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The Effects of Stress and Burden on Caregivers of Individuals with a Chronic Illness

Betty Wilborn-Lee
Walden University

Walden University

College of Social and Behavioral Sciences

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Betty Wilborn-Lee

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Review Committee
Dr. Nina Nabors, Committee Chairperson, Psychology Faculty
Dr. Augustine Baron, Committee Member, Psychology Faculty
Dr. Rodney Ford, University Reviewer, Psychology Faculty

Chief Academic Officer
Eric Riedel, Ph.D.

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Abstract

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Betty Wilborn-Lee

MSW, University of Illinois, Chicago

BA, Northeastern Illinois University

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

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Abstract

Informal caregivers have played a significant social and economic role in the care and treatment of individuals diagnosed with chronic illness. However, caregiving can have harmful effects on a caregiver's physical, psychological, and emotional well-being. Using caregiver stress theory as the theoretical framework, the purpose of this archival research was to determine the predictive relationship of stress in relation to caregiver quality of life for 309 selected cases. Correlational and hierarchical multiple linear regression analyses were used to examine the relationship between the independent variables and the dependent variable. The independent variables examined were environment and context, stressors related to the demands of caregiving, self-appraisal of ability to cope, and caregivers' knowledge and use of community and family resources. The dependent variable was the caregiver's quality of life. Findings showed that independent variables of environment and context (gender, age, marital status, education, employment status, income level) accounted for 14% of the variance in caregiver quality of life. The remaining independent variables (caregiver stressors, self-appraisal of ability to cope, and knowledge and use of resources) accounted for an additional 4% of the variance. The set of independent variables in this study collectively accounted for 18% of the variability in caregiver quality of life. Caregiver knowledge and use of resources had the strongest predictive relationship with caregiver quality of life. Researchers and practitioners may use the findings to assist in identifying antecedents to caregiver stress and the strongest predictors of caregiver stress, as well as in developing appropriate and efficient interventions and social support resources to meet caregivers' specific needs, reduce their stress, and promote and enhance their quality of life.

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Dedication

This dissertation is dedicated to caregivers who are the champions of compassion, resilience, and perseverance. Caring for a sick family member or friend with a chronic health condition can create a myriad of challenges and obstacles. I am inspired by your heroic efforts and the physical, emotional, and financial sacrifices that you make. You provide a vital contribution to society and your efforts have not gone unrecognized.

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Chapter 1: Introduction

Introduction

Over the past three decades, caregiving has become a growing interest among researchers (Haley, Levine, Brown, & Bartolucci, 1987; Pearlin, Mullan, Semple, & Skaff, 1990; Vitaliano, Russo, Young, Teri, & Maiuro, 1991:Vitaliano, Zhang, & Scanlan, 2003; Zarit, Femia, Kim, & Whitlatch, 2010; Zarit, Reeves, & Bach-Peterson, 1980). In the United States, 44 million caregivers are providing informal care to chronically ill individuals without the benefit of formal training (van Ryn et al., 2011). Across all domains of caregiving, caregivers experience high levels of stress and burden compared to their noncaregiving cohorts (Carek, Norman, & Barton, 2010; Chwalisz, 1992; del-Pino-Casado, Frias-Asuna, Palomin-Moral, & Pancorbo-Hidalgo, 2011; Dorfman, Holmes, & Berlin, 1996; Gallagher et al., 2011; Goode, Haley, Roth, & Ford, 1998; Grabel & Adabbo, 2011; Northfield & Nebauer, 2010; Ownsworth, Henderson, & Chambers, 2010; Pakenham, 2001; Perrig-Chiello & Hutchinson, 2010; Pinquart & Sorensen, 2003; Schulz, O'Brien, Bookwala, & Fleissner, 1995; van Ryn et al., 2011).

Family caregivers provide a social and economic value to society, in that they represent a fraction of the cost of care compared to hospital-based treatment. However, home care causes an increase in financial, physical, and emotional responsibility, and this responsibility rests with the person who provides care for the individual with a chronic illness (Dorfman et al., 1996; Emanuel, Fairclough, Slutsman, & Emanuel, 2000; Ownsworth et al., 2010). In addition to these responsibilities, informal caregivers are responsible for the use of complex and daunting medical equipment, extensive coordination of medical and diagnostic appointments (Keith, 2009)as well as management of all activities of daily living (Emanuel et al., 2000; Keith, 2009; Pearlin et al., 1990). Furthermore, informal caregivers may become frustrated, depressed, and feel demoralized because they are not adequately prepared to perform the caregiving responsibilities or have an outlet for voicing their concerns (Lim & Zeback, 2004). If they are employed, they may frequently miss time from work, using personal and sick days to provide care; they may even have to quit their jobs or retire early to provide care (Duxbury, Higgins, & Smart, 2011; Emanuel et al., 2000; Pinquart & Sorensen, 2003). Researchers have shown that caregiving for individuals with a chronic condition can affect a caregiver's physical, psychological, and social life, resulting in poor physical health, social isolation, and increased stress and burden (Pinquart & Sorensen, 2003; Schulz et al., 1995; Smith, Williamson, Miller, & Schulz, 2011). The multiple aspects of caregiving activities also influence the caregiver's quality of life, which, in turn, affects the caregiver's present socioeconomic circumstances, the extent to which the caregiver is able to manage stress, and the extent to which the caregiver is able to create and utilize a social support network (Lim & Zebrack, 2004; Pearlin et al., 1990).

Individuals with a chronic illness may qualify for a broad range of services that range from meals on wheels to nursing home care (Anderson & Knickman, 2001). However, these support services are not organized in such a way that the elderly person's family member can understand the full range of available services, how to obtain them, the costs involved or available subsidies, or the services’ relative advantages and disadvantages (Anderson & Knickman, 2001). Support services with these constraints, in addition to scarcity of funding, complex eligibility requirements, and a family's preferences for informal care, have created limitations on the provision of support services to individuals with chronic illness (Anderson & Knickman, 2001; Keith, 2009). The majority of persons with a chronic condition resulting in physical or cognitive limitations live in the community and receive support from family or friends. Of the population with chronic illness, “fewer than 10% rely exclusively on formal, paid long-term care providers” (Anderson & Knickman, 2001, p. 150).

Many individuals with chronic conditions experience physical, behavioral, cognitive and emotional problems for which they may require care by informal caregivers over extended periods of time, negatively affecting the caregiver's physical and psychological health (Blake, 2008; Carek et al., 2010; Haley, LaMonde, Han, Burton, & Schonwetter, 2003; Haley et al., 1987; Pakenham, 2001;Vitaliano et al., 2003).

Researchers have found major differences in the mental health impact of stress among family caregivers even when variables such as social status, type of care provided, and amount of time spent caregiving were similar (Haley et al., 1987; Lim & Zeback, 2004; Pearlin et al., 1990). The differences in the mental health impact were mediated by the caregiver's coping strategies, the extent of social support (Haley et al., 1987; Pearlin et al., 1990), and by the nature and complexity of the care recipient’s chronic condition, and its effect on the caregiver (Gottlieb & Wolfe, 2002; Grabel & Adabbo, 2011; Ownsworth et al., 2010;Schulz & Martire, 2004). Moreover, researchers have found that social support plays a significant role in the degree to which individual caregivers differ in their level of perceived stress (Pearlin et al., 1990). Social support can have a positive effect by buffering the negative consequences of stress (Roth, Mittelman, Clay, Madan, & Haley, 2005). However, the literature is inconsistent in identifying which type of support service is most effective in reducing caregiver stress for those caring for individuals with a chronic illness (Chang, Brecht, & Carter, 2001; Chappell & Dujela, 2009; Cheng et al., 2012; Cooke, McNally, Mulligan, Harrison, & Newman, 2001; Czaja et al., 2009; Whittier, Scharlach, & Dal Santo, 2005). Czaja et al. 2009 further suggested that more effective and robust measures are needed to assist in identifying needs and interventions to caregivers (Czaja et al., 2009). For example, there is limited empirical evidence that providing interventions involving family and community support as well as information on symptom management to caregivers has been equally effective among all caregivers for reducing stress and improving caregiver quality of life (Thompson et al., 2005). Gottlieb and Wolfe (2002) found that coping mechanisms used by family caregivers of individuals diagnosed with dementia had a significant and variable effect on the caregivers' health and morale. They suggested that the inconsistencies in findings might be related to the use of cross-sectional designs and the adoption of different coping and outcome measures over time. They further posited that reliance on retrospective reports, the use of inappropriate response formats, and limitations in interpreting the cumulative findings on caregiving have rendered results on caregiver quality of life questionable (Gottlieb & Wolfe, 2002).

This chapter provides a discussion of the background of the research, problem statement, purpose of the research, research questions and hypotheses, theoretical framework for the study, nature of the study, definitions, assumptions, scope and delimitations, limitations, and significance of this research. A summary and introduction to the literature review and methodology are included at the end of the chapter.

Background

This research adds to the body of knowledge on how specifc stress variables from the caregiver stress theory (Pearlin et al., 1990) is effective for predicting caregiver stress and identifying effective and efficient interventions for reducing caregiver stress and improving caregiver quality of life. Quality of life is a multidimensional, subjective construct that involves the health, socioeconomic status, and psychological, emotional, spiritual, and familial well-being of the informal caregiver (Chronister, Chan, Sasson-Gelman, & Yi-Chiu, 2010; Glozen, 2004; Haley et al., 1987; Kristjanson & Aoun, 2004; Lim & Zebrack, 2004; Pearlin et al., 1990). Therefore, quality of life is a concept that identifies how caregiving affects the informal caregiver &(Kristjanson & Aoun, 2004; Pearlin et al., 1990; Zarit et al., 1980). The caregiver places a great deal of energy and effort toward the health and well-being of the care recipient, and the caregivers' physical and psychological well-being goes unattended. Although the caregiver may have frequent contacts with medical professionals on behalf of the patient, the medical professional might fail to notice the negative impact of caregiving on the caregiver's quality of life (Kristjanson & Aoun, 2004). Health care professional might provide assistance to the caregiver by assessing and identifying support services for family members who might need assistanc with reducing the negative impact of caregiving on the caregiver (Kristjanson & Aoun, 2004).

Limited research has examined the predictive relationship of a broad range of variables on caregiver quality of life in the United States (Bainbridge, 2007; Keith, 2009) using the caregiver stress theory (Pearlin et al., 1990). This research was conducted in an attempt to add to the body of knowledge on how specific theory-driven caregiver stress variables are associated with caregiver quality of life (Prstlin et al., 1990). A sample of caregivers from an archival dataset who provided caregiving to individuals with a broad range of conditions was selected for this research.

The literature suggested that many social, psychological, and emotional factors contribute to caregivers' stress. Social support has been shown to have a significant influence on stress and burden among caregivers of individuals with various chronic health conditions (Chronister et al., 2010; Lim & Zeback, 2004; Pearlin et al., 1990). Chronister et al. (2010) examined the extent to which stress and coping influenced the quality of life among caregivers for individuals with a injury. Using stress and coping theory as the theoretical framework (Lazarus & Folkman, 1984), Chronister et al. found that emotional support and social needs mediated the connection between perceived burden and quality of life. This suggests that a caregiver's perceived social support system and the caregiver's belief that essential social needs have been met will lead to a reduction in feelings of caregiver burden, resulting in an improvement of the caregiver's quality of life. Given that social support resources mediate the effect of stress on caregiving, many community-based programs have been designed to assist caregivers in their caregiving activities. However, these programs vary from one community to the next. Social support resources vary in cost, availability, and their usefulness to the caregiver (Elliott, Burgio, & DeCoster, 2010; Stockwell-Smith, Kellett, & Moyle, 2010; Whittier et al., 2005). Caregivers are faced with barriers related to transportation to existing programs, hours of availability, and nearness or proximity of the program to the caregiver (Elliott et al., 2010; Grabel & Adabbo, 2011; Keith, 2009; Stockwell-Smith et al., 2010). Chronister et al. (2010) further examined the association of stress coping variables to life satisfaction and burden among caregivers of individuals with traumatic brain injury using the Lazarus and Folkman (1984) stress model. They found that resources that provided emotional support and met social needs mediated the relationship between caregivers' perceived burden and quality of life (Chronister et al., 2010). Using the caregiver stress theory as the theoretical framework, the purpose of this research was to examine how the characteristics of the stress process involving caregiver demographic factors, stressors related to caregiving, caregivers' appraisal and coping mechanisms, and caregivers' knowledge and use of resources influenced caregiver quality of life (Pearlin et al., 1990).

This research adds to the body of knowledge on challenges that have an adverse effect on caregivers. The caregiver stress theory (Pearlin et al., 1990) was used to identify which stressors within the stress theory had the greatest influence in predicting the caregiver's quality of life. The findings might provide researchers and practitioners with information that helps them to recognize caregiver vulnerabilities to stress along the caregiver stress process continuum (Pearlin et al., 1990). Appropriate and efficient interventions can be offered that meet the caregiver's individual needs for averting the adverse effects of stress.

Problem Statement

Caregivers for individuals with a chronic health condition continue to experience high levels of stress and burden. Although researchers and practitioners have offered various types of resources and interventions, these services have not produced the desired results for sufficiently reducing stress and burden (Cooke et al., 2001; Harding, List, Epiphaniou, & Jones, 2011, Gallagher et al., 2011; Gaugler, 2010; Grabel & Adabbo, 2011; Gure, Kabeto, Blaum, & Langa, 2007; Ownsworth et al., 2010; van Ryn et al., 2001).

Stress and burden among informal caregivers have resulted in physical and psychological health challenges stemming from financial insecurity, social isolation, and delaying or completely discontinuing personal and career goals in order to care for a chronically ill family member (Goode et al., 1998; Pearlin et al., 1990; Pinquart & Sorensen, 2003; Vitaliano et al., 1991; Vitaliano et al., 2003; Zarit et al., 1980). In the United States, approximately 44 million individuals are providing informal care to chronically ill family members and friends without the benefit of formal training (van Ryn et al., 2011). These individuals provide care for an estimated 4.5 million adults diagnosed with Alzheimer's disease (Elliott et al., 2010), 1.4 million diagnosed with cancer (van Ryn et al., 2011), and an estimated 600,000 adults who have survived stroke (Carek et al., 2010). Caregivers provide an average of 69 to 117 hours of care each week to individuals with debilitating chronic illnesses (Elliott et al., 2010). While there is a plethora of literature on available resources for reducing stress among caregivers to individuals with a chronic illness (Cooke et al., 2001; Elliot et al., 2010; Grabel &

Adabbo, 2011; Whittier et al., 2005; Williams & Bakitas, 2012; Zarit, Gaugler, & Jarrott, 1999), many caregivers are not using the existing resources that are designed to assist in reducing stress and burden (Elliott et al., 2010; Chang et al., 2001; Cheng et al., 2012; Grabel & Adabbo, 2011; Stockwell-Smith et al., 2010;). Major gaps involving transportation assistance, overnight, and weekend respite services to caregivers (Whittier, et al., 2005). In addition to stress and burden directly related to the task of caregiving, Keith (2009) suggested that caregivers experienced stress and burden associated with coordinating medical and health services outside the home environment. Existing resources that have had a significant impact in meeting the needs of caregiver and care recipient have been disproportionally small (Cheng et al., 2012; Elliott et al., 2010; Grabel & Adabbo, 2011).

Despite these research findings, there is a paucity of empirical research on effective and efficient interventions for reducing stress and burden among caregivers to individuals with chronic illnesses other than Alzheimers disease. Other chronic diseases that additional research is needed to identify the deleterious impact of caregiving include individuals iwith cancer, Parkinson’s disease and surivors of a stroke (Boschen, Gargaro, Gan, Gerber, & Brandys, 2007; Carek et al., 2010; Sorenson, Webster, & Roggman, 2002; van Ryn et al., 2011). This research focused on the gap in the literature on the impact of stress on caregivers to individuals with a chronic illness, in general, rather than focusing on caregiving for a particular chronic condition. Therefore, this research examined the effect of stress on the quality of life across a range of chronic diseases.

Researchers and practitioners have considered other types of single-component interventions that may have a positive impact in reducing caregiver stress and burden have provided varying results (Bainbridge, Krueger, & Brazil, 2009; Boschen et al., 2007; Chang et al., 2001; Cooke et al., 2001; Sorensen, Webster, & Roggman, 2002; Whittier et al., 2005). Sorensen et al. (2002) suggested that multicomponent measures (e.g., psychoeducational information, caregiver support groups, psychotherapy, and respite services) yielded a greater benefit in reducing caregiver stress and burden and enhancing coping compared to single interventions. While a number of factors influence caregiver stress and burden, not all caregivers will benefit equally from a single intervention (Grabel & Abaddo, 2011; Sorensen et al., 2002; Zarit, Femia, Kim, & Whitlatch, 2010).

Results from this study add to the body of knowledge on caregiver stress and burden. This research identified which caregiver stressors according to stress process theory are most significant in predicting caregiver vulnerability to stress. Findings from this research should assist organizaions and practitioners in identifying and developing resources for targeting stressors and providing interventions to prevent stress and burden from reaching the the point of causing physical and emotional deterioriation among caregivers. These findings may also contribute to the identification of theory-driven risk factors (Pearlin et al., 1990) for caregiver stress as well as assist with recognizing where caregivers are most vulnerable in order to ameliorate caregiver quality of life before stress becomes chronic.

Purpose of Study

The primary objective of this quantitative study was to gain insight into the effect of a wide range of variables within the context of stress theory associated with caregiver quality of life (Pearlin e al., 1990). This correlational study examined whether there is a relationship between certain stress variables based on the caregiver stress theory and caregiver outcome from caregiving responsibilities. Caregiver stress theory (Pearlin et al., 1990) suggested that the caregiver's context and environment, which include sociodemographic variables, act as antecedents to stressors involving physical, psychological, and emotional demands of caregiving and that these antecedents can take a significant toll on the caregiver's quality of life. This study also assessed which caregiver variables are the best predictors of caregiver stress, which, in turn, influences the caregiver's quality of life (Pearlin et al., 1990). The findings may assist practitioners and organizations with planning and developing efficient and effective interventions to reduce or eliminate stress and burden and improve quality of life among informal caregivers (Elliott et al., 2010; Montgomery & Kosloski, 2009; Pearlin et al., 1990; Sorensen, Pinquart, & Duberstein, 2002; Whittier et al., 2005).

Variables for this research were selected from caregiver stress theory. The independent variables for this research were environment and context, primary and secondary stressors related to the demands of caregiving, caregiver's appraisal of ability to cope, and knowledge and use of resources. The dependent variable was defined as caregiver's perceived quality of life. The statistical methods used to test the predictive relationship of the independent variables with the dependent variable were a correlational research design and a hierarchical multiple linear regression analysis.

Research Questions and Hypotheses

The following research questions guided this study, with the resulting hypotheses tested via statistical analyses:

RQ1: Is there a statistically significant relationship between caregiver stressors—environment and context, stressors involving the demands of caregiving, caregiver's appraisal of ability to cope, and knowledge and use of support resources—and caregiver quality of life?

H0: There is no relationship between caregiver stressors and caregiver quality of life.

H1: There is a relationship between caregiver stressors and caregiver quality of life.

RQ2: Which is the best predictor of caregiver outcome as measured by the caregiver's self-rating of quality of life: environment and context, stressors involving the demands of caregiving, caregiver's appraisal of ability to cope, or knowledge and use of resources?

H0: There is no predictive relationship between environment and context, stressors involving the demands of caregiving, caregiver's appraisal of ability to cope, or knowledge and use of resources and caregiver outcome involving caregiver’s quality of life.

H1: There is a predictive relationship between the variables of environment and context, stressors involving the demands of caregiving, caregiver's appraisal of ability to cope, and knowledge and use in predicting caregiver outcome involving caregiver’s quality of life.

Theoretical/Conceptual Framework

Lazarus and Folkman's Transactional Stress Theory provided the theoretical framework for this research (Larazus & Folkman, 1984). Lazarus and Folkman's Transactional Stress Theory has been used extensively in stress, burden, and coping research. The Transactional Stress Theory suggested that the individual and environment interact in a dynamic and mutually shared relationship. Stress occurs when the interaction between the person and the environment taxes the person's coping resources and threatens his or her physical and psychological well-being. Subsequent research and application of Lazarus and Folkman's theory by Pearlin et al. (1990) provided a framework for conceptualizing stress and burden among informal caregivers.

Building on Lazarus and Folkman's (1984) Transactional Stress Theory, Pearlin et al. (1990) provided a caregiver stress theory for conceptualizing stress within the context of caregiving. This theory has been the framework by which stress among caregivers has been examined across various chronic conditions (e.g., Alzheimer's disease, cancer, stroke, multiple sclerosis, Parkinson's disease). There are individual differences among caregivers in responses to stress and how the individual caregiver performs under stressful conditions. These stress reactions will ultimately affect the individual caregiver's quality of life. Therefore, according to Lazarus and Folkman (1984), psychological stress occurs when the individual encounters specific situations that is determined to be demanding beyond the individual's resources thereby creating a risk to the person's physical, mental, or emotional well-being. The theoretical framework that guides this study is covered in more detail in Chapter 2.

Nature of Study

In this quantitative research, I sought to determine which variables contributed to caregiver stress using caregiver stress theory, which relates to the extent to which social support buffers or mediates the negative effects of stress, as well as to identify the effectiveness of available resources (Gallagher et al., 2011; Grabel & Adabbo, 2011; Sorenson et al., 2002; Pearlin et al., 1990). With an emphasis on identifying and reducing and eliminating caregiving stress and burden and enhancing caregiver quality of life, this research was in line with caregiver stress theory (Pearlin et al., 1990). Survey items from an archival data source included multiple formats involving nominal, ordinal, and interval scale measures. An IBM-SPSS statistical software program was used to conduct data analysis. Spearman and Pearson product-moment correlation coefficient (*r*) was used to identify the strength and direction of the relationship between sociodemographic characteristics of caregivers, caregiver stress variables, caregiver appraisal of ability to cope, and caregiver knowledge and use of resources. Hierarchical multiple linear regression analyses were conducted to evaluate the predictive power of the independent variables to determine which independent variable had predictive ability concerning caregiver quality of life (George & Mallery, 2012). This quantitative analysis assisted in identifying which variables within the stress model (Pearlin et al., 1990) had the strongest predictive relationships with caregiver outcome or caregiver quality of life.

Definitions

Cognitive appraisal: This is the individual's cognitive process of that allows the person to determine the degree to which his encounter with another person or with the envirionment is percieved as stressful (Lazarus & Folkman, 1984)

Coping: Refers to the behaviors and practices that an individual uses to reduce or eliminate an event or situation that is causing stress (Lazarus & Folkman, 1984). Coping within the caregiving environment is described as the methods of managing the stress of home care (Grabel & Adabbo, 2011; Pearlin et al., 1990).

Caregiver quality of life: This is a multidimensional construct composed of well-being and functioning; socioeconomic status; psychological, emotional, and spiritual factors; and family life (Lim & Zebrack, 2004). Stress variables related to quality of life are patient and caregiver characteristics, stressors, stress appraisal, methods of coping with stress, and social supports (Lim & Zebrack, 2004; Pearlin et al., 1990).

Informal caregivers: Caregivers who are usually relatives or friends and who do not work in the field professionally. These caregivers have not been formally trained to provide care in the home, and any training they received was voluntary. Caregiving includes all assistance given in the home and may range from help with fundamental activities of daily living involving dressing and mobility to transportation services, organization, and administration of medication (Grabel & Adabbo, 2011).

Primary stressors: The stressors that occur as a direct result of caregiving. Primary stress is derived from assisting the care recipient with tasks that he or she is no longer able to perform independently. These tasks may include basic activities such as feeding and bathing. For example, managing the impaired cognitive status and functioning of an Alzheimer's care recipient requires a highly involved level of caregiving. Primary stressors are the caregiving stressors that are enduring and become intensified over a period of time (Pearlin et al., 1990).

Quality of life: The subjective evaluation of a caregiver's physical health, psychological health, social relationships, and environment (Pearlin et al., 1990).

Secondary stressors: Stress that is secondary to the role of caregiving. Secondary stressors may arise from primary stressors such as family members' disagreement concerning the care recipient's illness or impairment. Secondary stressors may include disputes over the seriousness of the illness and the choice of strategies for managing the disease. Secondary stress may also be related to disagreements concerning both the amount and quality of care that other family members offer to the caregiver, as well as lack of acknowledgement accorded to the caregiver for the care provided to the care recipient (Pearlin et al., 1990).

