

A PHENOMENOLOGICAL STUDY OF THE LIVED EXPERIENCES OF  
ADULT CAREGIVING DAUGHTERS AND THEIR ELDERLY MOTHERS

BY

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Advances in medical technology and improved standard of living have contributed to an increase in the elderly population. Aging is often accompanied by diminished physical and/or mental capacity. Families, most often adult daughters, provide the majority of informal caregiving. The largest cohorts of elderly are women. Studies of informal caregiving have focused on caregiving of the elderly who are cognitively impaired and have concentrated on the tasks, burdens and socio-economic impact of informal caregiving in families. This human science phenomenological study explored the meaning and significance of the caregiving, care receiving experiences of adult daughters and their elderly, physically frail mothers. Themes emerged from the data that provided a structure to describe the day-to-day experiential dimension for both mothers and daughters. For mothers the themes were feeling safe, comforted and free from worry within the safe haven created by their daughters' loving nurturing, attentive care and gratitude, appreciation and a yearning to reciprocate for the care they received.

Daughters were committed to protecting and preserving their mothers physical, mental and emotional integrity as a person and as their mother. Daughters experienced fatigue in the physical and emotional constancy of caregiving and in balancing of their roles as daughter and caregiver. They felt unprepared for the expectations of caregiving and uncertainty about future care needs as their mothers' declined. These elements of caregiving were overshadowed by daughters' commitment to providing attentive, loving care and the spiritual meaning and growth they experienced. Understanding of this experience and learning to listen to clients' stories can enhance nurses' assessment of the needs of the elderly and their caregiving daughters and help them to normalize the caregiving experience. Future research is needed to uncover ways to support family caregivers and in more diverse populations, economically, culturally, ambivalent or conflicted mother daughter relationships, and among the frail elder care receivers.

## CHAPTER 1 EVOLUTION OF THE STUDY

### **Introduction**

We sat on the edge of the bed together, the day's end ritual drawing to a close. I gently stroked her bent arthritic spine with the loving intent to ease the pain from the hours spent in immobility, moving only from the chair to the bathroom, to the dining table and back again to the chair. Her physical care for this day was complete. She relaxed under the soft touch of my hand and suddenly said: "You are such a good mother." I was jolted out of my reverie to reply: "Excuse me, Mom." Our eyes met, we laughed spontaneously and heartily, embraced and in that instantaneous moment transcended the mundane tasks of caring and entered into a special moment of togetherness--a mutual caring, compassion and recognition. This moment was not one of role reversal but one of experiencing the meaning of caregiving and receiving. Several days later, I shared this experience in a qualitative research class discussion in phenomenology. The class participants were visibly moved, and shared recognition of "having been there." Each and every one in turn, shared a similar poignant lived experience in caring for a mother, grandmother, or other significant maternal figure in her life. We shared a strong feeling of being an invisible caregiver (Bowers, 1987) who received little attention or recognition as a significant care provider. Each felt she was often excluded from research studies because she was not a high risk, profile caregiver.

The research literature has primarily focused on the measurable tasks and stresses of caregiving, in particular, for the elderly who are mentally impaired. Health care

policies reflect a stark absence in considering the need for support of the invisible caretakers and the frail elderly. The seed for this inquiry into the meaning of informal caregiving and the experience of aging mothers and adult daughters as a special experience of caregiving began to germinate with that class discussion. My personal journey into the experience of informal caregiving began ten years ago, as my then eighty-year-old mother began to experience decline in mobility and evidenced increasing physical frailty. The movement into caregiving was evolutionary. It was not an overnight experience or one time event.

### **Phenomenon of Interest**

The phenomenon to be explored is the experience of caregiving by mid-life daughters of their physically frail, mentally competent mothers in a shared living context. The experience of informal caregiving is not a new phenomenon. From the beginning of humankind, persons have cared for others in need. Informal caregiving for an increasing number of frail elderly by a decreasing number of adult children is, however, a recent phenomenon. Within the past century, profound socio-economic changes have taken place altering the patterns and meanings of elder caregiving. Family structures today are often more diverse and complex due to divorce and remarriage. Improved economic and social status has given senior citizens greater options and mobility in their retirement years. A hundred or even fifty years ago families, both nuclear and extended, lived in proximity and had kinship support; families are now often spread geographically. Elders in need, once cared for by a kinship of family, are now relegated to being cared for in a formal settings, such as, assisted living facilities and nursing homes. There has been a shift from a rural to an urban economy and way of life and from an industrial to a technological society. Retirement has become established as a social institution.

The advances in medical technology of the twentieth century and an improved standard of living have prolonged life and given rise to a seniors' boom. There is a rapid growth in the oldest old (over 85 years of age) population (U. S. Bureau of the Census, 2000). Diminished physical and/or mental capacity often accompanies longevity. The resultant inability of the elderly to care for their functional and instrumental needs is of salient interest to adult children. It is estimated that 75% to 85% of all care provided for the elderly takes place within the community (Langner, 1995). It has been well documented that adult daughters provide the majority of informal eldercare and that the largest cohorts of elderly care receivers are women (Brody, 1981; Himes, 1992, Horowitz, 1985; Neundorfer, 1991; Stoller, 1983; Stone, Cafferata & Sangl, 1987).

Women have traditionally been expected to assume and have accepted this role as nurturing caregivers. Daughters, in particular, are increasingly being called upon and are assuming caregiving responsibilities for their aged mothers. An only daughter, an unmarried daughter, daughters who are not employed, and daughters who live in close proximity are more likely to become caregivers for aging parents (Chadorow, 1978; Fingerman, 2001; Himes, 1992). The roles of women, however, have changed in dramatic ways since the beginning of the century. In today's world, the majority of women work outside the home or have professional careers. Women juggle being wife, mother, worker, and elder caregiver. Changes in traditional family structures include decreased birth rates, increased mobility, divorce, single family homes, and remarriage that, when combined with an improved standard of living, are impacting the ways in which life is experienced. Notable are the advances in scientific and medical technology that have contributed to increased longevity. Some of the challenges of longevity are

issues of financial security, new demands on health and long term care and intergenerational caregiving.

Nuclear family members are spread across the globe. Mothers have often moved to be in closer proximity to a daughter or to reside with her and her family. In addition, adult daughters are often caught in the middle, having borne children at a late age, and are simultaneously caring for dependent children and a parent or parents (Bowers, 1987; Brody, 1981; Himes, 1992). In the western societal milieu, paid work is more valued than the unpaid labor of childcare and elder care. The latter, caregiving of the elderly is particularly devalued, as there is no productive goal associated with it. Child-care, on the other hand, has a laudatory goal in the nurturing and bringing of the child to adult productivity in a society. The experiential dialogue between adult daughters and their mothers, as the physical dependence of the mother increases, exists and is experienced in a different milieu than it was at the turn of the 20<sup>th</sup> century. Changes in all areas of the human experience are accelerated. Informal caregiving is affecting family life, the economy, health care services, and health policies (Kart, 1996; Quadagno, 1999).

The effects of scientific and technologic advances continue to increase longevity in a society and culture that does not value or give meaning to “being aged.” While there are many in their golden years who remain active, vibrant, healthy and live independently there are others, some relegated to institutional care, who are burdened with multiple physically and mentally disabling disorders. In between these two ends of the scale of “being aged” is an ever growing group of elderly individuals, frail yet mentally competent, who are seeking assistance from their adult children, most often a daughter or daughter-in-law. With the focus in health care moving from acute care settings to

community settings, the needs of this in between group of elderly and their care providers are of interest and concern for nurses. Nurses in the community are in a central position to observe, describe, and understand the experience of the aged individual and the adult caregiver in their natural environment. These experiences of caregiving and aging are significant human events worthy of description and interpretation. The articulation of these experiences and the concern by nurses can contribute to nursing science and practice. The outcome can improve the quality of life for both caregiver and care recipient in a positive way (Paterson & Zderad, 1988).

### **Justification for Study**

Informal caregiving is a complex, evolutionary, and intersubjective life experience wherein connections are co-created (consciously or unconsciously) and expressed in behaviors and actions of concern, responsibility, and attention (Mitchell, 1990). Issues related to the concept of informal care and caregiving have become the focus of interest and research for social scientists, feminists, political policy makers, and health care professionals. Research has concentrated on the chores caregivers perform (Abel, 1986, 1990; Horowitz, 1985), and the stresses and burdens of caregiving (Bull, 1990; Montgomery, Gonyea, & Hooyman, 1985; Zarit, Reeves & Bach-Peterson, 1980). Other areas of study have included the roles that caregivers assume and are assigned (Franks & Stephens, 1992); and the socio-economic and ethical impact of caregiving (Sharlack, Sobel, & Roberts, 1991; Sharlack, 1994; Walker, Martin & Jones, 1992). What is needed in research is an exploratory study of meaning and significance of the day-to-day experience of informal caregiving of dependent aging parents by their children (Graham, 1983). In looking at the personal accounts of caregiving we may expand an understanding of how it is lived day-to-day (Futrell, Wondolowski, & Mitchell, 1993).

On the superhighway of technology and computer chip information, statistics, measurements and outcomes, the personal lived experience of the frail elderly and their caregivers has been neglected and is little understood. The prevailing research paradigm provides a measure of the labor intensiveness and stress of caregiving. It supports the labeling of the elderly as unproductive, dependent, and as a burden by a society in which they have long been contributory and independent members. A stereotypical image of the elderly as old, crippled, the prisoners of inevitable decline is deepened in the collective unconscious of our society. Policies are written, programs implemented, and interventions employed by health care practitioners, including nurses, with little or no understanding of what the lived experience is for the care receiver as well as for the caregiver within the context of their history, relationship, language and familial culture. According to Wilson and Hutchinson (1991), when nursing research provides an understanding of the human response, it advances nursing practice and facilitates the discovery and development of interventions in a search for ways to better serve those in our care. It is that fresh insight from nursing research that adds to the knowledge of the phenomena, and that specific nursing interventions may be identified for clinical practice, nursing education, and future studies.

### **Context**

Analysis of the day-to-day experiences of caregiving is intended to discover the subjective meaning of the living of the experience as separate from the objective components (e.g., the tasks) of the situation or circumstance. My interest in the experience of the mother-daughter dyad in caregiving evolved from professional and personal experience. Caring for the aged and their families in long term care, in home health, and in faculty practice at a university community nursing center for the elderly

and disabled, daughters always wanted to “bend my ear,” so to speak. They were eager to tell their stories and I had an intuitive sense that they were striving to find personal meaning in the whole of their subjective experience. This was true, also, of mothers who were mentally competent, although their revelations of self were more cautious and guarded. Sharing these experiences with nursing colleagues confirmed my clinical observations and intuition. For many of my colleagues this was a professional and personal experience. They confirmed that mothers and daughters in a dyadic informal caregiving experience were searching for meaning that went beyond the “doing for” tasks; a meaning, the understanding of which, bore influence on their perceptions and the outcomes for quality of life. If there were more information and a greater understanding about this phenomenon, then it would be possible for nurses to assist caregivers and care recipients in creating environments and interventions that addressed genuine concerns and life experience.

I experienced caring for an aged mentally competent mother with increasing physical care needs secondary to multiple fractures associated with osteoporosis and who, for twelve years, had lived either adjacent to or with me. During this period my mother, in spite of physical limitations, seemed to maintain a high level of health and well being. I found myself questioning: “Are there differences in the experience of caregiving? How do these affect the overall health and wellness of the caregiver and care receiver?” These professional and personal experiences influenced the framing of this study. My professional and personal knowledge and experience provided an extensive data base on caregiving the elderly. On the other hand, it placed an imperative to be alert to any bias that might hinder analysis of the data in a new light and from a different perspective.

The objective of this study is to gain a deep and thorough understanding of the experiences of mothers and daughters who live together. The study focuses on the subjective existential meaning of the phenomenon that occurs when daughters care for aged mothers with physical rather than cognitive decline. Through phenomenological exploration, this study seeks to discover the meanings at the heart of this unique relationship of mothers and daughters to distinguish and describe similarities and differences that create the day-to-day burdens or rewards.

### **Phenomenology**

Phenomenology is both a philosophy and a research method. As a philosophy, phenomenology is a particular way of approaching the world and apprehending lived experience (Merleau Ponty, 1962). As a research method, phenomenology is a rigorous process of reexamining what Husserl (1962) termed “the things themselves.” The question of phenomenological inquiry is about the meaning of human experience and asks, “What is it like?” Phenomenology is a way of thinking about what life experiences are like for people (Powers & Knapp, 1995) and is primarily concerned with interpreting the meaning of these experiences. Phenomenological research “explores the humanness of a being in the world” (Bergum in J. Morse, Ed., 1991, p. 55). Bergum refers to the phenomenological research method as an “action-sensitive-understanding” (p. 55) that begins and ends in the practical acting of everyday life and leads to a practical knowledge of thoughtful action. Phenomenological research is an introspective human science, the intent of which is to interpret and to understand as opposed to observing, measuring, explaining, and predicting (van Manen, 1984). The intention is to go beyond the aspects of life taken for granted and “to uncover the meanings in everyday practice in such a way that they are not destroyed, distorted, decontextualized, trivialized or sentimentalized”

(Benner, 1985, p. 6). To answer the question, “What is it like?” and to enter into the dialectic of the study and fully portray the reality of the experience, a process of phenomenological reduction is utilized. All previous or a priori knowledge gleaned from clinical practice, the study of gerontology and from personal experience is suspended or bracketed. Munhall (1994) says that “unknowing” may be a better term. She describes bracketing as the position of standing before an experience with an attitude of unknowing, even if and especially if one has lived the experience personally in order to allow multiple different possibilities to emerge. Personal experience is the material of beginning from which to work. The investigator’s personal experience, beliefs, and knowing, according to Husserl (1962), are suspended or bracketed in order to study realities of the natural world.

### **Relevance to Nursing**

Nursing research as a scientific process validates and refines existing knowledge and generates new knowledge (Burns & Grove, 1997). Nursing research directly or indirectly influences clinical nursing practice. The metaparadigm of nursing is a global and holistic umbrella under which the predominant concepts of nursing—persons, environment, health, and nursing—are related. The domain of nursing is, thus, conducive to multiple research paradigms as complementary and commensurate with each other in the development and discovery of nursing knowledge. Knowledge development in nursing reflects an epistemological shift toward inclusion of qualitative methodologies and research methods. These holistic, qualitative approaches are inclusive of process, patterns, and the meaning of the lived experience of persons, their environment, and health. Utilization and integration of qualitative methods with traditional quantitative methods enhance knowledge and expand methodological possibilities (Gubrium, 1991;

LoBiondo-Wood & Habec, 1998; Monte & Tingin, 1999). Lewis and Meridith (1988) refer to this as a “caring matrix” that is inclusive not only of the linear variables as defined by professionals but in contextual and historical reality of the caring relationships. According to Wilson and Hutchinson (1991), when nursing research provides understanding of the human response, it advances nursing practice and contributes to the development of interventions that benefit the client.

Phenomenological research is, thus, relevant to the discipline of nursing as it articulates subjective and personal lived experiences. This method has been called “the science of examples” (Munhall, 1994, p. 18) as readers can identify a deeper meaning or structure in the phenomenon being studied. Van Manen (1990) states: “Doing phenomenology, then, is ‘in the service of the mundane practice of [nursing]: it is a ministering of thoughtfulness.’ The results of phenomenological research provide a ‘knowing how to act tactfully in [nursing] situations on the basis of carefully edified thoughtfulness’ ” (p. 12). The value of the phenomenological method or human science approach is in the ability to uncover life processes “for qualitatively identifying intervention strategies and evaluating outcomes” (Morse, Penrod, & Hupcey, 2000, p.125). In addition, it is valuable in the generation and enhancement of theory and as a precursor to the development of quantifiable hypotheses and outcome research (LoBiondo-Wood & Habec, 1998; Munhall, 1994).

## CHAPTER 2 REVIEW OF LITERATURE

### **Overview**

The growth in elder care literature in the past 30 years has been in response to the rapidly expanding aging population. This literature review is presented in eight sections: 1) the history of caregiving of the elderly, 2) caregiving, 3) women as caregivers, 4) mother and daughter relationships in caregiving across the life span, 5) caregiving as portrayed in the literature of the day, 6) an overview of phenomenology as a philosophy and a method, 7) the experiential context of the study including personal and nursing experiences, and 8) summary.

### **History of Caregiving of the Elderly**

The twentieth century has witnessed major shifts in the population age patterns that have significantly affected generational role expectations. Notable is the fact that the American population is living longer. The population of those over 65 years of age is expected to grow from 31 million in 1990 to approximately 53 million in 2020. This would account for 18% of the population with the greatest increase in the age cohort over 85 years of age and the majority of survivors to old age being women (U.S. Bureau of the Census, 2000). Prevalence of degenerative and chronic diseases often accompany normal aging. These conditions bear with them an increased frailty, dependency and need for assistance with daily activities indispensable to maintain independent living.

Research has demonstrated that the major human resource for the support and maintenance of the frail (physically weak or disabled) elderly population is the family

with 82% of the primary caregivers being identified as women (National Family Caregivers Association (NFCA), 1997); Brody, 1981; Himes, 1992; Horowitz, 1985; Neundorfer, 1991; Stoller, 1983; Stone, Cafferata & Sangl, 1987). Of the 82% of women caregivers, 29% of the primary informal care providers are daughters (Stone, Cafferata & Sangl). As the frail elder family member grows older the intensity and the need for informal care, primarily determined by physical and mental ability for self-care, increases.

The research on intergenerational caregiving has primarily investigated the characteristics, content, and impact of caregiving. The Health Care Financing Administration 1982 Long Term Care Survey provided classification guidelines for long-term care facilities and Medicare providers for service reimbursement (Kart, 1996). Caregiving tasks are divided into specific activities of daily living (ADLs) and instrumental activities of daily living (IADLs) (Horowitz, 1985; Stone, Cafferata & Sangl). In addition, there are activities related to specific medical care needs, such as dressing changes and administration of injections.

### **Caregiving**

Caregiving is defined as an act of providing direct care. This usage is derived from the modern use of the word “care” as “a painstaking or watchful attention (Mish, Ed., 2002). Griffin’s (1983) analysis of the term “caring” identifies three characteristics of meaning: attention to or concern for, responsibility for, and attachment to. Noddings (1984) equates care with the word “engrossment” which is synonymous for “attention.” “Tending” is the term used by Graham (1983) as expressive of caring. Caregiving is an evolutionary human life experience within the circle of health-illness wherein

connections are co-created and expressed in actions of concern, responsibility, and attentiveness (Mitchell, 1990).

Familial caregiving of the elderly as an experience is multidimensional. It involves responses to the stressors and changes in life patterns for the caregiver and care-receiver as the dependency needs of the frail elderly family member increase. “Informal caregiving” is terminology that has emerged with aging studies. As a concept, it has long existed within families and societies. The emergence in our modern day of formalized health care systems has influenced a reconceptualization of informal intergenerational caring.

In order to understand the recent concept of informal caregiving, the origin of the words “informal,” “care,” “give,” and “caregiving” need to be explicated. According to the dictionary (Mish, Ed., 2002), “informal” is an adjective meaning marked by the absence of formality or ceremony; being characteristic or appropriate to ordinary; casual or familiar use. Etymologically, the word “care” is a noun derived from the Old English (*caru*) and the Gothic (*kara*) and means, “lament, sorrow, suffering of mind, grief.” Shipley’s (1945) Dictionary of Word Origins traces the meaning of sorrow to that of trouble as in “troubling yourself,” and thence to “taking care” or “being careful.” A common synonym used is “concern.” In other languages, Dutch, German and Scandinavian, the word for care is equivalent to the term for worry (van Manen, 2002). “The term “care,” thus, possesses the dual meaning of worry, trouble, anxiety, and lament on the one side, and charitableness, love, attentiveness, benefice on the other side” (van Manen, 1990, p. 58).

The verb “give” is derived from the Scandinavian “giva” and Old English “giftan” meaning “to make a present of; to accord or yield to another; to grant by legal action; to administer as a sacrament, medicine, to convey to another” (Mish, 2002). The use of the nouns caregiver and caregiving relate to the person who provides direct care and the act of providing direct care respectively.

The nursing literature reflects caring as integral to professional practice (Henderson, 1964; Gastmans, 1999; Leininger, 1981; Nightingale, 1976). Watson (1979, 1985) defines caring as a moral ideal where the end is protection, enhancement, and preservation of human dignity; a human transaction that takes place between two persons that affects health, healing, and well-being. Watson’s theory of caring has provided a base for further research by nurses into the concept of caring (Bottorf & Morse, 1994; Griffin, 1983; Langner, 1993, 1995; Swanson, 1991, 1993).

Swanson’s research on the theory of caring identified five categories of the caring process: knowing, being with, doing for, enabling, and maintaining belief. Caring is thus a way of relating toward another that is nurturing and for whom one feels a personal sense of commitment. In a similar vein, Gaut (1984) regards caring as an individual concern for another, individual responsibility for or providing for at some level, an individual regard, fondness and attachment. Others (Archbold, 1983; Boykin & Shoenhofer, 1993; Boykin & Winland-Brown, 1995; Cartwright, Archbold, Stewart, & Limandri, 1994; Gaut, 1984; Roach, 1987) have addressed the qualities of caring behaviors and caregiving as enrichment, mutuality, compassion, confidence, conscience, and commitment. Warren (1994) differentiates feeling cared for from being cared for or

being cared about. Feeling cared for means having one's needs met without asking. Being cared for or about implies a service or perfunctory act of care.

Caregiving is defined by Bowers (1987) as the meaning or purpose a caregiver attributes to a behavior rather than by the nature or demand of the behavior itself. This would include observable behaviors, mental activities and shared understandings. Thus, a caring behavior may have more than one purpose simultaneously, such as the preparation of a meal may also be an act of caring and attentive love, not just a task to be done. Bowers further identifies categories of caregiving as anticipatory, preventative, supervisory, instrumental, and protective.

