

SPIRITUALITY AND SOCIOECONOMIC DETERMINANTS
OF CAREGIVER BURDEN

by

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Submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy in
Social Work at the University of Texas at Arlington

Arlington, Texas

May 2017

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Abstract

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The University of Texas at Arlington, 2017

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Caregiver burden as a phenomena is a growing field of study, with great significance considering the aging population in America. This study conducted secondary analysis of the National Long Term Care Survey (2004) data, to analyze the impact of social proximity of family support, physical proximity of family support, spirituality, economic and social constraints, and care settings on the outcome variable of caregiver burden. Statistical significance is present and results highlight important areas of needed future research, as well as implications for social work policy and practice.

Dedication

First and foremost I must thank my husband, Daniel T. Felderhoff. Without his blind and unwavering love, support, sacrifice, and encouragement, this journey would never have begun. I love you more than words can express and I am so grateful that you said “yes” to this journey with me, before either of us had any idea what we were getting into. I also must thank my children, though this time will likely not even be much of memory for you, Madison & Aiden, you’ve blessed me with your unconditional love, even when life and this process have made me more than an imperfect mommy. Without your smiling faces at the end of every day, I am not certain I would have survived this journey. I would also like to thank my parents, Wes and Sherri Gideon for always embracing me with love, support, encouragement and encouraging me to set big goals, and then go and achieve them! From day one you have been my biggest supporters and I wouldn’t be where I am today with you. Though you’ve only been “mine” for a few years, comparatively, I must also thank my in-laws, Tom & Becky Felderhoff – you have loved, supported and encouraged me as if I have been yours my whole life and without you, this journey would not have been possible.

I am so grateful to all of the students, faculty, and staff in the School of Social Work. You all have been wonderful peers, colleagues, supporters and friends. There is a special place in my heart for each of you. To my cohort – the fantastic four – I cannot believe I am here. Two of you have lead the way for me, Lily and Cecilia, and have given me the courage, support and encouragement to see this journey through. Lester, my friend, you are nipping at my heels and I cannot wait to cheer you on as you cross that stage! I am so grateful to have been part of such a select group of aspiring and inspiring social work academics! To all those who paved the way for the PhD program to become what it is, I am forever grateful to you, and especially appreciate the

support and vision of Kristin Whitehill-Bolton, Pamela Hancock-Bowers, Kathleen Preble, Shannon Sliva, Tracey Barnett, Kingsley Chibgu, Arati Maleku, and of course, Cara Wallace who began the powerful legacy in aging research within our program. I must also thank some of my dearest friends who have supported, guided, talked me off of the ledge a few times, and helped me to realize I have something to offer the world: Alicia Hawley-Bernardez, Leona Peterson, Rosalind Evans, Rupal Parekh, Dorothea Ivey, Kris Hohn, and Vivian Miller.

Words do not do justice to appropriately acknowledge all of the faculty that have mentored me over the last five years, including (in no particular order) Dr. Richard Hoefer, Dr. Mike Killian, Dr. Katherine Sanchez, Dr. Gail Adorno, Dr. Jane Hickerson, Dr. Marta Mercado-Sierra, and Dr. Norman Cobb. Additionally I can truly say I would not have survived without the guidance, wisdom, and encouragement of Dr. Beverly Black, the PhD Program Director, who has been an amazing example of a leader in every sense of the word. And finally to my committee, Dr. Ann Wilder, Dr. Randall Basham, Dr. Noelle Fields, Dr. Alexa Smith-Osborne, and my dissertation chair, Dr. Vijayan Pillai. Thank you all for your support, encouragement, guidance, understanding, hope, and confirmation. You have made this process more seamless and uplifting than I could have ever imagined. I hope that someday I can provide an aspiring student with the same experience.

And finally, this dedication would not be complete without acknowledging the person who is the reason I began this journey in the first place, my grandfather Dr. Robert Eugene Collier, PhD in Microbiology and Biochemistry. Were it not for his soft guidance I would never have had the self-confidence to think I could complete a PhD. In some ways I believe that this was as much his dream as it was mine. Thank you Grandpa for celebrating every publication, every semester end, every achievement and accomplishment. Thank you for helping me to make

the tough decisions, for encouraging me to continue, and for allowing me to vent about “academia”. Graduation will not be the same knowing that you are not Earthly present to celebrate with me, to beam at me in my regalia and hood, to shine as you admire my diploma, and to recount memories of your own such accomplishments. I rest in knowing that you celebrate just as greatly in your heavenly home. I love you always Grandpa – this bird’s for you.

May 5, 2017

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CHAPTER 1

INTRODUCTION

The purpose of this study is to examine the direct and indirect relationship of family support, social and economic constraints, care setting, and spirituality on caregiver burden.

A caregiver is a person who supports, assists, protects or otherwise provides unpaid, direct care to an individual who in some way is not able to fully provide for their own needs (U.S. Department of Health and Human Services, Administration for Community Living, 2015a). This paper will be primarily focused on caregivers of Older Adults (OA), their subjective caregiver burden and the impacts of proximity of familial support, relatedness of familial support, spirituality, economic and social constraints and care settings, as they impact caregiver burden.

Though the concept of caregiver burden has in some form been a field of study for more than fifty years (Grad & Sainsbury, 1963). Though the terms may differ in certain areas of the literature, the definition, more or less, remains consistent that it is the characteristics of a caregiving situation coupled with the availability of resources that has a direct relationship to the well-being of the caregiver (George & Gwyther, 1986; Kasuya, Polgar-Bailey, & Takeuchi, 2000; Lazarus & Folkman, 1984; Stucki & Mulvey, 2000; & Zarit, Reever & Bach-Peterson, 1980)

Significant research has been conducted over the last decade, investigating the caregiver situation, caregivers themselves, caregiver stress and burden, and much more. As such, we know quite a bit about caregivers, and caregivers of older adults. In 2009, more than 30% of the American population reported providing unpaid care to at least one person (Collins & Swartz,

2011). Unpaid caregivers provide as much as 90% of the long-term care needed for community-dwelling patients (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014). In the United States, approximately 62% of caregivers of OA are Caucasian, 16% are Hispanic. Caregivers of OA's median household income (\$55,000) is slightly higher than that of the overall United States (53,046). Most live in an urban or suburban setting, most are married or living with a partner and just under a third have a child or grandchild under the age of 18 residing in their home. About 60% of OA caregivers are female, and a vast majority (86%) are caregiving for a relative. Approximately 60% are employed during the time of caregiving as well (National Alliance for Caregiving [NAC], and American Association of Retired Persons [AARP] Public Policy Institute, 2015).

In a meta-analysis of caregiver outcomes in anti-dementia trials, Lingler, Martire, & Schulz, (2005) found across the seventeen studies meeting their inclusion criteria, that none provided a theoretical framework for the use of caregiver burden. Without a theoretical framework underpinning the concept of caregiver burden much discrepancy is present in the literature toward consistent and rigorous definition of this phenomenon (Bastawrous, 2013; Braithwaite, 1992; Gräbel & Adabbo, 2011). Bastawrous (2013) highlights that 'caregiver burden' has been a useful way to consider how caregiving may adversely impact the caregiver; however it can encompass physical, psychological, emotional, social and financial stresses that result from the provision of care, making it multidimensional. This is one area where the research aligns – the fact that caregiver burden is a multidimensional concept (Unson, Flynn, Haymes, Sancho, & Glendon, 2016; Adelman, Tmanova, Delgado, Dion, & Lachs, 2014; Bastawrous, 2013; Townsend, Ishler, Shapiro, Pitorak, & Matthews, 2010; Braithwaite, 1992). As such, research into caregiver burden can focus on all, or just some of these aspects. More

recently, burden has been divided to include subjective (i.e. emotional/psychological impact, such as stress/anxiety) and objective (i.e. physical or instrumental provision of care, such as number of hours provided) burden (Bastawrous, 2013; Braithwaite, 1992). Again, some studies may focus on one or both of these areas, further complicating the definition issue. According to Gräbel and Adabbo (2011) caregiver burden generally can be described as a theoretical construct that describes the disproportion of demands and resources placed upon a caregiver in the caregiver – care recipient relationship. Braithwaite (1992) also highlights Poulshock and Deimling’s (1984) conceptualization of caregiver burden as a subjective phenomenon, asserting that what is burdensome for one may not be for another.

Neither the International Classification of Diseases (ICD-10), nor the Diagnostic and Statistical Manual (DSM 5) list codes or criteria for classifying caregiver burden (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014; American Psychiatric Association [APA], 2013; World Health Organization [WHO], 1992). The lack of a diagnostic code emphasizes not only a lack of uniformity of the conceptualization of caregiver burden, but also that it is not acknowledged as a mental or behavioral health disorder, with articulable criteria; despite the fact that many acknowledge an emotional or psychological component.

Despite these issues in defining caregiver burden, researchers continue to use and develop measurement(s) for the concept either from the focus of a personal reaction to the experience of providing care, or by characterizing the negative effects of the caregiving relationship (Braithwaite, 1992).

CHAPTER 2

REVIEW OF THE LITERATURE

Risk and protective factors

Though a consensus does not exist for codifying caregiver burden, a variety of factors have been identified that may be associated with the phenomenon. Across studies there does not seem to be consensus among these factors either, however some of the more common risk factors for reporting caregiver burden include, but are not limited to: being female, having low educational attainment, co-habiting with care recipient, pre-existing or prior bouts of depression/anxiety, social isolation, financial stress, spending a high number of hours providing care, reporting a lack of choice to serve as caregiver, being unmarried/unpartnered, being older, and concurrently being employed (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014; Chindaprasirt, J., Limpawattana, P., Pakkaratho, P., Wirasorn, K., Sookprasert, A., Kongbunkiat, K., Sawanyawisuth. K., 2014; Lero, Keating, Fast, Joseph, & Cook, 2007)

Contrary, factors that limit caregiver burden, or perhaps protect caregivers from experiencing caregiver burden have also been identified. Again there is great variation in the literature regarding the association of these factors, but commonly identified factors include, but are not limited to: being older, caregiving to cancer/heart disease patients at the end of life (as compared to other conditions), having positive intrapsychic resources, having others to assist in the provision of care, having self-reported better health (Townsend, Ishler, Shapiro, Pitorak, & Matthews, 2010), the perception of available social support, and family function (Chiou, Chang, Chen, & Wang, 2009),

Though the literature lacks a consensus regarding how to conceptualize caregiver burden and what specific factors may lead to positive or negative outcomes from the caregiving experience, there are clear areas where very little, if any research has been conducted. Those areas include 1) the proximity of the caregiver to the care recipient; 2) the closeness of the family relationship; 3) the impact of setting on caregiver burden; and 4) the impact of spirituality on caregiver burden. These variables specifically are important, and important to collectively investigate regarding their impact on caregiver burden as from a holistic systems perspective they provide an inspection of the multifaceted aspects of the caregiving phenomenon. These variables examine the external support relationship(s) provided to the caregiver, the quality of the caregiver's relationship to the patient, the relationship/belief the caregiver has in a faith-based, emotional-support relationship, and how where the patient (and potentially the caregiver) reside may impact the caregiving situation. These interactions create a caregiving system that can either support the care-relationship, or diminish it.

Of the research in these areas we know that dyad characteristics incorporate three factors that contribute to the caregiver relationship: 1) the nature of kinship or friend relationship; 2) the quality and closeness of the relationship; and 3) the distance versus co-residency of the caregiver and care recipient. Research findings are not consistent in identifying if the level of family relatedness of the caregiver to the patient, signifies that they will experience more negative outcomes (Lero, Keating, Fast, Joseph, & Cook, 2007). Cohabiting caregivers are at a greater risk of feeling physical and mental effects of caregiving, including social isolation (Lero, Keating, Fast, Joseph, & Cook, 2007). Less attention has been paid to investigating primary caregivers who consistently provide care from a distance, however some reports have shown that

these caregivers report a negative impact on their mental health (Lero, Keating, Fast, Joseph, & Cook, 2007).

