment to him.



Picture from *Love You Forever* by R. Munsch, illustrations by S. McGraw, 1987. Copyright 1987 by Firefly Books. Reprinted with permission of the publisher.

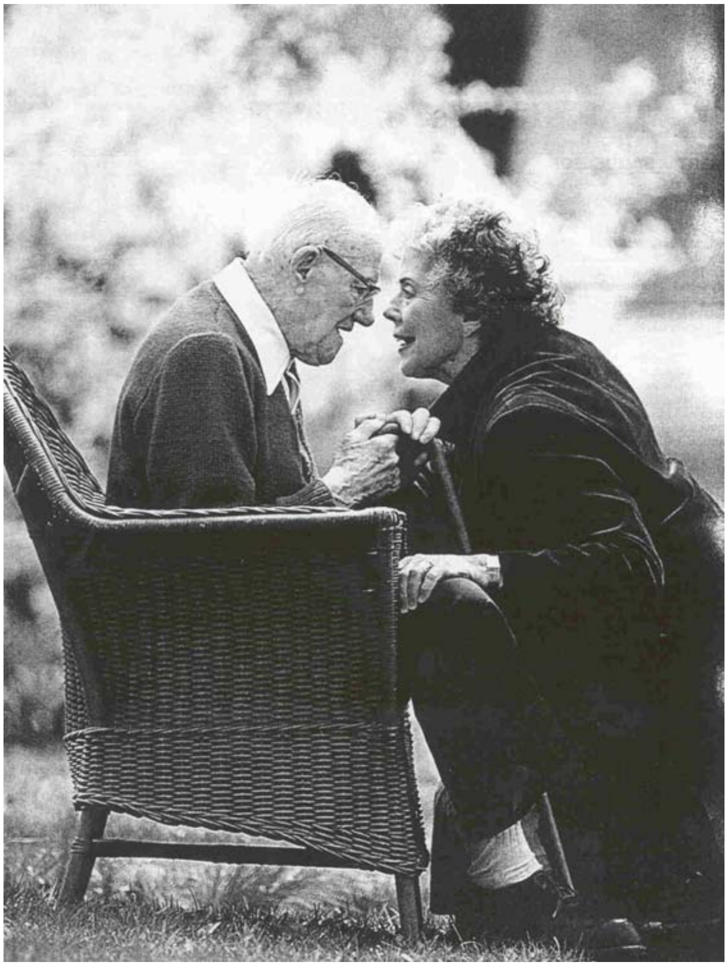
The son went to his mother. He picked her up and rocked her back and forth, back and forth, back and forth. And he sang this song:
I'll love you forever,
I'll like you for always,
As long as I'm living
My Mommy you'll be (Munsch, 1986).

In the final scene of the book, the son returns to his own home, slips into his baby daughter's room at night time, rocks her back and forth, back and forth, while singing his song of commitment to her.

Examination of this simple yet profound children's book reveals all but one of the themes elicited from the participants. The mother experiences raising the son as a crucible of individual effort. The son drives her crazy and at times she wants to sell him to the zoo. Sometimes she even thinks she is in the zoo. She embraces the wholeness of her commitment to him, however, and takes the bad with the good. She supports the boy 's attempts to becomes an autonomous human being. Details of the pictures reflect the intimate relationship that exists between the mother and her son as they care for one another. As the mother ages the boy reciprocates the care she has given him throughout his life. He is there for her when she needs him. The speed with which the boy answers his mother's request reflects the theme of self-discovery in that he knows his priorities. He is there without hesitation. The grief he feels at her decline is evident on his face as he rocks her in her room. It appears that the son is making the best use possible of the time he has with his mother, for the two of them are locked in a tender embrace. At the end of the story the theme of caregiving as a thread that can weave a family together is evident. The son of the aging mother returns to his own daughter. He sings to her the same song of commitment that he sang to his mother and that she had sung to him over the years. The only theme not reflected in the story is that caregiving is being torn between worlds, for the author shows us only the direct relationships between the parent and the child. Brief as it is, *Love You Forever* lends powerful support to the themes elicited in the study.

Experiential Descriptions in Photographic Art

Figure 6. Father and daughter



Picture from "Who's Taking Care of Our Parents?" by D. Gelman, M. Hager, D. Gonzolez, H. Morris, J. McCormick, T. Jackson, and E. Karagianis, 1985, Newsweek May 6, 1985, p. 60. Copyright 1985 by the photographer. Reprinted by permission of the photographer.

The above photograph was taken by photographer Burk Uzzle in 1985. It appeared in *Newsweek* magazine with an article entitled "Who is taking care of our parents?" The image is of a woman named Marion Cox, who was caring for her 98- year-old father. Mr. Uzzle conveys symbolically in this picture several themes elicited in the study. Most obvious of these is the intimacy that exists between parent and child. Their bodies are close, her hand is on his knee and they are gazing at one another in the “en face” position,” that is, their eyes are locked together in the same plane several inches apart. This position is recognized as a sign of attachment between newborns and parents (Lowdermilk & Perry, 2004). The father is sitting in a chair and the daughter is kneeling in front of him and his cane is between them. Several themes come to mind. The daughter still treats the father with respect. His status of father places him above her as he is in the picture. Even though his position is higher than hers, he has things to help him compensate for his age: a chair and a cane. What seems most evident in the picture is that these are two people who care about one another. The parent and child seem to saying to one another, “I’ll love you forever, I’ll like you for always, as longs as I’m living my baby/Daddy you’ll be.” Many of the themes found in the study are not represented in the picture. For those that are, however, the picture provides a visual interpretation of their meaning in the lives of two real people.

Summary

This chapter presented the data analysis of the study. Thematic analysis of the interviews was conducted to reveal the themes present in the interviews. Thematic statements were isolated. Linguistic transformations were performed, and essential themes were identified. Support for these themes was gathered from literary and artistic sources. These processes resulted in the identification of ten essential themes of the study.

Chapter 6: Findings

Remember that through your
parents you were born;
and what can you give back
to them that equals their gift
to you?
(Oxford Annotated Bible, Sirach, 8:28)

Introduction

Derivation of essential themes from the participant interviews, even though supported by descriptions from literary and artistic sources, does not represent the essence of the phenomenon. Instead, these themes serve as the foundation for the phenomenological text, which van Manen (1997) identifies as the object of the research process. The text does not convey the finding; rather, the text is the finding. The essence of the phenomenon has been conveyed if the textual description “reawakens or shows us the lived quality and significance of the experience in a fuller or deeper manner (van Manen, 1997, p. 10). This chapter conveys the lived experience of seven daughters caring for their frail elderly parents through discussion of the ten essential themes elicited from the interviews.

Hermeneutical Phenomenological Narrative

Caregiving for the women of this study is an experience of being torn between worlds. All of the women express a tension in their lives between feeling responsible to their aging parents and to other significant people in their lives. Whether these other people are spouses, children, grandchildren, or peers at work, each participant expresses some degree of frustration at trying to meet the demands of her conflicting responsibilities. Jackie gives voice to this tension by saying she feels like she has two lives now.

The circumstances of the conflicting responsibilities vary among the participants. Mary’s husband was transferred to Michigan for his job at the same time her mother was diagnosed with a brain tumor. Although she felt she should go to Michigan with her husband, she also felt she could not leave her parents in their time of need. She states “I had to stay here. You know, I didn’t want to leave them. They needed me; I just couldn’t do it.” Mary decided to stay and care for her parents; her husband moved to Michigan and came home whenever he was able. For Lynn, the issue of conflicted responsibility is not between her father and her husband, but rather between her father and her grandchildren. She believes her energy should be directed toward the younger generation of her family, not the older. She resents that she has had to turn down opportunities to baby-sit for her grandchildren because of responsibilities to her father; however, she has made this choice on multiple occasions. Victoria feels the tension between caring for her father and her responsibilities as a single mother, while Linda, who is used to “taking care of everyone” finds she is no longer able to do so.

Each of the participants experiences some degree of conflict in this area. Each loves her parent and also loves the other people in her life. The issue is not just about time and energy, but also about loyalty. The women want to be present to all of their significant others; they feel committed to them. The challenge at one level is how to balance one’s temporal resources; at another level the issue is how to balance one’s affective resources. For most of the participants the process is one of ongoing internal negotiation and is part of the challenge of caregiving.

Like the mother in *Love You Forever,* the participants of the study find that caregiving also is about embracing the wholeness of commitment. Sometimes the experience is positive and sometimes it is negative. Sometimes the caregiver experiences satisfaction;

sometimes she feels like she’s losing her mind. Caregiving is the yin and the yang of loving another human being.

Even though each of the caregivers experience both positive and negative perceptions of the caregiving experience, the range of the disparate feelings varies among the women. Sally describes the overwhelming sense of responsibility she has in providing and managing the care of her demented mother twenty-four hours a day, seven days a week. However, when her mother breaks through the cloud of her dementia and expresses gratitude to her daughter, everything seems worthwhile. Other women describe situations that are similarly paradoxical. Linda expresses frustrations about caring for her mother, but she also describes the experience as having “a soulful part of it,” a “spiritual part,” “a whole positive side.” Rosie explains the paradox as having “to work harder to get something that’s really worthwhile.” Jackie says sometimes caring for her parents is depressing and she comes home and cries. On the other hand, she states “I don’t mind it at all. I want to help them.” She says she can’t explain it.

Perhaps Jackie has caught the heart of this aspect of caregiving in that the contradictions involved in being committed to another human being cannot be explained. Each of the women expresses love for her parents, and with that love comes commitment. Commitment is not an easy thing. Commitment means accepting the bad with the good and remaining present to the other person. As a reflection of their love, these women are present to their parents through the good times and the not so good times. The women of this study are embracing the wholeness of commitment to their parents.

Another theme in the interviews is that caregiving is a crucible of individual effort. A crucible is a vessel used for melting down materials at the highest temperatures possible. It is considered to be a severe test or trial of a substance (The American Heritage Dictionary, 1985). Caretaking is an extreme test of an individual's efforts. All of the participants describe their experiences of caring for their frail, elderly parents as something they cannot do alone. Each of them describes the need for support in their efforts. Some of the women are more successful than others in finding the needed support, but all of them are aware of the need.

Jackie states she gets adequate support from her brother and her sister. Although Victoria is alone in her caregiving, she receives emotional support from her family, her friends, and the people of her church. Rosie expresses frustration and resentment that her many siblings who live in town are not involved in their mother's care. Lynn also is frustrated by the lack of support she receives from her brother who lives as close to her father as she does. She sees irony in the fact that her brother has time to be involved in multiple community volunteer activities, but that he actively will not help with their father. Lynn also expresses a sense of isolation within the community. Her parents grew up in other parts of the country and are reserved by nature. Lynn perceives these to be the reasons for the absence of a social network on which to call, the lack of which she is acutely aware. Lynn states "I firmly believe that I would probably be doing more if I didn't feel like I was the only one doing anything." On the other hand, Sally is a master of gathering and utilizing support. She describes her husband as a saint in that she can call on him for both emotional and physical assistance. She and her sister divide the responsibilities of caring for their mother. When Sally begins to feel she is carrying more than her share of the burden, she discusses the situation with her sibling. Since they provide and oversee care to their mother 24 hours a day, Sally takes advantage of every resource she can identify for help. She attends an Alzheimer’s support group and reads their newsletters and web sites to gather new information. She asks people as varied as her mother-in-law to her hairdresser if they can come to sit with her mother for short periods during the day. She states, “I think you need to take advantage of anyone who offers help.”