Caregiving of the frail elderly, is according to Gubrium (1991), a mosaic not only of measurable variables but of the "distinct and complex interpersonal experiences" (p. 17) of the real world of the persons involved.

Throughout the literature, there is evidence of mutual and shared meanings of the term caregiving as it relates to informal intergenerational caregiving. Its usage, however, ranges from a complex combination of tasks (Greene, 1991) to Watson's (1985) transpersonal concept. A universal definition and conceptualization of intergenerational informal caring and caregiving is absent in the literature. While informal caregiving is labor intensive and socially necessary work, it is more than domestic labor performed for another (Abel, 1990). There is an increasing awareness that informal caregiving can be more than the instrumental "doing for" or hands on care which is more commonly recognized as caregiving. Caregiving outcomes may be fulfilling and rewarding as well as burdensome (Noddings, 1984; Boykin & Winland-Brown, 1995). The phrase 'informal caregiving' implies a process of attending to that includes doing for and with the care

receiver (Bottorf & Morse, 1994), and presence in an interpersonal human caring relationship (Swanson, 1991, 1993; Watson). Mitchell (1990) conceptualized the integration of the day-to-day lived experiences of later life, within Parse's simultaneity theory of human becoming, as "co-creating cherished connections while living with the limitations and opportunities inherent in the unencumbered changing of familiar views" (P. 32). This is congruent with Watson's (1985, 1999) conceptualization of human caring as an inter-subjective response to health-illness conditions accompanied by knowledge of one's personal power, limitations and possibilities that involve will, a commitment to care, caring actions and consequences. The outcome is the creation of new perspectives, which Bowers (1987) presents as more important than the instrumental "doing for" tasks.

Extensive review of the caregiving literature does not provide a singular, clear definition of informal caregiving of the elderly. It is implied that informal elder care is the unpaid and often-invisible labor provided by family or friends to assist an elderly or aged person with at least one activity necessary for living life on a day-to-day basis. Integrating the etymology of words and the concepts of caring in the literature, "informal caregiving" is defined as an evolutionary intersubjective holistic human life experience. Experienced within the matrix of health-wellness-disease-illness connections are co-created (consciously or unconsciously) and expressed in behaviors and actions of concern, responsibility, and attentive love (Allen & Walker, 1992). In contrast, formal caregiving is classified as paid services of licensed or unlicensed strangers provided under the umbrella of a formal health care system (Abel, 1986, 1991; Brody, 1981; Himes, 1992; Horowitz, 1985; Stone, Cafferta & Sangl, 1987). Formal caregiving may be

open or closed. Closed formal caregiving is provided in acute care and long-term facilities. Open formal caregiving is community based and encompasses all the medical and social services that allow the elder to remain at home. These services support informal caregiving and avoid premature or unnecessary institutionalization (Dunkle & Kart, 1996). Formal and informal caregiving may occur independent from or as complementary to each other.

Gendron (1994) provides a metaphor of the warp and the weft of a tapestry that is useful in examining caregiving. The warp is the acontextual structure of the day-to-day tasks involved in caregiving. The tasks require knowledge, skills, time commitment, and physical presence in varying degrees of labor intensiveness and stress. The warp is the attending to specific needs related to the functional and instrumental activities of daily living; and is oriented to protection, preservation, and physical nurturing. The weft of the tapestry is the weave that imbues meaning into the caregiving situation. It includes the attributes of mutuality, attentive love, and compassion that enhance human-to-human caring and reciprocity. The warp is the horizontal continuum of events measurable by time and quantifiable tasks; and the weft is the contextual dimension that portrays the real life meaning. Both dimensions can take place simultaneously and are essential to the total experience of caregiving.

Caregiving is conceptualized by Pearlin (1992) as a career, a “panoply of changes” (p. 647) occurring during the caregiving period that reshapes and restructures the self-concept of the caregiver. His conceptual model identified caregiving career stages as residential, institutional placement and bereavement. Bowers (1987) referred to caring for an aging parent as “invisible work” (p. 24) and defined caregiving from the perspective

of the interpretation and perception of the situation, that is, by the meaning and purpose of the caregiving event. Employing a grounded-theory method, she categorizes caregiving conceptually into five distinct but overlapping dimensions: anticipatory, preventive, supervisory, instrumental and protective. Anticipatory caregiving informs the decisions and actions of the caretaker based on possible needs. Preventive caregiving involves the activities directed to hindrance of physical or mental deterioration. Supervisory care is a purposeful involvement in care that arranges for, checks up, makes sure, sets up and checks out; and may or may not be recognized by the parent and by others as caregiving. Instrumental caregiving is recognizable as actual hands on care and is the aspect of elder care most identified as the subject of research studies. Protective care is perceived as primarily preserving the parent's self image, insulating them from the inevitable consequences of physical and mental deterioration. Protection may be a simple ignoring of an inconsequential error or forgetfulness. Or, it may be the acknowledgment of an event or pattern of events and reconstructing the meaning or significance of it. For example, forgetting is insignificant in and of itself however, a general pattern of forgetfulness may have an inferred negative connotation of early senility or dementia.

Traditionally, instrumental or hands-on care has been the most identified as the indicator for studying caregiving of the elderly and aged. There is, however, an increasing recognition that the definition of caregiving is multidimensional. The definition of caregiving includes: level of physical and instrumental functioning, medical condition, frequency and number of tasks required of the primary caregiver, emotional dependency and the perception and interpretation of the caregiving ecology by both the caregiver and the care receiver (Malonebeach & Zarit, 1991).

This preponderance of concentration on the ‘doing for’ activities of caregiving has yielded a significant body of research literature on the burdens of elder caregiving. The major research focus has been to analyze the impact of caregiving on family care providers. Specific tasks or outcomes most often operationalize caregiving variables. Studies have shown that the caregivers experience an array of physical, emotional, and economic challenges. Archbold, Stewart, Greenlick and Havarth (1990) studied caregivers and care receivers (N=78 dyads) to determine whether mutuality and preparedness reduced caregiver role strain. Mutuality is defined as the caregivers’ ability to find reward, meaning, and reciprocity in caregiving an impaired person solely by his/her existence. Preparedness is defined as the caregivers’ confidence in their abilities as a caregiver to meet the needs of the care receiver. Controlling for other common variables, such as, gender, spouse, level of cognitive and functional impairment of the care receiver, and the amount of direct care provided, that relate to caregiver role strain, they found that mutuality and preparedness account only partially for amelioration of caregiver role strain. Other factors were economic burden and conflicting roles.

Bull (1990) in a study of post hospitalization factors and caregiver burden (N=60 dyads) suggests that higher levels of income, social support, and functional ability of both the caregiver and care receiver diminish the perceived burden of caregiving. Beach (1993), in a quasi-experimental descriptive study using features of the grounded theory method, interviewed a convenience sample of 10 caregivers (80% women; average age=62). Informants were asked to describe their caregiving experiences with reference to specific items, such as, previous patterns of caregiving, family roles, responsibilities, and employment problems associated with caregiving. Informants reported relinquishment of

personal activities, reluctance to solicit help from other family members and difficulty in balancing work and caregiving. Some significantly reduced their employment or ceased to work altogether.

Using in-depth interviews of 94 employed caregivers, Scharlach (1994) found the negative aspects of combined caregiving and employment to be out weighed by the positive aspects of a sense of accomplishment. In a study of 354 employed caregivers, Scharlack, Sobel, and Roberts (1991) previously found that caregiver burden was more adversely affected by conflict between the employing institution and the caregiver than the fact that the caregiver was employed. Employment when allowing for flexibility was shown to be a positive benefit for the caregiver.

Montgomery, Gonyea and Hooyman (1985) provide an understanding of the difference between the subjective and objective burdens of care giving. Interviewing 80 subjects involved in elder caregiving they found that while subjective and objective burdens were correlated they had different predictors. Younger age and necessity of employment for income of the caregivers were the best predictors of subjective burden. Tasks of caregiving that confine the caregiver in terms of time commitments and geographic location were the best predictors of objective burden. Time commitment was also a predictor of the burden in elder caregiving in a study by Stoller and Pugliesi (1989). Other roles, such as, wife and mother, outside the family were found to be associated with improved caregiver well-being. Zarit, Reever and Bach-Peterson (1980) found that subjective perception of burden dissolves informal care arrangements and contributes to institutionalization more often than does the level of objective care required.

Depression is often a variable measure of caregiver burden. Neundorfer (1991), in a survey of literature on caregiver health, reported that the caregiver's cognitive appraisal of the care receivers' problems was a significant predictor of depression and anxiety but not of health outcomes for the caregiver. Others (Brody, 1981; Killeen, 1990) report an association between caregiving and health problems of caregivers. In the analysis of data from the first wave of a longitudinal study of 307 caregivers, Stommel, Given and Given (1990) found depression to be a dominant predictor of measured caregiver burden. A comparison of the mental and physical health of caregivers (spouses, grandparents and adult children) by Strawbridge, Wallhagen, Shema and Kaplan (1997) found a correlation between caregiving and poorer mental health. Only the grandparents showed a correlation with poorer physical health. In a previous study, Strawbridge and Wallhagen (1991) studied conflict as a component of elder caregiving. Path analysis showed a significantly higher perception of burden and poorer mental health among subjects experiencing family conflict than those who were not (n=100).

Caregiver burden and well-being may be the opposite sides of the same coin (Stull, Koslowski & Kercher, 1994). A growing research interest in the subjective experience and in the perceived satisfactions and rewards/benefits of caregiving is beginning to appear in the more recent literature. In a critical review of the literature on gain in the experience of caregiving to the elderly from 1974 to 1996 Kramer (1997) identified 47 studies. The criteria for inclusion were the need for assistance with one or more functional or instrumental activities of daily living, cognitive, emotional or physical impairment of the care recipient, replicability of the study, generation of empirical data and, analysis of the correlation between gain and other variable in a caregiving context.

Twenty-nine met the review criteria. Nineteen were specific to caregiving of the cognitively impaired and seven were unspecified. None of the studies addressed the question of benefit for the care receiver.

The role experiences of women (n=106), as caregivers, wives, and mothers, studied by Franks and Stephens (1992) provided strong evidence for feelings of adequacy in caregiving as a mediating effect on affective well being, as measured by the Bradburn Affect Balance Scale, particularly in the roles of wife and caregiver. Question was raised as to whether role stress and role adequacy are antecedent to or a consequence of the affective states measured. The conclusions recommended a need to examine caregiving in context. Stephens, Franks and Townsend (1994) examined role specific stresses and rewards as predictors of well being (physical health, negative and positive affect, and role satisfaction). They also examined the effects of accumulation of role stresses and rewards across the 3 roles of mother, wife, and caregiver. Findings indicated that caregivers' experiences in multiple roles could be either a detriment or enhancement to physical and mental health. An accumulation of role rewards being related to higher reports of well-being and an accumulation of role stresses was related to reports of poorer well being.

A theoretical model of family social support and internal system resources was tested by Fink (1995) to explain family strain and well being of elder caregivers. Although a small non-random sample (n=65), the findings show that when adequate resources are present, strains within families do not of necessity have a negative effect on their well being. There was also support for previous research that positive perception of available resources and belief in life changes as a challenge can promote the maintenance of well being even in the face of stress in the caregiving situation.

Utilizing the construct of meaning in caregiving and the stress model of Pearlin (1992) Noonan and Tennstedt (1997) examined the association between meaning in caregiving and the psychological well being of informal caregivers. Meaning in caregiving is defined as the positive beliefs a person holds about the self and the caregiving experience from which some gain and benefit are constructed. They found meaning in caregiving was positively related to caregiver self-esteem and negatively related to depressive symptoms; however, meaning was not related to loss of self, role captivity, or mastery.

### **Women as Caregivers**

The phenomenon of informal caregiving is shaping the lives of women in a very profound way. Women are assumed to be homemakers and to have more time that is both flexible and free. Women have, therefore, been expected to assume and have accepted the role of nurturing caregiver as an extension of the traditional duties and responsibilities of being mothers, wives and daughters. Many women work outside the home. Some have professional careers. In 1997, 76.9% of women over 20 years of age were in the civilian workforce. This compares with an average of 31% in 1949 (U. S. Bureau of Labor Statistics, 1998). The dramatic increase in women's employment is due, in part, to the influence of the women's movement in the 1960s; however, many work out of economic necessity or personal choice. In a review of the theories and research on mothers and daughters Boyd (1989) found evidence that as women age the mother-daughter relationship is positively enhanced and, there is a transition and development of mutuality, interdependence and positive connection. This does not negate conflict within the caregiving relationship between daughter and mother – a relationship that is stressful and sometimes burdensome (Boyd, 1990). Baruch and Barnett (1983) conducted a two-

stage study (n = 62; n = 171 respectively) of adult daughters in the Boston metropolitan area. In this study of the relationship of adult daughters with their mothers, the findings contradict the stereotypical portrait of the mother-daughter relationship as one that is conflicted. The findings of their study supported daughters' positive feelings towards their mothers and that the rewards of the relationship were influenced by how well the daughters had resolved adolescent issues of self-identity. The rewards were also noted in later years when the mother was in poor health and the role and tasks associated with caregiving were stressful for daughters and mothers.

One of the first researchers to address the issue of adult daughters' caretaking their elderly mothers was an English sociologist, Lucy Fischer (1986). In a qualitative study, Fischer identified a mutual-mothering pattern, a moving back and forth between mothering and being mothered in the adult mother-daughter relationship. This pattern included a "sense of mutual responsibility and protectiveness" (p. 58), a shift of roles often referred to as role reversal.

Walker and Thompson (1983) studied intergenerational intimacy, aid and contact in two groups of mother-daughter dyads – 132 student women and their mothers, and 107 middle aged women and their mothers. In this study, they found that aid and contact did not predict intimacy between mother and daughter. There was a small association between proximal aid and contact as a predictor of intimacy. Wuest (1997), in a grounded theory study of environmental influences on caring behaviors, found that women repeatedly identify a need for resources that do not medicalize normal developmental issues of women.

The expansion of interest in health care issues of women has heightened consciousness of intergenerational caregiving by women as a stressor affecting women's health. The changing demographics and the call for daughters to assume greater informal caregiving of frail aging mothers has been observed in clinical nursing and has given rise to increased research on caregiving of adult women and daughters to the elderly. The research literature is replete with quantitative data and information based in structured interviews and statistical analysis. This traditional natural science approach focuses on the chores and stresses of the caregiver (Abel, 1990). While these studies provide an understanding of the labor intensiveness of the caregiving situation from an objective and abstract perspective, they do not disclose the meaning of the subjective human experience of caring (Abel; Abel & Nelson 1990; Graham, 1983).

From a feminist perspective, task oriented definitions of caregiving are particularly inappropriate for an activity that is predominantly engaged in by women (Abel; Abel & Nelson; Noddings, 1984). Women, while assuming the responsibility for the multiple tasks of caregiving, are more apt to focus on the experience of connectedness and love in the caregiving situation (Walker & Allen, 1991). Men are more likely to assume responsibility for the instrumental tasks of daily living of the elderly in their care (Miller, 1989). Caregiving by women is attributed to the multiple functions and way of thinking evolving from the culturalization of women in the role of mothering and caretaking, and men in the role of financial provider and protector (Walker & Allen, 1991).

A bibliographic review of intergenerational informal caregiving of the elderly from a cross-cultural perspective revealed similarities and differences. This review was drawn from the literature in social sciences, anthropology, psychology, gerontology, and nursing

covering the years from 1987 to 1997. The references reviewed represent a multi-cultural overview from developed and developing societies. Based on the review it is noted that the bulk of caregiving in most cultures falls principally on a single caregiver. Care is not generally shared equally among family members. Women assume the primary caregiving role, and daughters appear predominate in this role in almost all societies. There are, however, exceptions mediated by cultural attitudes and beliefs that guide familial caregiving structures. In studies conducted in Spain and Mexico (Brandes, 1993), Japan (Elliott & Campbell, 1993; Harris, 1993) and some developing countries, such as, Samin, Tswana and Malo, the daughter-in-law assumes the primary caregiving role and the grandchildren are introduced into the caregiving role very early in life (Cattell, 1997; Guillette, 1992; Rubenstein, 1994). In these societies adult men are prohibited by cultural taboos from caring for their grandmothers, mothers or aunts. Only in Chinese families, studied in Hong Kong, was there evidence that sons assume the primary caregiver role, or at least shared it equally with women (MacKenzie, 1996). Among Native American populations there was no one person as caregiver – the responsibility was shared by the intergenerational community at large, reflecting a strong cultural belief in the community as kin (Hennessey & John, 1996). A study of an Amish community (Hewner, 1993) where the image of community and kin support prevails, found that this stereotype was not supported. The daughter-in-law who resides in the home of the husband's parents is the primary caretaker. An interesting finding in this community is a lack of the oldest old limiting comparison with cohorts outside the Amish community. A shorter life expectancy in this community relates to underutilization of advanced health care services due to religious and cultural beliefs. Overall, the ordering for elder family caregiving,

excluding spousal care and cultural taboos seems to follow a hierarchy: daughters, daughters-in-law, grandchildren, sons, other relatives, friends, and formal caregivers. Caregiving by daughters-in-law was primarily linked to an obligation of the son inherent in cultural traditions often associated with inheritance.

### **Mother and Daughter Relationships in Caregiving across the Lifespan**

The caregiving research supports the observation that adult daughters predominate as caregivers' of the elderly of whom the majority are women living in the community, either semi-independently or with the primary caregiver (Abel, 1986; Brody, 1981; Horowitz, 1985; Lopata, 1993, 1996; Stone, Cafferata & Sangl, 1987). There is a strong integral dyadic relationship between mother and daughter that encompasses attachment, conflict, mutual identity, and satisfaction over the course of the life cycle (Boyd, 1985, 1987, 1989, 1990). Transition into a caregiving role is cast against the contextual warp of the mother-daughter relationship; it was found that the characteristics of the mother-daughter relationship are a predictor of commitment to caregiving (Pohl, Boyd, Liang & Given, 1995; Seltzer & Wailing Li, 1996; Walker & Allen, 1991). Often, this relationship is characterized by deep ambivalence reflected in increased perception of burden in caregiving (Chadorow, 1978; Luescher & Pellemer, 1998). Intergenerational caregiving has been referred to as a role reversal (Fischer, 1986). As a life experience, it is a developmental process in which both mother and daughter are interdependent and interactive (Boyd, 1985).

In a qualitative study of 29 widowed mothers and their caregiving daughters, Walker and Allen (1991), identified three relationship types: intrinsic (45%), ambivalent (34%), and conflicted (21%). Intrinsic relationships are characterized by mutuality. Burdens incurred in this type of relationship are reported as overshadowed by the

rewards, and conflicts are minimal and quickly resolved. Ambivalent dyads lacked mutuality with one person, generally the mother, depending more on the other for support. Conflicts were recurring and rarely resolved. Concern was expressed for each other, however, was not perceived as reciprocal especially by daughters. Each person in conflicted pair relationships was concerned about herself. The rewards were minimal and the conflicts ongoing and unresolved. Other mediating factors in the relationships were the duration of caregiving, and the number of children the daughter had, rewards from partners, ability to handle conflicts and express feelings of mutual concern. There was a tendency for mothers and daughters in the intrinsic group to live together (39%). The percentage for ambivalent pairs was 10% and zero percent for conflicted pairs. Mothers in intrinsic pairs were more often widowed (31%) than those in ambivalent or conflicted relationships who were more frequently divorced, separated or abandoned. Daughters in intrinsic relationships had fewer children and a shorter history of caregiving. Utilizing social exchange theory, Walker, Martin, and Jones (1992) examined the outcomes of caregiving for elderly mothers and their adult caregiving daughters. Daughters having better relationships with their mothers reportedly perceived caregiving as less burdensome. They also identified three factors that influenced relationship types for the mothers: helplessness, anger and feeling loved; and three for the daughters: insufficient time, anxiety and frustration. These three studies are among the few where the sample included the mother-daughter dyad in the caregiving situation.

Assuming the inherent uniqueness and validity of elder caregiving by adult daughters, Allen and Walker (1992) later applied the theory of attentive love (Ruddick, 1989) to data from interviews with twenty-nine adult daughters caring for their elderly

mothers. They explored the connections and distinctions between maternal caregiving to young children and the related caring by adult daughters to their aging mothers. What was evident was that daughters sought to protect their mothers, maintain their autonomy, dignity, and acceptability in the community. While similar to mothering labor, there is a difference. Unlike childcare where physical, emotional, and cognitive development is fostered and anticipated, daughters labored to minimize developmental decline in their mothers. Aging mothers with cognitive impairment were excluded from this study. A future exploration including interviews with the aging care receiving mothers may add additional light on this theory.

King (1993) integrated the themes evolving from a phenomenological study of the experiences of midlife daughters caring for their mothers into a developmental framework specific to the stages of caregiver development. The resulting Continuum of Care model identifies three major points in the development of a daughter's care giving experience of her mother, each with a set of sub themes. This model has implications for nursing interventions in assisting daughters to identify needs, abilities, constraints, realistic goals and strategies.

### **Caregiving as Portrayed in Literature of the Day**

There is renewed attention toward a postmodern epistemology to incorporate the context and the texture of human life in research, not as separate from, but as a part of life experience. Narrative story is fundamental to human life reality and experience. Storytelling has been an essential part of the human experience since the beginning of history. Literature is the expression of the narrative nature of human beings. It reflects the psychosocial and spiritual evolution of humankind. Artistic symbols found in early cave dwellings among the artifacts of archeological discoveries, such as, pottery paintings and

carved figurines are the earliest evidence of communication through story patterns. As cultures and societies developed, language became organized into the written word.

Stories, myths, and traditions were committed to paper and transcribed by hand.