The impact of religion/spirituality on caregiver burden has only recently begun to become more widely investigated. Evidence for the impact of religion/spirituality on caregiver burden is unclear, with the majority of studies finding either no, or a mixed association (Hebert, Weinstein, Martire, & Schulz, 2006), some with associations to specific cultural/ethnic groups (Morano, & King, 2005; Spurlock, 2005). Qualitative or pilot studies have produced positive associations but are not generalizable (Bull, 2014; Bialon, & Coke, 2012). This is another area where there is a variety of measures being used to examine a multidimensional issue, largely without theoretical underpinnings to guide the research.

Regarding care setting and caregiver burden, even less data exists specifically regarding this subject. Generally care setting is combined with other factors when examining caregiver burden, and often is not investigated at all. Kinoshita, Maeda, Morita, Miyashita, Yamagishi, Shirahige, Takebayashi, Yamaguchi, Igarashi, Eguchi, (2015) found that caregivers whose care recipient died at home, reported lower overall caregiver burden. Though we know that the care setting by and large can significantly impact the care relationship, the gap in the research about caregiving across care settings is apparent.

Theoretical approaches to explaining caregiver burden

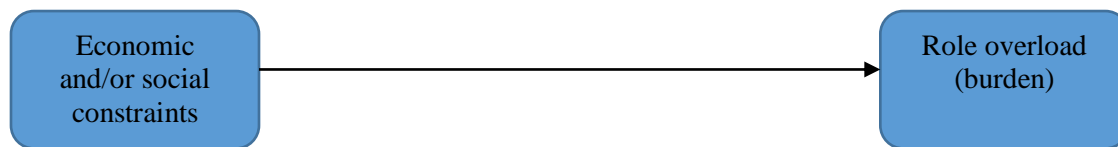
As previously highlighted, caregiver burden is not a consistently articulated concept, offering little in the way of unified theoretical frameworks underpinning its development, use, and measurement (Lingler, Martire, & Schulz, 2005). Many theories have been discussed in conjunction with the topic or applied to the issue. Some of the more applicable include role theory, equity theory and the life span perspective. These have been used in attempt to align

caregiver burden with a theoretical base (Bastawrous, 2013; Hogstely, Curry, & Walker, 2005; Quinn, Clare, & Woods, 2009; Guerrero, Andersen, & Afifi, 2007).

Role theory. Role theory postulates that humans act in varying yet predictable ways based on the expectations and circumstances of the social role within which they are operating (Bastawrous, 2013; Biddle, 1986). Role overload (or strain) and role conflict are two important facets of role theory that specifically apply to caregiver burden. Role overload occurs when people do not have adequate time and resources to accomplish obligations associated with their role(s). Role conflict then occurs when the expectations of the many roles a person may hold, contradict with one another (Bastawrous, 2013; Biddle, 1986). Role conflict and role overload arise for caregivers when individuals, agencies, and social institutions do not have mutually agreed upon role expectations, and when time and resources are limited. To be put more simply, when a person is facing economic or social constraints, they may experience role overload or burden (see figure below) This may be further complicated by the fact that the person may be of such a social stature or possess limited power in the situation and therefore may not be able to negotiate out of taking on a role that may cause strain (Bastawrous, 2013; Biddle, 1986).

Figure 1

Visual Depiction of Role Overload



Bastawrous (2013) highlights that there are many expectations of caregivers, including providing physical support to the care recipient, providing emotional support to the care recipient, perhaps providing executive support (such as assisting with paperwork and/or decision

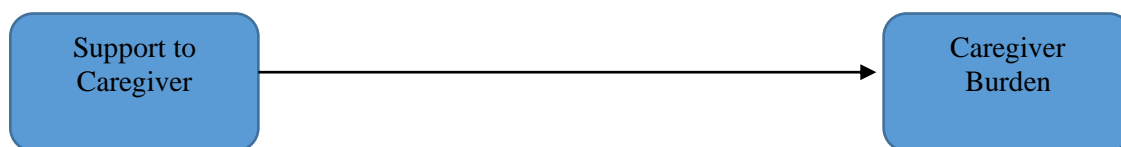
making), in addition to the expectations already placed upon them by their existing roles. These existing roles could be that of a spouse, a parent, a child, all of the above; they could be employed and fulfilling expectations in this role, perhaps they belong to civic organizations where they have ongoing responsibilities, etc. All of these roles require some sort of commitment and are “normed” within our society. The pressure to perform as a caregiver is compounded, for family caregivers, by the sense of duty, adding more strain to the role and relationship. Additionally, agencies providing services to the care recipient, often have expectations of the caregiver that are societally normed as well. Caregivers may be scrutinized or devalued for not meeting these expectations. As such, role theory provides a lens through which we can examine the roles and expectations caregivers fulfill and the supports they use to manage said expectations, in examining the weight of caregiver burden.

Social exchange theory. Relationship quality is a factor that is considered in some of the literature relating to caregiver burden. As such, relationships can have a significant impact on the caregiving experience. Social exchange theory draws on sociological conceptions by Homans (1961) and Blau (1964) and assumes that relationship decisions are driven by rewards and costs; both parties in the relationship take responsibility for one another and depend on each other. Very simply, costs are the aspects of the relationship that have negative value to a person, where rewards or benefits are the aspects of the relationship that have positive value. It is posited that people calculate the worth of a relationship by taking costs from benefits ($\text{Worth} = \text{benefits} - \text{costs}$). Homans established five key propositions that he purports’ structures people’s behaviors based on benefits and costs: 1) the Success Proposition believes that behavior that creates positive outcomes will likely be repeated; 2) the Stimulus Proposition states that if a person’s behaviors is rewarded, the individual will likely continue this behavior; 3) the Value Proposition

states that if a result of an action is considered valuable by the person, it is more likely to happen; 4) the Deprivation-satiation Proposition reasons that if an individual receives the same reward, over time that rewards value diminishes; and 5) this unnamed proposition purports that when a person receives more benefit than they expect, or are not punished as they anticipate, they will be emotionally satisfied and will behave positively (Blau, 1964; Call, Finch, Huck, & Kane, 1999; Cook & Rice, 2006; Homans 1961). Through the first three propositions, along with the fifth, help to explain why caregivers continue to engage in certain behavior toward patient care, even perhaps when they have been instructed not to do so by formal caregivers. The fourth proposition however, also highlights why overtime, some caregivers may identify feelings of burnout, or feelings of a lack of appreciation for the care provided, and at times may withdraw from, neglect or relinquish their caregiving duties (Liang, Krause, & Joan, 2001). In terms of caregiving this points to a need for support of the caregiver to be present. The more support available to a caregiver the less likely a caregiver might be to perceive or experience caregiver burden when viewed via social exchange theory.

Figure 2

Visual Depiction of the Potential Relationship Between Caregiver Support and Caregiver Burden.

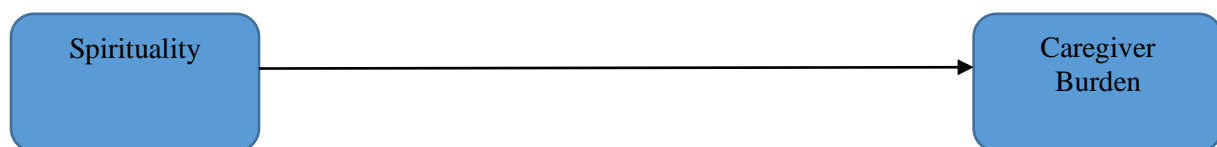


Gerotranscendence theory. Gerotranscendence is a relatively newer theory, developed in the late 1980's that examines the aging process from a quality of life perspective and asserts that people are constantly developing new and different ways of perceiving the world, their world (Thorsen, 1998). Tornstam (2006, 2011) asserts that people do not actually decline as they

age, but that they continue to shape and redefine their fundamental identity as an individual (Thorsen, 1998). Gerotranscendence purports that this sense of self does not fit the popular notion of “successful aging” particularly in the areas of purpose, and activity, but that the aging person still identifies a positive quality of life experience. Tornstam’s (2006, 2011) studies focused on three dimensions of self-reported behaviors that characterize gerotranscendence, they include: (a) the experience of time and nature, referred to as the cosmic level; (b) a sense of self; and (c) personal and social relationships. The changes that occur in each dimension are the shell of gerotranscendence. While each of these behavior clusters are characterized by specific activities or behaviors, the sense of self has some specific behaviors that are key to examining the caregiver and caregiver burden experience. One aspect of sense of self focuses on an older person abandoning their “body” in old-age, meaning they become less focused on the physical/body-preoccupation and become more focused on the spiritual and/or altruistic side of themselves. This aspect points to a spiritual connection as an important piece of self-acceptance, self-care, self-support and just self. In their review, Herbert, Weinstein, Martire, and Schulz (2006) found that a supportive spiritual social network impacts a persons/caregivers well-being.

Figure 3

Spirituality’s Potential Relationship with Caregiver Burden from Gerotranscendence Theory



Life span perspective. Life span perspective as a theoretical framework highlights ongoing interaction and integration of individual abilities with societal demands and available resources. This perspective offers a means to understand conflicts, opportunities and

achievements of people at different developmental stages, accounting for patterns of transition and transformation from one life stage to another. The assumptions of life span perspective that are useful in understanding caregiver burden include: individual development is a lifelong process; that growth occurs at every stage of life; social relations and emotional well-being are areas or types of growth; each person must be viewed from a holistic perspective; and that behavior must be viewed from the relevant context of personal relationships. It is posited that self-awareness, harnessing skills in self-regulation and having stable social relationships maybe the most crucial resources for the illness and aging processes (Baltes, Reese, & Lipsit, 1980; Baltes, 1987; Baltes & Lindenberger, 1997; Baltes, Staudinger, & Lindenberger, 1999; Baltes, & Smith, 2003; Hogstely, Curry, & Walker, 2005; Roberto, & Jarrott, 2008). Roberto and Jarrott (2008) concluded that research conducted on the basis of the principles of the life span perspective identify the individual and relational issues surrounding aging family care, and have the potential to inform policy and professional practice in supporting caregivers.

Policy/program initiatives that currently address caregiver burden

Government funded programs for the care of the elderly, or disabled continue to enjoy the cost savings provided by unpaid family caregivers (Braithwaite, 1992). It has been suggested in the literature that if these individuals were paid, it would reduce burden and maintain or increase their provision of care, thereby avoiding or at least postponing institutionalization needed for care provision; however there is not significant research to support this (Braithwaite, 1992). Existing research tends to focus more on issues of caregiver burden through educational programs, measures of caregiver burden and respite/support programs, in short term foci (Braithwaite, 1992). Policy development in this area should focus on items that examine long-

term caregiving situations, the time to institutionalization and the factors that lead to institutionalization.

National initiatives and legislation. The most notable policy program to help caregivers/caregiver burden is the Older Americans Act (OAA). Originally passed in 1965 to develop/strengthen social services for older adults, this program established the Administration on Aging and is now the Federal foci on matters related to older adults (U.S. Department of Health and Human Services, Administration for Community Living, 2015b). The OAA encompasses programs such as meals on wheels, caregiver support programs, elder abuse prevention, transportation, education, and so on (U.S. Department of Health and Human Services, Administration for Community Living, 2015b). In addition to the OAA, currently there is an income tax credit available to caregivers, to assist with offsetting financial burdens of caregiving; however it comes with significant criteria. Some of these criteria include a very low taxable income for the care recipient, the caregiver must be providing more than 50% of the financial support the care recipient receives, and so on (Hasson, 2015).