Stressors: Those conditions, experiences, and activities that are problematic for the individual caregiver (Pearlin et al., 1990, p. 586). Stress is a situation that is self-defeating, hinders efforts, causes fatigue, and defeats goals and aspirations of the caregiver (Pearlin et al., 1990).

Social support: The social network that provides psychological and material resources that are designed to assist the caregiver in his or her ability to cope with stress (Cohen, 2004). Social support involves structural aspects of the support network, which include the size of the network and the types of relationships within it, as well as functional social support, which refers to the actual availability of individuals to meet the identified need. It also includes emotional support in forms such as listening, trust, and respect. The nature of the support includes the extent to which it is helpful and the level of difficulty that the caregiver experiences in arranging it (Chang et al., 2001; Cohen, 2004).

Assumptions

The following assumptions guided this study. It was assumed that all participants answered the survey questions truthfully, honestly, and to the best of their ability, and that they did not alter or introduce any type of bias into their responses. Therefore, it was assumed that participants were unbiased in their answers to the caregiver survey. It was also assumed that the archival data used for this study were coded accurately and presented for replication purposes. It was also assumed that the responses were reported correctly in the national survey questionnaire. A final assumption of this study was that not all caregivers experience negative consequences as a result of their caregiving. This study was based on the assumptions that caregiving is a stressful experience and has an adverse impact on the caregiver's quality of life and, therefore, creates a low level of caregiver life satisfaction.

Scope and Delimitations

The results of this study provided insight into stress processes within the context of caregiving as well as insight into the types of stressors that showed a predictive relationship with caregiver quality of life. Insights from this study should assist researchers and practitioners in identifying and developing effective and efficient resources for managing stress and burden and ameliorating caregiver quality of life. With a growing need for in-home care, families will continue to assume greater responsibility for the care of individuals experiencing debilitating physical and cognitive decline (e.g., stroke, cancer, Parkinson's disease). Therefore, the physical health and psychological well-being of caregivers will remain a social priority (Gallagher et al., 2011; Grabel & Adabbo, 2011).

This study included a national cross-section of adults 18 years of age and older drawn from the 1999 Population Survey from the U.S. Census Bureau. Persons with chronic conditions who received informal care were considered for inclusion in the study. Individuals with a chronic illness who provided unpaid informal care to another chronically ill individual 18 years of age and older were also included for this study.

This study can be generalized to individuals who provide care to chronically ill and frail elderly adults. Health care professionals, policy makers, and administrators may also find these research findings useful.

Limitations

The use of archival data limited my ability to contact participants for response clarifications to ensure accuracy. A second limitation of this study is that the use of archival data limited my ability to examine all caregivers who were providing care to chronically ill individuals. The literature suggested that quality of life is defined as a multidimensional construct that includes psychological, emotional, and spiritual aspects of the caregiver's functioning, including caregiver levels of anxiety and depression (Lim & Zebrack, 2004). However, the archival data did not provide a measure or an assessment of the caregivers' psychological, emotional, or spiritual functioning.

Although the stress variables selected for this research were based on a theoretical foundation (Pearlin et al., 1990), another limitation of this study was that the questions chosen from the survey for this study were based on theory, similar research, and face validity. For example, there was no information in the archival data on instruments used to measure stress. or to establish validity and reliability of the survey questions. In other words, it was not clear whether the questions measured what they were intended to measure.

Significance

This research is significant because a considerable portion of the population in the United States is providing informal care to a family member. Caregiving responsibilities can be stressful and daunting, and caregiver stress has both an obvious and an insidious effect on the informal caregiver. Stress related to the demands of caregiving can have multiple contributing factors (Pearlin et al., 1990), yet there is a paucity of research on how a group of multiple variables from the caregivers stress model might influence the caregivers quality of life (Bainbridge et al., 2009).

This research is also significant because it adds to the body knowledge on the predictive influece of caregiver stress variables on the men and women who provide a valuable alternative to formal institutionalized care for individuals suffering from a chronic health condition (Bainbridge, 2009).

The findings from this research will inform practitioners and organizations of the benefit of taking a more holistic approach to examining predictors of caregiver stress and providing preventive services to caregivers who have the burden of providing caregiving as well as the burden of, in many instances, coping with grief and loss related to the imminent death of a care recipient who is a family member or friend (Bainbridge, 2009).

It is expected that the population of older people in the United States will continue to grow as people are living longer. The increase in the population of older individuals and reductions in the length of hospital stays could create an additional burden on informal caregivers. This research may inform administrators and policy makers of the importance of identifying factors that influence caregiver stress and the types of services that would be beneficial to caregivers for the the remediation of stress, which can have a detrimental effect not only on caregivers, but also on society as a whole (Grabel & Adabbo, 2011; Pearlin et al., 1990).

This research is also significant because only one other study could be located that addressed the issue of caregiving and chronic illness using Inter-University Consortium on Social and Behavior Research (ICPSR) data. Keith (2009) examined the impact of hassles with the health care system on the caregiver and care recipient. Hassles were characterized as those challenges with the health care system that were external to the caregiver's immediate home environment. Hassles involved difficulties with scheduling medical procedures, delays in getting test results, and delays in obtaining patient care and treatment (Keith, 2009).

Positive Social Change

This study's implications for social change include the possibility that it will promote a better understanding of caregiving for chronically ill individuals and the impact of caregiving on the informal caregiver. Changes in the U.S. health care system are increasingly requiring that individuals with long-term health care needs recover at home as a result of changes in medical practices over the last decade. Therefore, individuals with serious medical conditions have shorter inpatient hospital stays, and the identification of outpatient substitutes such as home-based care have meant cost savings to both the patient and the hospital (Roth et al., 2005). Although these changes are cost effective, there will be an increase in the financial, physical, and emotional responsibility that will fall upon the family members who care for chronically ill individuals (Bainbridge et al., 2009; Camans, Currin, Bauer & Haines, 2011; Covinsky et al., 1994; Czaja et al., 2009; del-Pino-Casada, 2011;Goode et al., 1998; Haley et al., 1987; Pearlin et al., 1990).

Summary of Chapter

Caregiver stress is conceptualized as a multidimensional, dynamic process (Haley et al., 1987; Pearlin et al., 1990; Zarit et al., 1980). The context and environment serve as antecedents to the stress process and lead to primary and secondary stressors that affect the level of burden that the caregiver experiences (Pealin et al., 1990). Perceived burden is the level of outcome and may manifest in caregiver experiences as a lower quality of life, low level of satisfaction, excessive burden, and ultimately the decision institutionalize the care recipient (Roth et al., 2005). Resources offered to caregivers have low outcome measures with little empirical evidence that resources have the desired outcome (Elliott et al., 2000). While caregiver support may improve caregiver health outcomes, it can also create stress for caregivers. For example, the amount or degree of conflict within a support network might cause extra stress for caregivers (Chang et al., 2001; Pearlin et al., 1990).

This research examined the impact of providing informal care to a heterogeneous group of individuals with chronic illness. Caregivers for people with a chronic illness are at risk of experiencing physical, emotional, and psychological problems related to stress, burden, coping, and social support that ultimately affect their overall quality of life (Peters, Jenkinson, Doll, Playford, & Fitzpatrick, 2013). For example, providing informal care to an individual diagnosed with Alzheimer's disease, stroke, cancer, or a neurological condition such as motor neuron disease (MND), multiple sclerosis (MS), or Parkinson's disease (PD) can place a significant strain on the caregiver, resulting in an adverse effect on the caregiver's quality of life (Aronson 1997; Boschen et al., 2007; Carek et al., 2011; Fredman et al., 2010; Pakenham, 2001; Peters et al., 2013). While it is recognized that there are adaptive, positive aspects of caregiving, this research focused on the negative, maladaptive aspects of caregiving. This research may enhance knowledge of services and interventions for caregivers who might be most vulnerable to the adverse consequences of caregiving.

In Chapter 2, the peer-reviewed literature on caregiving and chronic illness is discussed. The various theoretical foundations and the relevance of the different theories for understanding caregiver outcome or caregiver quality of life are discussed. In Chapter 3, the research design and methodology of the study are discussed in addition to the participants, settings, procedures, data analyses, threats to validity, and protection of the participants. In Chapter 4, I present the data, data analysis, and interpretation of the results of the data analysis. The procedures used to test the hypothesis and descriptive tables relevant to the discussion are included. Chapter 5 includes an interpretation of findings, limitations of the study, recommendations for future research, implications for social change, and conclusions.

Chapter 2: Literature Review

Introduction

The purpose of this chapter is to examine the theoretical, empirical, and developmental factors related to stress and maladaptive aspects of caregiving. Informal caregiving has been associated with various physical, emotional, and financial stresses, causing burden and decreased quality of life among caregivers. Various types of support services have been provided to caregivers. However, these support services have not provided the desired outcomes among caregivers (Elliott et al., 2010).

Prevalence of Problem and Impact

The purpose of this research was to examine the risk factors associated with poor well-being among informal caregivers for chronically ill individuals. Informal caregivers for chronically ill and elderly care recipients experience increasingly higher levels of physical health challenges and psychological distress during the course of their caregiving (Chwalisz, 1992; Comans, Currin, Brauer, & Haines, 2011; Dorfman et al., 1996; Goode et al., 1998; Pakenham, 2001; Pinquart & Sorensen, 2003; Schulz et al., 1995; Sorsenson et al., 2002) compared to individuals who are not caregivers but share similar social and demographic characteristics (Pinquart & Sorensen, 2003). The consequences of caregiving can to lead to decreased quality of life (Archbold, Caparro, Mutale, & Agrawal, 2008; Blake, 2008; Chronister et al., 2010; Goode et al., 1998; Glozman, 2004; Kim, Spillers, & Hall, 2012; Lui, Lee, Greenwood, & Ross, 2011; McConaghy & Caltabiano, 2005; Pearlin et al., 1990; Schulz et al., 1995; Schumacher et al., 2008; Tsai & Jirovec, 2005). In as much as caregiving for those who suffer from

Alzheimer's disease has been extensively researched, caregiving for individuals with Alzheimer's disease continues to present challenges, and negative outcomes among caregivers for these individuals (Cooke et al., 2001; Elliott et al., 2010; Gallagher et al., 2011) continue to exist. Although the research has not been as extensive concerning other chronic conditions (e.g., stroke, cancer, Parkinson's disease, traumatic brain injury), these conditions are significant in having negative effects on caregivers' quality of life (Boschen et al., 2007; Carek et al., 2010; Gaugler, 2010; Pinquart & Sorensen, 2003; van Ryn et al., 2011). Researchers and practitioners have offered various types of interventions for reducing caregiver stress and burden, yet the majority of existing resources have not produced the desired results (Cooke et al., 2001; Gallagher et al., 2011; Gaugler, 2010; Grabel & Adabbo, 2011; Gure, Kabeto, Blaum, & Langa, 2007; Harding et al., 2011; Ownsworth et al., 2010; van Ryn et al, 2011).

The results of this study will provide insight into caregiving stress within the context of caregiver stress theory (Pearlin et al., 1990) as well as insight into the types of stressors that are significant predictors of caregiver outcome or caregiver's quality of life. Insights from this study should assist researchers and practitioners in identifying and developing effective and efficient resources for reducing or eliminating caregiver stress and burden. With a growing need for in-home care, families will continue to assume greater responsibility for care of individuals experiencing debilitating physical and cognitive decline (e.g., Alzheimer's disease, stroke, cancer, Parkinson's disease). Therefore, caregivers' physical health and psychological well-being will remain a social priority (Gallagher et al., 2011; Grabel & Adabbo, 2011; Lau, Phil, & Au, 2011).

Concise Synopsis That Established the Relevance of Problem

Across diseases and disorders in both cross-sectional and longitudinal studies, caregivers have been found to experience many physical, psychological, and behavioral responses that ultimately affect their quality of life (Billings, Folkman, Acree, & Moskowitz, 2000; Butler, Turner, Kaye, Rufffin, & Downey, 2005; Fredman, Causey, Hochberg, Ensrud, & Doros, 2010; Gallagher et al., 2011; Kim et al., 2012; Lau et al., 2011; Lui, Lee, Greenwood, & Ross; 2011; Pakenham, 2001; Pearlin et al., 1990; Pinquart & Sorensen, 2003; Zarit, Femia, Kim, K., & Whitlatch, 2010). Caregiving for an individual with a chronic illness requires providing a wide range of assistance with activities of daily living. These activities often become more demanding over time as the chronic illness progresses and might require that the caregiver relinquish significant aspects of his or her social and work life (Dorfman et al., 1996; Emanuel et al., 2000; Eppiphaniou et al., 2012). Therefore, caregiving requires a continual balancing of the caregiver's time, effort, finances, occupation, and social interests (Boschen et al., 2007; Given et al., 2004; Pakenham, 2001).

The empirical literature on stress and coping among caregivers has focused primarily on caregivers of individuals with Alzheimer's disease. Researchers continue to search for effective and efficient social support resources for caregivers and their family members with other chronic conditions. Caregivers for individuals with other chronic illnesses (cancer, stroke, multiple sclerosis, and Parkinson's disease) experience stress and burden that have only been investigated to a limited extent in the caregiving literature. For example, Haley, LaMonde, Han, Narramore, and Schonwetter (2001) reported that cancer patients have higher levels of physical symptomatology than dementia patients, although caregivers for individuals with Alzheimer's disease provide care for longer periods of time. Therefore, caregivers of individuals with cancer provide care for more hours per week than caregivers of individuals with Alzheimer's disease (Haley et al., 2001). Caregiving for individuals with Alzheimer's disease as well as other chronic illnesses can result in decreased quality of life both physically and emotionally (Rivera, 2009).

The nature and magnitude of stress that caregivers experience are primary and secondary stressors that arise from attending the care recipient's needs and the caregiver's perceived ability to cope with the patient's needs (Pearlin et al., 1990). Caregiver stress may be related to patient needs involving assistance with activities of daily living (Pearlin et al., 1990) as well as assistance with tasks such as arranging for transportation to medical appointments, following up with diagnostic examinations, and maintaining chemotherapy visits (Keith, 2009).

With the growing decrease in days of hospital stays because of cuts in budgetary funding sources and people living longer, families will take on greater responsibility for providing informal care for individuals with chronic health conditions. Therefore, the health and well-being of the informal caregiver will remain a social priority (Gallagher et al., 2011; Grabel & Adabbo, 2011). Developing and providing effective interventions and support services to caregivers to prevent the deleterious effects of stress will continue to be a challenge for researchers, funding sources, and practitioners (Boschen et al., 2007; Grabel & Adabbo, 2011; Pearlin et al., 1990; Sorensen et al., 2002).

Before beginning a discussion of the literature review, I will provide a brief outline of the layout of the chapter. The first section provides a literature search strategy. This section consists of a list of library databases and search engines used. This section also includes a list of key search terms and combinations of search terms used as well as the scope of the literature reviewed.

The second section of this chapter addresses the various caregiver stress theories (Haley et al., 1987; Lazarus & Folkman, 1984; Pearlin et al., 1990;Vitaliano et al, 1991; Zarit et al., 2010; Zarit, Reeves, & Boch-Peterson, 1980), the antecedents of caregiver stress, and how caregiver stress influences caregiver quality of life (Pearlin et al., 1990). This section addresses the impact of caregiver coping mechanisms that lead to perceived stress and burden and ultimately to outcomes involving poor physical and psychological health (Pearlin et al., 1990). I discuss the origin of stress theory and the major hypothesis of Lazarus and Folkman's Transactional Stress Theory.

An overview of the relevant definitional, theoretical, and empirical literature on the stress process within the context of caregiver stress and burden is provided (Lazarus & Folkman, 1984; Pearlin et al., 1990). This chapter also provides a detailed review of caregiver stress theory (Pearlin et al., 1990) and the rationale for using this theory to address the research questions on caregiving and chronic illness. The variables discussed in caregiver stress theory include background and context variables, and primary and secondary stress variables that contribute to caregiver outcome or decreased quality of life. A review of the influence of caregiver coping skills and social support resources that mediate the relationship between caregiving activities and caregiver quality of life was also conducted. Additionally, a review of the literature on caregivers' use of existing resources is provided, along with a discussion of the findings on caregiver outcome or quality of life. The chapter concludes with a summary of the literature review.

Literature Search Strategy

The search terms and the combination of search terms used in this research were caregiver, adult coping, stress, burden, social support, coping, chronic illness, and caregiver burden. The literature search included a comprehensive and systematic search of the literature on caregiving and chronic illness from 1987 to 2013. The literature search also involved several literary data sources that included PsychArticles, PsyINFO, Medline, dissertation abstracts, ERIC, Google Scholar, and Academic Search Complete, which produced 151 articles for evaluation regarding the primary question of this dissertation research: The impact of stress on caregivers' quality of life for elderly and chronically ill adults.

Theoretical Foundation of This Research

The overarching theoretical framework for this research is the Transactional Stress Theory (Lazarus and Folkman, 1984). The Transactional Stress Theory suggested that a stress reaction occurs under situations where the demands of the environment exceed the individual's resources. In the presence of threat, the individual will engage in both primary and secondary appraisals of the perceived threat. Primary appraisal is set into action when the individual appraises the encounter as harmful, a threat, or a challenge (Lazarus & Folkman, 1984). The person makes a secondary appraisal or judgment regarding his or her available coping resources for managing the potential threat. Stress is the interaction between the person and the environment that is burdening to the person's coping resources or taxing to the extent that it threatens his or her physical and psychological well-being. The individual makes a cognitive assessment of his or her ability to cope with the situation. In turn, the individual copes with the stress by engaging in cognitive and behavioral efforts to manage the physical and emotional demands that are beyond the individual's resources to manage the stressful event (Lazarus & Folkman, 1984). The more negative or threatening the individual perceives the stressful situation; the more unfavorable the stress reaction. For example, the demands of caregiving can create stress that involves an increased number of caregiving activities that conflict with other responsibilities. The caregiving demands can cause a loss of opportunity to regenerate from caregiving activities, obtain adequate rest, or engage in social activities. The caregiver's stress may be exacerbated by inadequate caregiving skills to care for the patient and inadequate coping strategies to manage the caregiving stresses (Lazarus & Folkman, 1984: Pearlin et al., 1990). Therefore, stress will become a negative self-reinforcing process (Lazarus & Folkman, 1984; Pearlin et al., 1990).

Lazarus and Folkman's (1984) Transactional Stress Theory has been fundamental in conceptualizing the dynamic and interactional process of caregiver stress. Researchers have expanded Lazarus and Folkman's (1984) Transactional Stress Theory to articulate the occurrence of stress among caregivers of individuals with chronic health conditions (Haley et al., 1987; Pearlin et al., 1990; Vitaliano, 1991). Various formulations of the stress process have been created to examine the influence of stress on informal caregiving (Haley et al., 1987; Pearlin et al., 1990; Vitaliano et al., 1991; Zarit et al., 1980).

Zarit et al. (1980) developed the Caregiver Burden Interview to examine the effects of stress and burden on informal caregivers. Zarit et al. distinguished between the objective burdens associated with providing physical care and subjective burdens associated with the psychological consequences of providing care. Zarit et al. defined caregiver burden as the extent to which it affected the caregivers' emotional, physical, social, and financial well-being (Zarit et al., 1980). The Zarit Burden Interview (BDI) solicited factors that contributed to feelings of burden in caregivers of persons with dementia. It examined cognitive impairments, behavior problems, duration of care, and the care recipient's illness. The BDI was a measure of the change in perceived stress and burden over time as well as a measure the benefits of stress reduction interventions designed to reduce caregiver stress and burden (Zarit et al., 1980).

Haley et al. (1987) suggested a multidimensional approach to evaluating the outcome among caregivers. Based on findings from a sample of 54 caregivers of individuals with dementia, they found that appraisal, coping responses, and social support were significant predictors of caregivers' outcome (Haley et al., 1987). Haley et al. (1987) suggested that outcome was influenced by different patterns of stress appraisal, coping, and by the availability of social support (Haley et al., 1987). The stress and coping model was an effective model for measuring stress and coping outcomes among caregivers (Haley et al., 1987).

Vitaliano et al. (1991) provided a theoretical model of distress to predict burden among spouses of individuals with Alzheimer's disease. The model was based on a formula that states: "Distress = Exposure to Stressors +Vulnerability /Psychological, and

Social Resources" (p. 392). This model indicated that caregiver distress was a response to the responsibilities of caregiving that led to feelings of burden (Vitaliano et al., 1991). Exposure to stress is the caregiver's response to the care recipient's physical, emotional, or cognitive impairments (Vitaliano et al., 1991). Caregiver vulnerability is the caregiver's physical, mental, and emotional experiences to the demands of caregiving. Caregiver resources are the coping mechanisms, social supports, and outlooks on life. Therefore, the model suggested that caregiver burden was related to whether the caregiving responsibilities were deemed a negative or a positive experience (Vitaliano et al., 1991).

Vitaliano et al. (1991) examined the longitudinal effects of burden among 95 caregivers providing long-term care to individuals with Alzheimer's disease at the beginning of the research study, and 15 to 18-months afterward. Between 15 to 18-months, there was a significant decline in the care recipients' functioning and a concurrent increase in the caregiver's assistance with activities of daily living (Vitaliano et al., 1991). Approximately one-third of the caregivers reported mild to moderate levels of depression or anxiety. Variables that measured caregivers' physical health and coping abilities did not change. However, the mean scores decreased for the outlook on life measures (Vitaliano et al., 1991). The findings suggested that the distress model is useful in predicting burden and stress in caregivers (Vitaliano et al., 1991). Therefore, caregiver burden is the response to the exposure to stress, the level of influence of the vulnerability factors, and the extent to which the caregiver assess the available resources as useful (Vitaliano et al., 1991). They concluded that caregiver burden is a response to stress over time. They also concluded that caregivers differentially respond to the task of caregiving (Vitaliano et al., 1991).

In summary, based on Lazarus and Folkman's (1984) Transactional Stress Theory, researchers have formulated theories on the nature, cause, and management of stress among informal caregivers. (Haley et al., 1987; Pearlin et al., 1990; Vitaliano et al., 2003; Zarit et al., 1980). The Zarit Burden Interview identified specific caregiving characteristics that may have contributed to caregivers' perceived burden (Zarit et al., 1980). Caregivers with a high vulnerability to stress and fewer coping resources might experience an increase in burden and stress over time (Vitaliano et al., 1991). The caregiver's level of stress will depend on the pattern of stress, the caregiver's appraisal of his or her ability to cope, and the caregiver's perceived level of social support (Haley et al., 1987; Pearlin et al., 1990).

Pearlin et al. (1990) expanded on Lazarus and Folkman's (1984) Transactional Stress Theory in their caregiver stress process theory. The stress process theory suggested that caregiver stress occurs over time with various antecedents contributing to the stress process and the caregiver's quality of life (Pearlin et al., 1990). Pearlin et al. caregiver stress theory has been one of the most frequently used theories in caregiving research. Therefore, the caregiver stress theory was the theoretical frame of reference for this research. The theory suggested that caregiver stress included several major components: They included background and context, primary and secondary stressors, secondary intrapsychic strains, and caregiver outcome or quality of life (Pearlin et al., 1990). However, the caregiver's style of coping with stress and social support resources mediated the caregiver's outcome or quality of life (Pearlin et al., 1990).

Background and contextual factors have been significant variables in the stress process model (Pearlin et al., 1990). The background and context of the stress process included the caregiver's age, gender, ethnicity, educational background, economic status, and length and duration of care (Pearlin et al., 1990). Researchers have investigated the various components of the background and context variables (Pearlin et al., 1990) and the impact of these variables on the caregiver's quality of life. The section that follows is a review of the literature on background and context variables (Pearlin et al., 1990).

Background and Context

Researchers suggested that background and contextual antecedents of stress included sociodemographic characteristics, caregiving history, and caregiver network composition (Pearlin et al., 1990). Background and context are antecedents in the stress process that influenced outcome or quality of life for caregivers (Dorfman et al., 1996; Emanuel et al., 2000; Given et al., 2004; Haley et al., 1987; Kim, Spillers, & Hall, 2012; Pearlin et al., 1990; Pinquart & Sorensen, 2003; Soto, Rick, & Watson, 1996; van Ryn et al., 2011).