Within the scientific world, with its values on objectivity and validity, anecdotal information has been viewed as ambiguous, metaphoric, temporal, liminal and historically and socio-culturally constrained (Sandolowski, 1991). As research methodologies are evolving toward a postmodern epistemology there is an increased recognition of human narrative as valid knowledge. The behavioral, social science and nursing literature is showing an ever-increasing use of the ethnographic, phenomenologic, hermeneutic, case history, and life narrative methods of research. Researchers are finding the stories within the telling of personal history that reveal the drama in the life history (Sandolowski, 1991). Story stirs a deeper curiosity about the context and the texture of the human experience. Narrative is a way of expressing experience. Experience is individual and cannot be compartmentalized. What is real for each individual is shaped in the moment and is different for each. While individual, these ordinary stories also contain shared understandings (Gubrium, 1991). Themes emerge in story narrative as some wrinkle in the unfolding of life. These stories and themes are not simply literary constructs. Stories and themes keep us aware of the liminality of everyday experience, and pry open closed human understanding to view the purpose, meaning, and vision of the paradox of life events and circumstances. The use, then, of the narrative contextualizes meaningful events, social relations, cultural values, and historical trends. Narrative is defined as the representation in art of an event or story; something that is narrated: a story (Mish, Ed., 2002). One form of narrative art is found in the writings of

prose: novel, verse, biography, and autobiography. Authors often construct an imaginary world reflecting the meaning of life experiences through the lens of cultural and psychosocial influences and values. Characters in fiction can reveal greater complexity, subjectivity, and diversity. In a culture governed by secularism and objectivity, fictional narrative provides metaphor to clarify experience through literary character exemplars (Gadow, 1986). Through stories, researchers can gain insight into the way human beings understand and enact their lives (Sandelowski).

The literature on mothers and daughters provides narrative linkages to the caregiving research on adult daughters and their elderly mothers; and lends understanding of the experience. The mother-daughter relationship is complex and can only be understood in the context of the whole of life reality. There is an increasing attention to the quality of the mother-daughter relationship as an “a priori” influence on the dyadic relationship at the end of life cycle caregiving.

A search of the public library computer system, fiction and non-fiction, was conducted for exemplars of the mother-daughter relationship over the life span that bore influence on the end of life caregiving. Phillips (1991) discusses the body of narrative literature from the 18th and early 19th century including the works of Jane Austin, Emily Bronte, George Eliot, Florence Nightingale and Mary Wollenstonecraft that provide a picture of the roles of women and mother and daughter relationships in that time and culture. The bulk of the more recent literature, aside from self-help books, was published in the feminist and post feminist years. Writers, such as, Forster (1990), French (1987), Lessing (1984), Sarton, (1978), and Sexton (1994) whose works are set in the climate of the late 20th century focus on women as full participants in the economic, professional,

artistic and creative functions of society and shed light on the complexity of the relationship between mother and daughter. The predominant themes woven into classic and popular literature are that of attachment, identification, ambivalence, conflict and resolution or what may be noted as transition and transformation.

The mother-daughter relationship is innately contradictory, according to sociologist Lucy Fischer (1986). It is also pivotal for the development of a healthy self-concept and identity of women (Boyd, 1985; Chadrow, 1978; Gilligan, 1982). Miller (1995) developed a typology of mother-daughter relationship patterns that could be utilized not only in future caregiving research but also in analyzing the narrative characters in literature. She characterizes five types of dyadic mother-daughter relationships: avoiders (ambivalent), caretakers (role reversalist), repairers (tolerant and forgiving), negotiators (compromising and approving), and good friends (reciprocity). These relationship styles are transitional throughout life.

The narrative literature reflects the need to resolve unfinished business of childhood, to move through conflict and ambivalence to intrinsic healthy relationships. There is a described tendency for renewed closeness when daughters reach adulthood and transition into motherhood. This provides an opportunity to resolve old conflicts and to achieve self-identity and the development of a healthy relationship (Fischer, 1986; Patsdaughter & Killian, 1990). This opportunity is revisited and heightened when adult daughters assume caregiving of their mothers.

### **Overview of Phenomenology as a Philosophy and a Method**

The word phenomenology is derived from the Greek word phenomenon and means appearance, or to put in light or manifest something that can become visible in itself (Heidegger, 1962). Phenomenology is a both a philosophical movement and a research

method whose primary object is the direct investigation and description of phenomena as consciously experienced without being obstructed by pre-conceptions. As a research method it is the study of appearances, dedicated to describing the structures of experience as presented to consciousness without recourse to theories, deductions or assumptions from other disciplines (Spiegelberg, 1975; van Manen, 1984, 1990).

Phenomenology as a philosophy began with the work of Hegel (1770-1831). He believed that the mind, while having a universal structure, changed its content from time frame to time frame (Spiegelberg, 1975). Thus, reality is always becoming; and we come to know the mind as it is in itself through studying its appearances (van Manen, 1990). He did not, however, pursue the development of this concept as a philosophy or a methodology.

As a philosophical movement, phenomenology is rooted in the nineteenth century and the descriptive psychology (psychologism) of Franz Brentano (1859-1938). Brentano taught a philosophy of intentional relationship (intentionality) to distinguish between psychological and physical phenomena (Palmer, 1994; Spiegelberg). Intentionality references perceiving, judging, loving and caring to their perceiving, judging, loving and caring acts. He considered experience from both the empirical and the intuitive perspective (Spiegelberg).

The phenomenological movement evolved (Spiegelberg). In particular, it evolved in the philosophical reflections of Edmund Husserl during the latter part of the 19th century. Husserl (1859-1938), although a student of Brentano, rejected psychologism and set about the study of acts in their essential structures or from a natural standpoint – the world as actually lived (Husserl, 1962). Husserl's approach as a philosophy and method

of research spread during the 20th century and influenced the arts and humanities, architecture, law, politics, psychology, ecology and most recently medicine and nursing. Attributed to Husserl is the expression: “To the things themselves” which is often referred to as the natural viewpoint or the world as actually lived. For Husserl (1962) the intentional reflection on the lived experience was the source of all knowledge.

As a philosophy, phenomenology focuses on the inward experience, the absolute essence of an object separate from its existence. One is simply concerned with what things are, not whether they are. The context of the experience is a given reality. It is present in time and space. Phenomenology as a premise and methodology seeks and accepts only the evidence that is offered by the consciousness itself. We know to the extent that we grasp essence (Husserl). The only true knowledge of an experience comes from those living-in-the-world of the experience. It is from personal autobiography that meaning emerges and insight is revealed. Husserl says:

Insight, self evidence, generally, is thus an entirely distinct occurrence; at its “centre” is the unity of a rational positing with that which essentially motivates it, the whole situation here indicated being intelligible in terms of the noema as well as the noesis. (p. 352)

The noesis (the interpretive act directed to an intentional object) experience is the real content of the manifest data perceived. The material content (noema) is the object of noesis; but displays the vast possibilities and richness of genuine meaning of the perception in conscious intuition. A phenomenological pure experience has its real components. One arrives at this meaning or pure essence through intentional analysis and the suspension of all presuppositions and assumptions normally made about the experience (bracketing). Bracketing is described by Husserl (1962) when:

We put out of action the general thesis which belongs to the essence of the natural standpoint, we place in brackets whatever it includes respecting the nature of

Being: this entire natural world therefore is continually “there for us,” “present to our hand,” and will ever remain there, is a “fact-world” of which we continue to be conscious, even though it pleases us to put it in brackets. (p. 99-100)

The purpose of this reduction is to obtain pure and unadulterated phenomena before they are criticized by prior interpretation and beliefs (Cohen, 1987). Bracketing is a process by which the researcher suspends personal belief about what they think they know about the experience and ask the participant: Tell me what the experience is like for you (Thibodeau, 1993). Bracketing according to Munhall (1994) is an attempt to achieve a state of mind of unknowing as a condition to openness. The process of unknowing is a paradox in knowing that one does not know and is essential to the understanding of subjectivity and gaining of perspective in the conduct of human science research. Unknowing requires the researcher to be fully present in her/his personal world of values and perceptions and to be, at the same time, authentically open in interacting with the unknowingness about the life experience of the subject (Munhall). A researcher studying a phenomenon can never completely “unknow.” However, through reflective journaling and dialogue one can bring forth and examine personal beliefs and interpretations and hold them in abeyance.

The core of the phenomenological methodology is then to fully enter into the experience of another. It requires being intuitively present and aware of the inner meaning for the other. In this way, one can arrive at the structure behind the content. Because of its reflective and descriptive approach, it is sometimes referred to as descriptive phenomenology.

Heidegger (1889-1976), a student of Husserl, was interested in applying the phenomenological method to the question of Being itself. He delved into the language used to express Being and generated a phenomenological technical vocabulary.

Heidegger (1988) reinterpreted phenomenology into what is called hermeneutic or interpretive phenomenology. Unlike his teacher, Husserl, he articulates the position that presuppositions are what constitute the possibility of meaning.

Spiegelberg, as a historian of phenomenology, identified commonalities in phenomenological study. These include: direct investigation analysis and description of the phenomena as free as possible from presuppositions, perception and probing for the essential structures and relationships of structures, being attentive to the ways phenomena appear in different perspectives, exploring the way it takes shape in consciousness, detachment from the phenomena of everyday experience, and interpreting hidden meanings that are not immediate and direct. Swanson-Kauffman and Schonwald (1988) speak of the phenomenological researcher as one who intuits the other's reality by being open to identifying with the other's reality as a possible reality for oneself. Noddings (1984) captures the experience of intuiting others' reality as a striving to understand "as if"—as if the other's reality were one's own. Qualitative research, thus, requires an ability of the researcher to enter into an empathetic caring with the participant-partner. In the phenomenological study, this intuitive engagement is primary.

Although there are different techniques for data analysis in phenomenological research, LoBiondo and Hubec (1998) describe general steps in the movement from the participant's description to the researcher's synthesis of the data. These steps include:

1. Thorough reading and sensitive presence with the transcription of the participant's description.
2. Identification of shifts in participant thought resulting in division of the transcript into thought segments.
3. Specification of the significant phrases in each thought segment, using the words of the participant.

4. Distillation of each significant phrase to express the central meaning of the segment in the words of the researcher.
5. Preliminary synthesis of central meanings of all thought segments for each participant with a focus on the essence of the phenomenon being studied.
6. Final synthesis of the essences that have surfaced in all the participant's descriptions, resulting in an exhaustive description of the lived experience. (p. 225)

Phenomenological investigation of phenomena important to nursing knowledge and practice is an epistemological balance to quantitative research methods. It is a partner with quantitative methods of research in an attempt to make sense of the world as it is lived from the perspective of the persons living it. It provides the weft on the tapestry of life by which experience is blended into the whole picture of research. This method involves locating, gathering, sorting, retrieving, condensing and verifying the data (Swanson-Kauffman & Schonwald, 1988). It promotes an understanding of human beings in whatever environment they happen to be. There is a growing perception that the professional must be involved in the way that people experience and live with their health-illness challenges in different, and at times deeply personal and unique ways (van Manen, 1984, 1990). Phenomenology shows us what worlds people live in, what ranges of human experiences are possible, how these experiences may be described, and how language has powers to disclose the worlds in which we live as nurses, daughters, mothers and caregivers (van Manen, 1990). This approach into the phenomenon of elder caregiving may provide new understanding for nurses into the experience of adult daughters and their mothers within the environment of caregiving and give new directions for clinical practice and research.

### **Experiential Context**

Personally, I can clearly remember the moment in time when I realized that mother was less able to care for herself. Widowed at 58 years of age, she had kept house for and resided with my single sibling for over ten years. About a year before the awareness of increased dependency, I began to notice little things. She was less meticulous about housekeeping that she prided herself in; she began to walk with a cane for “fear of falling”. When my sibling moved to another state for work, mother chose to remain behind and moved to a planned subsidized retirement community. At the time, I lived 140 miles away. However, my best friend, who was like another daughter, lived within five miles of mother. It was a gradual process. She began to negotiate with both of us for errands, shopping, and assistance with housework. Physically, she was healthy but she was slowing down. Her mind was and remained alert and active until her death at age 93. These mutually negotiated tasks increased. By then, I lived only a short distance from her, and spent more time not only in tasks to maintain her independence in the community; but also in communication. We both found our encounters were occasions for sharing, for being connected. I was able to direct her occasional reminiscing to uncover a wealth and richness about the person, the human being who was my mother. At age 81, she suffered a severe epistaxis due to the dry climate we lived in and a 60-year history of cigarette smoking. It was frightening for her and she no longer felt safe living by herself. While she was in the hospital, we discussed options. We agreed that she would come to live with me for a few weeks until she felt stronger and we could re-evaluate after that time. Subsequently, she moved into an apartment next to mine. Our proximity gave her a sense of security and a reason for being since she could do things for both of us while I was at work. I, in turn, could attend to those tasks that she needed

to have done to maintain her dignity, health and healing. We mutually created a bonding and a relationship that gave new meaning to our dyadic connectedness. Inconveniences had to be evaluated and adjustments made. These were not always easy and at times created conflict; however the benefits and rewards transcended the “burden of care”.

The effects of aging both primary (normal physiological decline) and secondary (effects of environment and lifestyle) increased the need for caretaking. I secured resources to assist with the “doing for” tasks, and thus was able to maintain the connectedness of a relationship rich in rewards for each of us. Mother was in general good health and on no medicines aside from vitamins. She did, however, have severe osteoporosis. At 86 years of age she had bilateral hip replacement for fractures. And, several month post rehabilitation suffered a severe reaction to a spider bite and almost lost her leg. At ninety years of age, she suffered a cervical neck fracture with partial quadriplegia. Although the spinal cord insult was relieved by surgery and she rehabilitated well; it was evident to both of us that she could not be home alone safely. We mutually made a decision that she would go to a care facility of her choice and be able to come home as often as feasible.

My professional interest in the phenomenon of caregiving the frail elderly stems from nursing practice and caring for the aged in long term care, home health and in faculty practice at a university ‘community nursing center’ where the population was predominately elderly. Unlike childcare, this situation has no definitive end in sight and often goes unrecognized. Personal and professional knowledge and experience raised questions, for the researcher, about the elder caregiving matrix. The questions asked were: 1) What is the meaning of this experience?; 2) Can greater understanding of the

experience influence caregiving behaviors, interventions and outcomes?; 3) Can listening to the voices of caregivers and care receivers inform care providers, public policy makers and improve the well being and health of both?

### **Summary**

A considerable body of literature addresses intergenerational caregiving of the mentally compromised aged population. An extensive search of the caregiving literature reveals a scarcity of research that directly addresses caregiving by daughters to their aging/aged mentally competent but physically dependent mothers. There is limited evidence of study on the caregiving experience for the frail elderly care recipient. The elder caregiving research reveals a concentration of study of the caregiver for the mentally compromised elderly. It has, however, been well documented that adult daughters provide the majority of informal eldercare and that the largest cohorts of elderly care receivers are women (Brody, 1981; Himes, 1992, Horowitz, 1985; Neundorfer, 1991; Stoller, 1983; Stone, Cafferata & Sangl, 1987). There is an absence in the literature of the voices of the aged themselves; and, save for a few more recent studies, of their caregivers. We know that the majority of the elderly live in the community (U. S. Bureau of Census, 2000), many being of sound mind but diminishing physical ability and yet, there is a striking absence of research addressing the frail elderly and their often invisible caregivers—adult daughters.

This phenomenological inquiry focuses on understanding the meaning of the human experience of informal caregiving by adult daughters for their physically dependent, aging mothers whose mental competency is intact. Through phenomenological inquiry, a human science method, this study will seek to uncover, describe and interpret the common essences or meanings of this special dyadic

relationship of daughters and mothers. It is the intent of this phenomenological study to listen to the voices of aging mothers and their caregiving daughters, and to be open to the possibilities of discovering the essence and the meaning of the dyadic caregiving relationship between adult daughters and their frail elderly. To what end? A sense of meaning is the foundation that contextualizes all other levels of health (Thorne, 1997). Nurses are promoters of health, healing and quality of life for the elderly and their caregivers. An understanding of the meanings of the experience of caregiving is essential to effective nursing practice and health care interventions and outcomes.

## CHAPTER 3 METHODOLOGY

### **Method of Inquiry**

The purpose of this study was to gain an understanding of the experiences of caregiving adult daughters and their care receiving frail mentally competent elderly mothers who lived together. Phenomenology was used to explore the day-to-day lived experience for adult daughters caring for their physically frail mentally competent elderly mothers and for the mothers receiving the care. The researcher sought to uncover the essences, interpret, and describe the meaning of this relationship of daughters and mothers.

### **Rationale**

Hermeneutic phenomenology is a method used to describe, interpret, and understand lived experience in an effort to discover meaning rather than to explain and predict (Morse, 1991). The phenomenological research method is a “systematic, explicit, self-critical, and intersubjective study of its subject matter, of lived experience” (van Manen, 1990, p. 11). Phenomenology is a way to investigate subjective phenomena, and is based on the belief that essential truths about reality are grounded in everyday experience (Spiegelberg, 1975; van Manen, 1984, 1990). Because phenomenology examines the meaning that lived experience has in people’s lives, it is a valuable research method in nursing.

Several nursing theorists have attributed importance to meaning. For example, meaning is central to Leininger’s (1981) theory of transcultural nursing. Parse (1987)

defines meaning as the first principle of the theory of human becoming. Watson's (1979, 1985) theory of human caring is concerned with meaning for both the nurse and the patient in the concept of a transpersonal moment; and Newman (1990) equates meaning with "the pattern of the evolving whole" (p. 41) in her theory of health as human becoming.

### **Outcome**

The product of the phenomenological study is to uncover the meaning and essences in the experience being studied and to provide rich, in depth, descriptive and interpretive information that promotes greater understanding of a particular phenomenon. This illumination may give direction to nursing practice, such as, the formulation of other questions or a different way of responding to a health care situation. Above all is the understanding that provides the "material with which to build specific plans for nursing care" (Munhall, 1994, p. 182). Listening to adult daughters and their frail elderly mothers experiences of caregiving and care receiving may reveal new truths and may influence possibilities for nursing intervention and future research. "We must have a good clear picture of the qualities of the world before we can attempt to explain it, let alone predict or modify it" (Gubrium & Holstein, 1997). The results from this study can provide information for future interventions and policies, generate further research questions and enhance theory development and nursing knowledge.

### **Human Science Method**

The human science paradigm for phenomenological study of van Manen (1984, 1990, 2000) builds on the hermeneutic approach of Heidegger. Van Manen's concept of human science is directed at explaining the meaning of human phenomena and at understanding the meaning in the lived experience (1990). This approach is a reflection

on the text of lived experiences as described by the participants. The intent is to increase thoughtfulness and practical resourcefulness (van Manen, 1990). Van Manen's (1984, 1990) method of phenomenological research is predicated on the assumptions that phenomenological research is: 1) a study of lived experience, 2) an explication of phenomena as they present to the consciousness, 3) a study of essences, 4) a description of experiential meanings, 5) a human scientific study of phenomena, 6) a "poetizing activity" (van Manen, 1990, p.13), 7) an attentive practice of thoughtfulness, and 8) a search for what it means to be human. For van Manen, doing phenomenology is a questioning of the ways one experiences the world. The research project describes and interprets this experience from a particular perspective (Boyd, 1993).

In the human sciences, according to van Manen (1990), and specifically in hermeneutic phenomenological work, writing is closely bonded into the research activity and reflection itself. The objective for van Manen in human science research is to make some aspect of our lived world and experience more understandable and intelligible through reflecting on the linguistics of the described phenomenon. Van Manen's method requires a commitment to write since the process of research and reflection, reading and writing are indistinguishable.

### **Human Considerations**

The American Nurses Association (2002) provides ethical guidelines for the conduct of nursing research and the protection of human rights of research participants. Protection of human rights includes: 1) right to self-determination, 2) right to privacy and dignity, 3) right to anonymity and confidentiality, 4) right to fair treatment, and 5) right to protection from harm. Special consideration for vulnerable populations needs to be

assured in areas of sensitive research. Sensitive research is that which intrudes on personal experience and/or involves issues sacred to participants.

Procedures for protecting the basic human rights of the participants in this study included adhering to the standards and procedures of the Internal Review Board (IRB) and gaining informed consent. Participants were assured of confidentiality. No identifying information was placed on the identifying label of the audiotapes or transcriptions of the interviews. A code letter identified each participant. Only the researcher had the code and corresponding participant identification. Fictitious names were used in the analysis, narrative description, and interpretation of the data in the research report. Access to the transcripts was restricted to the researcher and members of the research dissertation committee. Names were removed from the master copy of the demographic information after being coded and only the researcher was able to identify the participant. This information was analyzed using descriptive statistical methods. Individual narratives were synthesized in the themes and anecdotal narrative to ensure complete participant confidentiality. The same procedure was used for the assessment of ADLs, IADLs, health care needs, and MMSE instruments. During the course of the research, the interview tapes, demographic, assessment instruments, signed consent forms and transcripts were kept in a locked file cabinet with access restricted to the researcher. These records, with the exception of the tapes, will be kept for three years after the completion of the study as evidence to support the findings of the study. The tapes will be magnetically erased and destroyed upon completion of the research. The written research report and publication of findings do not contain the actual name or location of the participants. Any quotes used have been altered so the participant cannot be identified.