The National Family Caregiver Support Program has been in effect since the year 2000. This program provides funding to the states, primarily via Area Agencies on Aging, to support family caregivers through educational programs, assisting with access, counseling/caregiver training, and respite care (U.S. Department of Health and Human Services, Administration for Community Living, 2015a).

Additionally several pieces of legislation have been proposed to either the house, senate or both, or legislation that is forthcoming include: The RAISE; Social Security Caregiver Credit Act of 2015; National Care Corps Act of 2015; the Family and Medical Insurance Leave (or FAMILY) Act; the Care Planning Act of 2015; Americans Giving Care to Elders (or AGE) Act;

Credit for Caring Act; Lifespan Respite Care Reauthorization Act of 2015; Congressional Assisting Caregivers Today (or ACT) Caucus; and the Social Security Caregiver Credit Bill. Collectively these pieces of legislation seek changes such as, setting up a National Family Caregiving Strategy and Advisory Council, provide a social security credit to persons serving as a caregiver, provide community volunteers to support family caregivers, to allow people to use the Family Medical Leave Act (FMLA) to take time from work to provide care to a loved one, to add a Medicare Benefit for people to receive advance care planning services, provide a tax credit for family caregivers, increase funding for existing caregiver programs, to extend previous federally funded respite programs, and to develop a Caucus that will inform Congress regarding issues pertinent to family caregivers/caregiving (National Alliance for Caregiving, 2016).

Initiatives and legislation designated for veteran caregivers. The Veterans Administration (VA) and supporters have a long-standing commitment to provisioning services not only to veterans but also to their caregivers. Recently, concerted efforts have been made to expand the current programming and support available.

The Caregivers Expansion and Improvement Act of 2013 (S.B. 851) was introduced by Vermont Junior Senator Bernard Sanders, in July of 2013 (govtrack, 2016a). This bill was designed to extend the current program and provide a more comprehensive assistance program to family caregivers of veterans with a serious service-connected injury. This bill was referred to and has been reported out of committee in the senate. The reciprocal house bill (H.R. 3383) is still in committee as of October 2013, and does not appear to have any momentum for movement (govtrack, 2016a).

The Military and Veteran Caregiver Services Improvement Act of 2015 (S.B. 1085) was introduced by Washington Senior Senator Patty Murray, in April 2015 (govtrack, 2016b). The

purpose of this bill is: to make veterans of all eras eligible to have access to all caregiver support services, to allow Post-9/11 GI Bill benefits to be transferred to dependents; to expand eligibility to VA caregiver programs allowing for more illnesses including mental health to be included; to make caregivers eligible for VA child care programs; to provide more assistance with Activities of Daily Living (ADLs); to reauthorize the LifeSpan Respite Care Act; and to further address many of the findings and recommendations from the RAND Corporation's report aimed specifically at improving and expanding the VA caregiving program(s) (govtrack (2016b ; Ramchand, Tanielian, Fisher, Vaughan, Trail, Epley, Voorhies, Robbins, Robinson, & Ghosh-Dastidar, 2014).

Caregivers Access and Responsible Expansion (CARE) for all Veterans ACT (H.R. 2894) was introduced in June 2015 by Congressman Ryan Costello of Pennsylvania and Congresswoman Elizabeth Etsy of Connecticut. This bill is proposed to increase access to the current VA caregiver support program to include services for all service-era veterans. This bill has been referred to committee and no further action has been taken at this time (National Alliance for Caregiving, 2016).

Davis, Gilliss, and Harper, (2011) highlight the need for policy and support programs specifically in rural communities, citing the high number of elderly that live alone, and at a distance, without primary caregivers or support systems to help them remain in their homes. The AARP public policy institute demands that better assessment and response to caregivers' needs though public programs should be a priority at every level (Feinberg, & Houser, 2012).

Methodological limitations of empirical research on Caregiver Burden

Much of the current literature on caregiver burden does not rely on theoretical frameworks that guide research to form an understanding of the processes by which some

caregivers experience negative outcomes and others do not (Kim, & Given, 2008; Hebert, Weinstein, Martire, & Schulz, 2006). Much of the available research has relied upon hypotheses that use analytical approaches examining the relationship of a factor to the outcome, after controlling for other variables, looking primarily at outcomes independent of direct effects of the caregiving situation to caregiver burden. However, the one thing that all sources agree upon, is that caregiver burden is a multidimensional phenomenon. Though these studies have been useful in pointing to a wide range of possible mediators to caregiver burden, they do not provide a comprehensive picture of direct and indirect relationships that impact caregiver burden. Extensive research, guided by theoretical frameworks must be conducted using advanced statistical techniques in order to more conclusively depict caregiver burden. Due to the lack of evidence in this area, factor analyses and multiple regression analyses, would be the introductory step to begin to codify the relational variables that impact caregiver burden.

CHAPTER 3

RESEARCH METHODOLOGY

Purpose

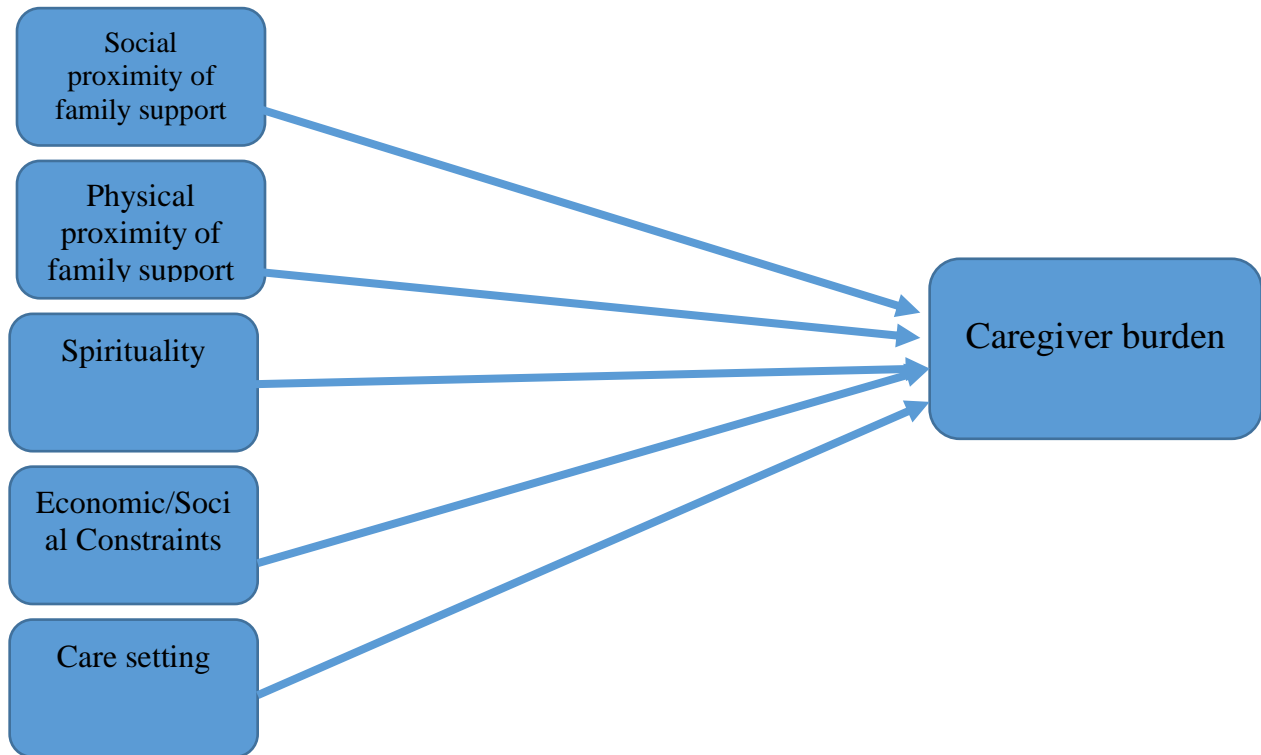
The purpose of this study is to examine the direct and indirect relationship of family support, social and economic constraints, and spirituality on caregiver burden, with the understanding that these relationships may vary based on the type of care setting (i.e. community, facility placement, hospice).

Hypotheses

Drawing on the literature where Lingler, Martire, & Schulz, (2005) found across the seventeen studies meeting their inclusion criteria, that none provided a theoretical framework for the use of caregiver burden, therefore it is important for any study examining caregiver burden that a theoretical framework is utilized to build the knowledge base. The proposed model (see below) views social proximity of family support to the caregiver, physical proximity of family support to the caregiver, spirituality of the caregiver, and social and economic constraints of the caregiver/household as all contributing to the caregiver burden of the primary caregiver.

Figure 4.

Hypothesized Model of Caregiver Burden



It is hypothesized that:

- 1) The more closely related a support person is to the caregiver (or the closer in social proximity of family support that they are) the less caregiver burden the caregiver will endorse. (H1)
- 2) The closer in physical proximity that support person(s) are to the caregiver, the less caregiver burden the caregiver will endorse. (H2)
- 3) The more spiritually engaged a caregiver is, the less caregiver burden they will endorse. (H3)
- 4) The fewer social/economic constraints a caregiver/household faces, the less caregiver burden that caregiver will endorse. (H4)

- 5) Caregivers experiencing any combination of hypotheses 1 – 4 will report a greater reduction in caregiver burden, than those with none or only one of these supportive factors in place. (H5)
- 6) The higher the level of residential care, the more burden a caregiver will endorse. (H6)
- 7) The proposed model will provide a statistically significant measure of caregiver burden. (H7)

Data Source

This study analyzed a portion of the 2004 data from the National Long-Term Care Survey (NLTC). This survey was funded by the United States Department of Health and Human Services, the National Institutes of Health and the National Institute on Aging and conducted by the U.S. Census Bureau.

Sampling

The study includes a sample that is nationally representative of community and institutionalized populations aged 65 and older. Sample members are selected from a list of eligible Medicare beneficiaries provided by the Centers for Medicare & Medicaid Services (CMS). The survey contains variables in the areas of information regarding ADL and Instrumental Activities of Daily Living (IADL) disabilities, helpers and hours of help provided, equipment use, medical conditions, cognitive function, and demographic and socioeconomic characteristics, and much more (National Archive of Computerized Data on Aging, n.d.). The NLTC began with a screener interview to determine a person's functional and residential status. Individuals who are not functionally impaired and living in the community were given an abbreviated interview. Persons with functional impairment and living at home, were administered a detailed community interview. Persons residing in nursing facilities were also

administered a detailed interview, along with administrators and care persons in those care settings. Proxies with knowledge about the sample person's health conditions and physical abilities were interviewed either instead of or along with the sample participant if said participant was unavailable or unable to respond. The proportion of proxies participating varied across sections of the survey instrument, but comprised about one fifth of all respondents. The 2004 NLTCs contained 20,474 persons who completed the survey (Inter-University Consortium for Political and Social Research, 2008).

