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Caregivers of Older Adults: Burden, Perception of Strain, and Health

Juana Ferrerosa PhD, MSN, RN, PHN
University of San Diego

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DOCTOR OF PHILOSOPHY IN NURSING

CAREGIVERS OF OLDER ADULTS: BURDEN, PERCEPTION OF STRAIN, AND HEALTH

by

Juana Ferrerosa, MSN, RN, PHN

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Dissertation Committee:

Jane M. Georges, PhD, RN, Chairperson

Ann Mayo, DNSc, RN, FAAN

Patricia A. Roth, EdD, RN

ABSTRACT

Background: By the year 2030, the older population in the United States is projected to double from 35 to 70 million. Consequently, increasing the number of informal caregivers required to care for an aging population. Research suggests that levels of caregiver strain and their ability to cope can impact the health of caregivers. Tsai's (2003) Middle-Range Theory of Caregiver Stress guided this study and was modified to present an innovative approach which used perceived caregiver strain as a specific stressor in the Control Process of the model; it provided a basis for examining caregiver strain and its effect on the caregiver's health.

Purpose: The overall purpose of this descriptive study was to describe the relationships between objective caregiver burden, relevant caregiver characteristics, perceived caregiver strain, and perceived caregiver health in a diverse group of adult caregivers providing assistance with instrumental activities of daily living (IADL) to care recipients in Southern California.

Methods: A descriptive, cross sectional, correlational and multivariate design was used to study a convenience sample of eighty-one caregivers. Caregivers were recruited from churches and adult day cares in the community areas of the Southern California region. Data was collected from caregivers who participated in an interview to include a demographic questionnaire, the Lawton Instrumental Activities of Daily Living Scale (IADL), the Modified Caregiver Strain Index (CSI), and the Short Form-12 v2 Health Survey.

Data Analysis Plan: SPSS version 19.0 was used to generate descriptive statistics, including measures of central tendency and dispersion include, frequencies (percentages), means, medians, standard deviations, and range for all variables. Inferential statistical analysis, including t-tests and a one-way ANOVA were performed to examine significant relationships among variables. The Chi-square/Fisher's Exact Test was used to determine significant associations between the dependent and independent variables. **Conclusion:** This descriptive study suggests a picture of care giving as far more complex and potentially hazardous to the health of caregivers than has been previously documented. Future research can elucidate further the factors that can promote optimal health in both the caregivers and recipients.

Key terms: Caregiver, caregiver burden, caregiver strain, theory of caregiver strain

DEDICATION

I dedicate this dissertation to:

- My precious daughters, Natalie Rose and Lillianne Karie
- To my parents and family

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I am heartily thankful to my chairperson, Dr. Jane Georges, whose encouragement, guidance and support from the initial to the final level enabled me to develop an understanding of the process of nursing research. Dr. Ann Mayo and Dr. Patricia Roth for their encouragement to find the “right” fit in nursing research to explore the topic of “caregiving”. Their commitment, contributions, and feedback were so valuable to the completion of this research.

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It was not possible to imagine the magnitude of this project, yet without question or hesitation “my personal” networks of support rose to the occasion to help in every way imaginable. Thank you:

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I am indebted to the caregivers who participated in the study. Lastly, I offer my regards to all of those who supported me in any respect during the completion of this project.

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CHAPTER 1

Introduction

Statement of the Problem

The role of caregiver has been highlighted as a complex event, consequently provoking a complex stress process (Valadez, Lumadue, Gutierrez, & de Vries-kell, 2005). Intuitively, the level of stress in a caregiver potentially can affect the quality of care an older adult is receiving. The literature on caregiver stress notes that stress can be both objective and subjective (Beach, Schulz, & Yee, 2000; Hunt, 2003). Consequently, caregiver strain, defined as the caregiver's subjective impression of being strained by excessive physical or mental tension (Hunt, 2003), can be posited to be an important subjective stress in this population. A study by McConaghy and Caltabiano (2005) supports that caregiver strain is related to negative effects of caregiver's health.

Nevertheless, little documentation exists regarding the role of caregiver strain as a perceived stressor in the caregiver population, or its relationship to such associated factors as objective caregiver burden, characteristics, and health. This study was undertaken to examine more fully the relationships between these factors.

Purpose of the Study

The overall purpose of this descriptive study was to describe the relationships between objective caregiver burden, relevant caregiver characteristics, perceived caregiver strain, and perceived caregiver health in a diverse group of adult caregivers providing assistance with instrumental activities of daily living (IADL) to care recipients in Southern California. This initial chapter presents the study's aims, definition of terms, and introduces the middle-range theory used to guide this study.

Specific Aims

The specific aims of this study are to:

1. Describe levels of objective caregiver burden, select caregiver characteristics (race/ethnicity, age, relationship to care recipient, and diagnosis of care recipient), perceived caregiver strain, and perceived caregiver health.
2. Describe the relationships between and among objective caregiver burden, select caregiver characteristics, perceived caregiver strain, and perceived caregiver health.

Definition of Terms

For the purposes of this study, *objective caregiver burden* is defined as the degree of care that the caregiver is required to administer. Thus, it includes how many instrumental activities the caregiver must perform, how many hours a day care is given, and how long the caretaking has been performed. It was measured by the degree to which the person being cared for requires instrumental care with ADLs, as indicated on the Instrumental Activities of Daily Living Scale (IADL), the number of hours providing care, and the length of time providing care (Beach et al., 2000; Tsai, 2003).

Caregiver characteristics include demographic characteristics of race, age, gender and relationship to the care recipient. This information was collected in the Demographic

Characteristic Questionnaire (Pressler, Gradus-Pizlo, Chubiniski, Smith, Wheeler, Wu & Soloan, 2009).

Perceived caregiver strain is defined as the caregiver's subjective impression of being strained by excessive physical or mental tension (Beach; Hansen, Archbold, Stewart, Westfall & Ganzini, 2005; Hunt, 2003, Lockenhoff, Duberstein, & Friedman, 2011). It was measured using the Modified Caregiver Strain Index (CSI).

Perceived caregiver health is defined as the caregiver's view of their health status and is self-reported by the caregiver using the Short-Form-12 Health v2 Survey. The structure of the instrument includes the following factors: Physical Function, Role Physical, Bodily Pain, General Health, Vitality, Social Functioning, Role Functional, and Mental Health (Lockenhoff et al., 2011; McConaghy& Caltabiano, 2005).

Caregivers are defined as " anyone" who provides unpaid help or arranges for help, to a relative or friend because they have an illness or disability that leaves them unable to do some things for themselves, or because they are simply getting older (Bell, 2009; Roth, Perkins, Wadle, Temple & Haley, 2009). The person is responsible for providing care to an older adult, including the performance of activities of daily living. The caregiver may be a spouse, adult child, sibling or unpaid caregiver.

A care recipient is someone who may be disabled, chronically ill, frail, or an older adult; who receives care and support from a caregiver to perform ADL's. Care recipients are addressed in the literature as both care recipients and care receivers (Pearlin et al., 1990; Pembroke, 2007).

An older adult is defined as a person who has reached the chronological age of 65 years, which is consistent with most developed world countries (WHO, 2010).

Conceptual Model

A Middle-Range Theory of Caregiver Stress, developed by Pao-Feng Tsai, R.N., PhD, guided this research study. Tsai's (2003) theory is based on the 1984 version of The Roy Adaptation Model (RAM). Similar to Tsai (2003), researchers Blevins & Troutman (2011) reference that concepts in their models have been expressed by Roy.

As such, the author asserts that the structure of Tsai's (2003) Middle-Range Theory of Caregiver Stress is appropriate to guide the development of future studies in this area. A review of literature and email communication with Dr. Tsai confirms that this theory has not been used as a conceptual framework in other studies (Dr. Tsai, personal communication, April 17, 2010, 2:01PM).

Thus, the structure of Tsai's Middle Range Theory of Caregiver Stress (2003) has been adapted as a sensitizing framework for this study. The structure of Tsai's Middle Range Theory consists of three processes, including an input, control, and the output process.

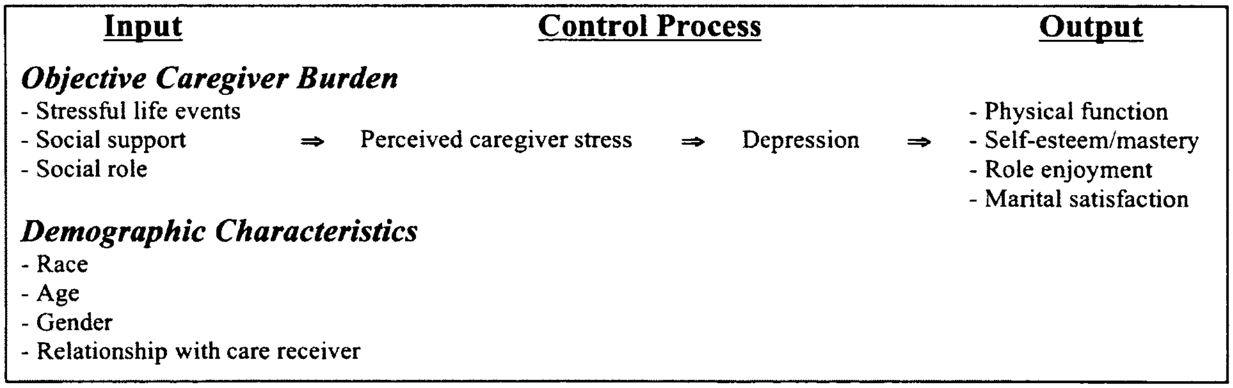

Figure 1. Theory of Caregiver Stress

Tsai (2003) states that these three process elements originate in the Roy Adaptation Model. Additionally, Tsai, 2003 notes that these process elements are used in an organizational manner in the Middle Range Theory of Caregiver Stress, and the theory does not attempt to identify the caregiver's adaptation level. Thus, they form a framework of process elements designed to organize study concepts in a broad manner.

The author has utilized Tsai's Middle Range Theory as an organizing and sensitizing framework for this study, but has modified it slightly in the following way. This study had as one of its main foci caregiver strain, understood as a perceived stressor, defined as the caregiver's subjective impression of being strained by excessive physical or mental tension (Hunt, 2003). Therefore, in this study, the overall intermediary control process of "stress" used by Tsai (2003) has been replaced with a more specific stressor, perceived caregiver strain. This modification was made after careful consideration of the exact stressor of interest in this particular research effort and is congruent with this study's overall purpose of examining more deeply the role of strain as a perceived stressor.

The overall study framework, adapted from Tsai's Middle-Range Model, is presented in Figure 2.

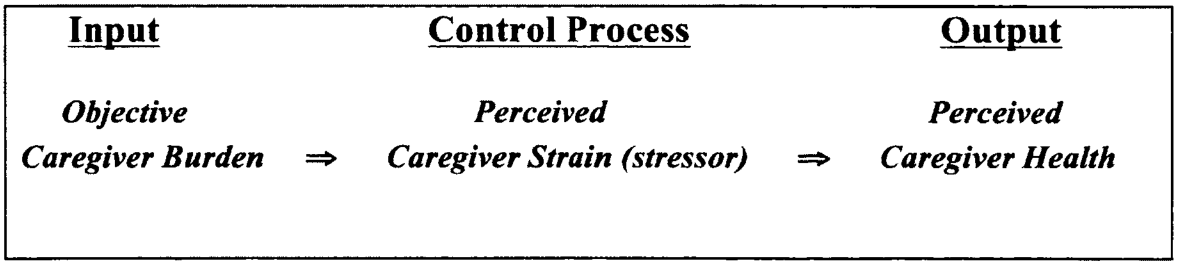

Figure 2. Modified Middle-Range Theory of Caregiver Stress

The input process is a stimuli in an open adaptive system (Blevins & Troutman, 2011; Tsai, 2003). In this study contributing factors (stimuli) such as objective caregiver burden and personal characteristics may have affected the caregiver's coping mechanisms. These contributing factors often play a role in influencing the perceived caregiver strain.

Tsai (2003) defines the control process as the caregiver's cognitive appraisal of stress in relation to caregiving for a chronically ill relative or friend. In this study, the specific stressor under consideration is perceived caregiver strain. The Modified Caregiver Strain Index (CSI) was used to determine the perceived level of caregiver strain.

The output process includes the outcome response of the input and control process which brings about adaptation (Blevins &Troutman, 2011; Tsai, 2003). In this study the output under consideration is the caregiver's perception of health. The Short Form-12 Health Survey Version 2 (SF-12v2 Health Survey) was used to measure the perceived level of caregiver health. Table 1 summarizes the study concepts, indicators, and measures used.

For the purposes of this study, the "Input Process" consisted of objective caregiver burden and relevant caregiver characteristics. Objective caregiver burden was measured by the IADL Scale as a measure of the degree of instrumental care provided by the caregiver, along with the number of hours providing care and the length of time providing care. The demographic characteristics include race, age, gender and the relationship to the care recipient. The "Control Process" process consisted of the stressor of perceived caregiver strain, which was measured using the Modified Caregiver

Strain Index. The "Output Process" consisted of perceived caregiver health, which was measured using the SF-12v2 Health Survey.

Table 1.

Study concepts, indicators, and measures

Concepts/Indicators	**Measure**
INPUT	
Objective Caregiver Burden	
- Degree of instrumental care provided by caregiver	- Lawton Instrumental Activities of Daily Living Scale (IADL)
- Number of hours providing care	- Demographic Characteristic Questionnaire
- Length of time providing care	
Caregiver Characteristics	
- Race	- Demographic Characteristic Questionnaire
- Age	
- Gender	
- Relationship to the care recipient	
CONTROL PROCESS	
Perceived Caregiver Strain	-Modified Caregiver Strain Index (CSI)
OUPUT	
Perceived Caregiver Health	-Short Form-12 v2 Health Survey

Importance to the Advancement of Nursing Science

Caregiving has now become a crucial issue in need of attention at the systemic levels of health care and government (Donorfio & Kellet, 2006). Caregiver health has been addressed by the U.S. Department of Health and Human Services and recognized in the nationwide health promotion and disease prevention agenda (Healthy People 2010). The health of caregivers has a direct impact on the ability to provide care, and the level of care that is provided to care recipients (Huynh-Hohnbaum, Villa, Aranda & Lambrinos, 2008). Additionally, many care recipients have multiple caregivers, and all are impacted by the patient's illness. Research studies and healthcare providers continue to administer caregiver assessments only to the primary caregiver of the care recipients (Sales, 2003).

Subsequently, caregiver health is of utmost importance to nursing researchers and practitioners, with implications for the field of nursing, future research and health policy. This study is of unique importance to nursing science in the following ways.

First, it was conducted in an extremely diverse group of caregivers in the Southern California region. As such, it was designed as a broad-spectrum study to capture newer trends in caregiving. The wide study inclusion criteria allowed for a "snapshot" of a wide range of persons in the caregiving role, rather than a narrow focus on specific caregiving relationships as the mother-daughter dyad, or a specific disease state. It was hoped that this wide ranging approach would capture newer trends in caregiving previously undocumented in the caregiving literature.

