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THE PREDICTORS OF THE ELDER CARE EXPERIENCE BY ADULT CHILDREN

By

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ABSTRACT

THE PREDICTORS OF THE ELDER CARE EXPERIENCE BY ADULT CHILDREN

By

Debra Lynn Sietsema

Elder care provided by adult children is a challenge faced by an increasing number of families. Most caregiving research has focused on the negative aspects of the caregiving experience. Based on Human Ecology theory, this investigation examined caregiving circumstances, resources, and deterrents as predictors of the intergenerational caregiver experience. A sample of 541 unpaid daughters and sons who were primary caregivers of their elderly parents were surveyed as part of the National Long Term Care Survey (NLTCS) in 1999. The National Informal Caregivers Survey (NICS) of the NLTCS was used for this study. Analyses included correlations, multiple regression, path analysis, t-tests, and one-way ANOVAs. Positive and negative outcomes of the caregiving experience were included: self-esteem, appreciation of life, energy expenditure, stress level, physical strain, and financial hardship. Caregiving time, the amount of care provided, external support, coping behaviors, and care recipient helpful behaviors predicted energy expenditure, stress level, physical strain, and financial hardship. Family or friend support, and care recipient helpful and difficult behaviors predicted self-esteem, and family or friend support and care recipient difficult behaviors predicted appreciation of life. Additionally, family or friend support, care recipient difficult behaviors, family conflict, and caregiving issues mediated the caregiving circumstances on the caregiving outcomes.

Caregiving sons and daughters differed, and daughters had a greater appreciation of life while experiencing greater energy expenditure and enduring greater financial hardship as a result of the caregiving experience. There was no significant difference in caregiving outcomes between sons and daughters when considering age and longevity of care. A comparative study of the next wave of NICS data from 2004 would be important for current implications for nursing practice and a qualitative approach would assist in further examining meanings embedded in the emotional response and feelings in the use of resources, deterrents, and outcomes of the caregiving experience. Realizing the predictors of the caregiving experience will assist in promoting caregiver and family well-being.

DEDICATION

This study is dedicated to my husband, Mark, who provides steadfast love, patience, genuine caring, encouragement, understanding, and support.

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Distinct recognition is given to my sons, Ryan and Kevin, for their cooperation, demonstration of pride in me, and for helping me to keep a focus on family priorities and a perspective on life throughout this project.

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CHAPTER 1

Introduction

Background

Life expectancy in the United States is increasing, and this greater longevity increases the risk of chronic medical conditions, which may require increasingly expensive long term care. Care provided by family members contributes to the maintenance of dependent elderly persons in the community, reducing societal costs and increasing quality of life for the elderly. Concurrently, families have fewer children to provide intergenerational care, and women are in the workforce in greater numbers, decreasing their availability for caregiving of elderly parent(s). Many adult children are faced with the decision to care for elderly parent(s), and most families are committed to do so. Understanding the many factors related to caregiving experiences and the relationships among them will enable professionals to address the needs of caregivers, care recipients, and families of caregivers. The role of the healthcare and family professional is to facilitate positive outcomes of the caregiving experience as the caregiver utilizes resources and balances multiple demands, issues, and concerns.

Understanding the factors that predict caregiving outcomes will help professionals empower family caregivers. It is important to assess caregiver risk for negative outcomes to decrease or alter these outcomes. However, another

approach is to enhance the resources and to emphasize the strengths and predictors for outcomes that may affect the experience and facilitate an overall understanding and promotion of caregiving benefits for the elderly parent, caregiver, the family, and the intergenerational relationship. It may be possible to optimize certain predictors to improve outcomes. Knowledge of predictors and outcomes also can be the basis for interventions that could improve the caregiving experience.

Purpose of Study

The purpose of this study was to determine the predictors of the intergenerational caregiving experience. Kramer (1997a) identified four important reasons to investigate caregiving. First, positive as well as negative aspects of caregiving are reported by caregivers, and caregivers are willing to share the positive results of caregiving. Caregivers report that giving care to an elderly parent increases their feelings of pride in their ability to meet challenges, improves their sense of self-worth, leads to greater closeness in relationships and provides an enhanced sense of meaning, warmth and pleasure. The second important potential contribution is that understanding positive and negative predictors and outcomes of caregiving may help professionals work more effectively with the family caregiver. Caregiving research may provide insights into how to enhance or increase the positive aspects of caregiving to offset potential negative outcomes. Professionals can validate feelings and experiences and promote a positive experience. Third, outcomes of caregiving experiences may be important determinants of the quality of care provided to

older adults. Lastly, information may be provided that could enhance theories of caregiver adaptation and psychological well-being.

Significance of the Problem

The United States Administration on Aging (AOA) (2004) reports that the population age 65 and older is projected to double within the next 30 years, growing to 70 million by 2030. Additionally, the AOA reports that the overall health of the elderly has improved, but since the life expectancy has lengthened and the number of elderly persons has dramatically increased, there is an increasing need for care. People aged 85 and older comprise the fastest growing population group, and the prevalence of disability is 58 percent (United States Administration Agency on Aging, 2004; U.S. Senate Special Committee on Aging, 2004). Of those elderly persons with disabilities living in the community and receiving care, 64 percent relied exclusively on informal unpaid care from relatives. Considering the increased number of elderly persons in the United States, caregiving for the elderly has become a major research concern.

Providing care to elderly parent(s) is a challenge faced by an increasing number of families. The U.S. Special Committee on Aging (2004) reported that there are 22 million family caregivers, and the number of families providing care to older relatives is expected to increase substantially in the next few decades. Among people between the ages of 45 and 55, over 80 percent have at least one living parent.

Research has revealed characteristics of caregivers, the type and amount of caregiving activities performed, and the negative effects of caregiving for

primary caregivers. The National Allliance for Caregiving and American Association of Retired Persons (2004) provide recent demographics of caregivers of the elderly. They estimate that sixteen percent of the U.S. population provides unpaid care to the elderly. Typically, primary caregivers of the elderly are daughters with an average age of 47. The elderly care recipients have an average age of 75 and are mothers, grandmothers, or fathers. Fifty-nine percent of the female caregivers are employed full-time, 62% are married, and they provide care for at least 4.3 years, with an increasing number providing care for ten years or more.

Caregiving research has focused on the primary caregiver and the negative aspects of caregiving. There is very little information related to the benefits of caregiving and the effects of caregiving on the caregiver's family.

Theoretical frameworks

Concepts from human ecology theory (Bubolz & Sontag, 1993) and a life course perspective (Bengston & Allen, 1993; Price, McKenrry, & Murphy, 2000) were used to determine predictors of the intergenerational caregiving experience. These concepts formulate a conceptual model of adaptation and appraisal of the caregiving experience as it occurs in the life course.

Human Ecology

Caregiving represents a dynamic process of interaction with and appraisal of the environment, a basic principle of the ecological perspective. The individual caregiver or family unit in interaction with the environment constitutes an ecosystem. The family ecosystem model includes three environments in which

the family interacts: the natural physical-biological, the social-cultural, and the human-built environments. The social-cultural environment includes the relationship of other people to the family, cultural constructions such as norms, cultural values, and patterns of behavior, and social and economic institutions that influence behavior (Bubolz & Sontag, 1993). Families interact with and are interdependent with the influences of these environments. While all three of the environments are important to the ecosystem, this study focuses on the relationship of the social-cultural environment to the caregiving family.

Bubolz and Sontag (1993) conceptualize the family ecosystem structure as families of diverse characteristics (structure, ethnic origin, life stage, and socioeconomic status) with individual and family attributes (needs, values, goals, resources, and artifacts) interacting in and with diverse environments (natural physical-biological, human built, and social-cultural). The family ecosystem involves the transformation of matter-energy expenditure and information by engaging in adaptation through activities and processes (perception, decision making, sustenance activities, organization, management, human development, communication, and use of technology). The outcomes of these family ecosystem structures and processes occur at the micro and macro levels to affect the quality of life of humans and the quality of the environment to achieve consequences for the realization of values and environmental goals (human betterment and stewardship and sustainability of the environment). A continual interactive feedback loop influences family structure, process, and outcome within the environment.

The family ecology model lends itself to exploring the adaptation and social-cultural influences when adult children care for their elderly parent(s). The social-cultural environment encompasses family characteristics, values, needs, the use of resources, and decision-making related to problem solving and achieving family goals (Bubolz & Sontag, 1993). The contextual and attribute variables of the caregiver and the care recipient are inherent in the social-cultural environment. Support and resources also are within the social-cultural environment. Adaptation is vital in the caregiving process. The caregiver's appraisal of the caregiving experience is key to adaptation when the caregiver is faced with resources and deterrents. The adaptation (utilization of resources, response to deterrents, modification of behavior, feelings) that families make to meet changed member or care recipient demands is an important ecological concept (Bristor, 1990). The extent to which resources such as external support, family or friend support, and coping strategies are utilized can determine adaptation and perception of the caregiving outcomes. In the context of the environments, adult children and families adapt to meet changing needs. Adaptation allows families to respond to the disequilibrium that can occur when elder care is needed. The outcome of the human ecology theory and the outcome of the caregiving experience is to achieve quality of life and human betterment.

Other ecological concepts important to this study include resources, time, space, and energy. Resources are important to the appraisal of the caregiving experience and its outcome, and resources in this study include external support,

such as respite care, family or friend support, coping behaviors, and care recipient helpful behaviors. Caregiver, care recipient, and the caregiving circumstances also may provide resources that influence the caregiving outcome. Length of time providing care and the amount of time spent in caregiving each week also can shape the perception of the experience. Space, such as the co-residence or proximity of residence of the caregiver could affect the intergenerational care. Space can be considered conceptually when other family members distance themselves from care or do not provide assistance in care. Also, the concept of energy for the ongoing care needed, the ability to utilize effective coping, and to manage deterrents appropriately is necessary to sustain caregiving activities for a positive outcome.

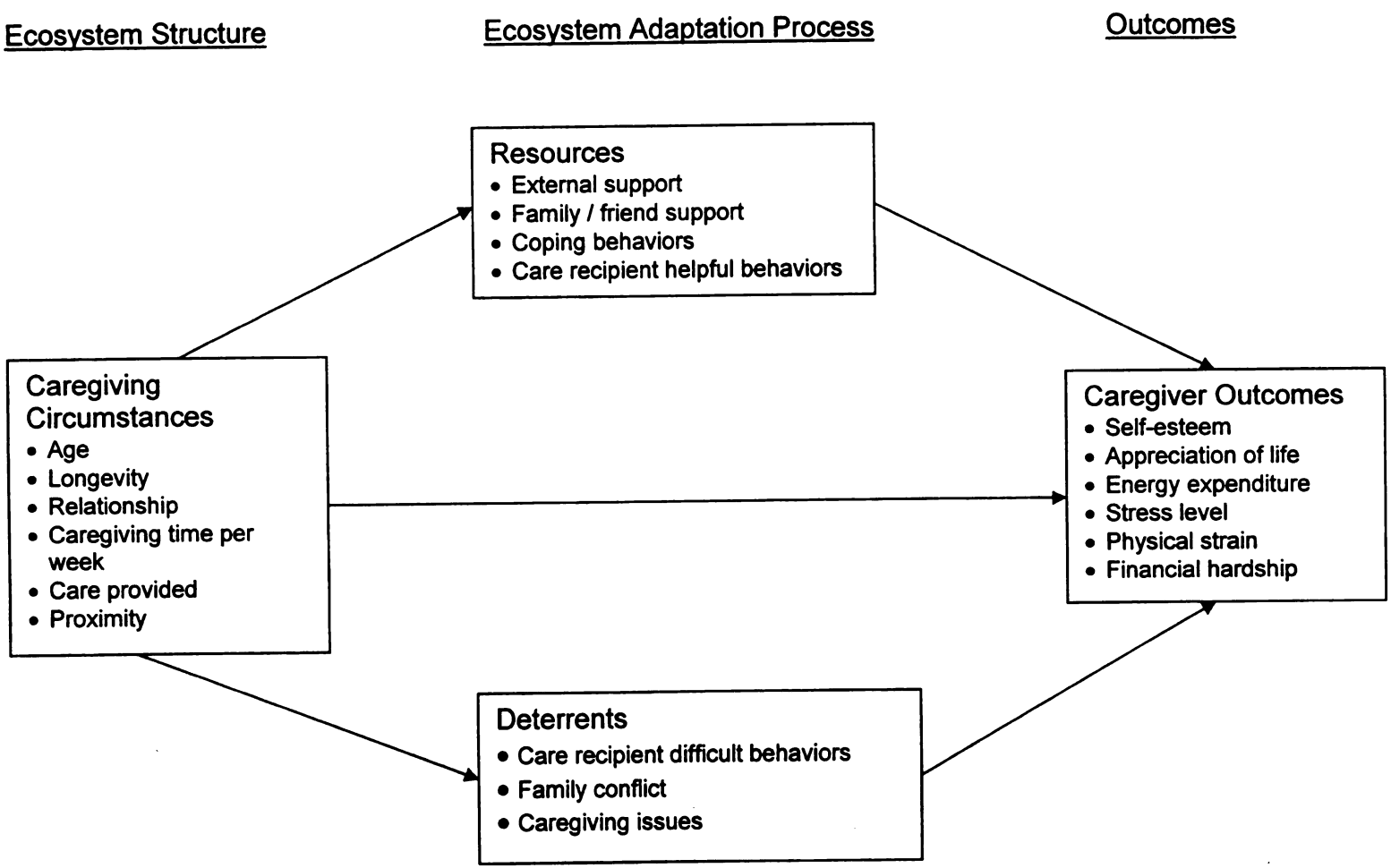
Life Course Perspective

A life course perspective provides the opportunity to view the family dynamics at different points in time. This perspective emphasizes the importance of time, context, process, and meaning of family life (Bengtson & Allen, 1993). Time was previously addressed in relation to ecological concepts. Time from a life course perspective considers individual time, generational time, and historical time (Price, McKenry, & Murphy, 2000). Individual time relates to the stage in which adult children are channeled into the caregiver role. Generational time refers to the rank order of positions held in the family, indicating that the adult child is in the following generation for provision of care for the elderly parent. Historical time focuses on societal or macro level changes over time, which could influence external resources and economics of caregiving.

The social structural context influences the caregiving process through the caregiving circumstances, the resources of support, family or friend support, and family conflict. The context also can refer to the cultural values and norms that may affect the caregiving experience. Lastly, meaning is related to the perception or appraisal of the situation. The degree to which one can create meaning of the situation or events can relate to the feeling of satisfaction regarding the outcome.

Kramer (1997a) suggests a conceptual model (see Figure 1) for caregiver adaptation that includes three primary domains including background and context, intervening processes, and well-being outcomes. Care recipient and caregiver characteristics and the context of the caregiving situation play a central role in understanding all other aspects of the caregiver's experience (Kramer & Kipnis, 1995). The context also includes the stressors that the caregiver must manage for adaptation to the situation. The nature and duration of the health condition of the care recipient can influence the resources that will be needed. Other role responsibilities, such as parenting or employment, can compound issues for the caregiver. Another component of the model is the intervening process, which includes the resources utilized. Internal resources can include coping strategies, and external resources are factors such as social support and respite services. Lastly, outcomes in the Kramer model can be positive or negative factors. Kramer (1997a) suggests that predictors of positive outcomes should include environmental mastery, personal growth, purpose in life, and self-acceptance.

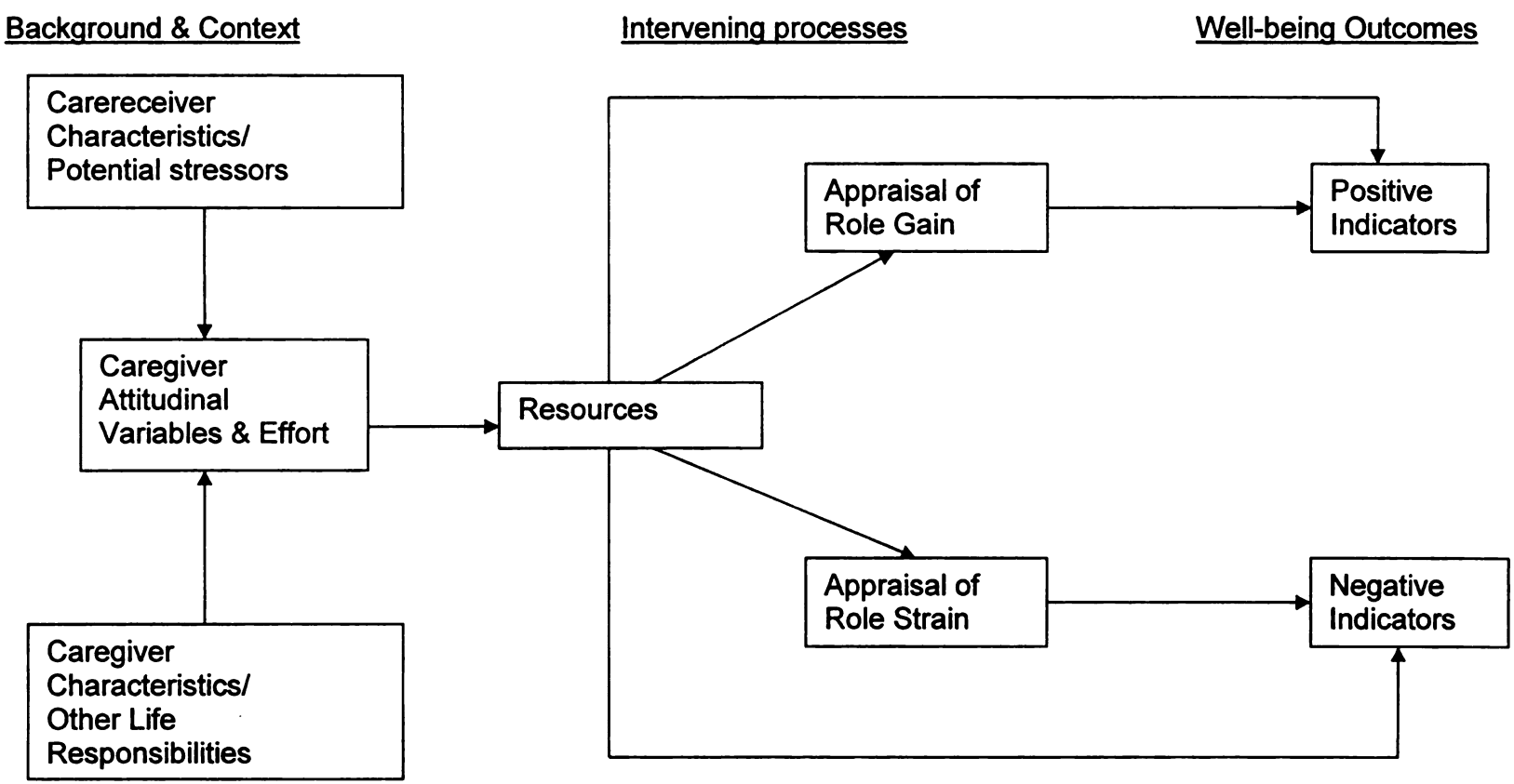
Figure 2. A Conceptual Model of Predictors in Elder Care by Adult Children



Conceptual Model

Figure 2 represents the conceptual model for this study. It is an adaptation of Kramer's model that also considers family ecology theory and the life course perspective. This conceptual model integrates this study's variables and research questions.

Figure 1. A Conceptual Model of Caregiver Adaptation



Note. From "Gain in the caregiving experience: Where are we? What next?" by B. Kramer, 1997a, *The Gerontologist,* 37(2), p. 229.

Assumptions

Assumptions of the Human Ecology Theory

The following assumptions of the human ecology theory are from Bubolz and Sontag (1993):

1. The properties of families and the environment, the structure of environmental settings, and the processes taking place within and between them must be viewed as interdependent and analyzed as a system.
2. As human groups, families are part of the total life system, interdependent with other forms of life and the nonliving environment.
3. Families are semi-open, goal directed, dynamic, adaptive systems. They can respond, change, develop, and act on and modify their environment. Adaptation is a continuing process in family ecosystems.
4. All parts of the environment are interrelated and influence each other. The natural physical-biological environment provides the essential resource base for all of life; it is influenced by the social-cultural and human-built environments and also influences these environments.
5. Families interact with multiple environments.
6. Families are energy transformation systems and need matter-energy for maintenance and survival, for interactions with other systems, and for adaptive, creative functioning. Information organizes, activates, and transforms matter-energy in the family ecosystem.

7. Interactions between families and environments are guided by two sets of rules: physical and biological laws of nature, such as the laws of thermodynamics, that are related to matter-energy interconversion and entropy; and human-derived rules, such as social norms, that are related to use and allocation of resources, role expectations, and distribution of power. Families can contribute to changing human-derived rules. An ecosystem perspective on the family requires that both sets of rules be taken into account.
8. Environments do not determine human behavior but pose limitations and constraints as well as possibilities and opportunities for families.
9. Families have varying degrees of control and freedom with respect to environmental interactions.
10. Decision making is the central control process in families that directs actions for attaining individual and family goals. Collectively, decisions and actions of families have an impact on society, culture, and the natural environment.

Assumptions of the Life Course Perspective Theory

The following assumptions from the life course perspective theory are from Bengston and Allen (1993).

1. Change in behaviors relate to interactions and identities in ontogenetic time, generational time, and historical time.
2. Social context influences social structure and the social creation of meanings in interpreting change over time.

3. Processes must be examined over time.
4. There is diversity in structure, aging, and response modalities in families.

Assumptions of this Study

1. Adult children make decisions and choices to care for their elderly parent(s) based on a consideration of alternatives, costs, benefits, the caregiving circumstances, available resources, and potential deterrents.
2. Adult children prefer to provide care to their elderly parent(s) and avoid institutionalization.
3. Resources are available for intergenerational caregiving.

Rationale for the Present Study

A review of the literature revealed that there has been ongoing descriptive research regarding caregiver burden. While several studies describe the attributes of the caregiver, care recipient, and caregiving circumstances, this study will contribute by determining whether there is a relationship between caregiving circumstances, resources, deterrents, and outcomes. Although some recent studies have begun to reveal the positive outcomes of caregiving experiences, there are very few studies that include both positive and negative outcomes of caregiving. This study investigated predictors of positive and negative outcomes. Furthermore, there are few studies that address men or children in-law as caregivers. This study included these caregiver types and determined if there were differences among these groups. Additionally, this study determined if there was a difference in caregiving outcomes during the length of the caregiving experience.

Study Type and Limitations

Polit and Beck (2004) describe secondary analysis as involving the use of data gathered in a previous study to test new hypotheses or explore new relationships. In some studies, researchers collect far more data than are actually analyzed. Secondary analysis of existing data is efficient and economical because data collection is typically the most time-consuming and expensive part of a research project.

A number of opportunities are available for making use of an existing set of quantitative data. Variables and relationships among variables that were previously unanalyzed can be examined. The secondary analysis can focus on a particular subgroup rather than on the full original sample. The unit of analysis can be changed if the data have not been aggregated to yield information about larger units of analysis. A large data set provides greater reliability due to the sample size (Polit & Beck, 2004).

Several preparatory activities are necessary when performing secondary data analysis (Polit & Beck, 2004). After determining the research questions and identifying data needs, identification, location, and gaining access to appropriate data sources are necessary. A thorough assessment of the identified data sets in terms of their appropriateness for the research questions, adequacy of data quality, and technical usability of the data also is required. The policies regarding public use of the data set must be reviewed.

The National Long Term Care Survey (NLTCS) provides a wealth of data and multiple variables of interest to determine relationships that predict the

outcome of intergenerational caregiving experiences. Even though secondary data analysis is an efficient and economical method, the use of secondary data limits the variables available for analysis to those from the original research. Because this researcher did not play a role in developing the survey tool or in collecting the data, there is some deficiency in the data set. Particular areas of interest or variables that would have benefited this study include: ethnicity of the caregiver, the values and beliefs of the caregiver, other life stressors that the caregiver may be experiencing unrelated to the caregiving experience, the quality of the caregiver's marital relationship (if married), the effect of the caregiving circumstances on other immediate family members, and subjective reasons for and benefits of intergenerational caregiving. The NLTCS is a longitudinal study, but the caregiver component was administered twice thus far at a ten-year interval. Because a majority of caregiving experiences do not last ten years, a cross sectional set of caregiving variables was used in this study. A comparison could not be made of the same caregiver over time. However, there are many caregiver dyads in the study representing various lengths of time of caregiving. Despite the lack of some interesting variables that could contribute to the caregiving body of knowledge, the potential benefits of the study with a large national data set can provide insights not otherwise available.

CHAPTER 2

Review of the Literature

This chapter presents a review of studies that examine caregiving of elderly parents by adult children. The review of literature is organized by caregiver and care recipient characteristics and components of the conceptual model: caregiving circumstances, resources, deterrents, and outcomes.

Caregiver Characteristics

Family members provide eighty percent of all care to elders (Westbrook, 1989). Most elderly care is provided by the adult daughter or the care recipient's spouse (Brody, 1985; Brubaker, 1990; Checkovich & Stern, 2002; Cicerelli, 1993; Dyer & Coward, 1991 & 1992; Horowitz, 1985; Neal, Ingersoll-Dayton, and Starrels, 1997; Pohl, Boyd, & Given, 1997; Stone, Cafferata, & Sangl, 1987). When a son's parent requires care, the son's wife usually becomes the caregiver (Globerman, 1996). In general, adult caregivers do not prepare, plan, or anticipate events associated with caregiving (Archbold, Stewart, Greenlick, & Harvath, 1990; Archbold et al., 1995; Horowitz, 1985; Pohl, Given, Collins, & Given, 1994; Tennstedt, 1999). Adult children are more likely to provide help to parents if they are: women (Dwyer & Coward, 1992); divorced, widowed, or never married (Stoller, 1983); the oldest child (Hanson, Sauer, & Seelbach, 1983); live nearby (Finley, Roberts, & Banham, 1988); or are the only child (Coward & Dwyer, 1990). Daughters are more likely to provide personal care (Chang & White-Means, 1991; Dwyer & Coward, 1991; Horowitz, 1985). Sons

are more likely to provide assistance with home repair and finances (Stoller, 1990).

Checkovich and Stern (2002) studied shared caregiving responsibilities of adult siblings using the National Long Term Care Survey. They found that women provided more care than men, distant offspring provided less care, full-time employment reduced care provided, and larger families meant less care was provided by any given sibling.

Much of the caregiving literature has focused on the caregiving daughter. While daughters typically provide a vast amount of care to elderly parents, children-in-law do provide a small proportion of care. Brody (1990) indicates that the daughter-in-law has less emotional involvement and less sense of responsibility as compared to daughters. The daughter-in-law has fewer feelings of reciprocity in caregiving. The role of the spouse (son) is central in this caregiving relationship. In a more recent study, Peters-Davis, Moss, and Pruchno (1999) found that the relationship with the elder was not significant in caregiving outcomes, but it was the quality of the relationship with the elder parent-in-law that consistently affected outcomes. The appraisal of the caregiving experience was found to be very similar for biological children and children-in-law.

Adult caregivers are recognized as juggling many roles, including spouse, parent, and employee. This is especially true of daughters, who continue to carry much of the responsibility of traditional roles. Mui (1995) found a greater complexity in the responsibilities and number and types of roles of the daughters

as caregivers. Voydanoff and Donnelly (1999) studied the multiple roles of the caregiver and the relationship to psychological distress. The roles investigated included caregiver, employee, spouse, and parent. Caring for an elderly parent increased psychological distress. Role satisfaction in the roles of employee and spouse reduced psychological distress, but role strain associated with these roles increased distress. The parent role was unrelated to distress.

On the other hand, some studies show that additional roles do not cause significant increases in the distress or strain in middle-aged women (Dautzenberg et al., 1999; Spitze, Logan, Joseph, & Lee, 1994; Stoller & Pugliesi, 1989). The subjective evaluation of the caregiver role affects the distress of the caregiver more than the time spent in caregiving. Women with multiple roles appeared to have better or similar physical health, mental health, and mortality risk as compared to women performing fewer roles (Adelmann, 1994; Dautzenberg, et al.; 1999, Froberg, Gjerdingen, & Preston, 1986; Jones, Jaceldo, Lee, Zhang, & Meleis, 2001; Spitze et al., 1994; Waldron & Jacobs, 1989). This is similar to other studies that indicated the significance of the quality of roles rather than the occupancy of multiple roles (Barnett & Baruch, 1985; Parris Stephens & Townsend, 1997).

Employment of daughters is a factor in the type of care provided, but not the amount of care. Many are forced to reduce or leave employment to take on the caregiving role (Haley, 1997). Studies on caregiver role related to employment yield inconsistent findings. The conflict between a daughter's employment and the caregiving role potentially affects the caregivers' sense of

satisfaction with the caregiving role (Robinson, 1997). Spitze, et al. (1994) found that the caregiving role had no significant effect on distress and subjective family burden. Stoller and Pugliesi (1989) found that employed caregivers had increased subjective care burden only when employment was combined with many hours of caregiving. However, Stoller and Pugliesi also found that employed caregivers who provided many hours of assistance had higher levels of well-being. Stephens and Franks (1995) studied the relationship between daughters' roles as wife and caregiver. Negative experiences in either of these roles interfered with both roles. On the other hand, positive experiences in one role were found to enhance both roles. Also, positive experiences were more frequently related to caregiver well-being than negative experiences. Current societal trends that require a dual income emphasize career responsibility and meeting of personal needs are in conflict with traditional values of caregiving.