The women who participated in the study all identify the need for support as an essential component of the caregiving experience. While some women are successful in eliciting that support, others are not. A frustration for women with siblings is that sometimes those siblings are not as committed to the caregiving commitment as the participant herself. This can lead to resentment and bitterness. When one child feels a primal desire to care for the parent at home, it is difficult to understand that other siblings do not. As Rosie states, “it’s kind of like all during life you grow up and your Mom teaches you all these things and you learn them, you know. And, where all my other brothers and sisters went I don’t know during that process. But, I guess I was the one under her wing more than I really realized.”

The caregiving experience also has become a means of self-discovery for the participants. Each of the women describes in great detail the things they have learned about themselves. Most of the knowledge is about positive personal qualities the women have discovered, but some of it is recognition of negative qualities. In addition to personal qualities, the caregiving experience has taught the daughters to recognize what their priorities in life are. Variations of this theme of self-discovery include recognition of how the caregiving role evolved, how the person has evolved within the role, and insight into the factors that might have influenced the daughters to view caregiving as an appropriate role in life.

All of the women express positive things they have learned through the caregiving experience. Jackie states it has given her “a purpose in life.” It makes her “appreciate more in life” and gives her compassion for other people. Mary has become “a lot more understanding and considerate” and believes she has learned much about the elderly that she never knew before. Linda states caregiving has made her a better person, has helped her recognize that she is aging herself, and has helped her “face a lot of realities base on that.” Sally has learned she can take more than she ever thought she could and that she has more inner strength than she thought. Rosie agrees that caregiving has made her a better person and has helped her realize she is stronger and more capable than she had thought. Victoria also perceives herself to be a stronger person because of her caregiving. She has come to realize that she is like her father who “will not give up” and who “is not a quitter.” Both Jackie and Lynn have discovered things about themselves that are not as positive, but are none-the-less honest. Both have learned they are short on patience and Lynn has learned she dreads her own reaction to her impatience. She says people tell her she is a saint. Her response is “if I were a saint I would be doing this with a smile on my face and a song in my heart---but I ain’t singing.”

Another component of self-discovery by the participants is their recognition of how they want to approach their own eventual aging. Sally and Vickie hope their children are learning by example and will, as Victoria says, “return that favor when I get that age and not discard me.” Jackie, Linda, and Lynn, however, have learned from their caregiving experiences that they do not want their children to have to care for them in the future. Each expresses the hope that she can make decisions along the way that will enable her to live without being dependent on her children.

Many of the daughters state they have learned what their priorities in life are because of caregiving. As the crucible melts down ore into its base elements, so too the daughters state they have come to recognize what is most important to them in life. Linda says she has become "…more insightful…about what things are important." She says "…it has also taught me I can't do everything" and "I'm a better person for that because my identity is no longer connected to I have to do everything. It's connected to I'm going to do these things and this is a big part of what I'm going to do, this caregiving thing with my Mom…"

One variation of the theme of self-discovery is how the caregivers learned to appreciate the caregiving role. When they were young, Mary, Sally, Rosie, and Lynn each had mothers who cared for elderly relatives. Caregiving was the context of Mary's childhood, since elderly relatives lived in her home. This was true for Lynn also. However, while this experience was positive for Mary, it was not for Lynn. Sally had aunts and uncles who cared for their elderly mom in their homes. She reports she "…always thought that was neat that they did that for her instead of sticking her someplace and going to visit her until she got bad." Rosie's mother took care of her father in his home. She states she grew up "…with that idea that family stuck together, that you always took care of your kind."

Another variation of self-discovery is how the caregiving role evolved for the daughters. Most of the daughters described a gradual process of helping their parents with certain things when the parents were younger. This was true for Linda, Mary, Sally, and Rosie. Rosie describes it best: "…you're just being there a little bit more at the time when the need arises…and eventually that need gets bigger and then you are a full-fledged caregiver." Lynn and Victoria did not experience a gradual transition into caregiving. Lynn recalls her mother being admitted to the hospital and her father being unwilling to interrupt his golf game, because he had done so too many times before. Suddenly Lynn found herself alone at age sixteen making health care decisions for her mother. Victoria describes caregiving as being a way of life. “It’s all I’ve ever known since my sister got married when I was ten years old; I’ve cooked, cleaned, did laundry, taken over the household duties. Because my Mother was ill, my Dad was ill.”

A final variation of self-discover is how the daughters have evolved within the role. Sally is the most explicit about this process. She states that although she operates a childcare center as a living, she had “…never, ever, ever taken care of an adult or anyone elderly…” prior to taking care o f her mother. “I didn’t know anything about how to do my Mom’s medicines. I didn’t know anything about how or where you could get help. I didn’t know anything about childproofing a house. So you know, I asked a lot of questions. Talked to a lot of people. Read a lot of stuff…you just gotta do all that…and still hope that you haven’t missed anything.” Since Mary’s mother requires the most physical care, it is understandable that the theme of self-discovery would include this variation for her.

The theme of self-discovery is significant to the caregivers. They have learned things about themselves, both positive and negative. They believe they have become stronger people because of caregiving and that they can do more than they thought they could. They have learned the depths of their abilities and how to recognize limits. Human life is a gradual and ongoing process of discovering who one is. For the participants of the study, caregiving has been a strong catalyst in that process.

Another theme elicited from the interviews is that caregiving is an experience with the potential to weave family members together, both across and within generations or to pull a family apart. Most of the daughters are having positive experiences in this area, although a few are not. Those who are not believe increased closeness is something that should be occurring.

Linda, Jackie, Mary, and Sally all describe situations in which their children have become closer to their grandparents through caregiving. Linda states that since she has been caring for her mother, her daughter "…became really interested in who Mother was and said 'I want to see where Grandma grew up'…so I see this really wonderful opportunity to impart this kind of family history and this thread of who we are and I think that's really important for people to know who they are." Jackie reports her father has just recently started talking about his World War II stories and that her kids find it fascinating. She attributes this change to the fact that she is spending more time with her parents and there seems to be more time for talk then in the past. Mary believes "…everybody, the family has been closer. Just like my daughter, she really likes to hear her Grandpa talk and it's good for the whole family probably." Rosie, who does not have children, states she has learned more about the grandparents she never knew. "But I feel I know them, because my Mom used to tell me different things that they would do…then she would tell me sometimes, well you were just like my Mother when you did that."

Most of the daughters find they have become closer with some of their siblings through caregiving. This is not the case for Rosie and Lynn, however. Rosie states she is irritated by the fact that none of her siblings show much attention to their mother. "…I wonder what happened to them, why they don't have that special---that they want to do something with my Mom or they want to just be there." Lynn also expresses frustration when she states about her brother "…I'm resentful of him. And I don't like that feeling either. That, you know, why is one child seeing the need and doing it and the other child is fighting against it? It doesn’t make sense. We came from the same family. We should be closer but it’s just he and I and it’s just two different kinds of people…”

The words of the daughters demonstrate that caregiving is a thread that can weave a family together. However, it is also a thread that sometimes pulls apart. The bonds that are forged within families are ones that may well last a lifetime. However, the bonds that are damaged because of caregiving may also never be repaired.

Just as caregiving has the potential to draw family members together, it also has the ability to draw the daughter and the parent closer together. Each of the participants describe feeling closer to her parents and having a greater appreciation of who her parents are since providing caring to them.

Linda believes one of the things she has gained is “a real appreciation for the total life of who someone is.” In a similar vein, Sally says, “…I’m really taking care of her, you know, spiritually, mentally, and, you know, physically---I don’t see how you could do that and not get close to someone.” Rosie speaks about the fact that she was one of eight kids growing up and that she never got the “ideal time” she now gets. Lynn says that although her relationship with her parents was strained while she was growing up, they are closer now than they ever have been. Veronica says “It’s made us a lot closer…and I have a new found respect for him and he has a new respect for me that neither one of us has known before…”

The doorway to intimacy that caregiving provides is highly valued by the participants. Amid the challenges and frustrations of the role, this increased closeness is something they receive in return. They speak of it as a gift---a gift they may not have received had they not taken on the role.

The theme of reciprocity is present in each of the interviews. To reciprocate means to give back for something that has been done (The American Heritage Dictionary, 1985). Reciprocity emerges as a basic assumption of the participants of this study. Whether the word itself is used, the daughters express attitudes that reflect beliefs about fairness, justice, and loyalty. These ideas emerge as an issue of pure reciprocity and also as several subtle variations dealing with the nature of the parent-child relationship, how the child treats the parent, caregiving as evidence of the child's love for the parent, and parental characteristics that call forth caregiving behaviors from the daughter.

A sense of pure reciprocity is expressed by most of the participants. Jackie states "…I just really appreciate that my parents took care of me and raised me and if I can just give them back a little bit, I'll do it." Similarly, Linda states about her mother who is experiencing the onset of dementia "And if I were in a similar situation, she'd be standing by me, you know?" Sally expresses an almost textbook example of her understanding of reciprocity when she says "But there's other things I do give up and I figure I---just do it. And I'm sure there were things Mom wanted to do but couldn't do when we were little so she gave it up." Veronica also sees her caregiving as repayment for the many ways in which her father has supported her over the years. She says "Yea, I feel like I'm paying him back for everything he's done for me for my life. Because he's helped me out financially, he's helped me out emotionally, two marriages, two divorces, kids without a dad, you know, he helps take over the role of being a male figure in my children's lives as well as being a PaPa. And I feel like I owe him so much because he's given me so much." She has been willing to put her life on hold while caring for him because "…it's his time to live his life and to do what he wants to do."

A variation of reciprocity is the view that caregiving is part of an ongoing significant relationship. Several of the daughters spoke of caregiving as an appropriate continuation of the life-long good relationships they have had with their parents. Mary says “They’re my Mom and Dad and I could not leave them and say ‘Well, here take care of yourself. I don’t have time for you.’ I just couldn’t do that. Not with the childhood I had and growing up the way we all did and the closeness and everything like that.” Veronica expresses a similar situation when she says “We’ve always been close. I mean I’ve always been Daddy’s little girl.” These women view caregiving as an integral part of their relationship with their parents. To not care for their parents is not an option to them.

Not all of the participants experienced such intensely close relationships with their parents while growing up, however. Linda describes her relationship with her mother as having been good when she was young, but not close. Lynn describes childhood relationships with her parents that were often strained. “…we’ve always been on speaking terms. You know, we’ve never severed ties of any kind. But so far as close, as in what my perception of what having a close relationship like I have with my daughter, no.” And yet both of these women are committed to caring for their parents. Linda states she cares for her mom “...because she’s my Mom. You know, because I love her and because I’m the one who’s here.” Lynn says she provides care for her father at home and her mother in a nursing home “…because I do <u>care</u> for my parents. That’s why…I love them…”

Lynn expresses a slight variation of this theme when she explains that cargiving is a way to show her father she loves him. She says “So I guess I just love him and I want him to know that I do and if it takes me washing a dish for him to know that…you can just say ‘I love you' so many times but you know, you still have to show that you can do with somebody, you know and spend some time with them."

Another variation of the theme of reciprocity is how the daughters treat their parents. Even though the role of caregiver has switched from the parents to the daughters, the daughters all express the desire to treat their parents respectfully because of their status as parent. Jackie says "…we let them do what they want to do and we're not enablers but we help them because that's…they really are mentally alert…and we can't argue with them about it because we just, maybe it's because they're our parents and we just can't…" Mary speaks about finding ways to give advice to her parents without making them "feel dumb." Lynn recognizes that it is difficult for her father to ask for help. She says "So, it's his pride probably prevents him from thinking that he needs anything. At least I know that and I accept that about him so I don't ask and I just step in and do it." Sally is most explicit in her view of her mother's status. She states, "I've told my kids this. I said, 'You know, my Mother is seventy-nine years old and she has Alzheimer's. And to this day, I would not talk back to my Mom. I would not say anything mean to her.' I said 'To this day, I still know, even though I'm taking care of her, she's my Mom and you respect your parents---no matter what."