Secondly, the Modified Theory of Caregiver Stress guided this research study, based on the work of Pao-Feng Tsai, R.N., PhD (Tsai, 2003). A literature search and conversation with Dr. Tsai confirms that no further studies have been conducted using this theory as a conceptual framework in other studies. The modification of Tsai's theory in an innovative manner, that is, the use of perceived caregiver strain as a specific stressor in the Control Process, is unique to this study. Data from this study have the potential to be used as a foundation for future more focused studies of the relationships between objective caregiver burden, perceived caregiver strain, and perceived caregiver health in specific populations. Additional areas of future research can include the examination of these phenomena in multiple caregivers per care recipient and the complex relationships present in such populations.

CHAPTER 2

Literature Review

Background

An unprecedented growth in our older adult population over the next thirty years will result in an increased number of caregivers required to safely care for older adults who live at home. The U.S. Census Bureau, International, 2009 anticipates that the life expectancy at birth by the year 2030 will be 81 years of age. Historically, there have been advances in medical technology and miraculous cures, which have in turn contributed to the increased life expectancy for the older adult population. Overall, the health status of the older adult population reveals that chronic and degenerative conditions are becoming more common among the older adult population (Martini, Garrett, Lindquist, & Isham, 2007; Pearlin, Mullan, Semple, & Skaff, 1990). In 2009, The American Geriatric Society concluded that improvement in healthcare, technology services and nutritional status are contributing factors to the increased need for caregivers (Talley & Crews, 2007).

Informal caregivers are a tremendous resource to society, given that they are usually relatives who provide an estimated $196 to $306 billion in uncompensated care (Arno, Levine & Memmott, 1999; Huynh-Hohnbaum et al., 2008; Navaie-Waliser, Feldman, Gould, Levin, Kuerbis, & Donelan, 2001, 2002). Changes in family structures have impacted their ability to care for aging parents in their homes and promote "aging in place" (Donelan, Hill, Hoffman, Scoles, Feldman, Levine & Gould, 2002). Consequently, families are finding that they are employing a network of family members and friends to help care for their parent or loved one (Elder Care 101).

More often, women have been found to take on higher levels of caregiving, consequently reporting higher levels of health concerns (NAC/AARP, 2004; LARC, n.d.; Pinquart & Sorensen, 2006; Talley & Crews, 2007). The aforementioned studies attribute increased health concerns in women because they attempt to manage home and work responsibilities and are less likely to place their loved ones in an institution.

Caregiving has recently been placed on the level of a public health matter; given that caregiver health has been recognized and addressed by the U.S. Department of Health and Human Services (Healthy People, 2010). An extensive body of research on caregiving, over the past 25 years has focused on an array of topics which addressed multiple facets of caregiving. Informal caregiving is the process of activities and the experience of providing unpaid care and support to an adult friend or family member who is disabled, chronically ill, frail, or an older adult (Pearlin et al., 1990; Pembroke, 2007). Landmark studies have shaped caregiving literature and include topics on stress, caregiving and quality of life (Pearlin et al., 1990; Schulz & Beach, 1999; Lawton, 1991). More recent studies include dementia, coping strategies and health concerns associated with caregiving (Bruce, Paley, Nichols, Roberts, Underwood & Schaper, 2005; Grasel, 2002; Roth et al., 2009; Talley & Crews, 2007).

A significant body of research exists for caregivers of care recipients of dementia and the dementia subtype of Alzheimer's disease; yet few studies evaluate caregivers without an emphasis on the type of care recipient (NAC/AARP, 2004; Pinquart & Sorensen, 2007, 2005). Knight and Sayegh (2009) contend that the findings of studies with caregivers of dementia can be applicable to those who do not have dementia but are physically frail. Therefore it brings to the forefront the basis for this study, further supported by a similar study conducted by de Frias, Tuokko and Rosenberg (2005). However the aforementioned study is a single time study and does not focus on one specific type of caregiver. The focus of the current study is in line with a similar study conducted by the National Alliance for Caregiving and American Association of Retired Persons (Huynh-Hohnbaum et al., 2008; NAC/AARP, 2004).

Anecdotal Cases in Clinical Practice

In addition to the above empirical documentation, the author's own experiences of caregiving, both formally and informally, also inform the basis of this study. While anecdotal in nature, cases experienced by the author in clinical practice highlight the challenges that caregivers encounter as they make choices amid caring for their own health or taking care of the care recipient. The following clinical cases are from the author's actual experience in working with this population. These experiences represent commonly occurring patterns of challenges that caregivers may encounter. These exemplar cases represented a starting place for planning a study centered on caregiver health.

Case #1: A wife took care of her husband with esophageal cancer for a period of five years. During this time, she lost weight, and was visibly tired and exhausted. The caregiver did not seek medical care because she did not want to leave her husband's bedside and the family could not afford the financial cost for her to seek medical care.

Shortly after his death, she sought medical attention and was diagnosed with uterine cancer.

Case #2: A daughter took care of her mother for a period of ten years. This caregiver began to feel ill and decided to seek medical attention. Subsequently, she was diagnosed with esophageal cancer with metastasis to the brain. Her medical care included chemotherapy and radiation. Her prognosis is poor and her immediate family is the caregiver for her and the "grandmother". The task of caring for two care recipients is overwhelming for this family, and they have resorted to using paid help to meet the caregiving needs of the two family members.

These two cases highlight the importance of promoting awareness of caregiver's health and having resources available to provide health screening or benefits for caregivers. Personal Assistance Services Council of Los Angeles County provides health insurance for caregivers; yet caregivers are challenged to find replacements for the time off they need to visit health care providers (McMurray-Avila, 2009). Therefore, caregivers may postpone their medical care. Research supports that an increase awareness of caregivers health concerns may be attributed to the extra time caregivers have after the death or institutionalization of a relative (Bruce et al., 2005; Grasel, 2002). Thus, this inquiry was conducted as a starting place for the investigation of the complex relationships between caregiver burden, characteristics, strain and health.

Caregiving

Caregiving is described as the experience of providing assistance and help to a care recipient who is not able to provide the care for themselves (Pearlin et al., 1990; Pembroke, 2007). Furthermore, this care is provided by a family member or friend

(Schulz & Sherwood, 2008). Pearlin et al. (1990) refer to caregiving as part of a relationship in which caring and providing care is an extension of such. Meanwhile, the caregiver attempts to facilitate the provision of care and improve the well-being of the care recipient. Interestingly, Pearlin et al. (1990) notes that caregiving should not be considered a role because it is part of an ordinary relationship. Nonetheless, caregiving becomes the primary focus, thus impacting and changing the relationship between the caregiver and the care recipient. Family members constitute the majority of caregivers, with women and children being the greatest number (Papastavrou, Kalokerinou, Papacostas, Tsangari & Sourtzi, 2007; Pinquart & Sorenson, 2006; Talley & Crews, 2007).

Caregiver Burden

Many families find themselves unprepared when caregiving descends upon them through a sudden crisis or a series of frequent hospital admissions. As such, family members struggle with the choice of providing care and the decision of how involved they will become in the care. Often their decision is based on finding a balance between existing family and work responsibilities.

Caregiver burden is the description of the extent to which the caregiver provides the care, length of care and the associated activities of the caregiving role (Honea, Britnall, Given, Colao & Northouse, 2008; Pinquart & Sorenson 2002; Sales 2003). Sales (2003) contends that the term "burden" is not viewed positively and that the strain of making decisions is often viewed by the caregivers as part of an obligation. Researchers document that the standard practice used to measure objective caregiver burden is a caregiver's self-report of the extent of their caregiving and notes a difference of delineation of categories of caregiver burden (Sales, 2003). The sandwiched generation, middle-aged children, are challenged to meet the demands of caring for their own families and their parents. It is imperative to take into consideration the limitations and challenges they encounter (Pierret, 2006; Sorenson, Webster & Roggman, 2002).

Caregiver Characteristics

Caregiver characteristics specific to this study are reflective of caregiver characteristics discussed in caregiver studies (Pressler et al, 2009; Schulz & Beach, 1999; Schulz, Newsom, Mittlemark, Burton, Hirsch, & Jackson, 1997). Characteristics captured in the demographic data and include race, age and gender of the caregiver. Additional variables include, the relationship to the care recipient, and educational level of the caregiver. Other variables are the number of hours worked and the length of time the caregiver has worked with the care recipient. Also of interest for this study is the distance driven by the caregiver and caregiver reimbursement. The researcher has selected caregiver characteristics that may be reported with categorical or continuous variables (Pressler et al., 2009).

Race, age, and gender. In the majority of studies reviewed, the percentage of participants who documented their race as White was between 54% to 90%. In these studies the mean ages of caregivers ranged from 58 to 65 years. The literature indicates that women are more likely to be caregivers than men (Andrén, & Elmståhl, 2008; Bainbridge, Lohfeld & Brazil, 2009; Braithwaite, 1996; Lockenhoff et al., 2011; McConaghy& Caltabiano, 2005; NAC/AARP, 2004; LARC, n.d.; Papastavrou et al., 2007; Pinquart & Sorensen, 2006; Roth et al., 2009; Talley & Crews, 2007).

Relationship to the care recipient. Several studies indicate that family members constitute the majority of caregivers, with spouses, specifically women and children being the most significant group (Andrén, & Elmståhl, 2008; Bainbridge et al., 2009; Braithwaite, 1996; Lockenhoff et al., 2011; McConaghy& Caltabiano, 2005; Papastavrou et al, 2007; Pinquart & Sorenson, 2006; Talley & Crews, 2007).

Educational level. The review of literature indicates that not all studies evaluated the caregivers' educational levels. Where reported, caregiver educational levels ranged from 12 to 14 mean years (Andrén, & Elmståhl, 2008; Bainbridge et al., 2009; Braithwaite, 1996; Lockenhoff et al., 2011; McConaghy& Caltabiano, 2005; Papastavrou et al., 2007).

Number of hours worked and the length of time the caregiver has worked with the care recipient. A review of the studies found that the number of hours worked and the length of time the caregiver has worked with the care recipient were not discussed in every study. When reported, there was variation on how time was reported. The majority of studies reported the hours worked per week with ranges from 28 to 66 hours. In others, the length of time was reported in weeks (48 weeks) or years (9 years) (Andrén, & Elmståhl, 2008; Bainbridge et al., 2009; Braithwaite, 1996; Lockenhoff et al., 2011; McConaghy& Caltabiano, 2005; Papastavrou et al., 2007).

Distance driven by the caregiver. An extensive review of the literature did not find any studies that documented the distance driven by the caregiver. An array of terms were used to describe living with a care recipient which includes "lives with", "residence with" and "cohabitating". The literature shows 62% to 90% of caregivers live with the care recipient (Andrén, & Elmståhl, 2008; Bainbridge et al., 2009; Braithwaite, 1996; Lockenhoff et al., 2011; McConaghy& Caltabiano, 2005; Papastavrou et al., 2007).

Caregiver reimbursement. Studies varied on the format to address reimbursement. While some studies did not address reimbursement, in other studies caregivers were excluded from studies because they received reimbursement. In multiple studies caregivers employed outside of the home were addressed (Andrén, & Elmståhl, 2008; Bainbridge et al., 2009; Braithwaite, 1996; Lockenhoff et al., 2011; McConaghy& Caltabiano, 2005; Papastavrou et al., 2007).

Perceived Caregiver Strain

Family care literature uses the term strain to describe the experience of caring for an older adult (Hansen et al., 2005). Caregiver strain is the caregivers' perception of the level of difficulty in performing their role or the feeling of being overpowered with the responsibility or task of caregiving (Honea et al., 2008, Thornton & Travis, 2003). Therefore, caregiver strain is a perceived stressor in the caregiver population. Over the caregiving period there are complex family and financial issues which complicate the caregiving experience (Hansen et al., 2005).

Family relationships become more complex due to the continuous complicated process of providing assistance. The constant requirement for care therefore becomes the center of the relationship, which consequently produces a strain described as the stressfulness of caregiving (Pearlin et al., 1990). Pearlin et al. (1990) make reference to the use of both terms, strain and stress, in their work. Seltzer and Li (2000) reference two decades of research that document caregiving as a stressful role with harmful consequences to the caregiver. The literature purports that some caregivers find positive rewards, enrichment and satisfaction in caring for the care recipient and recent studies have begun to include these positive aspects (Hunt, 2003). However, this does not negate that over time the stress process can impact the relationship between the caregiver and care recipient (Pearlin et al., 1990). A study by Thornton and Travis (2003) further documents that it is "well researched" that caregiving can have negative and detrimental outcomes on the care-recipient's care and the caregiver.

Caregiver studies that address stress and strain include an evaluation of Activities of Daily Living (ADL), which is the standard in caregiver studies to evaluate the levels of caregiver strain (Pearlin et al., 1990). The evaluation of ADL's has been used in some studies to see the outcomes in physical and mental health. An assumption is made that when there is deterioration of the caregiver's health, there will be a decrease in caregiving activities. Pearlin et al. (1990) purports that concepts of stress and strain provide a basis for dialogue to incorporate the Dr. Tsai's Middle-Range Theory of Caregiver Stress. In a mixed-methods study, Huyck, Ayalon, and Yoder (2007) documented that strain increases over time using the Caregiver Risk Screen (CRS). Based on findings in the study, the CRS was re-named the Caregiver Strain. This study generates additional support for the modification of the Middle-Range Theory of Caregiver Stress to the Modified Middle-Range Theory of Caregiver Stress.

The current researcher views caregiver strain as the caregiver's perceived stressor of the caregiving role. The perceived stressor is compounded by the level of complexity involved in providing care for an older adult. Caregiving occurs over time and family and financial issues make caregiving responsibilities more complicated. Caregivers "overstretch" to meet the demands of caregiving in addition to their own personal, family and financial responsibilities. The perceived stressor of the caregiving role is caregiver strain (Hunt, 2003; Pearlin et al., 1990; Tsai, 2003). Therefore, this study used the lens of the Modified Middle- Range Theory of Caregiver Stress as a conceptual framework.

Perceived Caregiver Health

Schulz and Beach (1999) is a landmark study in caregiver's health which documented a four-year mortality rate for caregivers based on the level of strain that was report by the caregiver. In the study conducted by Schulz and Beach (1999), care recipients ADL levels were assessed while caregivers' health was measured as prevalent clinical disease. Research indicates that the diverse experience of caregivers have varying contributing factors which make it more challenging to identify an equal risk that impacts caregiver's health (Pinquart & Sorensen, 2007). Various studies document evaluations of caregiver health and include a range of subjective single items to objective physical assessments (Lockenhoff et al., 2011).

Bruce et al. (2005) present seminal work in a landmark study that includes the use of the SF-12v2 Health Survey. Prior to this work, there had been no established database for the use of SF-12v2 Health Survey in caregiver studies. This study targeted dementia caregivers, structured as a onetime phone interview. In this self-reported measure, 76.9% of caregivers identified stress associated with the caregiving role. In this population 72.4% reported physical health problems with 67% taking medications. This study also reported 4 caregivers with mental problems. Bruce et al. (2005) contends that his research continues to have implications for future research because the link between caregiving and physical health were weak (Schulz, Newsom et al., 1997; Schulz, O'Brien, Bookwala et al, 1995).