Operationalization of Variables

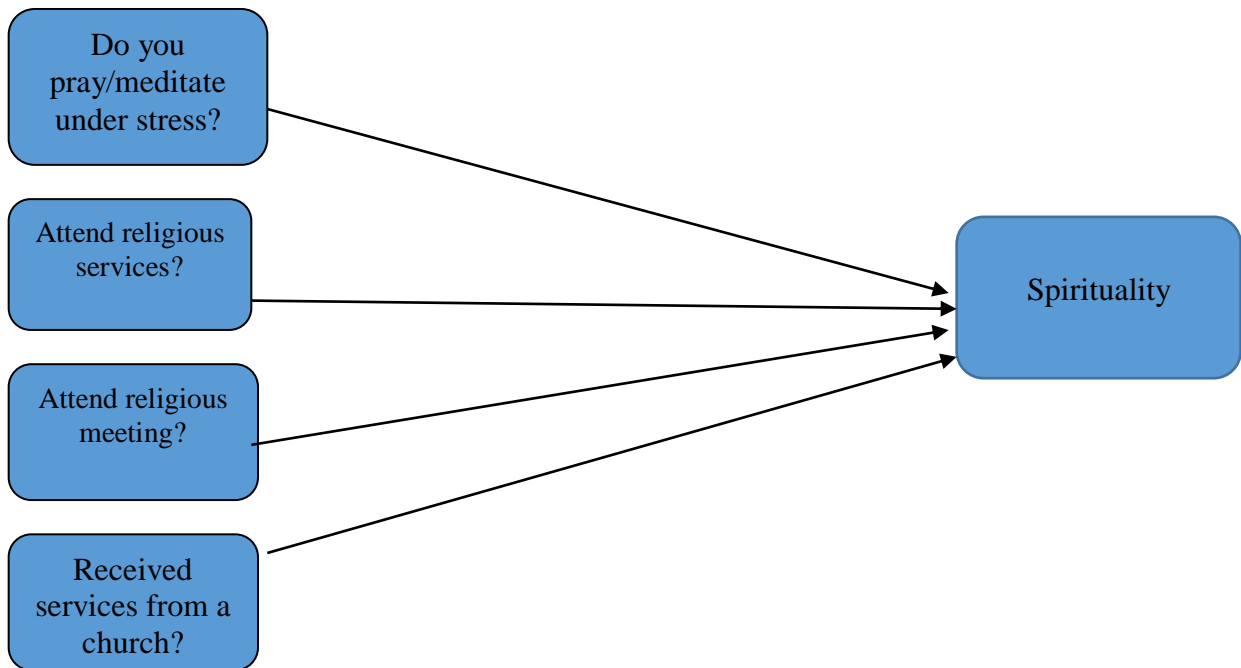
Caregiver burden. Caregiver burden is the outcome variable in this model. The longitudinal data within the NLTCs, along with other national data sets has been used to develop the Zarit Burden Interview of Caregiver Burden (Mathematica Policy Research, Inc., 2008). The Zarit is composed of eight categories that together measure the concept of Caregiver Burden; of the eight categories, six were taken straight from the NLTCs. These six categories will be used for purposes of this study to measure the outcome variable Caregiver Burden in this study. The categories are as follows: 1) the number of hours spent providing care in a given week; 2) the number of years spent providing care; 3) measure of the physical strain related to caregiving; 4) measure of the emotional strain related to caregiving; 5) measure of the financial strain related to caregiving; and 6) measure of other normal activities affected by caregiving (Mathematica Policy Research, Inc., 2008). The other two categories that have been added to complete the Zarit are 7) measure of the mental strain related to caregiving (Administration for Community Living, U.S. Department of Health and Human Services, 2016); and 8) measure of the impact of caregiving on employment (Schultz, Newson, Mittelmark, Burton, Hirsch, & Jackson, 1997). To complete the scale, though these last two items are not explicitly available in the NLTCs data

set, two items that are available in the dataset were added to complete the scale. These items are 7) measure of perceived mental strain related to completing caregiving tasks, and 8) measure of satisfaction of the quality of work, due to caregiving. These eight categories make up the Caregiver Burden Scale are each scale based items with nominal rank ordering. Each of these eight categories will be combined to create a composite scale. Cronbach's alpha will be used to determine internal consistency.

Spirituality. To measure whether or not the caregiver of a sample person is spiritually engaged, a weighted score was developed. The questions used to develop this score include: 1) "things people do when they are under stress from caregiving/how often do you pray/meditate"; 2) "During the past month did you/the sample person go to a religious service?"; 3) "During the past month did you/sample person attend a meeting of a ... religious ...; 4) and finally there was a series of ten questions where caregivers were asked to indicate whether a church/synagogue provided them/sample person with a needed service. For item 4 in this model, there were a number of response options for each of the 10 questions, one of which was a church/synagogue. Each variable was recoded with all other options coded to a "0" and the response option of church/synagogue recoded to a 1. Then these ten variables were added together to create one variable assessing whether or not services were provided by a church/synagogue.

Figure 5.

Model of Variables Proposed to Measure Construct of Spirituality



A confirmatory factor analysis (CFA) will be conducted using the aforementioned variables to measure the construct of spirituality/spiritual engagement of the caregiver. The above model displays the proposed factor loadings for this analysis.

Social proximity of family support. The 2004 NLTCS questionnaire and interview included over twenty levels of relationship for family members. Social proximity of family support has been operationalized to reflect the closeness in relationship of the family members providing support to the caregiver; i.e. kinship relation, not perceived intimacy. The family relationships considered here are listed as follows in the data: “spouse/spousal equivalent”, “son”, “daughter”, “son-in-law”, “daughter-in-law”, “mother”, “father”, “mother-in-law”, “father-in-law”, “brother”, “sister”, “brother-in-law”, “sister-in-law”, “other male relative”, “other female relative”, “male friend,” “female friend”, “male neighbor”, “female neighbor”,

“employee/someone hired”, “someone from helping organization”, “institution/assisted living center”, “legal guardian”, “unable to determine”, “someone else” “child gender unknown”. The categories of relationships listed for purposes of analysis were divided in to two variables coded as primary and secondary relationships. The recoded variable of primary relationships includes immediate familial relationships of spouse/equivalent, son, daughter, mother, father, brother, and sister. Secondary relationships include son-in-law, daughter-in-law, mother-in-law, father-in-law, brother-in-law, sister-in-law, other male relative, other female relative, male friend, female friend, male neighbor, female neighbor, employee/someone hired, someone from helping organization, institution/assisted living center, legal guardian, someone else, and child gender unknown. Unable to determine was coded as a no or non-response.

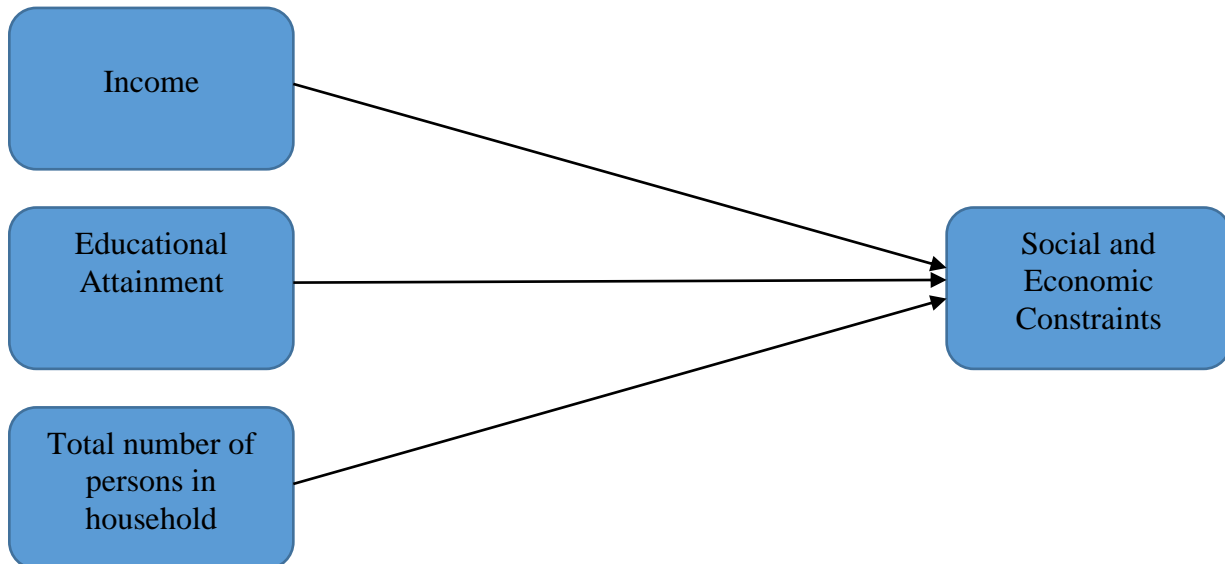
Physical proximity of family support. Of the many factors that impact support for caregivers, often the ability to quickly receive direct support from the caregivers’ network can be crucial. One question in the survey really focuses on how far a supportive person is from the caregiver, to lead to the proximity of this family support to the caregiver. This question asks “about how long does it usually take for [person] to get here from [where] (he/she) lives?”. The blank is to be filled in by the relative categories operationalized in this study as social proximity of family support. The original survey provided responses for all categories of relationship and as such they were combined similarly to those in the social proximity category, in order to maintain the integrity of the data. However, these 20 individual variables were combined into just one variable, representing all family members and their relative distance to the patient and caregiver. The time is given in with options of “10 minutes or less”, “11 – 30 minutes”, “31 – 60 minutes”, “61 minutes [or more], but less than one day”, “1 day or longer”.

Economic and social constraints. Several variables help to define the social and economic constraints of any life or relationship. Based on the data available in the 2004 NLTCs, the variables that most represent these constraints include total household income, educational attainment, and the number of persons residing in the home/with the sample person. For the variable of the number of persons residing in the home, the response options ranged on a scale from 1 to 8.

The data included five levels of household income that were listed as “\$5,000 or more?”, “\$10,000 or more?”, “\$25,000 or more?”, “\$50,000 or more?”, and “\$75,000 or more?”. These variables were coded to create a weighted score, if someone fell into the first category they were given a score of “1”, in the second category a score of “2” and so on, for a total available score of “5” if their total household income was listed as \$75,000 or more. Likewise, educational attainment was also recoded to a weighted score with four options that combined the prior 17 categories. If a person did not graduate from high school or have a GED equivalent they were given a score of 1; if a person graduated high school, had a GED or equivalent, completed some college but did not earn a degree, or received an associates or technical degree, they were given a 2; if a person completed a bachelor’s degree they were given a score of 3, and if they had completed a graduate degree and/or more, they were given a score of 4.

Figure 6

Visual Depiction of Economic and Social Constraints Proposed for the Larger Caregiver Burden Model



Using SPSS factor scores were obtained for the variables listed and a new variable created representing social and economic constraints using these scores.

Care settings. As discussed in the literature review, the type of care setting can greatly impact perceived caregiver burden. As such this study also seeks to compare the outcome variable results across care settings. Though the larger survey asks very specific questions about the types of care settings, for purposes of this study only two types of care settings will be broadly defined and examined: 1) living in the community; 2) living in a supported residence/facility. Living in the community is broadly defined as those not living in a setting that provides supports/assistance. Primarily this is those patients who still reside in their home/apartment either alone or with their caregiver, etc. Supported living includes assisted living facilities, nursing homes, group homes, and other residences that provide supportive assistance to the patient and/or caregiver.

Control variables. Several variables have been identified as control variables within this study that have the potential to significantly impact the outcome based on the model, if not controlled for: 1) the patient's level of functional ability, 2) the quality of the patient-caregiver relationship; 3) race; and 4) gender. The response options for gender in this study include only male or female. Race included over 50 response options for participants that for purposes of this study have been recoded to a nominal variable including: "Caucasian", "Hispanic", "African American/Black", "American Indian/Alaskan Native", "Native Hawaiian/Pacific Islander", "Asian", or "other". Gender was coded as 2 for female, 1 for male.

