

2023

The Influence of Spirituality on Caregiver Burden and Quality of Life in Older Adult Informal Caregivers

Stephanie Marie Young

West Virginia University, sayers1@hsc.wvu.edu

Follow this and additional works at: <https://researchrepository.wvu.edu/etd>

Recommended Citation

Young, Stephanie Marie, "The Influence of Spirituality on Caregiver Burden and Quality of Life in Older Adult Informal Caregivers" (2023). *Graduate Theses, Dissertations, and Problem Reports*. 12103.
<https://researchrepository.wvu.edu/etd/12103>

This Dissertation is protected by copyright and/or related rights. It has been brought to you by the The Research Repository @ WVU with permission from the rights-holder(s). You are free to use this Dissertation in any way that is permitted by the copyright and related rights legislation that applies to your use. For other uses you must obtain permission from the rights-holder(s) directly, unless additional rights are indicated by a Creative Commons license in the record and/ or on the work itself. This Dissertation has been accepted for inclusion in WVU Graduate Theses, Dissertations, and Problem Reports collection by an authorized administrator of The Research Repository @ WVU. For more information, please contact researchrepository@mail.wvu.edu.

The Influence of Spirituality on Caregiver Burden and Quality of Life in Older Adult Informal
Caregivers

Stephanie Young

**Dissertation submitted
to the School of Nursing
at West Virginia University
in partial fulfillment of the requirements for the degree of
Ph. D.
In
Nursing**

**Suzy Walter, Ph. D., Chair
Kesheng Wang, Ph. D.
Ubolrat Piamjariyakul, Ph. D.
Feylyn Lewis, Ph. D.**

School of Nursing

**Morgantown, West Virginia
2023**

**Keywords: Caregiver burden, Spirituality, Quality of life, Theory of Self-transcendence,
Structural Equation Modeling
Copyright, 2023: Stephanie Young**

ABSTRACT

The Influence of Spirituality on Caregiver Burden and Quality of Life in Older Adult Informal Caregivers

Stephanie Young

Background: Caregiver burden reduces quality of life (QOL) and is associated with poorer health outcomes. Older adults may be more susceptible to caregiver burden due to advancing age and declining health. Spirituality has been shown to reduce caregiver burden and improve QOL.

Purpose: The purpose of this study was to evaluate the direct or indirect influence of spirituality on caregiver burden and caregiver QOL in older adult caregivers. The specific aims were 1) to determine the prevalence of caregiver burden in a nationally representative sample of older adult informal caregivers of other adults and 2) to investigate the relationships among caregiver burden, spirituality, and quality of life in a nationally representative sample of older adult informal caregivers of other adults.

Methods: This was a cross-sectional, descriptive secondary data analysis of data from the 2020 Health and Retirement Study (HRS). The HRS collects data every other year from a large nationally representative sample of adults aged 55 or older and their spouses. Participants who identified as regularly providing care to another adult were included (n = 591). General linear models and structural equation modeling (SEM) were conducted to explore relationships among caregiver burden, spirituality, QOL, and demographic data.

Results: Caregivers had a mean age of 66.32 (7.84). Most caregivers were female (n = 368, 53.1%), White (n = 399, 81.5%), married (n = 378, 68.7%) and had a high school education or general education diploma (n = 290, 47.1%). More than half of the caregivers scored as having moderate (n = 289, 48%) or high (n = 18, 3.5%) levels of caregiver burden. Among all caregivers, 22.5% (n = 126) provided care for more than a year and found caregiving to be *somewhat upsetting* while 9.6% (n = 51) provided care for more than a year and found it to be *very upsetting*. GLM showed caregivers who were highly spiritual had lower caregiver burden ($p = .023$). Lower caregiver burden was correlated with higher QOL ($p = < .001$). Spirituality did not moderate the effect of caregiver burden on QOL, but an SEM depicting an influencing effect of spirituality revealed a good model fit (NFI = .902; IFI = .928; TLI = .862; CFI = .927; PCFI = .494, RMSEA = .065; $\chi^2 = 27.902$, $p = .000$, DF = 8, PCMIN/DF = 3.488)

Conclusions: Spirituality influenced QOL through caregiver burden in this population. Spirituality should be fostered in older adult informal caregivers to help reduce caregiver burden and improve QOL. Nurses can foster spirituality by providing spiritual care and making appropriate referrals. Further research is needed to explore other factors affecting spirituality in this population and to test spiritual interventions for effectiveness in improving QOL.

Dedication

This dissertation is dedicated to the memory of my mother, Bernice Jean Ayers. I wish you were here. You believed in me more than anyone. I will love you forever.

Acknowledgements

I would like to thank, first and foremost, my husband, Brian Young, who was with me on every step on this journey, taking on extra responsibilities and always lending an ear when needed. I would also like to thank my children, Megan, Erin, and Kylie, who also took on extra responsibilities and provided inspiration for me to keep going.

I am forever grateful for the support of my doctoral committee chair and mentor Dr. Suzy Walter, my mentor and committee member Dr. Ubolrat Piamjariyakul, my committee members Dr. Kesheng Wang, and Dr. Feylyn Lewis, the PhD faculty at WVU, and for my friend and mentor Dr. Angel Smothers, who was so instrumental in setting me on this path.

There are numerous others who have influenced me in so many ways and over many years. I could not have accomplished this without your influences in my life. I am ever grateful to you all. To my program peers, I'm so glad we took this journey together.

Disclaimer*

This analysis uses Early Release data from the Health and Retirement Study, 2020 HRS Early Core, sponsored by the National Institute on Aging (grant number NIA U01AG009740) and conducted by the University of Michigan. These data have not been cleaned and may contain errors that will be corrected in the Final Public Release version of the dataset” (HRS, 2020).