Pressler et al. (2009) is a subsequent study utilizing the Health Survey SF-12, including caregivers of heart failure patients. The study measured caregiving outcomes with the Bakas Caregiving Outcomes Scale. The results of this study are consistent with the poor physical health that was reported in the study by Schulz and Beach (1999). The findings of this study add to the body of scientific research which reinforce that poor caregivers health may influence their ability to provide care and may impact the safety of the care recipient (Pressler et al, 2009).

Caregiving is often a long-term commitment for family and friends. Over long periods of time caregivers find that they are too busy to take care of their own health issues (Matthews, Dunbar-Jacob, Sereika, Schulz, & McDowell, 2004). Researchers document that endurance and excellent physical health are vital for the role of a caregiver (King, 2009; Talley & Crews, 2007). The issue of caregiver health has been addressed by the U.S. Department of Health and Human Services and recognized in the nationwide health promotion and disease prevention agenda (Healthy People 2010). The caregiver is considered an important component of the health care system and it is essential to provide caregivers with time off from their responsibility and support from the public health system (Talley & Crews, 2007).

The focus of dealing with caregiving issues such as respite care is at the community level, while the funding is at the federal and state levels (Talley& Crews, 2007). Respite care can be provided as service in-home or out-of home; yet, many caregivers do not access respite care for various reasons; many waiting until their health becomes affected (Cangelosi, 2009). The daily challenge of caring for an older adult includes difficulties in finding replacement care for their loved ones (McMurray-Avila, 2009). Additionally, the cost for respite care is prohibitive to some families who are already paying for additional expenses, such a medications and special equipment. It is imperative to provide services that reduce caregiver strain by providing availability of support, and respite care while promoting quality of life for the caregiver and the care recipient (Lockenhoff et al., 2011; Talley & Crews, 2007).

Caregivers struggle to meet their caregiving responsibilities when they are not feeling well, consequently impacting the quality, safety, and practical provision of care they are providing to care recipients. The caregivers overall health and well-being can negatively impact the care recipients' health and well-being (Huynh-Hohnbaum et al., 2008; McCann, Hebert, Bienias, Morris, & Evans, 2004; Navaie-Walieser, Feldman, Gould, Levin, Kuerbis, & Donelan, 2002; Talley & Crews, 2007; Yaffe, Fox & Newcomer, 2002). Various research studies document that caregivers who report caregiver stress have an increased likelihood of dying within four years of providing care (Grasel, 2002; Rawlins & Spencer, 2002; Schulz & Beach, 1999). Additionally, research by Coe and Van Houtven (2009) suggests that while initially caregiver's negative health may not be apparent, symptoms or diseases may emerge after two years of providing care.

Traditionally, researchers have viewed stress and strain through different lenses, thus contributing to the interchangeable use of the terms stress, strain and burden and making it is difficult to have a clear differentiation (Bainbridge et al., 2009; Hunt, 2003; Pearlin et al., 1990; Thornton & Travis, 2003). Regardless of the term used by the researcher, caregiving can be a stress or strain which puts caregivers at risk for physical and health issues. For the purposes of this study, caregiver strain is a perceived stressor in the caregiving population. An abundant number of studies associate caring for older family members with negative mental and health outcomes (Knight & Sayegh, 2009; Vitaliano, Zhang, & Scanlan, 2003). Pinquart and Sorensen (2006) identify caregiving as both a chronic stress and strain, which puts caregivers at risk for physical and health issues.

Studies that include both objective and subjective aspects of caregiving as indicators of health outcomes are less common (Beach et al., 2000). A study conducted by Lockenhoff et al. (2011) supports the need for future studies that include both objective and subjective health and comprehensive measures of care recipient's characteristics and required hours of care. This study can potentially provide data to support the varying levels of objective caregiving demands and caregivers perceived health.

Bell (2009) compares and contrasts the similarities in the efforts required to raise a child and caring for an older adult at home; both require a village to accomplish the task. In an aging population, more Americans will assume the role of the caregiver. Currently 25% of American families are providing care to an older adult while balancing their own family needs and work responsibilities (Talley & Crews, 2007; Huyck et al., 2007). Former First Lady, Rosalyn Carter provides a practical, yet real-world view of the progression of caregiving.

> "There are only four kinds of people in the world-those who have been caregivers, those who are currently caregivers, those who will be caregivers and those who will need caregivers" (Rosalyn Carter, n.d.)

Conceptual Model

The structure of the Middle-Range Theory of Caregiver Stress, developed by Pao-Feng Tsai, R.N., PhD, has been adopted as a sensitizing framework for this research study. The intermediary control process of "stress" has been replaced with a more specific stressor, perceived caregiver strain. Tsai's (2003) theory is based on the 1984 version of The Roy Adaptation Model (RAM) which has three process elements which include input, control process and the output process. As such, the author contends that the design of the Middle-Range Theory of Caregiver Stress has a framework of the three process elements to facilitate the organization the concepts for this study. A review of literature and email communication with Dr. Tsai confirms that this theory has not been used as a conceptual framework since her original work (Dr. Tsai, personal communication, April 17, 2010, 2:01PM).

Researchers Laschinger & Leiter (2006) use a similar model to address the topic of nursing environments (stimuli), burnout (control) and patient safety outcomes (output). Research by Blevins & Troutman (2011) addresses the topic of successful aging with an emphasis on input in the form of stimuli which is followed by an output response which is brought about by adaptation. Similar to Tsai (2003), researchers Blevins & Troutman (2011) state that concepts in their models have been expressed by Roy.

Based on the aforementioned theory, Tsai's (2003) Middle-Range Theory of Caregiver Stress was modified to reflect the exact stressor of interest and examine more deeply the role of strain as a perceived stressor. The Modified Middle-Range Theory of Stress includes the input, control process, and the output. In this study the input is the objective caregiver burden and demographic characteristics, and the control process is perceived caregiver strain (stressor); the output is perceived caregiver health. The overall study framework adapted from Tsai's Middle- Range Theory is presented in Figure 3.

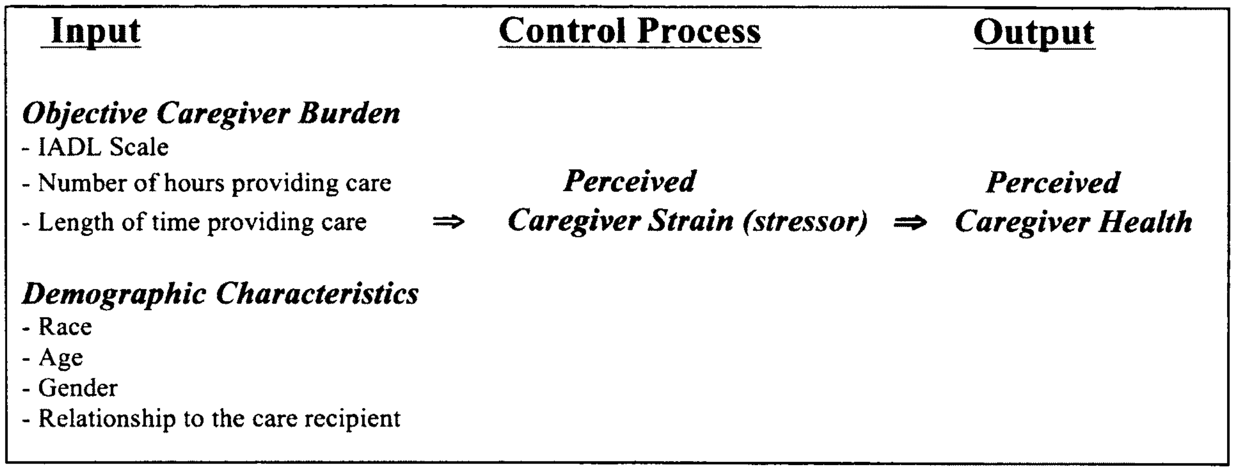

Figure 3. Modified Middle-Range Theory of Caregiver Stress

The terms used in the framework for this study, The Modified Middle-Range Theory of Caregiver Stress prompts further discussion and clarification.

Input. According to Blevins & Troutman (2011) and Tsai (2003) input is a stimuli in an open adaptive system. For the purposes of this study, input is defined as contributing factors (stimuli) such as objective caregiver burden and demographic characteristics which may activate the caregiver's coping mechanism. Measurable factors such as objective caregiver burden and demographic characteristics often play a role in influencing the perceived strain experienced by caregivers. Burden measures are used in caregiving literature to measure the stress involved in providing care to care recipients. Objective burden is typically included in caregiving research which measures the challenges that the caregiver encounters (Chronister & Chan, 2006).

Input consists of objective caregiver burden and demographic characteristics. Demographic characteristics include race, age, gender and the relationship to the care recipient. The caregiver assists the care recipient to complete tasks or duties categorized as objective burden (Tsai, 2003). Objective burden in this study was be measured by the IADL Scale, the number of hours the caregiver provides care to the care recipient and the length of time the caregiver has provided care to the care recipient. Pearlin et al. (1990) refers to the duration of caregiving as indicators of the chronic stress that the caregiver experiences. The objective burden is a caregiving demand that is an indicator of the caregiver's perceived strain (Beach et al., 2000).

Control process. According to Tsai (2003), control process is the caregiver's cognitive appraisal of stress in relation to caregiving for a chronically ill relative or friend. For the purposes of this study, control process is defined as the caregiver's ability to balance the tasks of caregiving and their perspective of the challenges they encounter while caring for the care recipient. Perceived caregiver strain is the stressor of interest for this particular research effort.

The caregiver's perception of strain was be measured by using the Modified Caregiver Strain Index. Caregiver strain is conceived as an indicator of perceived stress while providing care to the care recipient (Beach et al., 2000).

Output. According to Tsai, 2003 and Blevins & Troutman, 2011, the output process is the outcome response of the input and control process which brings about adaptation. For the purposes of this study output, is defined as the outcome which is reflective of the caregiver's perception of their physical and mental health. For this study the outcome was measured by the Health Survey 12 v2 instrument.

Summary of Literature Review

This review of literature has presented a summary of current published research in caregiver strain in relation to caregiver health. This study was undertaken to address the inconsistency of instrumentation as evidenced by the lack of published reports on this topic in the diverse population of Southern California. Prior studies did not address caregivers without an emphasis on the type of care recipients. In addition, no published studies were identified which used this conceptual framework, specifically in diverse populations examining the relationships with the major study concepts of caregiver burden, characteristics, strain, and health. Currently, this study area remains understudied and requires further elucidation. There are few studies that document the health of caregivers and fewer studies that correlate caregiver strain with objective measures of health such as the SF-12v2 Health Survey. In addition, documentation confirms that caregiving is an important public health concern and needs to be addressed. In particular, the relationships between objective caregiver burden, caregiver characteristics, perceived caregiver strain and health remain largely uninvestigated. Thus, this study was undertaken as an initial attempt to capture a broad overview of these phenomena in a diverse population. While this approach has limitations that are addressed in Chapter Five, it represents an initial attempt to identify patterns within a wide caregiving population. Therefore, this study was designed as a beginning step in filling an identified gap in the literature regarding caregiver burden, characteristics, strain, and health.

CHAPTER 3

Methods

The overall purpose of this descriptive study was to describe the relationships between objective caregiver burden, relevant caregiver characteristics, perceived caregiver strain, and perceived caregiver health in a diverse group of adult caregivers providing assistance with instrumental activities of daily living (IADL) to care recipients in Southern California. This chapter presents the research design and methodology of the study. The protection of human subjects is also described.

Specific Aims

The specific aims of this study are to:

1. Describe levels of objective caregiver burden, select caregiver characteristics (race/ethnicity, age, relationship to care recipient, and diagnosis of care recipient), perceived caregiver strain, and perceived caregiver health.
2. Describe the relationships between and among objective caregiver burden, select caregiver characteristics, perceived caregiver strain, and perceived caregiver health.

Research Questions

The research questions for this study are:

1. What are levels of objective caregiver burden, select caregiver characteristics (race/ethnicity, age, relationship to care recipient, and diagnosis of care recipient,) perceived caregiver strain (stressor), and perceived caregiver health in this group?
2. What are the strengths of the relationships between and among objective caregiver burden, select caregiver characteristics, perceived caregiver strain, and perceived caregiver health?

Research Design

A descriptive, cross sectional, correlational and multivariate design was used to study a convenience sample of 81 caregivers. The Modified Middle-Range Theory of Caregiver Stress and the research questions are consistent with the study design.

Data were analyzed using SPSS version 19. Descriptive statistics were used to describe central tendency and variability. Bivariate analysis explored the association between variables and the effect between variables. The independent t-test was used to examine differences between the means of groups that were significantly associated with the dependent variable. The one-way ANOVA examined the differences between the means of three or more independent groups. Statistical significance was set at $p \leq 0.05$. (Huck, 2008; Munro, 2005).

Self-reported surveys were used to document the caregiving experience with older adults. Demographic information was collected, along with self-reported measures of caregiver strain and caregiver health as related to the caregiving experience. A research proposal for the pilot study was submitted and approved prior to the initiation of the study by the University of San Diego's Investigational Review Board. Participants provided informed consent.

Sample

The sample for this study was a convenience sample of caregivers, who provide care for an older adult in the community areas of the Southern California region. The sample size was determined by using the power analysis criteria. The Significance level was 0.05, the number of predictor variables are 3 which include the (IADL, CSI & Health Survey v 2), the anticipated effect size 0.15 (medium), and the desired statistical power 0.8. (Hopkins, 2008; Soper, 2010). Using the aforementioned method, the minimum calculated sample size for this study was 76 participants.

Upon discussion and review of the standard effect size with the statistician, the recommendation was to leave the standard effect size at 0.15 (medium). The collection of data was completed at this point and the implication of changing the effect size would therefore require a change in the sample size.

The inclusion criteria for this study were: (a) The caregiver must be 18 years or older; (b) the caregiver must provide assistance with IADLs; and (c) the caregiver must be willing to participate in the study, provide written or verbal consent, and be able to read and write in English. Additionally, the caregiver must provide care in the Southern California region.

The researcher excluded participants if the care recipient was admitted to the hospital. The process of hospitalization of a care recipient changes the focus of the caregiver. The care recipient requiring hospitalization has a higher acuity and at times the caregiver may be concerned about the survival of the care recipient. As such, the role of the caregiver becomes that of a silent care coordinator, facilitator and advocate (Gibson, Kelly & Kaplan , 2012). Schulz & Sherwood (2008) explicate the transition out of the caregiving role when the care recipient improves, dies or is institutionalized. Therefore, it was not appropriate to include caregivers of hospitalized care recipients.

Setting

The date, time and location of the data collection was established at the convenience of the caregiver. The actual setting for the data collection occurred in the caregiver's home, or a public location in which confidentiality was maintained, such as a restaurant or coffee shop.

Operational Definitions

For the purposes of this study the following operational definitions have been ascertained.