Background and context addressed characteristics that are fundamental in influencing caregiver outcome (Pearlin et al., 1990). The background and context variables of the caregiver stress process theory reviewed for this research included age of caregiver, length of caregiving history, the nature of care recipient’s impairment, economic burden, family and social network resources, and caregivers’ use of resources

(Pearlin et al., 1990). The following is a literature review of the background and context variables:

Age. Researchers suggested that age played a significant role in how the caregiver perceived caregiving as stressful (Pearlin et al., 1990; Soto et al., 1996). With age comes concern for the mental and physical functioning of the caregiver and the care recipient (Pearlin et al., 1990). Soto et al. (1996) examined how age influenced caregivers' level of perceived stress. Based on a sample of 58 caregivers and care recipient pairs, they found a relationship between the caregiver's age and to the length of time providing care. Soto et al. suggested that there was an increased likelihood that an older caregiver would experience physical health problems after providing care to an individual with a chronic health condition for an extended period (Soto et al., 1996).

Given et al. (2004) found that among a sample of 152 caregivers of cancer patients, caregiver children between the ages of 45 and 54, showed more depressive symptoms and caregivers age 35-44 indicated a strong sense of abandonment. They suggested that the female adult child caregiver for cancer patients felt more burden related caregiving than spouse caregivers (Given et al., 2004).

Kim, Spillers, and Hall (2012) examined the demographic factors that influenced caregiver stress five years after diagnosis of a chronic health condition among a sample of 1,218, caregivers for five-years. Caregivers’ age, income, and care receivers’ poor mental and physical functioning were significant predictors of caregivers' quality of life at five years post cancer diagnosis. Although younger caregivers reported better physical health than older caregiver, younger caregivers reported higher levels of emotional distress (Kim et al., 2012).

Butler et al. (2005) found that among a sample of 62 rural informal caregivers, caregivers showed a small relationship between caregiver burden and age at the bivariate level. Perceived support and knowledge about the caregiving task were most prevalent among middle age women. However, younger caregivers felt more depressed than their older counterparts (Butler et al., 2005). Williams (2005) also found a correlation between age of caregiver and outcome among a sample of 295 Black and 425 White caregivers (N = 720) for individuals with dementia. Younger Whites and African Americans reported greater symptoms of emotional distress compared to their older counterparts who were likely to experience more age-related health problems (Williams, 2005). Other factors that influenced background and context (Pearlin et al., 1990) included caregiver history, patient needs, socioeconomic status (SES), family and network composition, and social support program availability (Pearlin et al., 1990).

Caregiver history. The length or duration of caregiving is an indicator of the chronicity of caregiver stress (Pearlin et al., 1990). However, Dorfman et al., (1996) suggested that a prolonged duration of caregiving had no relationship to burden and strain based findings from a sample of 80 caregivers. Although caregivers reported higher stress and burden at the beginning of their caregiving responsibilities, they reported less stress and burden over time (Dorfman et al., 1996).

Dorfman et al. (1996) suggested that the absence of an association between the length of time providing care and the caregiver’s' stress might exist because older caregivers may habituate to the caregiving tasks over time (Dorfman et al., 1996). Kim, Knight, and Longmire (2007) found that family history was associated with stress and burden based on findings from a convenience sample of 1,218 caregivers in a five -year follow up study (Kim et al., 2007). They suggested that the nature of the relationship between the care recipient and conflicts with significant others within the family context had an influence on caregivers' stress. The relationship conflicts that existed between the caregiver and the care receiver before the onset of the caregiving responsibilities were related to caregivers' stress and coping skills (Kim et al., 2007). Lou, Phil, and Au (2011) found that the intensity of care demands and the amount time the care recipient required care caused excess stress and strain among caregivers of individuals with Parkinson's disease (Lou et al., 2011). Martinez-Martin et al. (2005) also found that duration of care for individuals with Parkinson's disease had a significant effect on caregivers' quality of life. These findings were based on an observational, cross-sectional study of 64 pairs of caregivers and care recipient dyads (Martinez-Martin et al., 2005). Smith et al. (2005) conducted a longitudinal investigation of stress among caregivers of individuals diagnosed with Alzheimer's disease. The sample consisted of 310 caregivers' baseline stress levels at the beginning of the research investigation and a sample of 213 caregivers' stress levels after a one-year follow-up. As the care recipients' needs increased over time, caregivers experienced a concomitant increase in stress, and a decrease in quality of life (Smith et al., 2011). Aronson (1997) examined the quality of life among a sample of 345 caregivers for individuals with multiple sclerosis (MS). They found that a decline in quality of life was related to providing care for longer durations of time, worsening of symptoms in the care recipient, and a lack of stability of symptoms in MS care recipients (Aronson, 1997). In summary, the literature reviewed supported the caregiver stress theory (Pearlin et al., 1990). There is a relationship between specific caregiver variables and caregiver quality of life that can have an adverse effect on the caregiver's quality of life (Given et al., 2004; Kim et al., 2007; Pearlin et al., 1990).

Nature of care recipient impairment. The nature of the care recipient's impairment is a source of stress for the caregiver (Pearlin et al., 1990). The literature suggested that the negative impact of caregiving have produced varying results. For example, Monteko (1989) examined the relationship between caregiver’s well-being and recipients’ level of impairment in a sample of 50 older women providing care for a spouse with dementia. Monteko found that caregivers experienced frustration associated with a disruption of life plans in the initial phases of symptoms. However, as the caregivers developed a routine, frustration diminished, although the demand for care increased (Monteko, 1989). Haley et al. (1987) examined the influence of the care recipient’s impairment on the caregiver’s stress among a sample 54 family caregivers of elderly patients with dementia. Findings showed that the duration of the disease and the severity of the impairment had a small impact on caregivers' satisfaction with life (Haley et al., 1987). However, findings from more recent research suggested that care recipients’ impairment played a significant role in caregivers' perception of stress and burden. Based on a sample of 392 senior caregivers and 427 senior noncaregivers, Schulz and Beach (1999) found that a combination of loss, prolonged distress, and health challenges of the older caregiver increased the caregiver's risk of health problems and mortality. Outcome measures also showed that older spouse caregivers who were disabled and caregiving with mental or emotion strain reported the greatest amount of caregiver distress (Shulz & Beach, 1999). However, older caregivers with no health problems and no mental or emotion stress reported the least amount of caregiver distress (Schulz & Beach, 1999). The majority of spouses, who were disabled and caregiving with mental or emotional strain reported, were found to have mortality risks substantially higher than noncaregivers (Schulz & Beach, 1999). Knight, Devereux and Godfrey (1997) examined the relationship between recipient impairment and caregiver stress and burden in a sample of 52 caregivers of individuals with a traumatic brain injury. They found a correlation between patients' physical functioning and caregivers' distress (Knight et al., 1997). Care recipients' behaviors created the highest level of caregivers' distress. Findings also indicated a relationship between caregivers' distress and care recipients' mobility problems, sudden mood changes, incontinence, and pain (Knight et al., 1997). Pakenham (2001) found that receivers' level of disability increased caregivers' distress based on findings from a cross-sectional study of 89 caregivers of individuals diagnosed with multiple sclerosis (MS). Rivera-Navarro, Morales-Gonzalez, Benito-Leons, & Madrid Demyelinating Diseases Group (2003) surveyed 91 individuals diagnosed with MS and their caregivers. Approximately 24% of the sample of care recipients required caregivers to perform activities of daily living (Rivera-Navarro et al., 2003). The older caregivers who provided care over extended periods of time were more likely to experience physical health problems related to caregiving (Neugaard, Andresen, McKune, & Jamoom, 2008)..

Miller, Berrios and Politynska (1996) also examined the relationship between care recipients' impairment and caregivers' stress among caregivers of persons with Parkinson's disease. The sample consisted of 54 spousal caregivers and 36 married couples, where both spouses were in good health. Strain and burden among the caregiving spousal group were related to providing care to individuals with multiple symptoms of Parkinson's disease (Miller et al., 1996). Haley et al. (2001) examined stress among a sample of 80 spousal caregivers of individuals diagnosed with cancer or dementia who were in hospice care. Care recipients who received intensive therapies and care recipients at the end of life required a greater number of hours of informal care compared to patients with dementia. Cancer patients required more hours of care to manage symptoms of pain, constipation, and nausea compared to the amount of time spent caregiving to individuals with dementia (Haley et al., 2001).

Economic burden. Providing care to persons diagnosed with a chronic health condition poses a substantial financial burden on caregivers (Covinsky et al., 1994; Emanuel, 2000; Lai, 2012; Pearlin et al., 1990). Covinsky et al. (1994) investigated the economic impact of severe illness on caregiving in a cross-section of 2661, caregivers of persons with serious illness. Covinsky et al. found that approximately one-third of the care recipients required substantial caregiving assistance from a caregiver. In a large portion of the cases, a family member either quit their job or made significant social and environmental changes to provide care to family members. Approximately one-third of the caregivers either lost all of the family savings or a primary source of the household income (Covinsky et al., 1994). Emanuel et al. (2000) examined the effects of economic burden on caregivers in a sample of 988 terminally ill patients and 893 caregivers. Emanuel et al. found that stress and burden were related to financial strains as well as physical, social, and emotional stress related to finances (Emanuel et al., 2000). Older, low-income individuals with a severe chronic condition who experienced health challenges (e.g., incontinence, physical mobility) that were not amenable to medical interventions created an additional emotional and economic burden for family caregivers (Emanuel et al.,2000). For example, caregivers incurred additional expenses when the caregiver was not able to obtain addition assistance to meet the care receiver's needs for extra non-prescription products or for incontinence supplies (Emanuel et al., 2000). Li, Mak, and Loke (2012) examined the relationship between the economic costs of caregiving among a sample of 340 family caregivers. Their findings suggested that economic costs associated with caregiving were a principal feature of caregivers' burden (Lai, 2012).

Family and social network resources. Pearlin et al., (1990) suggested that the caregivers' family and the social support network can have a significant influence on outcome (Pearlin et al., 1990). The social support derived from a network and the caregiver's coping style can mediate or moderate the caregiver's quality of life (Pearlin et al., 1990). A network is the totality of the caregiver's relationships, and a social support provides either partial or total assistance to the caregiver. Social support may provide a particular type of aid to the caregiver (Pearlin, 1990). In an investigation involving 54 married individuals diagnosed with PD, Miller et al. (1996) examined the impact of the social network on caregivers of individuals with PD. They found no significant relationship between caregivers’ distress and the extent of the social network. Miller et al. suggested that the lack of a significant association between stress and the social network among caregivers of PD patients might reflect limitations in the measures used (Miller et al., 1996). They suggested that the measure used in their research was based on the number of individuals with whom the caregiver had contact. The social network did not require any substantive social contact to occur between the network and the caregiver (Miller et al., 1996). Therefore, the majority of contacts within the social network were brief, casual contacts (Miller et al., 1996). Monahan and Hooker (1997) examined perceptions of social support in spouse caregivers of individuals with PD (N = 84) and spouse caregivers with Alzheimer's disease (N = 88). They found that the progressive physical impairment in PD care recipients influenced the level and type of perceived social support the caregiver believed existed. The progressive cognitive impairment of Alzheimer's patients also influenced caregivers’ level of perceived and actual social support. The availability of someone to assist in a crisis was more prevalent among caregivers of individuals with Alzheimer's disease than the availability of someone to help in a crisis for caregivers of individuals with Parkinson disease. Caregivers for individuals with Alzheimer's disease compared to caregivers of individuals with Parkinson's disease had a wider range of social supports (Monohan & Hooker, 1997).

In more recent research, Kim et al. (2007) examined the relationship between caregivers' stress and caregivers' social support network in a culturally diverse population of caregivers. Kim et al. suggested that African American caregivers (N = 95) compared to White caregivers (N = 65) reported a greater likelihood to believed that providing care for a family member was a family responsibility (Kim et al., 2007). Therefore, African Americans caregivers were more likely to have a stronger family social network composition than White caregivers (Kim et al., 2007).

Use of resources. Caregiver stress theory suggested that caregivers' access to and use of social support resources will have a positive influence on the caregiver's quality of life (Pearlin et al., 1990). The relationship between the existence of resources and caregiver's use of existing resources remains a challenge for researchers, organizations, and practitioners (Grabel & Adabbo, 2011; Sorensen et al., 2002). Montgomery and Kosloski (2009) found that caregiving is a unique situation and that no two caregivers responded to the stress of caregiving in the same manner. Knowledge gained from how one caregiver experienced the role of caregiver provided little information on how another caregiver experienced the same role when performing objectively similar care tasks (Montgomery & Kosloski, 2009). Researchers have suggested that a multicomponent intervention program that addressed the individual needs of the caregiver at various stages of the caregiving process was the most effective and efficient (Boschen et al., 2007; Elliott et al., 2010; Harding et al., 2011; Schult & Martire, 2004).

In summary, Pearlin (1990) suggested that background and context variables were significant antecedents to the caregiver's outcome or caregiver quality of life. The influence of background and context are interwoven throughout the caregiver stress process and has an interactional effect on each of the other variables of the stress process model (Pearlin et al. 1990). Caregiving requires a significant investment of time and effort and can have a negative and deleterious effect on the caregiver's physical and emotional well-being (Haley et al., 1990; Pearlin et al., 1990; Pinquart & Sorensen, 2003; Schulz & Beach, 1999; Vitaliano et al., 1991).

Primary and Secondary Stressors

Stress is the hallmark of caregiving and has both primary and secondary pathways to the adverse effects of caregiving (Pearlin et al., 1990). Primary stressors are those objective, observable activities of caregiving that might surface from the caregiving tasks necessary for assuring the safety and care of the care recipient (Pearlin et al., 1990). Secondary stressors are the intangible strains and stresses that occur in the caregiving role and affect the caregiver’s emotional and psychological well-being (Pearlin et al., 1990). For example, secondary stress might occur if conflict arises between the caregiver and a family member regarding the quality of care the primary caregiver provided to the care recipient (Pearlin et al., 1990). The section that follows provides a detailed discussion of primary and secondary stressors.

Primary stressors. These are the objective and observable stressors derived from providing assistance with many of the activities of daily living (Pearlin et al., 1990). Rivera (2009) suggested that the care recipient’s inability to perform activities daily living can create extreme stress for the caregiver. Primary stressors may become more intensified over time (Dorfman et al., 1996; Pearlin et al., 1990). The influence of stress on caregiving has been extensively documented in the research literature (Covinsky et al., 1994; Emanuel et al., 2000; Given et al., 1993; Haley et al., 2003 Pearlin et al., 1990; Pinquart & Sorensen, 2003: Zarit, et al., 2010). Given et al. (1993) found that care recipients’ physical limitations impacted caregivers' daily schedules and emotional functioning. However, patient functions had no effect on caregivers’ physical health (Given et al., 1993). Given et al. (2004) examined the longitudinal impact of burden and depression for 152 caregivers of individuals with cancer. Data were collected during the first six weeks after diagnosis and at varying intervals for 52 weeks. Findings suggested that distress in caregiving was related to care recipients’ multiple symptoms and caregiver demographic variables of age, employment status, and income (Given et al., 2004). However, care recipients’ multiple symptoms created the greatest disruptions in caregivers’ schedules resulting in greater distress during the course of the one-year research study (Given et al., 2004). Distress, burden, and disruptions in the caregivers schedule were most prevalent both at the stage of the initial diagnosis and when the patient died (Given et al., 2004). Therefore, caregiving for individuals with extensive health challenges created distress and disruption in various domains of the caregiver’s life (Given et al., 2004,). Haley et al. (2003) examined caregivers’ stress and coping in a study of 40 caregivers of patients with cancer and 40 caregivers of patients with dementia. They found that caregivers’ with high levels of negative appraisal of care the recipients’ ability to carry out self-care needs and limited social interaction indicated low levels of life satisfactions (Haley et al., 2003). Emanuel et al. (2000) suggested that caregiving for persons with high care needs caused the caregiver to experience high levels of stress and burden related to the caregiving responsibilities (Emanuel et al., 2000).

Secondary stressors. Secondary stressors are those caregiving stresses that arise from both the caregiver's needs and the care recipient's needs that lead to emotional and psychological stress (Pearlin et al., 1990). Secondary stressors are role strains and emotional stressors that may arise from old family conflicts that might resurface between the caregiver and noncaregiving family members (Pearlin et al., 1990). For example, role strain might include disagreements among family members regarding the patient's level of disability or the amount and quality of attention provided by other family members. Conflicts might also arise from the lack of consideration and acknowledgment accorded to the caregiver for care given to the care recipient (Pearlin et al., 1990). Role strain can also be the results of the dual role of caregiving and maintaining employment outside (Duxbury et al., 2011). Duxbury et al. examined the influence of strain on caregiving in a cross-sectional study of caregivers. These findings suggested that employed caregivers may experience feelings of being overwhelmed and fearful, as well as feelings of anger, frustration, helplessness, and powerlessness (Duxbury et al., 2011). The disability of the care recipient and the level of difficulty in accessing affordable and dependable care created an additional strain for maintaining a wholesome work-life balance among employed caregivers (Duxbury et al., 2011).

The economic burden of caregiving has been a significant source of caregivers' role strain (Pearlin et al., 1990). Role strain might surface when there is a reduction in the household income and an increase in patient care expenditures (Covinsky et al., 1994; Duxbury et al., 2011). A lack of adequate household funds can, in turn, create concerns about not having enough money to make ends meet (Duxbury et al., 2011; Pearlin et al., 1990). Financial insecurity and losing one's sense of security was found among employed caregivers (Covinsky et al., 1994; Duxbury et al., 2011). Employed caregivers who shared the same household with the care recipient experienced the highest levels of financial role strain. However, caregivers who lived near, but not with the care recipient experienced the lowest levels of financial strain (Duxbury et al., 2011). The financial burden of caregiving also resulted in family members selling assets, taking out loans, or taking on an additional job to supplement the needs of the care recipient (Covinsky et al., 1994). Duxbury et al. (2011) suggested that employed caregivers who provided caregiving in their home tended to be unmarried women, with young children, and in a difficult financial situation. While no causality is suggested, these women might care for dependent relatives because they cannot afford any other type of care for their elderly parents (Duxbury et al., 2011). They also suggested that employed caregivers may provide care in their home because the care receiver is elderly with a pension that offers additional income to the caregiver's household (Duxbury et al., 2011). Garlo, O'Leary, Van Ness, and Fried (2010) found that about half (N = 175) of caregivers were concerned about not having enough income or just enough income to make ends meet (Garlo et al., 2011).

Intrapsychic strain was a significant aspect of role strain. However, it is significantly different from the other types of role strain previously discussed (Pearlin et al., 1990). This is a caregiver stressor that falls under the category of secondary stressors (Pearlin et al., 1990). Intrapsychic role strain involves aspects of the self-concept (Pearlin et al., 1990). The self-concept can become damaged under conditions of enduring hardship (Pearlin et al., 1990). When this occurs, the caregiver is likely to suffer physical and psychological symptoms of stress from the relentless and progressively intense demands of caregiving (Pearlin et al., 1990). Caregiving can lead to a reduction or an elimination of social activities as the caregiving demands and responsibilities increases. Intrapsychic role strain can also lead to psychological and emotion internal conflict (Pearlin, 1990). Therefore, role strains and intrapsychic stress are considered secondary stressors because they are the results of ongoing emotional stress incurred from caregiving responsibilities (Pearlin et al., 1990).

The caregiver's perception of stress, burden, and ability to provide care is related to the caregiver's preparedness for caregiving (Schumacher et al., 2008). Preparedness is an emotional and anticipatory preparation of the caregiver's readiness to provide care. In other words, it is the caregiver's perceived availability to take on the multiple domains of the caregiving role (Schumacher et al., 2008). Domains are the areas of caregiving that involves providing physical, emotional, and social support while simultaneously coping with the stress of caregiving (Schumacher et al., 2008). In a sample of 87 family caregivers, preparedness was a predictor of emotional strain rather than role strain related to caregiving activities (Schumacher et al. 2008). Kurz, Kurz, Given, and Given (2004), in an experimental design of 118 random control trials investigated the effects of teaching caregivers specific skills in symptom management, and stress management for 20 weeks. A control group of 119 participants was provided with training on symptom management and symptom recognition, but not stress management. The interventions did not show a significant reduction in caregivers' mental and emotional stress symptomatology over the course of the research study (Kurtz et al., 2005).

In summary, primary and secondary stress involved both the physical and psychological strain of caregiving. How the caregiver perceived the demands of caregiving determined the level of perceived burden, health, and well-being the caregiver experienced. Preparation for the caregiving task played a significant role in how well the caregiver adjusted to the caregiving role. While training and information may have play a role in improving caregiving activities, training, information, and stress reduction training did not significantly reduce caregiver stress (Kurz et al., 2005).

Caregiver Burden

Caregiving to a family member or friend with a chronic impairment creates stress and burden, both physically and emotionally. How caregivers perceived the caregiving experience influenced the caregiver's emotional response to the demands and responsibilities of caregiving (Grabel & Adabbo, 2011; Pearlin et al., 1990). Caregiver burden is the caregiver's subjective appraisal of the experiences of caregiving (Grabel & Adabbo, 2011; Lazarus & Folkman, 1984). Researchers have suggested that caregiving activities leading to subjective burden involved many aspects of caregiving including the caregiver's physical health and a restriction in the caregiver's social activities. Therefore, the care recipient's behavior and physical needs resulted in a gradual increase in stress and burden for the caregivers (Grabel & Adabbo, 2011; Smith et al., 2011). Perceived burden mediated how caregivers appraised and coped with the stresses that evolved from the multiple facets of caregiving (del-Pino-Casada, 2011 (Grabel & Adabbo, 2011;

Pearlin et al., 1990; Smith et al., 2011). Grabel and Adabbo (2011) examined burden in caregivers in a representative sample (N = 1,110) of informal caregivers of chronically ill older family members. They found that caregivers who were living in the household with care recipient reported greater burden than caregivers who did not live in the same household with the person with the chronic impairment (Grabal & Adabbo, 2011). del-Pino-Casado et al. (2011) conducted a literature review of empirical research on the effect of different coping strategies on subjective burden among caregivers. Findings suggested that caregivers engaged in different styles of coping to manage the subjective burden. The methods of coping used included problem-focused coping, emotion-focused coping, approach, and avoidance. Problem-focused coping entailed caregivers solving challenging problems, and emotion-focused coping was the caregiver's inclination to managing emotions (del-Pina-Casada et al., 2011). According to del-Pina-Casada et al. approach coping involved caregivers' attempt to reappraise, modify, and solve problems and avoidance coping falls into two categories. The first category is the caregiver's attempt to cope with feelings of burden behaviorally and the second is the attempt to cope with feelings of burden cognitively (del-Pina-Casada et al., 2011). Findings from this research suggested a positive association between avoidance coping and subjective burden in caregivers of relatives with cognitive impairments (del-Pina-Casada et al., 2011). Avoidance coping was an ineffective coping strategy (del-Pino-Casado, et al., 2011). Lau et al. (2011) also examined distress in informal caregivers involving burden and stress associated with caregiving for persons diagnosed with Parkinson's disease and concomitant cognitive deficits (Lau et al., 2011). Increased motor symptoms in persons with PD had the strongest relationship to caregivers' quality of life (Lau et al., 2011). The caregiver's distress and care the recipient's dependence in activities of daily living had the second most substantial relationship to caregivers' stress and burden. Decreased cognitive functioning had the least size effect with caregivers' stress and burden (Lau et al., 2011). The intensity of caregiving responsibilities was significantly correlated with caregivers' feelings of stress and burden (Lau, et al., 2011).

Mediating Circumstances

Caregivers respond and cope with stress differently. Researchers have suggested that coping and social support are the principal mediators that account for the difference in how caregivers may differentially respond to a stressful situation (Pearlin et al., 1990). Kim et al. (2007) examined how family burden and coping style mediated the relationship between ethnicity and caregivers' mental and physical health. In a sample of 160 Caucasians and African Americans (65 Caucasians and 95 African Americans), caregiver experiences of elderly family members with dementia were found to differ between the two ethnic groups. The researchers examined the effects of cultural values on the appraisal of caregiver stress, caregiver coping styles, and caregiver outcomes. Within the context of caregiving, they suggested that African Americans have adopted and embraced a positive traditional caregiving belief with fewer feelings that caregiving to family members is an intrusion (Kim et al., 2007). Kim et al. found that although family ties played a significant role in enhancing caregivers' mental and physical health, taking on the caregiving role was influenced to a greater extent by education rather than ethnicity (Kim et al., 2007). Kim et al. further indicated that ethnic differences between

African American and Caucasian caregivers were better explained by socioeconomic status (SES) than by culture. Family ties were found to influence an avoidant coping style that, in turn, led to a decline mental and physical health outcomes (Kim et al., 2007). Therefore, the relationship between familism and avoidant coping suggested that family ties may represent an obligation rather than positive feelings about family support (Kim et al., 2007).