Research reported in this publication was supported by the National Institute of General Medical Sciences of the National Institutes of Health under Award Number 2U54GM104942-07. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

Table of Contents

| | |
|---|-----|
| Abstract | iii |
| Dedication | iii |
| Acknowledgements | iv |
| Chapter 1: Introduction | 1 |
| The Problem | 1 |
| Purpose | 4 |
| Aims and Research Question | 4 |
| Theoretical Framework | 5 |
| Significance to Nursing | 7 |
| Chapter 2: Literature Review | 9 |
| The Literature | 10 |
| Theory of Self-transcendence | 12 |
| Caregiver Burden | 12 |
| Spirituality | 13 |
| Quality of Life | 14 |
| Relationships among Caregiver Burden, Spirituality, and QOL | 16 |
| Summary | 16 |
| Chapter 3: Methods | 18 |
| Design | 18 |
| Overview of the Health and Retirement Study | 19 |
| Ethics and Human Subject Protection | 20 |
| Study Sample | 21 |
| Measurements/ Instrumentation | 22 |
| <i>Demographics</i> | 22 |
| <i>Caregiver Status</i> | 22 |
| <i>Caregiver Burden</i> | 22 |
| <i>Spirituality</i> | 24 |
| <i>Quality of Life</i> | 25 |
| Data Management | 26 |
| Data Analysis | 26 |

| | |
|--|----|
| Summary | 28 |
| Chapter 4: Results | 29 |
| Demographic Analysis | 29 |
| Psychometric Properties | 30 |
| Dispersion..... | 30 |
| Descriptive Statistics | 31 |
| Bivariate Analysis | 32 |
| <i>Spearman Rank Correlations</i> | 32 |
| <i>Bivariate Linear Regression Analysis (GLM)</i> | 32 |
| <i>Independence Test Using Chi-square Test</i> | 34 |
| Multivariate Linear Regression Analysis | 36 |
| <i>GLM with Caregiver Burden, Spirituality, and QOL</i> | 36 |
| <i>GLM with All Predictors</i> | 37 |
| Structural Equation Modeling | 38 |
| Conclusion..... | 41 |
| Overview of the Study..... | 42 |
| Findings of the Study | 43 |
| Demographics: Caregiver Prevalence, Gender Race/ Ethnicity..... | 43 |
| Study Aims..... | 45 |
| <i>Aim 1</i> | 45 |
| <i>Aim 2</i> | 46 |
| Contribution to the Knowledge Base of Nursing | 48 |
| Implications of Findings for Further Research | 48 |
| Implications of Findings for Nursing Practice | 49 |
| Implications of Findings for Policy | 50 |
| Strengths and Limitations..... | 50 |
| Conclusion..... | 51 |
| References | 53 |
| Appendix A: Tables | 67 |
| Table 1. <i>Demographics and Attitude toward Providing Care for more than One Year</i> | 67 |
| Table 2. <i>Scale Scores</i> | 68 |
| Table 3. <i>Unweighted Spearman Correlations of Study Variables and Attitude</i> | 68 |

| | |
|--|----|
| Table 4. <i>Bivariate GLM with Caregiver Burden as Outcome</i> | 69 |
| Table 5. <i>Bivariate GLM with Quality of Life as Outcome</i> | 70 |
| Table 6. <i>Crosstabs Caregiver Burden as Dependent with Unweighted N & Weighted %</i> | 71 |
| Table 7. <i>Crosstabs Spiritual Level as Outcome with Unweighted N & Weighted %</i> | 72 |
| Table 8. <i>Crosstabs with QOL as Dependent with Unweighted N & Weighted %</i> | 72 |
| Table 9. <i>Caregiver Burden X Demographic Frequencies with Unweighted N & Weighted %</i> 73 | |
| Table 10. <i>Spiritual Level X Demographic Frequencies with Unweighted N & Weighted %</i> ... | 74 |
| Table 11. <i>Quality of Life X Demographic Frequencies with Unweighted N & Weighted %</i> | 75 |
| Table 12. <i>Crosstabs of Attitude Toward Providing Care > 1Year and Variables of Interest</i> .. | 76 |
| Table 13. <i>Multivariate GLM Testing Main Effects of Spirituality and Caregiver Burden on QOL and of Spirituality and QOL on Caregiver Burden</i> | 76 |
| Table 14. <i>Multivariate GLM Testing Main and Interaction Effects on QOL</i> | 77 |
| Table 15. <i>Multivariate GLM Testing Main and Interaction Effects on Caregiver Burden</i> | 77 |
| Table 16. <i>Multivariate GLM Testing Main Effects of Significant Variables on Caregiver Burden</i> | 78 |
| Table 17. <i>Multivariate GLM Testing Main Effects of Significant Variables on QOL</i> | 79 |
| Table 18. <i>Model 1 Path Analysis Results</i> | 80 |
| Table 19. <i>Model 1 Fit Indices</i> | 80 |
| Table 20. <i>Model 2 Path Analysis Results</i> | 81 |
| Table 21. <i>Final Model Fit Indices</i> | 81 |

Chapter 1: Introduction

This doctoral dissertation examines the relationships among caregiver burden, spirituality, and caregiver quality of life (QOL) in older adult (aged 54 and above) informal caregivers living in the contiguous United States (U.S.). The theory of self-transcendence, a middle range nursing theory, was used to guide this research. A literature review is presented to define the main concepts, to report the known relationships among the concepts, to identify a gap in the literature, and to obtain evidence to support the theoretical framework that guided this research. A study designed to address the gap in knowledge is presented as well as results, conclusions, and implications.