Reciprocity was defined earlier as giving back for something that has been done. However, to reciprocate also means to give and to take mutually (The American Heritage Dictionary, 1985). While all of the daughters are committed to caring for their parents, the presence of certain behaviors in the parent makes caregiving easier to do. Just as behaviors like smiling, cooing, and cuddliness make us eager to care for babies who exhibit these behaviors, parents have behaviors that make their children remain committed to them. Linda says “I mean if it wasn’t for her ability to deal with this the best she can, I wouldn’t be willing to do this.” Although Linda says she would continue to care for her mom if she became a mean or angry person, the fact that “she’s very appreciative and nice to me” helps a lot. Sally says that despite the Alzheimer’s, her mother is “easy to---you know, to be around and want to make happy.” Sometimes during showers her mother becomes confused and combative. Sally says “sometimes, you know, when you’re at your wits end, you’re trying to juggle and you’re thinking, ‘I don’t know, I can’t do this. How much longer can I do this’…and then she’ll, you know, she’ll hold your hand and she’ll say, ‘I really appreciate all you do, that you’ve been doing.’ You can’t put a time limit on it.” Victoria expresses the same feeling when she says “…when he looks at me I can see that he appreciates me and he doesn’t take me for granted. And, it---that makes it all OK, you know?”

Lynn is aware of the things her father does not do in terms of reciprocity. He doesn’t interact with his grandchildren, he doesn’t express affection or much interest in her, and he only calls when he needs something. She recognizes she needs more from him and now ends every phone call with him by saying “I love you.” She says “he is at least reciprocating now where he didn’t used to. He will say ‘I love you’ back…” As with the other daughters, Lynn’s recognition of her father’s appreciation is a strong motivator to keep her in the caregiving role. “I told my father at one point, I’d said like after I’d cleaned and spent quite a few hours over there trying to right the things that needed to be done. I told him, I said, ‘I don’t know whether I’m truly helping you, but I feel like I’m just buying you just a little more time in your house.’ He goes, ‘I know that and I appreciate it.’ So that made it worthwhile. So, OK, I’ll keep doing it. Buy a little more time each week.”

Reciprocity is a complex issue in the lives of these caregiver daughters. It is a phenomenon that reflects the totality of their relationships with their parents and it is something that continues to be played out in the day to day. Whether it is viewed as payment for what was done in the past or as a mutual exchange in the present, reciprocity is a strong motivator to keep the daughters in the caregiving role despite significant challenges.

The theme of attempting to maintain the autonomy of the parent is also integral to the daughters' perceptions of their caretaking activities. Personal autonomy is central to the American psyche, perhaps more so than to people of other cultures. We are a society founded by people who struck out on their own, who were self-reliant in settling unknown lands, who felt driven to wrest those lands from aboriginal people, and to break away from their colonial masters, all in an attempt to be free. Autonomy and self-reliance are the ethos of who we are as a people; it is ingrained in our collective consciousness. To be dependent upon others is to be less than whole. However, as people age and become frail, the ability to function as autonomous human beings diminishes and dependence on others becomes a reality if one is to survive. How the daughters deal with issues of autonomy reveals much about them as individuals and about the nature of their relationships with their parents. Each of the daughters goes out of her way to protect the parent's sense of autonomy. Variations in these responses exist, however, and include the desire for greater control over the parent, issues of helping the parent compensate, issues of control versus the parent's quality of life, and issues of control versus the unknown in life.

Jackie says she does not like to make her parents' decisions. When faced with a decision she tries to ask them what they want. Mary says she tries to keep her dad "…as independent as he can be because the more he can think, the more he keeps his brain going."

Linda says "I'm going to do whatever I can do to support her living independently because that's what's really important to her." Like Jackie, Lynn encourages her father to "Please make decisions that you want for yourself now while you still can---before I make a decision for you that I don't know whether you want or not." While Jackie does encourage her parents to make their own decisions, she also expresses a slight variation of this theme which is that caregiving might be easier if she had more control over her parents. She says "Both Mom and Dad have their minds one hundred percent, which is good but then it's not so great sometimes because you can't tell them what to do like you'd like to sometimes." It is interesting that Mary perceives that because her parents still have their minds she cannot tell them what to do.

All of the daughters express the desire to keep their parents as autonomous as possible because it is what the parents want. Even though the daughters do not always agree with the parents' wishes, they go out of their way to help them compensate for whatever it is they are no longer able to do for themselves. By filling in the gaps in the parents' abilities, the daughters facilitate a type of autonomy for their parents. Mary says "I'd go up there and clean the house and do the yard work and different things like that. And I could see him declining. You know, he couldn't do it anymore." Sally says her mother wants to stay in her own home. Even though she has Alzheimer's disease, she is aware enough to say "You're not going to put me in a nursing home are you?" Sally tells her, no, they're not going to put her in a nursing home but the price of helping her mom compensate is not light. "We've got to really watch her. We had to childproof the house. We can't let her cook. She micro-waved her girdle---it had the metal things on it---we had to childproof the whole house. All the medicine has to be put up. We have to have someone twenty-four hours so she doesn't try to leave the house…so you really have to be careful with things like that."

The theme of maintaining the autonomy of the parent plays out in yet another slight variation of experience. Although maintaining the autonomy of the parent is important, the daughters worry about the safety of the parents as they try to achieve this goal. Jackie says "I've just truly worried about my Mother and Father in their home. Mom---she thinks she can go out in the kitchen and do things and I've gone in there and I said 'Mom, what's that pan in the sink?' and it'll be totally burnt." Both Jackie and Mary worry their fathers will have a heart attack while shoveling snow, something they do even though the daughters tell them not to. Lynn worries her father will get food poisoning because he can't tell when things have gone bad in the refrigerator. The daughters experience a tension of wanting their parents to be as autonomous as possible, but recognizing there are inherent dangers in doing so.

Concern about their parents' safety is mediated by yet another variation in the theme of autonomy. While the daughters are aware of potential dangers, they also are concerned about the quality of their parents' lives. They seek to find a balance between protecting their parents and facilitating a life the parent wants to live. Jackie and her sister have accepted that "…if he goes out there and he thinks he has to sweep the sidewalk off when it snows and he has a heart attack, it was his decision, not ours." Linda recognizes her mother has high cholesterol and doesn't eat properly even though she knows she should. Linda reports "…I just said, 'OK, the hell with it.' You know, I don't care. I mean she takes a cholesterol medication and she does the best she can do at eighty years old; I'm certainly not going to be on this woman." In a similar vein, Lynn says her father has diabetes but she still buys him

Hershey Kisses. His blood sugars have stayed at a reasonable level and she says "…I'm not going to deprive that man of that pleasure he derives from that piece of candy." The daughters struggle to find a balance between autonomy and safety and safety and quality of life. It is not an easy balance to achieve and many issues must be considered. Perhaps Linda expresses the decision making process best when she says "I'm ready to live with the guilt of helping my Mom be as independent as possible if something would happen to her. Because to me, it's the better choice and to my Mom it's the better choice."

A final variation of the theme of parental autonomy is the daughters' ongoing struggle with issues of control and the unknown in life. While this variation is similar to concerns about safety for their parents, it is more global in nature. The daughters are not expressing fear about specifics concerning the well-being of their parents, but rather a more ephemeral concern about the fate of their parents and their frustration at not being able to control those fates. Linda says "I don't like what I can't control. Of course, we're never really in control of anything but we pretend we are and this is something which you just see changing all the time, you know. Like what Mom could do last year, she can't do this year. And what she can do today, you know, could change tomorrow." Lynn says when she drives by her father's house at 11:00 and the drapes are still shut, she figures he is still asleep. But when they are still shut at noon her "…first thought is, 'is today going to be the day that I find him dead? Is this what I'm walking into?' So, I have to steel myself every time to go into the house not knowing what I'm going to find." Mary says that the predictable parts of caregiving like cleaning the house, shopping, and cooking are fairly easy for her. What is difficult, however, is "…the actual meeting with the different mood swings---changes and hospital things all the time and trying to decide what she's got now on this, or who's got what now or something like that---that kind of stuff was more than I guess I was thinking…"

Doing their best to maintain the autonomy of their parents is an essential component of the caretaking experience for the daughters. They are willing to do many things to achieve this goal for their parents. When the daughters perceive a deficiency in their parents' abilities to function, they fill in as best they can for them even as the deficiencies increase in number and severity over time. The daughters struggle with concerns about their parents' right to be on their own versus their need for safety, while at the same time they weigh concerns about the parents' need for safety in light of their need for quality in their lives. The practical concerns about the daily well-being of the parents are framed within a larger anxiety about the future of their parents for some of the daughters. For these women the fear is a more complex issue of not being able to control the future for their parents, of facing changes and deficiencies that, no matter how much the daughters try, they will not be able to fix.

Another essential component of the caregiving experience for the daughters is grief at the gradual decline of their parents. Jackie says her mother "…has Parkinson's and she is crippled and she's got her walker and she has her seat on her walker that she carries her dishes---it breaks my heart to see her carry the dishes from the counter to the table on her little walker seat, you know." Mary says "…it's selfish---I just don't want nothin' to happen to them but yet I can see that they're just going down. I don't like that. I wish there was some way I could do something but there's nothing." Linda expresses the same thing when she says "More than anything else---because my kind of overwhelming emotion about it all is I don't want---since she is dealing with a short term memory problem I don't want it to be happening. I don't want---I don't like seeing my Mother become frail and older." Rosie had begun to tear up a little during her interview. When asked about it, she stated “I just know that my Mom’s toward the final end of her life right now. And, I know someday soon, I’m not going to have her. So, that’s where the tears are kind of welling up.” Victoria expresses this same dread of her father no longer being with her when she says “Now, if something were to happen to my Dad, yeah, I’ll probably be done for. I’ll probably be done for--- I’m not even---I know it could be this afternoon but I’m not---don’t even like to think about it. Don’t even want to prepare for it, nothing like that. Not a thing; no way. It’s kind of hard.” Lynn is also grieving the decline of her father, but for reasons that are perhaps a bit more complex than those of women who just do not want their parents to be gone. Lynn states “So, it’s not that that I’m grieving a close relationship because my father’s never had close relationships, sorry to say. He’s not been an open, sharing person or someone that you could go to with a problem or concern. He was---he’s very closed off about things like that---always has been. So, it’s not that our relationship from him being a nurturing, caring, giving, supportive father even though he is all those things in his own way, it’s not your typical ‘Ozzie and Harriet’ father. It’s a grieving for something that I never really had and know now that as he’s declining and I’m becoming more of a caregiver that I never will have. So, it’s also a grieving of something that I thought at some point in my life I was going to develop this relationship and it’s not ever materialized.”

The women are dealing with the fact that their parents are mortal and the time is approaching when the parent will no longer be present. Most of the women are grieving the decline for the parent’s sake but also for their own. They are grieving the inevitable loss of their parent from their lives. Sally’s experience is slightly different than those of the other women. The other women are working their ways through evolving experiences. Their decisions to give care are being made in the present. While Sally continues to make the decision on an on-going basis, she made her initial commitment to care for her mother not to her mother, but rather to her father about her mother. Her father had already been through years of dialysis when "He fell and broke his hip and we took him to the hospital and they operated and everybody went home. I was just sitting there with him, it was about seven o'clock and he said, 'I don't know what I'm going to do.' I said, 'I don't either Dad. This isn't going to be easy.' He said, 'I don't know what I'm going to do about your mom.' I said, 'Well, I've told you a hundred times, Dad, but you don't believe me.' I said, 'But, we'll take care of Mom. I promise you that.' And he died at eight o'clock that night." Sally admits that while she hates to see her mother in the condition she is in, she is happy she has not been in much physical pain. Sally's experience of her mother's decline is different than the experiences of the other women. The question arises if Sally's verbal commitment to her father in some way altered the evolution of this theme in her caregiving experience.