Objective caregiver burden is defined as the degree of care that the caregiver is required to administer. Thus, it includes how many instrumental activities the caregiver must perform, how many hours a day care is given, and how long the caretaking has been performed. It was measured by the degree to which the person being cared for requires instrumental care with ADLs, as indicated on the Instrumental Activities of Daily Living Scale (IADL), the number of hours providing care, and the length of time providing care (Beach et al., 2000; Tsai, 2003).

Caregiver characteristics include demographic characteristics of race, age, gender and relationship to the care recipient. This information was collected in the Demographic Characteristic Questionnaire (Pressler, Gradus-Pizlo, Chubiniski, Smith, Wheeler, Wu & Soloan, 2009).

Perceived caregiver strain is defined as the caregiver's subjective impression of being strained by excessive physical or mental tension (Beach; Hansen, Archbold, Stewart, Westfall & Ganzini, 2005; Hunt, 2003, Lockenhoff, Duberstein, & Friedman, 2011). It was measured using the Modified Caregiver Strain Index (CSI).

Perceived caregiver health is defined as the caregiver's view of their health status and is self-reported by the caregiver using the Short-Form-12 Health v2 Survey. The structure of the instrument includes the following factors: Physical Function, Role Physical, Bodily Pain, General Health, Vitality, Social Functioning, Role Functional, and Mental Health (Lockenhoff et al., 2011; McConaghy& Caltabiano, 2005).

Caregivers are defined as " anyone" who provides unpaid help or arranges for help, to a relative or friend because they have an illness or disability that leaves them unable to do some things for themselves, or because they are simply getting older (Bell, 2009; Roth, Perkins, Wadle, Temple & Haley, 2009). The person is responsible for providing care to an older adult, including the performance of activities of daily living. The caregiver may be a spouse, adult child, sibling or unpaid caregiver

A care recipient is someone who may be disabled, chronically ill, frail, or an older adult; who receives care and support from a caregiver to perform ADL's. Care recipients are addressed in the literature as both care recipients and care receivers (Pearlin et al., 1990; Pembroke, 2007).

An older adult is defined as a person who has reached the chronological age of 65 years, which is consistent with most developed world countries (WHO, 2010).

Instrumental Activities of Daily Living (IADL). Activities of Daily Living are tasks that the care recipient requires help to complete. The Lawton Instrumental Activities of Daily Living Scale (IADL) (Lawton & Brody, 1969) is self -reported, providing objective data and measures cognitive or physical function in older adults. For the purpose of this study, these are the tasks that the caregiver provides assistance to the care recipient in order for the care recipient to complete the ADL.

The Southern California region for the purposes of this study includes the following counties; Los Angeles, Orange, San Bernardino and Ventura (2010 Census Data). These counties have a population of 17, 877,006. The counties include approximately 183 incorporated and unincorporated cities, along with major businesses, telecommunications, utilities and chambers of commerce (2010 Census Data).

Variables

The dependent variable of interest for this study was perceived caregiver health (i.e., the perceived health status of the caregiver). The independent variables includes objective caregiver burden (e.g., IADL domains, number of hours providing care, and length of time providing care) and perceived caregiver strain (e.g., domains related to employment and time). Selective demographic variables for the study include race, age, gender and relationship to the care recipient.

Data Collection Instruments/Measures

The Demographic Characteristic Questionnaire (Appendix A), developed by the investigator was designed to capture sociodemographic data related to race, age and gender. The format for the collection of sociodemographic data included seven items which required circling the correct answer and writing in the age. Additionally, the caregiver was asked to provide data relative to the relationship with the care recipient, length of time providing care for the care recipient, number of hours providing care for a care recipient in a 24 hour period, and the caregiver's relation to the care recipient.

The additional survey instruments for this study were The Lawton Instrumental Activities of Daily Living Scale (IADL Scale) (Appendix B), The Modified Caregiver Strain Index (CSI) (Appendix C) and the Short-Form-12 v2 Health Survey (Appendix D). Permission was obtained on November 30, 2011 from Oxford University Press for the use of the (IADL Scale) (Appendix B) and CSI (Appendix C). Permission for the use of the Short-Form-12 v2 Health Survey (Appendix D) was granted by Quality Metric Inc.

The Lawton Instrumental Activities of Daily Living Scale (IADL) (Lawton & Brody, 1969) was used to measure cognitive or physical function in older adults (Appendix B). The scale is appropriate for baseline and periodic assessments. It provides objective data, can be administered in community or hospital settings, and is widely used in research and clinical practice. The Lawton IADL Scale was originally tested concurrently with The Physical Self-Maintenance Scale (Graf, 2008). Inter-rater reliability was established at .85. The validity was tested by determining the correlation of the Lawton IADL with four scales that measured domains of functional status and all correlations were significant at 0.1 or the 0.5 levels (Graf, 2008).

The Lawton IADL scale is self-reported and can be administered in 10-15 minutes. The scale has eight items: ability to use telephone, shopping, food preparation, housekeeping, laundry, mode of transportation, responsibility for own medications and ability to handle finances. The domains of the Lawton IADL are reported as a total score. Previous research has demonstrated the higher the score, the greater the person's ability to perform their own ADL (Graf, 2008). A woman's score can range from 0-8, (0=low function, 8=high function) and for men the range can be from 0-5, (0=low function, 5=high function). For men the food preparation, housekeeping and laundry domains are not scored. A limitation of this self-reported scale is that it can lead to an under or over estimation of the recipient's ability to perform their own IADL's.

The Modified Caregiver Strain Index (CSI) (Appendix C) was developed by Thornton, & Travis, et al, 2003. This instrument can be used to screen for caregiver strain in families who provide long term care. The modified CSI response scale is nominal. For data entry, the descriptors are coded as follows: 2 for Yes, on a regular basis; 1 for Yes, sometimes; and 0 (zero) for No. The modified version of this instrument has 13 items and a positive screen is a score of 7 or more items, which indicates a need further assessment. The modified instrument has an internal reliability coefficient of (α=0.90), and the retest data resulted in a test-retest reliability coefficient of 0.88 (Sullivan, 2003;Thornton & Travis; 2003). In the 1983 version of the modified CSI, the sample consisted of 158 family caregivers who provided assistance to adults aged 53 years and older. The internal reliability coefficient was reported as 0.86. In the modified CSI instrument the internal reliability coefficient was 0.90 (Sullivan, 2003). The modified CSI has 13 items, measuring strain related to the major domains of employment, financial, physical, social and time.

The Short-Form-12 Health Survey was developed in 1994, and a second version was revised in 1998 (Appendix D). The Short-Form-12 v2 Health Survey is a seven-domain profile which is self-reported by the caregiver, which scores areas for Physical Function, Role Physical, Bodily Pain, General Health, Vitality, Social Functioning, Role Functional, and Mental Health. The Short-Form 12 v 2 Health Survey was derived from the SF-36, SF-20 and the Short-Form-12 Health Survey version one. The Short-Form-12 v2 Health Survey was created to address the burden for the respondent and the investigator to complete a 36-item questionnaire. It is estimated to take one third less time to complete The Short-Form-12 v2 Health Survey than the 36-item questionnaire (Wee, Davis & Hamel, 2008).

The original description by Ware noted the test-retest reliability for the PCS-12 to be 0.89 in the United States. The manual describes the SF-12v2 Health Survey, with the reliability estimates range from 0.73 to 0.87 across the eight scales; with the value for Physical Health Component Scale (PCS-12) was 0.89 and Mental Health Component Scale (MCS-12), 0.86. The plan for scoring this instrument was based on the literature, which refers to the online scoring system for simplification of the process. The on line scoring system is able to handle incomplete data and provide calculations of PCS and MCS scores (McDowell, 2006; p. 666). Table 2 summarizes the variables, instruments, and Cronbach's alpha.

Table 2.

Instrument reliability

Variable	Instrument	Cronbach's alpha
IADL Scale	The Lawton Instrumental Activities of Daily Living (IADL) Scale	0.85
Caregiver Strain	The Modified Caregiver Strain Index (CSI)	0.90
Health Survey 12v2	The Short-Form-12 Health Survey v2	
PCS-12		0.89
MCS-12		0.86

Human Subjects

At all times during the study human subjects were protected under the guidelines of the Investigational Review Board (IRB) as set forth by the University of San Diego (Appendix E). The potential risk and benefits of the study were discussed with the caregiver who was the participant in the study and informed consent was obtained. The risks to the participant were minimal; if a participant desired to speak to someone about their feelings they were provided the contact information for the Los Angeles County Mental Health referral number. The Los Angeles County Mental Health referral number was made available to each participant at the time of obtaining consent. The benefit of the participant was to participate in the data collection and to contribute to the body of knowledge on caregiver strain and the impact it has on caregiver health.

All information obtained about the participants are kept private and confidential and reported in the aggregate. Participation in the study was voluntary and all participants were made aware that they could withdraw from the study at any time. A research proposal for the pilot study was submitted and approved prior to the initiation of the study by the University of San Diego's Investigational Review Board (USD IRB). Appropriate continuation requests were submitted and granted by the USD IRB.

Recruitment, Data Collection Procedure/Plan

Recruitment. The sample population for this study was recruited from the communities in the Southern California region. Churches, adult day care centers and caregiver organizations were contacted for permission to post flyers and distribute them to caregivers and older adults. The potential study participants were recruited from the caregiver organizations, adult day care centers and the community churches. It was anticipated that information regarding recruitment for the study would occur via word of mouth. Caregivers and care recipients shared the contact information about the research study with others in their network of friends and relatives.

Procedures. Permission to use the Lawton Instrument Activities of Daily Living Scale (IADL) and the Modified Care Strain Index (CSI) and was granted from Wolters Kluwer Health in November 2010 and was continuous throughout the data collection period. Additionally, permission to use the Short-Form-12 Health Survey version two was granted from Quality Metric Incorporated in November 2010 and was continuous throughout the data collection period.

A research proposal for the pilot study was submitted and approved by the Institutional Review Board at the University of San Diego. It was noted that due to the data collection occurring at churches and adult day care centers, there is no IRB for these locations. The researcher contacted the churches and adult day care centers to provide them with information regarding the study. Contact information was made available to the staff and posted on bulletin boards.

Once the researcher received a telephone call or was contacted in person by a potential participant, a brief description of the study and inclusion criteria was provided to each potential participant to secure commitment to participate in this study. Once a commitment to participate had been established the researcher arranged a mutually convenient time and location for obtaining an informed consent and confidential data collection. Participants were informed of their rights according to the Institutional Review Board (IRB) guidelines and were provided an opportunity to ask questions. Informed consent was obtained prior to data collection.

Initially, data collection occurred in the participant's home, or at a public location in which confidentiality was maintained, such as a restaurant, or coffee the data collection process took between 10-60 minutes. The researcher read out all the questions to the participant to standardize the data collection process (Pressler et al., 2009). All questionnaires, tools, or surveys were completed by the researcher as the participants responded to each question on the following documents: (a) the Demographic Characteristic Questionnaire (Appendix A); (b) the Lawton Instrumental Activities of Daily Living Scale (IADL) (Appendix B); (c) the Modified Care Strain Index (CSI) (Appendix C); and (d) the Short-Form-12 v2 Health Survey (Appendix D).

Following a pilot administration of the study instruments in person, the researcher was asked by potential participants if telephone participation might be an option, given the busy schedules of many of the caregivers. After consultation with the Dissertation Chairperson, the researcher received USD IRB approval to administer the protocol over the telephone when preferred by the participant. Verbal informed consent was obtained prior to beginning the survey over the telephone. No other part of the study protocol was changed.

When the interview occurred over the telephone, the researcher followed the same protocol as during an in person interview. The researcher maintained confidentiality and obtained verbal consent, a copy of the consent was mailed to the participant. The researcher read all the questions to the participant. All questionnaires, tools, or surveys were completed by the researcher as the participant responded to each question on the following documents: (a) the Demographic Characteristic Questionnaire (Appendix A); (b) the Lawton Instrumental Activities of Daily Living Scale (IADL) (Appendix B); (c) the Modified Care Strain Index (CSI) (Appendix C); and (d) the Short-Form-12 v2 Health Survey (Appendix D).

Upon completion of the interview, the researcher thanked the participant for his/her participation and personally gave a $5 gift certificate to the in-person participants or mailed the gift certificate to the telephone participants. Participants were notified should they wish to withdraw from the study for any reason, the $5 gift certificate would still be given to them.

Data Collection Plan. The data was collected from February 2012 to July 2012. Recruitment occurred on an on-going basis until the minimum number of caregivers were recruited. As detailed above, the researcher completed the forms as participants provided answers to each question on the various data collection instruments.

Data Management. The researcher established an Excel sheet with participant information, coded numerically. A data dictionary was developed to establish numeric codes and fields to organize data as it was collected. The researcher collected the study data as well as oversaw the logistics and data collection associated with this study. All study data are kept in a locked file cabinet in the researchers home. All results are reported in the aggregate.

Data Analysis

Data analysis was accomplished using the Statistical Package for the Social Sciences (SPSS/19.0). Descriptive statistics, including measures of central tendency and dispersion include, frequencies (percentages), means, medians, standard deviations and range for all variables. Inferential statistical analysis, including t-tests and a one-way ANOVA were performed to examine significant relationships among variables. The Chi-square/Fisher's Exact Test was used to determine significant associations between the dependent and independent variables. The Fisher's Exact Test was used for cells with expected counts of five or fewer observations. The data was analyzed and a p-value obtained for each inferential test. The Statistical significance was set at $p \leq 0.05$, which is indicative of a significant correlation.

During the data analysis process the following was taken into consideration (a) the domains of the Lawton IADL scale were reported as a total score; a woman's score ranging from 0-8 and a man's score ranging from 0-5 (b) the CSI response scale is nominal; 2 for Yes, on a regular basis; 1 for Yes, sometimes; and 0 (zero) for No (c) the Short-Form-12 v2 Health Survey was scored by QualityMetric Inc.

The specific aims of this study were to:

Aim (1): Describe levels of objective caregiver burden, select caregiver characteristics (race/ethnicity, age, relationship to care recipient, and diagnosis of care recipient), perceived caregiver strain, and perceived caregiver health. Aim #1 was achieved by using descriptive statistics such as mean scores and percentages to summarize demographic variables of the sample and to determine the frequency of distribution (Huck, 2008).

Aim (2): Describe the relationships between and among objective caregiver burden, select caregiver characteristics, perceived caregiver strain (stressor), and perceived caregiver health. Aim #2 was achieved using inferential statistical tests, including one-way ANOVA, independent t-test and the Chi-square test.

The Chi-square test was calculated to determine if there was a statistically significant association between: (a) the perceived objective burden variables, the Lawton

IADL scores, and the level of perceived caregiver strain; and (b) the perceived caregiver's level of strain and perceived caregiver's level of health.

An independent t-test analysis and the one- way ANOVA were performed to examine if there was a statistically significant difference between (a) the perceived objective burden variables and the Lawton IADL scores and the level of perceived caregiver strain; and if (b) the perceived caregiver's strain was significantly related to the perceived caregiver's health.