Much of the literature focuses on the primary caregiver and tends to obscure the involvement of or consequences to the entire family unit. Caregivers seek assistance to balance safety needs for the parent with caregiver needs for personal and marital fulfillment (Piercy & Blieszner, 1999). No significant association was found between the daughter as caregiver and distress and feelings of being over-burdened by family responsibilities (Spitz, Logan, Joseph, and Lee (1994). Martire, Stephens, and Franks (1997) found that caregiver role adequacy was positively related to family cohesion and marital satisfaction. Wife role adequacy had a positive effect on family cohesion, and mother role adequacy predicted less negative effect on family cohesion. Lieberman and

Fischer (1995) reported negative effects on both mental and physical health of the caregivers' spouse and offspring.

Other members of the caregivers' family also should be considered when there is simultaneous caregiving of children and parents. Lieberman and Fischer (1995) indicate that health effects on others in the caregiver's family are relatively unknown. Beach (1997) found a positive effect on adolescent relationships. The results include increased sibling activity and sharing between siblings, with the caregiving parent, and the care recipient grandparent. The adolescent gained greater empathy, compassion, and patience for the elderly. There was a significant increase in the bonding between the adolescent and the mother who was the most frequent caregiver. Lastly, it was found that peer relationship selection and maintenance was influenced by the caregiving experience. Peers were selected that were more empathetic, open, and objective. In another study, a positive effect of elder caregiving on adolescent relationships was identified (Farran, 1997). The positive result occurred in relationships or experiences such as increased sharing of activities with siblings, greater empathy for older adults, increased mother and adolescent bonding and a tendency to select empathetic peers for support.

The relationship of education to positive and negative perceptions of caregiving is unclear. Miller and Lawton (1997) provide some reasoning for a relationship between education and caregiving perceptions. More highly educated people may have higher expectations of their own and others' behavior in relation to caregiving. Additionally, higher education may likely result in a

greater investment of self in other roles and greater resentment of caregiving intruding on these roles. The pressures of daily life among the less educated may enable them to accept the demands of caregiving as one of many expected demands in their life.

Care Recipient Characteristics

The type and trajectory of the elder's illness also affects caregiver outcomes. Marchi-Jones, Murphy, and Rousseau (1996) reported that there was a statistically significant negative relationship between care recipient's cognitive function and caregiver strain. As the elder's cognitive function declined, the caregiver's level of strain increased. Additionally, witnessing the decline in health or cognition, suffering and death of a parent as care recipient was found to be among the most traumatic aspects of caregiving (Haley, 1997).

The care recipient's educational level may have a relationship with care provision. Checkovich and Stern (2002) found that a parent's higher level of education was related to less care by an adult child, apparently the result of greater financial resources and career responsibilities.

Caregiving Circumstances

Cicirelli (1983) examined the interpersonal relationship and the helping relationship between the parent and adult child caregiver. He found that the parent-child bond or attachment strongly influenced the commitment to care for an elderly parent. A sense of duty or obligation was a less frequent reason for providing care. Stronger attachment related to less subjective caregiver burden, whereas stronger obligation related to greater caregiver burden. Pohl, Boyd,

Liang, & Given (1995) also found the strength of the mother-daughter relationship related to the instrumental and affective commitment to the caregiving experience. Yet, caregiving also can improve relationships. As a result of assuming a caregiving role, about one third of caregivers reported an improvement in their relationships with their parent(s) (Ziemba, 2002).

Dellmann-Jenkins, Hofer, and Chekra (1992) conducted a five-year review of the caregiving literature. They found considerable demands and stresses associated with caregiving. The length of caregiving is expected to become more long-term, and demands of parent care were predicted to increase as the length of caregiving increased. For both daughters and sons, there was a strong association between the amount and type of caregiving tasks and time taken off from work, which in turn raised caregiver stress (Starrels et al., 1997). Yet, "the subjective evaluation of the caregiver role and not the number of hours of help affected distress of caregivers" (Dautzenberg, Diedricks, Philipsen, & Tan, 1999).

Caregiving Resources

External support from professionals can assist family caregivers and have a positive influence on the caregiver and the care recipient. Heinrich, Neufeld, and Harrison's (2003) qualitative study of caregiving women of elderly family members with dementia provided indications of influences and results of interaction with professional support. The perceived assistance with the caregiving role or direct assistance with the care recipient influenced the interaction with the professional. However, because of beliefs that women are responsible for caregiving and are the best caregivers, the caregivers were

vulnerable to a sense of failure when they sought external support. Heinrich, Neufeld and Harrison also found that women were hesitant to seek external support because of beliefs that external resources are scarce and that public resources should be available only to those who need them most. Mutuality of decision making related to caregiving is important for family caregivers when seeking external support and maintaining the relationship with the external support professionals, and there were negative outcomes in the relationships with external support when mutuality in decision making did not occur (Guberman & Maheu, 2002; Heinrich, Neufeld, & Harrison, 2003; Ward-Griffin & McKeever 2000; Walker & Jane Dewar, 2001). Results indicate that the emphasis should be on mutual interaction for caregiving decisions, facilitation of caregiving, and care recipient empowerment (Heinrich, Neufeld, & Harrison, 2003).

Furthermore, Greenberger (2003) reported that quality caregiving can coexist with burden, provided that ample caregiver resources are present. The most important resources were caregiver sense of competence and professional support. Social support has been shown to counteract stress and to strengthen caregivers' role performance (Braithwaite, 2000). Social support and self-esteem were found to moderate the effects of caregiving stress on distress (Stoller & Pugliesi, 1991).

In a review of the literature on family caregiving in later life, Brubaker (1990) found that families provided extraordinary care and that they were reluctant to use assistance outside of the family. Dwyer, Henretta, Coward, and

Barton (1992) reported that cooperation among siblings is an important factor in the initiation and continuation of care by offspring. Emotional support from siblings was found to mediate caregiver strain (Horowitz, 1985).

Spousal support is important in parental caregiving. Brody (1992) reported greater well-being for married caregivers as compared to unmarried counterparts. Franks and Stephens (1996) found that for caregiving wives, support from their husbands had a positive effect on marital satisfaction regardless of the amount of caregiving stress. Suitor and Pillemer (1994) studied intergenerational family caregiving and marital satisfaction during the first year of care. Changes in the marital satisfaction were related to the degree of emotional support from the husband of the caregiver. Emotional support was affected by the husbands' perception that caregiving interfered with the wives' ability to perform their own traditional family roles. The husbands' emotional support was more significant than instrumental support in the transition to caregiving. The husbands' instrumental support was not related to changes in their wives' marital satisfaction.

Subsequently, Suiter and Pillemer (1996) studied sources of support and interpersonal stress in married caregiving daughters over a two-year period. Sources of emotional support came primarily from friends, especially those who had previously cared for a family member, and sources of instrumental support and interpersonal stress came from siblings. High levels of emotional and social support are inversely related to distress and depression and are directly related to higher levels of satisfaction (Franks & Stephens, 1996).

Coping strategies are another resource to caregivers. Wilcox, O'Sullivan, and King (2001) compared caregiving wives and daughters and found that the three most commonly used coping strategies were the same for both groups. These coping strategies were counting their blessings, problem-focused coping, and seeking social supports. Atienza, Stephens, and Townsend (2002) examined the effect that dispositional optimism had on the stresses of caregiving and found that daughters with higher levels of optimism also attained higher scores of psychological well-being.

Another potential resource to caregivers is the provision of help from the elderly parent receiving care. Ingersoll-Dayton, Neal, and Hammer (2001) found that the receipt of help from the elderly care recipient was associated with costs and benefits. Receiving help was beneficial in terms of the quality of the relationship and self-appraisal of caregiving performance. Emotional support was consistently the most beneficial form of assistance. Tangible supports of financial, child care or household chore assistance were not consistently recognized as beneficial for daughters and sons. The caregivers experienced reduced work effectiveness in their own employment while being concerned about the parents' well-being and the support being provided. In addition to the quantitative measures, qualitative results of focus groups in the study described a range of caregiver feelings including dependence, sadness related to decreased helpful ability, frustration when assistance was inadequate, annoyance with unsolicited help, and a desire to protect the parent's sense of usefulness by finding helpful behaviors for the parent to perform.

Caregiving Deterrents

Starrels, Ingersoll-Dayton, Dowler, and Neal (1997) found that the parent's cognitive and behavioral impairment was more strongly related to employed caregivers' stress than the parent's physical impairments. The parent's ability to assist in his or her own care reduced caregiver stress.

Brody (1989) found that 45-60% of caregivers received as much help as they felt they should from siblings. Caregiving responsibilities are no longer shared when conflict between siblings becomes too great (Matthews & Rosner, 1988).

Caregiving Outcomes

The degree of the positive or negative nature of caregiving may be determined by the subjective appraisal of the caregiver. "Caregiver appraisal refers to the process by which a caregiver estimates the amount or significance of caregiving" (Hunt, 2003, p. 30). Oberst, Gass, and Ward (1989) defined caregiver appraisal as the caregiver's assessment of both the nature of the stressor and his or her resources for coping with it. Caregiver appraisal consists of subjective cognitive and affective appraisals of the potential stressor and the efficacy of one's coping efforts (Lawton et al., 1989). Caregiver appraisal can be positive, negative, or neutral feelings about the caregiving experience. Caregiver appraisal has been proposed as a mediator of burden and outcomes. Pot, Deeg, & van Dyck (2000) found that caregiver appraisal was a direct indication of psychological distress regardless of such factors as coping and social support. The caregiver may discontinue care as a result of distress from negative

caregiver appraisal (Weitzner et al., 1999). On the other hand, positive caregiver appraisals have been proposed as mediators of outcomes. Feelings of preparedness, level of caregiver self-esteem, and how well one feels about the caregiving situation have been shown to be positively related to improved psychological outcomes in caregivers of elders and those with cancer (Archbold et al., 1990; Lawton et al., 1989; Given et al., 1992; Kurtz, Given, Kurtz, & Given, 1994; Kurtz, Kurtz, Given, & Given, 1995; Nijboer et al., 1999a, b). Examining the effect of caregiving using caregiving appraisals indicates which of the caregiving concepts are present in the role relationship. In a study of caregivers of advanced cancer patients in Australia, Aranda & Hayman-White (2001) found that caregivers' appraisals were a more important determinant of outcomes than were objective indicators such as the patient's symptoms or dependence. The caregiver's appraisal of the degree of satisfaction with the caregiving experience can differentiate as to whether intergenerational caregiving continues or extended care facility placement is sought (Kasper, 1990).

As the demands of caring for an elderly parent accelerate, women experience a negative effect on their personal health (Lee & Porteous, 2002). With greater longevity of caregiving, it is often physically and emotionally draining (Foley, Tung, & Mutran, 2002). The following specific functional consequences of caregiving have been identified: depression, disturbed sleep, social isolation, family conflict, career interruptions, financial difficulties, lack of time for self, decreased physical health, impaired immune function, physical and emotional

strain, and feelings of anger, guilt, grief, anxiety, hopelessness, helplessness, and chronic fatigue (Acton, 2002; Larrimore, 2003).

Most of the caregiving literature has focused on caregiving burden. Brody (1985) initiated much of this work by describing parent care as a normative, but a stressful family experience for the caregiver and family. Yet, more recent studies have conflicting results. Middle aged caregiving women did not have significant distress levels (Dautzenberg, Diederiks, Philipsen, & Tan, 1999; Spitze, et al., 1994). In these same studies, caregivers became more distressed when their own health deteriorated, they lost a spouse, and the quality of the relationship with the parent decreased. In Brubaker's literature review, several studies found that wives experienced greater subjective caregiver burden than husbands early in the caregiving experience. Stress on the marriage of caregiving daughters was evident in some studies. Mui (1995) studied emotional strain in adult sons and daughters, and the daughters experienced higher levels of emotional strain than sons.

Caregiving burden is viewed differently across studies. For most Caucasians, caregiving burden is equivalent to a negative meaning and outcome for the caregiver (Lim, et al., 1996). Lim, et al. discuss measurement of family caregiving burden. When the value of family exceeds the individual self, positive feelings can result. One may feel that she is carrying out her duty. Additionally, family values and bonds can serve a positive and protective function. Strong family bonds and social networks can support and buffer the caregiving experience. There also may be a greater distribution of caregiving responsibility

among family members. When family is valued, the responsibility of elder care is evident, and this sense of responsibility may decrease perceptions of burden.

The value of independence, rather than family interdependence, also will affect one's view of caregiving. Caucasians strongly value independence, causing the elderly Caucasian parent to recognize himself or herself as a burden to his or her family (Henderson & Gutierrez-Mayka, 1992).

Finding meaning in the caregiving experience seems to relate to the caregiving outcome. Farran, Keane-Hagerty, Salloway, Kupferer, and Wilkin (1991) conducted a qualitative study of caregivers of elders with dementia. Six themes were identified that led to finding meaning in caregiving as a positive psychological variable. The qualitative data were used to construct a quantitative scale, the Finding Meaning Through Caregiving Scale, to assess positive aspects of and ways of finding meaning through caregiving (Farran, Miller, Kaufman, Donner, & Fogg, 1999). Additionally, caregivers who are able to find higher levels of meaning had lower depression scores (Farran, Miller, Kaufman, & Davis, 1997). Ayers (2000) conducted a qualitative study, which described the processes used by caregivers in creating meaning, and how meaning was related to the caregivers' more general ideas about themselves. The process of making meaning helped to make sense of the caregiving experience and to understand their affective responses. Making meaning through caregiving included expectations (predictions of events), explanations (reasoning to account for discrepancies among expectations and actual events), and strategies (actions taken to actualize expectations). Ayers recommended that further studies are

needed to determine which methods of making meaning predict risk for negative outcomes in caregivers.

Improved family relationships are another potential benefit of caring for elderly parent(s). Farran, Keane-Hagerty, Salloway, Kupferer, and Wilken (1991) reported that 90% of caregivers valued positive aspects of the family and the social relationship, the care recipients' love for them, the positive relationship that they experienced with the care recipient, memories of and accomplishments with others, feeling appreciated by the care recipient and feeling good about the quality of care they were providing. Tennstedt (1999) describes an unrelenting positive influence on aspects of caregiver burden as related to the quality of the relationship between caregiver and care recipient. Acton (2002) explains that caregiving can be a source of strength and personal growth.

McLeod (1999) describes the need to internalize the caregiving experience in terms of life goals and the importance of family caring relationships to grow from the event. By caring for elderly parents, the adult child is considered to gain maturity and wisdom for his or her own later life, becoming better prepared for his or her own later years. Reciprocity for care provided earlier in life also may be a life goal in the caregiving circumstances. Caregiving of elderly parents may provide added value after the parent's death in fulfilling a commitment or sense of duty. Underlying benefits for the caregiver may be rewarding memories or avoidance of guilt after the death of the parent.

Caregiver gain is "the extent to which the caregiving role is appraised to enhance an individual's life space and be enriching" (Kramer, 1997a, p. 219).

Caregiver gain may include anything positive resulting from the caregiving experience. Based on a literature review, Kramer (1997a) proposed that a model of caregiver adaptation in which appraisal of the gain from the caregiver role is an intervening process through which other variables act to influence caregiver well-being. A relationship also was found between caregiver coping and social support and caregiver gain. Yet, the nature of the relationships needs further study. Rapp & Chao (2000) found that caregiver gain moderated the relationship between stress and negative affect, and the effects of caregiver gain were independent of negative appraisal of caregiver strain. Caregiver gain has been recognized as event specific and role specific. Event specific gain includes those responses to specific caregiving tasks, while role specific gain relates to the assessment of the caregiving role. Caregiving strain and gain are often treated as opposites on a continuum when they may actually be related outcomes or independent of each other (Kramer, 1997b).

"Caregiver esteem is the extent to which performing caregiving enhances the caregiver's self-esteem" (Hunt, 2003, p. 29). As a direct result of caregiving, the caregiver feels a sense of confidence or satisfaction. In two separate studies, caregiver esteem was inversely related to depression (Given et al., 1992; Nijboer et al., 1999a; 1999b). Nijboer, et al. (2000) reported that caregiver esteem decreased over time while in the caregiving role and that female caregivers were more likely than were male caregivers to report decreased caregiver esteem over time.

A benefit for the elderly is the potential for a more positive well-being (Riedel, Fredman, & Langenberg, 1998). In a national survey (National Alliance for Caregiving & American Association of Retired Persons, 1997), 57% of family caregivers described their experiences positively, using terms such as "rewarding" or "enjoyable," and they identified benefits including: pride in doing a good deed, improving the quality of life, making the elder parent happy, and earning the parent's gratitude. Based on 1982 data of the National Long Term Care Survey (NLTCS), caregivers reported heightened self-esteem as a result of providing care (Select Committee on Aging, 1987). Caregiving can provide caregivers with opportunities to feel proud and competent (Hasselkus, 1988). Motenko (1989) reported that dementia caregivers could experience gratifications associated with reciprocity and giving tender, loving care.

Cohen, Gold, Shulman, and Zucchero (1994) identified enjoyable aspects in caregiving as listed by the caregiver. The positive aspects included those related to the relationship itself and the desire to see positive outcomes for the care recipient. Additional factors that related to enjoyment were caregiving because of love and a sense of duty. Caregiving mastery and satisfaction with the caregiving activity were identified less frequently.

Caregiver satisfaction is one of the most common terms used to address the positive aspects of caregiving (Kramer, 1997a). Caregiver satisfaction has been defined as "the benefits accruing to the caregiver through his or her own efforts" (Lawton, Kleban, Moss, Rovine, & Glicksman, 1989, p. P64). Later, Lawton, Moss, Kleban, Glicksman, and Rovine (1991) defined caregiver

satisfaction as "subjectively perceived gains from desirable aspects of or positive affective returns from caregiving" (p. P182). An additional definition is that caregiver satisfaction is "the result of caregiving experiences that give life a positive flavor" (Lawton, Rajagopal, Brody, & Kleban, 1992, p. S157). Even though definitions differ, caregiver satisfaction is related to positive affect, to burden, and to stress, and it may have differential effects in predicting negative and positive affective consequences in caregivers (Lawton et al., 1989; Lawton et al., 1991).

The caregiving role and tasks are perceived differently by various caregivers. The demand to provide care is not a stressor itself, and not all caregivers perceive the role as stressful or burdensome (Lawton et al., 1989). Distress levels are lower among those caregivers who view themselves as effective caregivers and their tasks as satisfying. Low caregiver depression has been associated with optimism and coping responses characterized by solving problems, seeking information and directly confronting caregiving problems (Hinrichsen & Niederehe, 1994). In a longitudinal study, Dautzenberg, Diederiks, Philipsen, and Tan (1999) examined whether the role of caregiver of an elderly parent affects levels of distress of middle-aged women and whether multiple roles or specific role combinations of caregivers affect distress and caregiver role strain. For middle-aged women, the parental caregiving was not found to have an effect on distress. Female caregivers had a slightly increased distress level, but not significant, when compared to women not providing care. Withdrawal from the caregiver role was associated with a small, but nonsignificant, decrease

in level of distress. Additionally, it was found that middle-aged women were more affected by a deterioration of their own health or the loss of a spouse than by the caregiving role responsibility for their elderly parent. Longitudinally, the caregivers only became more distressed when the caregiving demands became so extensive that they interfered with personal life of the caregiver.

Uplifts and hassles of caregiving have been examined. Kinney and Stephens (1989) defined uplifts as caregiving events that make one feel good, make one joyful, or make one glad or satisfied or "uplifts are daily events that evoke feelings of joy, gladness, or satisfaction" (Kinney, Stephens, Franks, & Norris, 1995). Caregivers' appraisal of daily caregiving tasks is determined to be uplifts or hassles. Uplifts have been hypothesized to buffer the effects of hassles (Kinney & Stephens, 1989). Less caregiving distress was reported when uplifts offset hassles (Kinney et al., 1995).

Perry (2004) conducted a qualitative study of daughters who cared for mothers with dementia and concluded that finding meaning in the caregiving experience rests on the ability to master requisite complexities. These complexities include recalling the memories of the mother and family experience, relearning how to associate with the mother, and readjusting to the caregiving experience accounting for the daughter's feelings and thoughts. This mastery in the caregiving experience has positive connotations.

Summary

In reviewing the literature, it appears that descriptive research clearly provides demographics of the caregiver characteristics. There is some evidence

describing characteristics of the care recipient and the caregiving circumstances and the resources and deterrents of caregiving. Caregiving is a multidimensional construct and has multiple variables that affect its outcome.

Most caregiving research has centered on the negative and detrimental aspects of the caregiving process and experience. However, caregiving is not always a negative experience or considered a burden. "Lack of attention to the positive dimensions of caregiving seriously skews perceptions of the caregiving experience and limits the ability to enhance theory of caregiver adaptation" (Kramer, 1997a, p. 218). In addition to the negative concepts related to caregiving, there has been some emergence of studies in the last decade that have shown the presence and influence of positive aspects of caregiving. Moreover, studies indicate positive experiences and that caregivers do not report negative consequences, burden, or role strain (Cartwright, Archbold, Stewart, & Limandri, 1994; Langner, 1995; Miller & Lawton, 1997; Tennstedt, 1999). Suwa (2002) emphasizes the need to assess the caregiving experience in the context of the caregivers' whole life and to identify burdensome as well as beneficial aspects.

CHAPTER 3

Methodology

This chapter includes an overview of the National Long Term Care Survey (NLTCS) research study and sample, the research objectives, research questions and hypotheses, variables of this study, and research design. An explanation of the data analysis concludes the chapter.

NLTCS Research Study

The NLTCS is a longitudinal survey designed to study changes in the health and functional status of Americans aged 65 and beyond. The NLTCS contains a public dataset from Duke University's Center for Demographic Studies. NLTCS is funded through the National Institute on Aging and Duke University's Center for Demographic Studies. The survey began in 1982, and follow-up surveys were conducted in 1984, 1989, 1994, 1999, and 2004. The surveys are administered by the United States Census Bureau using trained interviewers, and the response rate is above 95% for all waves of the study. The survey population consists of a sample of 35,000 people randomly selected from national Medicare enrollment files in 1982. The sample has been augmented by adding 5,000 people who have passed age 65 in successive surveys. Thus, there is a large nationally representative sample at each point in time. There are supplemental surveys, including the National Informal Caregivers Survey (NICS), which acquires data on informal caregivers. The supplemental surveys are done under subcontract with United States Department of Health and Human Services Assistant Secretary for Planning and Evaluation (ASPE) and the Research

Triangle Institute. The caregiver survey was done in 1989, 1999, and 2004. The 2004 data set was not publicly available at the time of this study.

There are several research projects using the NLTCS data set (Duke University's Center for Demographic Studies, 2005). Researchers generally have examined the health and behavioral factors associated with changes in chronic disability and mortality. The projects generally fall in the following categories: disability trends in the United States elderly population, severe cognitive impairment, changes in Medicare and Social Security expenditures, age- and relationship-specific effects of nutrition and functioning of United States elderly persons and the oldest-old, and methodology for investigation of the evolution of disability and mortality processes. Also, the NLTCS data are used widely by policy analysts and have been cited frequently in the debate over the extent of a revenue shortfall in the Medicare Trust Fund and when the fund might become insolvent. While there has been some research related to the caregiver survey of 1989, the 1999 informal caregiver survey has received very little attention. Considering this, there is a wealth of data to be studied regarding intergenerational caregiving needs.

Sample

The 1999 National Informal Caregivers Survey (NICS), or more informally labeled as the caregiver survey, was used for this study (see Appendix A). The sample includes caregivers of Medicare recipients 65 and older. In 1999, there were 1,600 primary caregivers, and 1,283 caregivers completed the interview instrument. Field staff from the U. S. Bureau of the Census conducted the 1999

Long-Term Care Survey by personal interview during the period August 1999 through November 1999.

The process of caregiver sample selection occurred by first identifying Medicare recipients who were noninstitutionalized and had an impairment or health problem lasting three months or longer requiring care. The responses to the activities of daily living (ADL) and instrumental activities of daily living (IADL) sections of the NLTCS determined the care recipients' level of disability and how they used help to function. Caregivers met two criteria: 1) they were either a relative who was paid or unpaid for providing care or a non-relative who was not paid for providing care, and 2) they provided ADL and/or IADL hours of care. The primary caregiver was the person who provided the most ADL and IADL hours of care. Primary caregiver interviews were conducted in person or by telephone. If the primary caregiver was present during the care recipient's interview for the NLTCS, her or his interview was conducted in person following the community care recipient interview. If the caregiver was not present or the caregiver interview could not be conducted following the care recipient's interview, the caregiver interview was done by telephone at a later date.

Research Design

The design of this study was descriptive, non-experimental and the associations among variables were analyzed with data collected in 1999. A correlational design was used to achieve the objectives. The study involved major categories of independent variables. The first set of independent variables included the intergenerational caregiving circumstances. The intergenerational

caregiving circumstances variables were: caregiver age, the longevity of caregiving, relationship to care recipient, amount of time spent in care giving per week, amount of care provided, and co-residency or geographic distance of caregiver from the care recipient. The second category of independent variables included caregiver resources, which consist of external support, family or friend support, coping behaviors, and helpful behaviors of the care recipient. There was another set of independent variables related to deterrents of caregiving, including care recipient's difficult behaviors, family conflict, and caregiver issues. The caregiver outcomes were examined using six dependent variables: self-esteem, appreciation of life, energy expenditure, stress level, physical strain, and financial hardship. The caregiving resources and deterrents also were considered as variables that mediate the relationship between the intergenerational caregiving circumstances and the caregiving outcome indicators. (See Figure 2)

The unit of analysis in the present study was the caregiver. This study assessed the extent to which the data available are consistent with the model presented in Figure 2. The data were from the National Long Term Care Survey (NLTCS), which is a longitudinal survey from Duke University's Center for Demographic Studies. To utilize the NLTCS, a data use agreement was signed and notarized. Permission for this study was obtained from the Michigan State University Committee on Research Involving Human Subjects (UCRIHS). (See Appendix B.)

Research Objectives

The overall purpose of the study was to determine the predictors of intergenerational caregiver experience. The specific objectives are as follows:

1. Determine which intergenerational caregiving circumstances predict the caregiver outcomes;
2. Determine which intergenerational caregiving resources predict the caregiver outcomes;
3. Determine which intergenerational caregiving deterrents predict the caregiver outcomes;
4. Determine whether resources mediate the relationship between intergenerational caregiving circumstances and the caregiver outcomes;
5. Determine whether deterrents mediate the relationship between intergenerational caregiving circumstances and the caregiver outcomes;
6. Determine whether there is a difference in intergenerational caregiver outcomes when the caregivers are sons, daughters, sons-in-law, or daughters-in-law.
7. Determine whether there is a difference in intergenerational caregiver outcomes when comparing age of the caregiver.
8. Determine whether there is a difference in intergenerational caregiver outcomes when comparing the length of time of the caregiving experience.

Research Questions and Hypotheses

Based on the research objectives, the following research questions and hypotheses were tested. All research questions and hypotheses refer to the

daughter, son, daughter-in-law, or son-in-law who had primary unpaid caregiving responsibility for elderly parent(s). While bivariate analysis is done to determine a relationship between two variables before progressing to a multivariate analysis, Polit and Beck (2004) suggest that multivariate hypotheses can be written when there is a prediction of a relationship between two or more independent variables and/or two or more dependent variables. Because of the multiple variables, multivariate hypotheses are provided. When the literature review does not provide adequate support for a hypothesis, the research question remains without a hypothesis or there are only hypotheses provided that relate to the literature, but not hypotheses for all variables within that category of variables.

1. What is the relationship between the intergenerational caregiving circumstances variables and each caregiver outcome variable?

   Ho 1: Intergenerational caregiving circumstances are unrelated to caregiving outcomes.

   Ha 1: Caregivers who care for their elderly parent(s) more hours per week will perceive increased energy expenditure and an increased stress level.

2. What is the relationship between intergenerational caregiving resources and each caregiver outcome variable?

   Ho 2: External support, family or friend support, caregiving coping behaviors, and helpful behaviors of the care recipient are unrelated to the caregiver outcomes.

Ha 2: Caregivers who receive family or friend support will appraise the caregiver outcome with a decreased stress level.

3. What is the relationship between intergenerational caregiving deterrents and each caregiver outcome variable?

   Ho 3: Care recipient's difficult behaviors, family conflicts, caregiver issues, and cost are unrelated to the caregiver outcomes.

   Ha 3: Caregivers who experience family conflicts will appraise the caregiver outcome with an increased stress level.

4. Do caregiving resources mediate the effects of intergenerational caregiving circumstances on the caregiver outcome variables?

5. Do caregiving deterrents mediate the effects of intergenerational caregiving circumstances on the caregiver outcome variables?

   Ho 5: Caregiving deterrents do not mediate the effect of the caregiving circumstances on the intergenerational caregiver outcome variables.

   Ha 5: Family conflict mediates the effect of the caregiving circumstances on the intergenerational caregiver outcome variables.