## Sample and Setting

Purposive sampling was used for this study to obtain a sample of five dyads (n=5). In this sampling method, the researcher selects participants who have the desired experience in order to obtain maximal accounts of the experience, and increase understanding of some facet of a phenomenon (Burns & Grove, 1997). The following criteria were used for inclusion in this study:

- Mothers must be over 70 years of age.
- Daughters must be over 40 years of age.
- Daughters must be the primary caregivers.
- Mothers must have physical restrictions that require assistance with one or more activities of daily living (ADL), such as, bathing or eating; or with two or more instrumental activities of daily living (IADL), such as, shopping or transportation; or one health care activity, such as, wound care or tube feedings. This will be determined at the time of the initial interview by an assessment of ADLs, IADLs and health care activity (Appendix A).
- Mothers and daughters must be cognitively intact as determined by a mini mental status examination (MMSE) (Appendix B) at the time of the initial interview. A score of 25 or above indicates no cognitive impairment; a score of 20 to 25 is indicative of depression without cognitive impairment. Scores below 20 indicate various levels of cognitive impairment with depression and or psychosis (Folstein, Folstein & McHugh, 1975). Only those with scores greater than 20 will be accepted for participation in the study.
- Mother and daughter must live in the same residence or in close proximity, such as, side by side apartments, a mother-in-law apartment attached to but separate from the main residence or a separate residence on the same property, or units of housing within no greater distance than one block.
- The caregiving situation must be of one-year duration or longer.
- The daughter must be an unpaid caregiver for her mother.
- Each participant must consent to a minimum of three sessions: one initial study inclusion interview, at least one unstructured taped interview, and possibly one visit when the study is completed for participant confirmation that the descriptions and interpretations captured the essence of the experience.

Newspaper advertisements and snowball sampling was used to solicit volunteers. Snowballing or network sampling is useful in finding participants of invisible or devalued populations. Once a researcher finds a few participants who meet the inclusion criteria they are recruited to assist in finding participants with like characteristics. The assumption is that, within social networks, friends share common life experiences. Inherent in this method is a built in bias as the subjects are interrelated through association (Burns & Grove, 1997).

The adequacy of the sample size was evaluated by the completeness and quality of the information provided by the participants rather than by the number of interviews. This was achieved when the researcher had information redundancy, or the information and understanding was complete in the circular, iterative analysis of the interviews. This type of theoretical sampling maximized access to data that represented the phenomena and contributed to understanding (Morse, 1994).

### **Data Collection and Procedure**

After the potential participants were identified an initial interview was scheduled at a time and place convenient to the participants. At this interview, demographic information (Appendix D), assessment of ADLs, IADLs and health care needs, and a MMSE (Appendices A & B) were done that validated the inclusion criteria for the study. The purpose of the study was explained and written IRB approved informed consent was obtained from each mother and daughter (Appendix D).

Oral process consent was solicited throughout the interview process. Process consent is an oral negotiation and renegotiation during the interview or series of interviews as unexpected situations or consequences occur. Process consent reflects

sensitivity to the dynamics of phenomenological research and to the participants' human rights in the telling of their story.

One topic for consideration in the process consent was self-disclosed secrets. Since all data obtained was part of the study, participants' secrets were discouraged. Disclosures of secrets pose a dilemma for the nurse researcher who also has an ethical and therapeutic concern for the well being of the participant. Due to the personal nature of the subject matter and the involvement of the researcher and participant in phenomenological research, there is a fine line between the research imperative and the therapeutic imperative. While the telling of one's story may have therapeutic value, this is not the intent of the research process. The nurse researcher was vigilant in anticipating problems, rendering appropriate support, providing and arranging appropriate resources and referrals and debriefing at the conclusions of the interviews. An informational copy of community resources was available for each participant at the time the informed consent was obtained. In the event that an illegal situation was revealed, such as, abuse, it would have been reported to the appropriate authorities in accordance with the laws of the State of Florida. All of these conditions were discussed with the participants at the beginning. No evidence was seen to require such action.

The right to self-determination allowed a participant to withdraw at any time without penalty. Due to the possible vulnerability of the elderly being interviewed, they were free to end an interview at any time if they were uncomfortable physically or from the sensitive nature of the information being shared. One mother became quite fatigued physically toward the end of the interview and the process was concluded at that time. None choose to withdraw from the study or asked to continue the interview at another

time. There was no monetary remuneration for participation in the study. A handwritten thank you note was sent to each participant after the interviews. On the completion of the research a summary of the descriptive and interpretive writing was given to each participant along with a small token of appreciation, such as, a small bouquet of flowers or pot pourri.

### **Interview Method**

The question asked of the adult caregiving daughter was: “What is the experience like for you in caring for your mother?” The question asked of the care-receiving mother was: “What it is the experience like for you to be cared for by your daughter?” Asking this type of grand tour question allowed the subjects the freedom to tell their story without constraint. During the interview prompt questions were used for clarification and focus. Prompt questions asked when, who, where, why, how and what. Prompt questions were not intended to lead the participant but to encourage and elicit examples and meaning about the experience they are describing. They were oriented to specific instances, situations, events, and persons (Munhall, 1994; van Manen, 2000).

Interviews were conducted in the participant’s home environment or at a local day care center at a time free of interruption and conducive to reflective storytelling. Mothers and daughters were interviewed separately at different times. The length of the interviews were not constrained; and lasted about one hour. At the end of the interview, a leading question was asked, such as: “Is there anything more about your experience that you feel is important that we may not have touched on?” In most instances this question elicited no new information.

All interviews were tape recorded and transcribed verbatim by the researcher. Participants were assured of confidentiality as explicated in the section of the consent

form on human consideration. Field notes were taken during the interview to record body language or other contributing factors that were not reflected on the recording. These were done so as to minimize distractions to the participant. The researcher was attentive to the words and the gestures of the participant's reality. In the phenomenological method, the interview is produced together. The researcher is not just doing research; but becoming a partner working with the participant as co-researcher (Wilson & Hutchinson, 1991).

### **Data Management and Analysis**

The researcher transcribed tape recordings as soon as possible after the interviews. Interviews continued, as the previous ones were being transcribed and analyzed. The analysis of data began during the interview and continued as they were transcribed to ascertain sufficient data to represent the various dimensions of the phenomenon. Participant dyads were added as necessary to produce exhaustive accounts of the lived experience.

Van Manen's (1984) human science method of hermeneutic phenomenology was used for analysis and interpretation of the transcripts (Table 1). The specific method of van Manen has four concurrent procedural activities involving eleven steps as presented in Table 1. The data was analyzed concurrently with collection. This concurrent and simultaneous method allowed for critical examination and use of previous experience and was crucial in determining the completeness of the data. When thematic analysis and determination of themes are complete, they should grab the essence of the phenomenon (Swanson-Kauffman & Schonwald, 1988). At this point, the esthetic of the study was undertaken through writing and rewriting. This process uncovered the universal yet individual experiences of each participant, simple and straightforward "like a skeleton

that can be filled in with the rich story of each informant” (Swanson-Kaufman & Schonwald, p. 100).

During data analysis the researcher employed reflective journaling to record aspects of the interview and personal reflections. The journaling process contributed to the trustworthiness of the research and provided an audit trail of ethical and methodological decision-making (Smith, 1999). It also provided an overview of the researcher’s horizon and personal experiences with this phenomenon (Gadamer, 1976). This reflective process of journaling was the researcher’s key tool to “bracketing.”

Bracketing is metaphorically akin to the practice of meditation. Meditation is a disciplined practice in which all external and internal influences are set aside, the mind is emptied for a time, and one goes to a space of unknowingness in order to discover new knowing, understanding, and insight about life. Accompanied by continuous reflective writing and rewriting these introspective processes heightened the researcher’s critical awareness of possible bias in interpretation and description (van Manen, 1984, 1990). The daily practice of meditation in conjunction with reflective journaling allowed the researcher to be aware of beliefs, assumptions and interpretations attributed to prior professional and personal knowledge and experience. These processes deepened reflective thoughtfulness about the seemingly trivial, taken-for-granted aspects of everyday life. In addition, it was a clearing house for the researcher’s professional and personal experience with the phenomena in order to assure the trustworthiness of the results of the study.

Table 1. van Manen's method of phenomenology.

Concurrent Procedures	Steps
Turning to the Nature of the Lived Experience	1. Orienting to the phenomenon 2. Formulating the question 3. Exploring assumptions and preunderstandings
The Existential Investigation	4. Exploring the phenomenon: generating data using personal experience, tracing etymological sources and idiomatic phrases, experiential descriptions from participants, literature, arts, etc. 5. Consulting phenomenological literature
Phenomenological Reflection	6. Conducting thematic analysis – uncovering themes, isolating statements, composing linguistic transformations, gleaning description from artistic sources
Phenomenological Writing	7. Determining essential themes 8. Attending to spoken language 9. Varying examples 10. Writing 11. Rewriting, etc.

Note: Adapted from van Manen, M. (1984). Practicing phenomenological writing. *Phenomenology and pedagogy*, 2(1), p. 5.

### Themes

Themes provide insights into how persons make sense of the events and situations in their lives and, are one way of assigning meaning to an experience. Themes emerge from the data in the telling and recording of the stories of mothers and daughters and describe their experiences of care receiving and caregiving. The world of lived experiences is both the object and source of phenomenological human science research (van Manen, 1990). In human natural science themes are given from the data in the primary sense of the word, 'datum' meaning something given or granted or admitted by

the participants themselves (Bermen, 1994; Mish, Ed., 2002). Themes are used as a means to arrive at a “fuller description of the structure of a lived experience” (van Manen, 1990, p. 92). In this research study, I sought a deeper understanding of the significance for nursing of the experiences related in the shared stories of adult caregiving daughters and their mothers.

Van Manen (1990) discussed three approaches in the identification of the thermatics of a phenomenon: 1) a wholistic or sententious approach, 2) a selective or highlighting approach, 3) a detailed or line by line approach. The wholistic approach looks at the text as a whole and allows for researcher license in interpretation. The selective or highlighting approach identifies words, phrases, and sentences that appear to stand out as essential to the experience. The detailed approach looks at every sentence or sentence cluster asking what it reveals about the phenomena of study. All three approaches were used by the researcher. However, the latter two predominated in the search for themes to shape the description of the phenomenon of study. Essential themes are those that “make a phenomenon what it is and without which the phenomenon could not be what it is” (van Manen, p. 107). They provide guidelines for discovery of the larger dimensions of the lived experience.

Van Manen uses the word “wholistic” in all his writings. I have followed his spelling in lieu of “holistic” when discussing his books and writings.

In the reflective reading and re-reading of the transcripts and listening to the audio tapes words, phrases, sentences and clusters of sentences that stood out were isolated. While it is important to glean a sense of the whole, the second and third approaches provided more rigor in the analysis of the data. They provided material for reflective

writing to uncover “fundamental lifeworld themes” (Merleau-Ponty, 1962, van Manen, 1990, p. 101). These themes were explored within four “existentials” (p. 101) or perspectives of: 1) spatiality (lived space); 2) corporeality (lived body); 3) temporality (lived time) and relationality or communality (lived human relation).

Lived space or spatiality is felt space (van Manen, 1990). When one thinks of space it is defined by such concepts as duration, atmosphere, and topology (Mish, 2002). Whatever the space is, however, there is a feeling one has when in it. The awe one feels in a great cathedral, the sense of freedom or insignificance standing on the top of a mountain surveying a panorama of beauty in nature, the feeling of excitement or of strangeness when being alone in the heart of an unfamiliar and busy city, and the comfort and security we feel being at home are all examples of lived space. We attend to providing space conducive to learning, space for healing, space for playing, and space for living. Lived space is “the world or landscape in which human beings move and find themselves at home (van Manen, 1990, p. 102).

Lived body or corporeality relates to existing in a physical material body (Mish, 2002). It is the spirit-self revealing and acting through a material form. Bodily presence reveals one in their lived space. It is the vehicle by which we come to know another human being.

Lived time or temporality is subjective (van Manen, 1990). It encompasses our past, present and future, our way of being in the world (expectant youth, visionary elder), our memories and past experiences, our interpretation and re-interpretation of whom we were, who we are and who we wish to be. It is unlike clock time that has specific time measurement.

Lived other or relationality is a quality of connectedness that we share with others in our interpersonal lived spaces (Mish, 2002; van Manen, 1990). It is in the physical presence that we have a greater existential sense of another, of community that encompasses life purpose, meaning, and the spiritual experience of an absolute relationship.

### **Standards for Evaluation**

A key caution in the conduct and analysis of all research data is error. Error may occur anywhere during the research process and can compromise the outcomes and limits the utility of the data (Morse, 1991). Error compromises the truthfulness of the research results. In quantitative methods there are techniques to control problems in the reliability and validity of research. The assertion is that reliability is an indicator of validity (Bear, 1990; Burns & Grove, 1997). The strength of the design of a research study to produce accurate, trustworthy results is determined by examining statistical methods, and internal, external and content validity. An outcome or finding is considered valid if it represents in an accurate and consistent way the phenomenon that it is intended to describe, explain or theorize (Bear; Burns & Grove; Cook & Campbell, 1979; Issac & Michael, 1995).

Accurate representation of findings is no less significant in qualitative research methods. The rigor of qualitative research is “less about adherence to the letter of the rules and procedures, than it is about fidelity to the spirit of qualitative work” (Sandelowski, 1993, p. 2). Truth in qualitative research depicts accurately an independent existing reality (Guba, 1990). The criteria for judging trustworthiness in a qualitative study may differ; however, the standards are equally rigorous. In the past several decades, researchers (Aamodt, 1983; Burns & Grove; Leininger, 1992; LoBiondo-Woods & Habec, 1998; Morse; Parse, Coyne, & Smith, 1985) have developed and refined criteria

for judging the scientific rigor of qualitative studies. Each presents a slightly different orientation, however there are four essential criteria: credibility, auditability, fittingness, and confirmability (Lincoln & Guba, 1985).

Credibility is characterized by the recognition of the truth of the findings by participants and expert practitioners within the discipline. Validating the final results rests with the recognition by the participants, not of their full story, but of the presence of the phenomenon as described in their experience. When the essence of the reality of the phenomenon has been captured, then anyone who has lived the experience and reads the description will recognize it as if it were their own telling of the story. The extent to which a study is judged as credible is achieved by: 1) the clear presentation of essential descriptive information, and 2) the mutual agreement of readers of the description (Sandolowski, 1986, 1993). Lincoln and Guba suggest that credibility is to qualitative research what internal validity is to quantitative research. Methods for ensuring credibility in this study were tape recording and supplementing the interviews with process notes taken by the researcher during the interviews. The circular and iterative analysis of data was done by listening and re-listening to the tapes, by reading and re-reading the transcripts, and by writing and re-writing descriptive data until saturation or redundancy occurred. The intention was to share the final results with the participants of the study for validation. However, since mothers and daughters were interviewed separately and confidentiality assured, and some of the descriptions were very sensitive a decision was made to only give them a brief synopsis of the findings. This decision was also grounded in the new federal regulations regarding privacy of information. In lieu of

sharing the descriptive findings with the participants, colleagues and friends, who had the experience of caregiving their mothers, read and validated the experience as their own.

Auditability provides for procedural rigor, accountability and reliability. It requires a clear presentation of all of the study elements from the development of the question to the interpretation of the findings in such a manner that a reviewer can follow the steps of the research process. The reporting must be in sufficient detail to allow a second researcher, using the original data and the decision trail, to arrive at conclusions similar to those of the original researcher (Miles & Huberman, 1994). This study was reviewed by other researchers and committee members with expertise in qualitative research. They critiqued the study for accountability and procedural rigor.

Fittingness or vividness of description (Burns & Grove, 1997) is closely linked to creditability and provides for a faithful description in enough detail so that the participants and readers have a sense of experiencing the phenomena themselves. This is known as the “phenomenological nod” (Munhall, 1994, p. 202). Fittingness is to qualitative design what external validity is to quantitative design. The description should be so vivid that “the reader can almost literally see and hear its people” (Glaser & Strauss, 1965, p. 9). Conclusions drawn from the data analysis was verified with friends and colleagues who had the experience of caregiving their mothers. They had an opportunity to validate interpretations of the data and exemplars, share comments and new insights, and clarify discrepancies and ambiguities in interpretation.

Confirmability establishes the accuracy of data information and the soundness of decisions and judgments in the sequence of the research process from the beginning to the end (Isaac & Michaels, 1995). The researcher demonstrated throughout the process

accurate recording of information that was reaffirmed by ongoing consultation with committee members. In addition, an expert research reviewer attested to the integrity and accuracy of the prior three criteria of credibility, auditability, and fittingness.

## CHAPTER 4 ANALYSIS

This chapter reports the analysis of a study on the care-giving experiences of five mother-daughter dyads. This chapter will: a) review the purpose of the research, b) provide background information on the participant sample, c) present mother-daughter profiles with emerging themes for each dyad, d) present essential themes, e) summary and description of themes, f) interpret the phenomenological dimensions of the themes, and g) provide a descriptive interpretation of the phenomenon.

### **Purpose**

The purpose of this study was to explore and describe the lived experience of daughters and their elderly mothers in a caregiving situation. The questions answered were: “What is the experience like for you to receive care from your daughter?” and “What is the experience like for you to care for your mother?” Understanding was sought in the participants’ stories to identify themes and dimensions that transcend the experience. Common themes were identified to create a whole and to describe the dimension of the phenomena to answer the question: What is the experience like for you to give or receive care?

### **Background Information**

This section will describe the participant sample and give a generalized sense of the whole from the interviews and transcriptions.

## **Participants**

The participants, five mother and daughter dyads were residents of one coastal county in Central Florida. Two dyads responded to an advertisement placed in a local Florida senior newspaper. The nursing director of a senior center responded to a second advertisement and recruited six other dyads for the study. Three of these dyads participated in the study. The final number for the study was five mother-daughter dyads (n=5).

Participants met all of the inclusion criteria. Mothers were over 70 years of age. The average age of mothers was 87.5 with a range of 82 to 93. Daughters were over 40 years of age and were the primary caregivers. The average age of daughters was 55.4 with a range of 49 to 63. The mothers had physical restrictions that required assistance with one or more activities of daily living (ADL), such as, bathing or eating; or with two or more instrumental activities of daily living (IADL), such as, shopping or transportation; or one health care activity, such as wound care or tube feedings. This was determined at the time of the initial interview by an assessment of ADL's, IADL's, and health care activity (Appendix A). Mothers and daughters were cognitively intact as determined by a mini mental status examination (MMSE) (Appendix B). All participants scored above 25. Thirty was the maximum possible score and 20 was the minimum for inclusion in the study. All participants lived in the same residence or in close proximity. Four dyads resided in the same home. One mother lived in her own home, but near her daughter's residence. The average number of years of close or co-residing and caregiving was 6.5 with a range of 5 to 9. Each daughter was an unpaid caregiver for her mother. Each participant signed an IRB approved consent form (Appendix D) prior to participation in the study.

All dyads reported a comfortable life style with the average annual household income of 52,500 dollars, although three of the mothers would be unable to sustain similar living conditions if living alone. All of the dyads reported their relationship as good.

The adequacy of the sample size was not predetermined before data collection. It was determined by the completeness and quality of the information provided by the participants rather than by the number of interviews. This was achieved when the researcher had information redundancy, or the information and understanding was complete in the circular, iterative analysis of the interviews. This type of theoretical sampling allows maximum access to data that fully represents the phenomena and contributes to understanding of the phenomenon (Morse, 1994).

### **Sense of the Whole for the Sample**

“What is it like for you to be cared for by your daughter?” When asked this question, I found the mothers reluctant to express what they were feeling. Rather, they used broad terms to describe the experience. When I looked beyond the language, read between the lines, I found the unspoken words alive with meaning beyond the words that were spoken. Four of the five mothers described themselves as independent and self-sufficient before the physical limitations came “creeping up” on them in the form of chronic and debilitating physiological conditions which made it necessary for them to need help. Daughters, overall, described their mothers as independent and strong willed women. In the transition to needing care this often resulted in “a butting of heads” and struggles to maintain their independence.

Daughters, on the other hand, were open and expressed emotions and their inner thoughts of the caregiving experience. They described the ups and downs, the joys and

tribulations of caring for their mothers. Daughters also told of the familiar conflicts between siblings, conflicts that often appeared to remain hidden to their mothers. Four of the five daughters were married and expressed gratitude for “supportive husbands.” The one unmarried daughter had a sister who supported her and relieved her for respite. Daughters described caregiving as a spiritual experience.

### **Mother-Daughter Profiles**

This section presents the individual stories and emerging themes of each mother-daughter dyad. To protect identity and yet give a sense of the persons in the experiences, fictitious names were assigned to each of the participants. These were chosen at random and have no relationship to the persons they represent.

#### **Dyad one**

Anne has been caregiving her mother Laetitia for seven years. She was proud of having been able to maintain Laetitia in her own home that is close to Anne’s home. Laetitia feels safe and cared for in her own home environment. She was proud of the fact that she lived alone and felt safe knowing her daughter was close by and that there was an intercommunication system between the homes. Laetitia was aware that the “very good care” Anne provided allowed her to continue to live in her own home with a quality of life she would not have had otherwise. She repeated many times with gratitude the numerous tasks her daughter did for her. “She takes good care of me. She gives me my food and takes me to the doctor. I don't have to worry for anything. My daughter is there and takes care of me. She is very good to me.” While Laetitia has other children who live at a distance, she stated that Anne “is the only one I have to take care of me. She is my family.” This was spoken with an expectation that what a family does is to take care of each other. For Laetitia the experience of receiving care on a day-to-day basis was that

her daughter was there for her and helped her with the physical tasks she could no longer do for herself. “She is my family. She takes good care of me. Otherwise, I would have no one to take care of me. She takes care of everything. “

Laetitia had multiple health care needs that required ongoing attentiveness on Anne’s part twenty-four hours a day, seven days a week. She required the most care of all of the mothers’ in the study. This required total commitment from Anne who also cared for her father for five of the seven years she has been caregiving.

Caregiving for Anne was a full time job. To achieve her commitment she chose early retirement. She was motivated by a desire to devote herself full time to providing care for her parents. She said:

I been taking care of my mom and my dad, I would say for the last six or seven years. I had to retire to be able to give them more of my full-time. It was difficult working and taking care of both my mom and my dad. So, I retired to be able to give them more care.