Coping. Coping has a mediating and a moderating effect on the caregiver's health and well-being (Pearlin et al., 1990). Coping refers to the cognitive and behavioral efforts to master, decrease, or endure the internal or external demands created by a stressful encounter (Lazarus & Folkman, 1984). Folkman, Lazarus, Gruen, and DeLongis (1986) suggested that there is a mutual and dynamic transaction between stress and coping with coping affecting subsequent appraisal of situations and whether or not the situation is perceived as stressful. Ineffective coping can lead to perceiving caregiving as more stressful and coping resources as scarce (Folkman et al., 1986). Thus, the caregiver has fewer coping resources to use with each subsequent appraisal of the situation over time. This reciprocal process can lead to a deterioration of the caregiver's resources as stress increases (Folkman et al., 1986; Lazarus & Folkman, 1984).

Caregiver appraisal is the level of distress experienced, and the caregiver’s self-efficacy in managing the problem is mediated between environmental stress and caregiver outcome (Folkman et al., 1986). Haley et al. (1987) examined the relationship between stress, coping, and appraisal. They suggested that coping mechanisms involving information seeking, problem-solving, and emotional release were useful for managing caregiving responsibilities and decreasing emotional distress. The availability and use of social support were also effective in coping with the stresses of caregiving (Haley et al., 1987). Based on a sample of 54 demographically diverse caregivers of moderately to severely impaired dementia patients, Haley et al. identified dimensions related to good versus poor adaptational outcomes among caregivers of individuals with dementia. Questionnaires and interviews were used to examine care recipients' impairment and caregivers' stress, appraisal, coping, social support, and caregiver outcome (Haley et al., 1987). They found that appraisal and coping responses were significant predictors of caregivers' quality of life.

Caregivers' stress and quality of life were related to the use of coping strategies and the availability and use of social support resources. Coping processes acted as primary mediators of the stress process (Haley et al., 1987; Lazarus & Folkman, 1984; Pearlin et al., 1990). Coping strategies involved behaviors and practices that the individual caregiver engaged in on their own behalf (Haley et al., 1987). Pearlin et al., (1990) identified several factors that are unique to coping among caregivers. Coping involves three important components that include managing the situation causing the stress, managing the interpretation of the meaning of the situation in order to reduce the perceived threat, and managing the stress symptoms that stem from the perceived stressful situation (Pearlin et al., 1990). These variables have validity because they assess the coping mechanism of stress that is specific to caregiving as a heterogeneous group (Pearlin et al., 1990).

Self-efficacy is the caregiver's perceived ability to cope with the demands of caregiving (Bourgeoise, Beach, Schulz, & Burgio, 1996). Self-efficacy has been shown to have a beneficial effect on the caregiver's physical and psychological health (Bourgeoise, et al., 1996; Chronister et al., 2010; Epiphaniou et al., 2012; Gallagher et al., 2011; Haley, et al., 1987; Pearlin et al., 1990). Gallagher et al. (2011) examined self-efficacy in caregiving tasks and symptoms of burden among caregivers. Using a sample of 84 caregivers and Alzheimer's patient dyads, the researchers examined caregiver burden, coping strategies, and self-efficacy. They found that 33% of the caregivers reported substantial levels of emotional and psychological distress. This suggested that self-efficacy was related to patient symptom management, had a beneficial effect on the caregiver's psychological health, and buffered the negative impact of the patient's behavioral symptoms (Gallagher et al., 2011). Bourgeois et al. (1996) examined the influence of disagreement between informal primary and informal secondary caregivers when a difference of opinion on the needs of the patient surfaced. They found that there was divergence in perceptions in varying areas of caregiving between primary and secondary caregivers. However, there was less disagreement between the two groups on the extent of the care recipient’s problem behaviors and the strain it imposed on the caregiver (Bourgeoise et al., 1996). There was more disagreement about primary caregivers' coping efficacy. Although the primary caregiver may have had contact with a secondary caregiver who had a negative and pessimistic attitude, these negative attitudes had little influence on the primary caregiver’s level of perceived social support, depression, and burden (Bourgeoise et al., 1996). The care recipient’ symptoms and the secondary caregiver's pessimistic attitude also had a small negative effect on the primary caregiver's self-efficacy (Bourgeoise et al., 1996).

Chronister et al. (2010) examined the direct impact of stress-coping variables on quality of life in a sample of 108 caregivers of individuals with a traumatic brain injury to identify the extent to which specific stress-coping variables affected the quality of life of the caregivers. Fifty-two percent of the sample included patients, and 34 % of the sample included spouses. The caregiver variables included functional competency, caregiving appraisal, coping skills, and perceived social and family needs on caregivers' quality of life. Functional competency included the caregiver's perception of the care recipient's emotional, cognitive, behavioral, physical, and daily functioning skills (Chronister et al., 2010). Family needs represented the caregiver's perceived needs and the extent to which needs were met in the areas of health, information, emotional support, instrumental support, and a community support network (Chronister et al., 2010). Quality of life was defined as the caregiver's perception or assessment of his or her physical, psychological, and social well-being (Chronister et al., 2010). They found that based correlational analysis, emotional, social support, and social needs mediated the relationship between perceived burden and social support (Chronister et al., 2010).

Researchers found that caregivers who were exposed to the same stressors reacted differently to the stress of caregiving (Haley et al., 1987). The stress and coping models (Haley et al., 1987; Pearlin et al., 1990) suggested that differences in coping responses and the use of social support can account for how two caregivers with similar stressors are uniquely affected by the stresses of caregiving (Pearlin et al., 1990). Pearlin et al.

suggested that a mediator might either serve to lessen the intensity of stressor or to "block their contagion at the point between the primary and secondary stressors" (Pearlin et al., 1990, p. 590). Therefore, coping and social support played a significant role in buffering the effects of negative outcomes (Pearlin et al., 1990). Buffering was found to have a direct impact because it can be judged by looking directly at the outcome (Pearlin et al., 1990).

Goode, Haley, Roth, and Ford (1998) found that changes in a domain of caregiving stress (care recipient memory and behavior problems) produced changes in one of the psychosocial resource variables (caregiver stressfulness appraisals). Changes in stressfulness appraisals were positively associated with changes in caregivers' physical and psychological health (Goode et al., 1998). Moreover, the care recipient's problem mediated the relationship between coping and the caregiver’s health outcome (Goode et al., 1998).

Romero-Moreno et al. (2011) examined the moderating effect of self-efficacy in managing feelings of distress and burden. In a study involving 167 caregivers of persons with dementia from Madrid (Spain), they found that frequent behavior problems of care recipients were associated with high subjective stress and burden and poor psychological well-being, including anxiety and depression among caregivers (Romero-Moreno et al., 2011). Although excessive stress was related to increased burden, elevated self-efficacy for managing disruptive behaviors among care recipients was linked to lower levels of burden (Romero-Moreno et al., 2011). Therefore, self-efficacy was found beneficial, even when caregivers experienced high stress (Romero-Moreno et al., 2011). Moreover, self-efficacy had a moderator or protective effect on the relationship between caregivers' burden and distress involving caregivers' psychological and emotional well-being (Romero-Moreno et al., 2005).

Empirical research on coping among non-dementia caregivers provided an evidence-based model for coping with the stress of caregiving (Epiphaniou et al., 2012). Epiphaniou et al. suggested that there is a high physical and psychological morbidity for the cancer patient and few interventions to meet the needs of these caregivers. Using a qualitative research approach, Epiphaniou et al. examined existing coping and support mechanisms utilized to identify appropriate interventions. They found that caregivers' existing coping strategies involved distraction, mental stimulation, emotional release, focus on the emotional rewards of caregiving, and disengaging from stressful thoughts had a beneficial effect. Caregivers' support strategies involved receiving help from family, friends, and help from some professionals who provided psychological support was also a helpful coping resource (Epiphaniou et al., 2012).

Pakenham (2001) examined the utility of stress and coping involving a sample of 89 MS caregivers and care recipients. Based on a hierarchical regression analysis, the data indicated that after controlling for gender, improved caregiver adjustment between time 1 and time 2 was related to less care recipient disability and higher social support (Pakenham, 2001)

Social support. Pearlin et al., (1990) suggested that social support can play a significant role in buffering or reducing the effect of stress in the caregiving situation. They further suggested that instrumental and expressive support were central to identifying social support resources. The instrumental support consisted of individuals or sources that may assist the caregiver in caring for the disabled person, household chores, and other instrumental activities. Expressive support was someone whom the caregiver perceived as caring, trustworthy, and emotionally uplifting. These mediators can have a positive impact the quality of life of the caregiver and at the same time predict the caregiver's outcome (Pearlin et al., 1990).

Social support is the resource provided by others when faced with a stressful situation or event (Chwalisz, 1992). Researchers suggested that social support acts as a buffer between the experience of stress and negative outcomes (Chwalisz, 1992; Haley et al., 1987). Social support protected the individual from the pathogenic effects of stress by preventing behavioral or physiological response to stresses that are associated with negative physical and mental outcomes (Chwalisz, 1992; Pearlin et al., 1990). According to Chwalisz (1992) support may disrupt the link between the potentially stressful event and the stress reaction. Disrupting the link will prevent a negative stress appraisal response and providing support will intervene between the experience of stress and the onset of the negative outcome. Therefore, social support can serve to reduce or eliminate the emotional reaction, reduce the physiologic process, or alter caregivers' maladaptive behavioral responses to stress (Chwalisz, 1992).

Social support had a significant role in the health and well-being of the caregiver. There were common outcomes that were unique to caregivers across a range of disorders (Monahan & Hooker, 1997). Miller et al. (1996) examined factors that contributed to caregiver's distress; including the level of social support available to the caregiver.

Miller et al. (1996) suggested that, "the caregiver is a sine quo non for social support potentially available on a long term basis" (p. 264). Social support was defined by the number of people outside the caregiver's household that the caregiver had been in contact with over the previous few weeks (Miller et al., 1996). Social support included visits to or from friends or relatives and contacts with neighbors and well as more casual contacts (Miller et al., 1996).

Limited research has been conducted on identifying predictors of social support for caregivers at risk for negative outcomes (Chang et al., 2001). Chang et al., examined predictors of social support for negative caregiver outcome using the caregiver stress model (Chang et al., 2001; Pearlin et al., 1990). They suggested that factors mediating or influencing social support have included caregiver and care recipient characteristics. According to Chang et al. (2001) most research has included the structural aspect of social support involving the composition of the network and the level of social participation. The size of one's network and structural aspects of that support refers to the physical existence of social supports and the types of relationships in the network (Chang et al., 2001). Based on their research involving a sample of 81 caregivers and care recipient dyads, they found that arranging assistance was more beneficial to caregivers than frequency of contact from the social network (Chang et al., 2001). However, not all social networks have been beneficial to the caregiver (Cheng et al., 2012). Caregivers have been found to experience feelings of anger and frustration related to a belief that they have not received adequate supports or because of conflicts related to disagreements between themselves and their social support system (Cheng et al., 2012).

Primary caregivers with a negative and pessimistic secondary caregiver, but a strong sense of self-efficacy, experienced less stress and burden than primary caregivers with more optimistic helpers (Chang et al., 2012).

The social network can provide emotional support, information and incentives to engage in healthy behaviors (Chang et al., 2001). The caregiver's perceptions of the availability of social support were related to less caregiver burden and depression, and the engagement in social activity was associated with greater caregiver life satisfaction (Chang et al., 2001). However, social networks can also be a source of additional stress when the caregiver believes that the social network can provide assistance but fail to do so, thereby leading to conflict within the network (Chang et al., 2001). Liu, Lee, Greenwood, and Ross (2011) examined the relationship between self-appraised problem solving, psychological distress, and social support for informal caregivers of stroke victims in a prospective correlational study of 103 family caregivers. They found that the caregiver's confidence in problem-solving predicted the caregiver's perceived social support and physical well-being (Liu et al., 2011).

Bourgeoise et al. (1996) examined the impact of social support on caregiving in a sample of 100 caregivers. They found that caregivers for chronically ill individuals had a strong need for support from family and friends in their social network to help with the demanding task of caregiving. Secondary caregivers were caregivers who provided emotional support to the primary caregivers (Bourgeoise et al., 1996). Secondary caregivers can assist the primary caregiver in a variety of ways including psychological, emotional, instrumental support, and with the activities of daily living. Secondary caregivers may be a significant force in the caregiver's life because of their knowledge and understanding of the caregiver as well as their knowledge and insight of the health of the care recipient. Secondary caregivers may also be an upsetting and stressful source because of the intimate knowledge of the caregiver and the care receiver. According to Bourgeois et al. (1996) little is known about the primary and secondary caregiver relationship, but the negative effects can be much stronger than the positive impact on the primary caregiver.

According to Bourgeois et al. (1996) the nature of the primary caregiver's social network can also have a significant influence on patient and caregiver outcomes including caregivers' perceived stress, burden, depression, and self-efficacy. Primary informal caregivers may have a range of support needs and expectations of support and assistance from family members. Secondary caregivers may have specific expectations and perception of the primary caregivers' responsibilities and may vary in his or her ability and willingness to provide support to the family member providing primary caregiving (Bourgeois et al., 1996).

Researchers found that perceptions provided different antecedents or consequences for caregiving outcomes (Pearlin et al., 1990). Situations of disagreement about the patient’s problem, the effects of these problems on the primary caregiver, and the caregiver's ability to cope have led to friction and conflict, low of perceived support and an increased in the primary caregiver's distress (Chang et al., 2001; Cheng et al., 2012). Bourgeois et al. (1996) found that significant differences were present in perceptions in all caregiving domains with comparably less agreement about patient problem behaviors.

Use of Resources

Boschen et al. (2007) suggested there is a need for evidenced-based resources for caregivers of individuals with a chronic health condition. Goode et al. (1998) suggested that social support resources interacted with self-care in predicting change in the psychological and physical health among caregivers. Goode et al. found that caregivers who reported the existence of social support resources at the beginning of their caregiving responsibilities demonstrated an improved quality of life over time based on findings from a longitudinal study of 122 caregivers of individuals with dementia (Goode et al., 1998). However, informal caregivers, who reported limited social support resources and engaged in limited self-care practices, reported an increase in physical health symptoms. They also found that psychosocial resource variables (appraisals, coping responses, social support) predicted changes over time in the caregiver's mental and physical health (Goode et al., 1998). Psychosocial resource variables may exert their influence through differing paths or mechanisms. For example, a problem-solving coping response instead of an avoidance coping style will have a positive effect on the outcome. Caregivers who reported an avoidance coping style reported increased stress over time (Goode, 1998). Ownsworth et al. (2010) examined the relationship between care receivers' impairment among individuals with cancer and caregivers' well-being. Based on a hierarchical regression analysis of 63 caregivers of individuals with brain cancer, they found that satisfaction with social support moderated the relationship between patient impairment and caregivers' psychological well-being (Ownsworth et al., 2010). Ownsworth et al. suggested that when care recipients experienced a decline in functional health status, the caregivers' involvement and satisfaction with the social support network played an important role in maintaining and enhancing physical and psychological well-being (Ownsworth, 2010).

Outcome

The caregiver's coping resources is an important determinant of outcome (Pearlin et al., 1990). The caregiver's physical, emotional, and psychological well-being depend on maintaining physical and emotional stability in the caregiving role (Pearlin et al., 1990). The challenges to well-being among caregivers included symptoms of anxiety, depression, inaccessibility to support resources, and cognitive disruptions. These types of challenges that lead to disruptions functioning occur under conditions of sustained chronic stress and burden (Pearlin et al., 1990).

Outcome denotes the impact of stressors on a caregiver's well-being. Caregiving to individuals with a chronic health condition can have an adverse effect on caregivers that put them at risk of psychological morbidity and physical health problems leading to mortality (Haley et al., 1987; Haley et al., 2001; Pearlin et al., 1990; Pinquart & Sorensen, 2003; Zarit et al., 2010). Researchers who examined variables related to caregiver well-being primarily addressed concerns of role overload and role capacity (Grabel & Adabbo, 2011; Pearlin et al., 1990). Outcome involving general well-being involved feelings of fatigue, depression, and a poor overall quality of life (Grabel & Adabbo, 2011; Pearlin et al., 1990; Pinquart & Sorensen, 2003; Schulz & Beach, 1999;

Zarit et al., 2010). Billings et al. (2000) identified a correlation between caregiver's mood and health status in an examination of the link between coping, mood, and health variables in a two year prospectus study of 86 caregivers of individual diagnosed with AIDS related health conditions. Schulz and Beach (1999) examined the risk factors for 392 elderly caregivers and 427 individuals who were not caregivers over a 4-year period. They found that caregivers with mental or emotional strain were more likely to die than the comparison group who were not caregivers (Schulz & Beach, 1999). Based on a prospective cohort study of 375 caregivers and 694 noncaregivers, Fredman, Cauley, Hochberg, Ensrud, and Doros (2010) found that the consequences of stress increased the risk of ill health among caregivers (Fredman et al., 2010).

Caregiver health. One of the variables that had a major influence on caregiver outcome was the caregiver's health. The quality of the caregiver's health was linked primary and secondary strain, depression, and dissatisfaction with life (Pinquart & Sorensen, 2003; Neugaard et al., 2008; Pearlin et al., 1990). Pinquart and Sorensen (2003) suggested that providing care is a stressful undertaking that can result in the erosion of the caregivers' physical well-being. In a meta-analysis of 84 studies on the differences between caregivers' and noncaregivers' psychological and physical health, a significant difference was found in the physical health status among caregivers of individuals with dementia and noncaregivers (Pinquart & Sorensen, 2003).

Neugaard et al. (2008) examined the impact of caregiving on the caregiver's physical health, and health-related quality of life using a cross-sectional study of 184,450, adults. They found an interactional effect between caregivers' health status and the age of caregivers. Caregivers, 55 years of age and younger had a 35% increased risk of having fair to poor health compared to noncaregivers in the age group. Caregivers 55 and older had a 3 percent decreased risk of experiencing fair to poor health compared to individuals in the same age who were not caregivers (Neugaard et al., 2008). They concluded that caregivers had a small to moderate decline in health-related quality of life compared to noncaregivers. Caregiving affected the health-related quality of life of younger more than older adults (Neugaard et al., 2008).

De Frias, Tuokko, and Rosenberg (2005) examined the health status of 133 caregivers ranging in ages from 31 to 96 years; and 177 care receivers ranging in age from 63 to 94 years. Using the five score Caregiver Reaction Assessment (CRA), they found that older individuals, as caregivers, experienced greater health problems. Caregivers reported more significant health challenges and worse physical health when the care recipient experienced higher levels of pain (De Frias et al., 2005). Conversely, caregivers with fewer health problems reported improved mental health and less depression. Therefore, caregivers with health challenges were at a greater risk of experiencing stress from caregiving compared to caregivers with no health challenges (De Frias et al., 2005)

Summary

Caregivers have played a significant role in the life and care of individuals with a chronic health condition (Pearlin et al., 1990). However, supporting the chronically ill individual at home can be challenging and can lead negative consequences (Pearlin et al., 1990). These consequences might include a decline in physical health, an increase in psychological distress, financial burden, and a reduced quality of life. Several theoretical formulations emerged that described the pathways to the negative consequences of caregiving. In this research, I focused on caregiving within the context of the caregiver stress process theory (Pearlin et al., 1990). Researchers and practitioners have offered various theories and findings on effective ways to reduce caregiver stress and burden and ameliorate caregivers' quality of life. These interventions have included psychoeducational measures, support groups, psychotherapy, relief measures, and multicomponent measures (Grabel & Adabbo, 2011; Sorensen et al., 2002). However, these measures have not produced the desired outcome (Boschen et al., 2007; Whittier et al., 2005). Many caregivers do not use caregiver services that are designed to help (Montgomery & Kosloski, 2009). For example, among caregivers who started respite care support services, one-third discontinued the service within the first 90 days (Montgomery & Kosloski, 2009). These findings suggested that the services provided might not have been consistent with the caregiver's needs, or a service that the caregiver could benefit from at the time (Montgomery & Kosloski, 2009). Moreover, no resource is efficient if it is not adequate to meet the caregiver's needs and, therefore, is not used by the caregiver (Grabel & Adabbo, 2011). In other words, if a service is hardly used it cannot become widely useful in reducing caregiver burden.

From a social change perspective, it will be necessary to ensure that informal caregivers can provide care for their family members in a manner that enables them to carry out caregiving activities along with the other responsibilities of their lives (Duxbury et al., 2011; Emanuel et al., 2000; Given et al., 2004). The results of this study provided insight into how the stresses of caregiving within the context of the stress theory (Pearlin et al., 1990) influenced caregivers. This research also examined which stress variables within the caregiver stress theory (Pearlin et al., 1990) were the strongest predictors of caregiver quality of life. Findings from this research study should assist researchers and practitioners in identifying and developing effective and efficient resources for reducing and alleviating caregiver stress and burden and improving caregivers’ quality of life.

The health and well-being of informal caregivers have been a force for social change over the past three decades (Grabel & Adabbo, 2011; Pearlin, et al., 1990; Sorensen et al., 2002). With a growing need for in-home care, families will continue to assume greater responsibility for the care of individuals experiencing debilitating physical and cognitive decline (e.g., stroke, cancer, Parkinson's disease). Therefore, the physical health and psychological well-being of caregivers will remain a social priority (Gallagher et al., 2011; Grabel & Adabbo, 2011). Identifying caregiver stress vulnerabilities and providing appropriate interventions and resources is a necessary ingredient for reducing and removing stress and burden and ameliorating caregivers' quality of life (Pearlin 1990).

There is a gap in the literature regarding the predictors of caregivers' stress and burden and the availability of existing resources for reducing stress and burden (Pearlin et al., 1990). The stress variables examined in this research were environment and context, stressors involving the demands of caregiving, appraisal of ability to cope, knowledge and use of resources, and caregiver quality of life or outcome. The research questions addressed in this study were:

Is there a statistically significant relationship between caregiver stressors: environment and context, stressor involving the demands of caregiving, caregiver's appraisal of ability to cope, knowledge and utilization support resources and caregiver quality of life?

Which is the best predictor of caregiver outcome or quality of life, as measured by the caregiver's self-ratings: environment and context, stressors involving the demands of caregiving, caregiver's appraisal of ability to cope, and knowledge and utilization of resources?

Chapter 3 discussed the research methods used to address the research questions to fill the gap in the literature. This chapter included a discussion of the research design and rationale, methodology, data collection, inclusion and exclusion criteria, the dependent and independent variables under study, sample size, and threats to validity. The Walden University Institutional Review Board (IRB) approval to conduct this research is also included in Chapter 3.

Chapter 3: Methodology

Introduction

The purpose of this study was to gain insight into how a broad range of variables from the caregiver stress process theory (Pearlin et al., 1990) influenced stress and burden among informal caregivers. In this correlational study, I sought to determine whether there is a statistically significant relationship between specific caregiver stress variable and caregiver outcome or caregiver quality of life. Additionally, I sought to identify which variables in the stress process are the best predictors of caregiver quality of life.

In this chapter, I outline and explain the research design, participants, instrumentation, procedure, threats to statistical validity, and rationale behind the chosen design and data analysis. The research questions and hypotheses are reexamined in order to defend the overall research design. The ethical issues and considerations in the research are also discussed.

Research Design and Rationale

The research method selected for the study was a nonexperimental, quantitative design. The quantitative research design was chosen instead of a qualitative design because the ICPSR archival secondary data are numerical and are used to statistically examine a representative sample of the population (Creswell, 2009). The quantitative design was used to establish whether caregiver characteristics have a statistically significant predictive relationship with caregiver quality of life, whether the caregiver's style of coping with stress and the availability of resources interacts with stress to predict caregiver quality of life, and whether there is a significant relationship between knowledge and use of support of social support and caregiver quality of life. I also sought to determine which is the best predictor of outcome as measured by the caregiver's self-rating of quality of life. A qualitative approach would not be appropriate for archival data that are numerical in nature.