6. Are there significant differences in the intergenerational caregiver outcome variables among daughters, sons, daughters-in-law, and sons-in-law?

   Ho 6: There are no differences in the intergenerational caregiver outcome variables among daughters, sons, daughter-in-laws, and son-in-laws.

   Ha 6: Daughters and daughters-in-law will appraise the caregiving outcome with an increased stress level and greater physical strain.

7. Are there significant differences in the intergenerational caregiver outcomes variables according to the age of the caregiver?
8. Are there significant differences in the intergenerational caregiver outcome variables as the length of the caregiving experience increases?

   Ho 1: The length of the caregiving experience is unrelated to caregiving outcomes.

   Ha 1: Caregivers who care for their elderly parent(s) more years will perceive increased energy expenditure and an increased stress level.

Research Variables

This section contains the conceptual and operational definitions of the dependent and independent variables.

Dependent Variables

Self-esteem (caregiver's as a result of caregiving)

Conceptual definition: The degree of worth the caregiver attributes to her or himself.

Operational definition: The caregiver indicated whether providing help to the care recipient has made him or her feel good about her or himself (Likert scale; 1 = disagree a lot, 2 = disagree a little, 3 = neither agree or disagree, 4 = agree a little, 5 = agree a lot).

Appreciation of life (caregiver's as a result of caregiving)

Conceptual definition: The caregiver's value, significance, or worth of life.

Operational definition: The caregiver indicated whether providing help to the care recipient has enabled him or her to appreciate life more (Likert scale; 1 =

disagree a lot, 2 = disagree a little, 3 = neither agree nor disagree, 4 = agree a little, 5 = agree a lot).

Energy expenditure (caregiver)

Conceptual definition: The degree of energy expenditure and time to complete what is expected in caregiving for the care recipient.

Operational definition: The caregiver described how much energy expenditure or time it took to do what was needed in caregiving. The categories included: exhausted when going to bed at night; having more things to do than can be handled; not having time just for herself or himself; and working hard as a caregiver, but never seem to make progress. The possible responses were: 1 = completely; 2 = quite a lot; 3 = somewhat; 4 = not at all. Energy expenditure was measured by four items and the mean score of the four items on a four-point scale indicates the energy expenditure score. The values were reverse coded to achieve low scores indicating lower amounts of energy expenditure and high scores indicating higher amount of energy expenditure.

Stress level (caregiver)

Conceptual definition: The degree of response from a relationship between persons or a person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being (Lazarus & Folkman, 1984).

Operational definition: The caregiver indicated the degree of perceived stress caused by doing all of the things to help the care recipient (10 point scale where 1 is not much stress at all and 10 is a great deal of stress).

Physical strain (caregiver)

Conceptual definition: The degree of the caregiver's physical strain.

Operational definition: The caregiver indicated the degree of physical strain created by caring for the care recipient (5 point scale where 1 = not a strain at all to 5 = very much of a strain).

Financial hardship (caregiver)

Conceptual definition: The degree of financial hardship for the caregiver.

Operational definition: The caregiver indicated the degree of financial hardship created by caring for the care recipient (5 point scale where 1 = no hardship at all to 5 = great deal of hardship).

Independent Variables

Caregiving Circumstances Variables:

Age (caregiver)

Conceptual definition: The number of years the caregiver had been alive.

Operational definition: The caregiver stated his or her age in years.

Caregiving longevity

Conceptual definition: The length of time that the caregiver has cared for the care recipient.

Operational definition: The caregiver indicated when she or he started taking care of the care recipient. Response choices included: 1 = less than 3 months; 2 = 3 months – less than 6 months; 3 = 6 months – less than 1 year; 4 = 1 year – less than 2 years; 5 = 2 years – less than 4 years; 6 = 4 years – less than 7 years; 7 = 7 years – less than 10 years; 8 = 10 years or more. Using the mean of

the response choices, the items will be recoded to be 1 = 0.2 years; 2 = 0.3 years; 3 = 0.8 years; 4 = 1.5 years; 5 = 3 years; 6 = 5.5 years; 7 = 8.5 years; 8 = 10 years.

Relationship (caregiver's relationship to the care recipient)

Conceptual definition: Whether the caregiver was a son or daughter.

Operational definition: The caregiver indicated the relationship.

Caregiving time

Conceptual definition: The number of hours per week that the caregiver provides care for the care recipient.

Operational definition: The caregiver indicated the number of hours that care was provided for the caregiver in a typical week. The total number of hours per week was the caregiving time.

Care Provided

Conceptual definition: The amount of help with physical activities of daily living (ADL), instrumental activities of daily living (IADL), and health care activities that the caregiver provided for her or his elderly parent.

Operational definition: The caregiver indicated the frequency of involvement with ADL, IADL, and health care activities. There was a total score for ADL, IADL, and health care activities. The ADL categories included mobility (assistance with walking or getting around with a wheelchair or similar device inside), eating, getting in or out of bed, getting dressed, bathing, and toileting. Caregiver involvement with IADL included categories of food preparation, financial management, making telephone calls for the care recipient, doing things around

the house (such as straightening up, putting things away, or doing the dishes), laundry, grocery shopping, other small errands outside of the house, mobility outside of the house, and transportation. For health care activities, the caregiver indicated whether she or he provided any of the following health care activities: gave shots or injections, gave medicine, pills, or changed bandages, and assisted with a catheter or colostomy bag. The caregiver indicated yes or no to each item. If yes, the caregiver indicated the frequency that help was provided, stating the number of times per day that help was given in each category. The sum of the individual items' frequency in times per day represented the care provided. High scores indicated more care provided than low scores.

Proximity

Conceptual definition: The proximity of residence of the caregiver to the care recipient.

Operational definition: The caregiver responded as to whether she or he lived with the care recipient or if not living together, the length of time to travel to care recipient's residence. The living proximity was coded as: 0 = caregiver lives with care recipient and all additional coding was in minutes traveling distance from the care recipient's residence to the caregiver's residence.

Resources Variables

External support

Conceptual definition: Whether the caregiver used external support services to assist in the provision of care for the elderly parent.

Operational definition: The caregiver indicated yes or no as to whether any of the following services were used: requested information regarding how to get financial help for care recipient; participation in a support group for caregivers; respite care; adult daycare or senior center service; assistance with personal care or nursing care; housework; meal delivery to home; transportation service; care recipient's home modification(s); and obtained assistive devices. The frequency of yes responses provided a total score for external support. The external support score could range from zero to ten. High scores indicated greater external support services utilized to assist in the provision of care and low scores indicated a lesser amount of assistance from external support.

Family or friend support

Conceptual definition: The degree to which family or friends provide support to the caregiver.

Operational definition: The mean score of family or friend's support. A scale of family or friend's support was created using responses on a Likert scale to questions regarding whether: family or friends understand what caregiver is going through; caregiver feels that family or friends care about her or him; confidence in family or friend's opinion regarding care; caregiver has someone whom she or he can trust; caregiver has family or friend that elevates spirits; caregiver has family or friend that makes her or him feel good about herself or himself; caregiver has family or friend to confide in; and caregiver has family or friend to be with when down or discouraged. The mean score of the eight items with a four-point scale indicated the family or friend's support. High scores

indicated a strong support from family or friends and low scores indicated minimal support from family or friends.

Coping behaviors (caregiver)

Conceptual definition: The thoughts and actions relevant to defining, attacking, and meeting the task (Lazurus & Folkman, 1984)

Operational definition: The caregivers indicated the frequency in which they did the following activities when under stress from caregiving: spend time alone; prayer/meditation; talk with friends or relatives; spend time on exercise or hobbies; watch TV; read; and get help from a counselor or other professional. The mean score of the eight items frequency of use on a four-point scale indicated the coping behaviors score. High scores indicated frequent use of coping behaviors and low scores indicated minimal use of coping behaviors while under stress from caregiving.

Care Recipient Helpful Behaviors

Conceptual definition: Care recipient behaviors that provide help to the caregiver.

Operational definition: The caregiver indicated the behaviors in which the care recipient has been helpful to the caregiver. The behaviors included: helping with household chores; helping with babysitting; buying things for caregiver or giving caregiver money; keeping the caregiver company; and making caregiver feel useful and needed. Response choices for each behavior were yes or no. The total score was the amount of helpful behaviors from the care recipient. The score could range from one to ten. High scores included a greater number of helpful behaviors, and low scores indicated a lower number of helpful behaviors.

Deterrents Variables

Care Recipient Difficult Behaviors

Conceptual definition: The amount and type of difficult care recipient behaviors encountered by the caregiver.

Operational definition: The caregiver indicated the frequency of particular care recipient behaviors that were encountered in the previous week. The behavior categories included: keeping caregiver up at night; repeated questions/stories; tried to dress the wrong way; had a bowel or bladder accident; hid belongings and forgot about them; cried easily; acted depressed or down hearted; clung to caregiver or followed caregiver around; became restless or agitated; became irritable or angry; swore or used foul language; became suspicious, or believed someone was going to harm the care recipient; threatened people; showed sexual behavior or interest at the wrong time/place; and destroyed or damaged property. Responses were 1 = no days; 2 = 1-2 days; 3 = 3-4 days; 4 = 5 or more days. The sum of the score indicated the frequency of care recipient behaviors. The care recipient difficult behaviors score could range from 15 to 60. High scores indicated more difficult care recipient behaviors.

Family conflict

Conceptual definition: The extent of disagreement between the caregiver and other family members regarding the care recipient and the caregiver.

Operational definition: Considering all of the caregiver's relatives, the caregiver indicated how much disagreement had occurred with any family member regarding issues related to the care recipient and caregiver. The caregiver

indicated the amount of disagreement regarding spending enough time with the care recipient; doing share of care for care recipient; showing enough respect for the care recipient; lacking patience with the care recipient; not visiting or telephoning the caregiver enough; not giving caregiver enough help; not showing enough appreciation of the caregiver's work as a caregiver; giving caregiver unwanted advice. For each area of disagreement, a response was given. Response choices included: 1 = no disagreement; 2= just a little disagreement; 3 = some disagreement; 4 = quite a bit of disagreement. The results were summed to create a score for family conflict. The family conflict score could range from eight to 32. A high degree of family conflict was indicated by high scores and a low amount of family conflict was indicated by low scores.

Caregiving issues

Conceptual definition: The number of issues that affected the caregiver as a result of caregiving.

Operational definition: The caregiver indicated whether any of the following were issues related to caregiving: sleep disturbance; caregiving despite not feeling well enough herself or himself; faced with providing specialized health care that was unable or unprepared to give; caregiving limited personal privacy; caregiving limited social life or free time; care recipient required constant attention; caregiver's health declined as a result of caregiving; less time for other family members; and need to give up vacations, hobbies or personal activities. The caregiver issues were summed for a total caregiver issues score. The caregiving

issues score could range from 9 to 18. High scores indicated a high number of caregiving issues, and low scores indicated a low number of caregiving issues.

Reliability Analyses of Variables

Because there were multiple items in some variable measures created by the researcher, it was necessary to validate the reliability with the adult children caregivers used in this study. The reliability was computed using Cronbach's alpha. Polit and Beck (2004) indicate that there is no standard for what a reliability coefficient should be. Yet, if making group level comparison, then coefficients of approximately 0.70 or even 0.60 are probably sufficient. When considering the reliability of variables, criteria were used to determine whether to retain or delete items for the measure. If the alpha was greater than 0.70 and there were not specific items that had low corrected item-total correlation, all items were kept in the measure. If the alpha was less than 0.7, the investigator examined the change in alpha if specific items were deleted from the scale. If an item lowered the alpha, it was deleted from the variable measure. Table 1 shows the alpha coefficients for the various measures created from multiple items. Considering this criteria, no items were deleted from the variable measures. The variable scales had an acceptable level of internal consistency.

Table 1. Reliability Measures of Variables Using Cronbach's Alpha

Measure	Cronbach's Alpha
Family / friend Support	0.91
Coping Behaviors	0.72
Energy expenditure	0.86

There were other measures that had multiple items. The variable was computed by summing the occurrence of the multiple items within the measure. Therefore, reliability measures were not obtained for these items.

Data Analysis

Data analyses were done using the Statistical Package for the Social Sciences (SPSS) version 13.0. The data analyses involved five major components: descriptive statistics, correlations, multiple regression, path analysis, and comparison of means through t-tests and ANOVAs.

Descriptive statistics were computed first. The caregiver sample in this study was described. The adult sons and daughters, sons-in-law, and daughters-in-law who were not paid for providing care were selected for this study. There was an insufficient sample size of unpaid caregiving sons-in-law (n=6) and daughters-in-law (n=39) to be included in this study. Descriptive statistics were used to describe the following adult caregiver characteristics: age, relationship to care recipient, marital status, employment status, health, and family income. Descriptive statistics were used to determine the distributional pattern and characteristics of each of the independent and dependent variables. Frequency tables and descriptive statistics including means and standard deviations were used to inspect the data. This process determined if assumptions were being met for various statistical procedures. It also determined how scores clustered for some variables. Transformation of some

variables occurred based on this information. Reliability analyses were completed for multiple item measures.

Correlations among variables were computed. Correlations were calculated to determine the extent of associations among the predictor variables; associations between the circumstances variables and resources; associations between the circumstances variables and deterrents; associations between the circumstances variables and the caregiver outcome variables; and associations among the dependent variables.

Multiple regression analyses were performed to examine the combined effects of predictor circumstance variables on the resource variables and the effects of predictor circumstance variables on the deterrent variables, and to identify which of the variables are related to the resources and to the deterrents when other variables are controlled. Further multiple regression analyses were performed to examine the effects on the caregiver outcomes. A chance probability level of less than 0.05 was set to reject the null hypotheses.

The multiple regression analyses provided initial analyses and facilitated elimination of the nonsignificant variables for the path analysis. Path analysis was computed to determine which of the predictor variables had a direct or indirect effect on the caregiver outcomes. The path analysis explained whether there was a direct relationship of circumstances, resources and deterrents to the caregiver outcomes and whether the resources and deterrents mediate the relationship between caregiving circumstances and caregiver outcomes.

Additionally, a comparison of groups on the dependent caregiving outcomes was made. The comparison of son and daughter on the caregiving outcomes was made using t-tests. One-way ANOVAs also were computed to test the significance of mean group differences for the caregiving outcomes related to caregiver age and caregiving longevity.

Specific data analysis procedures for each research question follow. Descriptive statistics are provided for each research question to provide comprehensive information needed to understand the statistical analysis.

Research question 1: What is the relationship between the intergenerational caregiving circumstances variables to each caregiver outcome variable?

To determine the relationship between the predictor caregiving circumstances variables and the dependent variables of caregiver outcomes, correlations were computed. Each intergenerational caregiving circumstances variable (age, longevity, amount of time spent caregiving per week, care provided, and living proximity) were computed separately with the caregiving outcome variables (self-esteem, appreciation of life, stress level, energy expenditure, physical strain, and financial hardship).

Research question 2: What is the relationship between intergenerational caregiving resources and the caregiver outcome variables?

To determine the relationship between the predictor caregiving resources variables and the dependent variables of caregiving outcomes, correlations were computed. Each intergenerational caregiving resource variable (external support, family assistance, coping behaviors, care recipient helpful behaviors)

was correlated separately with the intergenerational caregiver outcome variables (self-esteem, appreciation of life, energy expenditure, stress level, physical strain, and financial hardship).

Research question 3: What is the relationship between intergenerational caregiving deterrents and the caregiver outcome variables?

To determine the relationship between the predictor intergenerational caregiving deterrent variables and the dependent variables of caregiving outcomes, correlations were computed. Each caregiving deterrent variable (care recipient difficult behaviors, family conflict, and caregiving issues) was correlated separately with the caregiver outcome variables (self-esteem, appreciation of life, energy expenditure, stress level, physical strain, and financial hardship).

Research question 4 & 5: Do caregiving resources mediate the effects of intergenerational caregiving circumstances on the caregiver outcome variables? Do caregiving deterrents mediate the effects of intergenerational caregiving circumstances on the caregiver outcome variables?

Several stepwise multiple regression analyses were done to determine which of the predictor variables were related to the caregiving outcome variables. Path analysis determined whether there was a direct effect on the outcome variables or whether there was an indirect effect via caregiving resources or caregiving deterrents.

Research question 6: Is there a significant difference in the caregiver outcome variables among daughters, sons, daughters-in-law, and sons-in-law?

Because of an insufficient sample of children-in-law, a comparison of sons and daughters was computed. T-tests were run to examine the differences between sons and daughters on each of the caregiving outcome variables (self-esteem, appreciation of life, energy expenditure, stress level, physical strain, and financial hardship).

Research question 7: Is there significant differences in the intergenerational caregiver outcome variables among caregivers of different ages?

A series of one-way ANOVA analyses were run to examine the differences among different age groups on each of the caregiving outcome variables (self-esteem, appreciation of life, energy expenditure, stress level, physical strain, and financial hardship).

Research question 8: Is there a significant difference in the intergenerational caregiver outcome variables as the caregiving experience lengthens in time?

A series of one-way ANOVA analyses were computed to examine the differences of longevity of care provision on each of the caregiving outcome variables (self-esteem, appreciation of life, energy expenditure, stress level, physical strain, and financial hardship).

Data analysis procedures for each research question are summarized in Table 2.

Table 2. Data Analysis Methods for Each Research Question

Research Questions (Q)	Data Analysis Method
Q 1-8	Descriptive statistics
Q 1-3	Pearson r Correlation
Q 4-5	Stepwise Multiple regression
Q 4-5	Path analysis
Q 6	T-test
Q 7-8	One-way ANOVA

CHAPTER FOUR

Results of Data Analysis

In this chapter, the results of the data analysis are reported. First, characteristics of the sample and the descriptive data are reported. Next, the results of the analyses are reported: bivariate correlations, multiple regression, path analysis, and comparison of groups. Finally, a summary of results is presented.

Descriptive Statistics

Initially descriptive statistics of the care recipients and caregivers were examined. There were some missing items in some cases. Missing responses may have been because respondents did not find some questions relevant to their experience or chose not to answer.

Of the care recipients, there were 82% females and 18% males, ranging in age from 65 to 110 with a mean age of 84. Most of the care recipients were married (58%), and the marital status of the others were widowed (32%), divorced (6%), never married (3%), and separated (1%). A majority of the elderly parents lived in a house or duplex (81%), while others lived in an apartment (12%), mobile home (5%), boarding house (1%), or other (2%). Some of the elderly parents (60%) changed living arrangements at some point during the care experience, and of those who made a change, 50% moved to the caregiver's home, 35% of caregivers (and in some cases their families) moved into the care recipient's home, and 15% moved to a different home. In addition to being Medicare recipients, 24%) reported receiving Medicaid. Social Security

benefits ranged from $49 to $2,270 per month, with a mean of $664 and additional retirement income of $0 to $5,000 per month with a mean of $503. The total income per year of the care recipient and spouse, if present, ranged from less than $3,000 to greater than $100,000, with a mean of $16,000. Data regarding race were missing for the care recipients or could not be matched between care recipient and caregiver across data sets. The race of elderly in the entire NLTCS data set for 1999 included: Caucasian (86%), African-American (6%), Hispanic-American (5%), Asian or Pacific Islander (2%), American Indian, Aleut, or Eskimo (less than 1%), and other (1%).

There were 541 unpaid caregiving sons and daughters in this study, of which 406 (75%) were daughters and 135 (25%) were sons. There were only 45 unpaid sons and daughters-in-law available, leaving an insufficient sample size to statistically analyze the children-in-law. The age of the caregivers ranged from 31 to 93 with a mean of 55. Most of the caregivers were married (56%), and the marital status of the other caregivers were divorced (17%), never married (14%), widowed (9%), separated (3%), or partnered, not married (1%). The caregivers had provided care for less than one hour per week to 168 hours per week, with a mean of 24.9 hours per week. Caregiving duration ranged from less than three months to greater than ten years, with a mean of three years. There were 253 (47%) children who lived with their parents while providing care. Of the remaining caregivers, they described the distance as living from one minute to 30 hours away from the parent, with a mean of 28 minutes. Of the caregivers, 196 (48.3%) of the daughters were employed, working a mean of 37.3 hours per

week, and 78 (57.9%) of the sons were employed, working a mean of 41.9 hours per week. The mean family income of the caregiving sons and daughters was $27,500, and the median family income was $35,000.

The investigator attempted to include as many cases in the analyses as possible. When the method for deriving the multiple item variable was to sum the items, all responses given were summed for all subjects who provided responses. When a variable was measured with the mean of several items, a subject was included when he or she answered more than half of the questions for that variable measure. Table 3 is a summary of the descriptive statistics.

Table 3: Descriptive Data for Each Variable

Variable	# of items	Valid N	Miss-ing	Min.	Max	Mean	SD
Caregiving Circumstances							
Age	1	490	51	31	93	55.28	10.13
Longevity	8	509	32	1	8	5.28	1.90
Relationship	1	541	0	1	2	NA	NA
Caregiving time	1	512	29	0	168	24.94	10.16
Care provided	19	541	0	0	77.14	7.21	6.00
Proximity	1	507	34	0	1800	13.88	88.66
Resources							
External support	10	523	18	0	8	2.01	1.71
Family / friend support	8	505	36	0.13	4.0	2.96	0.72
Coping behaviors	7	502	39	0.14	3.43	2.04	0.59
Care recipient's helpful behaviors	5	508	33	0.0	5.0	2.42	1.41
Deterrents							
Care recipient's difficult behaviors	15	516	25	0.0	59.0	7.84	10.02
Family conflict	8	508	33	0.0	24.0	3.27	5.68
Caregiving issues	9	527	14	0.0	9.0	2.77	2.56
Caregiving Outcomes							
Self-esteem	1	509	32	1.0	5.0	4.30	1.11
Appreciation of life	1	506	35	1.0	5.0	4.29	1.03
Energy expenditure	4	514	27	0.5	4.0	1.84	0.84
Stress level	1	512	29	1.0	10.0	3.59	2.75
Physical strain	1	512	29	1.0	5.0	1.93	1.22
Financial hardship	1	510	31	1.0	5.0	1.74	1.21

Predictor Variables

The demographic variables that were part of the caregiving circumstances were described previously under the descriptive statistics. The remaining variables are described in greater detail in this section.

Type of Care Provided

The care provided was the sum of all caregiving activities. Overall, the caregivers provided the identified activities of daily living to some extent: assistance with mobility, assistance with eating/feeding, getting in and out of bed,

dressing, bathing, toileting, and assisting with a bedpan. The most frequent care provided was assistance with mobility, dressing, and bathing, and for each of these ADLs, the care occurred among at least 25% of the caregivers. Assistance with the instrumental activities of daily living occurred more frequently. Fifty to 70% of caregivers managed finances, helped with things around the house, did the laundry, and transported the care recipient when needed. Over 75% of caregivers obtained groceries and did small errands. Healthcare was undertaken much less among caregivers. Yet, 40% of caregivers did administer medications other than injections. Less than 7% of caregivers administered injections and provided care related to a urinary catheter or colostomy.

Resources

In regard to external support, the primary areas of help that caregivers sought were related to obtaining assistive devices (54%), provision of personal care or nursing care (38%), and making home modifications for the care recipient (24%). There was a high degree of family and friend support (3.0 on a 4.0 scale). However, more than 70% of caregivers agreed or strongly agreed that "there is really no one who understands what you are going through." The coping behaviors that were utilized most often when the caregivers were under stress from caregiving were prayer (45% of caregivers) and talking with a friend or family member (46%). Only 3% of caregivers sought professional help when under stress from caregiving. Care recipients provided helpful behaviors to caregivers, including making the caregiver feel useful and needed (77% of caregivers), keeping company with the caregiver (66%), helping with household

chores (37%), buying things for the caregiver or giving money to offset expenses (36%), and babysitting caregiver's children (12%).

Deterrents

When examining the difficult behaviors reported by caregivers, the behavior of greatest concern (28% of caregivers) was dealing with repeated questions on almost a daily basis. The difficult behaviors that occurred for 1% or fewer caregivers on a routine basis were threatening behavior, demonstrating sexual behavior at the wrong time or place, and destroying or damaging property. The areas that brought the greatest family conflict were when the caregivers felt that other family members did not spend enough time with the care recipient (16% of caregivers) and when family members did not do their share in caregiving (16%). All other family conflict areas occurred less frequently. In regard to caregiving issues, approximately 45% of caregivers identified needing to provide care when they do not feel well enough themselves, having a limitation on their social life or free time, having less time for other family members, and needing to give up vacations, hobbies, and personal activities. Other issues identified less often included lack of privacy (28%), interruption of sleep (24%), and needing to give constant attention to the care recipient (20%).

Outcome Variables

All of the outcome variables except energy expenditure were single item measures with each having Likert scales. The overall caregiver's energy expenditure was near mid-range (mean 1.8 on a 4-point scale) with the

statement that the caregiver works "hard as a caregiver but never seems to make any progress" as the greatest concern among caregivers.

Correlations Among Variables

Pearson correlation matrices were computed to determine the relationship among the caregiving circumstances variables (Table 4); associations between the circumstances variables and resources (Table 5); associations between the circumstances variables and deterrents (Table 6); associations between the circumstances variables and the caregiver outcome variables (Table 7); associations between the resources variables and the outcome variables (Table 8); associations between the deterrent variables and the outcome variables (Table 9); and associations among the dependent variables (Table 10). Polit and Beck (2004) describe that interpreting the strength of the correlation is dependent on the variables being considered: a correlation of greater than 0.5 is considered high; a correlation of 0.3 to 0.5 is considered moderate; and a correlation of 0.1 to 0.3 is of low magnitude.

Table 4. Correlation Matrix of Caregiving Circumstances Variables

	Age	Longevity	Relationship	Caregiving Time	Care Provided	Proximity
Age	1.00					
Longevity	**.10***	1.00				
Relationship	.04	.03	1.00			
Caregiving Time	.04	.02	.08	1.00		
Care Provided	-.01	-.02	.08	**.52****	1.00	
Proximity	-.02	**-.16***	.02	.04	-.05	1.00

** Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

Table 5. Correlation Matrix of Caregiving Circumstances and Resources Variables

	Age	Longevity	Relation-ship	Caregiving Time	Care Provided	Proximity	External Support	Family/ friend Support	Coping Behaviors	Helpful Behaviors
External Support	-.03	**.13****	-.02	**.16****	**.22****	-.03	1.00			
Family / friend Support	-.07	-.01	**.11***	.05	.02	.00	**.14****	1.00		
Coping Behaviors	-.03	-.02	.05	.11*	**.11***	-.03	**.28****	**.17****	1.00	
Helpful Behaviors	**-.19****	.07	.03	**-.12****	**-.14***	**-.12****	-.05	.02	.08	1.00

** Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

Table 6. Correlation Matrix of Caregiving Circumstances and Deterrent Variables

	Age	Longevity	Relationship	Caregiving Time	Care Provided	Proximity	Difficult Behaviors	Family Conflict	Caregiving Issues
Difficult Behaviors	-.02	.03	.07	**.28****	**.44****	-.01	1.00		
Family Conflict	**-.16****	.02	.08	**.19****	**.19****	.02	**.40****	1.00	
Caregiving Issues	-.07	.05	**.12****	**.42****	**.49****	.00	**.59****	**.41****	1.00

** Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

Table 7. Correlation Matrix of Caregiving Circumstances and Outcome Variables

	Self-esteem	Appreciation of life	Energy expenditure	Stress level	Physical strain	Financial hardship
Age	-.02	-.03	-.10*	-.08	.04	-.07
Longevity	-.02	-.02	.03	.05	.08	.07
Relationship	.05	.10*	.11*	.12**	.08	.03
Caregiving Time	-.02	.00	.31**	.34**	.33**	.26**
Care Provided	.01	-.01	.36**	.36**	.40**	.24**
Proximity	.03	-.11*	.06	-.03	-.05	-.05

** Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

Table 8. Correlation Matrix of Resources Variables and Outcome Variables

	Self-esteem	Appreciation of life	Energy expenditure	Stress level	Physical strain	Financial hardship
External Support	.07	.06	**.28****	**.32****	**.26****	**.27****
Family / friend Support	**.11***	**.13****	**.13****	.05	.02	.05
Coping Behaviors	.00	.05	**.23****	**.23****	**.22****	**.19****
Helpful Behaviors	**.10***	.07	**-.15****	**-.22****	**-.21****	**-.11**

** Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

Table 9. Correlation Matrix of Deterrent Variables and Outcome Variables

	Self-esteem	Appreciation of life	Energy expenditure	Stress level	Physical strain	Financial hardship
Difficult Behaviors	**-.11***	**-.10***	**.52****	**.52****	**.48****	**.32****
Family Conflict	-.03	-.07	**.40****	**.40****	**.35****	**.29****
Caregiving Issues	**.68****	**.61****	**.49****	**.59****	**.41****	**.49****

** Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

Table 10. Correlation Matrix of Outcome Variables

	Self-esteem	Appreciation of life	Energy expenditure	Stress level	Physical strain	Financial hardship
Self-esteem	1.00					
Appreciation of life	**.63****	1.00				
Energy expenditure	-.05	-.05	1.00			
Stress level	**-.11***	-.08	**.73****	1.00		
Physical strain	-.06	-.07	**.61****	**.68****	1.00	
Financial hardship	.03	-.02	**.43****	**.49****	**.49****	1.00

** Correlation is significant at the 0.01 level (2-tailed).
* Correlation is significant at the 0.05 level (2-tailed).

Correlations Between Predictor Variables

When examining the caregiving circumstances variables, there were some significant correlations. As expected, there was a high degree of correlation between the amount of caregiving time and the care provided. There were two low correlations between the circumstances variables. Caregivers that provided care over longer periods of time lived closer to the care recipient, and older caregivers provided care for longer periods of time. Although there were some significant positive correlations between resources variables and between the resource variables and circumstances variables, they were only low correlations. Caregivers utilized more external support as more care was provided that required more time and lasted a longer period of time. More daughters sought the support of family or friends. When caregivers enlisted family or friend support, they also utilized external support. With increased frequency of care, coping behaviors were needed. The caregivers who used effective coping behaviors also sought external, family, or friend support. There were fewer care recipient helpful behaviors when more care was provided, increased time was spent in caregiving, the caregiver was older, and the caregiver lived further away.