The Problem

Informal caregiving is care provided by “any relative, partner, friend or neighbor who has a significant personal relationship with, and provides a broad range of assistance for, an older person or an adult with a chronic or disabling condition” (Family Caregiver Alliance, 2022). This definition is selective to older adult care recipients. It used here because it is specific to the study population. The label “informal caregiver” is controversial because it can have a connotation that care provided is less important than the formal care provided by healthcare workers (Applebaum, 2022). However, informal caregiver is commonly used in the academic community to distinguish between providers who receive a salary versus those who do not. This term is used here to make the same distinction, though it in no way implies the care provided is any less important or appreciated.

Informal caregiving is a vital part of healthcare in the United States (U.S.) and accounts for roughly \$470 billion worth of care each year (Reinhard et al., 2019). Informal caregiving continues to increase as medical advances allow people to live longer at home with more

complicated health care needs. Although providing care for a loved one can be a rewarding part of life, the process can take a physical and emotional toll on those providing the care.

Caregiver burden among informal caregivers is recognized by academics, advocacy groups, and government agencies as a societal issue in need of attention (Centers for Disease Control [CDC], 2021; National Institute of Nursing Research [NINR], 2016; The National Alliance for Caregiving [NAC] & American Association of Retired Persons [AARP], 2020). Caregiver burden is well documented and has been defined as “the level of multifaceted strain perceived by the caregiver from caring for a family member and/or loved one over time” (Liu et al., 2020). Caregivers report a variety of physical, emotional, and financial burdens (Ferrell & Wittenberg, 2017; NAC & AARP, 2020) and have higher rates of morbidity and mortality (Ferrell & Wittenberg, 2017). Additionally, caregiver burden has been shown to reduce overall caregiver quality of life (Choi & Seo, 2019; NAC & AARP, 2020; Swartz & Collins, 2019).

The World Health Organization Quality of Life Group [WHOQOL] Group (1998) defines QOL as

an individuals’ perceptions of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the persons’ physical health, psychological state, level of independence, social relationships and their relationship to salient features of their environment (p. 1570).

In summary, the WHO considers QOL to be an important aspect of overall health, which they define as the state of physical, mental, and social well-being (WHO, 1998, 1995) Therefore, when QOL is decreased, overall health and well-being are affected. Because caregiver burden diminishes QOL, it can then be assumed overall health and wellbeing are adversely affected.

Further, the National Institute of Nursing Research (NINR; 2016) has called on nurse researchers to investigate ways to improve caregiver QOL.

Findings in the literature demonstrate that spirituality promotes better QOL in informal caregivers (Lalani et al., 2018). Spirituality is defined as a way to “express and/or seek meaning, purpose and transcendence, and...connect to the moment, to self, to others, to nature, to the significant and/or the sacred” (Nolan et al., 2011). Religion is one way people express spirituality. In a systematic review, Gonçalves et al. (2015) found a correlation between greater religious attendance and better health outcomes. Religion and spirituality have also been shown to help reduce stress and anxiety (Gonçalves et al, 2015; Whitehead, & Bergeman, 2012). Further studies have shown that increased spirituality might improve QOL in caregivers by giving meaning to the experience, enhancing coping skills, improving relationships between caregivers and care recipients, and assisting with role adaptation (Hebert, 2006; Koenig et. al, 2016).

There are associations between caregiver burden and spirituality (Simpson et al., 2020) as well as between caregiver burden and quality of life (Taha et al., 2021). Studies have also shown relationships among these three variables, including moderating effects of spirituality between caregiver burden and QOL in parents of adolescents with spina bifida (Taha et al., 2021) and in spousal caregivers of cancer patients (Colgrove et al., 2007). A moderator is “an independent variable that affects the strength and/or direction of the association between another independent variable and an outcome variable” (Bennett, 2000). Thus, these studies showed that spirituality affected the strength or association of caregiver burden on QOL. However, little is known about how spirituality in older U.S. adult caregivers, aged 54 and above, affects the relationship between caregiver burden and caregiver QOL. Older adult caregivers report less caregiver

burden (Choi & Seo, 2019; Morrison et al., 2020) but may be more vulnerable to the effects because they are impacted by advancing age and may have illnesses and conditions of their own needing to be managed (NAC & AARP, 2020). To date, there is a gap in the literature identifying the role of spirituality on caregiver burden and QOL in older adults. Therefore, understanding the direct and indirect effect of spirituality on caregiver burden and QOL will provide insight to develop interventions to improve QOL in these informal caregivers.

Purpose

The purpose of this study was to evaluate the direct or indirect influence of spirituality on caregiver burden and caregiver QOL in older adults who provide care to at least one other adult who is sick or disabled.

Aims and Research Question

This study used a quantitative approach. A cross-sectional, descriptive secondary data analysis of early release data from the 2020 Health and Retirement Study (HRS) (Institute for Social Research, 2020) was conducted. The HRS, a longitudinal dataset, collects large amounts of data every other year from a large nationally representative sample of older adults born in or before 1965 and their spouses. The purpose of the HRS is to follow those individuals into retirement and to examine interactions among health, family, and economics (Health and Retirement Study, 2008). Participants in the HRS who identified as regularly providing care to another adult were the focus of this study. The specific aims of this study are as follows:

Aim1: To determine the prevalence of caregiver burden in a nationally representative sample of older adult informal caregivers of other adults

Aim 2: To investigate the relationships among caregiver burden, spirituality, and quality of life in a nationally representative sample of older adult informal caregivers of other adults

Hypothesis.

Spirituality will moderate the effect of caregiver burden on quality of life resulting in higher quality of life outcomes in older adult informal caregivers living in the U.S.

Research Question:

Among older adult informal caregivers of other adults, does caregiver burden have a different effect on quality of life in those who are spiritual vs those who are not spiritual?