This study was based on survey research and examined the strength of the relationship between variables using a correlation and a hierarchical regression analysis of the independent variables. A Pearson's product-moment correlation (*r*) was used to explore the relationship between the dependent variable and the independent variables to determine the strength and direction of the relationship between the dependent variable (caregiver outcome) and the independent variables involving caregiver stress and burden. A hierarchical regression was used to explore the predictive ability of the dependent variables on the independent variables. For example, hierarchical multiple regression analyses identified characteristics of caregivers who experienced stress and burden and included five blocks of independent variables. Block 1 contained sociodemographic data, Block 2 comprised demands and activities of caregiving, Block 3 included the caregiver coping style; Block 4 addressed use of resources, and Block 5 involved caregiver quality of life. Because of the large number of independent variables, a factor analysis was completed to determine which variables overlapped.

Archival Research Methodology

An archival research method was used for this study. This archival quantitative study used information maintained by the Inter-University Consortium on Social and

Behavior Research (ICPSR). The archival data were originally collected by Harris Interactive, which, funded by the Robert Woods Foundation, gathered survey data through telephone interviews from March 17, 2000, to November 22, 2000, on caregiving and chronic illness using a broad spectrum of survey questions to obtain public opinions on chronic illness. The survey was conducted from the centralized telephone research centers of Harris Interactive Inc. in Youngstown, Ohio, and Binghamton, New York. Survey data were weighted to reflect the demographic composition of the U.S. population for age, education, race/ethnicity, household size and number of telephone lines in the household using the March 1999 Current Population Survey from the U.S. Census Bureau (Thamer, 2000).

Setting and Sample

This research was based on archival data sources from the ICPSR. A total of 1,663 adults 18 years of age or older participated in the survey. The sample included a national cross section of 1,490 adults, with an additional oversample of persons with a chronic illness and adults who provided informal care services, for a total of 663 chronically ill persons and 320 caregivers.

The sample for this research was drawn from a cross-section sample of 320 caregivers selected from the ICPSR archival data on caregiving and chronic illness (Thamer, 2000). The procedures for this study involved a correlational research design to determine the presence of a relationship between the dependent variable and a set of independent variables. As this study involved a secondary data analysis, demographic data were selected from the data provided by the ICPSR archival data source (see

Appendix A). Variables for this correlational research were selected based on face validity. However, the variable for the independent and dependent variables were chosen within the framework of caregiver stress theory (Pearlin et al., 1990). As the study was a secondary data analysis, indicators for the study variables (e.g., age, hours of care, nature of assistance provided to chronically ill, length of time providing care, nature of support provided to caregiver) were selected from the survey questions (See Appendix B).

Data Collection Measures

The ICPSR website permits downloading data from the caregiving and chronic illness cross-sectional survey. Therefore, all records were downloaded from the free ICPSR website.

Inclusion and Exclusion Criteria

Samples were selected based on questions that matched the criteria for this research. The participants selected to respond to the survey questions were required to meet the following criteria: being a caregiver for an individual 18 years or older who is experiencing a chronic illness. The caregiver was required to have been providing care to a chronically ill or frail, elderly individual at the time when the research was conducted. Respondents were included if they cared for an adult with a chronic illness who lived with the caregiver, alone, in his/her own home, with another family member or friend, or in a retirement community or elderly housing apartment complex.

Respondents who had not provided care for a chronically ill individual, who were receiving payment for caregiving, or who were caregivers for individuals in institutional care were excluded from the survey. Caregivers who had formal training in providing care, such as those with formal training as nurse assistants or other medical training, were also excluded from participation. Caregivers were excluded if the care recipient had been deceased for more than 1 year.

Independent Variables

A hierarchical multiple regression (HMR) was used to determine how the independent variables predicted the dependent variable at different steps, controlling for all other independent variables in the equation. The independent variables consisted of blocks or steps. Drawing from caregiver stress theory (Pearlin et al., 1990), independent variables from the hierarchical regression model were as follows: (a) environment and context including sociodemographic characteristics, (b) stressors involving demands of caregiving, (c) caregiver's appraisal of ability to cope with demands of caregiving, (d) caregiver's knowledge and use of social support resources, and (e) negative consequences of caregiving that affect the caregiver's quality of life. The survey responses to the questionnaire were recorded. The interview instrument used by Harris Interactive directed the interviewer to specific questions based on the participant's response.

The first through fourth blocks of variables acted as antecedents to the stress process and influenced the impact of stress on the caregiver throughout the caregiving experience. Caregiver quality of life was consistent with the outcome variables in the caregiver stress process theory (Pearlin et al., 1990).

With the ICPSR survey questionnaire functioning as a guide, questions were selected for independent and dependent variables based on caregiver stress theory (Pearlin et al., 1990). The five blocks of the independent variables and a sample of the questions that comprised each block of the independent variables are provided at the end of this chapter (Appendix C).

Data Analysis

This research study used a quantitative correlational and hierarchal multiple regression analysis to investigate the relationship between caregiver stress and burden and use of social support resources. The data collected from the surveys were analyzed using SPSS –Windows, version. 19.0. Demographic data were summarized using frequency distributions and crosstabulations. Questions selected from the caregiver survey were based on the ICPSR caregiver survey questionnaire for caregivers of chronically ill individuals. Scores from the survey were summarized using measures of central tendency and dispersion to provide baseline data on these measures. The data generated were interval and scale questions. Therefore, the research questions and hypotheses were tested using Spearman correlation, Pearson product moment correlation, and Hirarchcal Multle Linear Regression Analysis.

Sample Size, Effect Size, and Alpha Level

Creswell (2009) suggested that a sample size that is not of sufficient size to meet the desired effect size will alter the results and potentially create a Type I error. A Type I error is when concluding that there is an effect when there is none and therefore incorrectly rejecting the null hypothesis. In order establish sample size, statistical power, alpha level, and effect size was determined. The conventionally accepted statistical power of .80 and alpha level of .05 (G. Burkholder (http://www.waldenu.edu) was used for statistical power in this research study. Tabachnick and Fidell (2012) suggested that as rule statistical power can be calculated by a formula: “$N = \geq 50 + 8m$ with 8 (where m is the number of IV’s) for testing the multiple correlation and $N = \geq 104 + m$ for testing individual predictors” (Tabachnick & Fidell, 2012 p. 123). These ratios suggested a medium size relationship between the dependent variable and the independent variables $\alpha = .05$ and $\beta = .20$ (Tabachnick & Fidell, 2012). The G*Power 3.1 software tool was used to perform a priori computation of the minimum number of participants needed to run multivariate analyses with a power of .80 for five predictor independent variables and a medium effect size of 20. The minimum number computed was 191 participants. However, 309 respondents were used in this research. This sample size was sufficient to meet the desired effect-size without skewing the results, and causing a Type I error that would result in an incorrect rejection of the null hypothesis (Tabachnick & Fidell, 2012).

The research questions and research hypotheses that guided this research were as follows:

RQ1: Is there a statistically significant relationship between caregiver stressors: environment and context, stressor involving the demands of caregiving, caregiver’s appraisal of ability to cope, knowledge and utilization support resources and caregiver quality of life?

H0: There is no relationship between caregiver stress and caregiver quality of life.

H1: There is a relationship between caregiver stress and caregiver quality of life.

Pearson product moment correlations (*r*) were used to determine the relationship between stress and caregiver quality of life to determine the strength and direction of the relationship. A correlation between variables does not imply causation. Correlation coefficients can range in value anywhere between –1 and +1 with a correlation of 0 indicating the lack of a relationship and correlations of 1 indicating perfect relationships. A positive correlation between two variables occurs when the values for either variable increase or decrease at the same time (Gravetter & Wallnau, 2007). A negative correlation between two variables is found when the values of one variable increase while the values on the second variable decrease (Gravetter & Wallnau, 2007). The hypotheses were tested by the following steps:

A scatterplot was generated to check for violation of assumptions of linearity and homoscedasticity and to attain a better idea of the nature of the relationship between the variables. A scatterplot was also used to check data points to assess outliers and to determine the relationship between variables (Gravette & Wallnau, 2007).

A coefficient of determination (R^2) was computed to determine how much of the variance in the dependent variable (caregiver quality of life) can be accounted for by the independent variables). This statistic was used to measure the proportion of variability in one variable that could be determined from the relationship with the other variable (Gravetter & Wallnau, 2007).

RQ2: Which is the best predictor of caregiver outcome as measured by the caregiver's self-rating of quality of life: environment and context, stressors involving the demands of caregiving, caregiver's appraisal of ability to cope, and knowledge and utilization of resources?

H0: There is no predictive relationship between environment and context, stressor involving the demands of caregiving, caregiver's appraisal of ability to cope, knowledge and utilization in predicting caregiver outcome involving caregivers' quality of life.

H1: There is a predictive relationship between the variables of environment and context, stressor involving the demands of caregiving, caregiver's appraisal of ability to cope, knowledge and utilization in predicting caregiver outcome involving caregivers' quality of life.

The data assumptions addressed normality, linearity, and homoscedasticity. Linearity suggested that the relationship between the two variables was linear so that the scatterplot was roughly a straight line, not a curve. The statistical technique homoscedasticity addressed the variability, where scores for variable X was be similar to all values of variable Y.

A hierarchical multiple regression analysis was conducted based on caregiver stress theory (Pearlin et al., 1990). The relative contribution of each block of independent variables was computed to determine the extent to which the set independent variables predicted the dependent variable. This statistical procedure was appropriate for testing the hypotheses to determine if one variable can be used to predict another variable.

Threats to Validity

In this nonexperimental research, I collected data from public surveys and archives. Internal threats such as mortality, history, testing, and instrumentation were not applicable in this study (Creswell, 2009). However, consideration was given to statistical conclusions such as the sample size, the data, reliability, and validity of the questionnaire, and the face validity of the questions drawn from the survey database.

Threats to Reliability

The data examined to answer the research question were obtained from a secondary data source instead of from primary research. Therefore, it was difficult to examine the reliability and validity of the questions selected for this research. Demographic variables involving gender, and other socioeconomic data were previously coded into the dataset by the primary researcher. Participants were offered an honorarium of $15 if they qualified, to participate in the study. The survey took about 15 to 25 minutes to complete. However, the documentation provided by the ICPSR database appeared to provide a sound basis for future research and ensured reliability and validity of the survey.

Data Assumptions

The data assumptions addressed were normality, linearity, and homoscedasticity. The test used to address normality was the histogram to determine that each score on each variable is normally distributed. Linearity suggests that the relationship between the two variables should be linear so that the scatterplot is roughly as a straight line, not a curve.

Homoscedasticity addressed the variability where scores for variable X should be similar to all values of variable Y. The data was examined for homoscedasticity using Levine’s test. The homogeneity of variance assumptions suggested that the groups had equal variances. A scatterplot was generated to check for violation of assumptions of linearity and homoscedasticity and to attain a better idea of the nature of the relationship between the variables.

Ethical Procedures

The Inter-University Consortium for Political and Social Science Research (ICPSR) ensures that the confidentiality of public-use datasets is maintained by adhering to strict guidelines. The current study used a public version of an archival data source. No confidential information involving name and address of survey respondents were available for this researcher.

Data integrity, confidentiality and ethical concerns of Protected Health Information (PHI) and Informed Consent were reviewed prior to conducting this research by the original researcher. Protected Health Information (PHI) concerns were addressed by the designation of a preset coding system established to protect the confidentiality of individuals. With regards to informed consent, Health and Human Services Policy for the Protection of Human Subjects on existing documents, records and specimens specify that:

> Research involving the collection or study of existing data, documents, records, pathological specimens, or diagnostic specimens, if these sources are publicly available or if the information recorded by the investigator in such a manner that subjects cannot be identified directly or through identifiers linked to the subjects is exempted from informed consent (Health and Human Services Policy for the Protection of Research Subjects 45 CFR 46.101(b) [4]).

This research study was also in keeping with the American Psychological Association (APA) ethical standard 8.05 part (b), which provides for an exemption from the requirement of obtaining informed consent when using archival research data. However, approval from the Institutional Review Board (IRB) of Walden University was not exempted; therefore, IRB approval was given to conduct this research. The IRB approval number is 10-20-14-0011961.

Maintaining confidentiality is of paramount importance. ICPSR maintains stringent procedures to protect the confidentiality of individuals and organizations whose personal information that may be part of archival data. ICPSR established a preset coding system to protect the confidentiality of research participants. No identifiable survey respondent information was available; therefore no identifiable information was extracted from the ICPSR data source. Information from the archival data was entered on a data collection sheet using only the codes. The archival data from the ISPSR selected for this research were de-identified by use of a pre-established coding system. Only the codes were transferred to a separate data collection sheet for the purpose of conducting the statistical analysis using SPSS program. The data extracted from the online database was stored on a personal computer hard drive labeled as Chronic Illness and Caregiving and pass code protected. The data will be maintained for a minimum of five years and discarded appropriately after that (Creswell, 2009).

The Institutional Review Board of Walden University provided a Guide for Archival Research (Electronically Retrieved from Walden University Research Center September 23, 2013). The guide identified the role of Walden University for the protection of research participants who make a significant contribution to research and serves to protect those who may be impacted by the results of research findings. The major sections of the archival research IRB application are: Project Information, General Description of the Proposed Research, Community Research Stakeholders and Partners, Potential Risks and Benefits, Data Integrity and Confidentiality, Potential Conflicts of Interest, Final IRB Checklist, and Electronic Signatures.

A full IRB application addressing each of the sections was submitted to the board. No data collection or analysis began until the proposal received full IRB approval.

Summary

This chapter discussed the proposed research design, the criteria used for sample selection, and the sampling method used. This chapter also discussed the materials needed for the study and the statistical methods used to analyze the data. The chapter concluded with the ethical procedures implemented for the purpose of protecting confidentiality as well as compliance with Walden University's Institutional Review Board Guidelines.

Chapter 4 presented the data, data analysis, and the interpretation of the results of the data analyses. Chapter 4 also discussed the hypotheses testing procedures and included descriptive tables as applicable to the discussion.

Chapter 4: Results

Introduction

The purpose of this research was to gain a more refined understanding of the effectiveness of social support resources designed to reduce stress and burden in the lives of informal caregivers and to improve the quality of their lives. This correlational study examined whether there was a predictive relationship between the independent variables (environment and context, caregiver stressors, caregiver appraisal of ability to cope, caregiver knowledge and use of resources) and the dependent variable, caregiver quality of life. This chapter also identifies which stressors in the stress process are the best predictors of caregiver quality of life. Chapter 4 begins with frequencies and percentages of the archival data responses. Descriptive statistics are presented, including the four composite scores of interest.

Data Collection

The archival data used in this quantitative research study are maintained by the Inter-University Consortium on Social and Behavior Research (ICPSR) at the University of Michigan, Ann Arbor. ICPSR is a public website; therefore, no permissions were required. The Internet site from which the data were drawn from was http://www.icpsr.umich.edu.

The archival data were originally collected by Harris Interactive, funded by the Robert Woods Foundation, which gathered survey data through telephone interviews from March 17, 2000, to November 22, 2000, on caregiving and chronic illness using a broad spectrum of survey questions to obtain public opinions on chronic illness. The survey was conducted from the centralized telephone research centers of Harris Interactive Inc. in Youngstown, Ohio, and Binghamton, New York. Survey data were weighted to reflect the demographic composition of the U.S. population for age, education, race/ethnicity, household size, and number of telephone lines in the household using the March 1999 Current Population Survey from the U.S. Census Bureau (Thamer, 2000). Demographic information is provided (see Appendix A).

A total of 320 subjects were used in the initial analyses. After frequencies and percentages were compiled, outliers were examined via standardized values, or *z*-scores, where values below -3.29 or above 3.29 are considered outliers (Tabachnick & Fidell, 2012). A total of 11 respondents were removed due to outlying responses (caregiver stressors: 6, appraisal of ability to cope: 2, caregiver quality of life: 3). As a result, a total of 309 participants were used when conducting inferential analyses.

Results

A majority of the caregivers were female (189; 61%). A majority of the caregivers were between the ages of 35 and 64 (206; 67%). Most of the subjects were married (162; 52%). A majority of the participants had completed some college (82; 27%). Most of the caregivers were employed full-time (167; 53%). Most of the subjects earned an income greater than $75,000 before taxes (60; 19%). Frequencies and percentages of the responses from the archival data can be found in Table 1. Additional frequencies and percentiles are presented in Appendix B.

Table 1

Frequencies and Percentages for Responses

Demographic	*n*	%
Gender		
Male	120	39
Female	189	61
Age		
15 – 19	10	3
20 – 24	12	4
25 – 29	9	3
30 – 34	28	9
35 – 39	31	10
40 – 44	53	17
45 – 49	43	14
50 – 54	35	11
55 – 59	27	9
60 – 64	17	6
65 – 69	15	5
70 – 74	15	5
75 – 79	7	2

(*table continues*)

Demographic	*n*	%
80 – 84	5	2
85 – 89	2	1
What is your marital status?		
Married	162	52
Single	69	22
Divorced	35	11
Separated	5	2
Widowed	31	10
Living with partner	6	2
No response	1	1
What is highest level of education?		
Less than high school	14	5
Completed some high school	16	5
High school graduate	76	25
Completed some college	82	27
College graduate	80	26
Completed some graduate school level	8	3
Completed graduate school level	33	11
What is your employment status?		
Employed full-time	167	54

(*table continues*)

Demographic	*n*	%
Employed part-time	29	9
Self-employed	23	7
Not employed, but looking	9	3
Not employed and not looking	7	2
Retired	53	17
Student	5	2
Homemaker	13	4
Decline to answer	3	1
Which income category best describes your total house income before taxes (1999)?		
Less than $15,000	42	14
$15,000 to $24,999	54	18
$25,000 to $34,999	38	12
$35,000 to $49,999	46	15
$50,000 to $74,999	45	15
More than $75,000	60	19
Not sure	5	2
Decline to answer	19	6

Caregiver variables were designated into five categories or blocks. Block 1 consisted of demographic variables as described in Table 1. Variables for the five blocks were selected within the theoretical context of caregiver stress theory (Pearlin et al., 1990). Therefore, caregiver stress theory serves as the theoretical backdrop for the research questions selected from the ICPSR archival data. Variables were selected based on the research questions that attempted to identify if there was a correlation among the variables and the relative influence of one block of variables on another and ultimately on the caregiver's quality of life. For example, Block 1, environment and context, included demographic data. Environment and context comprised questions that identified the participants' gender, age range, marital status, level of education, employment status, and income category. The frequency distribution of demographic data is presented above in Table 1. Stressors Block 2 involved the respondent's response to the day-to-day demands of caregiving. Appraisal of ability to cope, Block 3, included questions from the survey that identified how the caregiver coped with the identified stressors. Caregiver knowledge and use of resources, Block 4, addressed how the caregiver used the available resources to aid the patient or the caregiver. Caregiver quality of life, Block 5, identified the caregiver's perceptions of his or her quality of life (see Appendix D).

Age of caregivers ranged from 18 to 89 years old with a mean of 47.13 years. Caregivers indicated that they provided support for a period of time ranging from 0-38 years, with a mean of 4.5 years. The number of people who provided unpaid help for the caregiver's care recipient ranged from 0-50 people, with a mean of 3.06 individuals. The number of hours per week providing care ranged from 0-110, with a mean of 15.72 hours of care. The number of hours spent talking on the phone with the care recipient to provide support and reassurance ranged from 0-48 hours, with a mean of 2.71 hours. Caregiver's stressors, Block 2, consisted of 22 questions regarding stress that caregivers endure on a daily basis. Composite scores ranged from 1.23 to 8.09, with mean of 3.06. Caregiver's appraisal of ability to cope, Block 3, consisted of seven questions regarding the ability to deal with everyday stressors. Composite scores ranged from 1.00 to 3.43, with a mean of 2.4. Caregiver knowledge and use of resources, Block 4, consisted of 71 questions regarding the use of support and resources. Composite scores ranged from .20-.83, with a mean of .42. Caregiver outcome related to quality of life, Block 5, consisted of 5 questions about how caregivers viewed their quality of life. Composite scores ranged from 1.00 to 3.00, with a mean of 1.5. Means and standard deviations of continuous variables can be found in Table 2. Raw data from the archival data can be found in Appendix C.

Table 2

Means and Standard Deviations of Continuous Variables

Continuous variable	Min.	Max.	*M*	*SD*
Age	18.00	89.00	47.13	14.94
How long have you been providing care to your care recipient?	0.00	38.00	4.47	5.81
How many other people like yourself, for example, friends and family, provide unpaid help to your care recipient?	0.00	50.00	3.06	5.20
About how many hours do you provide for care recipient?	0.00	110.00	15.72	19.69
How many hours do you spend talking on phone with relationship to provide support and reassurance?	0.00	48.00	2.71	5.77
Caregiver stressors	1.23	8.09	3.06	1.19
Caregiver appraisal of ability to cope	1.00	3.43	2.41	0.42
Caregiver knowledge and use of resources	0.20	0.83	0.42	0.13
Caregiver quality of life	1.00	3.00	1.51	0.47

Reliability

Cronbach's alpha tests of reliability and internal consistency were conducted on scales, one test per scale. The Cronbach's alpha provides a mean correlation between each pair of items and the number of items in a scale (Brace, Kemp, & Snelgar, 2006). The alpha values were interpreted using the guidelines suggested by George and Mallery (2012) where $\alpha > .9$ excellent, >.8 good, >.7 acceptable, >.6 questionable, >.5 poor, and $\leq .5$ unacceptable. Results for caregiver's stressors appraisal of ability to cope indicated unacceptable reliability. Results for caregiver's knowledge and utilization of resources indicated questionable reliability. Results for caregiver's quality of life indicated poor reliability. Low reliability can be caused by the use of archival data that had no prior reliability testing. Participant fatigue can also be a possible cause, with respondents not interpreting the questions accurately. Consequently, interpretation of the data for each block of independent variables and the dependent variable was made with caution. Reliability statistics for the four composite scores from the data are presented in Table 3.

Table 3

Cronbach's Alpha Reliability Statistics for the Four Composite Scores

Scale	No. of items	α
Caregiver stressors (Block 2)	22	.28
Caregiver's appraisal of ability to cope (Block 3)	7	-.01
Knowledge and utilization of resources (Block 4)	71	.67
Outcome related to caregiver quality of life (Block 5)	5	.58

Research Question 1: Is there a statistically significant relationship between caregiver stressors: environment and context, stressor involving the demands of caregiving, caregiver's appraisal of ability to cope, knowledge and utilization support resources, and caregiver quality of life?

To examine Research Question One, five Spearman correlations, and four Pearson correlations were conducted to assess the relationship between caregivers' stress and quality of life. The caregiver stress variables analyzed were environment and context variables involving gender, age, marital status, education, employment status, income, stressors, appraisal of ability to cope, and knowledge and use of resources. A Spearman correlation is a bivariate measure of association between two variables and is appropriate when one or both of the variables are measured on an ordinal scale. Spearman correlations were used to assess the relationship between the demographic variables and caregiver quality of life. A Pearson correlation is the appropriate analysis to conduct when the goal is to evaluate the relationship between two continuous variables (Pall ant, 2010). Pearson correlations were used to identify the relationship between the composite scores of caregiver stressors, appraisal of ability to cope, and knowledge and utilization of resources.

For gender, results of the Spearman correlation indicated significance (r = -.15, p = .007) with caregiver quality of life. For marital status, results of the Spearman correlation did not show significance (r = -.11, p = .063) with caregiver quality of life. For education, results of the Spearman correlation did not show significance (r = -.06, p = .300) with caregiver quality of life. For employment status, results of the Spearman correlation showed significance (*r* = -.24, *p* < .001) with caregiver quality of life. For income, results of the Spearman correlation showed significance (*r* = -.24, *p* < .001) with caregiver quality of life. Therefore, the Spearman correlations indicated a significant relationship with caregiver quality of life for gender, employment, income and caregiver quality of life. Results of the Spearman correlations are presented in Table 4.

Table 4

Spearman Correlations Between Caregiver Demographics and Quality of Life

	Quality of life
Gender	-.15**
Marital status	-.11
Education	-.06
Employment status	-.24**
Income	-.24**

* *p* < .05. ** *p* < .01.