The daughters' grief at the decline of the parents reflects their understanding that their parents will not be with them forever. Acceptance of this fact has led the women to find individual meaning in their caregiving activities. The daughters all identified their caregiving activities as an attempt to make the best use of the time they have left with their parents. The eloquence of the daughters' words speaks for itself in these core parts of the interviews.

Jackie says, "It's kind of neat. It's like sometimes they tell you the same thing three times and you never heard that your whole life till the last---it's like maybe they want to tell us everything too before they go and they're making up for lost time." She also says she'll miss her parents.

Mary reports that “…sometimes my daughter says to me, ‘I just wish the Lord would take Grandma. She just is so sad and has so many problems’---and this and that. And, I can see that. I can understand that but yet I still want her. I guess it’s selfish, you know. I just---I still want her and I still want him and because it’s like, I don’t know how to describe it. I guess from the closeness.” Mary admits “…sometimes I think, what am I’m going to do if they’re not there to talk to. You know, what am I going to do? Even though I know that I really can’t do anything and stuff like that but it’s like, well what am I going to do, who am I going to go tell these things to, and who am I going to talk to about all different things? I guess it’s kind of like I have my husband and our memories and our children’s memories, but I had my Mom and Dad and that memory. You know, we have different memories---separate memories that are not the same and they’re private and this and that. And, that’s our memories and so I can share and communicate that kind of stuff with them but the rest of them might not understand how that might be special to me, you know, or somethin’ like that. So, I mean I’m thinking to myself. Who am I going to talk to? Who am I going to share that with, you know, when they go, you know, and that’s hard. You know, that’s hard. It is, it just really is. I mean who am I going to talk to?”

Linda shares this sense of limited time when she says “…it’s become really important to me to know her as well as I can know her before she dies. And part of that’s selfish. Part of that is because I know that in knowing her, I’m going to know me better.” In a similar way Linda says “I’ve really been able for the most part to take this really, um, kind of attitude that I’m fortunate to still have my Mom here but I want to spend the time with her I can.” Linda and her mother use the time spent together to prepare for the future. “…recently Mom had started talking about the fact that she isn’t going to be here forever.

And, I think she's doing that for both of us. You know, she's not just doing it for her or for me---she's doing it for both of us. And, it isn't that she's ill or anything---it's just that she's going to be eighty-one this year, you know, she realizes her limitations. She gets tired easier. She's just a realistic person. She's a realist. And she thinks the way you prepare for things is you talk about them."

Although Mary does not express the same emotional distress over her mother's decline as do the other women, she none-the-less expresses a desire to maintain her relationship with her mother for as long as possible. She says "…you want to have a relationship with them as long as you can. And, I think once they're in a nursing home you know, you're just visiting. I don't know that that's a relationship. Because to me a relationship is you're doing with them and if you're just sitting there visiting I don't know that that's a relationship. And, I think that I don't want that until it has to be that way. I want---even though it's hard and there's time when they're---but that's what I want. And I think that's important. So, it's what we're going to do until they tell us we can't do it anymore."

Rosie is clear about what the time spent caring for her mother means to her. She says "I mean when you've lost one parent and the other parent's just barely hanging on, it's kind of like, you know, you grasp every part, every moment of that life that you can get." Digging a little deeper into herself, she says "It's just like when you lose both your parents, something inside of you is gone and it's gone forever. In a sense, I mean they're always still with you---part of them. But you've lost that grasp of---just going up and hugging them or telling them you love them or they're there to tell you the same thing. That's all the part that keeps you going."

Lynn’s understanding of what the time spent in caregiving means to her is poignant. She says “…the big thing for me has been, you have to accept people for what they are, not what you want them to be. So, my display of love for them is my way of doing it. They have their own ways that maybe I’m just not interpreting of saying I love you to me, even though it’s without words. And I’m still looking for where it is, what nuance, what look I’ve missed that tells me and I’m still looking. I know it’s there somewhere I just haven’t discovered which unspoken part it is. So, it’s there. It’s just a matter of finding it. That’s all.”

Victoria is equally clear about what the caregiving experience means to her. She says “If the information goes out to anybody, just that keep a hold of your parents as long as you can because they’re not going to be around and when they’re gone and you go to pick up the phone to call them because you need something or because you want to talk, and, they’re not there, then it really puts in perspective---did I do everything that I could for them? And, I’m going to know when my parents are gone that I did everything possible that I could for them and I’m not going to have any guilt at their funeral. You know, the only thing I’m going to----you know, I’ll have a lot of tears but I’m going to be one of the people up there that know that they’re looking down on me with respect and not, ‘Well, she should have done this for me. And, she should have done this for me.’ I’m going to know in my heart that I did everything that I could to take care of both of them. So, that’s it.”

In doing the second interview with the daughters, each agreed that these parts of their respective interviews got to the heart of what caregiving means to them. Caregiving is an attempt to make the best use possible of time left with a loved parent. The specific ways in which each daughter is using her time differ. For Jackie, it is an opportunity to catch up on all of the stories that haven't been shared. Mary is using the time to be with her parents, dreading the time when they are gone and along with them the unique relationship she has shared with no one else. Linda is using the time to know her mother and therefore herself better before her mother dies. She is also using the time to prepare for that inevitable loss. Sally's caregiving gives her the opportunity to continue a relationship, as she understands the meaning of the term, for as long as possible. Rosie is squeezing out every possible minute of time with her mother, since she has come to realize at a very visceral level that forever means never again. Lynn is using her caregiving experience with her parents to search for that unspoken gesture or glance that will prove to her they love her. Victoria is ensuring a clear conscious. She wants to know when her parents die that she did everything she possibly could for them. She wants them to look down from above and be proud of her. She wants to fulfill her commitment to them.

Caregiving is a deeply personal experience. While the essential themes are shared by all of the women of the study, the essence of what it means to the individuals is as primal as their relationship with their parents. Caregiving is not a negotiable option for these women. Rather it is a reflection of who they are, the depth of their bonded-ness to their parents, and the lengths they will go to honor that bond.

Summary

This chapter revealed the lived experience of the participants. The ten themes elicited through the research process were examined through use of the participants' own words and the interpretive efforts of the researcher. What is presented is the lived experience of daughters who care for their frail, elderly parents in the parents' home.

Chapter 7: Significance of the Findings

Life is a kind of boiling over
in which a thing wells up within itself,
floods itself and overflows
pouring itself into all of its parts
Until finally
it spills over
boiling and overflowing
into something external as well.
Meister Eckhart (1983, p. 31).

Introduction

This study has attempted to capture the essence of the lived experience of daughters caring for their frail, elderly parents in the parents' homes. The daughters shared their stories from the fullness of their hearts. The experiences of the caregivers were analyzed and broken down into themes that were validated by the caregivers. The researcher interpreted the meaning of the themes and examples from literature and art were presented to support these interpretations. The interpreted experiences of the daughters were then rewoven into a descriptive narrative that captured the wholeness of their reality as caregivers. The question then becomes "So what?" Do the findings of this study mean more than just an interpretive description of an experience? As Meister Eckhart (1983) writes, are they able to boil and overflow into something external as well?

This chapter examines the significance of the study within the nursing discipline. How the study fits within the context of the existing literature will be examined, as well as the manner in which it lends support to two existing theories. Issues of rigor and the limitations of the study will also be addressed. Finally, implications for future research and practice implications will be discussed.

Context of the Study within the Nursing Literature

Extensive research about family caregiving exists in the nursing literature. An overview of the body of work reveals the studies fall into noticeable categories of focus.

The main thrust of the early work was on the negative aspects of the caregiver role, particularly caregiver burden and caregiver strain (Archibald, Stewart, Greenlick & Harvath, 1990; Baille et al.,1988; Beach, 1993; Bull, 1990; Gaynor, 1990; Wallhagen, 1992). Each of these studies set out either to identify the presence of burden, strain, or other forms of psychological distress. More current studies continue the focus on the specific nature of caregiver burden (Faison et al., 1999; Jepson et al., 1999).

Investigations into the negative physical consequences of caregiving are present. Picot et al. (1999) studied the relationship between mood and blood pressure in caregivers. Although not from the nursing literature, Schulz & Beach (1999) found a higher mortality rate for elderly caregivers who experienced strain in the caregiving role.

Movement away from studying only the negative outcomes associated with the caregiver role has taken place over the past decade. Picot (1995) included perceived rewards as one of her independent variables. Researchers such as Carruth et al. (1997), Picot et al. (1997), and Schumacher et al. (1998) endeavored to improve measurement of positive outcomes.

The literature reflects another emerging trend in the focus of research into informal caregiving, namely, the appraisal of coping strategies carried out by the caregivers themselves. A qualitative study by Langner (1993) identified the coping mechanisms of establishing and maintaining routines, focusing on the present, and retelling the reasons for caregiving. Szabo and Strang (1999) used a qualitative approach to identify various coping strategies such as utilization of both internal and external resources employed by caregivers to bring some sense of control to their experiences.

Intervention studies have been conducted by nurses in the area of family caregiving. In a quasi-experimental study in Taiwan, Chen (1999) found that counseling from home health nurses resulted in healthier lifestyles for caregivers. Grant (1999) found that telephone contact with caregivers resulted in more positive outcomes for caregivers than did home visits on variables such as depression, problem solving, and caregiver preparedness. A European synthesis study by Hanson, Tetley and Clarke (1999) found that while respite care offered relief to caregivers, the caregivers themselves voiced a need for more information, education, training, and emotional support in their role. Multiple other intervention studies involving some type of counseling or training exist, such as those by Robinson and Yates (1994), Larsen (1998), and Chang (1999). The findings of these studies lend credence to the caregivers' perceived need for support identified in the current study.

Other categories of caregiving studies are those that consider caregiving for persons with particular diseases. Examples of these are caregiving to persons with cancer (Jepson et al. 1999), Alzheimer's disease (O'Donnell, 2000), and HIV/AIDS (Stajduhar, 1997). Although disease conditions of the parents were not a component of the current study, the presence of Alzheimer's disease in one parent did affect the experiences of her daughter and how her experiences evolved in analysis of the themes.

The qualitative studies constitute a final category of investigations into family caregiving. These works have been discussed in Chapter 4 and will not be re-examined here except as they differ from the present work.

The myriad of studies listed above are a small sampling of the existing body of work. The question arises if the current study varies in significant ways from these studies. The work differed from the quantitative studies in that it did not attempt to measure a specific aspect caregiving experience such as emotional or physical risks. Nor did the study attempt to identify positive outcomes or coping strategies of caregivers. No interventions were conducted and the caregivers were not selected in terms of the diseases the care recipient had. Instead this study, like the other qualitative investigations, attempted to capture the experience of caregiving from the perspective of those who are fulfilling the role.

This study varied from other qualitative studies in that factors within the caregiving experience were more carefully controlled. As was pointed out in Chapter 2, the samples in the other studies were mixed either in terms of gender and or the nature of the relationship between the caregivers and the care recipients. In all of the studies the caregivers were either children, spouses, or in-laws of the care recipient. In the one study that did control gender, the relationships were mixed. The current study is the only phenomenological investigation in which the caregiver was the biological daughter of the care recipient. The parents in this study were also relatively comparable to one another in terms of their health status. Despite varying level of cognitive impairment, none of the parents were bed ridden; none had been diagnosed with a condition that made them expect an eminent death. Although the parents did have a variety of diseases, they were able to remain in their homes with the help of the daughters. Thus, this study is one of a particular context. This study examined caregiving in a situation in which daughters are helping their parents choose a lifestyle that is important to the parents. The essential elements of this study are the relationship between the participants and the care the daughters give to a specific person, rather than to a person with a specific disease. This fact has implications for the significance of the findings within the context of other nursing studies, as well as how they relate to theory.