Two variables had a moderate correlation among the deterrent variables. There was more family conflict when there were greater caregiving issues for the caregiver and more difficult behaviors exhibited by the care recipient. There was one high correlation between deterrent variables. With more care recipient difficult behaviors, the caregiving issues increased significantly. There were moderate correlations between the circumstances and deterrent variables, and

the remainder were low correlations. As more care was provided that took more time in a week, all of the deterrent variables were recognized. Older caregivers had fewer family conflicts, and daughters had more caregiving issues than sons.

Correlations Between Predictor Variables and Outcome Variables

As would be expected, caregivers who provided more care that took more time during the week experienced greater exhaustion, stress, physical strain, and financial hardship. Those caregivers who perceived a greater drain of energy, stress, physical strain, and financial hardship utilized more external support and their own coping behaviors, but received fewer helpful behaviors from the care recipient. The caregivers who perceived support from family or friends also perceived a higher self-esteem and appreciation of life, while expending greater amounts of energy in providing care. Deterrent variables had significant correlations with the outcomes. Caregivers who experienced more issues, difficult behaviors from the care recipient and greater family conflict perceived greater stress, physical strain, financial hardship, and energy expenditure for caregiving. The care recipient's difficult behaviors decreased the perception of self-esteem and appreciation of life. Caregivers with greater self-esteem and appreciation of life also reported more caregiving issues. Daughters identified a greater appreciation for life while expending more energy and experiencing greater stress.

Correlations Between Outcome Variables

There were significant positive correlations between the outcome variables. Caregivers who reported higher self-esteem also reported a greater

appreciation of life even though they had a high stress level. Those that endured financial hardship expended more energy and had higher stress and physical strain. Physical strain among caregivers also was related to stress and the degree of energy for caregiving, and with greater energy needed for caregiving, there was greater perceived stress.

Multiple Regression Analysis

Multiple regression analyses were computed to determine which of the predictor variables were related to the caregiver outcome variables. The six caregiving circumstances predictor variables were regressed stepwise upon each outcome variable. The results are presented in Table 11. Five variables were significant predictors of caregiving outcomes when the other predictors were controlled: age, relationship, caregiving time, care provided, and proximity. Of these predictor variables, caregiving time and amount of care provided positively predicted four outcomes: energy expenditure, stress, physical strain, and financial hardship. There were two caregiving circumstances that predicted two outcomes; age predicted energy expenditure, and stress level and proximity predicted appreciation of life and energy expenditure. The relationship to the parent, specifically daughters, predicted the stress level in the regression model. Table 11 shows longevity was unrelated to all of the six caregiving outcome variables at the 95% confidence interval. This regression analysis provided a preliminary analysis for the path analysis, and as a result, the longevity variable was excluded from the path analysis.

Table 11. Stepwise Multiple Regression Analysis: Predicting Caregiving Outcomes from Caregiving Circumstances
Standardized Beta Coefficients

	Self-esteem (n=470)	Appreciation of Life (n=468)	Energy Expenditure (n=473)	Stress Level (n=473)	Physical Strain (n=471)	Financial Hardship (n=468)
Age	-.03	-.03	**-.09***	**-.09***	.04	-.08
Longevity	-.03	-.05	.05	.04	.07	.06
Relationship	.03	.09*	.08	**.09***	.05	.01
Caregiving Time	-.03	.00	**.16*****	**.20*****	**.17*****	**.19*****
Care Provided	.01	-.03	**.28*****	**.24*****	**.31*****	**.15****
Proximity	.04	**-.10***	**.08***	-.03	-.04	-.05
R-square	.004	.01	.17	.17	.18	.09
F-Value	.35	**4.80***	**23.49*****	**23.96*****	**50.00*****	**21.51*****
Degrees of Freedom	df=6 df=473	df=1 df=466	df=4 df=468	df=4 df=468	df=2 df=468	df=2 df=465

*Coefficient is significant at the .05 level
**Coefficient is significant at the .01 level
***Coefficient is significant at the .001 level

Additionally, the resources and deterrent variables were regressed in separate blocks upon each outcome variable, and the results are in Tables 12 and 13. All four of the resources variables had relationships with some of the caregiving outcome variables. Three variables were significant predictors of energy expenditure, stress level, physical strain, and financial hardship: external support, coping behaviors, and care recipient's helpful behaviors. Self-esteem was predicted by family or friend support and care recipient's helpful behaviors. Only family or friend support predicted appreciation of life. Similarly, all three of the deterrent variables had relationships with some of the caregiving outcome variables. All three of the variables were significant predictors of energy expenditure, stress level, and physical strain. Family conflict and caregiving issues predicted financial hardship. The care recipient's difficult behavior variable was the only predictor of self-esteem and appreciation of life.

Table 12. Stepwise Multiple Regression Analysis: Predicting Caregiving Outcomes from Resources
Standardized Beta Coefficients

	Self-esteem (n=495)	Appreciation of Life (n=493)	Energy expenditure (n=495)	Stress Level (n=494)	Physical Strain (n=492)	Financial Hardship (n=491)
External Support	.05	.02	**.21*** **	**.25*** **	**.19*** **	**.21*** **
Family / friend Support	**.10***	**.12****	.07	-.01	-.04	-.013
Coping Behaviors	-.03	.03	**.18*** **	**.17*** **	**.18*** **	**.14****
Care Recipient Helpful Behaviors	**.10***	.07	**-.16*** **	**-.22*** **	**-.22*** **	**-.11***
R-square	.02	.01	.12	.16	.13	.09
F-Value	**5.02****	**7.12****	**22.34*** **	**31.85*** **	**24.60*** **	**16.43*** **
Degrees of Freedom	df=2 df=492	df=1 df=491	df=3 df=491	df=3 df=490	df=3 df=488	df=3 df=488

*Coefficient is significant at the .05 level
**Coefficient is significant at the .01 level
***Coefficient is significant at the .001 level

Table 13. Stepwise Multiple Regression Analysis: Predicting Caregiving Outcomes from Deterrents

Standardized Beta Coefficients

	Self-esteem (n=504)	Appreciation of Life (n=502)	Energy expenditure (n=506)	Stress Level (n=505)	Physical Strain (n=504)	Financial Hardship (n=502)
Difficult Behaviors	**-.11***	**-.11***	**.12****	**.15*****	**.16*****	.02
Family Conflict	.02	-.04	**.10****	**.12*****	**.08***	**.10***
Caregiving Issues	-.02	.03	**.61*****	**.54*****	**.48*****	**.45*****
R-square	.01	.01	.54	.49	.40	.25
F-Value	**6.58***	**5.77***	**197.00*****	**162.41*****	**112.07*****	**82.81*****
Degrees of Freedom	df=1 df=502	df=1 df=500	df=3 df=502	df=3 df=501	df=3 df=500	df=2 df=499

*Coefficient is significant at the .05 level

**Coefficient is significant at the .01 level

***Coefficient is significant at the .001 level

Path Analysis

After examining the regression analyses, the path analysis was completed in a series of steps. Initially, the caregiving circumstances variables were entered as exogenous variables, and each of the resources and deterrent variables were entered as endogenous variables. Second, the caregiver outcome variables were entered one at a time as endogenous variables, while the predicting circumstances, resources, and deterrents variables were entered as exogenous variables. The predictor variable of longevity was unrelated to all of the six caregiving outcomes in the preliminary regression analysis and was excluded from the path analysis to trim the model. In the path analysis, the caregiving circumstances, resources, and deterrents explained the variance in caregiving outcomes to some degree. The significant path coefficients are summarized in Tables 14, 15, and 16. Figures 3 through 8 depict the predictors for each caregiving outcome.

Table 14. Path Analysis: Significant Path Coefficients (Standardized Beta) Between Circumstances Variables and Resource Variables as Mediators

	External Support (n=449)	Family / friend Support (n=447)	Coping Behaviors (n=447)	Care Recipient Helpful Behaviors (n=448)
Age	-.02	**-.09***	-.04	**-.21*****
Relationship	-.04	**.11***	.05	.05
Caregiving Time	.03	.05	**.11***	-.04
Care Provided	**.23*****	-.02	.07	**-.16*****
Proximity	-.00	.05	-.04	**-.12****
R-square	.05	.02	.01	.08
F-Value	**24.22*****	**4.59***	**5.25***	**12.97*****
Degrees of Freedom	df=1 df=447	df=2 df=444	df=1 df=445	df=3 df=444

*Coefficient is significant at the .05 level
**Coefficient is significant at the .01 level
***Coefficient is significant at the .001 level

Table 15. Path Analysis: Significant Path Coefficients (Standardized Beta) Between Circumstances Variables and Deterrent Variables as Mediators

	Care Recipient Difficult Behaviors (n=449)	Family Conflict (n=446)	Caregiving Issues (n=449)
Age	-.01	**-.17*****	-.07
Relationship	.04	.06	**.09***
Caregiving Time	.09	**.12***	**.21*****
Care Provided	**.44*****	**.14****	**.36*****
Proximity	.02	.02	.02
R-square	.19	.08	.27
F-Value	**105.96*****	**11.93*****	**54.07*****
Degrees of Freedom	df=1 df=447	df=3 df=442	df=3 df=445

*Coefficient is significant at the .05 level.
**Coefficient is significant at the .01 level.
***Coefficient is significant at the .001 level.

Table 16. Path Analysis: Predictors of the Elder Care Outcomes by Adult Children

Standardized Beta Coefficients

	Self-esteem (n=444)	Appreciation of life (n=444)	Energy expenditure (n=444)	Stress level (n=444)	Physical strain (n=444)	Financial hardship (n=444)
Caregiving Circumstances						
Age	-.04	-.02	-.04	-.04	**.07***	-.03
Relationship	.04	.09	.02	.02	-.00	-.04
Caregiving Time	.00	.01	-.01	**.07***	**.08***	.08
Care Provided	.02	-.01	-.01	-.02	.07	.02
Proximity	.03	**-.12***	**.07***	-.04	-.06	-.05
Resources						
External Support	.09	.05	-.01	.06	.02	.09
Family / friend Support	**.14****	**.15****	.03	-.04	-.06	-.02
Coping Behaviors	.04	.07	.03	.03	.06	.08
Care Recipients' Helpful Behaviors	.08	.05	.02	-.06	-.06	-.03
Deterrents						
Care Recipient Difficult Behaviors	**-.15*****	**-.13****	**.12****	**.15*****	**.14****	.03
Family Conflict	.02	-.04	**.12****	**.13*****	**.10***	**.11***
Caregiving Issues	-.07	-.05	**.59*****	**.50*****	**.45*****	**.43*****
R-square	.04	.05	.55	.50	.41	.23
F-Value	**8.93*****	**7.33*****	**131.30*****	**110.89*****	**61.86*****	**67.28*****
Degrees of Freedom	df=443	df=443	df=443	df=443	df=443	df=443

*Coefficient is significant at the .05 level.
**Coefficient is significant at the .01 level.
***Coefficient is significant at the .001 level.

Figure 3: Path Model of Predictors of Adult Children's Self-esteem as an Outcome of the Caregiving Experience

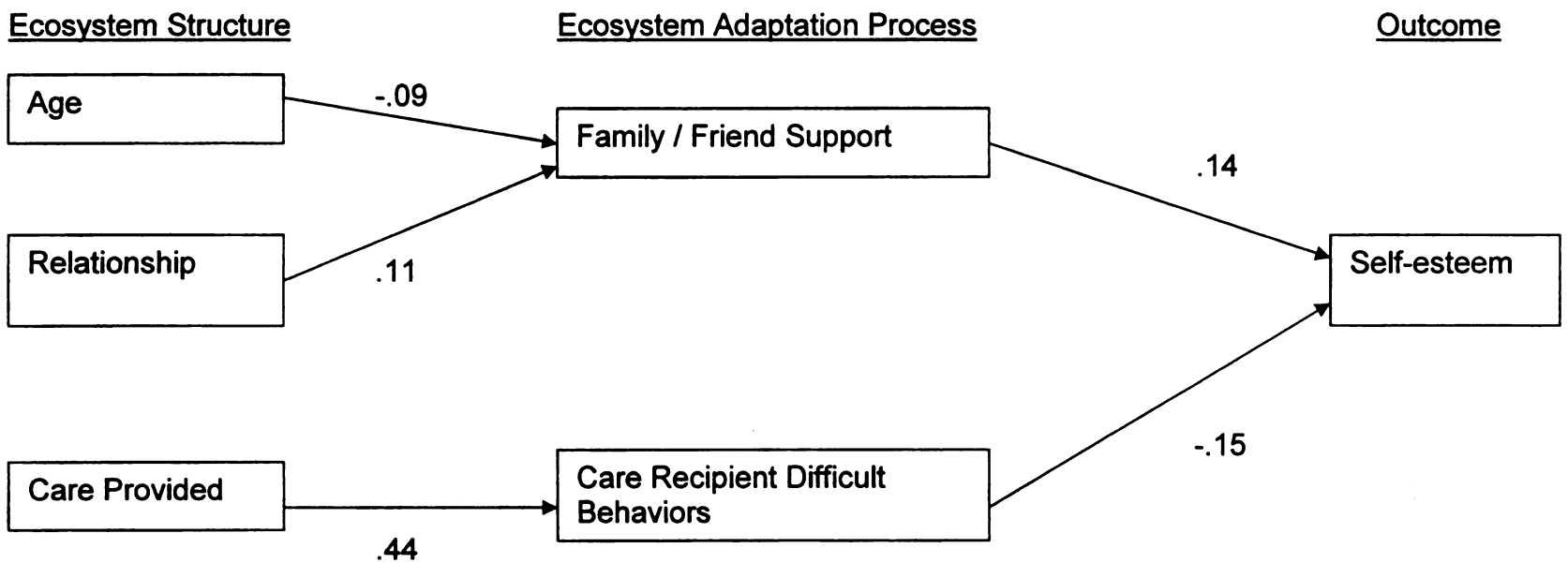


Figure 4: Path Model of Predictors of Adult Children's Appreciation of Life as an Outcome of the Caregiving Experience

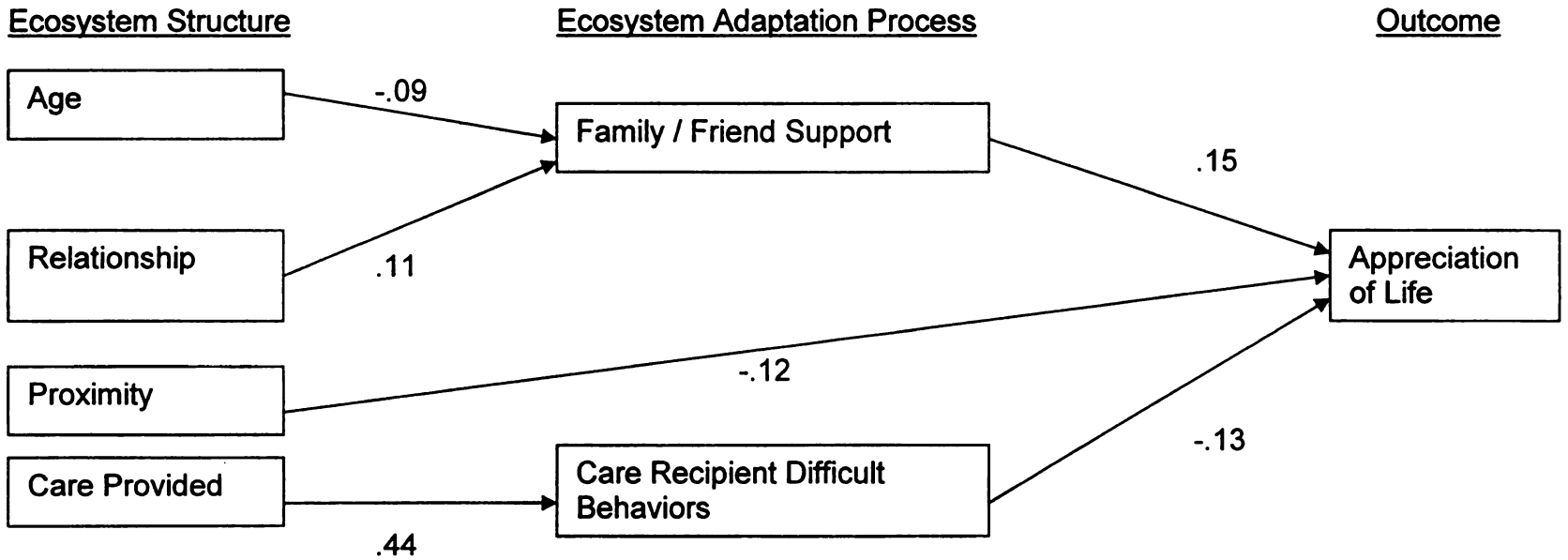


Figure 5: Path Model of Predictors of Adult Children's Energy Expenditure as an Outcome of the Caregiving Experience

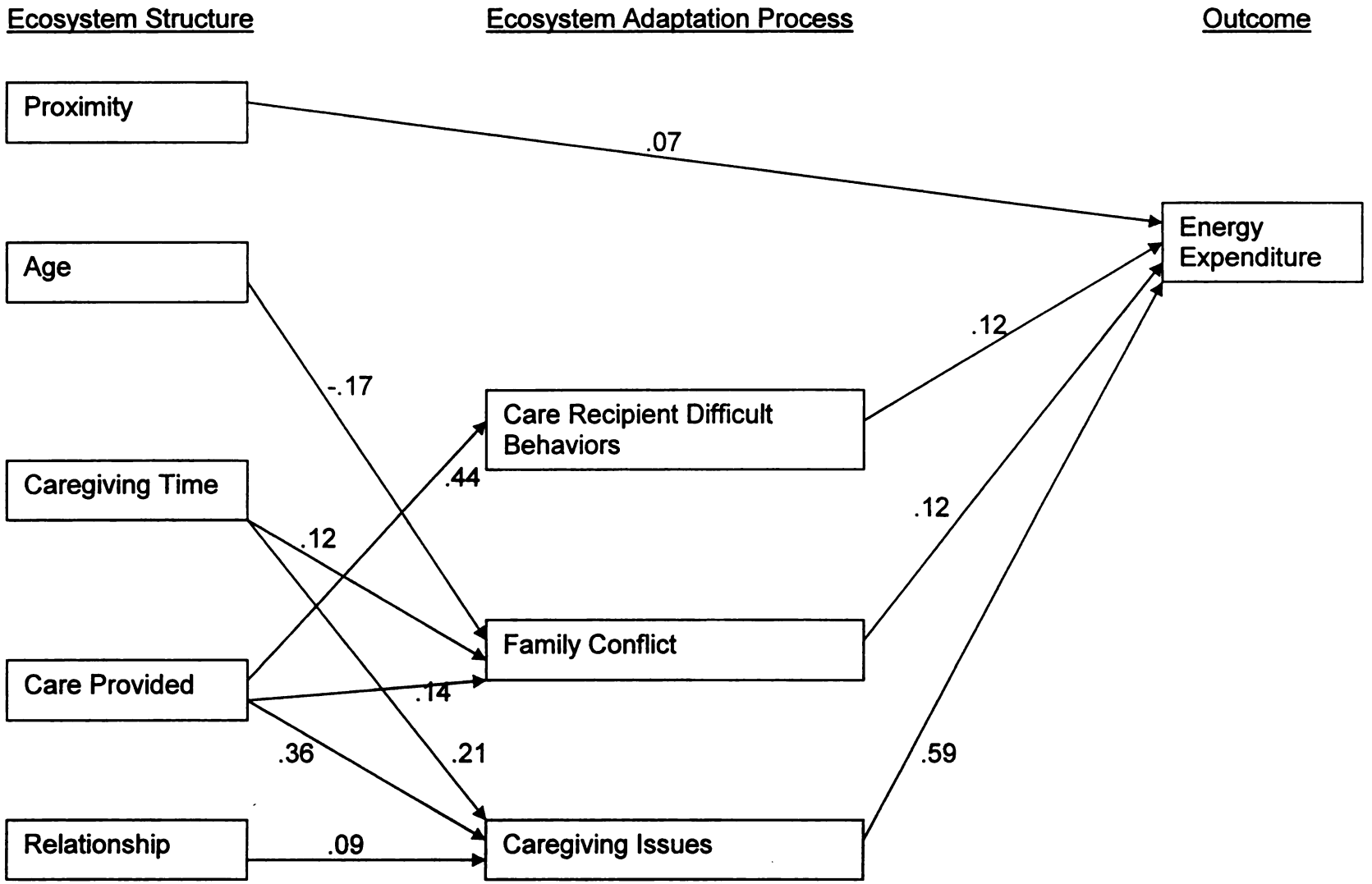


Figure 6: Path Model of Predictors of Adult Children's Stress Level as an Outcome of the Caregiving Experience

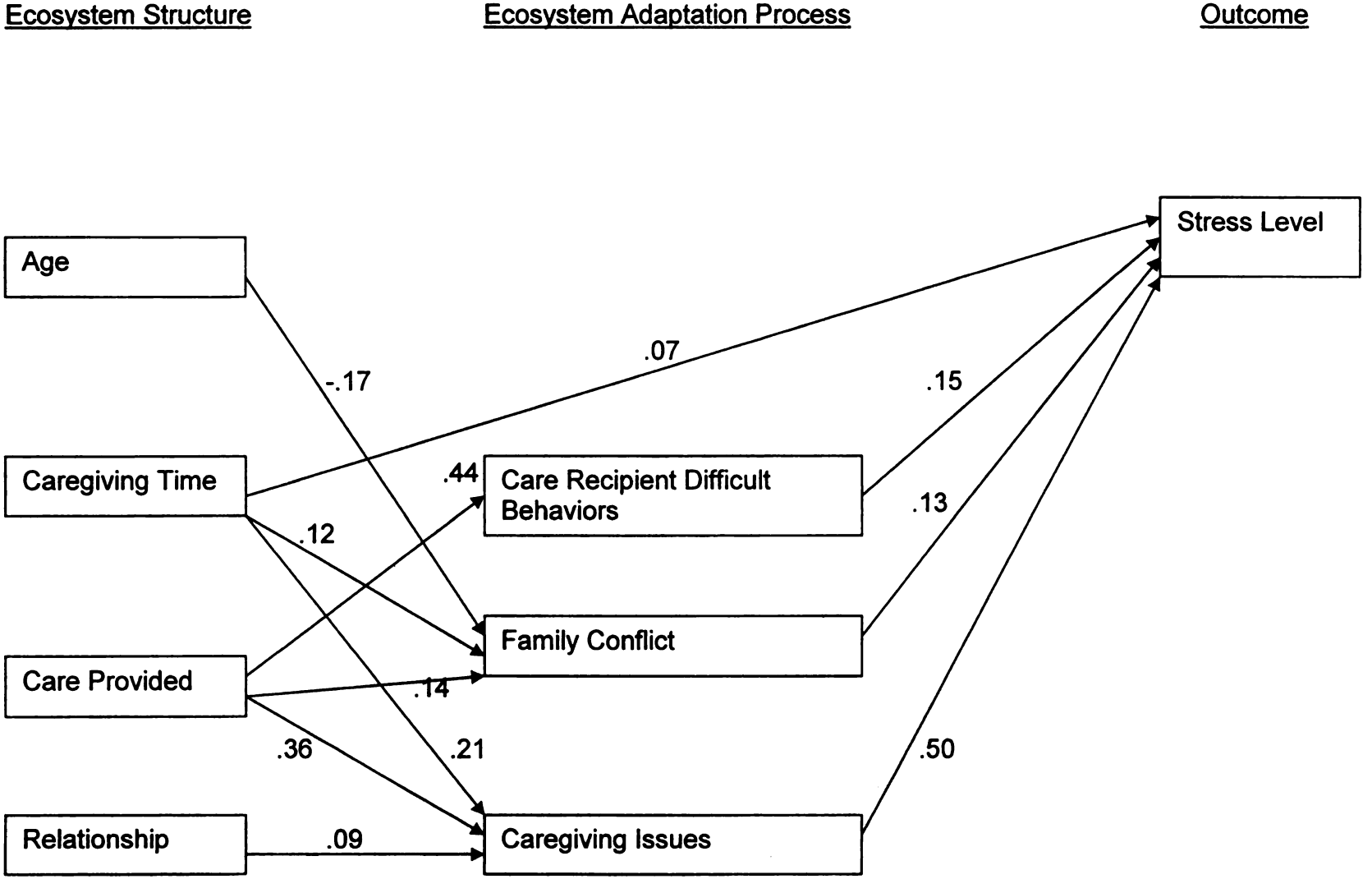


Figure 7: Path Model of Predictors of Adult Children's Physical Strain as an Outcome of the Caregiving Experience