Strengths and Limitations of Methods

A limitation of the study can be that self-health is measured using self-reports and perceived caregiver strain. In future studies an additional area for assessment may include a physical assessment to evaluate the caregiver's health status. Furthermore, this study provided an analysis of data acquired during one interview and did not include collection of data over a time period. Finally, it will be essential in future studies to collect more precise data concerning the care recipient, particularly the age and co-morbidities in the care recipient group.

Areas of future research may include the examination of the caregiving phenomena to encompass a study overtime and to collect comparative data of changes in the level of caregiver strain and caregiver health. Future research may also address the phenomena in multiple caregivers per care recipient and the complex relationships present in such populations.

Summary

This descriptive correlational study was performed to address an identified gap in the literature, as there are few studies that document the health of caregivers of caregivers without an emphasis on the type a of care recipients. Thus far even fewer studies were found that incorporate caregiver strain with the SF-12v2 Health Survey. While adopting a broad spectrum approach, data from this study provide a basis for future research into more focused investigations of the care giving population.

CHAPTER 4

Results

The overall purpose of this descriptive study was to describe the relationships between objective caregiver burden, relevant caregiver characteristics, perceived caregiver strain, and perceived caregiver health in a diverse group of adult caregivers providing assistance with instrumental activities of daily living (IADL) to care recipients in Southern California.

In this chapter the results of the study are presented including the data analysis and sample characteristics are presented followed by the results of the analysis which address the specific aims of this study.

The specific aims of this study were to:

Aim (1): Describe levels of objective caregiver burden, select caregiver characteristics (race/ethnicity, age, relationship to care recipient, and diagnosis of care recipient), perceived caregiver strain, and perceived caregiver health.

Aim (2): Describe the relationships between and among objective caregiver burden, select caregiver characteristics, perceived caregiver strain (stressor), and perceived caregiver health. Aim #2 was achieved using inferential statistical tests, including one-way ANOVA, independent t-test and the Chi-square test.

Instrument Reliability for this Study

As mentioned in Chapter 3 and in the literature review, The Lawton IADL has a documented Cronbach's coefficient of 0.853. The Modified Caregiver Strain instrument had an internal reliability coefficient of 0.813. The SF-12v2 Health Survey had a Cronbach's coefficient of 0.409.

The findings in this study for the Lawton IADL were that the standardized Cronbach's alpha was 0.862. The mean of responses of all 8 items was 3.307 (SD = 0.739) indicating that on average more care recipients had higher functional levels.

In this study the findings for the Modified Care Giver Strain were that the standardized Cronbach's alpha was 0.814. This is the value achieved if additional items were to be added for analysis. The mean of responses of all 13 items was 1.113 (SD = 0.205) indicating that on average a little over half of caregivers responded "yes" to most of the items.

The SF-12v2 Health Survey findings indicated that the standardized Cronbach's alpha was 0.397. The mean of responses of all 12 items was 3.169 (SD = 0.542) specifying that most caregivers reported that their health status was good based on the domains of health and well-being.

Data Analysis

Data were analyzed using SPSS version 19. Descriptive statistics was used to summarize variables. Bivariate analysis explored the strength and shape of association between variables. The Chi-square/Fisher's Exact Test was used to determine significant associations between the dependent and independent variables. The Fisher's Exact Test was used for cells with expected counts of five or fewer observations. The independent t-test was used to examine differences between the means of groups that were significantly associated with the dependent variable. The one-way ANOVA examined the differences between the means of three or more independent groups. Statistical significance was set at $p \leq 0.05$.

During the data analysis process the following was taken into consideration (a) the domains of the Lawton IADL scale were reported as a total score; a woman's score ranging from 0-8 and a man's score ranging from 0-5 (b) the CSI response scale is nominal; 2 for Yes, on a regular basis; 1 for Yes, sometimes; and 0 (zero) for No (c) the Short-Form-12 v2 Health Survey was scored by Quality Metric Inc.

Sample Characteristics

The data consisted of a convenience sample of 81 caregivers. Data was also collected from care recipients with the use of the Demographic Characteristic Questionnaire (Appendix A). The caregiver provided the data about themselves and the caregiver recipient for which they provided care. Sociodemographic data captured included race, age, and gender. Data was also captured relative to the relationship with the care recipient, length of time providing care for the care recipient, number of hours providing care for a care recipient in a 24 hour period, and the caregiver's relation to the care recipient. A few caregivers provided care for more than one recipient and therefore provided information of the recipient that needed the most help. The data was collected from February 2012 to July 2012.

Caregivers

The sample was composed of 71 women (87.7%). The mean age of caregivers was 55.07 years (*SD* = 12.94 years, range = 21 – 84 years). Most of the caregivers were daughters of the care recipients (48.1%). Approximately 11% of caregivers were spouses to the care recipient. The majority of caregivers were Hispanics (61.7%). Most of the caregivers had some education but a majority of them (44.4%) had high school education or had completed the GED. The majority of the caregivers (64.2%) lived with the care recipient. Caregivers who commuted to provide care for the recipient, on average traveled 16.72 miles (*SD* = 18.02 miles, range = 3 – 90 miles). Most of the caregivers were unpaid (71.6%). Among daughters, the most caregivers, 25.6% of them received compensation. About 47% of caregivers provided care to persons suffering from Dementia. Overall most of the caregivers reported a good health status (45.7%). Among those caregivers who reported good health status, most of them where within the ages of 45 and 64 years (56.8%). A little over half of the caregivers had provided care to care recipients for an amount of one to five years. About 32% of caregivers provided, on average, 19 to 24 hours of care daily. Among those caregivers who reported good health status, most of them where within the ages of 45 and 64 years (56.8%). A little over half of the caregivers had provided care to care recipients for an amount of one to five years.

Care Recipients

The sample composed of 81 care recipients and was made up mostly of women (76.5%). Caregivers self-reported that a total of 46.9% of care recipients suffer from dementia.

Bivariate Analysis for Caregivers

Bivariate associations were examined between demographic variables and the health status of the caregiver. Health status was categorized into two groups; excellent/very good/good and fair/poor. There was a statistical association between health status and education status, χ^2 (1, N = 81) = 1.90, p = 0.002. There was a statistical association between health status and number of hours of care provided per day, χ^2 (3, N

$= 81) = 3.60, p = 0.035$. There was no statistical association between health status and the variables gender, age, relationship of caregiver to recipient, race/ethnicity, amount of time providing care, and whether the caregiver received pay.

A test of independence examined the associativity of the dimensions of the SF-12v2 Health Survey with health status. The SF-12v2 Health Survey focuses on the physical and mental components of health. There was a statistical association between health status and the dimensions of Role Physical ("Accomplished less than you would like as a result of your physical health.") of caregivers, χ^2 $(4, N = 81) = 11.43, p = 0.001$; Role Physical ("Were limited in the kind of work or other activities as a result of your physical health.") of caregivers, χ^2 $(4, N = 81) = 7.32, p = 0.009$; Role Emotion ("Accomplish less than you would like as a result of any emotional problems.") of caregivers, χ^2 $(4, N = 81) = 13.04, p = 0.001$; Role Emotion ("Did work or other activities less carefully than usual as a result of any emotional problems?") of caregivers, χ^2 $(3, N = 81) = 9.20, p = 0.005$; Bodily Pain ("Did pain interfere with your normal work?") of caregivers, χ^2 $(4, N = 81) = 18.04, p < 0.001$; Mental Health ("Have you felt calm and peaceful?") of caregivers, χ^2 $(4, N = 81) = 3.59, p = 0.023$; Vitality ("Did you have a lot of energy?") of caregivers, χ^2 $(4, N = 81) = 5.36, p = 0.046$; Mental Health ("Have you felt downhearted and depressed?") of caregivers, χ^2 $(4, N = 81) = 7.61, p = 0.015$; and Social Functioning ("How much of your time has your physical health or emotional problems interfered with your social activities?") of caregivers, χ^2 $(4, N = 81) = 11.52, p < 0.001$. There was no statistical association between health status and the dimensions of physical functioning of caregivers when performing moderate activities, such as moving a table, χ^2 $(2, N = 81) = 2.88, p = 0.237$, and when climbing several flights of stairs, χ^2 (2,

$N = 81) = 3.74, p = 0.066$. Table 1 contains a summary of the findings for the Chi-square test for independence for health status of the caregiver across selected sociodemographic statistics. Tables 4A and 4B present results for the Chi-square test for independence for health state of the caregiver across mental and physical components. Table 5 summarizes the group statistics for domains by health status.

An independent t-test analysis was performed to examine the relationship between the domain scores on health status and to compare the means between the health status of caregivers. There was a significant difference in the mean score between caregivers who reported excellent/very good/good health status and those who reported fair/poor health status for the domains of physical role, bodily pain, vitality, social functioning, and emotional role.

Levene's test for equality of variance was used to determine if the variances were equal or unequal within each of the domains, and results are summarized in Table 6. The mean score of physical role for caregivers who reported good to excellent health ($M = 69.40$, $SD = 26.09$) was significantly higher in comparison to those who reported fair or poor health ($M = 55.98$, $SD = 18.02$), $t(58) = 2.64, p = 0.011$. This meant caregivers who had good to excellent health had little or no limitations in performing moderate activities or climbing several flights of stairs. Similarly, the mean score of bodily pain for caregivers who reported good to excellent health ($M = 69.40$, $SD = 24.35$) was significantly different from those who reported fair or poor health ($M = 44.57$, $SD = 21.26$), $t(79) = 4.28, p < 0.001$.

Table 3.

Chi-square test for independence for health status of caregiver, by selected sociodemographic characteristics.

	Excellent/ Very Good/Good N (%)	Fair/Poor N (%)	*p*-value
Gender [b]			0.268
Male	9 (90.0)	1 (10.0)	
Female	49 (69.0)	22 (31.0)	
Age [b]			
18-24 years	1 (50.0)	1 (50.0)	0.095
25 - 44 years	10 (71.4)	4 (28.6)	
45 - 64 years	31 (68.9)	14 (31.1)	
65 years and older	16 (80.0)	4 (20.0)	
Relationship of caregiver to recipient [b]			0.081
Mother	2 (100.0)	0 (0.0)	
Wife	4 (50.0)	4 (50.0)	
Husband	1 (100.0)	0 (0.0)	
Daughter	28 (71.8)	11 (28.2)	
Son	3 (100.0)	0 (0.0)	
Partner/Significant Other	1 (100.0)	0 (0.0)	
Other	19 (70.4)	8 (29.6)	
Race/Ethnicity [a]			0.920
Hispanic	36 (72.0)	14 (28.0)	
Non-Hispanic	22 (71.0)	9 (29.0)	
Educational status [b]			0.002
Less than High School	3 (33.3)	6 (66.7)	
High School/ GED	28 (77.8)	8 (22.2)	
Some college/undergraduate	17 (70.8)	7 (29.2)	
Graduate	10 (83.3)	2 (16.7)	
Hours of care provided in 24 hour period [b]			0.035
0 - 6 hours	15 (78.9)	4 (21.1)	
7 - 12 hours	15 (62.5)	9 (37.5)	
13 - 17 hours	7 (58.3)	5 (41.7)	
18 - 24 hours	21 (80.8)	5 (19.2)	
Amount of time providing care [b]			0.581
0 - 6 months	2 (66.7)	1 (33.3)	
7 - 12 months	9 (75.0)	3 (25.0)	
1 - 5 years	30 (71.4)	12 (28.6)	
6 or more years	17 (70.8)	7 (29.2)	
Was the caregiver paid? [a]			0.403
Yes	18 (78.3)	5 (21.7)	
No	40 (69.0)	18 (31.0)	

[a] Based on Chi-square test; [b] Based on Fisher's Exact test.
p-values are based on all cases with valid data.

Table 4a.

Chi-square test for independence for health status of caregiver, by physical and mental components

	Excellent/ Very Good/Good N (%)	Fair/Poor N (%)	*p*-value
Physical Functioning - Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf. [a]			0.237
Yes, limited a lot	5 (50.0)	5 (50.0)	
Yes, limited a little	17 (70.8)	7 (29.2)	
No, not limited at all	36 (76.6)	11 (23.4)	
Physical Functioning - Climbing several flights of stairs. [b]			0.066
Yes, limited a lot	4 (44.4)	5 (55.6)	
Yes, limited a little	22 (73.3)	8 (26.7)	
No, not limited at all	32 (76.2)	10 (23.8)	
Role Physical - Accomplished less than you would like. [b]			0.001
All of the time	2 (100.0)	0 (0.0)	
Most of the time	4 (57.1)	3 (42.9)	
Some of the time	20 (55.6)	16 (44.4)	
A little of the time	13 (86.7)	2 (13.3)	
None of the time	19 (90.5)	2 (9.5)	
Role Physical - Were limited in the kind of work or other activities. [b]			0.009
All of the time	2 (100.0)	0 (0.0)	
Most of the time	3 (60.0)	2 (40.0)	
Some of the time	19 (57.6)	14 (42.4)	
A little of the time	14 (77.8)	4 (22.2)	
None of the time	20 (87.0)	3 (13.0)	
Role Emotional - Accomplished less than you would like. [b]			0.001
All of the time	1 (50.0)	1 (50.0)	
Most of the time	8 (88.9)	1 (11.1)	
Some of the time	12 (48.0)	13 (52.0)	
A little of the time	16 (72.7)	6 (27.3)	
None of the time	21 (91.3)	2 (8.7)	
Role Emotional - Did work or other activities less carefully than usual? [b]			0.005
All of the time	0 (0.0)	0 (0.0)	
Most of the time	2 (50.0)	2 (50.0)	
Some of the time	18 (64.3)	10 (35.7)	
A little of the time	13 (59.1)	9 (40.9)	
None of the time	25 (92.6)	2 (7.4)	

Table 4b.

Chi-square test for independence for health status of caregiver, by physical and mental components

	Excellent/ Very Good/Good N (%)	Fair/Poor N (%)	*p*-value
Bodily Pain - During the past 4 weeks, how much did pain interfere with your work? [b]			<0.001
Not at all	16 (100.0)	0 (0.0)	
A little bit	18 (78.3)	5 (21.7)	
Moderately	20 (69.0)	9 (31.0)	
Quite a bit	3 (27.3)	8 (72.7)	
Extremely	1 (50.0)	1 (50.0)	
Mental Health - Have you felt calm and peaceful? [b]			0.023
All of the time	5 (100.0)	0 (0.0)	
Most of the time	19 (76.0)	6 (24.0)	
Some of the time	18 (62.1)	11 (37.9)	
A little of the time	14 (73.7)	5 (26.3)	
None of the time	2 (66.7)	1 (33.3)	
Vitality - Did you have a lot of energy? [b]			0.046
All of the time	4 (100.0)	0 (0.0)	
Most of the time	18 (85.7)	3 (14.3)	
Some of the time	25 (64.1)	14 (35.9)	
A little of the time	10 (66.7)	5 (33.3)	
None of the time	1 (50.0)	1 (50.0)	
Mental Health - Have you felt down-hearted and blue? [b]			0.015
All of the time	2 (100.0)	0 (0.0)	
Most of the time	2 (28.6)	5 (71.4)	
Some of the time	21 (75.0)	7 (25.0)	
A little of the time	19 (76.0)	6 (24.0)	
None of the time	14 (73.7)	5 (26.3)	
Social Functioning - During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities? [b]			<0.001
All of the time	5 (83.3)	1 (16.7)	
Most of the time	2 (28.6)	5 (71.4)	
Some of the time	18 (62.1)	11 (37.9)	
A little of the time	18 (81.8)	4 (18.2)	
None of the time	15 (88.2)	2 (11.8)	

[a] Based on Chi-square test; [b] Based on Fisher's Exact test
p-values are based on all cases with valid data.