For age, results of the Pearson correlation showed significance (*r* = .22, *p* < .001). For caregiver stressors, results of the Pearson correlation did show significance (*r* = .13, *p* = .024) with caregiver quality of life. For caregiver self-appraisal of ability to cope variables, results of the Pearson correlation indicated significance (*r* = .14, *p* = .016) with caregiver quality of life. For the knowledge and utilization of resources, results of the Pearson correlation did show significance (*r* = .17, *p* = .004) with caregiver quality of life. Therefore, the Pearson correlations indicated a significant relationship with age, stressors, appraisal of ability to cope, knowledge and use of resources, and caregiver quality of life. Results of the Pearson correlations are presented in Table 5.

The results of the Spearman and the Pearson correlations revealed that seven of the nine independent variables showed a correlation with the dependent variable: caregiver quality of life. Therefore, the null hypothesis for research question one was rejected in support of the alternative hypothesis.

Table 5

Pearson Correlations Between Caregiver Stressors and Quality of Life

	Quality of life
Age	.22**
Stressors	.13*
Appraisal of ability to cope	.14*
Knowledge and utilization of resources	.17**

* $p < .05$. ** $p < .01$.

Research Question 2: Which is the best predictor of caregiver outcome as measured by the caregiver's self-rating of quality of life: environment and context, stressors involving the demands of caregiving, caregiver's appraisal of ability to cope, and knowledge and utilization of resources?

To examine the research question two, a hierarchical multiple linear regression was conducted to assess the relationship between the independent variables: environment and context, stressors, appraisal of ability to cope, and knowledge and utilization in predicting caregiver outcome and the dependent variable: caregivers' quality of life. For the hierarchical multiple linear regression, the covariates (Block 1) were entered into the model first. For the second step, Blocks 2 – 4 were entered to assess how much additional variance is accounted for by the addition of the independent variables: caregiver stressors, caregiver appraisal of ability to cope, and knowledge and utilization of resources.

Prior to conducting the hierarchical linear regression, the assumptions of the analyses were assessed: normality, homoscedasticity, and absence of multicollinearity. A normal P-P plot was used to assess the normality of residuals among the predictor variables and the dependent variable.

The normal P-P plot can be found in Figure 1.

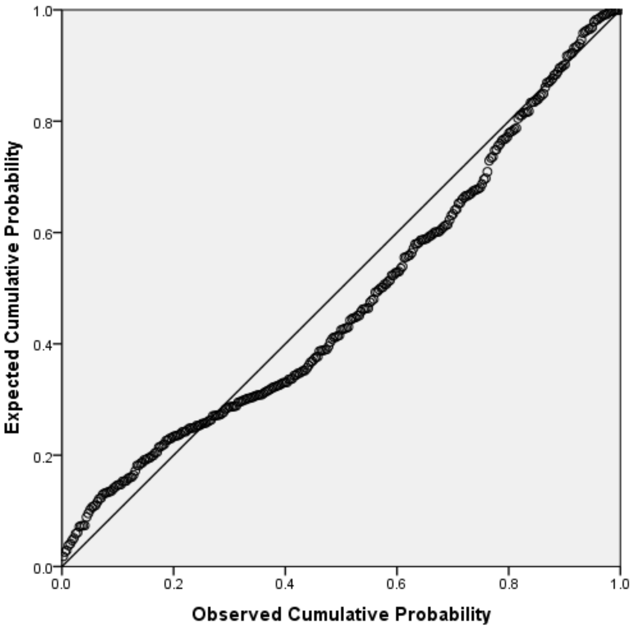

Figure 1. P-P scatterplot for normality for Block 1 through Block 5.

Homoscedasticity assumes that the scores are near equally distributed about the regression line. Homoscedasticity was interpreted through the standardized prediction versus standardized residual regression scatterplot. The presence of a rectangular distribution, one without a recognizable pattern, indicated homoscedasticity was present; thus, the assumption was met. The scatterplot for interpreting homoscedasticity can be found in Figure 2.

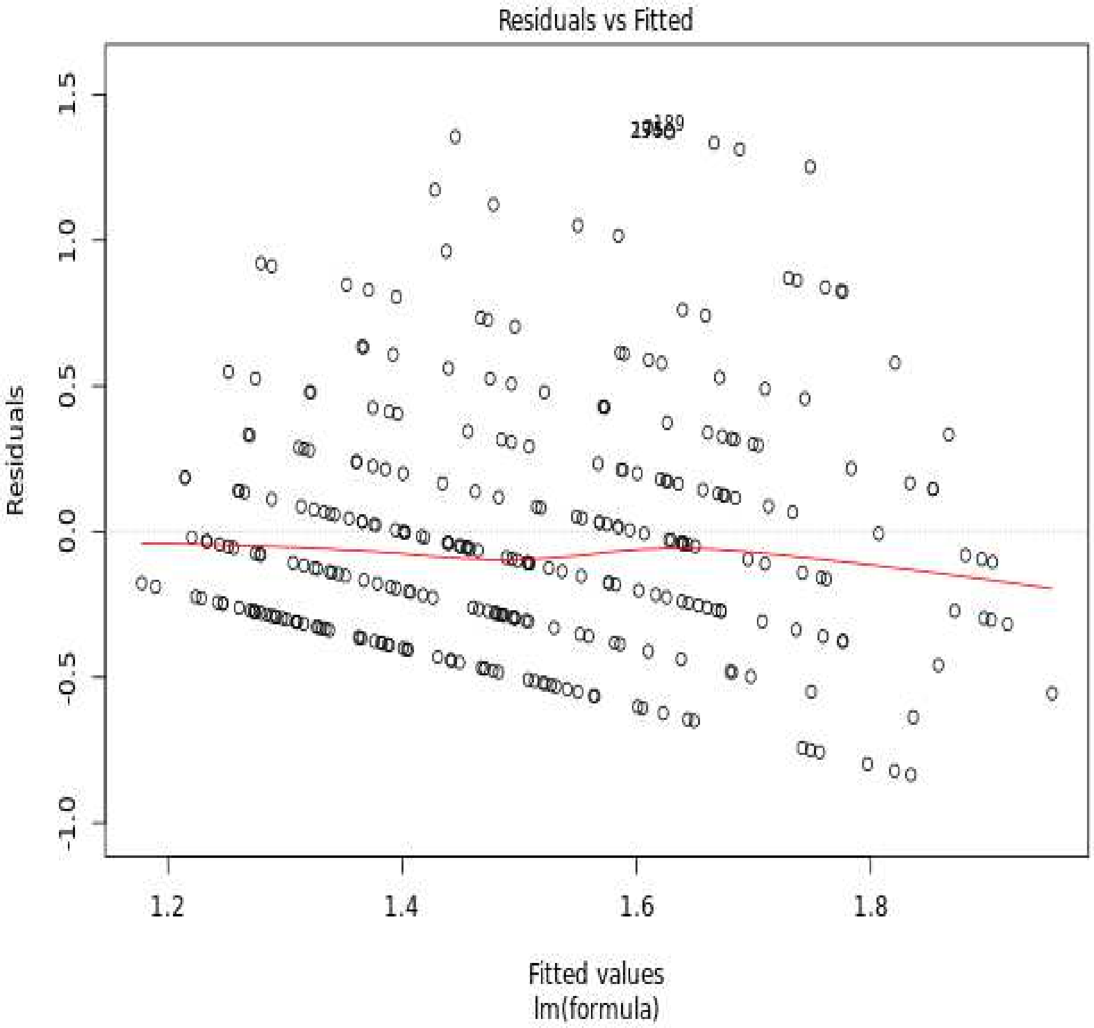

Figure 2. Residuals scatterplot for homoscedasticity for Block 1 through Block 5.

The absence of multicollinearity assumes that the predictor variables are not too closely related and was assessed using Variance Inflation Factors (VIFs). VIF values greater than 10 suggest the presence of multicollinearity and a violation of this assumption (Stevens, 2009). None of the predictor variables showed any signs of multicollinearity with the highest VIF value being 2.22; thus, the assumption was met.

The results of step 1 of the hierarchical linear regression were significant [$F(11, 297) = 4.28$, $p < .001$, $R^2 = .14$] suggesting that gender, age, marital status, college graduate level, graduate school level, employment status, \$15,000 to \$24,999 income level, \$25,000 to \$34,999 income level, \$35,000 to \$49,999 income level, \$50,000 to \$74,999 income level, and income more than \$75,000 accounted for 14% of the variance in caregiver quality of life. Results for step 1 of the hierarchical linear regression are presented in Table 6.

Table 6

Results for Hierarchical Linear Regression With Step 1 (Demographics Predicting Caregiver Quality of Life)

Source	*B*	*SE*	β	*t*	*p*
Gender (reference: female)	-0.09	0.05	-.10	-1.69	.092
Age	0.01	0.00	.15	2.45	.015
Marital status (reference group: single)	-0.02	0.06	-.02	-0.36	.717
Highest level of education (reference group: high school education)					
College graduate vs high school education	0.07	0.06	.07	1.16	.249
Graduate school vs high school education	0.08	0.09	.06	0.95	.344
Employment status (reference group: unemployed)	-0.14	0.07	-.13	-2.08	.038
Income (reference group: less than $15,000)					
$15,000 to $24,999 vs less than $15,000	-0.10	0.08	-.08	-1.23	.220
$25,000 to $34,999 vs less than $15,000	-0.15	0.10	-.11	-1.58	.115
$35,000 to $49,999 vs less than $15,000	-0.04	0.09	-.03	-0.43	.667
$50,000 to $74,999 vs less than $15,000	-0.23	0.10	-.17	-2.36	.019
More than $75,000 vs less than $15,000	-0.28	0.09	-.23	-2.93	.004

Note. Step 1: $F(11,297) = 4.28$, $p < .001$, $R^2 = .14$.

Results of step 2 (block 2 – block 5) for the hierarchical linear regression indicated that the covariates (gender, age, marital status, highest level of education, employment status, and income) and the independent variables (caregiver stressors, caregiver appraisal of ability to cope, and knowledge and utilization of resources) did significantly predict caregiver quality of life [$F(14, 294) = 4.70, p < .001, R^2 = 0.18$]. The R^2 coefficient of determination value suggested that up to 18% of the variability in caregiver quality of life can be collectively explained by the set of independent variables. An additional 4% of the variability in caregiver quality of life can be explained by the inclusion of the independent variables in the model beyond what is accounted for by demographic differences alone.

Upon further examination of the predictor variables in step 2, it was found that the following were statistically significant predictors of caregiver quality of life: age, marital status, education (graduate school), employment, income ($50,000 to $74,999), and knowledge and utilization of resources. Age was a significant predictor of caregiver quality of life ($B = .01, p = .009$). As the caregiver aged quality of life also improved. Employment status was a significant predictor of caregiver quality of life ($B = -.16, p = .016$). This finding suggested that employment had a negative influence on caregiver quality of life compared to their reference group of unemployed caregivers. For caregiver earning $50,000 to $74,999, income level was a significant predictor of caregiver quality of life ($B = -.23, p = .015$). The data suggested that caregivers within the $50,000 to $74,999 income level, quality of life was lower than caregivers in the comparison group earning less than caregivers in $15,000 income level. Caregivers earning more than \$75,000 was a significant predictor of caregiver quality of life ($B = -.28$, $p = .003$). Results showed that for caregivers earning more than \$75,000 quality of life was lower than in the previous income group (\$50,000 to \$74,999) as well as lower than caregivers earning less than \$15,000. These data suggested that caregiver income above \$75,000 was a negative predictor of caregiver quality of life. Caregiver knowledge and utilization of resources were a significant predictor of caregiver quality of life ($B = .51$, $p = .020$). These findings suggested that as caregiver knowledge and utilization of resources increased there was a concomitant elevation in the independent variable caregiver quality of life. Marital status, education level, the first three income groups, caregiver stressors, and caregiver appraisal of ability to cope were not significant predictors of caregiver quality of life. Results of step 2 of the hierarchical linear regression are presented in Table 7.

Table 7

Results for Hierarchical Linear Regression With Step 2 (Demographics and Independent Variables Predicting Caregiver Quality of Life)

Source	*B*	*SE*	β	*t*	*p*
Gender (reference: female)	0.05	0.05	.05	0.86	.340
Age	0.01	0.00	.15	2.64	.009
Marital status (reference group: single)	0.01	0.06	.01	0.10	.917
Highest level of education (reference group: high school education)					
College graduate vs high school education	0.06	0.06	.07	1.04	.300
Graduate school vs high school education	0.07	0.09	.05	0.79	.428
Employment status (reference group: unemployed)	-0.16	0.07	-.15	2.43	.016
Income (reference group: less than $15,000)					
$15,000 to $24,999 vs less than $15,000	-0.11	0.08	-.09	-1.37	.172
$25,000 to $34,999 vs less than $15,000	-0.16	0.09	-.11	-1.68	.093
$35,000 to $49,999 vs less than $15,000	-0.05	0.09	-.04	-0.50	.616
$50,000 to $74,999 vs less than $15,000	-0.23	0.10	-.18	-2.45	.015
More than $75,000 vs less than $15,000	-0.28	0.09	-.24	-3.03	.003
Block 2: caregiver stressors	0.03	0.02	.07	1.27	.205
Block 3: caregiver appraisal of ability to cope	0.12	0.06	.10	1.82	.070
Block 4: caregiver knowledge and utilization of resources	0.51	0.22	.14	2.34	.020

Note. Step 2: $F(11, 294) = 4.70$, $p < .001$, $R^2 = 0.18$.

Summary

Data were analyzed for 320 caregivers. As a result of outliers, there were 11 respondents who were removed (caregiver stressors: 6, appraisal of ability to cope: 2, caregiver quality of life: 3). As a result, a total of 309 participants were used when conducting inferential analyses.

To address Research Question 1, Spearman and Pearson correlations were used to analyze for significant relationships. For the Spearman correlations, significant relationships were identified between the independent variables gender, employment status, income, and caregiver quality of life. The correlation between the independent variables and the dependent variables suggested that employed female caregivers experienced a decreased quality of life. The caregiver's employment and income status indicated a negative relationship with caregiver quality of life. For the Pearson correlations, significant relationships were indicated between age, stressors, appraisal of ability to cope, knowledge and utilization of resources, and caregiver quality of life. The scores on the Pearson correlation suggested that the relationship between age, stressors, appraisal of ability to cope had a positive correlation with caregiver quality of life. Seven out of the nine independent variables were significantly correlated with caregiver quality of life; thus, the null hypothesis for research question was rejected in favor of the alternative hypothesis.

To address Research Question 2, a hierarchical multiple linear regression was conducted to assess the relationship between the independent variables: environment and context, stressors, appraisal of ability to cope, and knowledge and use of resources in predicting caregiver outcome and the dependent variable: caregivers’ quality of life. The model with all the independent variables saw a 4% increase in variability when compared to the model with only the demographic variable. The individual predictors were examined further, with age, employment status, an annual income of $50,000 to $74,999, an annual income greater than $75,000, and caregiver knowledge and use of resources. Each variable indicated significance with caregiver quality of life. As a result, there was significant evidence to reject the null hypothesis in favor of the alternative hypothesis for Research Question 2. The results suggested that there was a predictive relationship between caregiver stressors identified in this research and caregiver quality of life. The greatest predictor of caregiver quality of life was caregiver knowledge and use of resources. Chapter 5 discusses the interpretation of findings, the implications for social change, and recommendation for future research.

Chapter 5: Summary, Conclusion, and Recommendations

Introduction

The literature suggested that providing care to chronically ill individuals can have a detrimental effect on the quality of life for the caregiver (Elliott et al., 2010; Pearlin et al., 1990; Pinquart & Sorensen, 2003; Schulz & Beach, 1999). Various types of programs exist to assist caregivers in coping with the stress and strains of caregiving. However, these interventions and programs have not had satisfactory outcome measures (Whittier et al., 2005). The literature suggested that low outcome measures can be accounted for in part by caregivers not finding services useful (e.g., psychoeducation, respite care, transportation services, and caregivers support group) that are designed assist caregivers (Boschen et al., 2007; Cooke et al., 2001; Montgomery & Kosloski, 2009; Pearlin et al., 1990; Pinquart & Sorensen, 2003; Sorensen et al., 2002; Whittier et al., 2005). Various research findings have offered explanations for caregivers' lack of use of resources (Boschen et al., 2007; Elliott et al., 2010; Feinberg, Newman, & Van Steenberg, 2002; Schulz & Beach, 1999; Whittier et al., 2005). Lack of transportation, inconvenient hours of operation, lack of satisfaction with services rendered, stringent eligibility requirements, and existing services not meeting the needs of either the chronically ill individual or the caregiver have prevented caregivers from using services offered (Boschen et al., 2007; Elliott et al., 2010; Feinberg, Newman, & Van Steenberg, 2002; Gaugler 2010; Harding et al., 2011; Gallagher et al., 2011; Grabel & Adabbo, 2011; Whittier et al., 2005). Boschen et al. (2007) suggested that a lack of methodological rigor in measuring outcome might in part explain the lack of use of existing caregiver support resources. Pearlin et al. (1990) suggested that the caregiver's perceptions of the availability of social support resources had a positive association with the caregiver's self-appraisal of his or her ability to cope with the stress of caregiving if the caregiver believed the support was available and met his or her needs.

Stress theory suggested that caregiver stress is a dynamic process that occurs based on the individual's appraisal of the stressful event as beyond his or her ability to cope (Lazarus & Folkman, 1984; Pearlin et al., 1990). Within the theoretical framework of caregiver stress theory (Pearlin et al., 1990), this research attempted to determine whether there is a correlation between specific stress variables and caregiver quality of life (Pearlin et al., 1990). To achieve this goal, I sought to determine whether there is a statistically significant relationship between caregiver stressors—environment and context, stressors involving the demands of caregiving, caregivers' appraisal of ability to cope, and knowledge and use of support resources—and caregiver quality of life. A second goal of this research was to assess which variables within the stress model were the best predictors of caregiver outcome or caregiver quality of life: environment and context, stressors involving the demands of caregiving, caregiver's appraisal of ability to cope, or knowledge and use of resources.

Concise Summary of the Findings

Demographics involving environment and context revealed that the mean age of caregivers who responded to the research was 47.13 years. The majority of the caregivers were female, and most of the subjects were married. Most of the caregivers were employed full time, and most of the respondents earned an annual income of at least $75,000 before taxes.

To address the first research question, five Spearman and four Pearson correlations were conducted to assess the relationship between caregiver's stress and quality of life. The Spearman correlations assessed the statistical relationship between demographic variables and caregiver quality of life. Results of the Spearman indicated an association between the independent variables for gender, employment status, and income with the dependent variable, caregiver quality of life. However, the Spearman correlation did not show a statistically significant relationship between the independent variables of marital status and educational level with the dependent variable, caregiver quality of life.

Pearson correlations were used to identify the relationship between composite scores for the independent variables of age, stressors, appraisal of ability to cope, and knowledge and use of resources. Results identified significance between the independent variables of the age of caregiver, stressors involving the demands of caregiving, appraisal of ability to cope, and knowledge and use of resources with the dependent variable, caregiver quality of life. Results of the Spearman and Pearson correlations indicated an association with caregiver quality of life. Of the nine independent variables examined for Research Question 1, seven variables identified a statistically significant relationship with caregiver quality of life. Two independent variables, gender and marital status, did not show a significant relationship with caregiver quality of life. Based on the results of the

Spearman and Pearson correlations, the null hypothesis for the first research question was rejected in favor of the alternative hypothesis.

To address the second research question, hierarchical multiple linear regression analyses were conducted to assess which independent variables were the strongest predictors of caregiver outcome as measured by the caregiver's self-rating of the quality of life. Environment and context were significant predictors of caregiver quality of life. The variables in the first step—gender, age, marital status, educational level, employment status, and income—showed a significant predictive relationship with caregiver quality of life. The findings for environment and context are consistent with caregiver stress theory (Pearlin et al., 1990), which posits that environment and context have a correlation with caregiver quality of life. This relationship is discussed in further detail in the interpretation of findings.

Step 2 in the regression analysis identified how much additional variance was accounted for by adding the independent variables of caregiver stressors, caregiver appraisal of ability to cope, and knowledge and use of resources to the model. Two variables, caregiver stress and caregiver appraisal of ability to cope, did not indicate a predictive relationship with the dependent variable, caregiver quality of life. However, caregivers' knowledge and use of resources was the strongest predictor of caregiver quality of life. Covariates in the first step of the regression analysis accounted for 14% of the variance in caregiver quality of life. An additional 4% of the variability in caregiver quality of life was explained by the inclusion of the remaining independent variables. Therefore, each of the variables in Blocks 1 through 5 accounted for 18% of the variance in caregiver quality of life. Results for the second research question indicated that the hierarchical multiple linear regression analysis identified a predictive relationship between the independent variables and the dependent variable.

In summary, the Spearman and the Pearson correlation showed a significant association between the independent variables and the dependent variable. The hierarchical multiple linear regressions also showed a predictive relationship between independent variables and the dependent variable. The correlational analyses and the multiple regressions led to rejection of the null hypotheses for both Research Question 1 and Research Question 2 in favor of the alternative hypotheses.

Interpretation of the Findings

Caregiver stress theory indicates that caregiver stress variables are dynamic and that any one or several stress variables can have a significant impact on caregivers' physical, emotional, and psychological well-being (Pearlin et al., 1990). Within the caregiver stress theoretical framework (Pearlin et al., 1990), this research examined the relationship between selected independent variables and the dependent variable, caregiver quality of life. For the first research question, I sought to determine whether there was a statistically significant relationship between the independent variables of environment and context, stressors involving activities of caregiving, caregivers' appraisal of ability to cope, and caregiver knowledge and use of resources and the dependent variable, caregiver quality of life.

Findings on the Spearman correlations indicated that each of the environment and context independent variables involving gender, employment status, and income showed significance in a negative direction with caregiver quality of life. However, demographic variables of marital status and educational level attained did not reach statistical significance. The relationship between gender and caregiver quality of life was consistent with previous research (Given et al., 2004; Li et al., 2012). Given et al. (2004) examined the effects of gender on caregiver emotional well-being among a sample of caregivers for cancer patients in a prospectus longitudinal study. At baseline and 1 year later, they found that female caregivers showed greater symptoms of emotional distress compared to male caregivers. Given et al. also found that adult female children reported a strong sense of burden related to feelings of abandonment and a sense of disruption in their personal schedules to provide care. Li et al. (2012) found that female spousal caregivers experienced increased mental and physical health-related problems, decreased marital satisfaction, and a poorer quality of life. The literature also suggested that female caregivers were negatively affected by stress to a greater extent than male caregivers (Grabel & Adabbo, 2011; Given et al., 1993; Lee, Simontte, DeDois, Lee, & Fong, 2013; Perz, Ussher, Butow, & Wain, 2011). Although men are also negatively affected by stress, researchers suggested that there are gender differences in how men and women are affected by stress in general and stress specifically related to caregiving (Li et al., 2012).

Employment status of the caregiver indicated a relationship with caregiver quality of life. This finding was consistent with previous research where employed caregivers reported higher absentee rates and often retired earlier than planned to provide care for a chronically ill family member or friend (Pinquart & Sorensen, 2003). Similarly Lim and Zeback (2004) found a relationship between employed caregivers and their well-being or quality of life with employment having an adverse effect on the caregiver's quality of life. However, Caughlin (2010) examined the relationship between the combined role of caregiving and employment and its impact on caregivers' quality of life. He found that employment had a positive effect on caregiver quality of life. Limpawattana, Theeranut, Chindaprasirt, Sawanyawisuth and Pimporm (2012), reported no significant relationship between employed caregivers and caregiver burden based on the results of their research using the Zarit Burden Interview (Zarit, 1980). Bainridge, Krueger, Lohfeld and Brazil (2009) did not find a relationship between caregiver stress and quality of life in their research

Caregiver household income showed a relationship with caregiver quality of life with higher income having an adverse influence on the caregiver's quality of life. Lim and Zebrack (2004) found that lower income was related to negative experiences with caregiving. Gongalez, Polansky, Lippa, Walker and Feng (2011) suggested that caregivers who were at risk of experiencing higher levels of burden were more likely to be unemployed and to have an annual income of less than $8,000 per year. However, they found that there was less of a negative a negative impact on caregivers with high incomes. Pinquart and Sorensen (2011) suggested that spousal caregivers with lower education and limited revenue had poorer physical health compared to adult children caregivers. Other researchers (Emanuel et al., 2000; Duxbury et al., 2011) also found a link between caregiver income and caregiver quality of life.