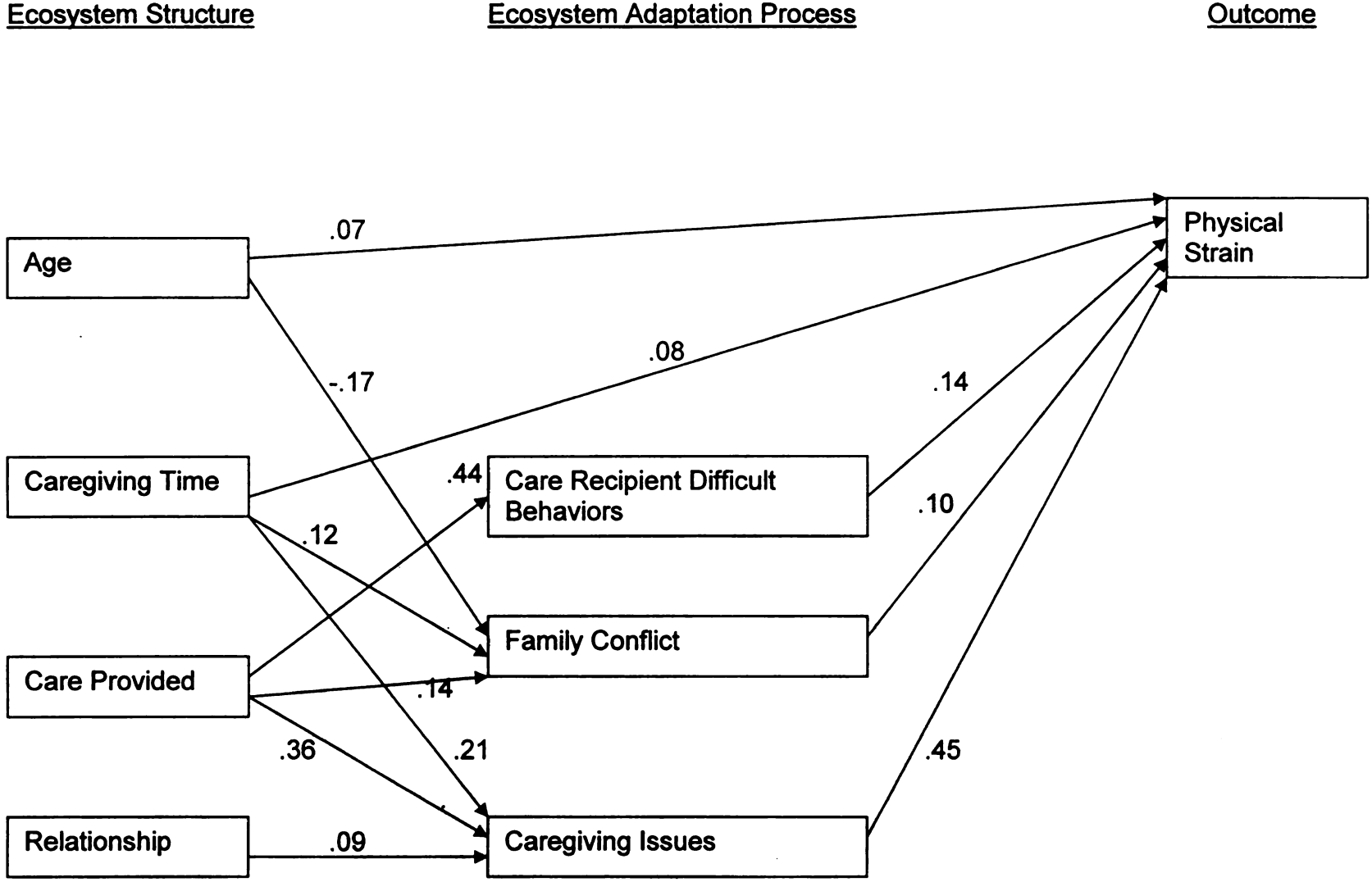
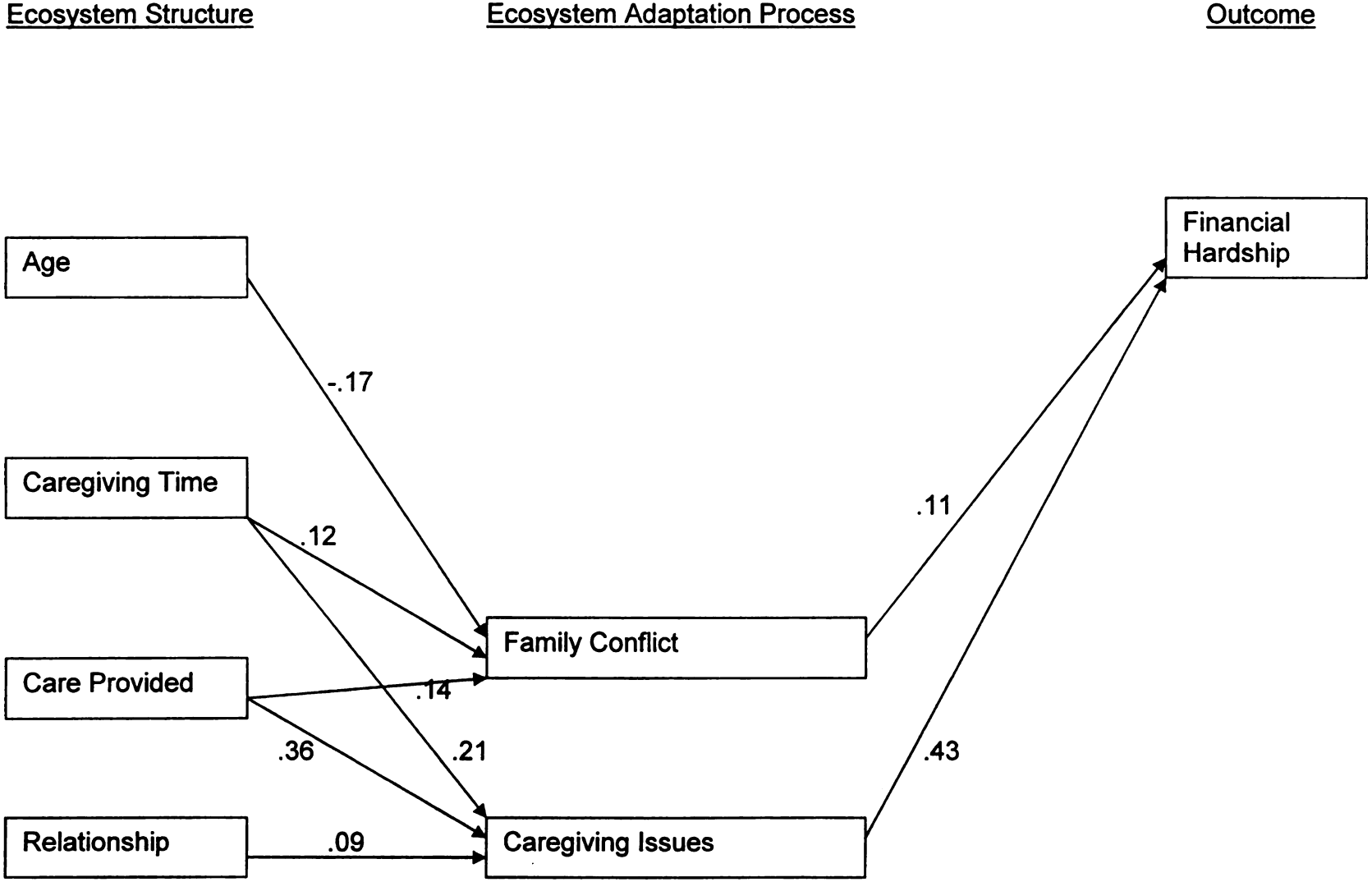


Figure 8: Path Model of Predictors of Adult Children's Financial Hardship as an Outcome of the Caregiving Experience



Several predictors affected the caregivers' outcomes. Younger daughters achieved greater self-esteem and appreciation of life when care was mediated by family or friend support. On the contrary, a lower self-esteem and appreciation of life was recognized when the care provided was mediated by the care recipient's difficult behaviors. Appreciation of life was gained when the caregiver lived closer to or with the care recipient. There was a direct effect of living close to or with the care recipient on the outcome of energy expenditure in care provision. Caregiving time had a direct effect on the caregiver's stress level. Caregiver age and caregiving time had a direct effect on physical strain, and family conflict mediated age for energy expenditure, stress level, physical strain, and financial hardship. Caregiving issues mediated the daughter's energy expenditure, stress level, physical strain, and financial hardship. The deterrent variables mediated caregiving time and the care provided for energy expenditure, stress level, and physical strain. Financial hardship was explained by age, caregiving time, care provided, and being a daughter which was mediated by family conflict and caregiving issues. As noted in Tables 16, three of the four resource variables (external support, coping behaviors, and care recipient helpful behaviors) were not mediators. All four deterrent variables were mediators.

Comparison of Groups

T-tests were computed at the 95% confidence interval to determine if there were significant differences among the caregiving sons and daughters in regard to each caregiving outcome. Table 17 demonstrates the results of the t-test analysis.

Table 17. T-tests of Caregiving Sons & Daughters for Caregiving Outcomes

	Relationship	n	Mean	SD	Df	T	Significance (2-tailed)
Self-esteem	Son	126	4.21	1.15	503	-1.15	.25
	Daughter	379	4.34	1.10			
Appreciation	Son	126	4.12	1.12	500	-2.22	**.03***
of Life	Daughter	376	4.35	0.99			
Energy	Son	127	1.68	0.74	506	-2.51	**.01***
expenditure	Daughter	381	1.90	0.87			
Stress Level	Son	127	1.76	1.11	504	-1.87	.06
	Daughter	379	2.00	1.25			
Physical	Son	125	1.68	1.09	502	-.68	.50
Strain	Daughter	379	1.77	1.26			
Financial	Son	127	3.03	2.34	504	-2.72	**.01****
Hardship	Daughter	379	3.79	2.86			

*T-test is significant at <.05 level.
**T-test is significant at <.01 level.

The results demonstrate that when comparing caregiving children, daughters had a greater appreciation of life while experiencing greater energy expenditure and enduring greater financial hardship.

One-way ANOVAs were calculated to determine whether there were significant differences between groups when considering age and longevity of care. Tables 18 and 19 show the results of the one-way ANOVAs. When comparing four groups of caregivers according to age (group 1 ages 31-48, group 2 ages 49-56, group 3 ages 57-62, group 4 ages 63-93), there was no significant difference in caregiving outcomes. The longevity of caregiving time was divided into five groups to create greater equality of numbers in each group. The groups were less than one year, 1-2 years, 2-4 years, 4-7 years, and greater than 7 years. There was no significant difference in caregiving outcomes when comparing these groups.

Table 18. One-Way ANOVA of Four Age Groups of Caregiving Children and Caregiving Outcomes

	Group 1 (ages 31-48) Mean (SD) n=116	Group 2 (ages 49-56) Mean (SD) n=121	Group 3 (ages 57-62) Mean (SD) n=133	Group 4 (ages 63-93) Mean (SD) n=113	F	Significance
Self-esteem	4.42 (1.06)	4.36 (1.09)	4.27 (1.12)	4.33 (1.14)	.40	.75
Appreciation of Life	4.39 (.99)	4.37 (1.03)	4.17 (1.15)	4.37 (.89)	1.27	.28
Energy Expenditure	1.95 (.85)	1.93 (.88)	1.79 (.89)	1.72 (.73)	2.14	.09
Stress Level	3.94 (2.87)	3.68 (2.84)	3.57 (2.93)	3.29 (2.37)	1.10	.35
Physical Strain	1.91 (1.03)	1.93 (1.23)	1.96 (1.37)	2.01 (1.26)	.15	.93
Financial Hardship	1.94 (1.42)	1.83 (1.34)	1.53 (.95)	1.73 (1.15)	2.56	.05

One-Way ANOVA is significant at <.05 level.

Table 19: One-Way ANOVA of Five Longevity Groups of Caregiving Children and Caregiving Outcomes

	Group 1 (< 1 year) Mean (SD) n=90	Group 2 (1-2 years) Mean (SD) n=71	Group 3 (2-4 years) Mean (SD) n=93	Group 4 (4-7 years) Mean (SD) n=119	Group 5 (> 7 years) Mean (SD) N=126	F	Significance
Self-esteem	4.29 (1.01)	4.21 (1.24)	4.49 (.95)	4.40 (1.01)	4.18 (1.26)	1.41	.23
Appreciation of Life	4.26 (1.12)	4.32 (.94)	4.46 (.96)	4.34 (.95)	4.18 (1.10)	1.08	.37
Energy expenditure	1.85 (.93)	1.78 (.83)	1.82 (.77)	1.84 (.80)	1.88 (.88)	.19	.94
Stress Level	3.33 (2.78)	3.34 (2.81)	3.96 (2.68)	3.65 (2.70)	3.63 (2.85)	.77	.54
Physical Strain	1.86 (1.24)	1.69 (1.02)	1.99 (1.18)	2.00 (1.23)	2.05 (1.34)	1.20	.31
Financial Hardship	1.52 (1.11)	1.75 (1.27)	1.78 (1.21)	1.83 (1.28)	1.80 (1.22)	.94	.44

One-Way ANOVA is significant at <.05 level.

Summary of Results

In this section, the results of the study are summarized. The summary is presented according to the research questions and research hypotheses addressed in this study.

Research question 1: What is the relationship between the intergenerational caregiving circumstances variables and each caregiver outcome variable?

Hypothesis 1: Caregivers who care for their elderly parent(s) more hours per week will perceive increased energy expenditure and an increased stress level.

The results are consistent with this hypothesis. The caregiving circumstances that had more significant relationships with caregiving outcomes included relationship, caregiving time, and the amount of care provided. Daughters demonstrated an increased appreciation of life, an increased stress level, and increased energy expenditure as a result of caregiving in correlations and in multiple regression analysis. The amount of time and care provided positively related to increased energy expenditure, stress level, physical strain, and financial hardship. Energy expenditure decreased as the caregiver age increased. Appreciation of life decreased as the proximity to the care recipient increased. Regression analyses further supported these findings, indicating that caregiving time and care provided significantly predicted energy expenditure, stress level, physical strain, and financial hardship.

Research question 2: What is the relationship between intergenerational caregiving resources and the caregiver outcome variables?

Hypothesis 2: Caregivers who receive family or friend support will appraise the caregiver outcome with a decreased stress level.

The data were not consistent with this hypothesis. The family or friend support did not correlate with or predict stress level.

External support and coping behaviors had a positive correlation and care recipient helpful behaviors had a negative correlation with energy expenditure, stress level, physical strain, and financial hardship. Regression analyses also revealed that external support and coping behaviors positively predicted energy expenditure, stress level, physical strain, and financial hardship, while care recipient helpful behaviors negatively predicted the same outcomes. Family or friend support positively correlated with self-esteem, appreciation of life, and energy expenditure. Again, similar results occurred with the regression analyses, demonstrating that family or friend support predicted self-esteem and appreciation of life. The care recipient helpful behaviors were found to correlate with and predict self-esteem.

Research question 3: What is the relationship between intergenerational caregiving deterrents and the caregiver outcome variables?

Hypothesis 3: Caregivers who experience family conflicts will appraise the caregiver outcome with an increased stress level.

The data were consistent with this hypothesis. All three caregiving deterrents (care recipient difficult behaviors, family conflict, and caregiving

issues) revealed a significant relation with energy expenditure, stress level, physical strain, and financial hardship. The multiple regression analyses revealed that care recipient difficult behaviors, family conflict, and caregiving issues predicted energy expenditure, stress level, and physical strain. Family conflict and caregiving issues predicted financial hardship. Additionally, the caregiving issues positively related to self-esteem and appreciation of life, while care recipient difficult behaviors had a negative relationship with the same outcomes.

Research question 4: Do caregiving resources mediate the effects of intergenerational caregiving circumstances on the caregiver outcome variables?

Research question 5: Do caregiving deterrents mediate the effects of intergenerational caregiving circumstances on the caregiver outcome variables?

Hypothesis 5: Family conflict mediates the effect of the caregiving circumstances on the intergenerational caregiver outcome variables.

Data supported this hypothesis. As presented in the path analysis section of this chapter, family or friend support was the only resource variable that mediated the effect of age and relationship for the outcomes of self-esteem and appreciation of life. The deterrent variables of care recipient difficult behaviors, family conflict, and caregiving issues mediated the effects of some caregiving circumstances on the outcomes. Difficult behaviors mediated the care provided for all six outcomes. Family conflict was found to mediate age, caregiving time, and the care provided on the outcomes of energy expenditure, stress level, physical strain, and financial hardship. Lastly caregiving issues mediated the

relationship, care provided, and caregiving time on energy expenditure, stress level, physical strain, and financial hardship.

Research question 6: Are there significant differences in the intergenerational caregiver outcome variables among daughters, sons, daughters-in-law, and sons-in-law?

Hypothesis 6: Daughters and daughters-in-law will appraise the caregiving outcome with an increased stress level and greater physical strain.

As was previously mentioned, there was an inadequate sample size to compare groups including the daughters-in-law and sons-in-law. However, the daughters and sons were compared to determine if there were differences in the caregiver outcomes. This hypothesis was not supported by the data. However, the results did show that daughters had a greater appreciation of life and energy expenditure while experiencing greater financial hardship.

Research question 7: Are there significant differences in the intergenerational caregiver outcomes variables according to the age of the caregiver?

Research question 8: Are there significant differences in the intergenerational caregiver outcome variables as the length of the caregiving experience increases?

Hypothesis 8: Caregivers who care for their elderly parent(s) more years will perceive increased energy expenditure and an increased stress level.

This hypothesis was not supported. There was no significant difference in caregiving outcomes when comparing caregivers of different ages and at different lengths of time of caregiving.

CHAPTER 5

Discussion and Conclusions

This chapter includes a summary and discussion of study findings, limitations of this study, and implications for practice, education, and future research.

Summary and Discussion of Findings

The overall purpose of this study was to determine the predictors of the intergenerational caregiving experience. Predictors included caregiving circumstances, resources, and deterrents. Positive and negative outcomes of the caregiving experience were measured including self-esteem, appreciation of life, energy expenditure, stress level, physical strain, and financial hardship.

As the caregiving circumstances are considered, the caregiving time and the amount of care provided related to and predicted the outcomes of energy expenditure, stress level, physical strain, and financial hardship. The increased stress level is consistent with previous research findings (Atienza, Stephens, & Townsend, 2002; Braithwaite, 2000; Brody, 1985; Mui, 1995). However, there are inconsistent findings related to the caregiving time. Dautzenberg, Diedricks, Philipsen, and Tan (1999) identified that the subjective evaluation of the caregiver role affected the daughters as caregivers more than the amount of caregiving time. Perceived financial hardship is significant, especially in relationship to caregiver stress. Starrels et al. (1997) found a strong correlation between the amount and type of care provided and time taken off from work, which resulted in increased caregiver stress. Realizing the effects of the type of

care provided and potentially the time spent providing care, the professional can identify resources that will support the caregiver.

When reviewing the resources, most caregivers utilized external support that would assist in the caregiving tasks, which eased the physical nature of the care, without attending to the caregivers' personal needs for support. This study demonstrated that there was minimal use of support groups, professional help, and respite resources. This finding is consistent with other studies of caregiving women's use of, interaction with, and influences of professional support (Brubaker, 1990; Heinrich, Neufeld, and Harrison, 2003). Issues surrounding external support may include access, time available, and perceived need. Because of a sense of responsibility or obligation, caregivers may sense failure if they seek external support. Coping behaviors were used, and among them, prayer and talking with a trustworthy friend or relative were used most often. The spiritual well being of the caregiver was a source of strength. This is consistent with findings of Wilcox, O'Sullivan, and King (2001) that the most frequently used coping strategies were recognizing blessings, problem-focused coping, and seeking social supports. While it is expected that immediate assistance for physical caregiving is attained, it will be important for professionals to refer additional sources of external support to promote positive outcomes of the experience. Not only is referral necessary, but also a means to be relieved of caregiving should be determined so that alternative methods of external support and coping can be utilized. Caregiver resources must be identified and utilized

so that quality caregiving, positive outcomes, and caregiving stress can coexist (Greenberger, 2003).

Family or friend support had positive correlations with self-esteem, appreciation of life, and energy expenditure. As caregivers use support systems and adapt to improve self-concept, they may transform these positive results into mobilized energy and therefore to provide a greater amount of care. In the regression analyses, self-esteem and appreciation of life was predicted by family or friend support. This finding is consistent with previous findings in which emotional and social support from family and friends related to higher levels of satisfaction and an inverse relationship with distress and depression (Franks & Stephens, 1996). Developing ways to engage in supportive contacts with trustworthy family and friends can enhance the positive outcomes of caregiving.

The care recipient helpful behaviors had a positive correlation and predicted self-esteem, but a negative correlation and prediction of energy expenditure, stress level, physical strain, and financial hardship. The most frequently identified helpful behavior was making the caregiver feel useful and needed, which should relate to an increased self-esteem. Previous researchers found that emotional support from the care recipient was most beneficial. Consistent with Ingersoll-Dayton, Neal, and Hammer (2001), tangible supports of helpful behaviors were not consistently recognized as beneficial by caregiving daughters and sons. Yet, receiving help from the elderly parent was beneficial in terms of the quality of the relationship and the self-appraisal of caregiving performance. Congruent with this study, emotional support was consistently the

most beneficial form of assistance from the elderly parent. Professionals can intervene by assisting to strengthen the emotional relationship between parent and caregiving child to reap the emotional rewards of caregiving.

All three caregiving deterrents, care recipient's difficult behaviors, family conflict, and caregiving issues, revealed a positive correlation with energy expenditure, stress level, physical strain, and financial hardship. Family conflict, especially among siblings, has an effect on caregiving stress, and sibling cooperation is an important variable in continuation of elder care (Dwyer, Henretta, Coward, & Barton, 1992). The care recipient's difficult behaviors had a negative correlation with self-esteem and appreciation of life. The most frequent caregiving issues primarily focused on the needs of the caregivers in relation to time for themselves or other family and the provision of care when they did not feel well enough themselves. These findings related to caregiver needs further reinforce the necessity for respite for the caregiver.

Self-esteem and appreciation of life was predicted by family or friend support, while it was negatively influenced by the care recipient's difficult behaviors. The deterrent variables of care recipient difficult behaviors, family conflict, and caregiving issues predicted energy expenditure, stress level, and physical strain. Physical strain also was predicted by age and caregiving time. Financial hardship was predicted by external support, family conflict, and caregiving issues. Additionally, caregiving issues, family conflict, and care recipient's helpful and difficult behaviors were mediators for several of the caregiver outcomes.

Among the predictor variables, deterrent variables explained most of the variance in the caregiving outcomes. This result is consistent with prior research (Acton, 2002, Larrimore, 2003). Horowitz (1985) found emotional support from siblings mediated caregiver strain, which was found for daughters in this study. Family and friend support was a significant mediator for the outcomes of self-esteem and appreciation of life. It is important to realize that there are both positive and negative outcomes in the caregiving experience. Costs and rewards may become balanced if it is determined which predictors explain the outcomes to the greatest degree. This further reinforces the need for a thorough individualized assessment of the caregiving experience in the context of the caregivers' whole life.

Daughters continue to provide the greatest amount of intergenerational care. Even though caregiving is generally considered a daughter's issue, more sons are providing various kinds of care (Houde, 2001). However, these men are less often the primary caregivers, and only primary caregivers were considered in this study. Differences were found regarding appreciation of life, energy expenditure, and financial hardship. For each of these outcomes, daughters experienced a higher level in the identified outcomes. This is especially important to note as daughters continue to juggle many roles contributing to the caregiving issues described in this study. There is a greater complexity in the responsibilities and number and types of roles of daughters as caregivers (Mui, 1995). This complexity of roles further affects the caregiving experiential outcomes. Yet, the quality of roles rather than the occupancy of

multiple roles are more significant when measuring caregiver distress (Parris Stephens & Townsend, 1997). Financial hardship may occur because it has previously been demonstrated that women often must reduce their employment status or quit working to provide care (Haley, 1997), and daughters often have fewer financial resources prior to the caregiving experience. Because daughters tend to continue to provide the greatest amount of care, the perception of a greater appreciation of life should be identified and enhanced for this group.

In this study, no significant differences were found in caregiving outcomes based on age and longevity of the caregiving experience. Considering the increase in the number of elderly persons, especially the oldest old, increase in family caregivers, and the prevalence of disability among the elderly (U.S. Administration Agency on Aging, 2004; U.S. Senate Special Committee on Aging, 2004), one would expect a difference in the caregiving outcomes as the caregiver ages and as length of caregiving experience lengthens. In this study, the care provided was measured as the total amount of any type of care provided. A majority of caregivers provided IADLs, with approximately half of the sample providing ADLs and health care. There may be a difference in groups as the type of care is distinguished.

Application of Theoretical and Conceptual Frameworks

Human ecology theory, a life course perspective, and Kramer's model of caregiver adaptation were used as frameworks in this study (Bengtson& Allen, 1993; Bubolz & Sontag, 1993; Kramer, 1997a; Price, McKenry, & Murphy, 2000). Each of these models had merit. Kramer's use of background and context were

similar to the caregiving circumstances used in this study with the exception of care recipient characteristics and caregiver attitudes. Kramer included stressors as part of the context, whereas, this investigator included deterrents as an intervening or adaptation process. Resources were instrumental mediators in both Kramer's model and the model used in this study. Positive and negative outcome indicators were also measured in both models. By altering Kramer's model as described, the conceptual model for this study was congruent with human ecology theory. Additionally, this study's conceptual model provided a framework to analyze the data in an appropriate manner for the research questions and hypotheses. Alteration of Kramer's model remains an overall fit for the model used in this study.

Furthermore, the human ecology theory is a supportive framework for this study. Linkages of concepts in the theory relate well to the model developed for this study. Caregivers with various characteristics interacted with the socio-cultural environment and encountered various resources and deterrents as they adapted to the caregiving process to achieve identified positive and negative caregiving outcomes. These conceptual linkages are consistent with the human ecology theory. The positive outcomes of caregiver self-esteem and appreciation of life are congruent with the improved quality of life outcome in the human ecology theory. Adaptation is a key process in human ecology theory and is vital in the caregiving process. Adaptation to caregiving occurred through several mediators and also was recognized with positive outcomes of self-esteem and appreciation of life, especially among daughters. The utilization of

resources and response to deterrents as mediators in the adaptation process were determinants of the caregiving outcomes.

Reflecting on human ecology theory, the caregivers may be effectively engaging in adaptation through processes of perception, organization, decision making, management, and sustenance activities that affect the judgment of the caregiving outcome. Also, when relating to Kramer's model, the caregiver's attitude and appraisal may be additional subjective factors that are not taken into account in this study. The caregiver's attitude may be derived from a sense of responsibility, reciprocity, and duty that can occur during the life course. Finding meaning in the caregiving experience may affect perceptions and bring the positive and negative outcomes in greater balance. Other studies have found that caregivers with higher levels of meaning through caregiving experienced lower depression, could make sense of the experience, and had a better understanding of themselves and their own feelings (Ayers, 2000; Farran, Miller, Kaufman, & Davis, 1997).

As a part of human ecology theory, Bubolz and Sontag (1993) describe human development as a "process of ongoing and interrelated changes in an individual's ability to perceive, conceptualize, and act in relation to his or her environment" (p. 437). Over the life course, human development occurs in interaction with the social-cultural environment. Filial responsibility and obligation to care for an elderly parent may be a result of the larger social-cultural context in which the role responsibilities between adult children and parents unfold. Daughters generally report higher levels of felt obligation than sons (Stein,

Wemmerus, Ward, & Gaines, 1998), and this is reflected in the greater number of daughters as caregivers. Additionally, daughters may have been socialized in the caregiving role as a part of their interaction with the social-cultural environment, particularly the influence from their mother related to caregiving responsibility. Rollins-Bohannon and White-Blanton (1999) explain that parent attitudes in general, and especially mothers' attitudes, are significant predictors of the attitudes of their daughters. Even though societal norms change over time, early gender socialization of daughters has life long effects.

When examining elder care, a life course perspective is foundational to understanding family health over time (Bengtson & Allen, 1993). Families continue across the lifespan to shift energy expenditure to address the demands and needs of the family members. Parent care has been proposed as a developmental task of the adult sibling network (Cicirelli, 1994). Additionally, from a life course perspective, elder care can be viewed as a developmental task of middle to later life. The adult child provides reciprocity for support and care received by the parent, gains maturity and wisdom, and becomes better prepared for his or her own later years. Despite using age as a measure of the life course and a circumstance variable in this study, developmental stage must be reviewed for its effect on the nature of the caregiving experience, family relationships, role responsibilities, and the needed support for the caregiver at a given life stage. Even though this study did not demonstrate differences among different ages of caregivers or differences in longevity of care, the developmental roles and tasks at different stages of adulthood would lead one to assume that variances should

occur. When considering the positive outcomes, reciprocity, and positive, helpful behaviors of the care recipient leading to improved caregiver self-esteem and appreciation of life, the life course perspective is also reinforced. These rewards and benefits accrue during the caregiving experience and continue in memory with increased value after the parent's death. A life course perspective reinforces these underlying benefits.

Human ecology theory and a life course approach are useful frameworks in planning elder parent care as a significant challenge to the family. These frameworks can direct emphasis to benefits of the experience as well as draw attention to the roles and needs of the family members involved.

Limitations of the Study

This study utilized secondary data analysis. This provided an opportunity to have a large representative sample, and involved analyzing the data in dimensions that previously have not been examined. Trained interviewers collected the data using structured interviews where the lengthy schedule of questions was pre-established. Using this method, the interviewer does not further explain the meaning of the question or modify the question. There may have been time constraints for some subjects due to the length of the survey. The subject was limited to the range of responses from the survey. Consequently, some items were missing because they did not apply, the subject chose not to respond, or there were time limitations to complete the entire survey.

While secondary analysis of this large data set from NLTCS was efficient and economical, it did lack some variables that were of interest to the investigator. For example, most noteworthy is the lack of data on the caregiver's race. Even though the care recipient's race was available, the caregiver's race was not available. One cannot assume that the race is the same for parent and child. These data would have been especially useful in understanding the cultural implications of intergenerational caregiving. Additionally due to the nature of a very large data set, the investigator anticipated that there would be more children in-law represented in the study. Elder care provided by children-in-law has rarely been studied. It was hoped that this study could have provided valuable results related to both adult children and children-in-law as caregivers.

Another limitation is the measurement of some variables as single-item responses. Outcome variables such as self-esteem, appreciation of life, stress level, and physical strain were measured with a single item. Single item measures can reduce the validity of the measure. Measurement and systematic error can be expected with single item measures (Polit & Beck, 2004).

The surveys were a self-report to the interviewer. The caregiving resources and deterrents were a measure of the degree to which they occurred for the caregiver. Additionally, the caregiving outcomes were the caregiver's perception of the experience. These data can best be obtained through honest self-report, and the investigator must assume that the information provided was accurate. However, subjects may respond according to what they believe is socially desirable or expected when responding to the interviewer. Subjects also

may interpret the questions differently than intended by the researcher. All of the data came from the same source. It is possible that shared method variances may increase the magnitude of relationships between variables.

The data set is from 1999. Considering the age of the data, there may be changes in caregiving circumstances, resources used, deterrents that are evidenced and the resulting outcomes as the 21st century unfolds.

Implications for Practice, Education, and Recommendations for Future Research Practice

There are several areas of application for practice. The professional must assist families in the preparation, planning, or anticipatory strategies for events associated with caregiving. This is especially true since studies indicate that failure to prepare and plan for caregiving is generally the situation (Archbold, Stewart, Greenlick, & Harvath, 1990; Archbold et al., 1995; Pohl et al., 1994). A thorough individualized assessment is essential for all caregiving families to determine the circumstances, resources, and deterrents of the caregiver and potential effects for the caregiver, care recipient, and other family members. In consideration of the human ecology model, the professional must assess the diverse characteristics, needs, values, goals, and resources of the caregiving family. Cultural sensitivity must be integrated in the family interventions. Assessment of the family structure, external support, coping behaviors, and decision making skills is essential to facilitate adaptation of the caregiving experience. The professional must demonstrate respect, comfort, and counsel. A significant caregiver need is to be appreciated for what they do and how they

are feeling (Levine, 1999), and the professional can be instrumental in fostering the sense of appreciation through his or her communication and by strengthening the support systems that affect the caregiver's feeling of appreciation.