For the past two years since her father’s death, she cared for her mother with “the best care that I can and I know she’s going to get the best care in her own home.” “Best care,” for Anne, was equated with being there for her mother when she needed her to fulfill her needs. “Best care” was reflected in her worry for her mother’s safety. This worry brought her to check on her mother every two hours and to be constantly aware of her mother’s activity even in the middle of the night via a communication system. Anne describes this constant vigilance as follows:

I'm very tired. I don't get a full night sleep because I am up and down every two hours. We hear her rustling, getting up and down. We hear her walker. We know when she's up and down. My husband and I hear her. I am up and down, and I'm so aware if she needs me or calls me. She knows I'm there if she needs my help or care. I have a monitor in my house and I wouldn't leave her alone if she didn't have her lifeline. I feel safe leaving her with her lifeline because I know she can just hit that button, and she does and she has. She has a problem sleeping at night and the problem I think is that she gets up very early to go to day care. In the evening, I

will feed her, or help her shower and then lay her in her chair to watch TV. I put compression pumps on her legs and she falls asleep. Well, that's my time to go home. My husband and I eat and so I'm gone sometimes for two hours. I may call her in between but I'm gone at that time. And, I guess it's the nap that she takes, so that when I come back over here at 830 p.m. to put her to bed, she'll take her pills and her eye drops and I'll put her bed. Then she'll sleep for two hours, and then she's up like every two hours. It has been constant duty everyday. I'm so aware if she needs or calls me.

She expressed a value that caring for family is an expectation and obligation, regardless of the sacrifices, the fatigue, the constancy, the worry, and the restrictions of lifestyle that accompany caregiving. Anne spoke of all of these aspects of caregiving with tearful emotion. She expressed being “very tired,” not from the “physicalness” of the caregiving, but from the emotional constancy of being there for her mother. She planned all the activities in her life around her mother. Anne’s own feeling validated Laetitia’s expression that her daughter was the only one she has to take care of her. Even with outside paid help and her mother’s participation in an adult day care program, Anne said “in mother’s mind no one but me can do the job. She has trust in me to take care of her.” Even when someone was with her mother and she went out for dinner with her husband, Anne worried that Laetitia would call her; because her mother felt that, she was the only one who knew what to do for her. Anne said:

I do have someone who comes in to help which is much appreciated. It's a help for me. If I didn't have anyone coming in here and helping me, that would be an extra duty that I would have to do. In fact, the girl was on vacation for three weeks and I missed her very much, because I ended up taking care of mom's total physical needs. The personal care aide gives her a shower three times a week on Monday, Wednesday, and Friday. She does laundry and light housekeeping. So, that does take some burden from me or I would have to do it. I do her shopping and her cooking. It's a full-time job. Some days she is in day care and that's a big help. It does give me a break because when she's not in day care I'm constantly here every hour or two checking on her and making sure that she's okay. I do have some respite on Mondays and Saturdays and that gives me a break if I go out to dinner with my husband. Then, I don't have to worry for four hours that I know someone is here taking care of her. However, even though somebody is here Mom doesn't think anybody can take care of her but me. She still doesn't trust people is far as

giving her pills and if she gets the jitters and if she needs to take her pill, she'll call me and see what she can take. Or, if I have her pills sitting out for dinnertime and someone else is with her, she'll have them call me to check to see if it's okay for her to take it. She doesn't trust. In her mind, she feels there's no one but me who can do the job. She has trust in me to be able to take care of her. She'll tell people that if something happens or if I have an ache or pain, or headache or my legs are hurting me I just have to call my daughter and she knows what to give me, no matter what.

Anne found rewards in what she referred to as a “stressful job.” She found satisfaction in providing the “best care possible” for her mother at home, and in knowing “that I’m doing a good job.”

I enjoy taking care of her and I give her the best care that I can. I know she's going to get the best care being in her own home than as if she were in a nursing home or another facility. I know that they're unable to give her the care that I can give her. She is comfortable. Being around family, gives her comfort. So, whenever she needs me, I'm here to take care of her and to fulfill her needs. And, it's been a tough time. It's been a tough road but I take a day at the time and I know that I will be rewarded for taking care of her someday.

Anne’s entire lifestyle was based on consideration of her mother’s needs. There were times when she chose not to do things with her family because she considered her mother’s happiness and ability to participate. “There are times when I can’t do things with my whole family because of my mom. I consider her and what I can do to make her happy. But, it is stressful” (started to cry). She was grateful for having a supportive husband and daughters of her own; however, she bore the overall responsibility for her mother’s care. She did this not only out of obligation but also for love of her mother. Her brother has been non-participatory in the mothers care. This has been distressing for her.

I think it would have been helpful if my brother had shared part of the responsibility. I think it would have helped physically and emotionally. He doesn’t call, doesn’t come to visit, and doesn’t think that what I do is a big deal. Sometimes when I need a break, I’ll ask my brother for funds to help pay for someone, and he doesn’t want to pay, to share, to give me, you know, to give me some money for someone to sit with her. He could care less. According to him, I should put her away. You shouldn’t be doing this, just put her away. I just can’t do that. There is no way I can put her away. I know that if I put her away, she would never last.

Laetitia's physical needs require a great deal of Anne's energy and attention. While Laetitia is unable to reciprocate physically Anne feels there is an exchange with her mother for:

She's very appreciative. She thanks me all the time for taking care of her. She knows that I love her. We love one another. She knows that with my help and my care that she's lived as long as she has because she knows she wouldn't get this type of care anywhere else.

One theme that emerged from the experience of the mother in dyad one was the deep appreciation and gratitude she felt towards her daughter. She felt her daughter's constant presence and believed she was the only one she had to care for her, although she did receive some assistance from a paid caregiver. She expressed feeling cared for and had an expectation that her daughter would take care of everything as that is what family does and she "is my family." This allowed her to remain safe in the familiar environment of her own home.

For the daughter, there was a sense of family obligation and also a loving commitment to provide the best care she could for her mother.

In order to accomplish this commitment she experienced restrictions on her personal life, fatigue from the constant expectation, responsibility and worry for her mother's safety and well being. Her life orbited about her mother's needs and making her happy. However, she found contentment in knowing she was living her belief in the family value of being here in a time of need and preserving her mother's integrity. She also found solace in her faith and ability to "take one day at a time."

### **Dyad two**

Pearl and her mother Ruby lived together for several years before Ruby's need for intensive care. Ruby's world at home was confined to her recliner chair. Due to injuries

from a fall, her physical limitations prohibited her from walking alone. It was difficult for her to navigate and she had a fear of falling. For a woman who prided herself on her vigorous activity and independence, this was difficult.

It is difficult getting out of this chair without (my daughter) holding my arm because I'm so, so unsteady and once I get up and turn around to go to the bathroom I'm fine but I can't go by myself. I tried one day and I fell. Fortunately, I didn't hurt myself. The doctor tells me I must walk. The doctor should know, shouldn't he? I agree with him it is a good idea. I can't walk (appeared upset and raised her voice) that much, I'll fall. I don't know what happened but a couple of months ago I was walking by myself. It has been very difficult. I wondered if I am giving into myself too much because I have (my daughter) here. If I wasn't living with her, I'd have to be in a nursing home.

Ruby saw her daughter as “my remedy” and rescuer from the dreaded nursing home. She expressed great appreciation for her daughter, and desired that her other children and grandchildren recognize all that her caregiving daughter did for her. She wrote to them often to reinforce this.

It is wonderful to have my daughter take care of me. I'm sure other daughters' in this world are the same but [my daughter] is wonderful. I hope that the other girls are the same but she is wonderful. I hope my other children realize. I was writing a note to each one of the children to tell them how much she does for me. I am so lucky to have her. I don't know what I would you without her. Oh, she's just great. Could not make her any better. She is as good as they come. In fact, I couldn't pay for her to be any better. I am lucky that I have my daughter. What would I do without my daughter? I think I have told you how much I appreciate my daughter. She is the most important person in my life.

Pearl viewed her experience, as a positive one that has “all in all has been positive and gone so well.” She expressed great delight in “always having a good relationship with mother. “Not like girlfriends because I've often been away but I came home on holidays and it's actually been very good.” She was grateful that as a single woman, in a good financial situation, she did not have to work and was able to be a full time caregiver for her mother.

I feel appreciative that I'm in a position to do it [care for her mother]. I couldn't if I worked. I just couldn't do it. I would probably be crazy (chuckles). And, I don't have the responsibility of children. I'm able to do this full time and I don't mind doing things around the house.

It saddened her to watch her mother's continued physical decline while her mind remained active. Pearl worried about what would happen to her mother if she herself became ill and could not care for her mother. She worried because:

She couldn't be left alone. If her balance were better, she could. [People] with Parkinson's walk pitched forward because they feel that they're going to fall backwards. I feel fear is a factor for her, but she is also stiff. She is doing better with increased medication but on the other hand, it kind of knocks her out. I'm sure there is a factor of fear. She doesn't fall that much; thank goodness, it has been a year since she fell.

Pearl did have a sister in another state with whom her mother lived in her healthier days and who was willing to assume the caregiving. However, her sister worked and had children and the daily routine at her home was "more active and less conducive to caregiving although she would have more social activity."

Day-to-day, the experience of caregiving for Pearl revolved around doing all that she could to keep her mother as active and involved as possible and keep her safe from falls.

We've done a lot more in the last couple of months. We're getting a routine of going to church. I need to walk her every hour and get a routine on the physical therapy stuff.

She worried, too, about making the "right decisions," particularly, when her mother had bouts of acute illness. The caregiving experience engendered a "deepened spiritual life and maturity" and "inner peace."

It helps a lot to have faith. This past year when she almost died, I was alone in the hospital. I started to panic in asking if we were making the right decisions. She didn't want to be intubated. She didn't want all that stuff. She tends to be a person to want to make things easier. And I just had a peace that came over me. It was good. I said: "God, please help me with this decision." I don't know how people

manage when they are trying to do it on their own when tragedy or challenges hit. I guess that is why some people drink and do drugs when they don't have a spiritual something to fall back on.

Pearl expressed that from the living of this experience she came to a degree of “spiritual maturity, an opportunity for growth, patience and, love.”

Feelings of appreciation and gratitude were expressed by the mother in dyad two. This was expressed not only to her daughter but to her other children who supported her daughter in her caregiving role. A self proclaimed independent woman, she was constrained by her inability to walk independently; and the fear of falling that in the past had resulted in injuries. Her daughter's constant presence was a reassurance of safety for her. She regretted her inability to do more around the house to help her daughter, however, provided companionship and continuation of a dyadic relationship of sharing a home together that began prior to her needing assistance with her daily living activities.

The daughter in dyad two found meaning in keeping her mother as active, and safe, physically and mentally, as possible and in their companionable relationship. It was difficult to observe her mother's continued, gradual physical decline. She believed her faith sustained her in the challenging aspects of caregiving, such as, the worry about making right decisions regarding her mother's medical care needs. For this daughter the evolution of the caregiving experience was for her an evolution in spiritual growth and maturity.

### **Dyad three**

Florence and her husband have lived with her daughter Cassandra and her husband for five years. Florence required the least amount of care of all of the mothers. However, in addition to her own needs she also needed assistance with caring for her terminally ill husband. Florence thought the experience of being able to be with her daughter and

receive help from her was wonderful. Cassandra had lived with Florence in the past when Cassandra needed help and “now the tables are turned.” She characterized her relationship with her daughter as always having been good, “the same as when she was a little girl.” Florence was happy to reciprocate with doing little things around the house, such as, laundry, and cooking. She described her experience as:

Being with my daughter is wonderful! I like it a lot. I really like it. She's lived with me and now the tables have turned and it's not bad at all. It is a good situation. I like to do things for people. I like the idea that I can help them. Like little things--doing her laundry, I don't mind doing that.

Her daughter monitored her mother's health care, her blood pressure, blood sugar, related dietary needs, and helped her mother care for her step father.

I get [daughter] to help me with my husband. He is in a hospital bed now and doesn't want you to leave him for very long, maybe because he is getting a little childish. It's hard on me, and she helps when she can. But when the time comes I'll have to have some outside help. I told him I would take care of him as long as I can.

Florence had several sons who while they “are all good to me, it is the girl who does the most toward her mother.” Florence talked of being a very social woman who loved people and enjoyed doing for others all her life. For social contacts, she attended the senior center a couple of days a week. This afforded her a degree of independent activity and sense of autonomy in her life. It was her time to “relax a little bit.”

Cassandra had a strong belief that caring for elderly parents was “part of who we are as children.” Her philosophy was that if you can, you really should do it. It doesn't make it easy having a philosophy like that because now after five years of living with my mother and watching, it's emotionally difficult

Among her friends, she is a minority because “they think that I am crazy to do such a thing.” She described her life as a caregiver as “emotionally difficult.” It was not so

much the physical challenges of care but the observing of her mother “growing older and older and older.” In the five years, that Cassandra had assisted her mother; this emotional worry loomed larger for her as they developed a closer relationship.

After five years of living with my mother and watching it, it’s emotionally difficult. Not so much the job of being the daughter but its difficult watching [her] growing older and older and older. So, that part of it is emotionally not easy. And I mentioned that as we grow closer and closer it is harder for me to get further away without the emotional concern as she grows older. You know . . . this is an opportunity for me to be here with my mother and this is an opportunity that I will never get again. So we're doing the back and forth being daughter and mother. At this moment, I am feeling it is really quite a blessing. I think too, that when I was a young girl, I kind of knew that I would be the caregiver. I've known it in my heart.

She expressed concern in maintaining a personal balance in her roles as wife, artist, teacher, daughter, and caregiver. Cassandra was challenged to establish clear boundaries to meet her own needs and to be the caregiver. For her, learning caregiving was learning boundaries and learning to live together.

And, those are not easy when there is an intense merging, and then sort of the disengagement of that in order for me to have a life and to sort that out. At what point do I have to not be taking care of my mother and take care of myself? So my concern is now, well, how do I get away and how do I continue to have a life and still be here for her. I have never had the experience of mothering a child. So, in some way maybe that has been diverted into mothering my mother. And so, those are the questions that I ask myself. When is it time to nurture, and when to have some clear boundaries? That's a real challenge--in any caregiving situation. It’s a challenge. It is a complex relationship, very complex. The caregiver, care receiver relationship but also the mother-daughter relationship.

Another challenge was learning to live together in a small house. She likened it to roommates adapting to each other’s little idiosyncrasies with the accompanying emotional struggles and battle of wills.

The challenges are daily in terms of the little things that really don't mean a lot, like the cooking in the kitchen. It is sort of my way or her way. I suppose that it is like any problem you would have with a roommate. Of course, it's also maddening when [there are] emotional struggles and power plays and all those things that, you know, the battle of wills that can happen. I just pray everyday for strength to be able to do it. She is still physically capable of doing her own laundry, some

cooking, and I take over in areas where she can't do and that's taking care of her. So, I help in the ways that I can. I take care of her health needs; I'm very much there for her. I also do laying on of hands. So, I do a lot of the alternative health care with her. I make sure she gets to the acupuncturist instead of always running to the allopathic (medical doctor). I help her to keep her blood pressure down and monitor her blood sugar for her. In that way it gives me an opportunity to practice all those things I tell everybody else to do in workshops.

In spite of these challenges, she characterized her caregiving experience as a blessing that led to self-discovery.

It has really been a blessing in many, many ways because I'm able to find out who I am through my mother, and getting to enjoy the moments which I know aren't going to last forever. So, it actually has been a blessing because at this time my mother has actually been able to help me. It has been quite beautiful in a deep and heartfelt way.

Cassandra knew in her heart from the time she was a young girl that there was an “unspoken, unwritten contract” for her role as primary caretaker for her mother. She described her experience of caring for her mother as having been “a transforming experience rooted in my personal spiritual beliefs of loving kindness and striving to live in the present moment.” For Cassandra this created a “profound spiritual connectedness that has been a deeply blessed way of being that goes beyond scientific reasoning, a mystery.” The following is her description of this connectedness.

Kindness is an important part of my spirituality and being in the moment which is oftentimes unreal and not easy to do. But, sometimes we're sitting together and playing cards, or just a few moments ago; I sensed a deep connection between my mother and me and in that way I felt connected to everything. Part of my spirituality is the goddess tradition that has a very profound connection to the mother. I believe she is my creator, my creatress that I came from her. So, I think that sense of connectedness and oneness, that feeling at one happens when we're together. I get these profoundly connected experiences that I've also had in nature and to me that's a very deeply blessed way of being. So, sometimes we're playing cards and I think, it's just a beautiful day or it's just a beautiful moment and I think I will remember this forever. And, I don't think I would get these things with just a once a year visit or twice a year visit. I think living with my mother on a day-to-day basis allows that to happen. We have these connections that are beyond scientific research, but to me are spiritual connections. It is a little scary too; because of how connected you can be to somebody and [how] to sort out the sense of self.

Cassandra had uncertainty and worry about the future and her ability to provide for her mother's increasing physical needs, the possibility of uprooting her with a geographical move and the isolation of caregiving. She spoke passionately about the need for intentional communities to care for our elderly.

If I had children or was closer to families with children, I would get to balance watching the end [of life] with new life and children. That would bring balance to what seems to be lopsided living. It is difficult to be isolated as we grow older and care for our elderly parents. The isolation is very difficult. It would be a lot easier in community, intentional communities, where everyone really understands the other. In village life, people are together, share wisdom and community. For just as it takes a village to raise our children; it takes a community to care for our elderly.

The mother and daughter in dyad three had great appreciation for each other. The mother relied upon her daughter to provide a safe environment for her and her terminally ill husband. The daughter, in addition to attending to her mother's health care needs, assisted her mother in caring for her terminally ill step-father. For the mother, the experience of her daughter's caregiving allowed her to maintain a quality of life that would have been very difficult otherwise. She reciprocates by assisting to a great degree in the household chores she is capable to do.

The daughter in the third dyad found that the experience of watching her mother's aging process was emotionally difficult as was the challenge of learning to live together. She did have a dominant experience of connectedness that was for her a spiritual one and a "blessed way of being." She did, have to work at balancing her caregiving role with her other life roles. She struggled to know when and how to set boundaries to nurture herself and her mother. This daughter worried about providing for her mother's increasing physical needs and being ill prepared to meet those. Overall, her experience had a profound spiritual dimension.

### **Dyad four**

The caregiving relationship of Naomi with her mother, Ruth, grew out of Naomi's concern for her mother's safety in her environment. Naomi had helped her mother live independently for about three years, however, Ruth had increasing health care needs, and the neighborhood in which she lived had become unsafe.

I began to care for my mother about 10 years ago. She lived on her own in a little house. Gradually she began to need more care. She is a diabetic and was having more and more problems with her feet and her walking. One Sunday, several years ago, my husband and I went to see her after church on Sunday and found a homeless person sleeping on her back porch. We realized that her safety was at risk and so we asked her to come live with us. The experience that I've had taking care of my mom has been very rewarding for me, because I'm here and she is very comfortable.

In the beginning of the co-residential arrangement, Ruth was reluctant to move in with her daughter and son-in-law. She admitted that it was hard to give up her own home and being her "own boss." The initial adjustment was "very hard" for both mother and daughter.

Another decision that Naomi and her husband made was to invite a friend of Ruth's, who was alone and needed some assistance to move in with them. Naomi's friends thought she was "crazy" to do this. However, this proved to be a good decision since Naomi is employed full time, and the two women were companions for each other and shared some of the minor household tasks. Naomi said:

A friend, who had lost her husband, moved in with my mom about four years ago. Everyone thought we were crazy when my husband and I let another elderly person move in. But, they're so mentally alert and both help each other in the physical capacity. When my husband and I would choose to go out for a date--Mom wasn't left alone and feeling neglected because they had companionship and friendship. So, that helped tremendously. Not that I would move a friend in earlier so that they'd have that buddy system. But, I think that made her feel that she sort of had someone she could talk over her problems and concerns with. They have the same concerns and problems. She didn't feel that she was the only old person in the home. She had someone to go through that process with.

Ruth characterized her relationship with Naomi as “getting along very well.” For her, after the initial adjustment, the experience of living with and being cared for by her daughter was a “good and wonderful experience.” Although she had multiple health care needs, she was ambulatory and relatively independent. Ruth delighted and prided herself in being able to do the household chores while her daughter worked fulltime. She was able to cook, do the dishes and laundry, and walk the dogs. Now, wheelchair bound, Ruth’s body language portrayed a calmness and serenity. She expressed gratitude for all the things her daughter did for her and for her ability to live a good life. Ruth’s greatest challenge was the loss of her ability to get around, to do what she wanted, to care for herself and to help her daughter.

The physical care has been so much because I can’t get around. This means so much to me, because I can’t get around and do what I want to do. [She] makes sure I take all my pills. I am on so many pills. She tucks me in and kisses me goodnight. And the same thing in the morning, she comes in. I’m usually up and I try to wash and dress myself and get ready for breakfast. Her time is so limited. It’s very hard for her to get sick. That would be disastrous. She is the main cog in the wheel.

She continued to do as much as she could to “hold the fort down.” She folded clothes and did the dishes with the help of her elderly friend, Connie, who came to live with them several years prior. Although older in age, Connie had more robust health and fewer physical limitations. Together they made a team to lighten the burden on Naomi.

Ruth said:

I still try to do as much as I can for her, which isn't much, folding clothes. And I have the dishes being washed now. I get them out and my friend will put them away because I can't stand up on my legs. I can't get up to do the things I did before like cook dinner and do everything so she wouldn't have to do it. Now she's chief cook and bottle washer. Like the wash . . . and I do try and take care of the dishes. I'll get the dishes out of the dishwasher and she'll [her friend] dry them and put them away. I can't get up and walk around. So she [her friend] helps. It helps. Then she feeds the dogs for lunch, takes them out for a run. It helps a lot. I go to Easter Seal and I make things. I like wood. I paint wood, I fix wood, and I give it to her. She [daughter] takes it to work and gives it away for Christmas gifts. So, I've

done quite a bit. I've fallen four times and it's very hard for me to adjust to that. I've had a lot of pain. I broke too many bones and it's hard for me to get around. The biggest problem is that I can't get up and do the things I did before like cook dinner and do everything so that she won't have to do it. Falling four times is a grind, you know. I still kind of do a few things around here. I dust and put the magazines away on the table. Try to keep up with the news and let her know what's going on. (Chuckled).