Theoretical Considerations

The findings of the study were examined in light of John Bowlby's attachment theory. As a psychoanalyst, Bowlby questioned the origins of human interactions. He theorized that people form bonds not solely because of need gratification as widely believed in his day, but rather because they are physiologically and psychologically programmed to do so (Bowlby, 1979). He identified the specific human attributes that foster attachment as the ability to touch, to make eye-to-eye contact, to vocalize, to smell and to omit odors, to move to the rhythm of the spoken voice, to develop the biorhythms of other people, and to develop reciprocity and synchronicity with other human beings (Bowlby, 1979). These attributes enable human beings from the earliest moments of birth to enter into relationships with other humans.

Attachment behavior is different than the concept of attachment. Attachment behavior is behavior that results when an individual perceives that the other person to whom he or she is attached is not present. Bowlby stated that "whilst especially evident during early childhood, attachment behavior is held to characterize human beings from the cradle to the grave" (1979, p.129). The nature, frequency, and intensity of attachment behaviors vary according to the person's age. In infants and young children these behaviors involve, crying, calling, following, clinging, and protest when left alone (Bowlby, 1979). Although the characteristics of the behaviors change with age, they still fall into the same categories of emotional response. The presence of attachment behaviors at separation is evidence that attachment exists between the two people.

Characteristics of human attachment exist and help identify the process. Bowlby (1979) identified the first characteristic as specificity, which indicates that human attachment exists toward one or a few specific persons, usually in an order of preference. The second characteristic, duration, means that attachment bonds usually exist for life. Engagement of emotion implies that the formation of the bond is perceived as falling in love, maintenance of the bond is perceived as loving the person, and loss of the person is experienced as grief. The threat of losing the person results in anxiety and attachment behaviors. The ontogeny of the bond is that the more interaction there is between the partners, the greater the likelihood of attachment. The characteristic of learning means a key factor in establishing the bond is learning to differentiate the familiar from the unfamiliar about people. The organization of the relationship states that attachment behaviors are activated by hunger, fatigue, or anything perceived by the person as frightening. The final characteristic of attachment is that proximity is sought to the other, initially probably as a means of protection (Bowlby, 1979). These characteristics define the attachment experience. In order for a relationship to be one of attachment, these characteristics must be present.

As daughters of the care recipients, the participants of the current study all displayed the characteristics of attachment. The care they give is directed at specific people, their parents. The duration of their relationships is the entire life spans of the daughters. Engagement of emotion is seen in the daughters' expressed love of the parent and the grief they feel at the thought of losing the parent. Bowlby's theory holds that this threat of losing the parent will result in the presence of attachment behaviors. While the nature of attachment behaviors is well documented in infants and children, it is unclear what these behaviors are in an adult. The characteristic of ontogeny describes the development of the relationship, that is, that the presence of interaction fosters attachment. The daughters in this study have maintained relationships with their parents throughout their lives. The characteristic of learning is seen as the daughters continue even into adulthood to recognize more specifics about their parents through caregiving. The organization of attachment is that attachment behavior is induced by anything perceived as threatening. As the parents age and become increasingly frail, dangers are present. The daughters express concern for the well-being and safety of the parents at many levels of their experience. The final characteristic of attachment is proximity, the perceived need to be with the other, particularly in times of threat. All of the participants express and demonstrate this characteristic as their parents become increasingly frail.

The findings of the study support Bowlby's theory that attachment, once it has formed, lasts for a lifetime. Understanding of attachment behaviors helps explain many of the daughters' behaviors: the need to be with the parent, the drive to know the parent better, concern about their safety and well-being, and distress at the thought of the parent's demise. Awareness of the primal nature of attachment characteristics and attachment behaviors can give insight into the process of caring for a parent, both to the caregivers themselves and to those who support them.

The findings of this study also have particular relevance in light of Kristen Swanson's theory of caring. The theory was developed in 1991 from information gathered through several phenomenological studies within the context of perinatal experiences, specifically care for women who had experienced unexpected early pregnancy loss (Swanson, 1986) and care for infants in an intensive care unit (Swanson, 1990). The findings of these studies led to the identification of five processes within a caring relationship and a definition of caring as “a nurturing way of relating to a valued other toward whom one feels a sense of commitment and responsibility” (Swanson, 1993, p. 354). Although the original studies had taken place in perinatal settings, Swanson theorized the findings might be applicable beyond that type of setting and beyond the domain of nursing. The five processes of Swanson’s theory were examined for fit with the findings of the current study.

“Maintaining belief” is the base of caring in Swanson’s theory. She describes this process as “a fundamental belief in persons and their capacity to make it through events and transitions and face a future with meaning” (Swanson, 1993, p. 354). She discusses the need for caregivers to maintain belief in care recipient’s ability to create “dignified passages” through life events. The daughters in the present study care for their parents with this belief. Each of them recognizes how their parents want to face their aging and their diminishing personal capabilities. Specifically, the daughters recognize their parents want to stay in their own homes for as long as possible. The daughters have embraced their belief in their parents’ right to do this, since this is what gives meaning to the parents’ lives. These beliefs are conveyed through the theme of reciprocity in the current study. The daughters speak of their belief that their parents deserve their caregiving because of everything the parents have done for them. The daughters express the desire to help their parents live as they wish because of their love for the parents. They want their parents’ aging to be dignified. The daughters continue to treat their parents with respect because of who they are and their role as parent. These caregiving daughters continue to believe in their parents as human beings.

The second process identified by Swanson is “knowing.” She defines this process as “striving to understand events as they have meaning in the life of the other” (Swanson, 1993, p. 355). She states that knowing is what enables the other three processes to be relevant and effective in helping the person. She also identifies self-knowledge as an essential component in one’s ability to recognize another person’s reality and to know the limits of one’s ability to support the person. The daughters in the present study identify knowing as an essential part of their caregiving experiences. Three themes were elicited in this area: caregiving as a doorway to intimacy with the parent, caregiving as a means of self-discovery, and caregiving as a thread that can weave a family together across generations. Through the caregiving experience, the daughters have come to know their parents, themselves, and their families better.

“Being with” is the third process identified by Swanson. It is defined as “being emotionally present to the other” (Swanson, 1993, p. 355). She describes being emotionally present as more than simply being with the person. Rather, it is a way to share in the total lived experience of the other. It is a “clearly conveyed message of availability and ability to endure with the other” (Swanson, 1993, p. 355). The interviews with the daughters conveyed this process in numerous ways. The themes that most explicitly capture the meaning are embracing the wholeness of commitment, the daughters’ grief at the decline of their parents, and their desire to make the best use possible of the time they have left with them. These themes reveal the daughters’ recognition of the reality of the parents’ lives, their willingness to go through the process of decline with them, and the heartbreaks and joys they experience by being present to them.

The fourth process in Swanson’s theory is “doing for.” Working from Virginia Henderson’s definition, Swanson defines this process as “doing for the other what they would do for themselves if it were at all possible” (Swanson, 1993, p. 356). She states this process includes the psychomotor things one does for another as well as the psychosocial support one gives. The daughters in the study demonstrate this process. They cook, clean, and shop for their parents. They oversee the parents’ nutrition. They monitor the parents’ health, take them to the doctor, and purchase medicines and supplies. They change Depends and monitor safety. The theme from the current study that reflects this process most closely is maintaining the autonomy of the other, but particularly the variation of helping the parent compensate. This particular variation reveals in great detail the lengths the daughters are willing to go to enable the parents fulfill their desire to live on their own.

The final process in Swanson’s theory is “enabling.” She defines this process as “facilitating the other’s passage through life transitions and unfamiliar events” (Swanson, 1993, p. 356). The author addresses the negative implications the term “enabling” has in its current usage and states it was not her intention to imply enabling as a way of fostering unhealthy behaviors in others. Instead she uses the word in the sense of facilitating. When one is doing for another, the focus should be on facilitating self-care as much as possible. The fit between the findings of the current study and the last two of Swanson’s processes is not completely congruent. The variation of helping the parent compensate supports Swanson’s process of “doing for.” However, the overall theme of maintaining the autonomy of the parent addresses the daughters’ desire to keep the parents functioning on their own as much as possible. The theme of maintaining the autonomy of the parent, minus the variation of helping the parent compensate, supports Swanson’s process of enabling. What evolved as one theme in the current study is broken into two processes in Swanson’s theory.

Eight of the ten themes elicited in the current study support Swanson’s theory of caring. These are summarized in Table 3.

Table 3

Comparison of Swanson's theory of caring and the study results

Swanson's Processes	Study Themes
Process I: Maintaining belief	Caregiving is an experience of reciprocity
Process II: Knowing	Caregiving is a doorway to intimacy. Caregiving is a means of self-actualization Caregiving is a thread that can weave a family together.
Process III: Being with	Caregiving is embracing the wholeness of commitment. Caregiving is grieving the decline of the other. Caregiving is making the best use of the time left with the other.
Process IV: Doing for	Caregiving is supporting the autonomy of the other (Helping the other compensate).
Process VI: Enabling	Caregiving is supporting the autonomy of the other.

Questions arise about the two themes from the current study that do not fit with Swanson's theory. These themes are that caregiving is being torn between worlds and that caregiving is a crucible of individual effort. The themes are essential to the experience of the daughters of this study, but are they essential to caregiving in general?

The answer to this question may come from Attachment Theory. The first characteristic of attachment identified by Bowlby is specificity. Bowlby postulates that humans attach to only one or a few people, and in order of preference. As daughters, the participants in this study had attached to their parents at an early age. Once the women married and had children, however, they also attached to these individuals. The drive they experience toward their parents, they now also feel toward other people at the same time. The daughters expressed emotions that were interpreted as being torn between worlds. At one level this perception can be seen as having conflicting responsibilities of a temporal nature, that is, the daughters feel torn between doing things for their parents and their children or spouses. On another level, however, the sense of being torn can be between their attachment bonds. The original attachment to the parent exists over a lifetime. The decline and recognition of the inevitable loss of the parent initiates attachment behaviors---behaviors that are consuming both in terms of time and emotional energy.

Caregiving affects attachment between adult children and parents in yet another way. Bowlby’s theory maintains that an order of attachment exists. The child attaches to the parent because the parent is the one who protects and nourishes. This fact was supported by the etymological origins of the words “mother” and “father” described in Chapter 4. The definitions of these words reinforce the order of attachment. The parent supports the child; the child does not support the parent. Thus in caregiving the natural order of attachment is reversed. The child is called upon to support, nourish, and protect the parent. The deeply embedded processes of a lifetime are turned upside down. This fact may help explain why the need for support is so great in the type of caregiving being done by adult children caring for their parents. In addition to needing support with doing things, they also need support in working through a developmental crisis of being in a role reversal with their earliest attachment figures.

The findings of the current study add to the body of knowledge about concepts relevant to nursing. Swanson’s understanding of caring is supported as is Bowlby’s theory that attachment lasts for the duration of one’s lifetime. Questions are raised about the particular nature of caregiving when this phenomenon exists within the context of human attachment. Answers to these questions will help identify ways in which attached caregivers can best be supported in their role as well as ways in which they can be supported when the role ends.

Conclusions

Credibility, Fittingness, and Auditability,

Scientific rigor in qualitative research is achieved differently than in quantitative research. Guba and Lincoln (1981) present a framework for assessing the rigor of any study and give insight into how the components of the framework are achieved in both paradigms. These components include the truth value, applicability, consistency, and neutrality of a study. Efforts taken to achieve these standards in the current study are addressed.