The professional serves to inform and guide during the caregiving experience. Caregivers often report a need for information (Levine, 1999). Caregivers may need assistance to access information and services and are not likely to externally seek this in the midst of providing care. Professionals can encourage opportunities for caregivers to reflect on the deeper meaning of caregiving and to strengthen their spiritual health (McLeod, 1999) which also was found as a significant coping behavior in this study. Promoting the health of the caregiver is important. While support groups and counselors are not frequently used, respite services should be referred by the professional, means to increase usage should be considered, and should be sought by the caregiver when possible. Additionally, the professional will serve as an accessible resource for information to the caregiver, care recipient, and the other family members. The professional may need to work with the family members to adjust to differing roles and family task norms to ease the stress for the caregiver. The professional can develop individualized intervention programs to strengthen positive outcomes, reduce stress, and promote the mental health of the caregiver.

Furthermore, the professional serves as an advocate to facilitate employer and public policy changes. Employer policies that provide benefits to the adult caregiver, permit varied work schedules, and assist with informational resources

are needed. It is less expensive to provide care at home; the annual cost to care for an elderly person with dementia at home is $18,000, whereas in a long-term care facility it is $42,000 annually (Plowfield, Raymond, & Blevins, 2000). Even though the expense is much less at home, the cost of caregiving can place a significant burden on many families. The professional should seek to support policy that will provide tax incentives for the caregiver and be alert to impending changes in Medicare and Medicaid funding. With an overall economic downturn in the United States, supportive resources for the growing number of elderly persons and their caregivers are essential to sustain optimal health and well-being.

Education

From an educational standpoint, it is important for professionals to teach foundational theories that relate to elder care. Family system theoretical frameworks and a life course perspective will guide therapeutic interventions with the caregiving family of elderly parents. Family studies and nursing professionals must assure conceptual understanding of common issues that families face as they provide elder care. Some of these common issues include: variations and changing family structure and degrees of family cohesiveness; changes in roles and relationships; family decision making processes; the role of extended families; social support; use of resources; and the family's ability to adapt as various needs arise. The professional must be prepared to facilitate the utilization of resources and to minimize the deterrents to achieve optimal outcomes from the caregiving experience. As demographic changes continue

toward an increased number of elderly persons and thus an increased need for elder caregivers, effects on family health and relationships as a result of caregiving will be increasingly important when curricular decisions are made.

Research

This study used a quantitative approach to examine the predictors of the caregiving experience of adult children who cared for their elderly parents. It explored caregiving circumstances and predictors that affected the caregiving outcome. One could assume that feelings were imbedded in several of the responses when variables such as support, coping behaviors, family conflict, self-esteem, and appreciation of life are considered. Furthermore, this study did not explore the motivations for providing care. A qualitative approach would assist in further examining the emotional response and feelings as outcomes of the caregiving experience. Qualitative research should aim to reveal the caregiver's perception of the caregiving experience.

Since the initial work of Brody (1966), elder care studies, in general, have focused on burden, stress, and the negative results of caregiving. While some recent work has begun to shift toward the positive results of caregiving, continued research is needed for the professional to have an evidence base for interventions to enhance strengths, resources, and outcomes.

This study addressed whether the caregiving outcomes changed over time. Based on this study, one cannot assume that there was a change in the intensity of the caregiver role over time. Caregiving usually changes in role and intensity over time and as the status of the care recipient changes (AOA, 2004).

This could best be measured by a longitudinal study or a comparative analysis of multiple waves of the NLTCS or other datasets.

While this study included various caregiving issues and did include responses related to decrease in social activities, time with family, and time for vacation or hobbies, it did not directly address the caregiver's potential for loneliness. The adult child as primary caregiver may be at risk for social isolation. As the caregiving time increases, the caregiver is separated from others who provide social and emotional interaction. Difficult behaviors of the adult parent may further contribute to social isolation. This area can be further researched to provide support for assessing the caregiver to meet the needs for social support and exchange.

While this study examined whether the amount of care provided predicted caregiving outcomes, it did not specifically identify whether certain types of care had a greater effect. Daughters tend to be involved in all types of care, whereas sons provide more IADLs. Further research could identify whether the specific type of care provided predicted caregiving outcomes.

Elder abuse has emerged as a major social problem and a significant aspect of family violence. One wonders about the negative outcomes of caregiving and whether there is a relationship to elder abuse. With the escalating need and incidence of caregiving, the stage may be set for elder abuse. Because adult children are increasingly being called upon to care for elderly parents, professionals should assess the skills and resources of the caregiver to facilitate enhancement of these skills and to decrease the stress that

may result in elder abuse. A retrospective study may be indicated to determine the predictors of elder abuse by adult children.

This study focused on the caregiver as the unit of analysis, and this approach is typical of most elder care studies. Examining the primary caregiver tends to obscure the relationships, involvement of and consequences to other family members and the family as a unit. Neither caregiver outcomes or the caregiver and care recipient relationship and experience should be considered in isolation. The relationships within any one subsystem affect and are affected by the interactions within the other family subsystems as the entire extended family system is considered. Effects on others in the caregiver's family, such as spouse, children, and siblings, are relatively unknown. Only one study was found that reported negative effects on both mental and physical health of the caregiver's spouse and children (Lieberman & Fischer, 1995). A strategy to address the care needs of the aging parent is for the parent or child to move in with the other (Tennstedt, 1999; Ziemba, 2002). This has implications for other family members in the household and requires adjustment. Yet, as in this study, helpful behaviors of the care recipient may offset demands within the family. Family health may become imbalanced when demands are placed on the caregiver decreasing the energy expenditure, emotional involvement, and time with other family members. Even with a primary caregiver, the elder care experience is by necessity a shared family event as responsibilities within the family unit shift. The degree of support from immediate family members to engage in elder care may affect the caregiving experience. Family cohesion and

marital satisfaction also may have an effect on elder care (Martire, Stephens, and Franks, 1997). Disrupted relationships with other family members including conflict with the caregiver's own children has been reported (Franks & Stephens, 1996). Adult children report feeling the loss of the parents' previous support, relatively little is known about the role or reactions of the caregiver's spouse, and it is unclear to what degree others in the caregiver's family experience loss (Ziemba, 2002). Therefore, the entire family should be studied, and there is much to be discovered regarding the effect of elder care on the family as a unit. Included in this family unit approach, the perception and reaction of the care recipient should be examined to more fully view the outcomes of caregiving.

Another important research topic would be the examination of differences in family caregiving and outcomes in diverse populations. Very little research is available regarding ethnicity and caregiving. Family roles and expectations are shaped by cultural norms and values with varying degrees of expectations. Some societies clearly designate the family member who should take primary responsibility for the elder care. Yet, assumptions are made that persons with some ethnic backgrounds receive added assistance from large, extended families and that family cohesiveness is positive. This assumption may lead to false assurance among professionals that the needs of intergenerational caregivers are being met. These assumptions and cultural norms in caregiving should be studied. With an increasingly diverse aging population, this research would benefit diverse caregivers, care recipients, professionals, and policy makers.

Health care professionals can examine the physical health of the caregiver especially as caregivers are aging. The primary focus has been the negative psychosocial effects of caregiving. There appears to be less evidence regarding risks for physical health (Schulz, Visintainer, & Williamson, 1990). Schulz and Beach (1999) found a 63% higher death rate in caregivers who reported role strain. The increased energy expenditure, physical strain, and emotional stress may result in harmful effects on the immune system, resulting in decreased resistance to disease. Healthcare professionals need to be prepared for alteration in the caregiver's emotional and physical health that results from the demands of caregiving. Professionals need to recognize that adult children may be responsible for the care of multiple parents at one time or sequentially. As a result, some adult children face cumulative loss and strain (Ziemba, 2002).

Conclusions

Caregiving can be a time of great meaning and potential benefit, and if the professional enhances the caregiving experience to strengthen the positive outcomes, it may contribute to pleasant memories of time well spent with the elder parent. The adult child can internalize caregiving in terms of life tasks and goals and the importance of family caring relationships to grow and gain meaning from the experience. Caregiver and family well-being can be promoted by recognizing the benefits of elder caregiving and strengthening those aspects of care. Anticipating the intergenerational caregiving needs and predictors that will enhance or mediate a positive caregiving experience can benefit the well-being of the elder, the caregiver, families, and society-at-large.

APPENDIX A: 1999 NLTCS Caregiver Survey

Final Version December 20, 2002: Section A - AMOUNTS AND KINDS OF HELP		
VERIFY CASE **FR:** Verify that you have the correct case. CGNAME Col. Char 42 CGPHN_AR Col. Char 3 CGPHN_EX Col. Char 4 CGPHN_NM Col. Char 7		☐ Blank ☐ Blank ☐ Blank ☐ Blank
NOTE TO INTERVIEWER: IF PERSONAL VISIT, HAND CAREGIVER A COPY OF THE CAREGIVER ADVANCE LETTER. ALLOW ENOUGH TIME FOR HIM/HER TO READ IT IF HE/SHE SO DESIRES Hello. I am (interviewer's name) from the United States Bureau of the Census. We are taking a survey of Long Term Care in the United States. This is a survey of health conditions and physical activities of persons 65 years of age and over who live in the United States. We have some additional questions to ask regarding [caregiver's] experience in helping [sample person]. May I speak to [caregiver]? CG_OPEN Col. 9289 Char 1	1 2 3	☐ Yes - SKIP to BEGIN CAREGIVER ☐ No - Inconvenient Time. Set OUTCOME=207 and hold pending rescheduling ☐ No - Noninterview
CHECK REASON **FR:** What is the reason you can't conduct an interview?	1 2 3 4 5 6 7 8 9 10	☐ No one home ☐ Temporarily absent ☐ Refused ☐ Unable to locate ☐ Language problem; no ☐ Type A Other - specify ☐ Armed Forces ☐ Correction Facility ☐ Deceased ☐ Mover } Set OUTCOME = 208 and SKIP to Control Card FINISH
BEGIN CAREGIVER Set AKH Start Time and Date: START_26 Col. 9290 Char 4 CGDAY1 Col. 9294 Char 6	00-23 00-59	☐ Hours ☐ Minutes ☐ MMDDYY
1. Are you paid to help [sample person]? AKH_1 Col. 9300 Char 1	1 2	☐ Yes ☐ No
2. I am going to mention some activities for which a person might need help, and ask whether you helped [sample person] with them in the past week. Did you - a. Help [sample person] walk around inside or get around inside with a wheelchair or similar device? AKH_AD_A Col. 9301 Char 1	1 2 3	☐ Yes ☐ No ☐ Does NOT get around inside at all
b. Help [sample person] eat? AKH_AD_B Col. 9302 Char 1	1 2 3	☐ Yes ☐ No ☐ Does NOT eat at all
c. Help [sample person] get in or out of bed? AKH_AD_C Col. 9303 Char 1	1 2 3	☐ Yes ☐ No ☐ Does NOT get out of bed at all
d. Help [sample person] get dressed - by getting and putting on the clothes [he/she] wears during the day? AKH_AD_D Col. 9304 Char 1	1 2 3	☐ Yes ☐ No ☐ Does NOT get dressed at all
e. Give [sample person] shots or injections?	1	☐ Yes

	AKH_AD_E Col. 9305 Char 1	2 ☐ No 3 ☐ Does NOT get shots or injections
f.	Give [sample person] medicine, pills, or change [his/her] bandages? AKH_AD_F Col. 9306 Char 1	1 ☐ Yes 2 ☐ No 3 ☐ Does NOT take medicine
	If "yes" was answered to any part (a. thru f.) of the question above, ask only the relevant parts of the question below.	
3.	On the days that you helped, how many times per day, on the average, did you -	
a.	Help [sample person] walk around inside or get around inside with a wheelchair or similar device? AKH_AT_A Col. 9307 Char 2	1-99 ☐ times a day
b.	Help [sample person] eat? AKH_AT_B Col. 9309 Char 2	1-99 ☐ times a day
c.	Help [sample person] get in or out of bed? AKH_AT_C Col. 9311 Char 2	
d.	Help [sample person] get dressed - by getting and putting on the clothes [he/she] wears during the day? AKH_AT_D Col. 9313 Char 2	1-99 ☐ times a day
e.	Give [sample person] shots or injections? AKH_AT_E Col. 9315 Char 2	1-99 ☐ times a day
f.	Give [sample person] medicine, pills, or change [his/her] bandages? AKH_AT_F Col. 9317 Char 2	1-99 ☐ times a day
4. a.	In the past week, that is since last [day], did you help [sample person] bathe by helping [him/her] get into or out of the bathtub or shower, or by washing [him/her] in a bathtub or shower or at a sink or basin? AKH_BTH1 Col. 9319 Char 1	1 ☐ Yes 2 ☐ No 3 ☐ Does not bathe at all } SKIP to 5 D,R ☐
b.	How many times in the past week did you help [sample person] bathe? AKH_BTH2 Col. 9320 Char 2	☐ times a day
c.	Did you actually bathe [sample person]? AKH_BTH3 Col. 9322 Char 1	1 ☐ Yes 2 ☐ No
5.	In the past week did you help [sample person] do any of the following? Did you help [sample person] -	
a.	Use the toilet by helping [him/her] get on or off the toilet, by arranging [his/her] clothes, or by cleaning [him/her]? AKH_TO_A Col. 9323 Char 1	1 ☐ Yes 2 ☐ No
b.	With a bed pan? AKH_TO_B Col. 9324 Char 1	1 ☐ Yes 2 ☐ No
c.	With a catheter or colostomy bag? AKH_TO_C Col. 9325 Char 1	1 ☐ Yes 2 ☐ No
d.	Clean up after bladder or bowel accidents? AKH_TO_D Col. 9326 Char 1	1 ☐ Yes 2 ☐ No
	If "yes" was answered to any part (a. thru d.) of the question above, ask only the relevant parts of the question below.	
6.	On the days that you helped, how many times per day, on the average, did you help [sample person] -	
a.	Use the toilet by helping [him/her] get on or off the toilet, by arranging [his/her] clothes, or by cleaning [him/her]? AKH_TT_A Col. 9327 Char 2	1-99 ☐ Times per day
b.	With a bed pan? AKH_TT_B Col. 9329 Char 2	1-99 ☐ Times per day
c.	With a catheter or colostomy bag?	1-99 ☐ Times per day

AKH_TT_C Col. 9331 Char 2		
d. Clean up after bladder or bowel accidents? AKH_TT_D Col. 9333 Char 2	1-99	☐ Times per day
If "yes" was answered to any part (a. thru d.) of question 6, ask the next question		
7. a. Does helping [sample person] [with any of the four activities in question 5] ever bother you? AKH_BOT1 Col. 9335 Char 1	1 2 D,R	☐ Yes ☐ No - SKIP to 8 ☐ - SKIP to 8
b. How much does it bother you? AKH_BOT2 Col. 9336 Char 1	1 2 3	☐ A great deal ☐ Somewhat ☐ Not too much
8. In the past week did you, BECAUSE OF [sample person]'s DISABILITY, help [him/her] by -		
a. Preparing special foods or fixing extra meals? AKH_ID_A Col. 9337 Char 1	1 2	☐ Yes ☐ No
b. Managing [sample person]'s money, like keeping track of bills or handling cash? AKH_ID_B Col. 9338 Char 1	1 2	☐ Yes ☐ No
c. Making telephone calls for [sample person]? AKH_ID_C Col. 9339 Char 1	1 2	☐ Yes ☐ No
d. Doing things around the house, such as straightening up, putting things away, or doing dishes? AKH_ID_D Col. 9340 Char 1	1 2	☐ Yes ☐ No
e. Doing [sample person]'s laundry? AKH_ID_E Col. 9341 Char 1	1 2	☐ Yes ☐ No
f. Shopping for [sample person]'s groceries? AKH_ID_F Col. 9342 Char 1	1 2	☐ Yes ☐ No
g. Doing other small errands for [sample person] outside of the house? AKH_ID_G Col. 9343 Char 1	1 2	☐ Yes ☐ No
h. Helping [sample person] get around outside, including helping [him/her] walk or use a wheelchair or walker? AKH_ID_H Col. 9344 Char 1	1 2	☐ Yes ☐ No
i. Helping [sample person] get around the neighborhood or city by driving [him/her] or helping [him/her] use public transportation? AKH_ID_I Col. 9345 Char 1	1 2	☐ Yes ☐ No
If "yes" was answered to any part (a. thru i.) of the question above, ask only the relevant parts of the question below.		
9. In the past week how many times did you help [sample person] by -		
a. Preparing special foods or fixing extra meals? AKH_IT_A Col. 9346 Char 2	1-99	☐ Times
b. Managing [sample person]'s money, like keeping track of bills or handling cash? AKH_IT_B Col. 9348 Char 2	1-99	☐ Times
c. Making telephone calls for [sample person]? AKH_IT_C Col. 9350 Char 2	1-99	☐ Times
d. Doing things around the house, such as straightening up, putting things away, or doing dishes? AKH_IT_D Col. 9352 Char 2	1-99	☐ Times
e. Doing [sample person]'s laundry? AKH_IT_E Col. 9354 Char 2	1-99	☐ Times
f. Shopping for [sample person]'s groceries? AKH_IT_F Col. 9356 Char 2	1-99	☐ Times
g. Doing other small errands for [sample person] outside of the	1-99	☐ Times

	house? AKH_IT_G Col. 9358 Char 2		
h.	Helping [sample person] get around outside, including helping [him/her] walk or use a wheelchair or walker? AKH_IT_H Col. 9360 Char 2	1-99	☐ Times
i.	Helping [sample person] get around the neighborhood or city by driving [him/her] or helping [him/her] use public transportation? AKH_IT_I Col. 9362 Char 2	1-99	☐ Times
10.	On average, about how many hours do you spend helping [sample person] in a typical week? AKH_GEN Col. 9364 Char 3	0-168	☐ Hours
11. a.	Can [sample person] be left at home without anyone else present? AKH_6A Col. 9367 Char 1	1 2 D,R	☐ Yes ☐ No - SKIP to 12a ☐ - SKIP to 12a
b.	How many hours at a time, on the average, can [sample person] be left at home with no one else present? Record the number of hours, OR AKH_6B_H Col. 9368 Char2 Record less than 1 hour, or no limit AKH_6B_O Col. 9370 Char 1	0-99 1 2	☐ Hours, OR ☐ Less than 1 hour ☐ No limit
12. a.	Can [sample person] be left alone in a room as long as someone else is at home? AKH_6C Col. 9371 Char 1	1 2	☐ Yes ☐ No--SKIP to 13
b.	How many hours at a time, on the average, can [sample person] be left alone in a room? Record the number of hours, OR AKH_6D_H Col. 9372 Char2 Record less than 1 hour, or no limit AKH_6D_O Col. 9374 Char 1	0-99 1 2	☐ Hours, OR ☐ Less than 1 hour ☐ No limit
13. a.	Is your sleep ever interrupted because you have to take care of [sample person]? AKH_7A Col. 9375 Char 1	1 2 D,R	☐ Yes ☐ No - SKIP to 14 ☐ - SKIP to 14
b.	About how many times in an average week is your sleep interrupted because you have to take care of [sample person]? AKH_7B Col. 9376 Char 2	0-99	☐ Times
14.	Now, I am going to read some statements that describe some problems or inconveniences that many people have when they take care of another person. As I read each statement, please tell me if that statement is TRUE or FALSE for you when you take care of [sample person]		
a.	I have to take care of [sample person] when I don't feel well enough. AKH_8_A Col. 9378 Char 1	1 2	☐ TRUE ☐ FALSE
b.	[Sample person] needs special medical care that I cannot give. AKH_8_B Col. 9379 Char 1	1 2	☐ TRUE ☐ FALSE
c.	Taking care of [sample person] is hard on me emotionally. AKH_8_C Col. 9380 Char 1	1 2	☐ TRUE ☐ FALSE
	This time, tell me if the statement is TRUE, FALSE, or does not apply.		
d.	Lifting or moving [sample person] is difficult. AKH_8_D Col. 9381 Char 1	1 2 3	☐ TRUE ☐ FALSE ☐ Does not apply
END AKH Set End Time		0-23	

END_AKH Col. 9382 Char 4	0-59	☐ HHMM
Subtract AKH start time from AKH end time CUML_AKH Col. 9386 Char 4	0000- 9999	☐ Minutes
Section B - HELP FROM OTHERS		
Set A41Start Time Time: START_27 Col. 9390 Char 4	0-23, 0-59	☐ HHMM
1. If you were unable to help [sample person], is there someone else who would do the things you do? HFO_1 Col. 9394 Char 1	1 2	☐ Yes ☐ No
2. Have you ever received any respite or caregiver support services from a government source to assist you in providing care for [sample person]? HFO_2 Col. 9395 Char 1	1 2	☐ Yes ☐ No
3. There are many services available to help you provide help to an older person such as [sample person]. Please tell me whether you have ever used the following service or not. a. Have you ever requested information about how to get financial help for [sample person]? HFO_3A Col. 9396 Char 1	1 2 D,R	☐ Yes ☐ No - SKIP to 3d ☐ - SKIP to 4a
b. Who provided you with this service? HFO_3B_1 Col. 9397 Char 1	1 2 3 4 5 6	☐ Church or synagogue ☐ Community or government agency ☐ Caregiver's employer ☐ Individual or private agency for which caregiver is paying ☐ Doctor, pharmacist, social worker, other health provider ☐ Other - Specify in HFO_3B_S HFO_3B_S Col. Char30 (blank)
c. How would you rate that financial information service? Did it meet your needs fully, only partly, or not at all? HFO_3C Col. 9398 Char 1	1 2 3	☐ Did not meet needs at all ☐ Partly met needs ☐ Fully met needs } SKIP to 4a
d. For what reasons have you never done this? HFO_3D_1 Col. 9399 Char 2	1 2 3 4 5 6 7 8 9 10 11	☐ Had no need for it ☐ Service is not available ☐ Not aware of service ☐ Cost, can't afford ☐ Can't find qualified people ☐ Don't want an outsider coming in/strangers ☐ Bureaucracy too complex, hassle, couldn't access service ☐ Language barrier ☐ Not eligible, make too much money, income too high ☐ No special reason/never thought of it ☐ Other - Specify in HFO_3D_S below HFO_3D_S Col. Char 30 (blank)
4. a. Have you ever taken part in support groups for caregivers? HFO_4A Col. 9401 Char 1	1 2 D,R	☐ Yes ☐ No - SKIP to 4d ☐ - SKIP to 5a
b. Who provided you with this service? HFO_4B_1 Col. 9402 Char 1	1 2 3 4 5 6	☐ Church or synagogue ☐ Community or government agency ☐ Caregiver's employer ☐ Individual or private agency for which caregiver is paying ☐ Doctor, pharmacist, social worker, other health provider ☐ Other - Specify in HFO_4B_S below HFO_4B_S Col. Char 30 (blank)

c. How would you rate that support group? Did it meet your needs fully, only partly, or not al all? HFO_4C Col. 9403 Char 1	1 2 3	☐ Did not meet needs at all ☐ Partly met needs ☐ Fully met needs } SKIP to 5a
d. For what reasons have you never done this? HFO_4D_1 Col. 9404 Char 2	1 2 3 4 5 6 7 8 9 10 11	☐ Had no need for it ☐ Service is not available ☐ Not aware of service ☐ Cost, can't afford ☐ Can't find qualified people ☐ Don't want an outsider coming in/strangers ☐ Bureaucracy too complex, hassle, couldn't access service ☐ Language barrier ☐ Not eligible, make too much money, income too high ☐ No special reason/never thought of it ☐ Other - Specify in HFO_4D_S below HFO_4D_S Col. Char 30 (blank)
5. a. Have you ever used a service to temporarily take care of [sample person] so that you get some time away? HFO_5A Col. 9406 Char 1	1 2 D,R	☐ Yes ☐ No - SKIP to 5d ☐ - SKIP to 6a
b. Who provided you with this service? HFO_5B_1 Col. 9407 Char 1	1 2 3 4 5 6	☐ Church or synagogue ☐ Community or government agency ☐ Caregiver's employer ☐ Individual or private agency for which caregiver is paying ☐ Doctor, pharmacist, social worker, other health provider ☐ Other - Specify in HFO_5B_S below HFO_5B_S Col. Char 30 (blank)
c. How would you rate that temporary care service? Did it meet your needs fully, only partly, or not al all? HFO_5C Col. 9408 Char 1	1 2 3	☐ Did not meet needs at all ☐ Partly met needs ☐ Fully met needs } SKIP to 6a
d. For what reasons have you never done this? HFO_5D_1 Col. 9409 Char 2	1 2 3 4 5 6 7 8 9 10 11	☐ Had no need for it ☐ Service is not available ☐ Not aware of service ☐ Cost, can't afford ☐ Can't find qualified people ☐ Don't want an outsider coming in/strangers ☐ Bureaucracy too complex, hassle, couldn't access service ☐ Language barrier ☐ Not eligible, make too much money, income too high ☐ No special reason/never thought of it ☐ Other - Specify in HFO_5D_S below HFO_5D_S Col. Char 30 (blank)
6. a. Have you ever enrolled [sample person] in a program outside the home such as an Adult Day Care or senior center? HFO_6A Col. 9411 Char 1	1 2 D,R	☐ Yes ☐ No - SKIP to 6d ☐ - SKIP to 7a
b. Who provided you with this service? HFO_6B_1 Col. 9412 Char 1	1 2 3 4 5 6	☐ Church or synagogue ☐ Community or government agency ☐ Caregiver's employer ☐ Individual or private agency for which caregiver is paying ☐ Doctor, pharmacist, social worker, other health provider ☐ Other - Specify in HFO_6B_S below HFO_6B_S Col. Char 30 (blank)
c. How would you rate that Adult Day Care/senior center? Did it	1	☐ Did not meet needs at all }

	meet your needs fully, only partly, or not at all? HFO_6C Col. 9413 Char 1	2 3	☐ Partly met needs ☐ Fully met needs } SKIP to 7a
d.	For what reasons have you never done this? HFO_6D_1 Col. 9414 Char 2	1 2 3 4 5 6 7 8 9 10 11	☐ Had no need for it ☐ Service is not available ☐ Not aware of service ☐ Cost, can't afford ☐ Can't find qualified people ☐ Don't want an outsider coming in/strangers ☐ Bureaucracy too complex, hassle, couldn't access service ☐ Language barrier ☐ Not eligible, make too much money, income too high ☐ No special reason/never thought of it ☐ Other - Specify in HFO_6D_S below HFO_6D_S Col. Char 30 (blank)
7. a.	Have you ever had a service come help with personal care or nursing care at [sample person]'s home? HFO_7A Col. 9416 Char 1	1 2 D,R	☐ Yes ☐ No - SKIP to 7d ☐ - SKIP to 8a
b.	Who provided you with this service? HFO_7B_1 Col. 9417 Char 1	1 2 3 4 5 6	☐ Church or synagogue ☐ Community or government agency ☐ Caregiver's employer ☐ Individual or private agency for which caregiver is paying ☐ Doctor, pharmacist, social worker, other health provider ☐ Other - Specify in HFO_7B_S below HFO_7B_S Col. Char 30 (blank)
c.	How would you rate that personal, or nursing care service? Did it meet your needs fully, only partly, or not at all? HFO_7C Col. 9418 Char 1	1 2 3	☐ Did not meet needs at all ☐ Partly met needs ☐ Fully met needs } SKIP to 8a
d.	For what reasons have you never done this? HFO_7D_1 Col. 9419 Char 2	1 2 3 4 5 6 7 8 9 10 11	☐ Had no need for it ☐ Service is not available ☐ Not aware of service ☐ Cost, can't afford ☐ Can't find qualified people ☐ Don't want an outsider coming in/strangers ☐ Bureaucracy too complex, hassle, couldn't access service ☐ Language barrier ☐ Not eligible, make too much money, income too high ☐ No special reason/never thought of it ☐ Other - Specify in HFO_7D_S below HFO_7D_S Col. Char 30 (blank)
8. a.	Have you ever had a service come help you with housework at [sample person]'s home? HFO_8A Col. 9421 Char 1	1 2 D,R	☐ Yes ☐ No - SKIP to 8d ☐ - SKIP to 9a
b.	Who provided you with this service? HFO_8B_1 Col. 9422 Char 1	1 2 3 4 5 6	☐ Church or synagogue ☐ Community or government agency ☐ Caregiver's employer ☐ Individual or private agency for which caregiver is paying ☐ Doctor, pharmacist, social worker, other health provider ☐ Other - Specify in HFO_8B_S below HFO_8B_S Col. Char 30 (blank)
c.	How would you rate that housework? Did it meet your needs fully, only partly, or not at all?	1 2	☐ Did not meet needs at all ☐ Partly met needs } SKIP to 9a