Table 5.

Group statistics of domains, by health status.

	Health Status	N	Mean	Std. Deviation	Std. Error Mean
Physical Functioning	Excellent/Very Good/Good	58	75.43	28.29	3.71
	Fair/Poor	23	61.96	36.83	7.68
Role Physical	Excellent/Very Good/Good	58	69.40	26.09	3.43
	Fair/Poor	23	55.98	18.02	3.76
Bodily Pain	Excellent/Very Good/Good	58	69.40	24.35	3.20
	Fair/Poor	23	44.57	21.26	4.43
General Health	Excellent/Very Good/Good	58	70.34	14.38	1.89
	Fair/Poor	23	22.83	7.20	1.50
Vitality	Excellent/Very Good/Good	58	56.03	22.12	2.90
	Fair/Poor	23	45.65	17.92	3.74
Social Functioning	Excellent/Very Good/Good	58	65.52	29.18	3.83
	Fair/Poor	23	51.09	24.40	5.09
Role Emotional	Excellent/Very Good/Good	58	73.49	24.00	3.15
	Fair/Poor	23	59.78	19.20	4.00
Mental Health	Excellent/Very Good/Good	58	61.21	20.50	2.69
	Fair/Poor	23	55.44	22.24	4.64

Table 6.

Independent samples test of domains.

		Levene's Test for Equality of Variances		t-test for Equality of Means						
									95% Confidence Interval of the Difference	
		F	Sig.	t	Df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	Lower	Upper
Physical Functioning	Equal variances assumed	3.737	0.057	1.769	79	0.081	13.475	7.615	-1.683	28.632
	Equal variances not assumed			1.580	32.807	0.124	13.475	8.530	-3.884	30.833
Role Physical	Equal variances assumed	7.733	0.007	2.258	79	0.027	13.4183	5.9429	1.5893	25.2473
	Equal variances not assumed			2.639	58.236	0.011	13.4183	5.0854	3.2396	23.5970
Bodily Pain	Equal variances assumed	0.850	0.359	4.282	79	0.000	24.831	5.799	13.289	36.374
	Equal variances not assumed			4.543	46.035	0.000	24.831	5.466	13.828	35.834
Vitality	Equal variances assumed	2.457	0.121	2.003	79	0.049	10.382	5.183	0.065	20.699
	Equal variances not assumed			2.194	49.622	0.033	10.382	4.733	0.875	19.890
Social Functioning	Equal variances assumed	2.753	0.101	2.097	79	0.039	14.430	6.883	0.731	28.130
	Equal variances not assumed			2.266	48.064	0.028	14.430	6.369	1.625	27.236
Role Emotional	Equal variances assumed	4.306	0.041	2.444	79	0.017	13.70877	5.61007	2.54221	24.87533
	Equal variances not assumed			2.690	50.261	0.010	13.70877	5.09538	3.47571	23.94183
Mental Health	Equal variances assumed	0.556	0.458	1.115	79	0.268	5.7721	5.1754	-4.5293	16.0735
	Equal variances not assumed			1.076	37.677	0.289	5.7721	5.3626	-5.0869	16.6312

Caregivers who reported good to excellent health reported their level of bodily pain to be moderate, a little, or none at all. The mean score of vitality for caregivers who reported good to excellent health (*M* = 56.03, *SD* = 22.12) was significantly different from those who reported fair or poor health (*M* = 45.65, *SD* =17.92), *t*(79) = 2.00, *p* = 0.049. A majority of caregivers reported having a lot of energy. The mean score of social functioning for caregivers who reported good to excellent health (*M* = 65.52, *SD* = 29.18) was significantly different from those who reported fair or poor health (*M* = 51.09, *SD* = 24.40), *t*(79) = 2.10, *p* = 0.039. A majority of caregivers reported that their physical or emotional problems had little or no interference with their social activities. The mean score of emotional role for caregivers who reported good to excellent health (*M* = 73.49, *SD* = 24.00) was significantly different from those who reported fair or poor health (*M* = 57.78, *SD* = 19.20), *t*(50) = 2.69, *p* = 0.010; Most caregivers reported that they rarely felt downhearted and depressed. There were no significant differences in the means for physical functioning and mental health among caregivers.

ADL of Care Recipients

The Lawton instrumental activities of daily living scale assesses the competence in skills, among the elderly, necessary for living in a community. It detects early functional decline in the ability of the elderly to shop, cook, and manage finances. Additionally it can also detect an early decline in ADL functions such as eating, bathing, or using the toilet. It is anticipated that early decline in function may lead to increased caregiver burden. IADLs were examined for associativity with the care recipient. The IADLs examined were shopping, food preparation, housekeeping, laundry, ability to use telephone, mode of transportation, ability to manage finances, and responsibility for own medications.

As presented in Table 7, there was a statistical association between gender and shopping abilities of the care recipient, χ^2 (3, $N = 81$) = 9.43, $p = 0.003$; food preparation abilities, χ^2 (2, $N = 81$) = 3.61, $p = 0.047$; housekeeping abilities, χ^2 (3, $N = 81$) = 5.65, $p = 0.020$, and laundry abilities of the care recipient, χ^2 (2, $N = 81$) = 5.60, $p = 0.020$. There was no statistical association between gender and ability to use telephone, χ^2 (3, $N = 81$) = 1.60, $p = 0.128$; mode of transportation, χ^2 (3, $N = 81$) = 5.23, $p = 0.060$; responsibility for own medication, χ^2 (2, $N = 81$) = 1.63, $p = 0.395$, and ability to handle finances, χ^2 (2, $N = 81$) = 1.01, $p = 0.125$.

Table 7.

Chi-square test for independence of IADLs among care recipients, by gender

	Male N (%)	Female N (%)	*p*-value
Ability to use telephone.[a]			0.128
Operates telephone by own initiative	3 (27.3)	8 (72.7)	
Dials a few well-known numbers	2 (18.2)	9 (81.8)	
Answers telephone, but does not dial.	9 (30.0)	21 (70.0)	
Does not use telephone at all	5 (17.2)	24 (82.8)	
Shopping.[a]			0.003
Takes care of all shopping needs independently	0 (0.0)	1 (100.0)	
Shops independently for small purchases	2 (66.7)	1 (33.3)	
Needs to be accompanied on any shopping trip.	5 (11.6)	38 (88.4)	
Completely unable to shop	12 (35.3)	22 (64.7)	
Food preparation.[a]			0.047
Plans, prepares, and serves adequate meals independently	0 (0.0)	0 (0.0)	
Prepares adequate meals if supplied with ingredients	0 (0.0)	10 (100.0)	
Heats and serves prepared meals or prepares meals	2 (22.2)	7 (77.8)	
Needs to have meals prepared and served	17 (27.4)	45 (72.6)	
Housekeeping.[a]			0.020
Maintains house alone with occasion assistance	0 (0.0)	0 (0.0)	
Performs light daily tasks such as dishwashing, bed making	0 (0.0)	3 (100.0)	
Performs light daily tasks, but cannot maintain acceptable level of cleanliness	0 (0.0)	4 (100.0)	
Needs help with all home maintenance tasks	1 (7.1)	13 (92.9)	
Does not participate in any housekeeping tasks	18 (30.0)	42 (70.0)	
Laundry.[a]			0.020
Does personal laundry	0 (0.0)	5 (100.0)	
Launders small items, rinses socks etc.	1 (6.3)	15 (93.8)	
All laundry must be done by others	18 (30.0)	42 (70.0)	
Mode of Transportation.[a]			0.060
Travels independently on public transportation	1 (50.0)	1 (50.0)	
Arranges own travel via taxi etc.	0 (0.0)	0 (0.0)	
Travels on public transportation when assisted	1 (50.0)	1 (50.0)	
Travel limited to taxi or automobile with assistance	13 (18.8)	56 (81.2)	
Does not travel at all	4 (50.0)	4 (50.0)	
Responsibility for own Medications.[a]			0.395
Is responsible for taking medication in correct dosages	2 (28.6)	5 (71.4)	
Takes responsibility if medication is prepared in advance	2 (12.5)	14 (87.5)	
Is not capable of dispensing own medication	15 (25.9)	43 (74.1)	
Ability to handle Finances.[a]			0.125
Manages financial matters independently	1 (50.0)	1 (50.0)	
Manages day to day purchases	6 (20.0)	24 (80.0)	
Incapable of handling money	12 (24.5)	37 (75.5)	

[a] Based on Fisher's Exact test.

p-values are based on all cases with valid data.

Summary of Findings

This study examined the health status of caregivers and associated factors. It postulated that the health status of caregivers would be negatively associated with the level of strain incurred with caregiving.

Significant findings indicated that most of the caregivers were Hispanic, daughters of the care recipients and commuted an average distance of about 17 miles to provide care. Findings also indicated that mean score of caregivers who reported good to excellent health within the health domains of role physical, bodily pain, vitality, social functioning, and role emotion were significantly higher in comparison to caregivers who reported fair or poor health. Most of the care recipients were women. About half of the care recipients suffered from dementia. An examination of IADLs among care recipients indicates some significant differences by gender. It is postulated that caregiver burden should increase with decrease in ADL functions.

There were some limitations in determining the relationships between caregiver burden and associated variables. The sample size was not large enough to perform advanced inferential statistical analysis. Moreover, it is unknown if a bias may have occurred in the level of strain reported by caregivers because of their relationship to the care recipient. Due to the constraints of the current study protocol, the researcher was not able to collect additional information regarding the relationship between the level of IADLs of the care recipient and specific aspects of the caregiver's health. Further research is therefore needed to identify additional factors that may affect the health of caregivers thereby affecting the quality of care received by care recipients. It is also important to examine if there are any differences in the health status of caregivers who are related by family or other social ties to care recipients in comparison to those who are not related to caregivers in these ways. Caregiver burden may also vary by location, and thus additional research is needed to investigate caregiver strain in different regions of California and at the national level.

Results from this study suggest that of the level of caregiver's health may be an important factor in both caregivers' ability to provide care and the level of care they are able to provide to care recipients.

CHAPTER 5

Discussion of Findings

The overall purpose of this study was to describe the relationships between objective caregiver burden, relevant caregiver characteristics, perceived caregiver strain, and perceived caregiver health in a diverse group of adult caregivers providing assistance with instrumental activities of daily living (IADL) to care recipients in Southern California. The data were collected from a sample of 81 caregivers. While the majority of the caregivers were Hispanic females, this study utilized a broad inclusion criteria, thus resulting in a diverse participant group. Tsai's (2003) Modified Middle-Range Theory of Caregiver Stress provided a conceptual framework for this study.

In the previous chapters, the research design and method, data analysis, and overall results were summarized. In this chapter, a discussion of findings is presented, including implications for nursing practice, limitations of the study, and future directions for research in this area.

Discussion

As stated above, this descriptive study was undertaken as a broad-spectrum starting point to describe newer trends in care giving. In 2009, The American Geriatric Society concluded that improvement in healthcare, technology services, and nutritional status are contributing factors to the increased need for caregivers (Talley & Crews, 2007). Caregiving in our society is apparent when caregivers accompany care recipients to the market, bank, church, or to doctor appointments. Some care recipients require companionship and assistance to complete ADL's, while others require total assistance.

Caregivers who participated in this study expressed that frequent hospitalizations give the care recipient opportunities to "keep going" as more medications and treatments are added to their care. Many care recipients require twenty-four hour care and therefore have multiple caregivers. Caregivers in this study expressed that their families are impacted by the patient's illness and the degree of care required, thus caregivers are facing challenges balancing their personal, family and financial responsibilities.

Sample

This study was conducted with a convenience sample of caregivers, who provided care for an older adult in the community areas of the Southern California region. The sample of 81 caregivers was collected from February 2012 to July 2012. Data from eighty-one caregivers were included in the final analysis, with the use of a Chi-square test, Fisher's Exact test, T-Test analysis, Levene's test and a one-way ANOVA. Caregivers who refused to participate in the study sited their reasons as not being able to leave the care recipient or attributed their lack of participation on the care recipient's illness. Of note is that some caregivers stated they were too stressed or busy to participate in the study, suggesting that the caregiver population may indeed be currently understudied.

Caregiver Characteristics

Caregiver characteristics were captured in the demographic data and included race, age and gender of the caregiver. Additional variables included the relationship to the care recipient and the educational level of the caregiver. Other variables included the number of hours worked and the length of time the caregiver worked with the care recipient. Also of interest for this study was the distance driven by the caregiver and caregiver reimbursement. The researcher selected caregiver characteristics that were reported with categorical or continuous variables (Pressler et al., 2009).

Race, age, and gender. In this study the majority of participants self-identified as Hispanic (61.7%), while in previous studies the majority of participants self-identified as White (54% to 90%). Obviously, not all the various ethnic backgrounds which constitute the entire population of Southern California were represented in this study. The mean age of caregivers in this study was 55.07 years (SD = 12.94 years, range =21-84 years). In the studies reviewed, the mean ages of caregivers ranged from 58 to 65 years. The results of this study indicate that 87.7% were women, which is congruent with the literature reviewed which indicates that women are more likely to be caregivers than men (Andrén, & Elmståhl, 2008; Bainbridge, Lohfeld & Brazil, 2009; Braithwaite, 1996; Lockenhoff, Duberstein, & Friedman, 2011; McConaghy& Caltabiano, 2005; NAC/AARP, 2004; LARC, n.d.; Papastavrou et al., 2007; Pinquart & Sorensen, 2006; Roth et al., 2009; Talley & Crews, 2007).

Relationship to the care recipient. In this study most of the caregivers were daughters of the care recipients (48.1%), and approximately 11% of the caregivers were spouses of the care recipient. The findings of this study are consistent with several studies that indicate that family members constitute the majority of caregivers, with spouses, specifically women and children being the most significant group (Andrén, & Elmståhl, 2008; Bainbridge et al., 2009; Braithwaite, 1996; Lockenhoff et al., 2011; McConaghy& Caltabiano, 2005; Papastavrou et al, 2007; Pinquart & Sorenson, 2006;

Talley & Crews, 2007).

Educational level. Most of the caregivers who participated in this study had formal education, with 44.4% of caregivers having a high school education or having completed the GED. The review of literature indicates that not all studies evaluated the caregivers' educational levels. Where reported, caregiver educational levels ranged from 12 to 14 mean years (Andrén, & Elmståhl, 2008; Bainbridge et al., 2009; Braithwaite, 1996; Lockenhoff et al., 2011; McConaghy & Caltabiano, 2005; Papastavrou et al., 2007).