General Linear Modeling and structural equation modeling (SEM) were utilized to answer the research question. Structural equation models are complex statistical models that can test relationships among variables and examine multiple and interconnected relationships in a single analysis (Jain & Chetty, 2021). In this study, the moderating effect of spirituality on caregiver burden and spirituality was examined.

Theoretical Framework

A distinction must be made between the terms construct and concept. Construct is defined here as an “abstract concept that is specifically chosen or created to explain a given phenomenon” (Libre Texts, 2021). Concepts are distinguished and defined as “generalizable properties or characteristics associated with objects, events, or people” (Libre Texts, 2021). Thus, construct is used when discussing this theory in general terms. Concept is used when discussing the application to the population.

The theory of self-transcendence, a middle range nursing theory, was used to guide this study. The theory was developed based on life span developmental psychology and guides understanding about how people facing adversity transcend and how psychosocial development, mental health, and well-being are related (Reed, 2018). This theory provides an appropriate framework for studying health promotion during challenging times especially in later adulthood

and at end-of-life (Reed, 2018, 1991). The theory of self-transcendence has two main assumptions. It assumes that humans are an integral part of their environment, being pan-dimensional (not confined by the spatial or temporal) and having a metaphysical awareness (beyond the temporal and physical) that moves past internal and external conceptual boundaries. It also assumes that self-transcendence is a necessary expression of human development essential for health and well-being (Reed, 2018, 1991).

The theory of self-transcendence consists of three interrelated constructs: self-transcendence, well-being, and vulnerability. Self-transcendence involves pushing beyond conceptual internal and external boundaries to grow into deeper connectedness with self, others, and environment (Reed, 2018, 1991). Well-being is a subjective “sense of feeling whole and healthy” (Reed, 2018, p. 123) and can be considered a correlate of self-transcendence (Reed, 1991) which inherently promotes health. Vulnerability is the sense that well-being is at risk and occurs during a significant life event which brings an awareness for the need to self-transcend (Reed, 2018, 1991). Thus, self-transcendence can impact the effect of vulnerability on well-being (Reed, 2018).

The theory of self-transcendence provides a good fit to study the relationships among the concepts of caregiver burden, spirituality, and QOL in informal adult caregivers because the documented caregiving experience is congruent with the theory constructs. The concept of caregiver burden is congruent with the construct of vulnerability. The concept of quality of life is congruent with the construct of well-being, and the concept of spirituality is congruent with the construct of self-transcendence. Just as vulnerability is a threat to well-being, as the theory suggests, caregiver burden is a threat to QOL. Self-transcendence is the means through which a person can overcome the effects of vulnerability and move to a better state of well-being.

Likewise, spirituality can be the means through which a person can overcome caregiver burden and achieve better QOL. In fact, Reed (1991) suggests religious expressions (which can be an expression of spirituality) can help people expand self-boundaries and could be researched for useful nursing approaches. So, in the setting of caregiver burden, which is a vulnerable state, the caregiver can use spirituality to self-transcend and promote better QOL/ well-being. Thus, spirituality is a potential moderator between caregiver burden and caregiver QOL.

Significance to Nursing

In a review to identify what is considered nursing research, Smith (2019) identified the triad of health, healing, and well-being as one of the fundamental concepts of nursing research. The focus of this study is about how QOL may be affected by spirituality in the presence of caregiver burden and, therefore, falls firmly within the realm of nursing research. This study included an examination of QOL, which is an important aspect of well-being. As previously discussed, QOL can be diminished in the presence of caregiver burden, contributing to overall morbidity and mortality making caregiver burden a public health concern and a nursing focus. Demonstrating a beneficial effect of spirituality on QOL outcomes in the presence of caregiver burden may lead to interventions that promote spirituality to improve QOL.

Conclusion

Caregiver burden is a public health concern because it adversely affects quality of life among older adult caregivers and contributes to overall morbidity and mortality. Older adult caregivers are vulnerable to the health effects of caregiver burden due to advancing age and medical conditions of their own. Spirituality has been shown to reduce caregiver burden by enhancing the ability to cope, providing meaning, and improving relationships between the caregiver and care recipient. It is important to explore the relationships among caregiver burden,

spirituality, and quality of life beyond what is already known. The theory of self-transcendence is a fitting model to help understand these relationships. If it can be shown that spirituality moderates the effect of caregiver burden on quality of life, interventions could be developed to foster spirituality in older adult caregivers to improve overall QOL. This study is based in nursing theory and addressed concepts of concern to the nursing profession. It will add to the body of nursing knowledge. This study could also be used to inform policy makers and advocacy groups whose desire it is to assist those affected by caregiver burden.

Chapter 2 will detail a review of the literature including search strategy and the questions that guided the search. The concepts of caregiver burden, spirituality, and QOL and what is known about their relationships will be further elaborated. Other research using the theory of self-transcendence in the caregiver setting and/or for spirituality as a means of self-transcendence will be highlighted. Rationale from the literature to support the undertaking of this study will be presented.

Chapter 2: Literature Review

As the population in the U. S. continues to age and medical advances allow people to live longer and with more complex medical conditions, the need for informal caregivers has also risen. In fact, more than 19% of Americans identify as informal caregivers (NAC & AARP, 2020). While informal caregiving is rewarding, it can also yield significant physical, psychological/ emotional, and financial burden (NAC & AARP, 2020). The burdens associated with caregiving, collectively understood as caregiver burden, have been linked with increased morbidity and mortality among caregivers (Pristavec & Luth, 2020). Informal caregivers can be faced with significant stress and often neglect their own health care needs in order to care for their loved ones (Ferrell et al., 2018; Lapid et al., 2016). The National Alliance for Caregiving [NAC] and American Association of Retired Persons [AARP] (2020) report that caregivers are in poorer health than they were five years ago. As caregivers are advancing in age and experiencing diminishing health, it is incumbent upon health care researchers to identify factors associated with caregiver burden and QOL.