HFO_8C Col. 9423 Char 1	3	Fully met needs
d. For what reasons have you never done this? HFO_8D_1 Col. 9424 Char 2	1 2 3 4 5 6 7 8 9 10 11	Had no need for it Service is not available Not aware of service Cost, can't afford Can't find qualified people Don't want an outsider coming in/strangers Bureaucracy too complex, hassle, couldn't access service Language barrier Not eligible, make too much money, income too high No special reason/never thought of it Other - Specify in HFO_8D_S below HFO_8D_S Col. Char 30 (blank)
9. a. Have you ever had an outside service deliver meals to [sample person]'s home? HFO_9A Col. 9426 Char 1	1 2 D,R	Yes No - SKIP to 9d - SKIP to 10a
b. Who provided you with this service? HFO_9B_1 Col. 9427 Char 1	1 2 3 4 5 6	Church or synagogue Community or government agency Caregiver's employer Individual or private agency for which caregiver is paying Doctor, pharmacist, social worker, other health provider Other - Specify in HFO_9B_S below HFO_9B_S Col. Char 30 (blank)
c. How would you rate that meal service? Did it meet your needs fully, only partly, or not at all? HFO_9C Col. 9428 Char 1	1 2 3	Did not meet needs at all Partly met needs Fully met needs } SKIP to 10a
d. For what reasons have you never done this? HFO_9D_1 Col. 9429 Char 2	1 2 3 4 5 6 7 8 9 10 11	Had no need for it Service is not available Not aware of service Cost, can't afford Can't find qualified people Don't want an outsider coming in/strangers Bureaucracy too complex, hassle, couldn't access service Language barrier Not eligible, make too much money, income too high No special reason/never thought of it Other - Specify in HFO_9D_S below HFO_9D_S Col. Char 30 (blank)
10. a. Have you ever had an outside service provide transportation for [sample person]? HFO_10A Col. 9431 Char 1	1 2 D,R	Yes No - SKIP to 10d - SKIP to 11a
b. Who provided you with this service? HFO_10B1 Col. 9432 Char 1	1 2 3 4 5 6	Church or synagogue Community or government agency Caregiver's employer Individual or private agency for which caregiver is paying Doctor, pharmacist, social worker, other health provider Other - Specify in HFO_10BS below HFO_10BS Col. Char 30 (blank)
c. How would you rate that transportation service? Did it meet your needs fully, only partly, or not at all? HFO_10C Col. 9433 Char 1	1 2 3	Did not meet needs at all Partly met needs Fully met needs } SKIP to 11a

d. For what reasons have you never done this? HFO_10D1 Col. 9434 Char 2	1 ☐ Had no need for it 2 ☐ Service is not available 3 ☐ Not aware of service 4 ☐ Cost, can't afford 5 ☐ Can't find qualified people 6 ☐ Don't want an outsider coming in/strangers 7 ☐ Bureaucracy too complex, hassle, couldn't access service 8 ☐ Language barrier 9 ☐ Not eligible, make too much money, income too high 10 ☐ No special reason/never thought of it 11 ☐ Other - Specify IN HFO_10D2 BELOW HFO_10D2 Col. Char 30 (blank)	
11. a. Have you ever had modifications made in [SAMPNAME]'s house to make things easier for [him/her]? HFO_11A Col. 9436 Char 1	1 ☐ Yes 2 ☐ No - SKIP to 11d D,R ☐ - SKIP to 12a	
b. Who provided you with this service? HFO_11B1 Col. 9437 Char 1	1 ☐ Church or synagogue 2 ☐ Community or government agency 3 ☐ Caregiver' s employer 4 ☐ Individual or private agency for which caregiver is paying 5 ☐ Doctor, pharmacist, social worker, other health provider 6 ☐ Other - Specify in HFO_11B2 below HFO_11B2 Col. Char 30 (blank)	
c. How would you rate that home modification? Did it meet your needs fully, only partly, or not at all? HFO_11C Col. 9438 Char 1	1 ☐ Did not meet needs at all 2 ☐ Partly met needs 3 ☐ Fully met needs	} SKIP to 12a
d. For what reasons have you never done this? HFO_11D1 Col. 9439 Char 2	1 ☐ Had no need for it 2 ☐ Service is not available 3 ☐ Not aware of service 4 ☐ Cost, can' t afford 5 ☐ Can' t find qualified people 6 ☐ Don' t want an outsider coming in/strangers 7 ☐ Bureaucracy too complex, hassle, couldn' t access service 8 ☐ Language barrier 9 ☐ Not eligible, make too much money, income too high 10 ☐ No special reason/never thought of it 11 ☐ Other - Specify in HFO_11D2 below HFO_11D2 Col. Char 30 (blank)	
12. a. Have you ever obtained assistive devices, such as wheelchairs, walkers, etc., for [sample person]? HFO_12A Col. 9441 Char 1	1 ☐ Yes 2 ☐ No - SKIP to 12d D,R ☐ - SKIP to 13	
b. Who provided you with this service? HFO_12B1 Col. 9442 Char 1	1 ☐ Church or synagogue 2 ☐ Community or government agency 3 ☐ Caregiver' s employer 4 ☐ Individual or private agency for which caregiver is paying 5 ☐ Doctor, pharmacist, social worker, other health provider 6 ☐ Other - Specify in HFO_12B2 below HFO_12B2 Col. Char 30 (blank)	
c. How would you rate that wheelchair, walker, or other assistive device? Did it meet your needs fully, only partly, or not at all? HFO_12C Col. 9443 Char 1	1 ☐ Did not meet needs at all 2 ☐ Partly met needs 3 ☐ Fully met needs	} SKIP to 13

d. For what reasons have you never done this?
HFO_12D1 Col. 9444 Char 2

1 ☐ Had no need for it
2 ☐ Service is not available
3 ☐ Not aware of service
4 ☐ Cost, can't afford
5 ☐ Can't find qualified people
6 ☐ Don't want an outsider coming in/strangers
7 ☐ Bureaucracy too complex, hassle, couldn't access service
8 ☐ Language barrier
9 ☐ Not eligible, make too much money, income too high
10 ☐ No special reason/never thought of it
11 ☐ Other - Specify in HFO_12D2 below
HFO_12D2 Col. Char 30 (blank)

13. INTERVIEWER: RECORD UP TO 2 RESPONSES. ENTER "N" FOR NOTHING

a. Sometimes, people who provide care to an older person could use some assistance. Please think about your situation, and tell me any kinds of help, information, or support that you would use as a caregiver. Response number 1:
HFO_13_1 Col. 9446 Char 2

1 ☐ Extra money; more money to help pay for things; financial support
2 ☐ Free time; time for myself, a break
3 ☐ A central place to go/to call to find out what kind of help is available/where to get it
4 ☐ Someone to talk to/counseling/support group
5 ☐ Help with housekeeping
6 ☐ Help with shopping
7 ☐ Help with transportation, getting to places
8 ☐ Help with making meals
9 ☐ Help with bathing, dressing, grooming, toileting, feeding, other personal care
10 ☐ Help with medicines (administering, side effects, etc.)
11 ☐ Information about [sample person]'s condition
12 ☐ Information about developments or changes in laws which might affect your situation
13 ☐ Help in understanding how to select nursing home/ group home/other facility
14 ☐ Help in understanding how to pay for nursing homes, adult day care, or other services (financing)
15 ☐ Information about services for persons with Alzheimer's/memory problems
16 ☐ Help dealing with bureaucracy to get services
17 ☐ Tax break, stipend, government subsidy
18 ☐ Other - Specify in HFO_13_3 below
HFO_13_3 Col. 9448 Char 30

b. Response number 2:
HFO_13_4 Col. 9478 Char 2

1 ☐ Extra money; more money to help pay for things; financial support
2 ☐ Free time; time for myself, a break
3 ☐ A central place to go/to call to find out what kind of help is available/where to get it
4 ☐ Someone to talk to/counseling/support group
5 ☐ Help with housekeeping
6 ☐ Help with shopping
7 ☐ Help with transportation, getting to places
8 ☐ Help with making meals
9 ☐ Help with bathing, dressing, grooming, toileting, feeding, other personal care
10 ☐ Help with medicines (administering, side effects, etc.)

	11 ☐ Information about [sample person]'s condition 12 ☐ Information about developments or changes in laws which might affect your situation 13 ☐ Help in understanding how to select nursing home/ group home/other facility 14 ☐ Help in understanding how to pay for nursing homes, adult day care, or other services (financing) 15 ☐ Information about services for persons with Alzheimer's/memory problems 16 ☐ Help dealing with bureaucracy to get services 17 ☐ Tax break, stipend, government subsidy 18 ☐ Other - Specify in HFO_13_5 below HFO_13_5 Col. 9480 Char 30
END HFO Set End Time END_HFO Col. 9510 Char 4	0-23 0-59 ☐ HHMM
Subtract HFO start time from HFO end time CUML_HFO Col. 9514 Char 4	0000- 9999 ☐ Minutes
Section C - CAREGIVER'S EXPERIENCE	
Set Start Time START_28 Col. 9518 Char 4	0-59 ☐ HHMM
1. Now I am going to read some statements that describe some other problems people sometimes have when taking care of another person. As I read each statement, please tell me if that statement is TRUE or FALSE for you, when you take care of [sample person].	
a. I don't have as much privacy when I take care of [sample person]. CGE_1_A Col. 9522 Char 1	1 ☐ TRUE 2 ☐ FALSE
b. Taking care of [sample person] limits my social life or free time. CGE_1_B Col. 9523 Char 1	1 ☐ TRUE 2 ☐ FALSE
c. I have to give [sample person] almost constant attention. CGE_1_C Col. 9524 Char 1	1 ☐ TRUE 2 ☐ FALSE
d. Taking care of [sample person] has caused my health to get worse. CGE_1_D Col. 9525 Char 1	1 ☐ TRUE 2 ☐ FALSE
e. Care costs more than I can really afford. CGE_1_E Col. 9526 Char 1	1 ☐ TRUE 2 ☐ FALSE
2. On a scale from 1 to 5, where 1 is not a strain at all and 5 is very much of a strain, how much of a physical strain would you say that caring for [sample person] is for you? CGE_2 Col. 9527 Char 1	1 ☐ not a strain at all 2 ☐ 3 ☐ 4 ☐ 5 ☐ Very much of a strain
3. Using the scale from 1 to 5, where 1 is not at all stressful and 5 is very stressful, how emotionally stressful would you say that caring for [sample person] is for you? CGE_3 Col. 9528 Char 1	1 ☐ Not at all stressful 2 ☐ 3 ☐ 4 ☐ 5 ☐ Very stressful
4. Using the same scale from 1 to 5 where 1 is no hardship at all and 5 is a great deal of hardship, how much of a financial hardship would you say that caring for [sample person] is? CGE_4 Col. 9529 Char 1	1 ☐ No hardship at all 2 ☐

	3 ☐ 4 ☐ 5 ☐	Great deal of hardship
5. Here are some statements about your energy level and the time it takes to do the things you have to do. How much does each statement describe you?		
a. You are exhausted when you go to bed at night. CGE_5_A Col. 9530 Char 1	1 ☐ 2 ☐ 3 ☐ 4 ☐	Not at all Somewhat Quite a lot Completely
b. You have more things to do then you can handle. CGE_5_B Col. 9531 Char 1	1 ☐ 2 ☐ 3 ☐ 4 ☐	Not at all Somewhat Quite a lot Completely
c. You don't have time just for yourself. CGE_5_C Col. 9532 Char 1	1 ☐ 2 ☐ 3 ☐ 4 ☐	Not at all Somewhat Quite a lot Completely
d. You work hard as a caregiver but never seem to make any progress. CGE_5_D Col. 9533 Char 1	1 ☐ 2 ☐ 3 ☐ 4 ☐	Not at all Somewhat Quite a lot Completely
6. On a scale from 1 to 10 where 1 is not much stress at all, and 10 is a great deal of stress, how much stress does it cause you to do all of the things you do to help [sample person]? CGE_6 Col. 9534 Char 2	1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 ☐	Not much stress at all Great deal of stress
7. Providing help to [sample person] has -		
a. Made me feel good about myself. CGE_7_A Col. 9536 Char 1	1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐	Disagree a lot Disagree a little Neither agree or disagree Agree a little Agree a lot
b. Enabled me to appreciate life more. CGE_7_B Col. 9537 Char 1	1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐	Disagree a lot Disagree a little Neither agree or disagree Agree a little Agree a lot
8. In the past week, on how many days did you personally have to deal with the following behavior of [sample person]? How many days did [he/she]:		
a. Keep you up at night CGE_8_A Col. 9538 Char 1	1 ☐ 2 ☐ 3 ☐ 4 ☐	No days 1-2 days 3-4 days 5 or more days
b. Repeat questions/stories CGE_8_B Col. 9539 Char 1	1 ☐ 2 ☐ 3 ☐ 4 ☐	No days 1-2 days 3-4 days 5 or more days
c. Try to dress the wrong way CGE_8_C Col. 9540 Char 1	1 ☐ 2 ☐ 3 ☐	No days 1-2 days 3-4 days

	4	5 or more days
d. Have a bowel or bladder accident CGE_8_D Col. 9541 Char 1	1 2 3 4	No days 1-2 days 3-4 days 5 or more days
e. Hide belongings and forget about them CGE_8_E Col. 9542 Char 1	1 2 3 4	No days 1-2 days 3-4 days 5 or more days
f. Cry easily CGE_8_F Col. 9543 Char 1	1 2 3 4	No days 1-2 days 3-4 days 5 or more days
g. Act depressed or downhearted CGE_8_G Col. 9544 Char 1	1 2 3 4	No days 1-2 days 3-4 days 5 or more days
In the past week, how many days did [sample person]: h. Cling to you or follow you around CGE_8B_H Col. 9545 Char 1	1 2 3 4	No days 1-2 days 3-4 days 5 or more days
i. Become restless or agitated CGE_8B_I Col. 9546 Char 1	1 2 3 4	No days 1-2 days 3-4 days 5 or more days
j. Become irritable or angry CGE_8B_J Col. 9547 Char 1	1 2 3 4	No days 1-2 days 3-4 days 5 or more days
k. Swear or use foul language CGE_8B_K Col. 9548 Char 1	1 2 3 4	No days 1-2 days 3-4 days 5 or more days
l. Become suspicious, or believe someone is going to harm [him/her] CGE_8B_L Col. 9549 Char 1	1 2 3 4	No days 1-2 days 3-4 days 5 or more days
m. Threaten people CGE_8B_M Col. 9550 Char 1	1 2 3 4	No days 1-2 days 3-4 days 5 or more days
n. Show sexual behavior or interest at the wrong time/place CGE_8B_N Col. 9551 Char 1	1 2 3 4	No days 1-2 days 3-4 days 5 or more days
o. Destroy or damage property CGE_8B_O Col. 9552 Char 1	1 2 3 4	No days 1-2 days 3-4 days 5 or more days
CHECK RELATIONSHIP [Refer to CGREL in Caregiver Selection section of Community Int.] CGREL Col. 8734 Char 2	1 2 3 4 5 6 7 8	Spouse (not used here) Son / Daughter Son-in-law / Daughter-in-law Parent Parent-in-law Brother / Sister Brother-in-law / Sister-in-law

		9 ☐ Grandchild 10 ☐ Other relative 11 ☐ Employee 12 ☐ Other nonrelative 13 ☐ Ex-Spouse	SKIP to 14
9.	Do you feel that other relatives are doing their fair share of caregiving for [sample person]? CGE_9 Col. 9553 Char 1	1 ☐ Yes 2 ☐ No N ☐ Don't have other relative/does not apply--SKIP to 11	
10.	To what extent has there been any family conflict over caregiving regarding [sample person]? Would you say there's been a lot of conflict, some conflict, or none at all? CGE_10 Col. 9554 Char 1	1 ☐ Not at all 2 ☐ Some conflict 3 ☐ A lot of conflict	
11.	Family members may differ among themselves in the way they deal with a relative who is ill. Thinking of all your relatives, how much disagreement have you had with anyone in your family because of the following issues? How much disagreement have you had with anyone in your family because they: a. Don't spend enough time with [sample person]? CGE_11_A Col. 9555 Char 1	1 ☐ No disagreement 2 ☐ Just a little disagreement 3 ☐ Some disagreement 4 ☐ Quite a bit of disagreement	
	b. Don't do their share in caring for [sample person]? CGE_11_B Col. 9556 Char 1	1 ☐ No disagreement 2 ☐ Just a little disagreement 3 ☐ Some disagreement 4 ☐ Quite a bit of disagreement	
	c. Don't show enough respect for [sample person]? CGE_11_C Col. 9557 Char 1	1 ☐ No disagreement 2 ☐ Just a little disagreement 3 ☐ Some disagreement 4 ☐ Quite a bit of disagreement	
	d. Lack patience with [sample person]? CGE_11_D Col. 9558 Char 1	1 ☐ No disagreement 2 ☐ Just a little disagreement 3 ☐ Some disagreement 4 ☐ Quite a bit of disagreement	
12.	I've just asked you how your relatives act toward [sample person]. Now I'd like to ask how they act toward you, the caregiver. Again, thinking of all your relatives, how much disagreement have you had with anyone in your family because of the following issues? How much disagreement have you had with any one in your family because they: a. Don't visit or telephone you enough: CGE_12_A Col. 9559 Char 1	1 ☐ No disagreement 2 ☐ Just a little disagreement 3 ☐ Some disagreement 4 ☐ Quite a bit of disagreement	
	b. Don't give you enough help? CGE_12_B Col. 9560 Char 1	1 ☐ No disagreement 2 ☐ Just a little disagreement 3 ☐ Some disagreement 4 ☐ Quite a bit of disagreement	
	c. Don't show enough appreciation of your work as a caregiver? CGE_12_C Col. 9561 Char 1	1 ☐ No disagreement 2 ☐ Just a little disagreement 3 ☐ Some disagreement 4 ☐ Quite a bit of disagreement	
	d. Give you unwanted advice? CGE_12_D Col. 9562 Char 1	1 ☐ No disagreement 2 ☐ Just a little disagreement 3 ☐ Some disagreement 4 ☐ Quite a bit of disagreement	
13.	Let's turn now to the help and support you get from your friends and relatives. Thinking about your friends and family,		

	other than [sample person], please indicate the extent to which you agree or disagree with the following statements:		
a.	There is really no one who understands what you are going through. CGE_13_A Col. 9563 Char 1	1 2 3 4	☐ Strongly disagree ☐ Disagree ☐ Agree ☐ Strongly agree
b.	The people close to you let you know that they care about you. CGE_13_B Col. 9564 Char 1	1 2 3 4	☐ Strongly disagree ☐ Disagree ☐ Agree ☐ Strongly agree
c.	You have a friend or relative in whose opinion you have confidence. CGE_13_C Col. 9565 Char 1	1 2 3 4	☐ Strongly disagree ☐ Disagree ☐ Agree ☐ Strongly agree
d.	You have someone whom you feel you can trust. CGE_13_D Col. 9566 Char 1	1 2 3 4	☐ Strongly disagree ☐ Disagree ☐ Agree ☐ Strongly agree
e.	You have people around you who help you to keep your spirits up. CGE_13_E Col. 9567 Char 1	1 2 3 4	☐ Strongly disagree ☐ Disagree ☐ Agree ☐ Strongly agree
f.	There are people in your life who make you feel good about yourself. CGE_13_F Col. 9568 Char 1	1 2 3 4	☐ Strongly disagree ☐ Disagree ☐ Agree ☐ Strongly agree
g.	You have at least one friend or relative you can really confide in. CGE_13_G Col. 9569 Char 1	1 2 3 4	☐ Strongly disagree ☐ Disagree ☐ Agree ☐ Strongly agree
h.	You have at least one friend or relative you want to be with when you are feeling down or discouraged. CGE_13_H Col. 9570 Char 1	1 2 3 4	☐ Strongly disagree ☐ Disagree ☐ Agree ☐ Strongly agree
14.	Here are some things that some people do when they are under stress from caregiving. How often do you do them?		
a.	Spend time alone. CGE_14_A Col. 9571 Char 1	1 2 3 4	☐ Never ☐ Once in a while ☐ Fairly often ☐ Very often
b.	Eat CGE_14_B Col. 9572 Char 1	1 2 3 4	☐ Never ☐ Once in a while ☐ Fairly often ☐ Very often
c.	Take some medications to calm yourself CGE_14_C Col. 9573 Char 1	1 2 3 4	☐ Never ☐ Once in a while ☐ Fairly often ☐ Very often
d.	Drink some alcohol CGE_14_D Col. 9574 Char 1	1 2 3 4	☐ Never ☐ Once in a while ☐ Fairly often ☐ Very often
e.	Prayer/Meditation spirits up. CGE_14_E Col. 9575 Char 1	1 2 3 4	☐ Never ☐ Once in a while ☐ Fairly often ☐ Very often
f.	Talk with friends or relatives	1	☐ Never

CGE_14_F Col. 9576 Char 1	2	☐	Once in a while
	3	☐	Fairly often
	4	☐	Very often
g. Spend time on exercise or hobbies	1	☐	Never
CGE_14_G Col. 9577 Char 1	2	☐	Once in a while
	3	☐	Fairly often
	4	☐	Very often
h. Smoke	1	☐	Never
CGE_14_H Col. 9578 Char 1	2	☐	Once in a while
	3	☐	Fairly often
	4	☐	Very often
i. Watch TV	1	☐	Never
CGE_14_I Col. 9579 Char 1	2	☐	Once in a while
	3	☐	Fairly often
	4	☐	Very often
j. Read	1	☐	Never
CGE_14_J Col. 9580 Char 1	2	☐	Once in a while
	3	☐	Fairly often
	4	☐	Very often
k. Get help from a counselor or other professional	1	☐	Never
CGE_14_K Col. 9581 Char 1	2	☐	Once in a while
	3	☐	Fairly often
	4	☐	Very often
l. Other - Code CGE_14_L and explain in CGE_14_S below.	1	☐	Never
CGE_14_L Col. 9582 Char 1	2	☐	Once in a while
CGE_14_S Col. 9583 Char 30	3	☐	Fairly often
	4	☐	Very often
15. There may be or may have been other ways in which providing care to [sample person] affects your life. As a caregiver, have you had:			
a. Less time for other family members than before?	1	☐	Yes
CGE_15_A Col. 9613 Char 1	2	☐	No
b. To give up vacations, hobbies, or your own activities?	1	☐	Yes
CGE_15_B Col. 9614 Char 1	2	☐	No
END CGE			
Set End Time	0-23		
END_CGE Col. 9615 Char 4	0-59	☐	HHMM
Subtract CGE start time from CGE end time	0000-		
CUML_CGE Col. 9619 Char 4	9999	☐	Minutes
Section D - CAREGIVER'S LIVING SITUATION			
Set Start Time			
START_29 Col. 9623 Char 4	0-59	☐	HHMM
CHECK RELATIONSHIP			
Refer to CGREL. Is relationship 'spouse'?	1	☐	Yes - SKIP to 7a
CLS_CK1 Col. 9627 Char 1	2	☐	No
CHECK HH MEM			
Refer to CGHOME. Does caregiver live with sample person?	1	☐	Yes
CLS_CK2 Col. 9628 Char 1	2	☐	No - SKIP to 3
1. a. Did you and [sample person] live together before [he/she] needed your care?	1	☐	Yes - SKIP to 7a
CLS_1A Col. 9629 Char 1	2	☐	No
b. Before you began living together, did you live less than 1 mile away, between 1 and 10 miles away, 10 and 50 miles away, between 50 and 100 miles way, between 100 and 500 miles away, or more than 500 miles away?	1	☐	Less than 1 mile away
	2	☐	Between 1 and 10 miles away
	3	☐	Between 10 and 50 miles away
	4	☐	Between 50 and 100 miles away
CLS_1B Col. 9630 Char 1	5	☐	Between 100 and 500 miles away

			6	☐	More than 500 miles away
2.	a.	If you didn't have to help [sample person] because of [sample person]'s disability, do you think you would still live together in the same household? CLS_2A Col. 9631 Char 1	1 2 D,R	☐ ☐ ☐	Yes - SKIP to 7a No - SKIP to 7a
	b.	Would you live in the same neighborhood, in a different neighborhood but in the same city or town, or somewhere else? CLS_2B Col. 9632 Char 1	1 2 3	☐ ☐ ☐	In the same neighborhood In a different neighborh but in the same city or town Somewhere else } SKIP to 7a
3.		About how long does it take you to get to [sample person]'s house from where you live by the usual way? NOTE: Minutes **OR** Hours CLS_3_MN Col. 9633 Char 2 CLS_3_HR Col. 9635 Char 2			 1-60 ☐ Minutes 1-99 ☐ Hours
4.	a.	Have you ever changed your place of residence because of [sample person]'s disability? CLS_4A Col. 9637 Char 1	1 2 D,R	☐ ☐ ☐	Yes No - SKIP to CLS_5A - SKIP to CLS_5A
	b.	Did you make that move from less than 1 mile away, between 1 and 10 miles away, between 10 and 50 miles away, between 50 and 100 miles away, between 100 and 500 miles away, or more than 500 miles away? CLS_4B Col. 9638 Char 1	1 2 3 4 5 6	☐ ☐ ☐ ☐ ☐ ☐	Less than 1 mile away Between 1 and 10 miles away Between 10 and 50 miles away Between 50 and 100 miles away Between 100 and 500 miles away More than 500 miles away
5.	a.	Has [sample person] ever changed [his/her] place of residence to live closer to you because of [his/her] disability? CLS_5A Col. 9639 Char 1	1 2 D,R	☐ ☐ ☐	Yes No - SKIP to 6a - SKIP to 6a
	b.	Did [sample person] make that move from less than 1 mile away, between 1 and 10 miles away, between 10 and 50 miles away, between 50 and 100 miles away, between 100 and 500 miles away, or more than 500 miles away? CLS_5B Col. 9640 Char 1	1 2 3 4 5 6	☐ ☐ ☐ ☐ ☐ ☐	Less than 1 mile away Between 1 and 10 miles away Between 10 and 50 miles away Between 50 and 100 miles away Between 100 and 500 miles away More than 500 miles away
[Note: Letter c not used.]					
	d.	Did [sample person] move mainly so that it would be more convenient for you to take care of [him/her]? CLS_5D Col. 9641 Char 1	1 2	☐ ☐	Yes No
6.	a.	Have you ever wanted to change your place of residence but did not because you needed to live close to [sample person] because of [sample person]'s disability? CLS_6A Col. 9642 Char 1	1 2 D,R	☐ ☐ ☐	Yes No - SKIP to 7a - SKIP to 7a
	b.	Would you have liked to live in a different neighborhood in the same city or town, or somewhere else? CLS_6B Col. 9643 Char 1	1 2	☐ ☐	Different neighborhood Somewhere else
7.		Often, a person you take care of can be helpful to you. I am going to read you a list of ways people can be helpful. As I read each statement, please tell me if [sample person] has been helpful to you in that way.			
	a.	Helping with household chores CLS_7_1 Col. 9644 Char 1	1 2	☐ ☐	Yes No
	b.	Helping with babysitting CLS_7_2 Col. 9645 Char 1	1 2	☐ ☐	Yes No
	c.	Buying things for me or giving me money CLS_7_3 Col. 9646 Char 1	1 2	☐ ☐	Yes No
	d.	Keeping me company CLS_7_4 Col. 9647 Char 1	1 2	☐ ☐	Yes No
	e.	Making me feel useful and needed CLS_7_5 Col. 9648 Char 1	1 2	☐ ☐	Yes No

f. Another way - Specify CLS_7_6 Col. 9649 Char 1	1 2	☐ ☐	Yes - Specify in CLS_7_S below No CLS_7_S Col. 9650 Char 40
END CLS Set End Time END_CLS Col. 9690 Char 4	0-23 0-59	☐	HHMM
Subtract CLS start time from CLS end time CUML_CLS Col. 9694 Char 4	0000- 9999	☐	Minutes
Section E - CAREGIVER'S WORK SITUATION			
Set Start Time START_30 Col. 9698 Char 4			
1. a. How long ago did you start taking care of [sample person] because of [sample person]'s disability? CWS_1A Col. 9702 Char 1	1 2 3 4 5 6 7 8	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐	Less than 3 months 3 months - less than 6 months 6 months - les than 1 year 1 year - less than 2 years 2 years - less than 4 years 4 years - less than 7 years 7 years - less than 10 years 10 years or more
b. Do you provide more care, less care, or the same amount of care now as you did then? CWS_1B Col. 9703 Char 1	1 2 3 D,R	☐ ☐ ☐ ☐	More Less Same - SKIP to 2a - SKIP to 2a
c. How long ago did you start taking care of [sample person] as much as you do now? CWS_1C Col. 9704 Char 1	1 2 3 4 5 6 7 8	☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐	Less than 3 months 3 months - less than 6 months 6 months - les than 1 year 1 year - less than 2 years 2 years - less than 4 years 4 years - less than 7 years 7 years - less than 10 years 10 years or more
2. We are interested in knowing more about the kinds of people who give care. The next few questions are about you. a. How old are you? CWS_2 Col. 9705 Char 2	15-99 D, R	☐ ☐	YY
b. What is your current marital status? CWS_2B Col. 9707 Char 1	1 2 3 4 5 6	☐ ☐ ☐ ☐ ☐ ☐	Married Widowed Divorced Separated Never Married Partnered, not married
c. **INTERVIEWER: IS CAREGIVER MALE OR FEMALE?** CWS_2C Col. 9708 Char 1	1 2	☐ ☐	Male Female
3. a. Are you currently working for pay at a job or business? CWS_3A Col. 9709 Char 1	1 2 D,R	☐ ☐ ☐	Yes No - SKIP to 4a - SKIP to 4a
b. How many hours per week do you usually work? CWS_3B Col. 9710 Char 3	1-34 35-160	☐	Hours Hours - SKIP to 5a
c. Are you working fewer hours than you would like to because you help [sample person]? CWS_3C Col. 9713 Char 1	1 2 D,R	☐ ☐ ☐	Yes - SKIP to 6a No - SKIP to 5a - SKIP to 5a
4. a. Have you ever worked at a job for pay? CWS_4A Col. 9714 Char 1	1 2 D,R	☐ ☐ ☐	Yes No - SKIP to 10 - SKIP to 10
b. How long ago did you stop working at your last job? CWS_4B Col. 9715 Char 1	1 2 3	☐ ☐ ☐	Less than 3 months 3 months - less than 6 months 6 months - les than 1 year