Number of hours worked and the length of time the caregiver has worked with the care recipient. Data was captured relative to the relationship with the care recipient, length of time providing care for the care recipient, number of hours providing care for a care recipient in a 24 hour period, and the caregiver's relation to the care recipient. A few caregivers provided care for more than one recipient and therefore provided information regarding the recipient who required the most help.

There was a significant statistical correlation between health status and number of hours of care provided per day. It was not possible to perform a comparison of means for the number of hours of care provided per day because respondents provided this information by selecting from a range of hours with a class width of 6 hours. In order to determine if the number of hours of care provided per day by the caregiver had an effect on the caregiver's health status, it was important that the caregiver report the exact number of hours for which care was provided. There was also the possibility of the interactive effect of the number of hours care was provided in a 24-hour period and the distance driven by the caregiver participant to the care recipient's home. This effect could not be measured because the caregiver did not report the exact number of hours worked in a 24-hour period.

A review of the studies found that the number of hours worked and the length of time the caregiver has worked with the care recipient were not discussed in every study. When reported, there was variation on how time was reported. The majority of studies reported the hours worked per week with ranges from 28 to 66 hours. In others, the length of time was reported in weeks (48 weeks) or years (9 years) (Andrén, & Elmståhl, 2008; Bainbridge et al., 2009; Braithwaite, 1996; Lockenhoff et., 2011; McConaghy & Caltabiano, 2005; Papastavrou et al., 2007).

Distance driven by the caregiver. Caregivers who commuted to provide care for the recipient on average traveled 16.72 miles (SD = 18.02 miles, range = 3-90 miles). Given the stressful nature of driving in the Southern California region, it can be posited that caregivers may experience their commute as a factor in contributing to caregiver strain. Some caregivers described their commute as "making the drive" to care for their parents for a few days at a time.

An extensive review of the literature did not find any studies that documented the distance driven by the caregiver. An array of terms were used to describe living with a care recipient which includes "lives with", "residence with" and "cohabitating". The literature shows 62% to 90% of caregivers live with the care recipient (Andrén, & Elmståhl, 2008; Bainbridge et al., 2009; Braithwaite, 1996; Lockenhoff et al., 2011; McConaghy & Caltabiano, 2005; Papastavrou et al., 2007).

Caregiver reimbursement. In the largest care giving group in this study (daughters), 25.6% reported receiving reimbursement. Current published studies vary on how reimbursement is addressed. While some studies did not address reimbursement, in other studies caregivers were excluded from studies because they did receive reimbursement. Caregivers' employment outside of the home are addressed in multiple studies (Andrén, & Elmståhl, 2008; Bainbridge et al., 2009; Braithwaite, 1996; Lockenhoff et al., 2011; McConaghy & Caltabiano, 2005; Papastavrou et al., 2007).

Perceived Caregiver Strain

Caregiving is usually an unexpected responsibility in families. Caregiving literature establishes that caregiving increases the emotional and mental strain of caregivers (Huyck, Ayalon, Yoder, 2007). The balancing of caregiving by the "sandwich generation" increases the strain, especially when financial strain is added to the caregiver's struggles (Pierret, 2006). Caregivers in this study shared their experiences with complex family relationships. They described relationship and financial issues as being the center of their caregiving experience. These findings are congruent with the challenges faced by families documented by Hansen et al., 2005.

Intuitively, the quality of communication among siblings and family members may improve the relationships among family members as they face the challenges of providing daily care. Similarly, the presence of clear advance health directives by the care recipient may decrease conflict regarding any health care issues of the care recipient. While this study did not address these factors directly, future research regarding the relationships between these factors and caregiver health will be important.

The behavior of the care recipient as well as the assistance required to perform ADLs may change over time (Donelan, Hill, Hoffman, Scoles, Hollander, Levine & Gould, 2002). Care recipients may side or have preferences for one caregiver, which can cause resentment among caregivers. Often caregivers have different personal opinions and views about the management of the care that is provided to the care recipient and consequently this causes areas of conflict among caregivers. The coordinator or advocate caregiver is the one who usually mediates between various caregivers (Hansen et al., 2005; Sales 2003). Again, while this study did not directly address these issues, the finding that multiple groups of caregivers often are involved in giving care for one care recipient during a 24-hour period suggests that future study is needed regarding the specific role and stressors of the care coordinator.

Perceived Caregiver Health

Researchers document that endurance and excellent physical health are vital for the role of a caregiver (King, 2009; Talley & Crews, 2007). Research indicates that the diverse experience of caregivers have varying contributing factors which make it more challenging to identify an equal risk that impacts caregiver's health (Pinquart & Sorensen, 2007). Matthews et al., 2004 documents that caregivers neglect their own health while caring for an older adult. This contributes to the findings of previous literature that contends caregiving can have an effect on caregiver health.

Key significant findings in this study indicated that the health status of caregivers is positively correlated with the caregiver's ability to provide care and the level of care that is provided to care recipients. Caregivers who reported good to excellent health had higher mean scores in the health domains of role physical, bodily pain, vitality, social functioning, and role emotion. Caregivers verbalized that they "thought" it was not too bad and considered it their responsibility and just dealt with the challenges.

Relationships with Caregiver Participants

As caregivers became aware that the researcher was a nurse, they volunteered more information. While maintaining a clear separation between the nurse and researcher role, the researcher found that caregivers volunteered information regarding additional challenges that were not included in the survey. This experience suggests that future qualitative studies that examine more deeply the lived experience of being a caregiver in a specific context are needed. Such studies could bring to light the unique individual experience of care giving in the specific contexts of being a daughter or being situated in a particular ethnic identity. Of note from this study is the finding that forming positive researcher relationships with caregiver participants are important to allow caregivers to be comfortable to discuss their role, responsibilities and experience.

Caregivers in this study discussed an array of challenges including relationships with the care recipient, finances and balancing their caregiving responsibilities. Caregivers shared their concerns about missing their previous relationships with the person they care for and described their struggle as they saw the deterioration of their loved ones. Caregivers expressed challenges with paying for monthly medications, non-emergency transportation to the hospital and the financial burden of twenty-four hour care. The most frequently mentioned challenge was dealing with caregiving and maintaining a balance with their immediate family and caregiving responsibilities. Additionally, some caregivers described attempts to balance caring for grandchildren or more than one aging parent or relative. These anecdotal themes suggest a rich area for future qualitative studies.

Limitations

The inclusion criteria for this study included the ability to provide written or verbal informed consent, and be able to read and write in English. Some caregivers for whom English was a second language chose not to participate in the study as they felt that they could potentially misinterpret the questions or give incorrect answers. An additional limitation was that this sample population of caregivers was limited to the caregivers who were able to leave their caregiving responsibilities to participate. Thus, it can be posited that this study did not include those caregivers for whom care was all encompassing. Strategies for accessing the caregiver population who self-identify as unable to participate in research due to the nature of their responsibilities will be an important consideration for future researchers.

The number of caregivers that could be interviewed in person per day became a challenge as the researcher drove across town in heavy traffic to meet with caregivers. Permission was requested and granted to be able to complete the interviews over the telephone. This facilitated the gathering of data, as it could be done early in the morning or late at night. A few caregivers asked to be contacted as early as two and four o'clock in the morning.

It was the researcher's impression that the in-person interview allowed for a more in-depth observation of the context in which the care was being provided, including the environment of care. Although not part of the study aims, the researcher did note that in-person interviews tended to last longer than the telephone interviews and provided more non-verbal information. A wide range of data collection times (10-60 minutes) was noted and was possibly due to the dual types of data collection. Thus, the implementation of two different data collection methods during the conduct of the study can be seen as a limitation to this study.

It can be posited that study participants' perceived need to give "the correct answer" could potentially explain the findings that their caregiving responsibilities did not impact their health. Previous caregiving experience was not evaluated. The verbalization of questions for the participants of the study facilitated the completion of the questionnaires. Some participants verbalized that they would prefer a study in which they could complete the information online, an important consideration for future research strategies in accessing this population.

The majority of the participants in this study self-identified as predominately Hispanic; thus, this study did not provide information from multiple races and ethnic backgrounds characteristic of Southern California. Therefore, the results cannot be applied across all racial and ethnic backgrounds. The predominance of Hispanic participants may reflect the snowball approach to recruitment initiated by a Hispanic researcher. Interestingly, some caregivers with an ethnic background different from that of the researcher declined to participate in the study. It can be posited that they may have chosen to participate in the study if a researcher of a similar racial/ethnic background had approached them; however, the complex relationships between researchers, respondents, and ethnic identity currently remain an understudied area.

Although recruitment occurred widely throughout the Southern California region, the snowball approach to recruitment in this research study could potentially have resulted in caregivers of a similar racial and ethnic background passing on study information to individuals in their immediate social circle. This could have potentially impacted the findings and may explain that the majority of the caregivers were Hispanic. The racial and ethnic background of the care recipient was not captured during the study and therefore could not be correlated for statistical analysis. This would be important in future studies to identify the racial and ethnic background of the care recipient.

A significant limitation of this study is the lack of data regarding the age of the care recipients and in this study. While the caregivers' ages were recorded, no data were gathered regarding the age of the care recipients. Therefore, it is not possible to correlate information from this group of care recipients with the prediction of the U.S. Census Bureau International (2009) that anticipates that the life expectancy at birth by the year 2030 will be 81 years of age.

Although information on the relationship of the caregivers to the care recipients was collected in the Demographic Questionnaire, the researcher noted a need to collect more complete information on the relationship of the caregivers to the care recipients, given that many self-reported their relationship as "Other". An examination of this category revealed that relationships of caregivers to care recipients included: grandson, granddaughter, son-in-law, daughter-in-law, sister, niece, friend, neighbor and caregivers.

A limitation was noted in caregiver reimbursement, as the sources of the caregivers' reimbursement were not identified. Of importance, would also be the collection of data to include how many hours of care provided to the care recipient in a 24 hour period were actually paid hours.

In future studies, it will be a very important point for this researcher to record as much data as possible on the demographic characteristics of both the caregiver and care recipient.

Importance to the Advancement of Nursing Science

Whereas caregiving in the United States was once considered a personal matter within family functioning, it has now become a crucial issue in need of attention at both the community and federal levels (Donorfio & Kellet, 2006). Caregiver health has been placed on the level of a public health matter; addressed by the U.S. Department of Health and Human Services and recognized in the nationwide health promotion and disease prevention agenda (Healthy People 2010). Caregivers' health has a direct impact on the ability to provide care, and the level of care that is provided to care recipients (Huynh-Hohnbaum, Villa, Aranda & Lambrinos, 2008).

The findings of this study are congruent with the assertion by Bruce et al. (2005) that future research in this area is essential, given the understudied link between caregiving and physical health (Schulz, Newsom et al., 1997; Schulz, O'Brien, Bookwala et al, 1995). In more recent studies, researchers document that endurance and excellent physical health are vital for the role of a caregiver (King, 2009; Talley & Crews, 2007). It is critical to incorporate the evaluation of all caregivers and the changes in families as they transition in their caregiving roles. Within the US healthcare system, it is important to implement and facilitate programs that can evaluate older adults as well as caregivers. It is also essential to advocate for funding of caregiver time off and respite care. Nurse scientists can be instrumental in developing programs of research that focus on successful strategies in achieving these goals.

Research

Data from this study have the potential to be used as a foundation for future more focused studies of the relationships between objective caregiver burden, perceived caregiver strain, and perceived caregiver health in specific populations. Future caregiver studies that explore perceived caregivers health will need to be conducted in order to determine the effects of caregiving on caregivers' health over time.

A specific area of interest would be to collect data that would provide data on the perceived health of caregivers on a longitudinal basis, with follow-up interviews in one, two and five years. This would provide information regarding changes in caregiver characteristics/health along the trajectory of the care recipient's condition. Additional areas of future research can include the examination of these phenomena in multiple caregiver groups per care recipient and the complex relationships present in such populations. Utilizing the same instruments, e.g., IADL, CSI and the Health Survey 12 v 2 to standardize the collection of data in multiple geographic locations would provide a clearer analysis of the meaning of these initial data. In addition, future studies focused on the specific characteristics and needs of caregivers and recipients across a trajectory could be useful in providing information regarding critical points of health risk for both groups. Such findings could be used to guide strategies for the provision of enhanced support to caregivers during such critical points by health care agencies.

In addition to future empirical studies, the researcher's experiences suggest that future qualitative studies are needed to examine more deeply the lived experience of care giving. It can be posited that an adequate understanding of the barriers and promoters to health among caregivers could be gained by a more narrative approach, given the complex context of caregivers in a rapidly changing health care environment.

Conclusion

In conclusion, this study provided a “snap shot” of caregivers in the Southern California region. The relationships between caregiver burden, select caregiver characteristics, perceived caregiver strain, and perceived caregiver health in a group of adult caregivers providing assistance with instrumental activities of daily living (IADL) to a care recipient were examined. The use of Tsai’s (2003) Middle-Range Theory of Caregiver Stress guided this study and was modified to present an innovative approach with the use of perceived caregiver strain as a specific stressor in the Control Process of the model.

Key significant findings indicated that the health status of caregivers was significantly related to the caregiver’s ability to provide care and the level of care that is provided to care recipients. Caregivers who reported good to excellent health had higher mean scores in the health domains of role physical, bodily pain, vitality, social functioning, and role emotion. Descriptive analysis indicated that most of the caregivers were Hispanic and daughters of the care recipient. Even though most of the caregivers were related to the care recipients, findings from this study provide supporting evidence that strain has a direct impact on the health of the caregivers and as a result may have an impact on the ability of caregivers to provide care to recipients.

Other study findings that were particularly salient are the documentation of long driving distances to give care, the multiplicity of caregivers for one care recipient in a 24 hour period, and the identification of at least one caregiver within the caregiver group as a full-time worker. These findings are suggestive of newer trends in care giving that have not been documented in previous research. In sum, this descriptive study suggests a picture of care giving as far more complex and potentially hazardous to the health of caregivers than has been previously documented. While not without its limitations, this study represents an initial approach to this complex area that can be built upon in the future to elucidate further the factors that can promote optimal health in both the caregivers and recipients.