Caregiver burden has been shown to have an inverse relationship with caregiver QOL (Giovanetti et al., 2015). Likewise, spirituality has been shown to influence both caregiver burden (Simpson, 2020) and QOL (Taha et al., 2021). Further exploration into the nature of the relationship among these three variables is needed to better understand how spirituality could be utilized to improve caregiver QOL in those experiencing caregiver burden. Specific aims of this study are:

Aim 1: To determine the prevalence of caregiver burden in a nationally representative sample of older adult informal caregivers of other adults.

Aim 2: To investigate the relationships among caregiver burden, spirituality, and QOL in a nationally representative sample of older adult informal caregivers of other adults.

Hypothesis.

Spirituality will moderate the effect of caregiver burden on quality of life resulting in higher quality of life outcomes in older adult informal caregivers living in the U.S.

Research Question:

Among older adult informal caregivers of other adults, does caregiver burden have a different effect on quality of life in those who are spiritual vs those who are not spiritual?

A relationship among these variables was hypothesized based on a situation that arose from clinical practice where a daughter took on the challenge of providing informal care for her ill mother out of a sense of duty and responsibility to her faith. This situation brought hardship along with the joy of knowing she was creating a place of refuge for her mother. The burden created a state of vulnerability that necessitated finding a way to promote well-being in the midst of suffering. This caregiver found strength in her faith to meet the challenges she faced. The middle-range nursing theory of self-transcendence (Reed, 1991) is a good fit to guide this dissertation study. This theory is structured by three constructs: self-transcendence, vulnerability, and well-being. Self-transcendence is the means through which a person facing a vulnerable situation, (informal adult caregiving) can move beyond personal boundaries (via spirituality) and into a new state of well-being (improved quality of life). The theory of self-transcendence explains how caregiver burden, spirituality and QOL are related.

The Literature

A literature search was conducted to study the relationships among caregiver burden, spirituality, and QOL. The following databases were searched using Ebscohost: Academic

Search Complete, Medline CINAHL Complete, APA Psych info, APA Psych Articles, Health Source: Nursing/ Academic Edition. Search terms using Boolean phrases included quality of life AND spirituality AND caregiver burden or caregiver stress or caregiver fatigue or caregiver burnout or caregiver strain or caregiver overload. Articles were limited to peer-reviewed articles in English with populations in the United States (U. S.). This search yielded 124 results after exact duplicates removed. Articles were included if they were primary sources that presented relationships among variables of interest in current caregivers. Articles were excluded if the population of caregivers were paid, were outside of the United States or were parents of infants or children with autism. Studies were also excluded if the variable was religion or religiosity, spiritual support, spiritual well-being, or religious or spiritual coping, as these are all separate concepts, despite being related. No specific age group was used to limit the search in effort to not exclude studies that included both older and younger adults.

Searches were also conducted in the same data bases to explore how researchers were studying the variables in caregivers. A search of peer-reviewed articles in English, using populations in the US since 2016 with the following terms: quality of life AND informal caregivers or family caregivers or informal carers or family carers yielded 176 articles. A similar search using the terms caregiver burden AND spirituality yielded 121 results. It was not necessary to search specifically for older adult caregivers, as this population could be identified while reviewing the articles.

A search of peer-reviewed articles in English was conducted to identify how the theory of self-transcendence has been used in relation to the research question. Search terms of caregiver burden AND theory of self-transcendence yielded seven results. A search using the terms “theory

of self-transcendence” AND spirituality or religion or faith or belief system in English yielded eight results.

Finally, Google scholar was searched using various combinations of the terms spirituality, caregiver burden, caregiver quality of life and the theory of self-transcendence. No new articles returned. Many of the same articles appeared in the different searches. After removing duplicates, reviewing abstracts, and reading articles, a total of 25 were included.

Theory of Self-transcendence

The theory of self-transcendence has been used in research involving spirituality and in caregiving populations. Runquist and Reed (2007) used this theory to examine relationships among spirituality, physical variables like health status and fatigue, and well-being in homeless American women with breast cancer. Acton (2000) used this theory in a qualitative study to investigate self-transcendence in family caregivers of adults with dementia. The CARES tool to assist family caregivers at the end of life was designed using the theory of self-transcendence as the guiding framework (Freeman, 2015). The theory was also used to guide an investigation of resilience, self-transcendence, and positive and negative well-being in caregivers of children with cancer (Bajjani-Genera, 2019). These studies validate the use of the theory of self-transcendence to study spirituality in caregiving populations ages 19-90.

Caregiver Burden

Caregiver burden has also been studied extensively but conceptualized in varying ways. Liu et al. (2020) performed a concept analysis and defined caregiver burden as “the level of multifaceted strain perceived by the caregiver from caring for a family member and/or loved one over time”. Caregiver burden has also been described as the physical, emotional, psychosocial, and financial strains experienced by caregivers (NAC & AARP, 2020). In one longitudinal

secondary data analysis, researchers found a correlation between greater reported levels of caregiving stress at T1 and later development of heart diseases generally and higher rates of arthritis and chronic back pain in spousal caregivers (mean age = 55.02, SD12.9; Kim et al., 2015). Tkatch et al. (2017) tested a mindfulness intervention in older adults (mean age = 71) that reduced caregiver burden, perceived stress, anxiety, and loneliness and improved mental well-being. Glueckauf et al. (2022) pilot-tested a caregiver training and support program for African American Alzheimer's caregivers to reduce caregiver burden. The intervention, which relied heavily on spiritual components, improved burden outcome measurements and was well-received by participants. Bialon and Coke (2012) conducted interviews with informal caregivers of terminally ill patients and identified four themes: decline in overall health of the caregiver, role conflict, lack of physical and educational support, and the importance of faith in the caregiving process. Saleh et al. (2022) conducted a mixed-methods study of caregiver burden in caregivers of family members with cirrhosis. They found many factors that affected caregiver burden including factors related to the caregiver such as fear, anxiety, and lack of self-care; factors related to the loved one such as symptoms, non-adherence, and inability to perform certain roles; and factors related to the health care system such as access to care, provider communication, and physician ability. These studies confirm the need for further investigation.