	4 ☐ 1 year - less than 2 years 5 ☐ 2 years - less than 4 years 6 ☐ 4 years - less than 7 years 7 ☐ 7 years - less than 10 years 8 ☐ 10 years or more
c. What was the MAIN reason you stopped working at that job? CWS_4C_1 Col. 9716 Char 1	1 ☐ Retired 2 ☐ Ill/disabled 3 ☐ Had to take care of [sample person] } SKIP 4 ☐ Wanted to take care of home/family (other than sample person) } to CWS_CK2 5 ☐ Fired/Laid off 6 ☐ Went (back) to school 7 ☐ Other - Specify in CWS_4C_S below D,R ☐ CWS_4C_S Col. Char 40 (blank)
d. Would you have continued working longer if you were not taking care of [sample person]? CWS_4D Col. 9717 Char 1	1 ☐ Yes 2 ☐ No
CWS_CK2 [Refer to 4b and 1a] Did caregiver stop working BEFORE he/she began caring for sample person? CWS_CK2 Col. 9718 Char 1	1 ☐ Yes - SKIP to 9a 2 ☐ No
5. a. Have you ever worked fewer hours a week at a job than you wanted to because you were taking care of [sample person]? CWS_5A Col. 9719 Char 1	1 ☐ Yes 2 ☐ No - SKIP to 6a D,R ☐ - SKIP to 6a
b. How long ago did this happen (the last time)? CWS_5B Col. 9720 Char 1	1 ☐ Less than 3 months 2 ☐ 3 months - less than 6 months 3 ☐ 6 months - les than 1 year 4 ☐ 1 year - less than 2 years 5 ☐ 2 years - less than 4 years 6 ☐ 4 years - less than 7 years 7 ☐ 7 years - less than 10 years 8 ☐ 10 years or more
6. a. Have you ever had to rearrange your schedule at a job because you had to take care of [sample person]? CWS_6A Col. 9721 Char 1	1 ☐ Yes 2 ☐ No - SKIP to 7a D,R - SKIP to 7a
b. How long ago did this happen (the last time)? CWS_6B Col. 9722 Char 1	1 ☐ Less than 3 months 2 ☐ 3 months - less than 6 months 3 ☐ 6 months - les than 1 year 4 ☐ 1 year - less than 2 years 5 ☐ 2 years - less than 4 years 6 ☐ 4 years - less than 7 years 7 ☐ 7 years - less than 10 years 8 ☐ 10 years or more
7. a. (Besides what you have already told me) Have you ever had to take time off without pay from a job because you had to take care of [sample person]? CWS_7A Col. 9723 Char 1	1 ☐ Yes 2 ☐ No - SKIP to 8a D,R - SKIP to 8a
b. How long ago did this happen (the last time)? CWS_7B Col. 9724 Char 1	1 ☐ Less than 3 months 2 ☐ 3 months - less than 6 months 3 ☐ 6 months - les than 1 year 4 ☐ 1 year - less than 2 years 5 ☐ 2 years - less than 4 years 6 ☐ 4 years - less than 7 years 7 ☐ 7 years - less than 10 years 8 ☐ 10 years or more

c.	How long were you off from work without pay (the last time)? **Number:** CWS_7C_N Col. 9725 Char 2 **Units:** CWS_7C_U Col. 9727 Char 1	0-99 ☐ Amount 1 ☐ Hours 2 ☐ Days 3 ☐ Weeks 4 ☐ Months
8. a.	Have you ever had to quit a job because you were taking care of [sample person]? CWS_8A Col. 9728 Char 1	1 ☐ Yes 2 ☐ No - SKIP to 9a D,R - SKIP to 9a
b.	How long ago did this happen (the last time)? CWS_8B Col. 9729 Char 1	1 ☐ Less than 3 months 2 ☐ 3 months - less than 6 months 3 ☐ 6 months - les than 1 year 4 ☐ 1 year - less than 2 years 5 ☐ 2 years - less than 4 years 6 ☐ 4 years - less than 7 years 7 ☐ 7 years - less than 10 years 8 ☐ 10 years or more
9. a.	For whom do or did you work? CWS_9A	☐ Blank
b.	What kind of business is this or was this? CWS_9B Col. 9730 Char 50	☐ Kind of business
c.	What kind of work are or were you doing? CWS_9C Col. 9780 Char 50	☐ Kind of work
d.	What are or were your most important duties? CWS_9D Col. 9830 Char 90	☐ Most important duties
e.	Are you or were you: CWS_9E Col. 9920 Char 1	1 ☐ An employee of a PRIVATE company, business, or individual for wages, salary, or commission? - SKIP to 9g 2 ☐ A FEDERAL government employee? - SKIP to 10 CWS_10 3 ☐ A STATE government employee?--SKIP to 10 4 ☐ A LOCAL government employee?--SKIP to 10 5 ☐ Self-employed in your OWN business, professional practice or farm? D,R ☐ SKIP to 10
f.	Is this business incorporated? CWS_9F Col. 9921 Char 1	1 ☐ Yes 2 ☐ No } SKIP to 10 D,R
g.	Is this or was this a nonprofit organization? CWS_9G Col. 9922 Char 1	1 ☐ Yes 2 ☐ No
10.	Has taking care of [sample person] ever kept you from looking for a job? CWS_10 Col. 9923 Char 1	1 ☐ Yes 2 ☐ No
11. a.	Have you ever had to turn down a job because you were taking care of [sample person]? CWS_11A Col. 9924 Char 1	1 ☐ Yes 2 ☐ No - SKIP to CWS_CK3 D,R - SKIP to CWS_CK3
b.	How long ago did this happen (the last time)? CWS_11B Col. 9925 Char 1	1 ☐ Less than 3 months 2 ☐ 3 months - less than 6 months 3 ☐ 6 months - les than 1 year 4 ☐ 1 year - less than 2 years 5 ☐ 2 years - less than 4 years 6 ☐ 4 years - less than 7 years 7 ☐ 7 years - less than 10 years 8 ☐ 10 years or more
CWS_CK3		

[Refer to 3a, 4a, and 4b] Is caregiver currently or did caregiver ever have to work and take care of the sample person at the same time? CWS_CK3 Col. 9926 Char 1	1 ☐ Yes 2 ☐ No - SKIP to CWS_CK4
12. In your experience as both a worker and caregiver, did you ever . . .	
a. Have to go from working full time to part-time? CWS_12_1 Col. 9927 Char 1	1 ☐ Yes 2 ☐ No
b. Have to take a less demanding job? CWS_12_2 Col. 9928 Char 1	1 ☐ Yes 2 ☐ No
c. Have to turn down a promotion? CWS_12_3 Col. 9929 Char 1	1 ☐ Yes 2 ☐ No
d. Choose early retirement? CWS_12_4 Col. 9930 Char 1	1 ☐ Yes 2 ☐ No
e. Lose any job? CWS_12_5 Col. 9931 Char 1	1 ☐ Yes 2 ☐ No
CWS_CK4 [Refer to 3a] Is caregiver currently working? CWS_CK4 Col. 9932 Char 1	1 ☐ Yes 2 ☐ No - SKIP to END CWS
f. How would you rate your employer's attitude toward the demands of your caregiving: Would you say they were very understanding, somewhat understanding, or not very understanding? CWS_12B Col. 9933 Char 1	1 ☐ Not very understanding 2 ☐ Somewhat understanding 3 ☐ Very understanding 4 ☐ They were not aware of it
13. From your own personal experience, how much do you agree or disagree with the following statements about your present work situation? In the last 2 months or so:	
a. You have had less energy for your work. CWS_13_1 Col. 9934 Char 1	1 ☐ Strongly disagree 2 ☐ Disagree 3 ☐ Agree 4 ☐ Strongly Agree
b. You have missed too many days. CWS_13_2 Col. 9935 Char 1	1 ☐ Strongly disagree 2 ☐ Disagree 3 ☐ Agree 4 ☐ Strongly Agree
c. You have been dissatisfied with the quality of your work. CWS_13_3 Col. 9936 Char 1	1 ☐ Strongly disagree 2 ☐ Disagree 3 ☐ Agree 4 ☐ Strongly Agree
d. You worry about [sample person] while you are at work. CWS_13_4 Col. 9937 Char 1	1 ☐ Strongly disagree 2 ☐ Disagree 3 ☐ Agree 4 ☐ Strongly Agree
e. Phone calls about or from [sample person] interrupt you at work. CWS_13_5 Col. 9938 Char 1	1 ☐ Strongly disagree 2 ☐ Disagree 3 ☐ Agree 4 ☐ Strongly Agree
END CWS Set End Time END_CWS Col. 9939 Char 4	0-23 0-59 ☐ HHMM
Subtract CWS start time from CWS end time CUML_CWS Col. 9943 Char 4	0000- 9999 ☐ Minutes
Section F - GENERAL INFORMATION ON CAREGIVER	
Set Start Date and Start Time Time: START_31 Col. 9947 Char 4	

1.	The next questions are about your health. Since we are talking to a wide variety of people, some of the questions may not seem to apply to you. Even so, it is important that we have complete answers from everyone.	
	a. Compared to other people your age, would you say your health, in general, is excellent, good, fair, or poor? GIC_1A Col. 9951 Char 1	1 ☐ Excellent 2 ☐ Good 3 ☐ Fair 4 ☐ Poor
	b. Do you usually do heavy work around the house such as moving furniture, scrubbing floors, or washing windows OR does someone usually help you do heavy work around the house because of a disability or health problem (including old age)? GIC_HVW Col. 9952 Char 1	1 ☐ Yes-can do heavy work around the house 2 ☐ No-someone helps because of a disability or health problem
	c. Do you usually do light work around the house such as straightening up, putting things away, or washing dishes OR does someone usually help you do light work around the house because of a disability or health problem (including old age)? GIC_LTW Col. 9953 Char 1	1 ☐ Yes-can do light work around the house 2 ☐ No-someone helps because of a disability or health problem
	d. Do you usually do your own laundry OR does someone usually help you do your own laundry because of a disability or health problem (including old age)? GIC_LND Col. 9954 Char 1	1 ☐ Yes-can do own laundry 2 ☐ No-someone helps do laundry because of a disability or health problem
	e. Do you usually prepare your own meals OR does someone usually help you prepare your own meals because of a disability or health problem (including old age)? GIC_MLS Col. 9955 Char 1	1 ☐ Yes-can prepare own meals 2 ☐ No-someone helps prepare meals because of a disability or health problem
	f. Do you usually shop for groceries, that is, go to the store, select the items, and get them home OR does someone usually help you shop for groceries or do it for you because of a disability or health problem (including old age)? GIC_SHP Col. 9956 Char 1	1 ☐ Yes-can shop for groceries 2 ☐ No-someone helps shop for groceries because of a disability or health problem
	g. When you go outside, does someone usually help you get around because of a disability or health problem? GIC_OUTA Col. 9957 Char 1	1 ☐ Yes 2 ☐ No
	h. When you go outside, do you use special equipment like a cane or walker or a guide dog to help you get around because of a disability or health problem? GIC_OUTB Col. 9958 Char 1	1 ☐ Yes 2 ☐ No
	i. How do you USUALLY go places outside of walking distance? GIC_WLK1 Col. 9959 Char 1	1 ☐ Car 2 ☐ Van 3 ☐ Taxi 4 ☐ Bus 5 ☐ Other public transportation 6 ☐ Other - Specify in GIC_WLK2 below 7 ☐ Does not travel at all - SKIP to k GIC_WLK2 Col. 9960 Char 60
	j. Does someone usually help you go places outside of walking distance because of a disability or health problem? GIC_WLK3 Col. 10020 Char 1	1 ☐ Yes 2 ☐ No
	k. Do you usually manage your own money by yourself including things like keeping track of bills or handling cash or does someone help you manage your own money because of a disability or health problem (including old age)? GIC_MON Col. 10021 Char 1	1 ☐ Yes-manage own money 2 ☐ No-someone helps manage money because of a disability or health problem
	l. Does someone usually help you take your medicine because of a disability or health problem?	1 ☐ Yes 2 ☐ No

GIC_MED Col. 10022 Char 1	3	Does not take medicine at all
m. Do you usually make your own telephone calls without the help of another person or does someone usually help you make your own telephone calls because of a disability or health problem (including old age)? GIC_TEL Col. 10023 Char 1	1 2	Yes-can make own telephone calls No-someone helps make calls because of a disability or health problem
GIC_CKHP [Refer to GIC_HVW, GIC_LTW, GIC_LND, GIC_MLS, GIC_SHP, GIC_OUTA, GIC_OUTB, GIC_WLKB,GIC_MON, GIC_TEL] Is caregiver disabled on any of these activities? GIC_CKHP Col. 10024 Char 1	1 2	Yes No - SKIP to GIC_CK1
2. You said that health or age has kept you from doing: [GIC_HVW, GIC_LTW, GIC_LND, GIC_MLS, GIC_SHP, GIC_OUTA, GIC_OUTB, GIC_WLK3, GIC_MON, GIC_TEL]? About how long has your health or age kept you from doing this? **INTERVIEWER:** Probe as necessary, code for longest GIC_IDL1 Col. 10025 Char 1	1 2 3 4 5	Less than 3 months 3 months to less than 6 months 6 months to less than 1 year 1 year to less than 5 years 5 years or over
3. What health conditions, either mental or physical, cause you to have trouble [as indicated by one or more of your answers to GIC_HVW, GIC_LTW, GIC_LND, GIC_MLS, GIC_SHP, GIC_OUTA, GIC_OUTB, GIC_WLK3, GIC_MON, GIC_TEL]? **INTERVIEWER:** Probe for specific condition. Enter verbatim response with each new condition on a separate line. Re-ask until no more conditions named. ENTER N FOR NO OTHER CONDITIONS GIC_ID01 Col. 10026 Char 50 GIC_ID02 Col. 10076 Char 50 GIC_ID03 Col. 10126 Char 50 GIC_ID04 Col. 10176 Char 50 GIC_ID05 Col. 10226 Char 50 GIC_ID06 Col. 10276 Char 50 GIC_ID07 Col. 10326 Char 50 GIC_ID08 Col. 10376 Char 50 GIC_ID09 Col. 10426 Char 50 GIC_ID10 Col. 10476 Char 50	N,D,R	Allow up to 50 characters
GIC_CK13 If only one condition is listed in 2b, SKIP to GIC_CK1		
4. What is the MAIN condition: GIC_ID11 Col. 10526 Char 2	1-10	Condition number from 3 above.
GIC_CK1 [Refer to CGHOME] Is caregiver a member of sample person's household? GIC_CK1 Col. 10528 Char 1	1 2	Yes - Set OUTCOME='201' and SKIP to Control Card FINISH No OUTCOME Col. Char 3
5. Other than yourself, is there anyone else currently living or staying in your home? GIC_HHME Col. 10529 Char 1	1 2 D,R	Yes No - SKIP to 12a - SKIP to 12a
CREATE FAMILY ROSTER		
6. Please give me the name of the person(s) currently living or staying in your home. MEMNAM1 - MEMNAM20		blank
7. What is [MEMNAMbox]'s relationship to you? GICREL1 - Col. 10530 20 * Char 2 GICREL20	2 3 4	Spouse Son/daughter Son-in-law/daughter-in-law

		5 ☐ Parent 6 ☐ Parent-in-law 7 ☐ Brother/sister 8 ☐ Brother-in-law/sister-in-law 9 ☐ Grandchild 10 ☐ Other relative 11 ☐ Employee 12 ☐ Other non-relative
8.	Is [MEMNAMxx] male or female? **INTERVIEWER: FILL WITHOUT ASKING IF APPARENT BY OBSERVATION** GICSEX1 - GICSEX20 Col. 10570 20 * Char 1	1 ☐ Male 2 ☐ Female
9.	How old is [MEMNAMxx] as of today? **INTERVIEWER: IF LESS THAN 1 YEAR OLD, ENTER 1** GICAGE1 - GICAGE20 Col. 10590 20 * Char 3	1-110 ☐ Years
10.	Is [MEMNAMxx] now: GIC_MS1 - GIC_MS20 Col.10650 20 * Char 1	1 ☐ Married 2 ☐ Widowed 3 ☐ Divorced 4 ☐ Separated 5 ☐ Never married 6 ☐ Partnered/not married
11.	Is there anyone else who is currently living or staying with you? GICMOR1 - GICMOR20 Col. 10670 20 * Char 1	1 ☐ Yes - Return to 6 2 ☐ No
	Close family roster	
12. a.	During [previous month], did you or any members of your family who live here receive Social Security benefits or Railroad Retirement benefits? GIC_12A Col. 10690 Char 1	1 ☐ Yes 2 ☐ No - SKIP to 13a D,R ☐ - SKIP to 13a
b.	How much did you [and all members of the family] receive in [previous month]? GIC_12B Col. 10691 Char 4	1 - 5001 ☐ Dollars - SKIP to 13a D,R ☐
c.	Which category would you say best represents the amount that you [and all members of the family] received in [previous month]? GIC_12C Col. 10695 Char 2	1 ☐ Under $200 2 ☐ $200 - $399 3 ☐ $400 - $599 4 ☐ $600 - $799 5 ☐ $800 - $999 6 ☐ $1000 - $1499 7 ☐ $1500 - $1999 8 ☐ $2000 - $2999 9 ☐ $3000 - $3999 10 ☐ Over $4000
13. a.	During [previous month], did you or any members of your family who live here receive any other retirement, pension, or annuity income? GIC_13A Col. 10697 Char 1	1 ☐ Yes 2 ☐ No - SKIP to 14a D,R ☐ - SKIP to 14a
b.	How much did you [and all members of the family] receive in [previous month]? GIC_13B Col. 10698 Char 4	1 - 5001 ☐ Dollars - SKIP to 14a D,R ☐
c.	Which category would you say best represents the amount that you [and all members of the family] received in [previous month]? GIC_13C Col. 10702 Char 2	1 ☐ Under $200 2 ☐ $200 - $399 3 ☐ $400 - $599 4 ☐ $600 - $799 5 ☐ $800 - $999

		6	$1000 - $1499
		7	$1500 - $1999
		8	$2000 - $2999
		9	$3000 - $3999
		10	Over $4000
14. a.	During the last month, that is, in the month of [previous month], did you [or any members of your family who live here] receive Supplemental Security Income, that is, SSI payments? These can come from either the Federal government or the State government. GIC_14A Col. 10704 Char 1	1 2 D,R	Yes No - SKIP to 17a - SKIP to 17a
b.	How much did you [and all members of the family] receive in [previous month]? GIC_14B Col. 10705 Char 4	1 - 5001 D,R	Dollars - SKIP to 17a
c.	Which category would you say best represents the amount that you [and all members of the family] received in [previous month]? GIC_14C Col. 10709 Char 2	1 2 3 4 5 6 7 8 9 10	Under $200 $200 - $399 $400 - $599 $600 - $799 $800 - $999 $1000 - $1499 $1500 - $1999 $2000 - $2999 $3000 - $3999 Over $4000
(Note: Numbers 15 and 16 are not used)			
17. a.	During [previous month], did you [or any members of your family who live here] receive food stamps? GIC_17A Col. 10711 Char 1	1 2 D,R	Yes No - SKIP to 18a - SKIP to 18a
b.	What was the value of the stamps received? GIC_17B Col. 10712 Char 4	1 - 5000 D,R	Dollars - SKIP to 18a
c.	Which category would you say best represents the value of the stamps received? GIC_17C Col. 10716 Char 2	1 2 3 4 5 6 7 8 9 10	Under $200 $200 - $399 $400 - $599 $600 - $799 $800 - $999 $1000 - $1499 $1500 - $1999 $2000 - $2999 $3000 - $3999 Over $4000
18. a.	During [previous month], did you [or any members of your family who live here] receive any payments from Aid to Families with Dependent Children, sometimes called "AFDC" or "ADC," or any other welfare payments? GIC_18A Col. 10718 Char 1	1 2 D,R	Yes No - SKIP to 19a - SKIP to 19a
b.	How much did you [and all members of the family] receive in [previous month]? GIC_18B Col. 10719 Char 4	1 - 5000 D,R	Dollars - SKIP to 19a
c.	Which category would you say best represents the amount that you [and all members of the family] received in [previous month]? GIC_18C Col. 10723 Char 2	1 2 3 4 5 6 7 8	Under $200 $200 - $399 $400 - $599 $600 - $799 $800 - $999 $1000 - $1499 $1500 - $1999 $2000 - $2999

	9	☐	$3000 - $3999
	10	☐	Over $4000
19. a. During [previous month] did you [or any members of your family who live here] receive any (other) welfare payments? GIC_19A Col. 10725 Char 1	1	☐	Yes
	2	☐	No - SKIP to 21a
	D,R	☐	- SKIP to 21a
Open Family Roster			
b. Whose name was on the check? (Enter all that apply) CGFMXE01 - CGFMXE20 Col. 10726 20 * Char 1		☐	'X' if selected
Close Family Roster			
c1. How much was the check for? GIC_19C1 Col. 10746 Char 4	1 - 5000	☐	Dollars - SKIP to 19d
	D,R	☐	
c2. Which category would you say best represents the amount the check was for? GIC_19C2 Col. 10750 Char 2	1	☐	Under $200
	2	☐	$200 - $399
	3	☐	$400 - $599
	4	☐	$600 - $799
	5	☐	$800 - $999
	6	☐	$1000 - $1499
	7	☐	$1500 - $1999
	8	☐	$2000 - $2999
	9	☐	$3000 - $3999
	10	☐	Over $4000
Open Family Roster			
d. Whom did the check cover? Anyone else? FAM_XF1 - FAM_XF20 Col. 10752 20 * Char 1		☐	'X' if selected
Close Family Roster			
(Note: Number 20 is not used)			
21. a. During the last twelve months, what was the total combined income before deductions for you [and all members of your family who live with you] ? Include money from jobs, net income from business or farm, pensions, dividends, interests, net income from rent, Social Security payments, and any other money income received by you [and all members of your family]. GIC_21A Col. 10772 Char 2	1	☐	Under $3,000
	2	☐	3,000 - 3,999
	3	☐	4,000 - 4,999
	4	☐	5,000 - 5,999
	5	☐	6,000 - 6,999
	6	☐	7,000 - 7,999
	7	☐	8,000 - 8,999
	8	☐	9,000 - 9,999
	9	☐	10,000 - 11,999
	10	☐	12,000 - 14,999
	11	☐	15,000 - 19,999
	12	☐	20,000 - 24,999
	13	☐	25,000 - 29,999
	14	☐	30,000 - 39,999
	15	☐	40,000 - 49,999
	16	☐	50,000 - 59,999
	17	☐	60,000 - 69,999
	18	☐	70,000 - 79,999
	19	☐	80,000 - 99,999
	20	☐	100,000 or more
	D, R	☐	Continue
a1. Would it be $25,000 or more? GIC_21A1 Col. 10774 Char 1	1	☐	Yes - SKIP to a4
	2	☐	No
	D,R	☐	- SKIP to GIC_CK2
a2. Would it be $10,000 or more? GIC_21A2 Col. 10775 Char 1	1	☐	Yes - SKIP to GIC_CK2
	2	☐	No
	D,R	☐	- SKIP to GIC_CK2
a3. Would it be $5,000 or more?	1	☐	Yes

SKIP to GIC_CK2

GIC_21A3 Col. 10776 Char 1	2 D,R	☐ ☐	No } SKIP to GIC_CK2
a4. Would it be $50,000 or more? GIC_21A4 Col. 10777 Char 1	1 2 D,R	☐ ☐ ☐	Yes No - SKIP to GIC_CK2 - SKIP to GIC_CK2
a5. Would it be $75,000 or more? GIC_21A5 Col. 10778 Char 1	1 2	☐ ☐	Yes No
Open Family Roster			
GIC_CK2 [Refer to GICRELxx above. Are relatives other than spouse living with the caregiver?] If no, SKIP to 22a. If yes, continue.			
21. b. Now only consider you [and your spouse]. Which category on this card represents the total combined income before deductions during the LAST 12 months? Include money from jobs, net income from business or farm, pensions, dividends, interests, net income from rent, Social Security payments, and any other money income received by you [and your spouse]. G_21B1 - G_21B20 Col. 10779 20 * Char 2	1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 D, R	☐ ☐	Under $3,000 3,000 - 3,999 4,000 - 4,999 5,000 - 5,999 6,000 - 6,999 7,000 - 7,999 8,000 - 8,999 9,000 - 9,999 10,000 - 11,999 12,000 - 14,999 15,000 - 19,999 20,000 - 24,999 25,000 - 29,999 30,000 - 39,999 40,000 - 49,999 50,000 - 59,999 60,000 - 69,999 70,000 - 79,999 80,000 - 99,999 100,000 or more } Skip to 22a Continue
b1. Would it be $25,000 or more? G1_21B1 - G1_21B20 Col. 10819 20 * Char 1	1 2 D,R	☐ ☐ ☐	Yes - SKIP to b4 No - SKIP to 22
b2. Would it be $10,000 or more? G2_21B1 - G2_21B20 Col. 10839 20 * Char 1	1 2 D,R	☐ ☐ ☐	Yes - SKIP to 22 No - SKIP to 22
b3. Would it be $5,000 or more? G3_21B1 - G3_21B20 Col. 10859 20 * Char 1	1 2 D,R	☐ ☐ ☐	Yes No } SKIP to 22
b4. Would it be $50,000 or more? G4_21B1 - G4_21B20 Col. 10879 20 * Char 1	1 2	☐ ☐	Yes No - SKIP to 22
b5. Would it be $75,000 or more? G5_21B1 - G5_21B20 Col. 10899 20 * Char 1	1 2	☐ ☐	Yes No
Close Family Roster			
22. a. In [previous month], about how much of your own money have you spent taking care of [sample person]? GIC_OWN Col. 10919 Char 4	0- 9999 D,R	☐ ☐	Dollars - SKIP to 23
b. Which category would you say best represents the amount of your own money you have spent taking care of [sample person] in [previous month]? GIC_OWNC Col. 10923 Char 2	1 2 3 4 5	☐ ☐ ☐ ☐ ☐	Under $200 $200 - $399 $400 - $599 $600 - $799 $800 - $999

	6 ☐ $1000 - $1499 7 ☐ $1500 - $1999 8 ☐ $2000 - $2999 9 ☐ $3000 - $3999 10 ☐ Over $4000
23. In order to determine how health practices and conditions are related to the use of medical services, we would like to refer to Medicare records for other health information in this study. In order to do this, we need your Social Security number. What is your Social Security number? Providing your Social Security number is optional and will not affect your benefits in any way. GIC_SOC	☐ Blank
END GIC Set Caregiver End Date CGDAY2 Col. 10925 Char 6	☐ MMDDYY
Set End Time END_GIC Col. 10931 Char 4	0-23 0-59 ☐ HHMM
Subtract GIC start time from GIC end time CUML_GIC Col. 10935 Char 4	0000- 9999 Minutes - SET OUTCOME = '201' and SKIP to Control Card FINISH

APPENDIX B: UCRIHS Approval Letter

MICHIGAN STATE
UNIVERSITY

Initial IRB Application Approval

April 9, 2005

To: Barbara Ames
13f Human Ecology
Dept. Human Ecology

Re: **IRB # 05-185** Category: EXEMPT 1-4
Approval Date: April 9, 2005
Expiration Date: April 8, 2006

Title: THE PREDICTORS OF THE CAREGIVING EXPERIENCE: OUTCOMES OF ELDER CARE BY ADULT CHILDREN

The University Committee on Research Involving Human Subjects (UCRIHS) has completed their review of your project. I am pleased to advise you that **your project has been approved.**

The committee has found that your research project is appropriate in design, protects the rights and welfare of human subjects, and meets the requirements of MSU's Federal Wide Assurance and the Federal Guidelines (45 CFR 46 and 21 CFR Part 50). The protection of human subjects in research is a partnership between the IRB and the investigators. We look forward to working with you as we both fulfill our responsibilities.

Renewals: UCRIHS approval is valid until the expiration date listed above. If you are continuing your project, you must submit an ***Application for Renewal*** application at least one month before expiration. If the project is completed, please submit an ***Application for Permanent Closure.***

Revisions: UCRIHS must review any changes in the project, prior to initiation of the change. Please submit an ***Application for Revision*** to have your changes reviewed. If changes are made at the time of renewal, please include an ***Application for Revision*** with the renewal application.

Problems: If issues should arise during the conduct of the research, such as unanticipated problems, adverse events, or any problem that may increase the risk to the human subjects, notify UCRIHS promptly. Forms are available to report these issues.

Please use the IRB number listed above on any forms submitted which relate to this project, or on any correspondence with UCRIHS.

Good luck in your research. If we can be of further assistance, please contact us at 517-355-2180 or via email at UCRIHS@msu.edu. Thank you for your cooperation.

Sincerely,

Peter Vasilenko, Ph.D.
UCRIHS Chair

c: Debra Sietsema
901 Perry St SW
Byron Center, MI 49315

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