Ruth was attuned to her environment and prided herself in keeping up with the world news. No longer able to reciprocate by doing many of the household chores she did at one time; she kept abreast of current events so that she could brief her daughter when she came home from work. She recognized the responsibilities that accompanied her daughter's caregiving role while also working full time. She wanted to do all that she could to lighten her daughter's heavy load.

Loss, a sense of time passing quickly, and a deep sense of gratitude to God was evident throughout the telling of Ruth's story of her "being better every day" because of the wonderful care she received from her daughter. She was proud of all her daughter had accomplished. She admired Naomi as a professional, a daughter, and a caregiver.

The challenge for Naomi in the transition to caring for her mother in her home was in establishing their roles as mother and daughter, caregiver and care receiver. Her concern and worry was to allow her mother to have "control of her own life and decisions" while Naomi continued as the authority in her own home. She portrayed her mother as a strong person, always used to being "the boss," a woman with good coping skills who raised her children alone "scrapping and scraping her way through the world." This "take charge attitude," however, at times led to conflicts with her mother. Naomi's approach to this was to have what she referred to as "frank talks" with her mother. She wanted to assure her mother that she was still in control of her own life decisions. However, at times, Ruth would have to accept help; and that Naomi was the authority

when it came to matters of their home. The talks were ongoing and “helped tremendously” to keep roles clear. Speaking of this Naomi said:

Naomi was able to provide for paid caregiver help several days a week for Ruth’s personal care, doctor’s visits, and other daily activities. This freed Naomi from some of the physical caregiving and allowed her to maintain her relationship as a daughter with her mother.

If Naomi could change one thing in her caregiving experience, it would be to have “active support in the caregiving process by her sibling,” an older brother. Naomi was tearful when she spoke of this. The pain that Naomi experienced from the “excuses” for his lack of attention and unwillingness to participate both financially and emotionally. She felt that she “set herself up” for this situation since she did not involve him in the decision regarding Ruth’s need for more supervised care. Over time, Naomi has used this as an opportunity to understand and forgive and, a “letting go of the hurt.” They have since mended their relationship. Her realization was that “it needs to be a family decision” when considering elder caregiving.

If I could change anything I would like to have both siblings share the responsibility and that didn't happen. If not an equal share, at least where both siblings took an active part in the caregiving process. That has caused a lot of tension and friction (sad and tearful). I think when you take on the responsibility of being a caregiver you need to understand that unless it is a family decision with all the siblings--I think you need to understand and get in your mind that there may or may not be help. But you cannot let that influence you're succeeding at what you are attempting to do. Once I worked it out and understood that I could let that hurt go--things have been much better. I have a much greater peace about what is going on.

During episodes of acute illness, when her mother was “medically needy,” Naomi felt “the physicalness, the medicalness” of caregiving was overwhelming. These times were very hard and speaking of them evoked tears. She had home health nurses coming

in to help, but “not at two o’clock in the morning when mother was in severe pain”.

Naomi did what she did out of love. She believed that she needed more information and preparation for the nursing skills required. Naomi also believed she had to do it all, to be “superwoman.”

So, the medicalness of the caregiving aspects were overwhelming. I think if I were to go back and know what I know now during that period of time when she was so medically needy--it would have been better if she had been placed where there was full time nursing staff. I was doing a job that I was not qualified to do out of love for my Mom. It was hard. It was really hard (tearful). No one really taught you how to do those things. It was just medically overwhelming and I'm not trained to do that. Since then, one of the frank talks I have had with her is that as much as I love you--when the time comes that medically you need more care then you and I will find a place where you feel really cared for. And, that was very hard to do because I didn't want her to feel threatened. And, that as she got more needy that she would become such a burden that I couldn't give her care. That was a real fine thing to try and work out to have conversations about I've had that conversation with her several times to try and work things out and to let her know that I am not a nurse. I am her daughter and the feelings of trying to care for her and not making the right decisions cause me great fear and great guilt. What if she were to die in my care when if she had been a facility where they had a nurse she wouldn't die. You know they would be able to give her the right kind of care. Those kinds of conversations are ongoing. Of course, she doesn't understand as fully as I would like her to understand. She may feel that she may just be too much for me to take care of and that's just a way out of my taking care of her, I hope not, but that's a concern. I know that God will help us cross that bridge when we come to it.

I wanted to be superwoman and that took a major toll on me. The medical attention she needed was overwhelming. There would be days when I wouldn't sleep at night because we had an intercom system at home and I would keep it on. As the infection spread up her leg, of course, the pain was excruciating. She was on a lot of painkillers so her mind was not normal. I thought I was losing my mind. I think at that point I really needed to get medical help for her and I didn't. And, that was a mistake on my part. Now, we did have home health. We did have nurses coming in, but it wasn't on a daily basis, and of course, that certainly wasn't at two in the morning. You know, my husband found me one time at two a.m. in the morning leaning against the counter in the kitchen asleep just waiting to hear the next cry of pain. One time she was sick with a cold and she was having trouble breathing. It was late afternoon and my husband and I said--if you need to go to the doctor, let's go now. No, No. Then, she waited until 0200 in the morning and decided she needed to go to the ER. I said no--you have waited this long--you can wait until 0900 in the morning. No, I'm going now. And, I can honestly remember driving her to the hospital at 2 a.m. in the morning thinking this is my all time low. That was

the start of the period in those 5 years where I about got physically worn out. That's when our family doctor got involved. I was physically worn out. I was emotionally worn out. You should never let yourself get to that point. That's my advice for other daughters who are going through this. You need to recognize the signs that caregiving has taken over 99%. I think that was the dramatic turn around. Then our family doctor hospitalized mom. I got a rest for almost four months that time and kind of regrouped.

It was a constant worry that she was not trained to do it all and to make the right decisions. This created great fear and anxiety for her. She feared her error might hasten her mother's death. She considered placing her mother in a nursing home. At one point, when her mother needed hospitalization and post-hospitalization rehabilitation, she had a break to reevaluate the situation. However, after she and her husband visited several facilities they came home, cried, and said: "We can't do this to Mom." Since then, she engaged outside help, asked for, and listened to the advice of professionals. Naomi realized caring for her mother was a team effort and that she did not always have the best answers. If she was faced with the choice of caregiving her mother again, Naomi would do it "in a heart beat." "Caregiving," Naomi said, "is a biblical calling that one needs to follow for as long as one is able."

I strongly feel biblically that you're called to take care of your parents as long as you are able to give that kind of care. I feel very strongly about doing what I do. To me it was not easy in the beginning. It [caregiving] is a wonderful gift of love. My mother blesses me every day. She [her mother] is a trial and a blessing every day. (Chuckled.)

It was for her a "wonderful gift of love" by which her mother "blesses her every day." With laughter she said that her mother was "a trial and a blessing every day." Her one regret was that she felt that the focus of their relationship switched from mother-daughter to care receiver-caregiver and that the mother-daughter relationship was not as strong as it once was. She expressed that "caregiving love is deeper than mother-daughter love. Caregiving love is rooted in nurture, worry, and safety. Mother-daughter love is

more rooted in memories and the fun you have as a mother and daughter.” To preserve this mother-daughter love, Naomi attempted to take her mother out for dinner and to do fun activities dissociated from the caregiving. Naomi was reflective in stating her need to “know I am still her daughter.” She found it hard to balance being a caregiver and a daughter. Through the experience, however, Naomi came to a “real sense of who I am as a person.”

She always has been a very strong person. When she first came, she played the mother in charge and I was the child. I had to talk with her and tell her that although she was still my mother, however, now some things had changed. I'm kind of the adult in charge of you. Simply saying that to her, I also let her know that I would never take away her decisions. I would always try to talk through decisions. I would never take that away from her. She has always been used to being the boss because she is very strong willed. She raised us alone and always had to sort of scrap and scrape her way through the world. So, she knows how. She has some real good coping skills. So, to try and turn that around and, yes, to let her know that she was still in control of her own life and her own decisions but, that there would be times when I would have to help her guide those decisions. I was real frank about that; and there would be times when she would have to abide by my decisions, because I realized that this is our home and that somebody had to establish the authority. I just had to talk with her real frankly about those things and most of the time it went real well. Sometimes we would butt heads, and I would say if you are not comfortable we need to find a place where you feel safe and if this is not it then let me help you find another place. Those kinds of frank talks would benefit the caregiver a lot sooner (laughs). That just made a world of difference.

I really need to know that I am still the daughter. At home, I'm on the phone, and she needs to go to the potty whereas in a mother-daughter relationship it wouldn't be that way. So, it's important for me to have the mother-daughter type of love. Now, she maybe not feels that that's missing. I feel that with me being the caregiver that the mother-daughter bond is not as strong. I have to weigh that if she was in an assisted care place I could just pick her up and have fun and wouldn't have to take care. You know, in some ways it's like dealing with a toddler but, I have to respect her as my mother. Trying to balance that, that's tough. That's really hard. What I mean is that if I was just in the mother-daughter situation, I wouldn't have to do those caregiving things. I wouldn't have to go in and scrounge through her underwear dresser to look for aspirin or Sudafed, and I have to and then she gets mad (laughter). I have to make sure she is okay. I have to make sure that she is mentally okay too. That's hard. It takes away from the mother-daughter relationship.

If I had one fear, it's that the mother daughter relationship is not as strong. Sometimes I wonder that if she had been in an assisted living facility and I just took her and we went to lunch if it would have been a different type of love than this caregiving love. This caregiving love is a different type of love than the mother-daughter love. The mother-daughter relationship has switched to me kind of being the mother and she being the daughter. I tried for a while but it's my fault. I am so busy. I tried for a while to do it once a month sounds like so long, and I can't even do that. We would do a mother-daughter dinner and go to Red Lobster for dinner, just she and I. And we did pretty good. But now it's not once a month. You know, I have to clean the house, do the laundry, do the grocery shopping, pay the bills, and do all those things. I think the mother-daughter love is just kind of not as deep as the caregiving love. It is based more on fun and memories, where the caregiving love is based more on nurturing and making them feel safe and secure like a mother-child love versus the fun you have as a mother-daughter. I try to make the caregiving fun. I try to make Mom an active part of her care and encourage her to do things that she does really well. But the relationship definitely switches. I'm being left in charge and this brings all sorts of relationships and feelings for her as for me. On Saturday's when I take her to Sam's or we go to the Flea Market or like even when I come home from work in the afternoon--I'll get her wheelchair and we'll walk outside and sit on the park bench. And, that doesn't have any of the caregiving elements in it. That's really important. I don't know if it is important for her but it is really important for me (reflective). I love her and that gives me great joy.

Safety of environment was for mother and daughter of dyad four, what brought them together in co-residence. For five years, the mother participated fully in helping her daughter, who worked full time with caring for the home and their many rescued animals. The acute illness led to chronic disabilities and a need for intensive caregiving by the daughter. This mother expressed appreciation and gratitude for her daughter and continued in small ways to reciprocate and to “hold the fort down.” Now, confined to a wheelchair, safety of her person is a concern.

The daughter was perhaps the most eloquent of all of the participants. The emerging themes for the daughter in dyad four were similar to other participants; however, she was more descriptive in the telling of her story. The challenges for Naomi in her caregiving experience were balancing the roles of caregiver and being a daughter, concern that caregiving love was stronger than mother-daughter love, maintaining and

preserving her mother's integrity and autonomy within her present abilities, realizing that she could not do it all, and coping with the overwhelming fatigue of constancy of caregiving. She worried about making right decisions and most particular about her lack of knowledge and skills to provide safe and effective care for her mother. The balancing factors that reduced the stresses of caregiving where her belief that caring for her mother was a biblical calling, a wonderful gift of love that was a blessing by which she came to a greater sense of who she (Naomi) was as a person.

### **Dyad five**

Rebecca had cared for her mother, Eve, for nine years. Eve was an active nonagenarian who claimed she always had a great relationship with her daughter. Without her daughter, she "would not know what to do." For Eve, the care receiving experience provided great comfort because "she just knows all that I need." Her daughter's care was care that she "could not pay for." She felt she did not have to worry because her daughter took care of everything. She worried; however, about what would happen to her if something untoward befell her daughter. She became tearful and her voice was stressed when she spoke of this possibility. Her grandsons and son-in-law have assured her that they would do their best to care for her; however, Eve felt that it was "not the same as having a daughter care for you." She expressed concern that she took her daughter for granted and did not give enough in return for all her daughter did for her. Although Eve is active in a senior day care program, she claimed that her daughter was the most important person in her life.

[My daughter] takes care of everything. She takes care of everything so I don't have to worry. I do wonder what I would do without her. I asked my son-in-law the other day what I would do without my daughter. He said, "I don't know." But, what if anything happened to her, what would I do? (Her voice sounded stressed and she was near tears). He said he would try and my grandsons say I can live with them.

But, it is not the same, not the same as having a daughter do for you. It is very nice [having my daughter care for me] because if I want to go anywhere, anyplace, she takes me. She takes me everywhere. She just knows all that I need. I have so much medication, so many pills. So, in the morning, when I get out of bed she puts drops in my eyes. I am so lucky to have her. I don't know what I would do without her. She's everything, everything I ever thought about in someone taking care for me. Oh, she's just great. Could not make her any better. In fact, I couldn't pay her to be any better. For one thing, I do not have to worry. She takes care of everything. I don't have to worry for anything. My daughter is there and takes care of me. She is very good to me.

Rebecca believed that her experience of caregiving her mother brought them into a close relationship, one that they did not have when she was younger. "I really consider it a blessing that the Lord has given me in this time with my Mom to just really do some bonding. The Lord knew and I really feel that it has brought us closer. It certainly has done that." Although the caregiving is confining and at times frustrating, she found the rewards outweighed the difficulties. A "religious person," Rebecca questioned why, in retirement years, her life and that of her husband, was limited by caregiving. "To me, it was not easy to understand because we felt that the Lord had called us to a mission and after we accepted Mom fell and had to have brain surgery. It was hard for me to understand why the Lord would have called us."

The constancy of caregiving limited their activities. Caregiving limits me as to what I can do. If we go on vacation, if we go anywhere then I have to take her with us, which is not always good. It's not as easy for us to have things taken care of here when we go somewhere. Sometimes my husband and I would like to do something together and that is not real conducive with the situation. As far as frustrating, that would be the most frustrating. Thank God, there is day-care. That has just been the most helpful. Before I had gotten day-care, I was doing this all on my own and it was just very hard. Although

daycare for her mother did ease the burden, there were limits to what Rebecca and her husband could do.

Rebecca believed that the spiritual lessons she had to learn was patience and to find good in every situation. She worried about not being attentive and patient enough. She focused on things that her mother enjoyed.

She is so easy to care for. It's easy to forget to do things for her because she doesn't demand. One of the rewards is that I have learned patience. I have to really stop myself sometimes because I would get frustrated and I would have to stop and think, okay, this is really a very little thing and, you know, just be patient. You need a lot of patience.

You need to look for the good in the situation, not look at how it is going to disrupt your life but at how it will enhance the life of the one you are caring for. It is hard for her. She had a total change of lifestyle, whereas, for us we just had to expand our lives to include her. She had to totally change the way she lived. I am sure that was very frustrating and she never complained. And, not to make them feel guilty about what you are doing for them. I think, a lot of the time that is what happens with elderly people who is being cared for. You just need to focus, to zero in on the things that they enjoy doing and make that available even though it may not fit in your schedule. You know, the years that someone spent raising you may not have always been good. But, you're here and someone took a lot of time to do that, usually it was your parents. I don't have anything else to go on other than being a parent. There are so many benefits to helping out at a time when your parents are in need. The other blessing and reward would be the patience that I have gained from it.

The mother in dyad five found great comfort and security in her daughter's care. She felt cared for in that her daughter knew all she needed. She worried about the future if something befell her daughter, although she had sons and grandsons who were supportive. For her, as other mothers in the study, the daughter was the most important person in her life and she was effusive in her praise and appreciation.

For the daughter in dyad five, the experience of caregiving was bittersweet, a blessing and a frustration. Caregiving afforded a bonding and closeness with her mother, however, the constancy of caregiving limited her personal lifestyle. Daycare helped to

relieve the day-to-day stresses of caregiving. She too had a deep spiritual belief and that she had learned the virtue of patience.

### **Essential Themes**

Essential themes are the infrastructure for the descriptive and interpretive dimension of the lived experiences of adult caregiving daughters and their elderly mothers. They are fundamental to the experience and understanding of the total phenomenological dimension. They are the “aspects or qualities that make a phenomenon what it is and without which the phenomenon could not be what it is” (van Manen, 1990, p. 107).

The following are the essential themes fundamental to the caregiving, care receiving experiences of mothers and daughters in this study. In response to the question, “What is the experience like for you being cared for by your daughter or in caring for your mother?” major themes emerged from the data within each of the existential perspectives (van Manen, 1990) described in the chapter on methodology. The fundamental themes that emerged for mothers were: 1) feeling safe, comforted and protected, 2) feelings of gratitude, appreciation, and desire to do in return.

For the daughters, the themes were: 1) concern and worry for mothers’ safety, 2) fatigue in the constancy of caregiving, 3) commitment to loving attention, 4) balancing roles, and 5) spiritual growth.

#### **Feeling Safe, Comforted and Protected**

One emerging theme for mothers was that of feeling safe with their caregiving daughters. This was linked to feeling comfort from the caregiving of their daughters. Being in an environment that was safe and in which all their day-to-day needs were met provided comfort and protection. Three of the five mothers could not walk without

assistance and one needed some assistance. They had a pervasive fear of falling. Unless one is incapacitated, walking is taken for granted. One can move about at will, go to the bathroom, answer the doorbell or phone, feed a cherished pet, and walk outside to experience the warmth or coolness of fresh air. Confined by loss of physical ability, the mothers' world is restricted and they become dependent on another, in this case, a daughter. Mothers expressed an expectation that their daughters would always be there for them to care for them, protect them from falls and preserve their quality of life in a comfortable and familiar environment.

### **Feelings of Gratitude, Appreciation, and Desire to Reciprocate**

Mothers also expressed gratitude for all their daughters did and a worry that they were robbing her of her life. Each recognized and appreciated the constancy of the caregiving of the daughter. Mothers were quick to tell of the many tasks daughters performed that allowed them to have the quality of life they would not have if they were in a nursing home. At the same time, each of the mothers in some way attempted to reciprocate for the care. No longer able to do many physical chores around the house, one mother listened to the news and read the daily paper and capsulated the day's news and shared it with her daughter when she came home from work. Mothers expressed frustration with the physical limitations that restricted their activities and ability to "help out more."

### **Concern and Worry for Mothers' Safety**

Daughters expressed worry and concern for their mothers' environmental and personal safety. Concern for personal safety was centered about their mother's continuing decline from the normal aging process and associated disabilities from chronic diseases. The move into the caregiving role was in most cases initiated because of concern for their

mother's environmental safety. They worried too about their lack of knowledge and skills to provide safe and effective care for their mothers during acute episodes of illness.

### **Fatigue in the Constancy of Caregiving**

Daughters spoke of an overwhelming fatigue that at times pervaded their caregiving. Four of the five daughters had paid caretaker help; however, they spoke of the fatigue not only of providing physical care, but also of the constancy of the mental and emotional responsibility for their mother's health and well-being. There was the bittersweet burden of being the primary care provider

### **Commitment to Loving Attention**

Daughters spoke with emotions of joy and worry about caregiving their mothers. While they expressed a filial obligation, it was an obligation chosen with love and a desire to provide all they could to their mothers in return for all their mothers had done for them throughout their lifetime.

### **Balancing Roles**

Daughters were challenged in balancing their roles as daughter and caregiver along with the other roles in their lives, such as, wife, sister, friend, and professional. Daughters recognized their responsibility in the shifting of role balance to honor and respect their mothers' selfhood while still needing appropriate caretaking

### **Spiritual Growth**

Each of the daughters' stories reflected to a greater or lesser degree their belief that caregiving was a spiritual gift or blessing that enriched their lives. The experience fostered a connectedness that enhanced personal growth and self discovery.

### **Summary and Description of Themes**

Mothers and daughters share the same joys and worries, from different perspectives. All shared a worry for safety. For most of the mothers, their disabilities limited their mobility. They worried about falling and injuring themselves. They felt safe and comfortable knowing that their daughter was there to “take care of everything.” For them, their daughters protected them and were a safe haven. Mothers felt secure and found comfort in the attentive care of their daughters in whom they had unconditional trust. They worried about their fate in the event something would happen to their daughters, and the possibility of being in a nursing home. Living in her own or daughters’ home was comfortable and comforting. The sense gleaned from the interviews was that they felt safe and protected not only in their environment but in the watchful, loving attention of their daughters.

For daughters, safety had a broader scope than just providing a safe environment and protecting their mothers from physical harm and injury. It encompassed a worry and need to preserve their mothers’ autonomy and integrity as a person and as their mothers. Thus, for daughters caring provided not only comfort and quality of life but allowed them to protect and preserve their mothers’ life. Daughters were committed to providing a safe environment and the best care possible that allowed their mothers’ optimal health and well-being. Daughters worried about making right decisions that affected their mothers’ health and that might hasten their demise because they did not have a mastery of caregiving skills. While similar to what a mother would do for a child, daughters also expressed a need to preserve their mothers’ autonomy and involvement in the decisions regarding their care whereas, in mothering a child, the mother is the primary decision maker. Childcare also has an expected developmental time frame at which point

adulthood and emancipation is achieved. Elder care is fraught with uncertainty as to the end point, as daughters watch their mothers “growing older and older and older.”