Spirituality

Spirituality is another concept that has been studied and conceptualized in a variety of ways. The definition guiding this study is from the European Association for Palliative Care (EAPC) Taskforce, which defines spirituality as a way people “express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred” (Nolan et al., 2011). While this definition was developed in

Europe and study participants are North American, this definition is broad enough to be universal, yet specific enough to capture the essence of the intended concept.

Spirituality is an important topic for nurses because it is part of the “ontologic foundation of nursing; it is regarded as a basic characteristic of humanness important in human health and well-being” (Reed, 1992, p. 349). Research on spirituality in caregivers reveals that caregivers who were older, female, ethnic minority, less educated, affiliated with a religion, and who provided care to more than one individual had higher levels of spirituality (La et al., 2020). Spirituality also provides a sense of meaning and purpose and can lower depression scale scores (La et al., 2020) and can partially mediate the effects of subjective stress in caregivers (Hodge & Sun, 2012). Although spirituality is an important aspect of caregiver well-being, research also shows that caregivers face existential crises and can experience spiritual doubts, conflicts, and loss of faith (Ferrell et al., 2018). Thus, identifying the role of spirituality on caregiving burden and quality of life among caregivers is important.

Quality of Life

Quality of life has received much attention in the literature and has been conceptualized in a variety of ways. The definition that guides this study was developed by the WHOQOL Group (1995). They define QOL as

an individuals’ perceptions of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the persons’ physical health, psychological state, level of independence, social relationships and their relationship to salient features of their environment.

Quality of life is an important concept to study because it is an important aspect of overall health and well-being (WHO, 1998). It can be concluded then that diminished QOL among caregivers results in poorer overall health. This is recognized by the NINR (2016), who has called for ways to improve caregiver QOL.

A number of disciplines are interested in improving QOL, and researchers have made it the primary outcome in a number of studies. Morrison et al. (2020) investigated contributions of caregiver and care recipient risk and resistance factors on QOL in dementia caregivers. The authors found that younger caregivers (specific ages not given, population mean age 67.45, SD = 12.56) had significantly lower QOL compared to older caregivers and that spousal caregivers had higher QOL than caregivers who were offspring. The researchers also found that care recipient functional dependence was a significant predictor of caregiver QOL and that social problem-solving, as well as perceived social support, had a positive correlation with caregiver QOL. Lapid et al. (2016) tested a 4-week psychosocial, educational intervention aimed at improving caregiver QOL in spouses of cancer survivors. They found no improvement in overall QOL, though there was improvement in some domains.

More recently, Dionne-Odom et al. (2022) conducted a pilot study to test a lay-person led intervention to improve QOL, among other things, in Southern African American and rural caregivers. The intervention, Educate, Nurture, Advise, Before Life Ends (ENABLE), produced improved QOL, anxiety and depression scores in informal caregivers. Likewise, Lapid et al. (2022) pilot-tested a virtual group therapy program for informal caregivers. While not statistically significant, caregivers reported higher levels of QOL.

Ferrell et al. (2018) conducted a qualitative analysis to better understand the quality of life needs of informal caregivers of those with cancer. The results showed that care is needed

across all domains of QOL. Although caregivers experience spiritual doubts, conflicts, and loss of faith, they also view faith as an important support. Another secondary data analysis found disparities among caregiver QOL. Black caregivers reported higher levels of caregiving intensity and more financial impact, but less impact on QOL (Cohen et al., 2017).

Relationships among Caregiver Burden, Spirituality, and QOL

This review helped to inform what is currently known about the relationships among caregiver burden, spirituality, and QOL. Research shows that caregiver burden has inverse relationships with caregiver QOL (Taha et al., 2021) and with spirituality (Huang et al., 2021). Findings from the literature also revealed a positive correlation between spirituality and caregiver QOL (Taha et al., 2021). Additionally, a moderating effect of spirituality between caregiver burden and caregiver QOL was reported. Colgrove et al. (2007), who explored the moderating effect of spirituality on cancer caregiving stress in spousal caregivers (ages 29-88), found that spirituality has a moderating effect on QOL by buffering caregiver stress. Taha et al. (2021) explored the relationship among caregiver burden, spirituality, quality of life, and depression in parents of adolescents with spina bifida. The researchers found that spirituality moderates the relationship between caregiver burden and QOL, that as spirituality increased, negative effects of caregiving decreased.

Summary

A review of the literature has revealed linear relationships among caregiver burden, spirituality, and quality of life. Caregiver burden and QOL have an inverse relationship that can be influenced by spirituality. However, little is known about the moderating effect of spirituality on caregiver burden and quality of life in older adult informal caregivers living in the U. S. Further investigation into how spirituality impacts the relationship between caregiver burden and

QOL in older adults could help researchers identify ways to improve caregiver QOL using spirituality as a mitigating force.

Chapter 3 details study methods including an overview of the Health and Retirement Study, conceptual and operational definitions, the sample, the study design, ethical considerations, and data analysis.

Chapter 3: Methods

A secondary data analysis, using data from the Health and Retirement Study (HRS), was conducted with the following aims.