The truth value of a qualitative study is reflected in the credibility of the work (Guba & Lincoln, (1981). Credibility is established if the descriptions and interpretations of a phenomenon ring true for other people. If people who have had or who are having the experience recognize the experience as their own, or if others who have not had the experience are able to recognize the experience for what it is, the work is credible (Sandelowski, 1986). A major threat to credibility is that the researcher would become so involved with the participants that she would have difficulty keeping her own experiences separate from theirs (Sandelowski, 1986). Techniques to enhance credibility in this study included bracketing my own experiences as a caregiver through journaling prior to beginning data collection. Field notes were taken after each interview to describe the interactions between researcher and participant. These notes were used to refresh my memory of the context of the interview, thereby increasing my understanding of what the participant shared. The themes elicited from the first interview were validated by the participants during the second interview. On one occasion the researcher had interpreted a participant statement incorrectly and this interpretation was discarded.

The applicability of a study indicates the degree to which the findings of the study have meaning to people in similar situations. Guba and Lincoln (1981) identified this criterion as fittingness. A study has fittingness when people outside of the study find the results to be meaningful and representative of their experience. Threats to fittingness are the "elite bias" and "holistic fallacy" (Sandelowski, 1986). Elite bias is present when only the most highly articulate or most highly educated members of a group are in the study. Holistic fallacy occurs when the researcher manipulates the data in such a way as to make the findings appear more homogenous than they are. Efforts were taken to avoid these threats to fittingness. Although the sample was a convenience sample of women who fit the inclusion criteria, they did represent a wide range of backgrounds, educational levels, fields of employment, and verbal abilities. Evidence of the coding practices and decision making processes were maintained. Care was taken to include all of the experiences of the daughters, both those that were typical and those that were not. Finally, a colleague of the researcher who was not a participant but who had given care to his father for a year in the father's home read the final narrative and validated it as being reflective of his experience.

Consistency in a study means that another researcher would arrive at somewhat similar results if the study were to be repeated. Guba and Lincoln (1981) identify this criterion in qualitative research as auditability. Auditability is achieved when another researcher can follow the logic of decisions made in the study and when that researcher would draw similar conclusions from the data. While absolute consistency is not possible in qualitative research, efforts can be made to enhance its presence. This study included a statement of how the researcher became interested in the topic of caregiving and how caregiving is related to her own experiences. The purpose of the study was clearly stated and an accurate account of how the participants were recruited was given. Notes were kept on how the researcher and participants interacted, how the interviews were conducted, and the location of the interviews. The method by which the data were analyzed and interpreted was described in the study. All records pertaining to data analysis and interpretation have been maintained. The truth value of the analysis and interpretation of the data was validated by the participants.

The final criterion in assessing rigor in research is neutrality, or the assurance that bias is not present in the study or the findings (Sandelowski, 1989). Guba and Lincoln (1981) have identified this standard as confirmability in qualitative research. The presence of credibility, fittingness, and auditability in a study reflect the presence of confirmabilty. The efforts described above to enhance the presence of the first three criteria are also the evidence of confirmability.

Limitations

Despite efforts to ensure rigor in the study, several limitations exist. The first of these is the lack of racial diversity in the sample. Efforts were made to recruit women of color, however these efforts were not successful.

A second limitation is that the original proposal called for the placement of a poster in various places announcing the study. This poster was not placed. The community center where the researcher had planned to place the poster was closed permanently due to internal problems. Permission was asked of the pastoral administrator of an African-American church to place the announcement in the back of the church. The administrator felt better results would be achieved if she announced the request to the church members. Consequently the poster was not placed in the church.

Another limitation is that women who were having different caregiving experiences than the women in the study may not have volunteered. If women felt overwhelmed by stress they may not have had time for the study. If they had negative feelings about the caregiving experience or were working through difficult relationships with their parents, they may not have wanted to share those feelings.

The interview process itself may have provided some limitations to the study. Ten of the interviews were conducted in the participants' homes, two were conducted in my home at the participant's request, and two were conducted at a small town diner at the participant's request. Several of the interviews in the participants' homes were interrupted by phone calls or the arrival of family members. One interview in my home was interrupted by the pet passing through the room. This interruption had not been anticipated since the dog was old and rarely left her bed. The noise in the diner sometimes became loud and may have interfered with the participant's concentration.

All of the interviews were audio-tape recorded. The presence of the recoding machine may have affected the comfort level of the participants. This influence was noticeable at the beginning of the interviews but diminished greatly with time. Several of the interviews lasted over an hour. In these situations the tape had to be turned over, interrupting the flow of what the participant was saying.

An outside agent transcribed all of the interviews. I checked the typed transcriptions against the audio-tapes for accuracy. Corrections were made to the transcriptions when errors were noted. One of the participants spoke very rapidly, however, and one spoke very softly. A few words from each of these interviews were inaudible to both the transcriptionist and me.

Some of the limitations to the study were unavoidable; some, however, were not. In future studies I will be more attuned to these things and know how to prevent them.

Implications for Practice

The aim of phenomenological research is to gain an understanding of a particular phenomenon. The understanding of what it is like for a daughter to care for a frail, elderly parent in the parent’s home demonstrated in this study has ramifications for the practice of nursing.

With understanding comes the potential for greater empathy. Dissemination of the findings will enable nurses to know what daughters are going through even though they themselves have not had the experience. Nurses who interact with the elderly and their caregivers in the hospital setting and in home care can have greater insight into what the issues being faced by the caregiver are. Enhanced insight can lead to improved practice through more sensitive interaction with the caring dyad and more focused assessment of their needs.

More focused and relevant assessment could be achieved through development of an assessment tool based on the findings of the study. Caregivers are not usually the patient.

However, when elderly patients are admitted to the hospital or seen by home health nurses, assessment of the caregiver could be included. Simple questions could address each of the ten themes thus eliciting an overview of how the caregiver is doing in her role. In this way some of the physical and emotional consequences of caregiving could be averted before they become problematic. Referrals could be made to appropriate support sources, counseling, or medical services.

The interviews of this study revealed that sometimes daughters do not identify themselves as caregivers, but simply as daughters. External guidance may be needed to see when a balance has shifted and one is assuming more and more responsibilities for the parent’s well-being. Appropriate assessment by a nurse would help these daughters identify for themselves what their role is. Not recognizing that one is a caregiver can mean the resources and support to which one is entitled, are not utilized. A focus on identification of caregivers would be an appropriate role for advanced practice nurses within medical groups and for nurses in the home health field.

If the goal of nursing practice is to improve the well-being of caregivers, dissemination of the findings to the caregivers themselves is important. This goal could be achieved in several ways. First, articles published in the popular press would be accessible to caregivers. The themes could be discussed in terms that are understandable to lay people. The power of such an approach exists at several levels. Caregivers can learn they are not alone in their efforts or the emotions they experience. Reading about caregiving validates it as something that is larger than the individual. Recognition that one is part of a national phenomenon enhances the stature of the role and of the individual. Tips for dealing with the stressful parts of cargiving could be addressed and the inherent joys could be celebrated. The local media also could be used to disseminate the findings. Talk shows on local public service channels or local public radio stations provide formats that would be appropriate for discussion of the topic.

All of the daughters expressed satisfaction in doing the interviews for the study. Telling one's story and having it heard is a catharsis as well as an empowering experience. Since it is not realistic to think about interviewing large numbers of caregivers individually, focused support groups could be developed. These groups would be time limited and theme specific. Ongoing general support groups for caregivers already exist. The proposed group would not deal with the general issue of caregiving, but rather would focus on the story the caregiver has to tell and the themes elicited by the study. Allowing the participant to tell her story facilitates catharsis and empowerment. Focusing on the themes of the study for discussion allows the essential aspects of caregiving to be addressed in a shorter period of time. Since caregivers are usually pressed for time, the benefit of this approach is that it would allow in-depth discussion to occur in a controlled time span. Another benefit of such a group is that with the permission of the participants, the stories could be audio or video recorded and possibly published. One of the things discovered by the researcher is that the stories of the caregiving daughters are inherently beautiful. They are deep, they are soulful, and they deserve to be heard.

A more specific function of a time limited support group would be to help daughters work through the transition of roles they are experiencing with their parents. This transition is one for which adult children are usually not prepared, for unless the parent has been sick or dependent earlier in life, no precedent for the reversal exists. Adult children do not have the opportunity to practice the caregiving role until it is upon them. In addition to the physical strain of caring for another person, the emotional strain of this role reversal can be debilitating. A nurse led support group focused on this one aspect of caregiving would give participants the opportunity to understand the transition and learn coping skills that would enable them to more successfully navigate their way through it.

In order for such support groups to be viable, resources would be needed to fund them. This issue will be addressed in the considerations for future research. However, recognition of the importance of policy issues is central to the practice domain. Nurses have direct experience and expertise in dealing with the needs of the elderly and those who care for them. Political activism is a method through which this expertise can be put to use for the benefit of these groups. Letters and written testimony to public officials at the appropriate levels of government are a means of gathering support for legislation that affects caregivers. Support for the expansion and increased funding of legislation such as the Older Americans Act and the Family Medical Leave Act can have direct bearing on the lives of the elderly and those who care for them.

A final implication for practice is a simple reminder about the power of listening. One of the participants brought this issue clearly to light when she expressed her frustrations when people tell her she is a saint for taking care of her mother. She said there is nothing she can say in response to such a statement and that it would be much more helpful if people would just ask her what it is like for her to do what she does. Although this insight is the basis of phenomenological research, it also is the basis of good communication. If we truly are interested in our patients and others with whom we talk, we will give them the opportunity to say what they want to say rather than blocking them with meaningless praise.

People have stories to tell. If we as nurses are to be genuinely present to people, we can ill afford not to draw out those stories.

Caregiving is a role that is in many ways invisible since it occurs within the privacy of the home. By virtue of their role, caregivers are at increased risk for physical, psychological, and economic damage. If their stories are heard, intervention and support are more likely to occur. The presence of adequate support can improve outcomes for caregivers, their spouses and children, and ultimately for the frail, elderly people for whom they care.

Implications for Future Research

Family caregiving is a phenomenon that affects millions of people in the United States and the world. The current study examined the experiences of a small group of daughters who provide such care. While the investigation led to insights about what the experience is like for them, it also raised questions. These questions form the basis of potential future research investigations.

The current study is the only phenomenological inquiry in the nursing literature that looks at caregiving from the perspective of a particular relationship, that is, between daughter and parent. Further study is needed to determine if the presence of an attached relationship between the caregiving dyad results in issues that are unique to those categories of people. If so, what are these issues and how can they be used to improve services to those people? A similar phenomenological study of son-parent caregiving would be helpful to see if the findings from the sons are similar to those of the daughters. If so, do they inform us of a specific type of attached caregiving?

Extensive research has been done and much is known about attachment behaviors in infants and children. Little is known, however, about how attachment behavior evolves across the life span. Investigation in this area would help clarify the meaning of behaviors and emotions, both to the person experiencing them and to those who support them, both professionally and personally. Such knowledge would benefit caregivers, care recipients, and the population as a whole.

The question arose of what role attachment actually plays in the caregiving role. In the absence of attachment, is the caregiving experience altered? When adult children assume care for their parents in the absence of an attached relationship, is the risk of poor outcomes increased for both the parent and the child? Is the risk of elder abuse higher for the parent and is the risk of burden and stress on the part of the caregiver increased? What becomes of caregiving situations in which abuse from either the parent or the child toward the other has occurred? Understanding of these factors could lead to more focused interventions from those who work with such families.

The findings of the study indicate that perhaps children who assume a caregiving role for their parents are facing a new developmental stage, that is, the transition from being the one who is nurtured by the parent to being the one who nurtures the parent. The daughters expressed distress at watching their parents gradually fail. Investigation into the emotional burden of this experience can give insight into ways that people can best be supported during this time.