The patient's level of functional ability is assessed in accordance with the Katz Index of Independence in Activities of Daily Living (Katz, 1983; Kresevic, Mezey, 2003). This is a reputable scale that looks at six areas of functional ability, giving an overall score for a patient's functional status. These areas include bathing, dressing, toileting, transferring, continence, and feeding. If a person is able to complete each of these items independently, they are given a point of "1" for that item, if they require assistance, they are given a "0". As such the larger questionnaire contains questions in each of these areas that were examined and recoded to follow this same scoring method. The questions from the survey are as follows: 1) "bathing without help", 2) "dressing without help", 3) "getting to the bathroom or using the toilet", 4) "getting in or out of chairs without help", 5) "controlling bowel movements or urination or ever have any accidents", and 6) eating without the help of another person or special equipment". Each of these items offered response options of "yes" or "no" which were recoded to "1" and "0" to match the Katz Index scoring method.

Though there may be several items within the questionnaire that could be used to define the quality of the patient-caregiver relationship, several were used to construct the concept of

caregiver burden, and therefore would be highly correlated within the model, if recycled as a control variable. These items include questions regarding perceived stress of the caregiver. One question however speaks to satisfaction and therefore may be the most appropriate indicator of a quality relationship, available within the data. This question asks “generally speaking, how satisfied are you...”. Quality relationships are often characterized by how satisfied each person in the relationship feels with the relationship status. This item offers a likert scale of “very satisfied = 1”, “satisfied = 2”, “not satisfied = 3”.

Statistical Analysis

This section will review the statistical analyses used to test the model discussed above (see page 17).

Cronbach’s Alpha. The Cronbach’s Alpha was used to test the internal consistency of the caregiver burden scale that is the outcome variable in this study. As prior research has used these items to measure caregiver burden we have a working knowledge of the internal consistency of this scale. Cronbach’s alpha validates the scale within this data set.

Confirmatory factor analysis (CFA). A confirmatory factor analysis was conducted to test the construct validity of spirituality for use in the larger model. As these activities are generally indicative of spiritual/religious engagement, this provides a working knowledge of the underlying latent variable structure. A CFA provides a goodness-of-fit specific to this study and the data collected. Each of the categories was loaded to verify measurement of the spirituality construct (Byrne, 2010).

Principal component analysis (PCA). The variable-reduction technique, PCA was used to reduce the variables listed, to one variable representing social and economic constraints, while still accounting for most of the variance of the original variables.

Hierarchical regression. Following the CFA a hierarchical regression was conducted to analyze the impact of the five proposed independent variables on the proposed outcome variable of Caregiver Burden, hypothesis seven. Hierarchical regression is indicated for this model structure as it is designed to build successive linear regression models upon one another, allowing for examination of each additional component and their impact on the overall model (Gelman, & Hill, 2007). The control variables listed will first be loaded into the regression model in IBM SPSS Statistics version 24 and the analysis run. Following this each independent variable will be loaded into the model for testing and comparison to determine model prediction and variance/covariance. Additionally, individual hierarchical regressions will be conducted to test hypotheses one through six.

CHAPTER 4
ANALYSIS

Caregiver Burden

A Cronbach's Alpha was conducted to determine internal consistency of the Caregiver Burden scale. The Caregiver Burden scale was found to be relatively reliable (8 items; $\alpha = .717$).

Table 1

Reliability statistics output for Caregiver Burden Scale analysis.

Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
.717	.947	8

Spirituality

A confirmatory factor analysis was conducted to assess the model fit of the concept of spirituality. See Table 2 for a visual of the factor analysis model. Due to a high error variance, e1 and e2 in the model were associated. Once these were linked, the model shows a strong goodness of fit, with an RMSEA of .009 and an AGFI of .999 to demonstrate model fitness. The factor score weights from this model were used to develop a composite scale for the variable of spirituality within the larger caregiver burden model for this study.

Table 2

Confirmatory factor analysis model of the concept of Spirituality.

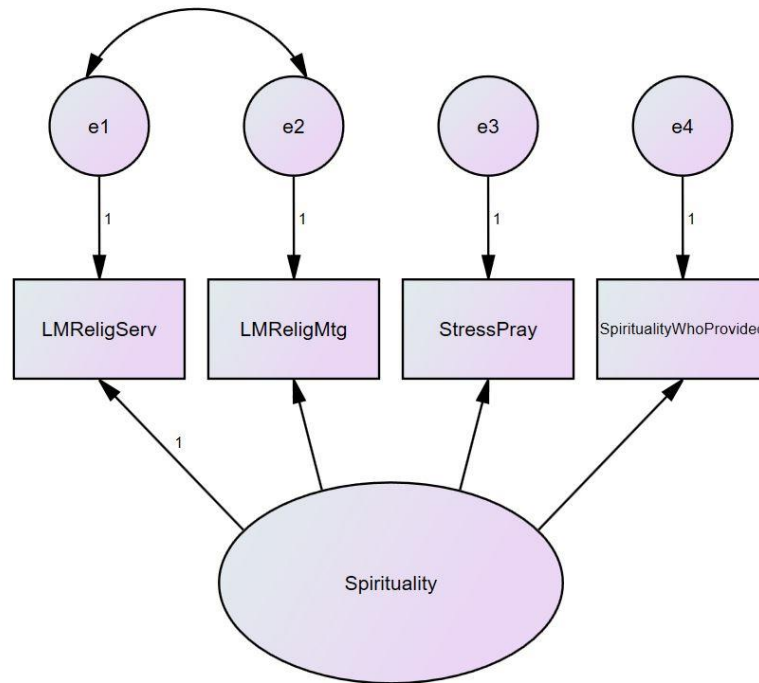


Table 3.1

AGFI output from Amos, for Spirituality model fitness.

Model	RMR	GFI	AGFI	PGFI
Default model	.000	1.000	.999	.100
Saturated model	.000	1.000		
Independence model	3.250	.555	.259	.333

Table 3.2

RMSEA output from Amos, for Spirituality model fitness.

Model	RMSEA	LO 90	HI 90	PCLOSE
Default model	.009	.000	.023	1.000
Independence model	.866	.861	.871	.000

Social proximity of family support

Analysis on this variable was not required in preparation for inclusion in the model, however these variables were transformed into two variables (down from over 20 individual variables) classifying primary and secondary relationships. Descriptive statistics are provided for these two variables below.

Table 4.1

Descriptive statistics for the variable of Primary Relationships.

		Primary Relationship			
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	19799	96.7	96.7	96.7
	spouse	442	2.2	2.2	98.9
	son	110	.5	.5	99.4
	daughter	85	.4	.4	99.8
	mother	15	.1	.1	99.9
	father	5	.0	.0	99.9
	brother	12	.1	.1	100.0
	sister	6	.0	.0	100.0
	Total	20474	100.0	100.0	

Table 4.2

Descriptive statistics for the variable of Secondary Relationships.

		Secondary Relationship			
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	20408	99.7	99.7	99.7
	son in law	1	.0	.0	99.7
	daughter in law	2	.0	.0	99.7
	brother in law	1	.0	.0	99.7
	sister in law	1	.0	.0	99.7
	other male relative	19	.1	.1	99.8
	other female relative	27	.1	.1	99.9
	male friend	4	.0	.0	99.9
	female friend	5	.0	.0	100.0
	employee/someone hired	2	.0	.0	100.0
	someone from a helping organization	1	.0	.0	100.0
	someone else	3	.0	.0	100.0
	Total	20474	100.0	100.0	

Physical proximity of family support.

As described in the previous chapter, this variable was manually transformed from twenty individual variables representing the distance of each family member from the patient/caregiver, into one variable, representing the distance of all family members/support to the patient caregiver.

Table 5

Descriptive statistics for the variable of physical proximity of family support

		Distance from family member to caregiver and patient			
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	7366	36.0	36.0	36.0
	10 minutes or less	2666	13.0	13.0	49.0
	11 to 30 minutes	3031	14.8	14.8	63.8
	31 to 60 minutes	1661	8.1	8.1	71.9
	61 minutes but less than 1 day	3723	18.2	18.2	90.1
	1 day or longer	2027	9.9	9.9	100.0
	Total	20474	100.0	100.0	

Economic and social constraints

A principal component analysis (PCA) was conducted and a new variable created within the data set, from that analysis.

Table 6

Output from SPSS of PCA analysis of economic and social constraints.

Total Variance Explained						
Component	Total	Initial Eigenvalues		Extraction Sums of Squared Loadings		
		% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	1.525	50.817	50.817	1.525	50.817	50.817
2	.996	33.211	84.028			
3	.479	15.972	100.000			

Extraction Method: Principal Component Analysis.

The table displays that the majority of the variance can be explained by the first component of total household income, therefore there is no rotation in this analysis, as only one variable was extracted.

Care settings

The variable for care settings did not require independent analysis, however it was recoded from 10 options of levels of care, down to only two: independent living in the community, or living in a supported residence/facility (to include assisted living, nursing care, etc.). Descriptive statistics are provided below.

Table 7

Descriptive statistics for care settings variable.

		Care Settings			
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	None reported, no response	15591	76.2	76.2	76.2
	Independent	4024	19.7	19.7	95.8
	Supported Living	859	4.2	4.2	100.0
	Total	20474	100.0	100.0	

Control variables

Descriptive statistics are provided below for the control variables of gender and race.

Table 8

Descriptive statistics for gender of caregiver.

		Caregiver Gender			
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No response	20426	99.8	99.8	99.8
	Male	14	.1	.1	99.8
	Female	34	.2	.2	100.0
	Total	20474	100.0	100.0	

Table 9

Descriptive statistics for control variable of race.

		Race Categories			
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No data, no response	18221	89.0	89.0	89.0
	Caucasian	1664	8.1	8.1	97.1
	Hispanic, Spanish Origin, Mexican Origin	251	1.2	1.2	98.3
	African American, Black, African	179	.9	.9	99.2
	American Indian, Alaskan Native	22	.1	.1	99.3
	Native Hawaiian, Pacific Islander	19	.1	.1	99.4
	Asian	91	.4	.4	99.9
	Other	27	.1	.1	100.0
	Total	20474	100.0	100.0	

To assess the control variable of the patients level of functional ability, as discussed in the previous chapter, six variables were recoded according to the Katz Index of Independence in Activities of Daily Living (Katz Index).

Table 10

Descriptive statistics for the Katz Index variable, signifying the patient's level of functional ability.

		Katz Index		Valid Percent	Cumulative Percent
		Frequency	Percent		
Valid	.00	13401	65.5	84.9	84.9
	1.00	996	4.9	6.3	91.2
	2.00	386	1.9	2.4	93.7
	3.00	257	1.3	1.6	95.3
	4.00	238	1.2	1.5	96.8
	5.00	246	1.2	1.6	98.4
	6.00	259	1.3	1.6	100.0
	Total	15783	77.1	100.0	
Missing	System	4691	22.9		
Total		20474	100.0		

The final control variable considered in this model is the quality of the patient-caregiver relationship, measured via satisfaction.

Table 11

Descriptive statistics for quality of the patient-caregiver relationship.

		Quality of Patient Caregiver Relationship			
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Refused	42	.2	.2	.2
	Dont Know	19	.1	.1	.3
	Non-response	2497	12.2	12.2	12.5
	Skip	13608	66.5	66.5	79.0
	Breakoff	18	.1	.1	79.0
	Very satisfied	1572	7.7	7.7	86.7
	Satisfied	2376	11.6	11.6	98.3
	Not satisfied	342	1.7	1.7	100.0
	Total	20474	100.0	100.0	

Caregiver burden model (H7)

Hierarchical linear regression was used to test the proposed Caregiver Burden model. The output tables below display the analysis results which demonstrate statistical significance within the model.

Table 12.1

Model summary for hierarchical linear regression of Caregiver Burden model, displaying predictive power of the model.