Aim 1: To determine the prevalence of caregiver burden in a nationally representative sample of older adult informal caregivers.

Aim 2: To investigate the relationships among caregiver burden, spirituality, and quality of life in a nationally representative sample of older adult informal caregivers.

Hypothesis. Spirituality will moderate the effect of caregiver burden on quality of life resulting in higher quality of life outcomes in older adult informal caregivers living in the U.S.

Research Questions. Does caregiver burden have a different effect on quality of life in those who are spiritual vs those who are not spiritual?

A description will be given of the study design, the HRS, conceptual and operational definitions, the sample, ethical considerations, data analysis, and limitations.

Design

This was a cross-sectional secondary data analysis using general linear modeling and structural equation modeling (SEM). SEM was chosen because it provided a way to explore relationships among measured variables, as will be described later in this chapter. Secondary data analysis is a research methodology using data previously collected, by the researcher or someone else, to answer new research questions (O'Connor, 2020). Secondary analysis for nursing research is both efficient and cost-effective because large amounts of data are readily available for analysis (Dunn et al., 2015).

Overview of the Health and Retirement Study

The Health and Retirement Study was created to collect high quality data on older adults as they moved into retirement; to examine interactions among health, family, and economics; and to make the data available to researchers interested in studying this population (Health and Retirement Study [HRS], 2008). As of 2017, HRS data has been used in over 1,800 peer-reviewed publications and in over 3,500 publications of any type (HRS, 2017). The HRS collects data related to health and well-being and is the largest and most comprehensive data set on older Americans aged 55 and above and their spouses, who may be <55 (HRS, 2017). The comprehensive nature provides opportunity to researchers to study a wide array of phenomena relative to older adults. The psychosocial data in particular offers insight into human development of older adults, a subject less studied than development in children and younger adults (HRS, 2017). The psychosocial data includes well-validated instruments that have been used to study the variables of interest to this author. Therefore, using existing data from the HRS was an appropriate choice to explore the relationships among caregiver burden, spirituality, and quality of life.

The HRS began collecting data in 1992 from older adults living in the contiguous U. S. born from 1931 to 1941 and in 1923 or earlier. Other subgroups were added through the years to now include adults born in 1965 or any year before and their spouses. Black and Hispanic individuals are over sampled at a rate of about 2 to 1 (HRS, 2017). Because Alaska and Hawaii are not included in the survey, Asian and Indigenous populations may be under sampled. Data is collected every two years either in person, over the phone, or on the internet. Demographic information was collected at the initial interview and updated as needed. It is kept in a separate

crosstracker file and was merged based on participant household and personal identification numbers.

In 2006, participants were randomly divided into two groups for alternating enhanced face-to-face interviews. Each group gets an enhanced face-to-face interview every four years because they alternate every two-year collection cycle. At this interview, a leave-behind questionnaire, which started being used in 2004, is given to complete at the participant's convenience. This leave-behind questionnaire contains the psychosocial part of the overall survey. Therefore, leave-behind data is collected from only half of the participants each cycle (those whose turn it is to receive the enhanced face-to-face interview). Due to the COVID-19 pandemic, face-to-face interviews were suspended. Those participants who were scheduled for the enhanced face-to-face interview were mailed the leave-behind survey which was the collection instrument used for this secondary data analysis. Data was collected from March 2020 through May 2021.

Ethics and Human Subject Protection

The HRS original data collection was approved by the Institutional Review Board (IRB) at the University of Michigan in 1992. Data is de-identified and kept in a secure server. The HRS was granted a Federal Certificate of Confidentiality from the National Institutes of Health, which shields it against court ordered forced disclosure of study participants. Participants are given information about informed consent at each interview. Participation in the surveys is evidence of consent. Risk of harm is low, especially for the leave behind data. Re-identification could be a possibility, though unlikely, as data is made publicly available. However, sensitive and personal data is restricted, and access requires greater scrutiny. Participants are given a stipend of \$100 for the core interview and \$20 for the psychosocial survey that is left behind for them to

complete. They also have the knowledge that the de-identified data is easily available to researchers for the common good.

For the purpose of this study, the sample is considered as “not human subject” by the West Virginia University IRB because the data is de-identified secondary data that very likely cannot be re-identified. Nevertheless, application was made to the IRB as required by the HRS and for publication purposes. Data was made available to download after registering with the HRS and agreeing to maintain it securely. The data is being stored on an encrypted server for at least three years as required by the West Virginia University IRB and will be deleted afterward.

Study Sample

This study sample consisted of the 2020 HRS participants who were scheduled for the enhanced face-to-face interviews (half of the total HRS sample). Due to the COVID-19 pandemic, participants were mailed the survey. The sample consisted of older adults born in 1965 and before, and their spouses, living in the contiguous U. S. Households are geographically stratified and clustered based on data from the U. S. Census. Data is also carried over from the Social Security Administration.

From the 2020 half-group, data from weighted participants who identified as providing care for another adult at least once a month and who completed the surveys of interest ($n = 591$) are included in this secondary data analysis. Thus, the sample is a nationally representative sample of older adult caregivers, of other adults, who participated in the psychosocial survey portion of the 2020 HRS. Suggested weights were provided by the researchers of HRS and were based on the 2016 data. Though these weights vary due to shifting demographics over four years, it is the same population of caregivers.

Measurements/ Instrumentation

Demographics

Demographics included in this analysis are as follows: age, gender, race, Hispanicity, marital status, living alone status, and educational attainment. Race and Hispanicity were collected in two separate questions. Race choices were: White/ Caucasian, Black or African American, Other. Hispanicity choices were: Mexican, Other Hispanic, unknown Hispanic, and not Hispanic.