APPENDICES

Appendix A

Demographic Characteristic Questionnaire

Demographic Characteristic Questionnaire

Caregiver Information

Race

African American ☐ Hispanic/Latino/Latina ☐ Asian American/ Pacific Islander ☐

Native American/American Indian ☐ White ☐ Other____________

Age____________________

Gender Male ☐ Female ☐

Relationship to care recipient

Mother ☐ Father ☐ Wife ☐ Husband ☐

Daughter ☐ Son ☐

Partner/significant other ☐ Other___________________________

Education: HS/GED ☐ Bachelors ☐ Graduate ☐ Other______________

Number of Hours providing care for a care recipient in a 24 hour period

0-6 hours 7-12 hours 13- 18 hours 19-24 hours

Length of time providing care for a care recipient

0-6 months 7-12 months 1-5 years 6 or more years

Distance driven to care for the care recipient _____________***miles***

Caregiver Reimbursement YES NO

Care Recipient Information

Gender Male ☐ Female ☐

Diagnosis of care recipient

Dementia YES NO
Alzheimer's YES NO

Appendix B

The Lawton Instrumental Activities of Daily Living Scale (IADL)

INSTRUMENTAL ACTIVITIES OF DAILY LIVING SCALE (IADL)

M.P. Lawton & E.M. Brody

A. Ability to use telephone

1. Operates telephone on own initiative; looks up and dials numbers, etc.	1
2. Dials a few well-known numbers	1
3. Answers telephone but does not dial	1
4. Does not use telephone at all.	0

B. Shopping

1. Takes care of all shopping needs independently	1
2. Shops independently for small purchases	0
3. Needs to be accompanied on any shopping trip.	0
4. Completely unable to shop.	0

C. Food Preparation

1. Plans, prepares and serves adequate meals independently	1
2. Prepares adequate meals if supplied with ingredients	0
3. Heats, serves and prepares meals or prepares meals but does not maintain adequate diet.	0
4. Needs to have meals prepared and served.	0

D. Housekeeping

1. Maintains house alone or with occasional assistance (e.g. "heavy work domestic help")	1
2. Performs light daily tasks such as dishwashing, bed making	1
3. Performs light daily tasks but cannot maintain acceptable level of cleanliness.	1
4. Needs help with all home maintenance tasks.	1
5. Does not participate in any housekeeping tasks.	0

E. Laundry

1. Does personal laundry completely	1
2. Launders small items; rinses stockings, etc.	1
3. All laundry must be done by others.	0

F. Mode of Transportation

1. Travels independently on public transportation or drives own car.	1
2. Arranges own travel via taxi, but does not otherwise use public transportation.	1
3. Travels on public transportation when accompanied by another.	1
4. Travel limited to taxi or automobile with assistance of another.	0
5. Does not travel at all.	0

G. Responsibility for own medications

1. Is responsible for taking medication in correct dosages at correct time.	1
2. Takes responsibility if medication is prepared in advance in separate dosage.	0
3. Is not capable of dispensing own medication.	0

H. Ability to Handle Finances

1. Manages financial matters independently (budgets, writes checks, pays rent, bills goes to bank), collects and keeps track of income.	1
2. Manages day-to-day purchases, but needs help with banking, major purchases, etc.	1
3. Incapable if handling money.	0

Source: Lawton, M.P., and Brody, E.M. "Assessment of older people: Self-maintaining and instrumental activities of daily living." Gerontologist 9:179-186, (1969).

Appendix C

The Modified Caregiver Strain Index (CSI)

Modified Caregiver Strain Index

Directions: Here is a list of things that other caregivers have found to be difficult. Please put a checkmark in the columns that apply to you. We have included some examples that are common caregiver experiences to help you think about each item. Your situation may be slightly different, but the item could still apply.

	Yes, On a Regular Basis=2	Yes, Sometimes =1	No=0
My sleep is disturbed (For example: the person I care for is in and out of bed or wanders around at night)			
Caregiving is inconvenient (For example: helping takes so much time or it's a long drive over to help)			
Caregiving is a physical strain (For example: lifting in or out of a chair; effort or concentration is required)			
Caregiving is confining (For example: helping restricts free time or I cannot go visiting)			
There have been family adjustments (For example: helping has disrupted my routine; there is no privacy)			
There have been changes in personal plans (For example: I had to turn down a job; I could not go on vacation)			
There have been other demands on my time (For example: other family members need me)			
There have been emotional adjustments (For example: severe arguments about caregiving)			
Some behavior is upsetting (For example: incontinence; the person cared for has trouble remembering things; or the person I care for accuses people of taking things)			
It is upsetting to find the person I care for has changed so much from his/her former self (For example: he/she is a different person than he/she used to be)			
There have been work adjustments (For example: I have to take time off for caregiving duties)			
Caregiving is a financial strain			
I feel completely overwhelmed (For example: I worry about the person I care for; I have concerns about how I will manage)			

[Sum responses for "Yes, on a regular basis" (2 pts each) and "yes, sometimes" (1 pt each)]

Total Score =

Thornton, M., & Travis, S.S. (2003). Analysis of the reliability of the Modified Caregiver Strain Index. *The Journal of Gerontology, Series B, Psychological Sciences and Social Sciences, 58*(2), p. S129. Copyright © The Gerontological Society of America. Reproduced by permission of the publisher.

Appendix D

The Short-Form-12 Health Survey Version 2

Your Health and Well-Being

This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. ***Thank you for completing this survey!***

For each of the following questions, please mark an ☒ in the one box that best describes your answer.

1. **In general, would you say your health is:**

Excellent	Very good	Good	Fair	Poor
▼	▼	▼	▼	▼
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

2. **The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?**

	Yes, limited a lot	Yes, limited a little	No, not limited at all
	▼	▼	▼
a Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	☐ 1	☐ 2	☐ 3
b Climbing several flights of stairs	☐ 1	☐ 2	☐ 3

(SF-12v2® Health Survey Standard, United States (English))

3. **During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?**

	All of the time ▼	Most of the time ▼	Some of the time ▼	A little of the time ▼	None of the time ▼
a Accomplished less than you would like	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
b Were limited in the kind of work or other activities	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

4. **During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?**

	All of the time ▼	Most of the time ▼	Some of the time ▼	A little of the time ▼	None of the time ▼
a Accomplished less than you would like	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
b Did work or other activities less carefully than usual	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

5. **During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?**

Not at all ▼	A little bit ▼	Moderately ▼	Quite a bit ▼	Extremely ▼
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

6. **These questions are about how you feel and how things have been with you <u>during the past 4 weeks</u>. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the <u>past 4 weeks</u>...**

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a Have you felt calm and peaceful?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
b Did you have a lot of energy?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
c Have you felt downhearted and depressed?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

7. **During the <u>past 4 weeks</u>, how much of the time has your <u>physical health or emotional problems</u> interfered with your social activities (like visiting with friends, relatives, etc.)?**

All of the time	Most of the time	Some of the time	A little of the time	None of the time
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Thank you for completing these questions!

Appendix E

Tables of Results

Table 8.

Reliability statistics for Lawton IADL scale

Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
0.853	0.862	8

Table 9.

Item statistics for Lawton IADL scale

	Mean	Std. Deviation	N
Ability to use telephone.	2.95	1.023	81
Shopping.	3.36	0.619	81
Food preparation	3.64	0.695	81
Housekeeping	4.62	0.751	81
Laundry	2.68	0.588	81
Mode of Transportation	4.00	0.592	81
Responsibility for own Medications	2.63	0.641	81
Ability to handle Finances	2.58	0.545	81

Table 10.

Summary item statistics for Lawton IADL scale

	Mean	Minimum	Maximum	Range	Maximum / Minimum	Variance	N of Items
Item Means	3.307	2.580	4.617	2.037	1.789	0.546	8

Table 11.

Reliability statistics for Modified Caregiver Strain Index

Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
0.813	0.814	13

Table 12.

Item statistics for Modified Caregiver Strain Index

	Mean	Std. Deviation	N
Is my sleep disturbed?	0.84	0.749	81
Is caregiving inconvenient?	1.05	0.705	81
Caregiving is a physical strain.	1.04	0.813	81
Caregiving is confining.	1.56	0.548	81
There have been family adjustments.	1.38	0.681	81
There have been changes in my personal plans.	1.14	0.703	81
There have been other demands on my time.	1.17	0.738	81
There have been emotional adjustments.	0.96	0.732	81
Some behaviors are upsetting.	1.01	0.733	81
It is upsetting to find the person I care for has changed so much from his/her formal self.	1.14	0.771	81
There have been work adjustments.	0.83	0.787	81
Caregiving is a financial strain.	1.07	0.833	81
I feel completely overwhelmed.	1.28	0.553	81

Table 13.

Summary item statistics for Modified Caregiver Strain Index

	Mean	Minimum	Maximum	Range	Maximum / Minimum	Variance	N of Items
Item Means	1.113	0.827	1.556	0.728	1.881	0.042	13

Table 14.

Reliability statistics for the SF-12v2 Health Survey

Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
0.409	0.397	12

Table 15.

Item statistics for the SF-12v2 Health Survey

	Mean	Std. Deviation	N
In general, would you say your health is: Excellent, very good, good, fair, poor?	2.99	0.901	81
Physical Functioning - Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf.	2.46	0.708	81
Physical Functioning - Climbing several flights of stairs.	2.41	0.685	81
Role Physical - Accomplished less than you would like.	3.57	1.048	81
Role Physical - Were limited in the kind of work or other activities.	3.68	1.035	81
Role Emotional - Accomplished less than you would like.	3.68	1.082	81
Role Emotional – Did work or other activities less carefully than usual.	3.89	0.935	81
Bodily Pain - During the past 4 weeks, how much did pain interfere with your work (including both work outside the home and housework)?	2.51	1.038	81
Mental Health - Have you felt calm and peaceful?	2.88	0.967	81
Vitality - Did you have a lot of energy?	2.88	0.857	81
Mental Health - Have you felt down-hearted and blue?	3.64	1.016	81
Social Functioning - During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?	3.46	1.141	81

Table 16.

Summary Item Statistics for the SF-12v2 Health Survey

	Mean	Minimum	Maximum	Range	Maximum / Minimum	Variance	N of Items
Item Means	3.169	2.407	3.889	1.481	1.615	0.294	12

Appendix G

Permission use of Lawton's IADL Scale

WOLTERS KLUWER HEALTH LICENSE
TERMS AND CONDITIONS

Nov 09, 2010

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Appendix I

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License Number: CT131481 / OP011888
Effective Date: December 15, 2010
Licensee Name: Juana Ferrerosa
Licensee Address: 15068 Mountain Spring St.
Hacienda Heights, CA 91745 USA
Requested Administrations: 100
Approved Use: Non-commercial academic research - unfunded - The effects of caregiver strain on caregiver health
Term: Beginning on January 1, 2011 and ending on December 31, 2011
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Manuals: Licensee must purchase (or have purchased) from QM a copy of the manuals indicated in Appendix B attached
Royalty Fee: None, because this License is granted in support of the non-commercial Approved Use below
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Juana Ferrerosa
15068 Mountain Spring St.
Hacienda Heights, CA 91745 USA

Signature:
Name:
Title: RN, PHN, MSN, PhD Nursing Student University of San Diego

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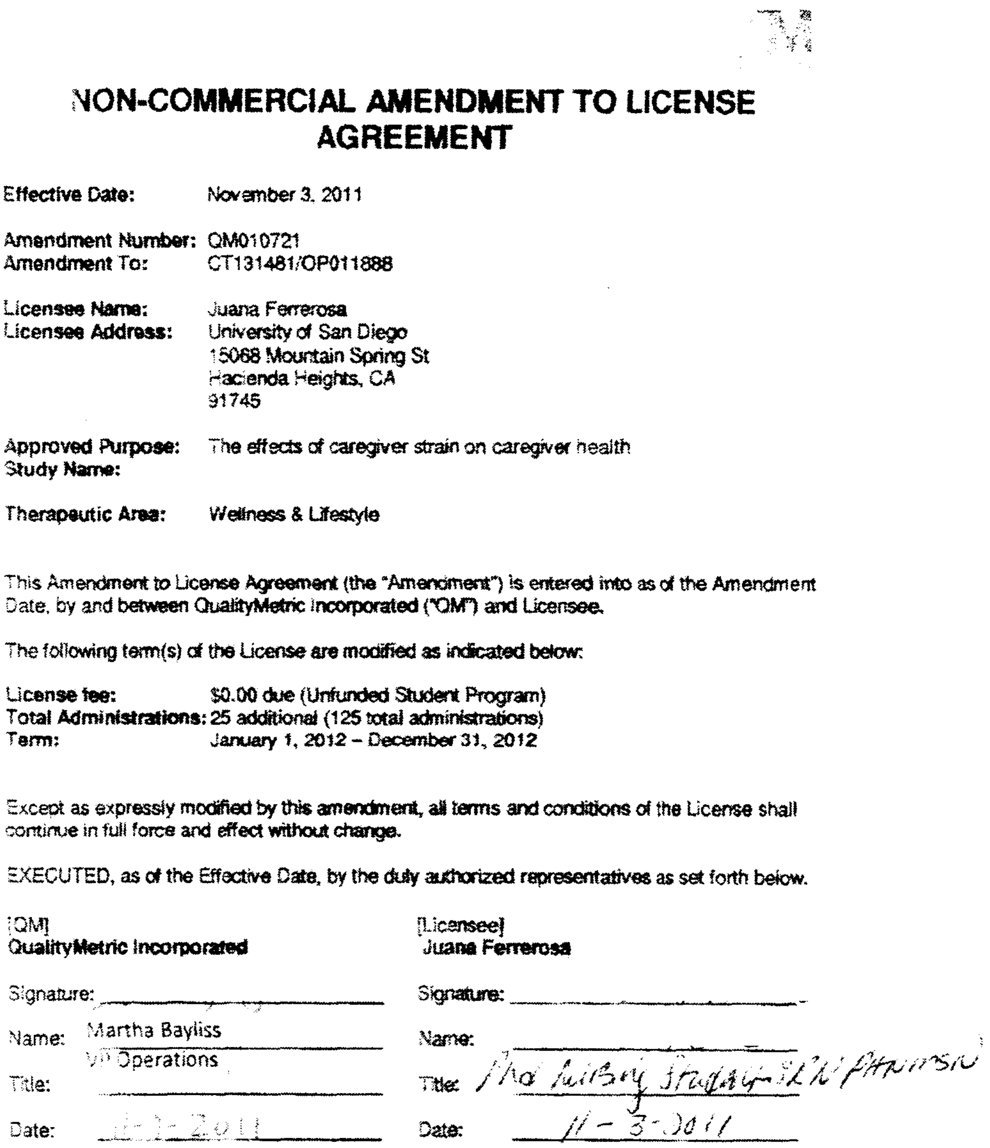

NON-COMMERCIAL AMENDMENT TO LICENSE AGREEMENT

Effective Date: November 3, 2011

Amendment Number: QM010721
Amendment To: CT131481/OP011888

Licensee Name: Juana Ferrerosa
Licensee Address: University of San Diego
15068 Mountain Spring St
Hacienda Heights, CA
91745

Approved Purpose: The effects of caregiver strain on caregiver health
Study Name:

Therapeutic Area: Wellness & Lifestyle

This Amendment to License Agreement (the "Amendment") is entered into as of the Amendment Date, by and between QualityMetric Incorporated ("QM") and Licensee.

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License fee: $0.00 due (Unfunded Student Program)
Total Administrations: 25 additional (125 total administrations)
Term: January 1, 2012 – December 31, 2012

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EXECUTED, as of the Effective Date, by the duly authorized representatives as set forth below.

[QM] **QualityMetric Incorporated**	[Licensee] **Juana Ferrerosa**
Signature:	Signature:
Name: Martha Bayliss	Name:
Title: VP Operations	Title: PhD Nursing Student-USD [illegible]
Date: [illegible]-2011	Date: 11-3-2011

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