Other questions arose about the nature of the caregiving experience for daughters. If the same study were conducted with daughters from a different cultural background, would the findings be the same or are caregiving experiences culturally specific? Do generational differences exist within cultures? For example, do perceptions of the caregiving experience vary between generations of people? Do caregivers from the baby boom generation view their responsibilities to their parents differently than women from generation-X? Knowledge of potential differences would have significance for future maintenance of the informal caregiving network that supports so much of elder care in America today.

The daughters of this study discussed their need for support in the caregiving role. For some of the women this support came partially from their churches. Knowledge of this fact raises questions about the significance of both religion and spirituality as a component of the caregiving role. Investigation into these areas might shed light into motivations for people's assumption of the caregiving role and lead to expanded means of support.

The care recipients of this study were limited to parents who were frail and elderly. If a similar investigation were conducted with daughters caring for terminally ill patients would the findings be the same, or does the knowledge of the parent's impending death alter the caregiving experience for the caregivers? If so, knowledge of the differences could lead to development of support systems that are more specifically appropriate to people in the the different situations.

The daughters in the current study were helping their parents remain at home because it is what their parents want. Each of the daughters expressed though words and actions the commitment to keep her parent living as independently as possible for as long as possible. The question arises of what happens to the daughter when, for whatever reason, she is no longer able to keep the parent at home. What is the daughter's experience when she is not able to allow the parent to live as he or she wishes? What kind of support is required to help facilitate this transition for the daughter?

The value of several potential intervention studies was identified. The need for greater identification of caregivers was addressed in the previous section. If a program were developed to facilitate such identification, what effect would it have on the caregivers? Would recognition of themselves as caregivers at an earlier point in their experience foster positive outcomes for them? Many of the daughters expressed satisfaction at being able to share their caregiving stories with the researcher. Would attendance at a theme specific, time limited support group give caregivers an increased sense of satisfaction in their role? Numerous variables could be investigated related to both these areas of interest.

In order to obtain insurance coverage of support groups for caregivers, it must be demonstrated that such groups are medically necessary. Existing research gives evidence that caregiving can have a negative impact on the physical and emotional health of those in the role. If theme specific support groups for caregivers were initiated, longitudinal studies could be conducted in which the well-being of the participants is compared to the well-being of a control group of caregivers who did not attend such a group. If improved outcomes were found in those people who attended the groups, evidence could be garnered that funding of the groups would be a cost-effective measure for insurance companies to adopt.

Questions were raised about the relationship between the current findings and Kristen Swanson’s theory of caring. Two of the themes that are essential to the caregiving experiences of the daughters are not represented in Swanson’s theory. Does the emergence of these themes enhance the existing body of knowledge on cargiving or are they particular to the women of this study? Further research in this area could help clarify these questions of theory development.

The current study has answered some questions and raised new ones. Continued research in the area of family caregiving can increase the body of nursing knowledge and enhance the quality, scope, and depth of nursing services provided to caregivers.

Implications for Education

The findings of the study have implications for nursing education. As faculty become more aware of the experiences of caregivers, and caregiving daughters in particular, this content can be incorporated into gerontology courses. Understanding of the significance of the caregiver in the life of the elderly person is equally important for beginning nurses. Students exposed to the issues of caregiving in their generic educational programs will be better prepared to meet the challenges of this phenomenon in the future. As the population continues to age, such knowledge will become increasingly necessary if the current network of caregiving is going to be maintained.

Another implication for education is, again, recognition of the need to pass on to students an appreciation of the power of human presence and listening. As the knowledge base and the technological aspects of nursing continue to increase, it is easy for faculty to become consumed by content. The voices of the daughters remind us that what people want and need in addition to competent technical care, is someone to support them as they try to do the best they can with the life they have.

Summary

This chapter has looked at the study of family caregiving by daughters in light of the existing literature. The place of this study with in the literature was identified. The findings were discussed in terms of Kristen Swanson’s theory of caring and John Bowlby’s theory of attachment. The question of rigor was addressed, as were the limitations of the study. Implications of the findings for practice, research and education were presented.

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Appendix A

Letter to Physicians and Adult Day Care Directors

Dear

I am writing to ask your assistance in facilitating a research study I am conducting in fulfillment of my doctoral dissertation requirements at the University of Cincinnati, College of Nursing. The study is a qualitative investigation into the lived experience of daughters who care for their frail elderly parent or parents in the parents' home.

My request is if you would be able to identify for me individuals who meet the following criteria: women 18 years of age or older who currently provide at least 15 hours per week of physical or emotional support to their frail elderly (at least 65 years of age) parent or parents in the parents' home, and who have done so for at least six months. Other inclusion criteria are that the person be a daughter, either biological or adoptive, but not a daughter-in-law, that the daughter is not being paid for her services, and that the daughter not be particularly vulnerable for other reasons (for example, due to the presence of multiple current life crises).

If such eligible women gave consent to you for me to contact them, I would do so with a letter explaining the purpose and nature of the study. A follow-up phone call would be made to set up a time and place to meet with them at their convenience. An interview of approximately one to two hours would be scheduled individually with each woman, followed by a second interview approximately one month later. Both interviews would be audio-taped with the participant's knowledge. Any data that would be cited within the study would be pesented without the participant's name and with no identifying information connected with it. This would be the limit of the participant's participation in the study unless they requested information about the research findings.

The study has been approved by the University of Cincinnati Institutional Review Board. Any questions may be addressed to myself at 859-291-6892, or to the chair of the doctoral dissertation committee, Dr. Margaret Miller at 513-558-5212. I will contact you in approximately a week to discuss the matter further with you.

Thank you for your assistance in this matter.

Sincerely,

Margaret (Peg) Owens, RN, MSN
106 Sterrett Ave.
Covington, KY 41014

Appendix B

Letter to Potential Participants

Dear _____,

I am writing to ask your participation in a research study I am conducting as part of my doctoral studies at the University of Cincinnati, College of Nursing. The study is about the experiences of daughters who care for their frail, elderly parent or parents in the parents' home.

You were identified either by your doctor, the director of an adult day service, or yourself as someone who meets the following criteria: that you are a woman at least 18 years of age who currently provides at least 15 hours per week of physical or emotional support to your frail, elderly parent or parents in their home and that you have done so for at least six months; that you are either the biological or adoptive daughter of your parents; that your parent is at least 65 years of age; that you are not being paid for your services, and that you are not feeling unusually vulnerable for any reason at this point in time.

Your participation in the study would include the following things. I will call you in about a week to see if you are interested in participating. If you are, we will set up a time and place to meet that is convenient for you. This could be at your home, the adult day service setting, or a small room in a public building. I will ask you to read and sign a statement agreeing to participate in the study. If you are still willing to participate, we will have an interview that will probably last from one to two hours, depending on how much you have to say. I will audio-tape record the interview. Approximately one month later you and I will meet for a second interview that will also be audio-tape recorded. The link between the information you share with me and your identity will be kept confidential and known only to me. If any data from your interview is cited in the study, it will be done with no personally identifying information present. This would be the limit of your participation unless you were interested in the findings of the study.

I certainly hope you will consider participating. The work you do is very important and it would be helpful to health care workers to learn how the experience really is for those who do it.

If you have any questions you may call me at 859-291-6892 or my advisor, Dr. Margaret Miller at 513-558-5212.

Sincerely,

Margaret (Peg) Owens, RN, MSN

Appendix C
Flyer

RESEARCH STUDY on FAMILY CAREGIVING

A research study focused on daughters who care for their parent or parents in the parents' home is being conducted. In order to participate, the daughter should have the following characteristics:

1. Is at least 18 years of age
2. Is the biological or adopted daughter of the parent/parents
3. Spends at least 15 hours/week caring for the parent/parents in the parents' home
4. Receives no money on a regular basis for the care given to the parent/parents
5. Has cared for the parent/parents in the parents' home for at least six months.

If you meet the criteria and would like more information about participating in the study, please call Peg Owens at 859-291-6892 or 859-344-3410.

Thank you for your interest.

Appendix D

University of Cincinnati
College of Nursing
Consent to Participate in a Research Study
Margaret N. Owens
859-291-6892
powens3@aol.com

Title of Study: Caring for Frail, Elderly Parents in Their Home

Introduction: Before agreeing to participate in this study, it is important that the following explanation of the proposed procedures be read and understood. It describes the purpose, procedures, risks and benefits of the study. It also describes the right to withdraw from the study at any time. It is important to understand that no guarantee or assurance can be made as to the results of the study.

Purpose: This purpose of this study is to gain understanding of what it is like for daughters to care for their frail, elderly parent or parents in the parents' home. This understanding will add to the body of nursing knowledge and improve understanding of the needs of daughter as caregivers. You will be one of approximately 10 to 12 participants taking part in this study.

Duration: Your participation in this study will last for the length of time it takes to conduct two interviews. Each interview may take approximately one to two hours, or slightly more or less. The two interviews will be scheduled about a month apart and at a time that is convenient for you.

Procedures: During the course of the study, the following things will occur:
You will be asked to participate in two interviews that will take place in a mutually agreed upon private place, probably either your home, an adult day service center or a room in a public building such as a library. The two interviews will be audio-taped by Ms. Owens. A typist who will not be Ms. Owens will type up the content of these interviews. However, your name or any other identifying material will not appear on the tapes or transcripts and the typist will have signed a confidentiality statement. The information you provide in the interviews will be combined with the information from other participants to come up with one description of what it is like for daughters to care for their parents. Some quotes will be cited directly, but when this occurs, the statements will be anonymous, with no personally identifying information given.

Exclusion: You will not be able to participate in this study if any of the following apply to you: If you are not the daughter of the person you care for, or if you think talking about taking care of your parent or parents will make you too upset.

Risks/Discomforts:

The study is not expected to involve any risks or discomforts. However, some people may find talking about caring for their parents to be mildly upsetting. The safeguards to avoid these discomforts or risks are that Ms. Owens has been a registered nurse for thirty years and would be able to talk with you if you became upset. If you wished, she would contact other means of support for you, such as your primary care provider.

Benefits: You will receive no direct benefit from your participation in this study, but your participation may help nurses and other health care providers to better understand what it is like for daughters to take care of their frail, elderly parents at home. You may also find it personally helpful to talk about these experiences.

Confidentiality: Every effort will be made to maintain the confidentiality of your study records. Agents of the University of Cincinnati will be allowed to inspect sections of the research records related to the study, but neither your name nor any personally identifying information will be present. The findings from the study will be presented as a written doctoral dissertation with the possibility of publication or presentation at conferences. Your identity will remain confidential unless disclosure is required by law, such as mandatory reporting of elder abuse, or immediate danger to yourself or others. Some of the things you say will be directly quoted in the study, but always in an anonymous manner. Neither your name nor any other personal identifiers will be associated with what you say. Upon completion of the study the audio-tapes will be destroyed. Transcripts, without any personally identifying information, will be kept in a secure location and not accessed by anyone other than the researcher.

Payment to Participants: There are no incentives or payment for participating in this study.

Right to Refuse of Withdraw: Your participation is voluntary and you may refuse to participate, or may discontinue participation AT ANY TIME, without penalty or loss of benefits to which you or your parent are otherwise entitled. The investigator has the right to withdraw you from the study AT ANY TIME. Your withdrawal from the study may be based on reasons related solely to you (for example, being unavailable for interviews) or because the entire study has been terminated.

Offer to Answer Questions: If you have any other questions about this study, you may call Margaret Owens at 859-291-6892, Dr. Margaret Miller at 513- 558-5212, or Dr. Theresa Beery at 513-558-5006. As Chair of the Institutional Review Board-Social and Behavioral Sciences, Dr. Miller would also be able to answer any questions you may have about your rights as a research participant.

Legal Rights: Nothing in this consent form waives any legal right you may have nor does it release the investigator, the institution, or its agents from liability for negligence.