Model Summary				
Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.437 ^a	.191	.191	21.634
2	.799 ^b	.639	.639	14.458
3	.799 ^c	.639	.639	14.458
4	.799 ^d	.639	.639	14.456
5	.825 ^e	.680	.680	13.613
6	.825 ^f	.680	.680	13.614

a. Predictors: (Constant), KatzIndex, Caregiver Gender, Generally speaking, how satisfied are (you)/[SAMPNAME] with your life as a whole - would (you/he/she) say (you/he, Race Categories

b. Predictors: (Constant), KatzIndex, Caregiver Gender, Generally speaking, how satisfied are (you)/[SAMPNAME] with your life as a whole - would (you/he/she) say (you/he, Race Categories, Zscore(SpiritualityWhoProvided), Zscore: Things people do when they are under stress from CG - prayer meditation, Zscore(LMReligServAdjusted), Zscore(LMReligMtgAdjusted)

c. Predictors: (Constant), KatzIndex, Caregiver Gender, Generally speaking, how satisfied are (you)/[SAMPNAME] with your life as a whole - would (you/he/she) say (you/he, Race Categories, Zscore(SpiritualityWhoProvided), Zscore: Things people do when they are under stress from CG - prayer meditation, Zscore(LMReligServAdjusted), Zscore(LMReligMtgAdjusted), PrimRelation, SecondRelation

d. Predictors: (Constant), KatzIndex, Caregiver Gender, Generally speaking, how satisfied are (you)/[SAMPNAME] with your life as a whole - would (you/he/she) say (you/he, Race Categories, Zscore(SpiritualityWhoProvided), Zscore: Things people do when they are under stress from CG - prayer meditation, Zscore(LMReligServAdjusted), Zscore(LMReligMtgAdjusted), PrimRelation, SecondRelation, Distance from family member to caregiver and patient

e. Predictors: (Constant), KatzIndex, Caregiver Gender, Generally speaking, how satisfied are (you)/[SAMPNAME] with your life as a whole - would (you/he/she) say (you/he, Race Categories, Zscore(SpiritualityWhoProvided), Zscore: Things people do when they are under stress from CG - prayer meditation, Zscore(LMReligServAdjusted), Zscore(LMReligMtgAdjusted), PrimRelation, SecondRelation, Distance from family member to caregiver and patient, Combined variable, Total household income, How many family members are in the household?

f. Predictors: (Constant), KatzIndex, Caregiver Gender, Generally speaking, how satisfied are (you)/[SAMPNAME] with your life as a whole - would (you/he/she) say (you/he, Race Categories, Zscore(SpiritualityWhoProvided), Zscore: Things people do when they are under stress from CG - prayer meditation, Zscore(LMReligServAdjusted), Zscore(LMReligMtgAdjusted), PrimRelation, SecondRelation, Distance from family member to caregiver and patient, Combined variable, Total household income, How many family members are in the household?, Care Settings

Table 12.2

Hierarchical Multiple Regression Analyses Predicting Caregiver Burden From Spirituality, Social Proximity of Family Support, Physical Proximity of Family Support, Economic and Social Constraints, and Care Setting

Model		Coefficients ^a		Standardized Coefficients	t	Sig.
		Unstandardized Coefficients	Std. Error			
		B		Beta		
1	(Constant)	-20.678	.268		-77.219	.000
	Caregiver Gender	2.087	2.055	.007	1.016	.310
	Race Categories	1.346	.272	.036	4.950	.000
	Satisfaction	1.651	.057	.209	28.901	.000
	KatzIndex	7.281	.148	.355	49.062	.000
2	(Constant)	-30.433	.271		-112.373	.000
	Caregiver Gender	.041	1.374	.000	.030	.976
	Race Categories	.214	.182	.006	1.178	.239
	Satisfaction	-1.418	.069	-.179	-20.471	.000
	KatzIndex	2.050	.109	.100	18.844	.000
	Zscore(ReligServ)	3.125	.280	.141	11.151	.000
	Zscore(ReligMtg)	2.794	.308	.126	9.062	.000
	Zscore(WhoProvided)	.390	.101	.018	3.847	.000
	Zscore: Stress – Prayer	14.287	.122	.668	117.060	.000
3	(Constant)	-30.424	.271		-112.315	.000
	Caregiver Gender	.515	1.927	.002	.267	.789
	Race Categories	.284	.187	.008	1.521	.128
	Satisfaction	-1.420	.069	-.179	-20.491	.000
	KatzIndex	2.052	.109	.100	18.861	.000
	Zscore(ReligServ)	3.136	.280	.142	11.186	.000
	Zscore(ReligMtg)	2.794	.308	.126	9.063	.000
	Zscore(WhoProvided)	.390	.101	.018	3.852	.000
	Zscore: Stress – Prayer	14.283	.122	.668	116.987	.000
	PrimRelation	-.597	.363	-.008	-1.646	.100
	SecondRelation	-.059	.342	-.001	-.172	.863
4	(Constant)	-30.751	.305		-100.771	.000
	Caregiver Gender	.519	1.927	.002	.269	.788
	Race Categories	.334	.188	.009	1.776	.076

Note. Control Variables included caregiver gender, race, life satisfaction and care recipient's functional ability.

* $p < .05$, ** $p < .001$

Table 12.2 (continued)

Model		Coefficients ^a				
		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
4	Satisfaction	-1.426	.069	-.180	-20.575	.000
	KatzIndex	2.057	.109	.100	18.907	.000
	Zscore(ReligServ)	3.146	.280	.142	11.219	.000
	Zscore(ReligMtg)	2.803	.308	.126	9.094	.000
	Zscore(WhoProvided)	.391	.101	.019	3.863	.000
	Zscore: Stress – Prayer	14.280	.122	.668	116.964	.000
	PrimRelation	-.560	.363	-.008	-1.543	.123
	SecondRelation	-.058	.342	-.001	-.169	.866
	Distance	.149	.064	.011	2.328	.020
	(Constant)	-28.548	.435		-65.588	.000
	Caregiver Gender	.549	1.815	.002	.303	.762
	Race Categories	.099	.179	.003	.555	.579
	Satisfaction	-1.406	.070	-.178	-20.113	.000
	5	KatzIndex	1.834	.103	.089	17.865
Zscore(ReligServ)		1.375	.272	.062	5.058	.000
Zscore(ReligMtg)		.469	.330	.021	1.423	.155
Zscore(WhoProvided)		.459	.095	.022	4.808	.000
Zscore: Stress – Prayer		8.996	.165	.421	54.480	.000
PrimRelation		-1.232	.603	-.017	-2.045	.041
SecondRelation		-.119	.323	-.002	-.368	.713
Distance		.156	.060	.012	2.591	.010
Total household income		.492	.406	.010	1.210	.226
Educational Attainment		11.311	.261	.340	43.355	.000
Members In Household		1.185	.116	.137	10.221	.000
(Constant)		-28.601	.439		-65.189	.000
Caregiver Gender		.544	1.815	.002	.300	.765
Race Categories		.100	.179	.003	.559	.576
Satisfaction	-1.405	.070	-.178	-20.086	.000	
6	KatzIndex	1.835	.103	.089	17.870	.000

Note. Control Variables included caregiver gender, race, life satisfaction and care recipient's functional ability.

* $p < .05$, ** $p < .001$

Table 12.2 (continued)

Model	Coefficients ^a				
	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error	Beta		
Zscore(ReligServ)	1.372	.272	.062	5.045	.000
Zscore(ReligMtg)	.456	.330	.021	1.382	.167
Zscore(WhoProvided)	.459	.095	.022	4.816	.000
Zscore: Stress – Prayer	8.995	.165	.421	54.478	.000
PrimRelation	-1.232	.603	-.017	-2.045	.041
SecondRelation	-.120	.323	-.002	-.373	.709
Distance	.157	.060	.012	2.605	.009
Total household income	.491	.406	.010	1.209	.227
Educational Attainment	11.308	.261	.340	43.340	.000
Members In Household	1.186	.116	.138	10.226	.000
Care Settings	.222	.232	.004	.957	.339

a. Dependent Variable: CaregiverBurden

Note. Control Variables included caregiver gender, race, life satisfaction and care recipient's functional ability.

**p < .05, **p < .001*

H1

This hypothesis proposed that the more closely related a support person was to the caregiver (i.e. the closer in social proximity of family support they were) the less caregiver burden the caregiver would experience/endorse. There was no statistical significance found in the association between primary and secondary relationships and caregiver burden, after controlling for demographic variables. The tables below illustrate the lack of relationship.

Table 13.1

Model Summary of Hierarchical Regression Testing Hypothesis 1

Model Summary				
Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.437 ^a	.191	.191	21.634
2	.437 ^b	.191	.191	21.633

a. Predictors: (Constant), Generally speaking, how satisfied are (you)/[SAMPNAME] with your life as a whole - would (you/he/she) say (you/he, Caregiver Gender, KatzIndex, Race Categories)

b. Predictors: (Constant), Generally speaking, how satisfied are (you)/[SAMPNAME] with your life as a whole - would (you/he/she) say (you/he, Caregiver Gender, KatzIndex, Race Categories, PrimRelation, SecondRelation)

Table 13.2

Coefficient matrix of hierarchical regression testing Hypothesis 1

Model		Coefficients^a				
		Unstandardized Coefficients	Std. Error	Standardized Coefficients	t	Sig.
	B		Beta			
1	(Constant)	-20.678	.268		-77.219	.000
	Race Categories	1.346	.272	.036	4.950	.000
	KatzIndex	7.281	.148	.355	49.062	.000
	Caregiver Gender	2.087	2.055	.007	1.016	.310
	Satisfaction	1.651	.057	.209	28.901	.000
2	(Constant)	-20.659	.268		-76.991	.000
	Race Categories	1.379	.279	.037	4.936	.000
	KatzIndex	7.281	.148	.355	49.052	.000
	Caregiver Gender	-1.082	2.883	-.004	-.375	.707
	Satisfaction	1.652	.057	.209	28.917	.000
	PrimRelation	-.637	.542	-.009	-1.176	.240
	SecondRelation	.865	.512	.017	1.691	.091

a. Dependent Variable: CaregiverBurden

Note. Control Variables included caregiver gender, race, life satisfaction and care recipient's functional ability.

* $p < .05$, ** $p < .001$

H2

This hypothesis proposed that the closer in physical proximity that support person(s) are to the caregiver, the less caregiver burden, the caregiver will endorse. There was no statistical significance found in the relationship between physical proximity of family support and caregiver burden, after controlling for demographic variables. The tables below illustrate the lack of relationship.

Table 14.1

Model Summary of Hierarchical Regression testing Hypothesis 2

Model Summary				
Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.437 ^a	.191	.191	21.634
2	.437 ^b	.191	.191	21.635

a. Predictors: (Constant), Generally speaking, how satisfied are (you)/[SAMPNAME] with your life as a whole - would (you/he/she) say (you/he, Caregiver Gender, KatzIndex, Race Categories

b. Predictors: (Constant), Generally speaking, how satisfied are (you)/[SAMPNAME] with your life as a whole - would (you/he/she) say (you/he, Caregiver Gender, KatzIndex, Race Categories, Distance from family member to caregiver and patient

Table 14.2

Coefficient matrix of hierarchical regression testing Hypothesis 2

Model		Coefficients ^a		Standardized Coefficients	t	Sig.
		Unstandardized Coefficients	Std. Error			
		B		Beta		
1	(Constant)	-20.678	.268		-77.219	.000
	Race Categories	1.346	.272	.036	4.950	.000
	KatzIndex	7.281	.148	.355	49.062	.000
	Caregiver Gender	2.087	2.055	.007	1.016	.310
	Satisfaction	1.651	.057	.209	28.901	.000
2	(Constant)	-20.851	.333		-62.554	.000
	Race Categories	1.377	.274	.037	5.021	.000
	KatzIndex	7.286	.148	.355	49.062	.000
	Caregiver Gender	2.100	2.055	.007	1.022	.307
	Satisfaction	1.650	.057	.209	28.874	.000
	Distance	.083	.096	.006	.873	.383

a. Dependent Variable: CaregiverBurden

Note. Control Variables included caregiver gender, race, life satisfaction and care recipient's functional ability.