Pearson correlations showed a relationship between the independent variables age, stress related to tasks of caregiving, caregivers appraisal of ability to cope and knowledge and use of resources and the dependent variable with caregiver quality of life. The positive and adversive effects of age on the caregiver's quality of life has been extensively researched (Butler et al., 2005; Given, et al., 2004; Moreley et al., 2012; Pearlin et al 1990; Schulz & Beach, 1999). The effects of age on quality of life was influenced by the length of time providing care, the physical effect on the caregiver, and the caregivers' willingness to use concrete assistance to help carry out the practical demands of caregiving. This might include assistance with activities of daily living as well as other physical or emotional strains of caregiving (Garlo et al., 2010; Given et al., 2004; Lim & Zeback, 2004; Limpawattama et al., 2013). Given, et al. (2004) found that adult children between the ages of 45 and 54 who provided care showed depressive symptoms and caregivers between the ages of 35-44 reported a strong sense of abandonment and isolation. Similarly, Butler et al. (2005) and Williams (2005) found that younger women experienced greater symptoms of emotional distress. Perrig-Chiello and Hutchinson (2010) suggested that younger adult caregiving daughters reported high levels of stress and feelings of burden compared to their older counterparts who were more likely to report more age-related health problems. Neugaard et al. (2008) suggested that caregivers age 55 years and younger had an increased risk of having fair to poor health compared to noncaregivers in the same age group. Caregivers 55 and older had a smaller risk of fair to poor health compared to noncaregivers in the same age (Neugaard et al., 2008). The strength of the relationship between the independent variables and the dependent variable for the Spearman and the Pearson was small based on Cohen's d calculations of correlational strength (as cited in Pallant, 2010).

Stressors related to the demands of caregiving showed a relationship with caregiver quality of life. This finding was consistent with caregiver stress theory, which suggested that the multiple demands of caregiving contributed to caregiver quality of life. Stress intensifies as the care recipient become increasingly dependent upon the caregiver to meet basic needs (Pearlin et al., 1990). Caregivers in the sample selected for this research provided an average of 16 hours of care per week for about five years. The literature suggested that level and intensity of care demands and the length of time the patient required care resulted in caregiver strain over time (Aronson, 1997; Lau et al., 2011; Smith et al., 2011; Schulz & Beach 1999).

The caregiver's self-appraisal of his or her ability to cope with the demands of caregiving showed a relationship with caregiver quality of life. The literature suggested that inadequate coping skills can result in the perception that caregiving is more stressful and an appraisal that the caregiving situation as more burdson (Bourgeois et al., 1996; Chronister et al., 2010; Folkman et al., 1986; Gallagher et al., 2011; Haley et al., 1987; Kim et al., 2007; Pearlin et al., 1990; Romero-Moreno et al., 2011). Therefore, the caregiver's perceptions and beliefs the about his or her ability to cope with the demands of caregiving will to a great extent, influence his or her physical, emotional and psychological well-being (Haley et al., 1987; Pearlin et al., 1990; Schulz & Beach, 1999; Chronister et al., 2010; Gallagher, 2011).

Results from this research found that knowledge and use of resources showed a relationship with caregiver quality of life. The existence of family and community resources played a crucial role in buffering the adverse effects of caregiving (Pearlin et al., 1990). The usefulness of social support resources depends on the caregiver having knowledge of the resources and a belief that the support resources will meet their individual needs (Chang et al., 2001; Elliott et al., 2000). Interventions for reducing caregiver stress have focused primarily on providing respite services, skills training to enhance caregivers' competence with the task of caregiving, psychotherapeutic, and psychoeducational services (Sorensen et al., 2002). Research findings have varied on which type of interventions are most beneficial. For example, Sorensen et al. (2002) found that psychotherapeutic and psychoeducational interventions had the most efficient outcome. Other findings suggested that support resources for caregivers must offer services that have multiple components and provide long-term multiple opportunities to access services because of caregivers' changing needs and readiness for assistance (Boschen et al., 2007; Harding et al., 2011; Schulz & Matrie, 2004).

Research Question 2: Which stressors within the caregiver stress process theory were predictors of caregiver quality of life: Environment and context variables of gender, age, marital status, education, employment, and income showed a predictive relationship with caregiver quality of life? Environment and context accounted for 14% of the variance in caregiver quality of life. This finding is in line with caregiver stress theory (Pearlin et al., 1990), which suggested that environment and context variables are dynamic and multidimensional. Researchers found that environment and context variables had an impact on other domains of stress that interact together to affect the caregivers'overall well-being (Bainbridg et al., 2009; Grabel & Adabbo, 2011; Pearlin et al., 1990). For example, caregivers may be employed full time and need respite services for evenings or weekends. However, the needed service may offer limited hours and therefore, not be available when the service is needed (Pearlin et al., 1990).

Individual independent variables in the environment and context category that showed a significant predictive relationship with the dependent variable caregiver quality of life were age, employment status, and income. The caregiver's age was a significant predictor of quality of life in a positive direction. Findings showed that as the caregiver aged, there was a concomitant improvement in caregiver quality of life. This finding is supported by the literature, which suggested that the longer the caregiver provided care, the more competent the caregiver became at the caregiving task. Butler et al. (2005) suggested that older caregivers felt knowledgeable about the caregiving tasks and supported by a social support network of family and community resources. Although older caregivers were less likely to experience stress related to coping with the strains of caregiving, they experienced more age-related health problems (Emanuel et al., 2000; Garlo et al., 2010; Pearlin et al., 1990). In contrast, Neugaard et al. (2008) found that caregivers under age 55 had a one-third increased risk of having fair to poor health and higher levels of emotional distress compared to noncaregivers in that age group. For younger caregivers, the literature suggested that the relationship between caregiving and quality of life was influenced by dual roles of adult child and caregiver (Given et al., 2004). The literature suggested that at both ends of the age spectrum, age is a significant predictor of caregiver quality life (Given et al., 2004; Neugaard et.al., 2008; Pinquart & Sorensen, 2011). At one end of the age spectrum, age was predicted to have a negative effect on older caregiver’s quality of life because of age-related health problems (Perrig-

Chiello & Hutchinson, 2010; Williams, 2005). At the other end of the age spectrum, younger caregivers experienced emotional distress related to feeling forced into the caregiver role (Perrig-Chiello & Hutchinson, 2010; Williams, 2005). For example, caregivers may experience challenges of maintaining a balance between work responsibilities and caring for young children while simultaneously proving caregiving to a chronically ill family member (Butler et al., 2005; Neugaard et al., 2008; Perrig-Chiello & Hutchinson, 2010; Williams et al., 2005).

Findings from this research revealed that employment status was a significant predictor of caregiver quality of life. Employed caregivers experienced increased stress resulting in a lower quality of life than unemployed caregivers (Duxbury et al., 2011). Researchers suggested that the caregiver's ability to maintain a work-life balance and caregiving responsibilities had a major influence on the caregivers overall well-being (Duxbury et al., 2011;Pearlin et al., 1990; Pinquart & Sorensen, 2003). Although employed caregivers had the opportunity to take a break from caregiving responsibilities while at work, employed caregivers experienced higher absentee rates, and retired early to provide care to a relative or friend (Pinquart & Sorensen, 2003). Duxbury et al. (2011) suggested that the quality of life among employed caregivers was related to how the caregiver believed he or she was able to manage a work-life balance. Caregiver quality of life was negatively affected when employed caregivers experienced feelings of being overwhelmed and not having autonomy over their own lives (Duxbury et al., 2011). They further suggested that the care recipient’s physical condition and problems with finding dependable help had an influence on caregiver’s strain and burdn (Duxbury et al., 2011). Therefore, based on research findings, an employed caregiver was likely to experience higher stress and a lower quality of life than unemployed caregivers because of the increased demands of caregiving.

Results showed that income was a significant negative predictor of caregiver quality of life. Findings from the data showed that for caregivers who earned between $50,000 and $75,000, quality of life was significantly lower than the quality of life for caregivers who earned less than $15,000 per year. At first glance, this might appear counterintuitive because higher income suggests having financial resources for assessing support services; and thus a higher quality of life. The literature suggested that caregivers reported concerns related to quitting their job or retiring early to assume full-time caregiving responsibilities (Duxbury et al., 2011). Making the decision to quit their job or retire early created stress and burden associated with the loss of income and financial security (Covinsky et al., 1994; Duxbury et al., 2011). These findings parallels concerns related to secondary role strain linked to psychological stress and burden (Pearlin et al., 1990). Garlo (2010) found that employed caregivers reported fear of losing financial security. Researchers suggested that the impact of a serious illness on the relationship between caregiving and income are noteworthy (Covinsky et al., 1994). Caregivers spent up to approximately 10% of their income on health care and caregiving and approximately 20% of family caregivers quit their jobs to provide caregiving (Covinsky et al., 1994). Duxbury et al (2011) suggested family members who quit their job to provide caregiving were single mothers with financial difficulties. Providing care to elderly relatives might buffer the negative effects insufficient household income

(Duxbury et al., 2011). Regardless of the motivations for providing care in their homes, the findings showed that income had no effect on caregivers' quality of life until the income reached the $50,000 to $75.000 per year income level. Environmental and context variables of marital status, educational and income level between $15,000 and $49,999 were not significant predictors of caregiver quality of life. Findings indicated that environment and context independent variables accounted for 14% of the predictive relationship with the dependent variable caregiver quality of life.

When caregiver stress related to the demands of caregiving was added to the multiple linear regression analysis, no significant predictive relationship was identified. This finding is inconsistent with the majority of the research literature. There is a plethora of literature on the relationship between stress and caregiving. Caregivers reported high levels of stress and burden related to disruption of life plans and high stress related to the cognitive and behavioral impairment in care recipients (Haley et al., 2001; Haley et al., 1987; Knight et al., 1997; Monteko, 1989; Perrig-Chiello & Hutchinson, 2010; Schulz & Beach, 1999; Schulz et al., 1995; Sorensen & Pinquart, 2005). Moreover, Schulz and Beach (1999) suggested that the mortality risks for caregivers are higher than for noncaregivers. Researchers on caregiving across a broad spectrum of chronic health conditions confirmed that the nature and extent of the demands of caregiving can have a negative and deleterious effect on the caregiver (Boschen et al., 2005 Haley et al., 2001; Miller, Berrios, & Polityska, 1996; Pakenham, 2001; Rivera-Navarro et al., 2003). Although this research did not find a significant predictive relationship between caregiver stress and caregiver quality of life, the theoretical framework on which this research was developed (Pearlin et al., 1990) and the literature (Butler et al., 2005; Dorfman et al., 1996; Haley et al., 1987) are contradictory to these findings.

The independent variable caregiver appraisal of ability to cope was not a significant predictor of caregiver quality of life. This finding is not supported by the literature. Pearlin et al. (1990) suggested that the caregiver's coping mechanisms determined how the caregiver appraised and coped with the stress of caregiving. The literature suggested that appraisal and coping played a significant role in predicting the outcome or quality of life among caregivers in many domains of caregiving (Chronister et al., 2010; del-Pino-Casado et al., 2011; Folkman et al., 1986; Haley et al., 1987). Butler et al. (2005) suggested that caregiver burden is related to caregivers' depression. The caregiver’s vulnerability to stress increases with the demands of caregiving and caregivers quality of life decreases with increased stress and burden.

The independent variable knowledge and use of resources was the strongest predictor of caregiver quality of life. As the caregiver's knowledge and use of resources increased, caregiver quality of life improved. This finding is consistent with the literature, which suggested that when caregivers used social support resources, there was a simultaneous increase in caregivers' physical, psychological, and emotional well-being (Haley et al., 1987; Pearlin et al., 1990). Knowledge and utilization of resources have played a significant role in buffering the effects of negative outcomes (Pearlin et al., 1990). Although findings from this research regarding the positive influence of support resources to caregivers is consistent with the literature (Boschen et al., 2007; Goode et al., 1998; Ownsworth et al., 2010; Pearlin et al., 1990), there is a growing body of reseach which suggested that the existing resources did not have the desired effect in meeting the caregiver's needs or in the improving overall well-being of caregivers (Boschen et al., 2007; Elliott et al., 2010; Feinberg et al., 2002; Whittier et al., 2005). A lack of effectiveness in support resources is related to programic obstacles in accessing social support services (Elliott et al., 2010;Whittier et al., 2005) Reducing and eliminating extraneous barriers that have limited caregivers' ability to use existing resources (Feinberg et al., 2002; Pearlin et al., 1990; Whittier et al., 2005) will assist in enhancing caregiver coping skills and in improving caregivers' quality of life. Wuest Ericson, Stern and Irwin (2001) suggested that the extent to which the caregiver can connect and find the support resources beneficial, will have a strong influence on the caregiver's health and well being. Haley et al. (1987) and Grabel and Adabbo (2011) also found that the extent that caregivers used family and community social support services depended on how useful the resources were for caregivers.

In summary, this research was conducted to determine if specific variables based on caregivers stress process theory (Pearlin et al., 1990) had predictive ability on caregiver quality of life. The first research question assessed if there was a statistically significant relationship between the independent variables environment and context, stressors, caregiver appraisal of ability to cope, and knowledge and use of resources and the dependent variable, caregiver quality of life. Results of the Spearman and the Pearson correlation found a statistically significant relationship between the independent variables and the dependent variable. The Spearman correlations involving gender, being employed and earning an income above $50,000 had a negative influence on caregiver quality of life. The Pearson correlation showed significance in a positive direction suggesting that caregivers' age, stressor involving caregiving, caregiver's appraisal of ability to cope, and knowledge and use of resources showed a correlation with caregiver quality of life.

Age, employment status, income, and knowledge and utilization of resources were significant predictors of caregiver quality of life. The results indicated that as the caregiver increased in age, the caregiver’s quality of life improved (Dorfman et al., 1996). Employment status was a significant predictor of the caregiver’s quality of life in the negative direction. Employed caregivers reported fewer life satisfactions than unemployed caregivers (Caughlin, 2010; Dorfman, 1996; Given et al., 2004).

Results found that among caregivers with a yearly income between 50,000 and 74,999 and above $75,000 respectively, quality of life was lower than for caregivers earning less than $15,000 per year before taxes. Therefore, as caregiver income increased, caregiver quality of life decreased (Covinsky et al., 1994; Emanuel et al., 2000; Garlo et al., 2010; Pearlin et al., 1990). Results showed that caregiver’s knowledge and use of resources was the strongest predictor of caregiver quality of life. As caregivers' knowledge and use of family and community support resources increased, caregiver’s quality of life improved (Bainbridge, 2009; Boschen et al., 2007; Haley et al., 1987; Ownsworth et al., 2010 Pearlin et al., 1990). The result found that overall, up to 18% of the variability in caregiver quality of life can be explained for by the independent variables.

Limitations of Study

The caregiver stress process theory provided a multidimensional model that consists of multiple variables (Pearlin et al., 1990). To include all variables from a theoretical model of this magnitude would have been a daunting task. Therefore, not all variables identified in the caregiver stress theory (Pearlin et al., 1990) were included for this research. Variables selected for this research were based on theory, research findings, and face validity. The research questions were selected from the archival dataset and mapped onto the caregiver stress model (Pearlin et al., 1990) based on face validity.

No evidenced based measure was used to examine caregiver stress. Therefore, several aspects of the study may limit the generalizability of the study. The alpha test showed low reliability and internal consistency for the variables examined in this research. Measures identified for caregiver's stressors and appraisal of ability to cope indicated unacceptable reliability. The results for caregiver's knowledge and use of resources indicated questionable reliability, and the reliability of caregiver's quality of life indicated poor reliability. The low reliability could result from using archival data that had no prior reliability testing. Participant fatigue can also be a possible cause; with respondents not interpreting the questions accurately. Consequently, interpretation of the results must be made with caution.

There is a lack of available information on instruments used to establish validity of the research survey questions. In other words, are the questions designed to measure what they are intended to measure? Questions selected for this research were based on caregiver stress theory (Pearlin et al., 1990). The literature suggests that quality of life is defined as a multidimensional construct that includes psychological, emotional, and spiritual aspects of the caregiver's functioning, including caregiver anxiety and depression (Lim & Zebrack, 2004). The archival data did not provide a measure or an assessment of the caregivers' psychological and emotional functioning.

There was no objective measure of the caregiver's perceived of stress at the time the survey was completed. For example, one caregiver may perceive the demands of caregiving as a threat and as thwarting their daily activities while another caregiver might perceive it as a challenge (Folkman et al., 1986).

Inferential statistics showed 38% (N= 121), of the sample selected for this research were male caregivers. The impact of stress by gender has been found to be different for males and females. However, there is no data to evaluate which proportion of men contributed to predicting how males compared to female contributed to findings on the relationship between the individual independent variables and the dependent variable.

Using archival data limited the ability to contact participants for response clarification to ensure accuracy and it limited the researcher's ability to examine all caregivers providing care to chronically ill individuals. The sample for this research was limited to certain regions of the Midwest and the Northeastern parts of the United States and might not be representative of other regions of the United States.

Recommendations for Further Research

The literature suggested that quality of life includes psychological, emotional, and spiritual aspects of the caregiver's functioning; including canxiety and depression resulting from caregiving (Lim & Zebrack, 2004). Results were not based on an empirically validated measure of caregiver stress related to the demands of caregiving. Further research is needed using an empirically validated instrument to examine the psychological and emotional aspects of caregiving within the context of caregiver stress theory.

This archival data research found no statistical significance influence of the independent variables, caregiver stress related to the demands of caregiving or caregivers' appraisal of ability to cope and the dependent variable caregiver quality of life. However, there is a plethora of literature, that suggested that caregiver stress and caregiver coping skills influenced caregiver quality of life. Further research is needed on the predictive relationship of stress and coping, within the context of the caregiver stress model, with a heterogeneous population of caregivers for individuals with a broad range of chronic health conditions.

Although women are primarily caregivers, men are becoming primary informal caregivers as evidenced by the percentage of men and women participants in the survey for this research. Researchers suggested that men manage stress differently than women because men have been socialized to delegate, whereas women have been socialized to perform the task themselves (Lee et al., 2013; ; Perz et al., 2011). While these social and cultural explanations might be plausible descriptions for the gender differences in managing stress, further research is needed to identify the extent to which male caregivers respond differentially to the stressful demands of caregiving.

Implications for Social Change

The potential implications for social change include a better understanding of caregiving to chronically ill individuals and the impact of caregiving on the informal caregiver. Changes in the U.S. health care system over the last decade are increasingly requiring that individuals with long-term health care needs recover at home rather than recover in a hospital. Therefore, individuals with serious medical conditions have shorter inpatient hospital stays. The identification of outpatient substitutes such as home-based care has meant cost savings to both the patient and the hospital. The cost-cutting changes will mean an increase in financial, physical, and emotional responsibility to the family who cares for the chronically ill individual (Goode et al., 1998; Haley et al., 1987; van Ryn et al. 2011).

The implications for positive social change will include adding to the body of knowledge on reducing stress and improving quality of life for informal caregivers. Gaining a better understanding of the variables that most significantly contribute to caregiver stress and poor quality of life will offer insight into how to reduce caregiver stress and burden. To promote optimal quality of life among caregivers, hospitals or treatment facilities should develop education and training programs on the care recipients' specific health care needs and the level of care required to ensure that the caregiver is prepared for the caregiving task before the care recipient is discharged from the hospital or rehabilitation facility. Providing the caregiver with education and training prior to discharge would help minimize caregiver stress at the beginning of the caregiving responsibilities. Experienced caregivers who have provided care over an extended period could provide mentoring and peer support to new less experienced caregivers. This would help build confidence and resilience for new caregivers.

Home health care visiting physicians, nurses, and social workers could use this information to develop caregiver assessment tools that identifies caregiver stressors and provide interventions that would help reduce or eleminate stress before it has a strong-hold on the caregiver's quality of life.

Results found that as caregiver's knowledge and use of resources increased, caregiver's quality of life was enhanced. Findings from this research could promote social change by providing caregivers with community resources including telephone numbers, hours of operation, and emergency or on-call resources that are available 24 hours per day, seven days per week. Offering Internet resources and telephone access to local community-based social support resources might be utilized by caregivers who are not able to leave the home environment to attend caregiver support resources. These resources should provide practical support relevant to the needs of caregiving.

Researchers, professionals, and organizations can use the findings from this research to develop and facilitate family and community multicomponent resources that would meet the individual needs of the caregiver and the care recipient. Clinicians and practitioners can identify the caregiver's level of stress along the stress process continuum and provide appropriate and efficient interventions at an early stage of the onset of stress. Findings from this research should be particularly useful for policy makers at the local and national level by providing and funding resources for employees who are caregivers in order to help the caregiver maintain a wholesome work-life balance and financial security.

Conclusion

Informal caregivers for chronically ill individuals experience stress and burden that can lead to poor physical, emotional, and psychological health that compromise the caregiver's well-being. With the increase in longevity and the aging baby boomers, more people will experience age-related health conditions that require the assistance of an informal caregiver. Because of medical advancement, shorter hospital stays, reductions in funding for medical care; caregivers are likely to provide care for increasingly longer periods of time for serious chronic medical conditions without the benefit of formal training. Caregivers are also likely to experience higher levels of stress and burden related to increased caregiving demands as well as the multipe responsibilities of work and family life..

The purpose of this research was to examine the predictive ability of specific stress variables, based on caregiver stress theory (Pearlin et al., 1990), for predicting caregiver quality of life among informal caregivers. Findings indicated that age, employment status, income, and knowledge and use of resources were statistically significant predictors of caregiver quality of life. The final multiple linear regression model in this research found that caregiver stress could be explained by the independent variables. Caregiver knowledge and use of resources was the strongest predictor of caregiver quality of life. The availability and utilization of family and community support resources to caregivers’ and recipients’might counterbalanced the negative and deleterious effects of caregiver stress and burden (Haley et al., 1987; Pearlin et al., 1990)

The results of this research indicated that caregiver demographic variables of age, employment status and income are significant predictors of caregiver quality of life. The age of caregivers had a positive effect on caregivers' outcome. Research findings suggested that the positive effect of age on caregivers’ quality of life was related to the caregiver becoming habituated to the demands of caregiving over time, therefore finding the task less stressful (Duxbury et al., 2011; Emanuel et al., 2000; Garlo et al., 2010, Given, et al., 2004). A mentoring and a caregiver peer support group could assist caregivers who are new to the role of caregiving. Employment and income predicted a negative influence on caregiver quality of life compared to caregivers who were unemployed and earned less than $15,000 per year before taxes.

Caregiver stress theory (Pearlin et al., 1990) is a useful theoretical framework for examining the impact of stress on the caregiving. It is also a useful theory for developing and implementing social support resources that will reduce stress and burden and ameliorate caregiver quality of life. Knowledge and use of resources had the strongest predictive relationship with caregiver quality of life. Accessibility of resources is particularly important since the caregivers' role intensifies in response to the progression of the chronic condition (Bainridge et al., 2009; Pearlin et al., 1990).

The literature suggested that quality of life is defined as a multidimensional construct that includes psychological, emotional, and spiritual aspects of the caregiver’s functioning, including caregivers level of anxiety and depression (Lim & Zebrack, 2004).

Further research is needed that would use an empirically validated instrument to examine the psychological and emotional aspects of caregiving within the context of caregiver stress theory.

This archival data research found no statistical significance in the influence of the independent variables caregiver stress and appraisal of ability to cope on the caregiver quality of life. However, there is substantial empirical evidence to support the conclusions that caregiver stress and caregiver appraisal of ability to cope influenced caregiver quality of life. Additional research is needed to explore the predictive relationship of caregivers stress related to the demands of caregiver and caregivers' appraisal of ability to cope for a heterogeneous population of caregiver who provide care to individuals with a wide range of chronic conditions.

Although women are primarily caregivers, men are becoming primary informal caregivers as evidenced by the percentage of men and women participants in this archival dataset. The literature suggested that men manage stress differently from women because men have been socialized to delegate whereas women tend not to delegate responsibilites (Lee et al., 2013; Perz et al., 2011). While these social and cultural explanations might be plausible, further research is needed to identify the extent to which male caregivers are impacted by stress relative to caregiving to an individual with a chronic condition.

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Appendix A: Demographics

DEMOGRAPHICS
Gender Respondents
1 Male
2 Female

What is your marital status?