Daughters had a desire to know they were still the daughter and made efforts to maintain the mother-daughter relationship. However, like a mother towards a child, daughters were knowingly perceptive about their mothers’ vulnerabilities and responded in caring for them in the best manner they could.

The mothers testified, through their stories, to the loving attention and caring they received. Overall, they believed that no one else could care for them as well as their daughters. They spoke with gratitude of the daily tasks of caring their daughters performed. They also felt cared for. They worried only about what would happen to them if their daughters became ill. The thought of institutionalization was frightening for them. According to Warren (1994), feeling cared for differs from being cared for. The latter implies a service or perfunctory act of instrumental care. Although not mutually exclusive, the essence of feeling cared for is in having one’s needs met without asking.

It saddened and frustrated mothers that they no longer were able to fully reciprocate in sharing the day-to-day chores about the house. All but one mother contributed in some small way to lighten the caregiving of their daughters. One mother often writes to her other children to remind them that she remains as healthy as she is because of the care she receives from her caregiving daughter.

The themes of balancing roles for daughters and the need of the mothers to reciprocate are linked. Daughters worry and struggle to balance roles as caregiver, daughter, wife, sibling, mother, friend, and professional. In caregiving, they still need to be “the daughter” and find nurturance in their relationship with their mothers. Mothers

desire to do all they could to help their daughters reflected a need to still be “the mother.” Mothers provided mothering by their expressions of gratitude and appreciation for all their daughters do for them. They also provided maternal nurturing within their physical limitations by reciprocating in doing whatever they can to lighten their daughters’ responsibilities, and in worry about their daughters health and well-being.

Daughters were committed, out of love for their mothers and duty as children, to respect and preserve their mothers’ health and dignity. They felt that the rewards outweighed the burdens of overwhelming fatigue, worry about making right decisions, efforts to acquire mastery in performing the physical tasks of caregiving, the struggle to keep perspective in balancing many roles, and maintaining some personal space for themselves. The rewards were found in the appreciative recognition by their mothers for all they did, the personal satisfaction from knowing their mothers were receiving the best care they could provide, and the strengthening of the relationship with their mothers.

Daughters expressed sadness and worry as they watched their mothers continuing decline of health. For two of the daughters this was linked to feelings of abandonment by another sibling who did not provide, even upon request, physical, emotional, or financial support. However, they remained totally committed to provide loving attention and care for their mothers and to move past the disappointment and hurt.

In addition, daughters attested to a personal spiritual growth dimension that accompanied their caregiving. This included a search for meaning in the experience, the developing of the virtue of patience, a sense of inner peace, the practice of living in the present moment and a realization of spiritual connectedness.

The preceding reflective thematic analysis was extrapolated from the data and field notes, and portrayed the experiences of adult caregiving daughters and their mothers from their personal stories. It allowed the researcher to enter into the text, so to speak, and to allow for interpretation of the overall dimensions of the experience of caregiving and care receiving.

### **Phenomenological Dimension**

The purpose of the phenomenological reflection is to grasp the meaning of an experience as a whole. Understanding of an experience is arrived at through the analysis of the themes. Each emergent theme is a statement of a concept or category, and provides structure for a fuller description of the larger phenomenological dimension of the lived experience (van Manen, 1990). “The meaning of the text resides in its themes, but the meaning of the text also resides in its connection with the larger discourse” (Berman, 1990). Themes provide insights into the beliefs and values that instill powerful experiences and motivations and shape how individuals plan, make sense of, and respond to events” (Lubosky, 1994). The phenomenological dimension is that which goes “beyond the data” (Coffey & Atkinson, 1996, p. 153). From the themes that emerged from the stories of the mother-daughter dyads in this study, the following interpretative dimensions portray the lived experience of caregiving for mothers and daughters in this study.

The experience of caregiving and care receiving was, for mothers and daughters in this study, inspired by an enduring respect and love that balanced the difficulties, worries and sacrifices in the day-to-day lived experience. Difficulties and worry give rise to opportunities to see others-in-situation in a new light and to cherish (appreciate) what may have previously been hidden. Mothers experienced the comforting presence of

daughters as strength, protection, and resting in a safe haven. They felt cared for, nourished, and cherished. Daughters discovered unexpected revelations of self and the other (mother) in striving to create balance in the existential dance of caregiving. Loving attention was a living presence of comfort and safety.

They co-created a new bonding and relationship that was a blessing expressed in mutual concern, loving attention and appreciation amidst the uncertainties of the future. Living with the uncertainties of aging and its inevitable but unknown course opens new ways of being for caregiver and care receiver. Being with the “what if” gives rise to being in the present moment and giving expression of appreciation for the “what is.”

Meaning was found in reciprocal loving connections and spiritual growth in seeking to transcend the day-to-day vicissitudes of caregiving and care receiving. Connectedness as a state of being opens ways to rising above the ever changing life situations of caregiving and care receiving and enhances discovery of new meaning in relationship.

### **Phenomenological Description**

One daughter speaks of caregiving as a “gift of love.” Others discovered the opportunity to care for their mother as a blessing. The worries, sacrifices, and fatigue of constant care giving are challenges in the day-to-day fulfillment of a commitment to the “invisible work” (Bower, 1987, p. 24) of caregiving. There is a shifting and balancing of roles between being a daughter and being caregiver. One mother refers to this as a “turning of the tables.” The necessity for and commitment to caregiving does not, however, negate the desire to be recognized as a daughter. Daughters search to equalize the mother-daughter relationship, then the relationship shifts.

Mora's (1991) poetry describes this as a "tug-of-war that started in the womb, the fight for space, the sharp jab deep inside as the weight shifts" (p 79). As a baby shifting in the mother's womb, there is a shifting of maternal nurturing between mothers and daughters, a mutual mothering. Daughters care for their mothers in appropriate ways. They are committed to protecting and preserving their mothers' integrity, not to swapping places with them. Daughters maternal nurturing reflects the modeling they learned from their mothers early in life. Remembrance of care given evokes an imperative to care.

When once daughters sought to create boundaries and establish independence they are now a source of knowledge, strength, and nurturance for their mothers. Now, as caregivers, they strive to preserve and protect their mothers' integrity and independence (Allen & Walker, 1992; McFarland & Watson-Rouslen, 1997).

In addition to a desire to reciprocate, mothering by mothers' is evident in their desire to remain in control of their lives, expressing a desire to "not to bother her" and wanting to do things on their own schedules that may be in conflict with the daughters'. This stance of "because I am the mother" at times creates tension in the relationship. These occasions of tension rather than being a burden for daughters were opportunities for redefining their relationship with their mothers, creating a mutual constructive relationship and for finding meaning in their caregiving. For mothers, there is a deep sense of serenity in knowing there is someone they trust to turn to when they cannot do for themselves. For daughters, there is a deep sense of self-fulfillment and connectedness overriding the fatigue, the sacrifices, and the worry of being ill prepared for the job of caregiving. Daughters portray an inner strength and resilience, perhaps a reflection of their mothers, for as the poet May Sarton (1974) writes:

There is in each of us a healing mother . . .  
There is the help we can give each other,  
And every morning, light at our first waking  
As if the day a blessing did take place.  
Despite all fumbles, bungling, we endure,  
Manage to go on building the hard inner core,  
A free self that might harbor faithful love.  
There is more in us than we have learned to give.

Excerpt from Reflections in a double mirror (p. 197)

## CHAPTER 5 DISCUSSION

This chapter will a) present an overview of the study, b) discuss the relevance and significance of the study, c) present a comparison with recent literature, d) discuss the implications and recommendations for nursing practice, education, and research, and e) present personal reflections.

### **Overview**

This study evolved from a personal and professional need to understand the lived experiences of adult caregiving daughters' and their elderly mothers. Lived experiences are the everyday experiences that are real to those experiencing them. I chose phenomenology as a research method to allow for discovery of the meanings within the context of this lifeworld experience of caregiving to study this experience of caregiving from the perspective of the participants.

As a human science research method, phenomenology facilitates understanding the meaning of an experience. It provides a context for exploring more meaningful nursing practice (Bishop & Scudder, 1990). According to Wilson and Hutchinson (1991), when nursing research provides understanding of the human response, it advances nursing practice and contributes to the development of interventions that benefit the client, the family, and community.

Themes from the analysis of the transcripts and field notes and in reflective writing provide the structure for describing the lived experience. The truest meaning is in the individual life of each study participant. Each viewed living the caring experience from a

different perspective. There were commonalities and singularities in the participants' stories that captured the meaning of the experience in the time frame when they were interviewed. At another time, place, or with a more diverse sample, the data and interpretation may be different. Lived experiences, from the perspective of the poet T. S. Eliot (1943), at best impose a pattern that is new in every moment, and every moment is new and shocking. According to van Manen (2002), "all interpretive phenomenological inquiry is cognizant of the realization that no interpretation is ever complete, no explication of meaning is ever final, no insight beyond challenge (p. 7)." In qualitative research, emphasis on human experiences disallows exactness but seeks the uniqueness and variability in a given phenomenon. The credibility of a qualitative study is found in the descriptive interpretive dimensions of the experience so that others in a similar life situation would recognize it as their own story.

All of the study participants were willing and eager to tell their stories, and portrayed their relationship as mutually supportive. This excluded from the study mother-daughter dyads that may have ambivalent or conflicted relationships. The sample was homogenous and did not allow for differences that might occur in rural settings or large metropolitan areas, and of diverse ethnic, economic, and cultural backgrounds. Inclusion of any of the preceding groups may reflect differences in the perceptions of familial relationship, the process of aging, and caregiving. The nature of the purposive sample limited generalization of the findings.

Daughters had the ability to employ outside help for personal care, homemaking service and respite care. This may have reduced the burdens and tensions of caregiving reflected in the literature on caregiving. All but one of the daughters were married and

characterized their husbands as supportive. Only two of the five daughters were employed fulltime. Two daughters did not have children, and the other daughters did not have children at home. That placed them outside what is commonly considered the sandwich generation where daughters care for aging parents and children simultaneously.

All research is subject to bias or error either from investigator subjectivity, design or research process. In this study, my personal experience of caring for my elderly mother presented a threat to the creditability or validity of the study findings. Effort was made from the beginning of the study process, for accurate and truthful representation of the experiences of mothers and daughters. To assure credibility, all of the taped interviews were transcribed verbatim and supplemented with field notes. Listening many times to the taped interviews, writing the transcripts, reading and re-reading the transcripts, and writing and re-writing descriptions of the experience achieved an iterated, circular analysis of the data.

Bracketing was an important factor in isolating personal experiences of caregiving. Keeping a journal of personal reflections throughout the study facilitated bracketing. In addition, discussions with geriatric nurses caring for elderly clients at home, with colleagues caring for their mothers, and with my committee members were ongoing to preserve the integrity of my interpretations. Credibility is most often sought from the participants' validation of the final description of the experience. However, in deference to the sensitivity of the data, the fact that mothers and daughters were interviewed separately and guaranteed confidentiality, and recent government regulations related to confidentiality, final verification from the participants was not possible. Expert readers, colleagues, and friends who were caregivers for their mothers assured validity. After

reading interpretive descriptions of the experience, these persons validated my observations and conclusions by recognition of their own experiences. These methods assured credibility or validity of the presentation of the descriptive findings. The following is an exemplar of comments received from one non-nurse friend who read the descriptions of the experience.

I personally found the stories difficult to read because of my recent experiences [assisting her mother in caring for her grandmother and step father over a five year period]. I am still healing more than I thought. I think this work can serve as a wonderful resource/benchmark by which to affirm one's experience and emotions around it [caregiving]. It is valuable to all who face the possibility of caring for an aging parent. I think it is important as a care taker to realize when we cross over the line to it being the sole purpose of a piece of ones life. A recent insight when mother was away for a month was that I felt lost without the constant "watching."

### **Relevance and Significance of the Study**

Nursing research has influence on clinical nursing practice. The use of research findings to inform and direct client care is one way to participate in evidenced-based nursing practice. This approach facilitates change for improved client outcomes, promotes reflective practice, validates and/or challenges existing procedures and interventions, and ensures efficient use of nursing resources (Gillis & Jackson, 2002). Nursing is concerned with the health of people which includes both wellness and illness. The ethic of nursing practice is caring (Benner, 1991; Watson, 1985, 1999). From a holistic perspective, knowledge is expanded and enhanced when it includes rational/quantitative and intuitive/qualitative research (Watson, 1999). Qualitative research is concerned with the human experience. Phenomenological or human science research, in particular, is relevant to nursing as it articulates the lived experiences of clients. It has value in the ability to discover and identify meaning to show new approaches for positive outcomes (Morse, Penrod, & Hupcey, 2000). In addition, it is

valuable in generating and enhancing theory and developing hypotheses to be tested (Munhall, 1994). Understanding of the meaning of caregiving by adult daughters and their elderly mothers was the purpose of this phenomenological study.

The mothers and daughters in this study provide understanding about the effect of aging and caregiving on individuals and families. Understanding the multidimensionality of the caregiving experience as a mosaic of “distinct and complex interpersonal experiences” (Gubrium, 1991, p. 17) is important in enabling nurses to address the needs of the caregivers and care receivers. This understanding is integral to providing holistic or “authentic care” (Heidegger, 1962, p. 158), and can be used to promote and maintain wellness.

The aged population continues to increase and the need for caregiving increases with greater need for physical care. The present health care system tends to splinter and fracture this care among various specialties and agencies. Patients, the elderly being most vulnerable, are at risk along with their caregivers of being lost in the system. Nurses are ideally situated within the system to be existential advocates (Gadow, 1980) to help elderly patients and their caregivers achieve positive outcomes. Present in all areas of the system, nurses are best able to address the needs of care receivers and caregivers. Understanding of the caregiving matrix can alert nurses to potential problems for which they can provide health promotion and early interventions. Important for nurses is recognizing the overwhelming physical and emotional fatigue experienced by daughters in constant day-to-day caregiving and the impact this may have on their health. In addition, understanding of the caregivers’ needs to be prepared and feel confidence in their abilities to provide “best care” for their mothers heightens the need for nurses to

provide ongoing teaching and support. Nurses may also intervene and assist mothers in accepting and trusting others who provide care, and in helping them to understand the need for the daughter to have balance and respite time in her life.

### **Comparison with Recent Literature**

A recent search of the literature reveals little additional research on adult caregiving daughters and their mothers from the first review. The experiences of caregiving in this study encompass all the dictionary (Mish, 2002) definitions explicated in Chapter 2 relating to care and giving, both in the common and the less common use of the terms. The sense of “suffering of mind” and “worry” is portrayed by daughters as they “trouble” themselves to provide the “best care” for their mothers. Van Manen (1990) addresses care as having a dual meaning of worry and loving attention. In a later work on care-as-worry, van Manen (2002) describes “care” in many languages where the word for care and worry are synonymous. In English, the terms are separated, although the meanings retained in the dictionary are similar. Both mothers and daughters express worry as a characteristic of the interpersonal exchange in the caregiving, care receiving relationship. Mothers worry about “what if” something happened to their caregiving daughters. They worry about their daughters sacrificing their lives to care for them. Daughters worry about “what if” something happened because they were lacking in the knowledge and skills to make the right decisions in caring for their mothers.

The work of Fingerman (2001) sheds light on aging mother-adult daughter relationships, however, was conducted outside the caregiving experience. Fingerman studied mothers and daughters in later life when mothers were still healthy. She found that mothers viewed daughters in the context of a larger family in which they, the mothers, remain the central figure in the kinship network. Daughters, on the other hand,

had relationships with their mothers that were described as dyadic where they related one to one as daughter and mother. Daughters in this present study validate this notion in the expression of the desire to “still be the daughter” in their relationship with their mother. Mothers, however, appeared to be the central figure in the kinship network. Within the caregiving matrix, daughters were the central nurturing person in their mothers’ lives.

Beard (1999), in a journalistic study, provides additional insights into the relationships of adult daughters and their aging mothers. Some of her profiles include dyads in a caregiving situation. She found mothers identified three qualities in “good daughters” (p. 96). They are responsible, companionable, and loving. Daughters sought acceptance and enhancement of the mother-daughter relationship by being aware of their mothers needs, and loving attention to them.

The daughters participating in this present study portrayed responsibility while striving to separate caregiving love from mother-daughter love and maintain a balance in their own lives. They strove to create opportunities to do mother-daughter companionable activities separate from the caregiving activities. Daughters had the ability to provide some paid caregiving help to facilitate mother-daughter companionship. They were loving in the attention and care they provided to meet their mothers needs. The “good care” the mothers in this study experienced was closely linked to feeling cared for and safe. Care from their daughters took on a singular and special significance.

Mothers portrayed their daughters as the “only one,” the “most important person,” “my remedy,” and the “main cog in the wheel.” Good care was equated with a good daughter.

Daughters were the singular center of their mothers' day-to-day lived experience. While mothers in this study had other caregivers and participated in other activities outside the home, the daughter was the primary person who gave meaning to their life. They felt cared for, safe, and comfortable. Daughters, on the other hand, had out of love and duty fit the caregiving of their mothers into the more complex matrix of their life experiences. They were committed to and provided loving attention and care; however, struggled with maintaining a sense of identity and balance in multiple roles. In addition, the daughters strove to protect and preserve the integrity of the role identity of their mothers. A qualitative study by Coeling, Biordi and Theis (2003) looked at how caregivers and care receivers negotiate dyadic rules that influence their identity and affect burden and/or satisfaction in the informal caregiving, care receiving relationship. They identified three archetypical dyadic relationships: 1) complete and mutually accepted immersion of an identity into the care process by both caregiver and care receiver, 2) retention of personal identities and yet acceptance of their roles as caregiver and care receiver, and 3) rejection of the roles by either the caregiver or the care receiver or by both. The dyads in this study would fit into the first two categories; however, except for one dyad the relationships were negotiated by tacit agreement. Coeling, et al address the need to further analyze informal caregiving from a dyadic perspective and to teach and facilitate active negotiation in informal caregiving. This was also evidenced in the experiences of two participants in this study with regard to sibling involvement in the decisions regarding caregiving.

In a grounded theory study, Sheehan and Donorfio (1999) examined mother-daughter relationships in caregiving. They interviewed 11 mothers and daughters. The

mothers all needed physical assistance but were free of cognitive impairment. Other characteristics of this sample were similar to those in this present study. The themes common to each in the dyad were: an increase in tolerance in the relationship, a redefinition of the mother-daughter roles, respect and acceptance of each other as individuals, aging awareness, and relationship priority. Only the daughters revealed an additional theme of sacrifice. The sacrifice is not described as a burden but as reciprocation, for all that their mothers had done for them through their lifetime. Some of these same themes, such as seeking to balance roles, mutual respect and acceptance of each other and sacrifice, are found in the experiences of the participants in the present study.

In Sheehan and Donorfio's study (1999), some daughters reject using the term "caregiver" to describe their role in caring for their mothers. The term caregiver has negative connotations of strain and burden that was not how they experienced what they did for their mothers. In this present study, daughters experiences of caring were positive and did balance any of the sacrifices that accompanied caring for their mothers. Sacrifice for daughters in both studies reflected daughters' belief that they were repaying mothers for all they had done for them. The desire of daughters to preserve their mothers' integrity, autonomy, and self-esteem emerged in both studies. Daughters in both studies strove to make meaning of aging and frailty. They were saddened by the continuing decline of mothers. Mothers in both studies expressed frustration at needing their daughters help and worried this infringed on their daughters' lives.

### **Implications and Recommendations for Nursing Practice, Education and Research**

This phenomenological interpretive description of the care experiences of mothers and daughters provides insight into how they frame and find meaning in their experience.

As nurses, we are presented with implications for future nursing practice, education and research. Nurses are the most frequent contact and continuous presence for family caregivers. Thus, improved positive outcomes might be expected from nurses' heightened awareness of the caregiving experience.

### **Nursing Practice**

One of the major worries of daughters in this study was feeling inadequate and ill prepared for the tasks of caregiving, especially during periods of acute episodic illnesses. Daughters feel a need for more information and competence in the skills required for caregiving. They often feel overwhelmed by the "physicalness" and "medicalness" of caregiving as they dedicate themselves to provide the best care possible to protect and preserve their mothers' physical, mental, emotional, and spiritual well being. Shortened hospital stays and a decrease in allowable home health nurse visits limits the opportunities for evaluation of the effectiveness of client and caregiver education. This is combined with the increasing complexity of care being provided at home. Caregivers have a definitive need for more information and preparation for the caregiving role and for support. Archbold, Stewart, Greenlick, and Harvath (1990) did find that preparedness accounts, in part, in ameliorating caregiver strain. Nurses are in a key position to provide education and support for caregivers.

The findings of this study place emphasis on the need for nurses to assure that caregivers feel confident in the skills of caregiving. The mothers never question the daughters' abilities. The worries of daughters appear hidden from mothers. Nurses can provide information, encouragement, and a supportive presence to allay caregivers' worries and fears. Partners in caregiving, nurses and daughters can provide a peaceful, centered presence and create a safe and nurturing environment for health and healing.

Nurses who understand the meanings of the caregiving experience can mediate a normalizing of the caregiving experience by assisting daughters to recognize when caregiving is taking over their entire life and assisting them in developing skills to negotiate the rules of the caregiving and care receiving relationship (Coeling, Biordi, & Theis, 2003). As advocates and partners in caregiving, nurses can provide resources and counseling to strengthen daughters coping abilities. One daughter in the study addressed the effect that nurses had on her ability to ask for help.

I felt I knew what was best for Mom. I wanted to be superwoman. One time after an illness when I brought her home the nurses impressed on me that they worked three shifts and that I was only one person with a full time job. I learned that I needed to listen to the professionals and ask for help when I needed it.

Just as this daughter learned to listen, nurses need to listen to hear the often hidden cries for help and support.