**p < .05, **p < .001*

H3

This hypothesis proposed that the more spiritually engaged a caregiver is, the less caregiver burden they will endorse. The relationship is significant at the .05 level. The tables below illustrate the association.

Table 15.1

The Model Summary of Hierarchical Regression Testing Hypothesis 3.

Model Summary				
Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.437 ^a	.191	.191	21.634
2	.799 ^b	.639	.639	14.458

a. Predictors: (Constant), Generally speaking, how satisfied are (you)/[SAMPNAME] with your life as a whole - would (you/he/she) say (you/he, Caregiver Gender, KatzIndex, Race Categories

b. Predictors: (Constant), Generally speaking, how satisfied are (you)/[SAMPNAME] with your life as a whole - would (you/he/she) say (you/he, Caregiver Gender, KatzIndex, Race Categories,

Zscore(SpiritualityWhoProvided), Zscore: Things people do when they are under stress from CG - prayer meditation, Zscore(LMReligServAdjusted), Zscore(LMReligMtgAdjusted)

Table 15.2

Coefficient Matrix of Hierarchical Regression testing Hypothesis 3

Model		Coefficients^a				
		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	(Constant)	-20.678	.268		-77.219	.000
	Race Categories	1.346	.272	.036	4.950	.000
	KatzIndex	7.281	.148	.355	49.062	.000
	Caregiver Gender	2.087	2.055	.007	1.016	.310
	Satisfaction	1.651	.057	.209	28.901	.000
2	(Constant)	-30.433	.271		-112.373	.000
	Race Categories	.214	.182	.006	1.178	.239
	KatzIndex	2.050	.109	.100	18.844	.000
	Caregiver Gender	.041	1.374	.000	.030	.976
	Satisfaction	-1.418	.069	-.179	-20.471	.000
	Zscore(ReligServ)	3.125	.280	.141	11.151	.000
	Zscore(ReligMtg)	2.794	.308	.126	9.062	.000
	Zscore(WhoProvided)	.390	.101	.018	3.847	.000
Zscore: Stress – Prayer	14.287	.122	.668	117.060	.000	

a. Dependent Variable: CaregiverBurden

Note. Control Variables included caregiver gender, race, life satisfaction and care recipient's functional ability.

* $p < .05$, ** $p < .001$

H4

This hypothesis proposed that the fewer social and economic constraints a caregiver/household faces, the less caregiver burden the caregiver reports. Though the relationship is significant at the .05 level, the social/economic constraint of total household income appears to be highly correlated with the control variables of race and gender. The tables below illustrate the association.

Table 16.1

The Model Summary Hierarchical Regression Testing Hypothesis 4

Model Summary				
Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.437 ^a	.191	.191	21.634
2	.786 ^b	.617	.617	14.880

a. Predictors: (Constant), Generally speaking, how satisfied are (you)/[SAMPNAME] with your life as a whole - would (you/he/she) say (you/he, Caregiver Gender, KatzIndex, Race Categories

b. Predictors: (Constant), Generally speaking, how satisfied are (you)/[SAMPNAME] with your life as a whole - would (you/he/she) say (you/he, Caregiver Gender, KatzIndex, Race Categories, Total household income, Combined variable, How many family members are in the household?

Table 16.2

Coefficient Matrix of Hierarchical Regression Testing Hypothesis 4

Model		Coefficients ^a		Standardized Coefficients	t	Sig.
		Unstandardized Coefficients	Std. Error			
		B		Beta		
1	(Constant)	-20.678	.268		-77.219	.000
	Race Categories	1.346	.272	.036	4.950	.000
	KatzIndex	7.281	.148	.355	49.062	.000
	Caregiver Gender	2.087	2.055	.007	1.016	.310
	Satisfaction	1.651	.057	.209	28.901	.000
2	(Constant)	-26.823	.228		-117.875	.000
	Race Categories	.075	.194	.002	.386	.699
	KatzIndex	2.416	.110	.118	21.907	.000
	Caregiver Gender	.578	1.422	.002	.407	.684
	Satisfaction	-1.514	.073	-.191	-20.774	.000
	Educational Attainment	21.653	.197	.651	109.718	.000
	Total household income	-.450	.250	-.009	-1.802	.072
	Members In Household	2.293	.088	.266	26.007	.000

a. Dependent Variable: CaregiverBurden

Note. Control Variables included caregiver gender, race, life satisfaction and care recipient's functional ability.

* $p < .05$, ** $p < .001$

H5

This hypothesis is a combination effect proposing that caregivers experiencing a combination of the first four factors will report a greater reduction in caregiver burden, than those with none or only one of these supportive factors in place. The relationship statistically significant at the .05 level, even though there are some highly-correlated aspects. The tables below illustrate the associations present.

Table 17.1

The Model Summary of Hierarchical Regression Testing Hypothesis 5

Model Summary				
Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.437 ^a	.191	.191	21.634
2	.437 ^b	.191	.191	21.633
3	.437 ^c	.191	.191	21.633
4	.799 ^d	.639	.639	14.456
5	.825 ^e	.680	.680	13.613

a. Predictors: (Constant), Generally speaking, how satisfied are (you)/[SAMPNAME] with your life as a whole - would (you/he/she) say (you/he, Caregiver Gender, KatzIndex, Race Categories)

b. Predictors: (Constant), Generally speaking, how satisfied are (you)/[SAMPNAME] with your life as a whole - would (you/he/she) say (you/he, Caregiver Gender, KatzIndex, Race Categories, PrimRelation, SecondRelation)

c. Predictors: (Constant), Generally speaking, how satisfied are (you)/[SAMPNAME] with your life as a whole - would (you/he/she) say (you/he, Caregiver Gender, KatzIndex, Race Categories, PrimRelation, SecondRelation, Distance from family member to caregiver and patient)

d. Predictors: (Constant), Generally speaking, how satisfied are (you)/[SAMPNAME] with your life as a whole - would (you/he/she) say (you/he, Caregiver Gender, KatzIndex, Race Categories, PrimRelation, SecondRelation, Distance from family member to caregiver and patient, Zscore(SpiritualityWhoProvided), Zscore: Things people do when they are under stress from CG - prayer meditation, Zscore(LMReligServAdjusted), Zscore(LMReligMtgAdjusted)

e. Predictors: (Constant), Generally speaking, how satisfied are (you)/[SAMPNAME] with your life as a whole - would (you/he/she) say (you/he, Caregiver Gender, KatzIndex, Race Categories, PrimRelation, SecondRelation, Distance from family member to caregiver and patient, Zscore(SpiritualityWhoProvided), Zscore: Things people do when they are under stress from CG - prayer meditation, Zscore(LMReligServAdjusted), Zscore(LMReligMtgAdjusted), Combined variable, Total household income, How many family members are in the household?

Table 17.2

Coefficient Matrix of Hierarchical Regression Testing Hypothesis 5

Model		Coefficients ^a		Standardized Coefficients	t	Sig.
		Unstandardized Coefficients	Std. Error			
		B		Beta		
1	(Constant)	-20.678	.268		-77.219	.000
	Race Categories	1.346	.272	.036	4.950	.000
	KatzIndex	7.281	.148	.355	49.062	.000
	Caregiver Gender	2.087	2.055	.007	1.016	.310
	Satisfaction	1.651	.057	.209	28.901	.000
2	(Constant)	-20.659	.268		-76.991	.000
	Race Categories	1.379	.279	.037	4.936	.000
	KatzIndex	7.281	.148	.355	49.052	.000
	Caregiver Gender	-1.082	2.883	-.004	-.375	.707
	Satisfaction	1.652	.057	.209	28.917	.000
	PrimRelation	-.637	.542	-.009	-1.176	.240
	SecondRelation	.865	.512	.017	1.691	.091
3	(Constant)	-20.824	.334		-62.282	.000
	Race Categories	1.406	.281	.037	4.999	.000
	KatzIndex	7.285	.149	.355	49.052	.000
	Caregiver Gender	-1.080	2.883	-.004	-.375	.708
	Satisfaction	1.651	.057	.209	28.889	.000
	PrimRelation	-.617	.543	-.008	-1.138	.255
	SecondRelation	.866	.512	.017	1.692	.091
	Distance	.079	.096	.006	.828	.408

Note. Control Variables included caregiver gender, race, life satisfaction and care recipient's functional ability.

**p < .05, **p < .001*

Table 17.2 (continued)

Model		Coefficients ^a				
		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
4	(Constant)	-30.751	.305		-100.771	.000
	Race Categories	.334	.188	.009	1.776	.076
	KatzIndex	2.057	.109	.100	18.907	.000
	Caregiver Gender	.519	1.927	.002	.269	.788
	Satisfaction	-1.426	.069	-.180	-20.575	.000
	PrimRelation	-.560	.363	-.008	-1.543	.123
	SecondRelation	-.058	.342	-.001	-.169	.866
	Distance	.149	.064	.011	2.328	.020
	Zscore(ReligServ)	3.146	.280	.142	11.219	.000
	Zscore(ReligMtg)	2.803	.308	.126	9.094	.000
	Zscore(WhoProvided)	.391	.101	.019	3.863	.000
	Zscore: Stress – Prayer	14.280	.122	.668	116.964	.000
5	(Constant)	-28.548	.435		-65.588	.000
	Race Categories	.099	.179	.003	.555	.579
	KatzIndex	1.834	.103	.089	17.865	.000
	Caregiver Gender	.549	1.815	.002	.303	.762
	Satisfaction	-1.406	.070	-.178	-20.113	.000
	PrimRelation	-1.232	.603	-.017	-2.045	.041
	SecondRelation	-.119	.323	-.002	-.368	.713
	Distance	.156	.060	.012	2.591	.010
	Zscore(ReligServ)	1.375	.272	.062	5.058	.000
	Zscore(ReligMtg)	.469	.330	.021	1.423	.155
	Zscore(WhoProvided)	.459	.095	.022	4.808	.000
	Zscore: Stress – Prayer	8.996	.165	.421	54.480	.000
	Members In Household	1.185	.116	.137	10.221	.000
	Total household income	.492	.406	.010	1.210	.226
Educational Attainment	11.311	.261	.340	43.355	.000	

a. Dependent Variable: CaregiverBurden

Note. Control Variables included caregiver gender, race, life satisfaction and care recipient's functional ability.

* $p < .05$, ** $p < .001$

H6

This hypothesis proposed that the higher the level of residential care, the more burden a caregiver will endorse. The relationship is significant at the .05 level. The tables below display the statistical significance present.