1 Married
2 Single
3 Divorced
4 Separated
5 Widowed
6 Living with partner
98 Not sure
99 Decline to answer

What is the highest level of education you completed or the highest degree you have received?

1 Less than high school
2 Completed some high school
3 High School graduate or equivalent (e.g., GED)
4 Completed some college, but no degree
5 College Graduate (e.g., BA.A., A.B., B.S.
6 Completes some graduate school, but no degree
7 Completed graduate school (.g., MS., M.D., Ph.D.)

What is your employment status?

1. Employed full-time
2. Employed part-time
3. Self-employed
4. No employed, but looking for work’
5. Not employed and not looking for work
6. Retired
7. Student
8. Homemaker

(*table continues*)

Which of the following income categories best describes your total house income before taxes (1999)?

01 Less than $15,000
02 $15,000 to $24,999
03 $24,000 to $34,999
04 $35,000 to $49,999
05 $50,000 to $74,999
06 More than $75,000

What is the Respondent's status?

04 Neither Chronically ill nor Caregiver
05 Chronically Ill Only
06 Caregiver only
07 Both Chronically Ill and Caregiver

Appendix B: Frequency and Percent

	F	%
What is person's relationship to you who you spend most time caring for?		
Spouse	23	7
Parent	104	34
Son/Daughter	18	6
Grandparent	34	11
Aunt/Uncle	10	3
Sibling	18	6
Father-in-law/Mother-in-law	29	9
Non-relative/friend	46	15
Companion/partner	4	1
Some other relations	21	7
Decline to answer	2	1
What is/was primary medical, mental, or other health condition that leaves your relationship unable to fully care for himself/herself?		
ALS or Lou Gehrig's	2	1
Alzheimer's disease	30	10
Arthritis	11	4
Asthma	4	1
Blindness	6	2
Cancer	46	15
Chronic bronchitis	2	1
Chronic back problem	2	1
COPD	3	1
Depression	4	1
Developmental disability	2	1
Diabetes	9	3
Digestive or gastro	1	1
Elderly or frail	32	10
Epilepsy	2	1
Emphysema	11	4
Fibromyalgia	2	1
Heart disease	35	11
HIV/AIDS	1	1
Hypertension	1	1
Kidney disease	4	1
Liver disease	2	1
Lupus	1	1
Multiple sclerosis	2	1

(*table continues*)

Osteoporosis	3	1
Other mental health condition	14	5
Paralysis of the exterior	2	1
Parkinson’s disease	2	1
Stroke	21	7
Problem with bones	10	3
Other impairment not listed	38	12
Not sure	3	1
Decline to answer	2	1
Is the person still living?		
Yes, still living	58	19
No, not living	67	22
Decline to answer	184	59
Where does person caring/cared for live?		
In your household	73	24
Alone, in his/her own	99	32
With another family	74	24
In a retirement community	9	3
In a nursing home	34	11
In some other facility	13	4
Somewhere else not specified	1	1
Decline to answer	6	2
How long have you been providing care to relationship?		
0 – 4	186	60
5 – 9	57	18
10 – 14	29	9
15 – 19	11	4
20 – 24	6	2
25 – 29	3	1
30 – 34	0	0
35 – 38	2	1
Decline to answer	15	3

(*table continues*)

How many other people like yourself, for example friends and family provide unpaid help to your relationship (Relationship)?		
0 – 9	283	91
10 – 19	9	3
20 – 29	3	1
30 – 39	1	1
50 – 59	2	1
90 – 99	11	11
Do you provide help with bathing or showering?		
Yes	94	30
No	215	70
Do you provide help with getting dressed or undressed?		
Yes	124	40
No	184	60
Not sure	1	1
Do you provide help with feeding?		
Yes	108	35
No	201	65
Do you provide help with using the toilet or managing incontinence?		
Yes	89	29
No	219	69
Decline to answer	1	1
Do you provide help with getting in and out of chairs or walking short distances?		
Yes	189	71
No	118	38
Not sure	1	1
Decline to answer	1	1
Do you provide help with shopping and errands?		
Yes	261	85
No	48	16
Do you provide help with household chores or preparing meals?		
Yes	233	75
No	76	25

(*table continues*)

Do you provide help with taking prescription medication, such as reminding (him/her) when it is time to take the next dose or measuring out the dosage?		
Yes	161	52
No	148	48
Do you provide help with exercise or massage?		
Yes	129	42
No	180	58
Do you provide help with transportation, either by driving or helping with the use of public or private transportation?		
Yes	254	82
No	55	18
Do you provide help with managing finances, paying bills or filling out insurance claims?		
Yes	1730	56
No	136	44
Do you provide help with arranging for government assistance through programs like Medicare, Medicaid or SSDI?		
Yes	112	36
No	195	63
Not sure	1	1
Do you provide help with arranging for needed medical or personal care services, such as medical appointments, supplies, or medical equipment or home health care?		
Yes	195	63
No	114	37
About how many hours do you spend providing assistance, in an average week?		
0 – 9	115	37
10 – 19	75	24
20 – 29	37	12
30 – 39	11	4
40 – 49	15	5
50 – 59	7	2
60 – 69	6	2
70 – 79	3	1
80 – 89	4	1

(*table continues*)

90 – 99	2	1
100 – 109	1	1
110 – 119	1	1
No response	32	10
About how many hours do you spend providing assistance on the phone, in an average week?		
0 – 9	283	59
10 – 19	19	6
20 – 29	3	1
30 – 39	1	1
40 – 49	3	1
90 – 99	1	1
In terms of financial burden, is the cost of your (relationship's) overall care, a major problem to you, a minor problem, or not much of a problem at all?		
A major problem	41	13
A minor problem	81	26
Not much of a problem	182	59
Not sure	2	1
Decline to answer	3	1
During the past 12 months, have you felt that you need anyone else to help arrange or coordinate your (relationship)'s medical and personal care?		
Yes, needed someone	77	25
No, did not	232	75
Which of the following statements best describes the level of involvement you would like to have in coordinating your (relationship)'s overall care?		
Prefer to coordinate it yourself	57	18
Prefer to have occasional assistance from others to help with coordination	101	33
Prefer to have someone else to take the lead in coordinating it, with some involvement on your part	83	27
Prefer to have someone else to fully coordinate it	52	17
Not sure	5	2
Decline to answer	11	4

(*table continues*)

How important is/was it to you to have one person to coordinate medical and personal care?		
Absolutely essential	70	23
Very important	130	42
Somewhat important	66	21
Not very important	18	6
Not at all important	14	5
Not sure	8	3
Decline to answer	3	1
Was there a time in the past year when you needed paid care or help for the person being cared for, but did not get it, or not?		
Yes, needed but did not get	71	23
No	235	76
Not sure	2	1
Decline to answer	1	1
What was the main reason that you did not get the care or help you needed for your (relationship)?		
It costs too much	15	5
Not covered by insurance	9	3
Transportation problems/too far	1	1
Didn’t know how or where to get it	6	2
Provider/service not available when needed	8	3
Quality of provider not adequate	1	1
Didn’t like provider	2	1
Didn’t have anyone to arrange or coordinate the service	1	1
Didn’t think services were needed that badly	3	1
Didn’t pass the certification process	6	2
Not enough time	1	1
Other not specified	14	5
Not sure	4	1
Is/was there anyone who you think of as the person who coordinates/coordinated all of the person’s medical and personal care needs?		
Yes, someone coordinates needs	236	76
No, no one coordinates needs	67	22
Not sure	6	2

(*table continues*)

Do you feel you receive all the support you need when you feel stress or overwhelmed or would you like to receive more support?		
Yes, receive all the support I need	75	24
No, would like more support	19	6
Not sure	1	1
Decline to answer	214	69
In the course of caring for your (relationship), have you ever contacted any groups or organizations in your local community that provider information, services, or other help to the elderly, chronically ill, or disabled or to their families?		
Yes, have contacted	95	31
No, have not contacted	213	69
Not sure	1	1
Decline to answer	0	0
What king of help were you looking for?		
Accompanying (relationship) outside the home	3	2
Help arranging services	10	7
Help with personal care such as eating, dressing, bathing	14	10
Home delivered meals	7	5
Homemaker services	8	6
Information and referral services	22	15
Making appointments for your (relationship)	0	
Making telephone call for the (relationship)	0	
Senior center or adult day services	7	5
Shopping and errands	4	3
Support for the caregiver	21	15
Transportation	9	6
Visiting and companionship for the (relationship)	10	7
Other	27	5
Did you receive the type of help you needed?		
Yes, received	75	24
No, did not receive	19	6
Not sure	1	1
Declined to answer	214	69

(*table continues*)

If it were available, what kind of (other) help would you be interested in receiving form a group or organization in your local community?		
Information and referral service	24	6
Help arranging service	5	1
Senior center or adult day care	6	2
Transportation	24	6
Home delivered meals	7	2
Homemaker services	17	4
Shopping and errands	7	2
Making telephone call or (relationship)	1	1
Visiting and companionship	29	8
Making appointments	5	1
Support for caregiver	48	13
Help with personal care for (Relationship) such as eating, dressing, and bathing	14	4
Accompanying (relationship) outside the home	9	2
Other	37	10
Not sure	40	10
Decline to answer	2	1
None	108	31
How likely would you be to contact a group or organization to receive the help?		
Very likely	93	30
Somewhat likely	68	22
Not very likely	25	8
Not at all likely	14	5
Not sure	3	1
Decline to answer	3	1
If you would like to receive additional support, what type of people or organizations do you think should provide that support?		
Relative	27	8
Friend	8	2
Your relationship’s doctor	1	1
Local church or other religious organization	17	5
Support or community organization providing assistance to caregiver	23	6
Social service providers	10	2
Therapist/counselor	4	1

(*table continues*)

Your doctor	2	1
Other	28	8
Not sure	18	5
Decline to answer	2	1
Not any	219	61
In the past 12 months, how often did you get information or advice from news or magazine program you have seen on television to help you care for your (relationship)?		
Often	27	9
Sometimes	81	26
Hardly ever	59	19
Never	140	5
Not sure	2	1
Decline to answer	1	1
In the past 12 months, how often did you get information or advice from news or radio talk shows you have heard to help you care for your (relationship)?		
Often	16	5
Sometimes	65	21
Hardly ever	53	17
Never	173	56
Not sure	2	1
In the past 12 months, how often did you get information or advice from advertisement on TV, radio, newspaper, or magazine to help you care for your (relationship)?		
Often	15	5
Sometimes	58	19
Hardly ever	53	17
Never	182	59
Not sure	1	1
Decline to answer	1	1
In the past 12 months, how often did you get information or advice from articles in the newspaper, magazine, or other periodicals to help you care for your (relationship)?		
Often	27	8
Sometimes	99	31
Hardly ever	65	20
Never	126	39

(*table continues*)

Not sure	1	1
Decline to answer	2	1
In the past 12 months, how often did you get information or advice from materials you or your (relationship) received by mail to help you care for your (relationship)?		
Often	21	7
Sometimes	53	17
Hardly ever	64	21
Never	166	54
Not sure	4	1
Decline to answer	1	1
In the past 12 months, how often did you get information or advice from patient support group to help you care for your (relationship)?		
Often	17	6
Sometimes	43	14
Hardly ever	42	14
Never	202	66
Not sure	3	1
Decline to answer	1	1
In the past 12 months, how often did you get information or advice from family and friends to help you care for your (relationship)?		
Often	89	29
Sometimes	117	38
Hardly ever	52	17
Never	48	16
Not sure	3	1
Decline to answer	4	1
In the past 12 months, how often did you get information or advice from the Internet to help you care for your (relationship)?		
Often	19	6
Sometimes	42	14
Hardly ever	29	9
Never	218	71
Not sure	1	1
Decline to answer	1	1
In the past 12 months, how often did you get information or advice from other source to help you care for your (relationship)?		
Often	19	6

(*table continues*)

Sometimes	40	
Hardly ever	20	7
Never	201	65
Not sure	3	1
Decline to answer	26	9
How would you say your health is in general?		
Excellent	61	20
Very good	109	36
Good	103	33
Fair	29	9
Poor	5	2
Not sure	1	1
Decline to answer	1	1
All things considered, how satisfied are you with your life these days?		
Very satisfied	173	56
Somewhat satisfied	118	38
Not very satisfied	12	4
Not satisfied at all	4	1
Not sure	1	1
Decline to answer	1	1
Do you currently need or use medicine prescribed by a doctor (other than vitamins)?		
Yes	149	48
No	159	52
Decline to answer	1	1
Do you need or use more medical care, mental health or other health services than is usual or routine for other people your same age?		
Yes	40	13
No	260	84
Not sure	8	3
Decline to answer	1	1
Are you limited or prevented in any way in your ability to do things most people your age can do such as go to school, do housework, socialize, cook, or pay bills?		
Yes	41	13
No	267	86
Not sure	1	1

Appendix C: Research Questions

BLOCK 2: CAREGIVER STRESSORS

Q1500. You indicated that you are currently caring/have recently cared for someone who is frail, sick or disabled. Are you caring for one person or more than one person (in the past 12 month)

1 One person
2 More than one person
8. Not Sure
9. Decline to answer
10.

Q1505: When answering the following questions, please answer about the person you spend the most time caring for. What is the person's relationship to you?

01 Spouse
02 Mother
03 Father
17 None-related/friend
18 Companion/partner
96 Some other Relationship

Q1515. What is the primary medical mental or other health condition that leaves your (RELATIONSHIP) unable to fully care for himself/herself?

04 Alzheimer's disease
07 Cancer
33. Multiple sclerosis
37. Parkinson's disease
39. Stroke
96 Something else
98. Not sure (V)
99. Decline to answer

Q1525: Is the person still living?

1 Yes, still living
2 No, not living
8. Not sure (V)
9. Decline to answer

Q1535. Does your (Relationship) live?

01 In your household
02 Alone, in his/her own home

03 With another family member or friend, in their own home
04 In a retirement community or elderly housing apartment complex
05 In a nursing home
06 In some other facility where some care and supervision is provided, like and assisted living facility or a group home.
98. Not sure (V)
99. Decline to answer (V)

Q 1540: In total, how long (have you been providing care to your (Relationship)

/_____/_____/_____/___Years (Range 0-100)

Q1544: How many other people like yourself, for example friends and family provide unpaid help to your (Relationship)

/____/____/____ People (Range 0-100).

Q1550/1551: Next, I have some questions about the kind of help you might be giving/have given your (RELATIONSHIP). Please tell me if you provide/provided any kind of help at all with:

Question	**Yes**	**No**	**Not sure (V)**	**Decline to answer (V)**
A. Bathing or showering	1	2	8	9
B. Getting dressed or undressed	1	2	8	9
C. Feeding	1	2	8	9
D. Using the toilet or managing incontinence	1	2	8	9
E. Getting in and out of chairs or walking short distances	1	2	8	9
F. Shopping a errands	1	2	8	9
G. Household chores or preparing meals	1	2	8	9
H. Taking prescription medication such as reminding (him/her) when it is time to take the next dose or measuring out the	1	2	8	9

correct dosage				
I. Exercise or message	1	2	8	9
J. Transportation, either by driving or helping with the use of public or private transportation	1	2	8	9
K. Manage finances, paying bills or filling out insurance claims	1	2	8	9
L. Arranging for government assistance through programs like Medicare, Medicaid, or SSDI	1	2	8	9
M. Arranging for needed medical or personal care services, such as medical appointments, suppliers or medical equipment or home health care	1	2	8	9

Q1550: Thinking now about the kinds of help you provide for your (RELATIONSHIP). About how many hours do spend, in an average week?

/______/________/________/___ Hours per week (Range 0-168).

Q1560: In a typical week how many hours do you spend talking on the phone with your (relationship) to provide support and reassurance? 998 = unsure and 999 = Decline to answer?

/______/______/______ House (range 0-168).

BLOCK 3: CAREGIVER'S APPRAISAL OF ABILITY TO COPE

Q1565: In terms of financial burden is the cost of your (relationship)'s overall care , including all services he/she needs to cope with their chronic medical condition, a major problem to you, a minor problem, or not much of a problem at all?

1. A major problem
2. A minor problem
9. Not a problem at all

Q1610: During the past 12 months, have you felt that you need anyone else to help arrange or coordinate your (relationship)'s medical and personal care?

1 yes, needed someone (some else) to coordinate care
2 No, did not
8. Not sure (V)
9. Decline to answer (V)

Q1615. Which of the following statements best describes the level of involvement you would like to have in coordinating your (relationship)'s overall care?

1. Prefer to coordinate it by yourself
2. Prefer to have occasional assistance from other to help with coordination
3. Prefer to have someone else to take the load in coordinating it, with some involvement on your part
4. Prefer to have someone else to fully coordinate it for you (relationship).
8. Not sure (V)
9. Decline to answer (V)

Q1620: How important is it to you to have one person to coordinate you (relationship)'s medical and personal care ---absolutely essential, very important, somewhat important, not important, not at all important?

1. Absolutely essential
2. Very important
3. Somewhat important
4. Not very important
5. Not at all important.
8. Not sure (V)
9. Decline to answer (V)

Q1570. Was there a time in the past year when you needed paid care or help for your (relationship) but did not get it for the relative who does not live in your household

1 Yes, but did not get it
2 No.
8 Not sure (V)
9 Decline to answer (V)

Q1575: If you did not get help, what was the main reason that you did not get the care or help you needed for your (relationship)?

01 It cost too much
02 Not covered by insurance
03 Transportations problems/too far
04 Didn't know how or where to get it
05 Had to wait too long
06 Provider/service was not available when needed
07 Quality of provider not adequate
08 Didn't like provider
09 Didn't have anyone to arrange or coordinate the service
10 Didn't think service were needed that badly
11 (Relationship) didn't pass the certification process
12 (Relationship) got better and did not need service anymore
13 Needed to save in case things got worse
14 Other (Specify)
98 Not sure (V)
99 Decline to answer (V)

Q1600: Is there anyone who you think of as the person who coordinates/coordinated all your (relationship) medical and personal care needs? By coordinating care I mean keeping in touch with different doctors or health care workers whom your (relationship) sees, keeping track of test results, arranging for home health care, scheduling appointments and home visits, and other services?

1 Yes, someone coordinates needs
2 No, no one coordinate needs
8 Not sure (V)
9 Decline to answer

BLOCK 4: KNOWLEDGE AND UTILIZATION OF RESOURCES

Q1805: Do you feel you receive all the support you need when you feel stress or overwhelmed or would you like to receive more support?

1. Yes, received all the support I needed
2. No, I would like more support
8. Not sure (V)
9. Decline to answer (V)

Q1815: In the course of caring for your (RELATIONSHIP), have you ever contacted any groups or organizations in your local community that provide information, services, or other help to the elderly, chronically ill, or disabled or to their families and caregivers?

1. Yes, you have contacted
2. No, have not contacted
8. Not sure (V)
9. Decline to answer (V)

Q1820: For caregivers who contact local group/organization, what kind of help were you looking for?

1. Accompanying (relationship) outside the home
2. Helping arranging services
3. Help with personal care for the (Relationship) such as eating, dressing bathing
4. Home delivered meals
5. Homemaker services
6. Information and referral services
7. Making appointments for your (relationship)
8. Making telephone call for the (relationship
9. Senior center or adult day services
10. Shopping and errands
11. Support for the caregiver
12. Transportation
13. Visiting and companionship for the (relationship)
96. Other Specify
98. Not sure (V)
99. Decline to answer (V)

Q1825. Did you receive the type of help you needed

01. Yes, received
02. No, did not receiver
08. Not sure (V)
09. Decline to answer

Q1830. If it were available, what kind of (other) help would you be interested in receiving from a group or organization in your local community?

01. Information and referral service
02. Help arranging service
03. Senior center or adult day care
04. Transportation
05. Home delivered meals
06. Homemaker services
07. Shopping and errands
08. Making telephone call or (relationship)
09. Visiting and companionship

10. Making appointments
11. Support for caregiver
12. Help with personal care for (Relationship) such as eating, dressing, and bathing
13. Accompanying (relationship) outside the home

Q1835: How likely would you be to contact a group or organization to receive the help – very likely, likely, somewhat likely, not very likely, not at all likely?

1. Very likely
2. Somewhat likely
3. Not very likely
4. Not at all likely
8. Not Sure (V)
9. Decline to answer (V)

Q1810: If you would like to receive additional support, what type of people or organizations do you think should provide that support?

1. Relative
2. Friend
3. Your (relationship)'s doctor(s)
4. Local church or other religious organization
5. Support or community organization providing assistance to caregiver
6. Social service providers
7. Therapist/counselor
28. Your doctor
98. Not sure (V)
99. Decline to answer (V)

Q1900: In the past 12 months how often did you get information on advice to help you care for your (RELATIONSHIP)? Was it often, sometimes, hardly ever or never?

Question	Often	Sometimes	Hardly Ever	Never	Not sure	Decline to Answer
A. News or magazine program you have seen on television	-1	-2	-3	-4	-8	-9
B. News or radio talk shows you have heard	-1	-2	-3	-4	-8	-9
C. Advertisement on TV, radio, Newspaper or magazine	-1	-2	-3	-4	-8	-9

D. Articles in the newspaper, magazine or other periodicals	-1	-2	-3	-4	-8	-9
E. Materials you or your (RELATIONSHIP) received by mail	-1	-2	-3	-4	-8	-9
F. Patient support group	-1	-2	-3	-4-	-8	-9
G. Family and friends	-1	-2	-3	-4	-8	-9
H. The Internet	-1	-2	-3	-4	-8	-9
I. Other source (Specify at 1902)	-1	-2	-3	-4	-8	-9

BLOCK 5: OUTCOME RELATED TO CAREGIVER QUALITY OF LIFE
BASE: ALL RESPONDENTS

Q215: Would you say your health, in general, is excellent, very good, good, fair or poor?

1.Excellent
2. Very good
3. Good
4. Fair
5. Poor
8. Not sure (V)
9. Decline to answer (V)

BASE: ALL RESPONDENTS

Q220: All things considered, how satisfied are you with your life these days – very satisfied,
somewhat satisfied, not very satisfied, or not satisfied at all?

01. Very satisfied
02. Somewhat satisfied
03. Not very satisfied
04. Not satisfied at all
98. Not sure (V)
99. Decline to answer (V)

BASE: ALL RESPONDENTS

Q310: Do you currently need or use medicine prescribed by a doctor (other than vitamins)?

1. Yes
2. No
8. Not sure
9. Decline to answer

BASE: ALL RESPONDENTS

Q320: Do you need or use more medical care, mental health or other health services than is usual or routine for other people your same age?

1. Yes
2. No
8. Not sure
9. Decline to answer

Q330: Are you limited or prevented in any way in your ability to do things most people your age can do such as go to school, do housework, socialize, cook, or pay bills?

1. Yes
2. No

Appendix D: Variables—Hierarchal Regression Model

BLOCK 1	**BLOCK 2**	**BLOCK 3**	**BLOCK 4**	**BLOCK 5**
Environment and Context	Stressors: Demands of Caregiving	Caregivers Appraisal of Ability to Cope	Knowledge and Utilization of Resources	Caregiver Quality of Life/ Outcome
Variables	Variables	Variables	Variables	Variables
Caregiver gender Marital status Educational level Employment status Income level	Number of people providing care? Relationship to care recipient Care recipients chronic condition Age of care recipient Where does your care recipient live? How long has caregiver been providing care? ADL and IADL activities provided to care recipient Number of hours provide care to care	In the past 12 months, did you need someone to help arrange care recipients health personal care? Do you feel you received all the support you needed when stressed or overwhelmed? Frequency which caregiver has experienced problems when getting care recipients need care? Caregiver’s preference for involvement in coordinating care recipients health care How important is it to have one person coordinate	Did you care recipient receive any paid help at home? Was there a time in the past year when you needed paid help but did not get it? What was the main reason you did not get the help you need? Number of other people who provide unpaid help to your relative What type of people or organizations do you think should provide that support? Organization contacted in the	Would you say your health, in general, is excellent, very good, good, fair or poor? All things considered, how satisfied are you with your life these days – very satisfied, Somewhat satisfied, not very satisfied, or not satisfied at all? Do you currently need or use medicine prescribed by a doctor (other than vitamins)? Do you need

	recipient	relative's medical care Level of financial burden to caregiver	local community that provided services or other help to chronically ill or elderly?	or use more medical care, mental health or other health services than is usual or routine for other people your same age? Are you limited or prevented in any way in your ability to do things most people your age do?

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