There is potential for establishing groups, telephone networks or web sites to provide information, support, and assistance with coping (Farran, Miller, Kaufman & Davis, 1997). This would advance nursing practice in taking advantage of technology and reaching people where they are. Caregiving is an added dimension to people's busy lives. Support group meetings may not fit into caregivers' busy schedules; however, sharing support with others in an on line caregivers' chat room or telephone network might be feasible. Telephone contact by nurses post discharge of an elderly patient, or in between home health visits could also identify potential problems areas and allow for early interventions.

### **Nursing Education**

Nurses need ongoing education in evidence-based practice including both quantitative and qualitative current research findings. Findings enhance nurses'

knowledge and understanding of the science and the art of caring. This knowledge can help their assessment and evaluation skills and contribute to creative approaches to care. Examination of caregiving experiences from a holistic perspective reinforces for nurses the validity of intuitive caring and the need to fine-tune their attentive listening skills. Listening to stories is an opportunity to gain insight into and understand the experience of caregiving/care-receiving from those living the experience, and serves as a bridge to planning care that takes into account all resources, barriers, and competing concerns. Understanding the life of a client can help nurses deduce what the persons' needs and problems might be that affect their health-illness trajectory.

Listening skills are best instilled early in a nurses' career beginning in nursing school. Incorporating the importance of listening to the client's story can be integrated throughout the curriculum. Teaching through exemplars exposes students to the multi-dimensions of the lived experience of whatever phenomenon they are studying. Integrating the humanities with the biological sciences would expand their appreciation of the diversity in the lives of those they will be caring for. Opening their minds to diversity through incorporation of literature, art, and music expands their horizons to consider greater possibilities in assessing, evaluating and planning care.

It is important for students to be exposed to the concepts of family development and dynamics across the lifespan, the complexity of family relationships, and how these affect caregiving and care receiving in later life. Understanding of these concepts and their relationship to the caregiving process and experience will better equip nurses to address the needs of caregivers and care receivers. The nursing education community should teach students the importance of supporting caregivers and assessing their skills

and strengths. Students need to have the experience of teaching caregiving skills, providing information, and accessing community resources. Community clinical experiences across the lifespan would contribute to students' awareness of and future abilities as professional nurses to contribute to identify resources and to promote the health of a large segment of the population. Given the continued growth of the older population, incorporation of the concepts of gerontology and geriatrics are needed throughout nursing curricula.

### **Nursing Research**

There is a need in nursing research to study caregiving. It is discouraging to note in a recent literature search that there is so little research on caregiving of the frail elderly and their caregivers as the aged population increases. The majority of research is focused on elderly persons with cognitive impairment. Caregiving to the frail population of older persons remains invisible. More data would be helpful to know how to prepare families, in particular daughters, in the skills needed to give care. How do they develop confidence and mastery in the skills of caregiving? Does competence reduce their worry and anxiety? Does having paid outside caregiving assistance and use of respite care make a difference in the objective and subjective evaluation of caregiving? There is a marked absence of research that examines the participation of sons in parental caregiving. One study by Harris (1993) suggests that sons may be assuming greater responsibility in the caregiver role and warrants more study. This contradicted earlier research, such as that of Dwyer and Coward (1991) that found daughters are three times more likely than sons to be caregivers.

Research on the impact that fatigue and constancy of care with no defined time frame has on the health of the caregiver would be advantageous in preventing illness and

promoting health. Comparison of the health and satisfaction with care of care receivers being cared for at home and those in institutional care may provide insight into redesigning institutional policies and procedures.

Studies should allow for a holistic approach. Research should examine the caregiving bond between mothers and daughters and the quality of the relationship to health. Walker and Allen (1991) identified three types of mother-daughter relationships in caregiving situations; however, no correlational studies have been done to examine the impact of these relationships on health. Understanding of the mother-daughter relationship might contribute to uncovering ways to help mothers and daughters define and balance their roles. The experience of bonding and sense of connectedness made explicit by daughters and implied by mothers has a definitive spiritual dimension. Burkhardt (1989) in a concept analysis of spirituality, defines spiritual dimension as an integrating and unifying force giving meaning to life and that creates a bonding between persons. Further, spiritual well-being is characterized by harmonious interconnections, life affirming relationships and a perception of life as having meaning. Clark, Cross, Deene and Lowry (1991) pose that spirituality is integral to quality care and promote interpersonal bonding and enhance meaning in life. Haase, Britt, Coward, Leidy and Penn (1992) studied the concepts of spiritual perspective, hope, acceptance and self transcendence and identified five common factors that relate to the dimensions found in the participants of this study. They are serenity, personal growth, connectedness, purpose and meaning, and self-transcendence. Emblen (1992) addresses spirituality as a key factor in producing loving behaviors. Heriot (1992) highlights the place of spirituality in the development of personal identity. Spiritual relationships, according to Walton (1996),

enhance wellness and promote positive physical outcomes. Acton and Wright (2000), in a study of caregivers to persons with dementia, pose that self-transcendence is a spiritual dimension that may provide a framework for holistic nursing intervention to help caregivers relieve the stresses of caregiving. Although concepts are identified, and often described in the literature, further study needs to be conducted to assess the relationship of spirituality to caregiver stress and satisfaction. King (1993) developed a Continuum of Care (COC) model to help daughters in developing healthy caregiving relationships with their mothers. Exploration of the literature and conversation with the researcher reveals that the model has never been tested. This may be a valuable tool for future outcomes research.

If I repeated this study, one approach would be to conduct joint interviews with the mothers and the daughters. This may allow for discovery of how the mothers and daughters negotiate rules of caregiving as discussed by Coeling, Biordi and Theis (2003). There may also be differences in the interpersonal dialog and language that might reveal themes that provide new dimensions of the experience. Additional descriptive research is needed to define the experience in more diverse populations, including economical, cultural, ambivalent or conflicted mother-daughter relationships, mother-son caregiving experiences, and among the frail elder care receivers themselves. It would be advantageous to also study the role of nurses as advocates for caregivers and the role they play in normalizing the caregiving experience.

Another area for exploration is to study the concept and possibility of intentional communities for the elderly. One daughter in this study considered this as a viable option

to caring for the elderly to reduce isolation and the burden of care on one person in a family.

### **Personal Reflections**

I discovered, in the reflective process of this study, I was able to find new dimensions of the experience of mother-daughter caregiving I was unaware of while caring for my mother. Since her death in 2001, I find that I am able to step outside the frame of caregiving and see with a fresh perspective. Throughout the research process, I was inspired by the resiliency, commitment, courage, and love revealed by mothers and daughters in the telling of their stories. I found in these stories the mutual caring, compassion, and recognition of each other as individuals similar to what I experienced in caring for my mother. I found, also, the frustrations and the ongoing search for meaning in the experience. There is a connectedness that goes beyond the day-to-day mundane tasks of caregiving. One daughter expressed this connectedness as a mystery that defies scientific explanation. Perhaps in caring for the bodily needs of our frail mothers an early memory of skin to skin connection is rekindled, the fond memory of which provides daughters with a satisfaction that supercedes any downside to caregiving. For mothers and daughters caregiving is a lifetime work of learning “the marvelous skill to make life grow in all its forms” (Sarton, 1974, p. 77) from conception and birth to aging and death, and all the stages in between.

As serendipitous as the seed that was planted for this study, was a letter from a nurse colleague with a reflective piece about her caregiving her mother in the year prior to her death. I am including segments that speak to the bonding, loving connections and growth that are potential in the mother-daughter caregiving, care receiving experience.

Turning and Returning

Not only was it laundry day, it was my mother's birthday. Standing at the clothesline it was easy to recall the months of her dying as if it had just happened. Time lost all meaning as my mind sought the right prayer to thank her again for giving birth to me. Through the cataract of tears, the realization that I was orphaned became more clear, and it was past time to relinquish my former role. Holding Mom's windbreaker to be pinned, a lifetime of childhood memories flooded my eyes. We had shared the blessings of each day while she drifted toward death.

As the wind flapped the sleeves of Mom's, I saw into the past when my little hands helped her large fingers hang the laundry. How strongly do our first relationships cause our heart's growth, teaching our connection to God and Creation. Yet I never knew my mother until my months with her as caregiver. After I left childhood we had been unable to find common ground. The gulf between us was inexplicable until we exposed our unshared secrets. For a lifetime we had lived as if it didn't matter.

An eagle shrieked above and brought me out of contemplation and back to very real visceral pain. An eagle used to fly near Mom as she sat in a wheelchair while enjoying her last days of sunshine. She had stopped sighing and unveiled her secrets. This brought her peace.

With a child's voice she had asked me if it would be hard to die. Her world had shrunk away from food, music, people and pain, but included my face and hands, and the flowers of the day. I told her it was only living that was hard, and that God had made dying a pleasant passage from one dimension to the next. She smiled sweetly and communed with the spiritual realm. I could not join her or see who she spoke to. I provided the flowers, God brought us peace.

Mom would hold the flowers I daily picked for her as if it was her last connection to earth. Returning to my laundry, it occurred to me that the jacket pockets should be pulled inside-out to allow them to dry. Inside one pocket was a handful of jasmine and wildflowers, left where she could still touch them. Mysteriously they retained a fresh scent.

If we value the prolongation of life then we must also commit to a quality of that life and continue to search for ways to provide health care that recognizes lived experiences as an integral part of maintaining and promoting the health and well-being of the elderly and their caregivers, and thus of our society as a whole.

APPENDIX A  
ASSESSMENT OF ADLS, IADLS, AND MEDICAL CARE NEEDS

Please indicate the level that applies to the task.

ADL's	No Assistance	Assistance
Bathing/showering		
Dressing		
Getting in and/or out of bed/chair		
Using toilet		
Preparing meals		
Taking medication		
Getting around inside		
Laundry		
Housework		

IADLs	No Assistance	Assistance
Shopping for groceries		
Driving		
Manage money/checkbook		
Walking outside		
Climbing stairs/steps		
Using Telephone		
Yard work		
Minor household repairs		
Dealing with agencies/appointments		

Health care needs	No assistance	Assistance
Dressing changes		
IV medication		
IV feeding		
Gastric feeding		
Colostomy care		
Catheter care		
Wound care		
Insulation administration		
Other		

APPENDIX B  
MINI MENTAL STATUS EXAMINATION (MMSE)

Name \_\_\_\_\_ Date \_\_\_\_\_

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Maximum      Score

Score

Orientation

- 5      (   )      What is the (year) (season) (day) (month)?
- 5      (   )      Where are we: (state) (country) (town) (hospital) (floor)

Registration

- 3      (   )      Name three objects: 1 second to say each. Then ask the patient all 3 after you have said them. Give 1 point for each correct answer. Then repeat them until she learns all 3. Count trials and record trials.

Attention and Calculation

- 5      (   )      Serial 7's. I point for each correct. Stop after 5 answers. Alternately spell "world" backwards.

Recall

- 3      (   ) Ask for the three objects repeated above. Give 1 point for each correct.

Language

- 9      (   )      Name a pencil and watch (2 points)
- Repeat the following "No ifs, ands or buts." (1 point)

Follow a 3- stage command: Take a paper in your right hand and fold it in half, and put it on the floor. (3 points)

Read and obey the following:

Close your eyes. (1 point)

Write a sentence (1 point)

Copy design (1 point)

\_\_\_\_\_ Total Score (Maximum Score = 30)

Assess a level of consciousness along a continuum

/ \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_ /

Alert

Drowsy

Stupor

Coma

#### Instructions for Administration of Mini-Mental Status Examination

##### Orientation

1. Ask for the date. Then ask specifically for parts omitted, e.g., Can you tell me what season it is? One point for each correct.
2. Ask in turn: "Can you tell me the name of this city (town, apartment, hospital, etc.) One point for each correct.

##### Registration

Ask the person if you may test her memory. Then say the name of 3 unrelated objects, clearly and slowly, about 1 second for each. After you have said 3 ask her to repeat them. The first repetition determines the score (0-3) but keep saying them until she can repeat all 3, up to 6 trials. If she does not eventually learn all 3, recall cannot be meaningfully tested.

### Attention and Calculation

Ask the person to begin with 100 and count backwards by 7. Stop after 5 subtractions (93, 86, 79, 72, 65) Score the total number of correct answers.

If the person cannot or will not perform this task, ask her to spell the word “world” backwards. The score is the number of letters in correct order, e.g. DLROW = 5, DLORW =3.

### Recall

Ask the person if she can recall the three words you previously asked her to remember. Score 0-3.

### Language

Naming: Showing the person a wristwatch and ask her what it is. Repeat for pencil. Score 0-2.

Repetition: Ask the person to repeat the sentence after you. Allow only 1 trial. Score 0 or 1.

3-Stage command: Give the person a piece of blank paper and repeat the command. Score 1 point for each part correctly executed.

Reading: On a blank piece of paper print the sentence “Close your eyes”, in letters large enough for the person to see clearly. Ask her to read it and do what it says. Score 1 point if she actually closes her eyes.

Writing: Give the person a blank piece of paper and ask her to write a sentence for you. Do not dictate a sentence, it is to be written spontaneously. It must contain a subject and a verb to be sensible. Correct grammar and punctuation are not necessary.

Copying: On a clean piece of paper, draw intersecting pentagons, each side about 1 inch, and ask her to copy it exactly as it is. All 10 angles must be present and 2 must intersect to score 1 point. Tremor and rotation are ignored.

Estimate the person's level of sensorium along a continuum, from alert on the left to coma on the right.

### Scoring

Scores above 25 indicate no cognitive impairment.  
Scores from 20 -- 25 indicate depression without cognitive impairment.  
Scores from 10 – 20 indicate depression with cognitive impairment or psychoses.  
Scores of 9 or less reflect organic cognitive impairment.

APPENDIX C  
DEMOGRAPHIC DATA SHEET

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

Phone: (\_\_\_\_) - \_\_\_\_\_

Birth Date \_\_\_\_\_

What is your living arrangement? \_\_\_\_\_

Length of time living together: \_\_\_\_\_

Length of time of caregiving: \_\_\_\_\_

Are you employed? \_\_\_\_ IF yes: Full time \_\_\_\_ Part Time \_\_\_\_

Are you paid for your caregiving services? \_\_\_\_\_

Are you the primary caregiver? (ask of daughter) \_\_\_\_\_

How much time per week do you average caregiving/care receiving? \_\_\_\_\_

Do you have any other help? \_\_\_\_ If yes: Is it:

Professional \_\_\_\_\_ Other \_\_\_\_\_

Physical condition(s) or disabilities requiring care: \_\_\_\_\_

Average Income: Less than \$5000, \_\_\_\_ \$5001 to \$10,000, \_\_\_\_\_

\$10,001 to \$20,000, \_\_\_\_ \$20,001 to \$40,000 \_\_\_\_ \$40,001 to

\$80,000, \_\_\_\_ Above \$80,001 \_\_\_\_\_

Marital Status: Married \_ Single \_ Widowed \_ Separated \_ Divorced \_

Religion \_\_\_\_\_

Ethnicity: White, non-Hispanic, \_\_, Hispanic \_\_, African-American \_\_,

Asian \_\_, Asian Pacific \_\_, Other \_\_\_\_\_

APPENDIX D  
INFORMED CONSENT TO PARTICIPATE IN RESEARCH



You are being asked to take part in a research study. This form provides you with information about the study. The Principal Investigator (the person in charge of this research) or a representative of the Principal Investigator will also describe this study to you and answer all of your questions. Before you decide whether or not to take part, read the information below and ask questions about anything you do not understand. Your participation is entirely voluntary.

Name of Participant:

---

**Title of Research Study:** A Phenomenological Study of the Lived Experiences of Adult Caregiving Daughters and Their Elderly Mothers

**Principal Investigator and Telephone Number:** I will be conducting the study. My name is Patricia J. Connell, and my telephone number is (321) 773-2447.

**Source of Funding or Other Support:** University of Florida

**Purpose of this research study:**

The purpose of this study is to explore the experiences of adult daughters who (live with and) care for their mothers; and of their elderly mothers who receive the care.

**What will be done if you take part in this research study?**

If you decide to be a part of the study, you and I will talk to see if you, daughter and mother, meet the guidelines for the study. These guidelines include such things as age, number of caregiving tasks, living arrangements and, duration of caregiving. I will ask you to fill out a personal data questionnaire; cares needs assessment and, take a mini mental status test.

If you agree, I will need a minimum of two interviews of no more than two hours each. The first will ask you to tell of your experiences as a caregiver/care receiver. This interview will be audiotape recorded. During the second interview, I will share any findings of my study with you and ask for any comments you may have.

If during any interview you want to stop for any reason that is okay. If you want to continue at a later time, we can do that in an additional interview.

In the event you do not meet the guidelines for the study, the interview will be ended. If for any reason you are concerned and/or need professional assistance, I will provide you with a list of appropriate community resources.

**What are the possible discomforts and risks?**

The possible risks or discomforts from this study may be:

Possible fatigue and/or emotional distress as you tell you story of caregiving and care receiving.

Disclosure of secrets may be a problem. Telling ones story may be helpful but this is not the intent of the interviews. If there is a problem that you would like assistance with, I will provide you with a list of various resources in the community.

In the event of a reportable offense, I must report it to the appropriate authorities in accordance with the laws of the State of Florida.

Throughout the study I will notify you of new information that may become available and might effect your decision to remain in the study.

If you wish to discuss this information or any other discomforts you perceive, you may ask questions now or call the Principal Investigator listed on the front page of this form.

**What are the possible benefits to you?**

The only benefit to you is that you may gain greater understanding of your experience of caregiving and receiving.

**What are the possible benefits to others?**

Possible benefit to health care providers and others is unknown at this time.

**If you choose to take part in this study, will it cost you anything?**

The only cost to you is the time for the interviews.

**Will you receive compensation for your participation in this study? No.**

**What if you are injured because of the study?**

If you do experience an injury that is directly caused by this study, only professional care that you receive at the University of Florida Health Science Center and my professional consultative services will be provided without charge. You or your insurance provider must pay any hospital expenses. No other compensation is offered.

**What other options or treatments are available if you do not want to be in this study?**

This study does not include experimental intervention or treatments.

**Can you withdraw from this research study?**

You are free to withdraw your consent and to stop participating in this study at any time. If you do withdraw your consent, there will be no penalty, and you will not lose any benefits entitled to you.

If you decide to withdraw your consent to participate in this study for any reason, you should contact Patricia Connell at (321) 773-2447.

If you have any questions regarding your rights as a research participant, you may phone the Institutional Review Board at (352) 846-1494.

**If you withdraw, can information about you still be used and or collected?**

No. If you withdraw from the study any information you shared will be kept confidential and in a locked cabinet. Any audiotapes will be erased. All other forms and records will be kept for three years and then destroyed. At no time will any of the information be used for any other purpose or research.

**Can the Principal Investigator withdraw you from this research study?**

You may be withdrawn from the study without your consent for the following reasons: Inability of either of the participants in the study to continue to meet the criteria for the study.

If you have any questions regarding your rights as a research subject, you may phone the Institutional Review Board (IRB) office at (352) 846-1494.

**How will your privacy and the confidentiality of your research records be protected?**

Authorized persons from the University of Florida and the Institutional Review Board have the legal right to review your research records and will protect the

confidentiality of those records to the extent permitted by law. Otherwise, your research records will not be released without your consent unless required by law or a court order.

No identifying information will be placed on the labels of the audiotapes or the transcripts of the interviews. A code letter will identify each participant. Only I will have the code and the corresponding participant identification. Names will not be used in the narrative description and interpretation of the data in the research report. You will be asked not to identify yourself during the tape-recorded interviews. Access to the transcripts will be restricted to the researcher and members of the research committee. Your name will be removed from the master copy of the demographic information, the assessment forms and the mini-mental state questionnaire after being coded by the researcher. All the interview audiotapes, demographic and assessment instruments, signed consent forms and transcripts will be kept in a locked file cabinet. After completion of the research the interview audiotapes will be erased. All other forms and records will be kept for three years and then destroyed.

If the results of this research are published or presented at scientific meetings, your identity will not be disclosed.

**How will the researcher benefit from your being in this study?**

In general, presenting research results helps the career of a scientist. Therefore, the Principal Investigator may benefit if the results of this study are presented at scientific meetings or in scientific journals.

## Signatures

As a representative of this study, I have explained to the participant the purpose, the procedures, the possible benefits, and the risks of this research study; and how privacy will be protected:

---

Signature of person obtaining consent

Date

You have been informed about this study's purpose, procedures, possible benefits and risks; and how your privacy will be protected. You have received a copy of this form. You have been given the opportunity to ask questions before you sign, and you have been told that you can ask questions at any time.

You voluntarily agree to participate in this study. By signing this form, you are not waiving any of your legal rights.

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Participant Signature

Date

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Patricia J. Connell graduated from Maryview Hospital School of Nursing in Portsmouth, Virginia, in 1958 and completed a baccalaureate degree in nursing from Catholic University of America in Washington, D.C., in 1964. She completed graduate studies at the University of Colorado with a Master of Science degree in community health nursing in 1972. Patricia is a practitioner of Therapeutic Touch, and is a certified holistic nurse practitioner. She holds certifications in reality therapy, clinical hypnosis, and neurolinguistic programming. Her professional nursing career includes a wide variety of clinical, administrative, and teaching experiences. She co-founded and was the first director of the Community Health Agency in Aspen, Colorado. Patricia has been actively involved in professional associations throughout her career and is past president of the Colorado Nurses Association and the Virginia Catholic Nurses Association. She is a member of the American Nurses Association, Florida Nurses Association, Sigma Theta Tau International Honor Society for Nurses, American Holistic Nurses Association, and Nurse Healers-Professional Associates International. She has presented on the topics of holistic nursing, Therapeutic Touch, and elder care at local, state, national, and international levels. In addition to her faculty position at the University of Central Florida, School of Nursing, she presently maintains a holistic counseling practice, Healing Connection, in Melbourne, Florida.