I HAVE READ THE INFORMATION PROVIDED ABOVE. I VOLUNTARILY AGREE TO PARTICIPATE IN THIS STUDY. I WILL RECEIVE A COPY OF THIS CONSENT FORM FOR MY INFORMATION.

____ ____________________

Participant Signature Date

____ ____________________

Signature and Title of Person Obtaining consent Date

____

Identification of Role in the Study

____ ____________________

Witness to the Signature Date
(Used only when the content is read to the participant)

Appendix E

Interview Guide

After the initial question, the interview should proceed as more of a conversation than an interview. Several questions are listed as possible ways to help the participant to continue if she becomes stalled.

Initial question: What is it like for you to provide care for your parent?

Are there things you gain by being a caregiver?

Are there things you lose by being a caregiver?

Has the care giving role affected your relationship with your parent?

Have you learned anything about yourself through the caregiving experience?

Have you learned anything about your parent/parents through the caregiving experience?

What does your care giving role mean to you?

Why do you care for your parent or parents?

What would you like for people to know about what it’s like for you to care for your parents?

Has caregiving been what you expected it to be?

Now that we have had this interview, I wonder if you would just sit quietly with me for a bit and see if any other thoughts or feelings come to you about caregiving. We’ll just relax for a bit and see if anything else comes.

Appendix F

Confidentiality Statement

I agree to transcribe the audio-tape recordings collected in the research being conducted by Margaret Owens for her doctoral dissertation. In doing so, I recognize and acknowledge the need for complete confidentiality concerning the content of the audio-tapes. I hereby agree to keep this data confidential.

__________________________________ ____________________

Signature Date

Appendix G

Copyright Permissions

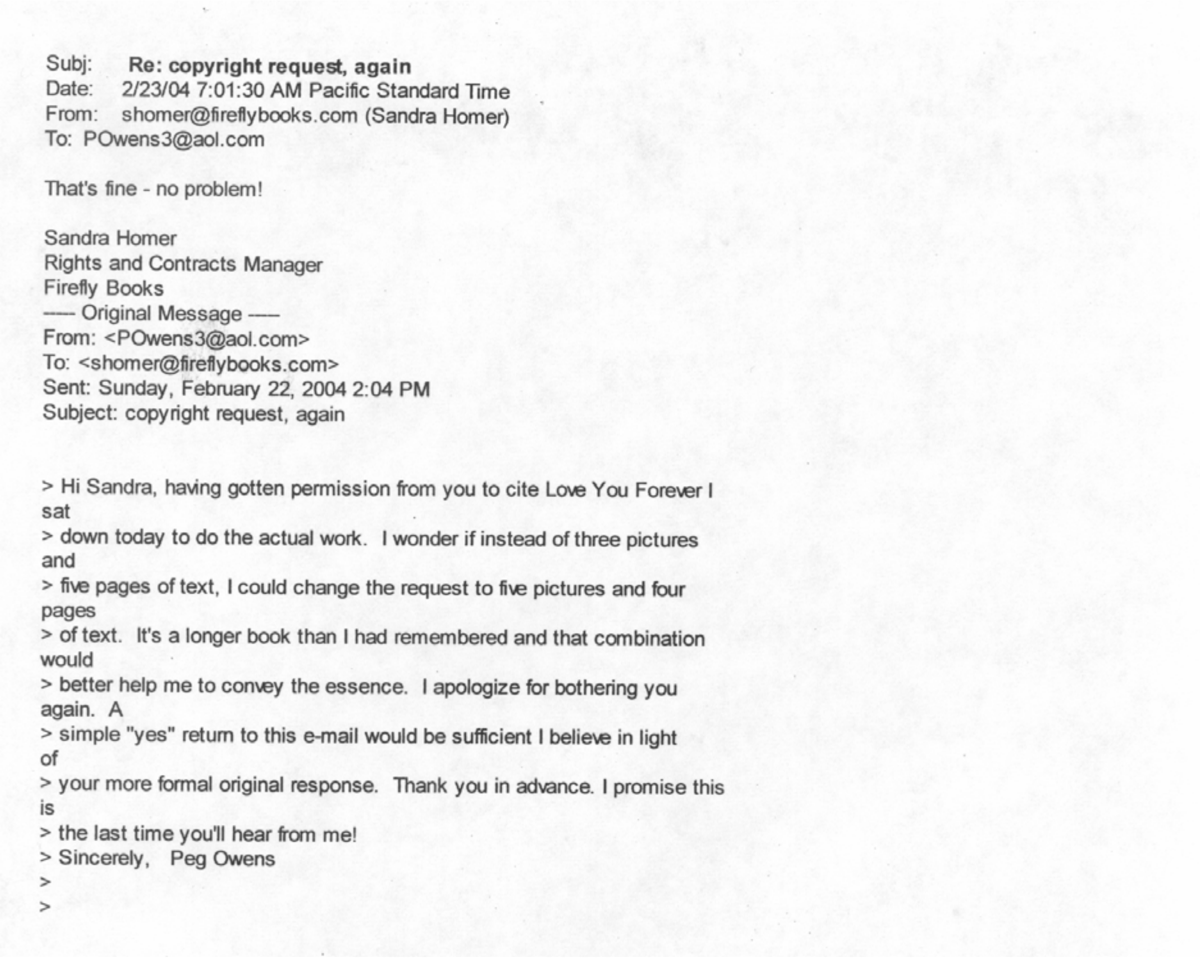
ubj: permission
Date: 2/23/04 6:58:09 AM Pacific Standard Time
From: buzzle@tampabay.rr.com (Burk Uzzle)
To: powens3@aol.com

For: Peg Owens
This is to confirm our conversation in which I was pleased to give my permission for you to use the photograph we spoke about, which appeared In Newsweek, and showed a parent and child.
Best Regards -Burk Uzzle

Subj: Re: copyright permission
Date: 2/20/04 6:43:12 AM Pacific Standard Time
From: shomer@fireflybooks.com (Sandra Homer)
To: POwens3@aol.com

Dear Margaret:
Thanks for your request to cite 3 pictures and 5 pages of text from Love You Forever by Robert Munsch with illustrations by Sheila McGraw. Permission is granted to you to do so on a one-time only, non-exclusive basis. Please provide the proper credit line acknowledging the book title, author, illustrator and Firefly Books Ltd. as the publisher.

Sincerely,
Sandra Homer
Rights and Contracts Manager
Firefly Books



Subj: **Re: copyright request, again**
Date: 2/23/04 7:01:30 AM Pacific Standard Time
From: shomer@fireflybooks.com (Sandra Homer)
To: POwens3@aol.com

That's fine - no problem!

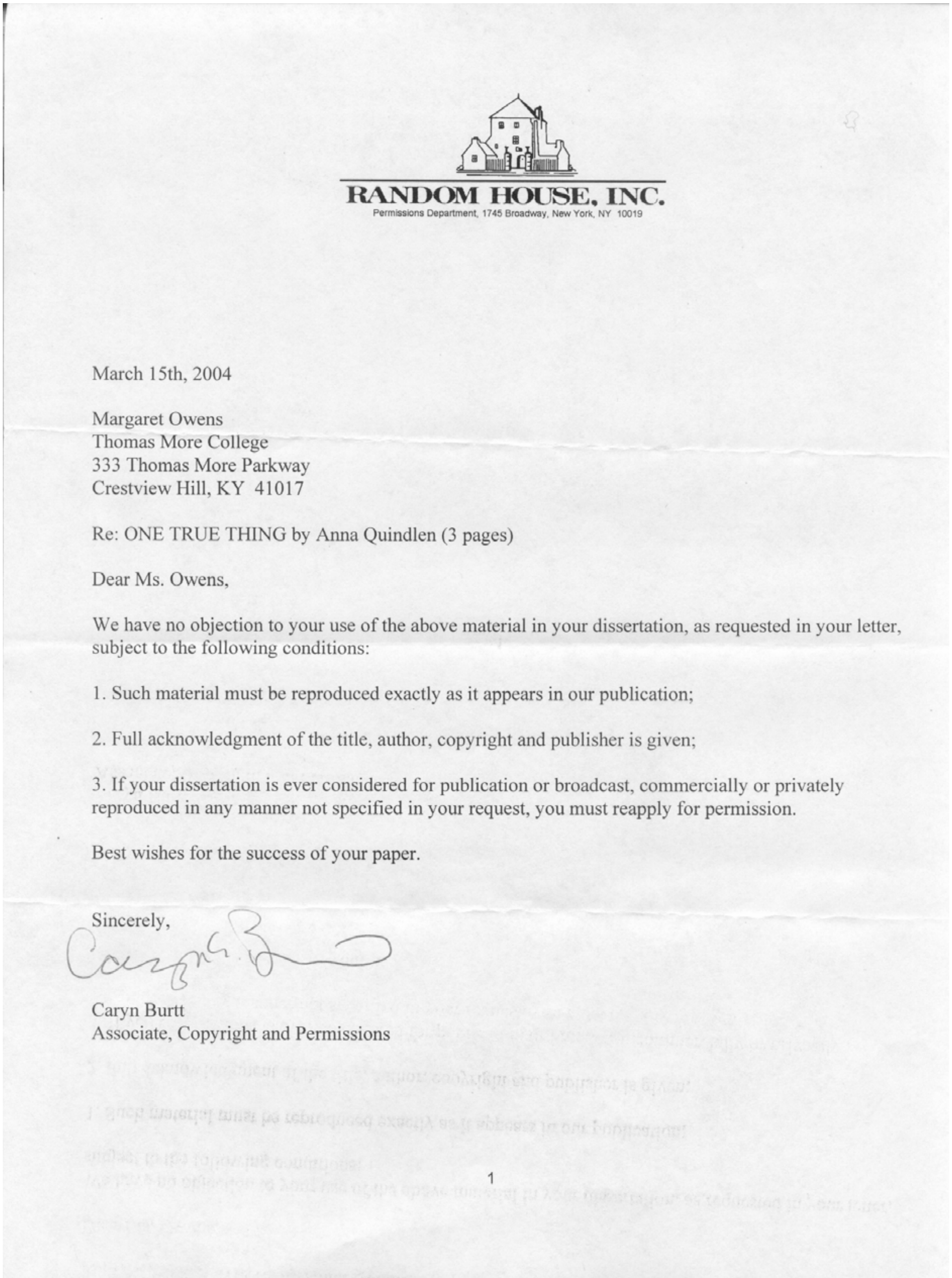
Sandra Homer
Rights and Contracts Manager
Firefly Books
----- Original Message -----
From: <POwens3@aol.com>
To: <shomer@fireflybooks.com>
Sent: Sunday, February 22, 2004 2:04 PM
Subject: copyright request, again

> Hi Sandra, having gotten permission from you to cite Love You Forever I
sat
> down today to do the actual work. I wonder if instead of three pictures
and
> five pages of text, I could change the request to five pictures and four
pages
> of text. It's a longer book than I had remembered and that combination
would
> better help me to convey the essence. I apologize for bothering you
again. A
> simple "yes" return to this e-mail would be sufficient I believe in light
of
> your more formal original response. Thank you in advance. I promise this
is
> the last time you'll hear from me!
> Sincerely, Peg Owens
>
>

Re: copyright request, again
Date: 2/23/04 7:01:30 AM Pacific Standard 1ime
From: shomer@fireflybooks.com (Sandra Homer)
To: POwens3@aol.com

That's fine - no problem!

Sandra Homer
Rights and Contracts Manager
Firefly Books



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Permissions Department, 1745 Broadway, New York, NY 10019

March 15th, 2004

Margaret Owens
Thomas More College
333 Thomas More Parkway
Crestview Hill, KY 41017

Re: ONE TRUE THING by Anna Quindlen (3 pages)

Dear Ms. Owens,

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Best wishes for the success of your paper.

Sincerely,

Caryn Burtt
Associate, Copyright and Permissions