Table 18.1

The Model Summary of Hierarchical Regression Testing Hypothesis 6

Model Summary				
Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.437 ^a	.191	.191	21.634
2	.439 ^b	.193	.193	21.607

a. Predictors: (Constant), Generally speaking, how satisfied are (you)/[SAMPNAME] with your life as a whole - would (you/he/she) say (you/he, Caregiver Gender, KatzIndex, Race Categories

b. Predictors: (Constant), Generally speaking, how satisfied are (you)/[SAMPNAME] with your life as a whole - would (you/he/she) say (you/he, Caregiver Gender, KatzIndex, Race Categories, Care Settings

Table 18.2

Coefficient Matrix of Hierarchical Regression Testing Hypothesis 6

Model		Coefficients ^a				
		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	(Constant)	-20.678	.268		-77.219	.000
	Race Categories	1.346	.272	.036	4.950	.000
	KatzIndex	7.281	.148	.355	49.062	.000
	Caregiver Gender	2.087	2.055	.007	1.016	.310
	Satisfaction	1.651	.057	.209	28.901	.000
2	(Constant)	-21.405	.290		-73.687	.000
	Race Categories	1.342	.272	.036	4.939	.000
	KatzIndex	7.249	.148	.353	48.877	.000
	Caregiver Gender	1.961	2.053	.007	.955	.339
	Satisfaction	1.622	.057	.205	28.337	.000
	Care Settings	2.350	.367	.046	6.412	.000

a. Dependent Variable: CaregiverBurden

Note. Control Variables included caregiver gender, race, life satisfaction and care recipient's functional ability.

* $p < .05$, ** $p < .001$

CHAPTER 5

RESULTS

Demographics

There were 20,474 participants in the study from across the country in the 2004 data capture. The reported gender of participants was 8041 male (39%) and 12433 female (61%). Caregivers however did not as readily report their age, with only 0.07% reporting being male (14) and only 0.16% (34) reporting being female. Racially the participants identified as White/Caucasian (1664 or 8%), Hispanic/Spanish Origin/Mexican Origin (251 or 1.2%), African American (179 or 0.8%), American Indian/Alaskan Native (22 or 0.01%), Native Hawaiian/Pacific Islander (19 or 0.09%) Asian (91 or 0.4%), “other” (27 or 0.01%). Only 3% (688) of participants reported being a spousal caregiver to the patient. Daughters were more likely to be the primary caregiver than any other person evaluated at 3.8% (773).

Hypothesis results based on analyses

H1. The first hypothesis proposed that the more closely related a support person is to the caregiver (or the closer in social proximity of family support that they are) the less caregiver burden the caregiver will endorse. We failed to reject the null hypothesis. There was no statistically significant relationship between social proximity of family support and caregiver burden.

H2. The next hypothesis proposed that the closer in physical proximity that support person(s) are to the caregiver, the less caregiver burden the caregiver will endorse. The results failed to reject the null hypothesis as there was no statistically significant relationship between physical proximity of family support and caregiver burden.

H3. Spirituality is the focus of the third hypothesis which suggested that the more spiritually engaged a caregiver is, the less caregiver burden they will endorse. The null hypothesis was rejected, spirituality is indeed an indicator of caregiver burden.

H4. The fourth hypothesis suggested that the fewer social/economic constraints a caregiver/household faces, the less caregiver burden that caregiver will endorse. The null hypothesis was rejected, social and economic constraints are an individual indicator of caregiver burden.

H5. This hypothesis is a combination effect purporting that caregivers experiencing any combination of factors in this hypothesis will report a greater reduction in caregiver burden, than those with none or only one of these supportive factors in place. The null hypothesis was rejected; the combination of the aforementioned hypotheses produced an indicator of caregiver burden.

H6. This hypothesis suggested that the higher the level of residential care, the more burden a caregiver will endorse. The null hypothesis was rejected. Care setting is indeed an indicator in assessing caregiver burden.

H7. This is the final hypothesis that proposed that the model in this paper would provide a statistically significant measure of caregiver burden. The null hypothesis was rejected. Indeed the model is statistically significant.

CHAPTER 6

DISCUSSION, IMPLICATIONS, AND CONCLUSION

Discussion

Timeframe. It is important to note that this data was collected in 2004; 13 years and now two presidencies ago. This was also prior to most baby boomers reaching retirement age, and prior to the influx of war veterans returning (which along with the aging population, is projected to only increase significantly). During the year in which this data was collected President George W. Bush won the election for his second term as President of the United States of America. Though much has changed since then, it is important to note that the social policies in place when this data was collected have been radically altered since that time. The Republican President's term ended in 2008 with the election of President Barak Obama. President Obama's subsequent eight years in office were marked by significant changes primarily to healthcare and related policy and programming. Reportedly over 17 million Americans gained access to healthcare coverage they would not otherwise have had during President Obama's time in office (Uberoi, Finegold, & Gee, 2016). Funding for social programs was a central focus during President Obama's administration as well, which lends itself well to a focus on older adults and their caregivers in our aging society (Uberoi, Finegold, & Gee, 2016). President Donald Trump is now the 45th President of the United States of America and has spent just over 100 days in office. Though it is too early to determine what impact his conservative views will have on social policies, he has been very vocal about the fact that he intends to reverse much of the policy implemented during his predecessor's regime. The results in this data, specifically in the areas of social support could have important implications in the near future as a result of the potential changes in our Nation's social programs.

Cronbach's alpha. Though the Cronbach's Alpha for the Caregiver Burden scale is in an upper range at $\alpha = .717$, this is a number that is not always accepted in social research. It is accepted as "better than chance" but also leaves much to chance. It was accepted for purposes of this study, due to the fact that this scale has been elsewhere validated.

Spirituality. The significance of the spirituality factor, as well as the significance of spirituality in the overall model are both substantial outcomes in this study. These findings do not come without limitations, however. The use of secondary data limits the ability to fully explore the concept of spirituality. It could be argued that the variables used to build this factor may more appropriately represent spiritual or religious service, civic engagement, outreach, or any other number of concepts. This argument however does not discredit the findings of this study, in that the factor of spirituality was built on concepts specific to some type of spiritual engagement and this in turn has a direct impact on caregiver burden, which is of noteworthy importance. Primary data collection should focus on more direct approaches to assessing the spirituality of a caregiver, perhaps with questions of how caregivers identify with or view their faith, the personal importance of their faith, and perceived direct support received from their faith and faith communities – such questions should be the focus of future endeavors in this area.

Support. Social and physical proximity of family support to the caregiver are new areas of study. Though this study did not find statistical significance in the relationship between these factors and caregiver burden, theory continues to suggest that caregiver support is essential to reducing caregiver burden. One potential explanation for the lack of findings in this area could be the operationalization of the social proximity of family support variables. This variable primarily measured kinship relationships; degrees of intimacy or perceived support might be more appropriate ways to measure this concept that would yield more significant findings.

Further research into support for caregivers that positively impacts caregiver burden is needed. Additional research that examines the perceived quality of support from caregiver supports would also be beneficial to this area of study.

Level of care. The significant findings here are relatively preliminary. Additional inquiry into the myriad of factors impacting caregiver burden are needed to determine exactly which care settings, and how these care settings positively or negatively impact caregiver burden. Gaugler, Mittelman, Hepburn, and Newcomer, (2009) found that initially, a nursing home admission of the patient for dementia caregivers, was a relief. Their study points out though that a relief in one area of burden may not equal an overall reduction in burden as new issues area added with the change in setting (Gaugler, Mittelman, Hepburn, & Newcomer, 2009). This points to just way in which these results are not unidimensional, and highlight the need for continued, investigative inquiry.

Caregiver burden. Spirituality, social and economic constraints, and care setting all individually directly affect caregiver burden. Though the entire model is statistically significant, future research should focus specifically on these factors and their direct, and combined relationships with caregiver burden. Additional model building should examine emerging concepts of aging, such as gerotranscendence, to build a contemporary, holistic framework for examining caregiver burden. These findings are a foundational basis for continued exploration in this direction.

Implications

This research provides a new perspective through which we can examine caregiver burden. Though caregiver burden is more commonly researched than it was a decade or more ago, there is still very little education to the public, or support to caregivers in need. Programs to

assist with reducing caregiver burden exist, but are generally targeted to persons caring for people with very specific illnesses/diseases. These programs, additionally, are not always accessible for caregivers and require caregivers take time away from their care recipient which may not be possible ((Adelman, Tmanova, Delgado, Dion, & Lachs, 2014; Bastawrous, 2013; Bialon, & Coke, 2012; Bull, 2014; Carretero, Garcés, Ródenas, & Sanjosé, 2009; Chindaprasirt, Limpawattana, Pakkaratho, Wirasorn, Sookprasert, Kongbunkiat, Sawanyawisuth. 2014; Chiou, Chang, Chen, & Wang, 2009; Collins, & Swartz, 2011; Davis, Gilliss, & Harper, 2011; Feinberg, & Houser, 2012; Gaugler, Mittelman, Hepburn, & Newcomer, 2009; Gräbel, & Adabbo, 2011; Kim, & Given, 2008; Kinoshita, Maeda, Morita, Miyashita, Yamagishi, Shirahige, Takebayashi, Yamaguchi, Igarashi, Eguchi, 2015; National Alliance for Caregiving, and American Association of Retired Persons Public Policy Institute, 2015; Quinn, Clare, & Woods, 2009; Roberto, & Jarrott, 2008; Townsend, Ishler, Shapiro, Pitorak, & Matthews, 2010).

The findings around spirituality have significant implications for policy and practice. These findings suggest that churches and religious organizations have the potential to serve as a platform for caregiver support. For people of a faith belief, these organizations may be a common source of support for individuals in the community, and therefore have the opportunity to play a key role in supportive services. Services integrated with faith-based organizations have the potential to significantly relieve caregiver burden. Future policy initiatives for caregivers would be well served to investigate this opportunity. Spirituality is a key aspect of a well done biopsychosocial assessment, however these questions may be difficult to ask in certain circumstances. Social workers should be encouraged by these findings, to not only ascertain information regarding religion and spirituality of their patients and caregivers, but to also seek out these institutions and avenues as a potential source of support for their clients.

These results also yield important findings for social workers in long-term care settings. Exploration of potential change in caregiver burden can assist social workers in providing for patient, caregiver and family needs. This information can also assist in long-term planning, quality of life, and has the potential to reduce negative responses to the transition both from the patient and caregiver. Social workers are key to advocacy and education of other facility staff in long-term care settings, a deeper understanding of the ongoing needs and burden of caregivers has great potential for improving the long-term care experience for all involved.

An understanding of caregiver specific supports will allow social workers, the helping professions, and politicians to better prepare potential interventions to meet the needs of this expanding population. Social work interventions with older adults often encourage caregivers to seek out support from family, close relationships and those in their immediate area.

Corroborating of these results may be important to adapt education to caregivers regarding the benefits of related and local informal supports.

The society we live in is aging. Therefore if for no other reason there will likely be a continuing increase in caregivers as well. It serves all persons to provide support services for caregivers that maintain current lifestyles and support needs of caregivers, considering that older adults programs carry a significant financial cost. Social workers and other helping professionals can significantly improve outcomes by understanding caregiver needs, abilities, and having education on how best to support caregivers.

Conclusion

Caregiver burden is a “trendy” term in today’s society. This is often presented in respect to caring for children, caring for the ill/disabled, and in caring for older adults. The results of this study highlight the multifaceted phenomena that is caregiver burden. Though the overall model

was statistically significant, it is important to note that social and physical proximity of family support very likely played little if any role in the execution of the overall model. This indicates that relative familial closeness and physical proximity are less important to caregiver burden, than other factors in the model.

The proposed model estimates caregiver burden looking at key areas specific to the caregiver, in a way never before analyzed collectively. Though there is existing literature on spirituality and caregiver burden, as well as care setting and caregiver burden – social and economic constraints, and physical and social proximity of family supports have never been studied directly regarding their relationship with caregiver burden. Additionally no model to date has combined these areas to provide an estimate of protective factors for caregivers. Though future research is needed, this study provides the opportunity to begin building a holistic model of caregiver burden, to test hypotheses, and to work to develop standards of caregiver care to be implemented within direct caregiver settings in social work, as well as other helping professions that directly encounter caregivers.

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