Caregiver Status

Caregiving status was determined by how the participant answered the following question: please tell us how often you care for a sick or disabled adult? Choices were as follows: daily, several times a week, once a week, several times a month, at least once a month, not in the last month, never/not relevant. Participants who reported providing care to another adult at least once a month were included in the analysis. Additionally, participants were asked if they had been providing on-going care to another adult who is sick, limited, or frail for longer than a year and if this was upsetting. Choices were as follows: no, didn't happen; yes, but not upsetting; yes, somewhat upsetting; yes, very upsetting. Those caregivers who answered no, didn't happen were considered to have been caregiving less than one year. This question was used to analyze attitudes toward providing care for more than one year in relation to demographics and the variables of interest (caregiver burden, spirituality, and QOL).

Caregiver Burden

Caregiver burden, which Liu et al. (2020) defined as “the level of multifaceted strain perceived by the caregiver from caring for a family member and/or loved one over time” was measured using the Perceived Stress Scale (PSS) (Cohen et al., 1983), which is also embedded

into to leave-behind survey. The 10-item Likert-style PSS was developed to measure perceived stress related to life events. This is consistent with the construct of vulnerability from the theory of self-transcendence. Vulnerability is the risk to well-being in the presence of a life altering event. Original psychometric testing on the PSS produced Cronbach's alphas of .84 - .86 in three samples (Cohen et al., 1983). The HRS reported an alpha of .85 in the 2020 survey and an alpha of .85 in the 2018 survey. The Perceived Stress Scale has been used to measure caregiver burden (Chwalisz, 1996; Mioshi et al., 2009) with good results. Chwalisz (1996) reported alphas of .81. Additionally, Chwalisz and Kisner (1995) suggest that the PSS measures caregiver burden more accurately than other caregiver burden scales because it measures not only the stressor, but the response to the stressor (Chwalisz, 1996).

The PSS, found in its entirety in the HRS, consists of the following questions for which participants were asked to respond 1. never, 2. almost never, 3. sometimes, 4. fairly often, 5. very often.

In the last month, how often have you...

Been upset because of something that happened unexpectedly?

Felt that you were unable to control the important things in your life?

Felt nervous and "stressed"?

Felt confident about your ability to handle your personal problems?

Felt that things were going your way?

Found that you could not cope with all the things that you had to do?

Been able to control irritations in your life?

Felt that you were on top of things?

Been angered because of things that were outside of your control?

Felt difficulties were piling up so high that you could not overcome them

Scores range from 10 - 50. Higher scores indicate increased caregiver burden. Burden scores were also categorized into low (10 - 23), moderate (24 - 36), and high burden levels (37 - 50) (Ilesanmi, et al., 2021) for further analysis.

Spirituality

The definition of spirituality guiding this study is from the European Association for Palliative Care (EAPC) Taskforce, which defines spirituality as a way people “express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred” (Nolan et al., 2011). The spirituality scale embedded in the leave-behind survey consists of four items from the Multidimensional Measure of Religiousness/Spirituality (MMRS) (Fetzer Institute [FI], 1999). The MMRS was developed to aid researchers in measuring religiousness and spirituality. The MMRS is based on the assumption that religiousness and spirituality can improve health outcomes (FI, 1999). Krause (2003) found that “older adults who derive a sense of meaning in life from religion tend to have higher levels of life satisfaction, self-esteem, and optimism”. This adds validity to the assumption that spirituality can be a means of self-transcendence leading to a better QOL. The included questions measure the meaning of, not the practice of, religion and therefore, fit the definition of spirituality being used.

The four-item scale, based upon findings from Krause (2003), measured spirituality. Participants were asked to say how much they agree or disagree (ranging from 1. strongly disagree, 2. somewhat disagree, 3. slightly disagree, 4. slightly agree, 5. somewhat agree, 6. strongly agree) with each of the following statements:

I believe in a God who watches over me.

The events in my life unfold according to a divine or greater plan.

I try hard to carry my religious beliefs over into all my other dealings in life.

I find strength and comfort in my religion.

Total scores range from 4 - 24. Average score (M/SD) were calculated across all four items.

Higher scores indicate higher spirituality. While belief in a God is not necessary for one to be spiritual, the decision was made to keep this question because it is part of the survey and was included in HRS psychometric testing. The HRS report alphas of .92 - .93 from the 2006 to the 2014 data collection periods.

Quality of Life

Quality of life was measured using the Satisfaction with Life Scale (SWLS) (Pavot & Diener, 1993), which is fully embedded into the leave-behind survey. Global QOL has previously been measured using the SWLS (Ravyts & Dzierzewski, 2020; Rogers et al., 2012), and other researchers have correlated life satisfaction with QOL (Lorenzo-Seva et al. 2019; Teresi et al, 2017). Additionally, the definition guiding the development of the SWLS is that life satisfaction is a person's global assessment of their quality of life (Pavot & Diener, 1993). Furthermore, the WHO definition of QOL emphasizes the subjective nature of QOL, so, it is appropriate to measure overall QOL with the participants perception of it. This is also consistent with the theory of self-transcendence which views well-being as a subjective "sense of feeling whole and healthy" (Reed, 2018, p. 123). Well-being is the theoretical construct congruent with QOL in this analysis.

The 5-item Likert Satisfaction with Life Scale (SWLS) consists of the following five questions:

In most ways my life is close to ideal.

The conditions of my life are excellent.

I am satisfied with my life.

So far, I have gotten the important things I want in life.

If I could live my life again, I would change almost nothing.

Choices are: 1. strongly disagree, 2. somewhat disagree, 3. slightly disagree, 4. neither agree nor disagree, 5. slightly agree, 6. somewhat agree, 7. strongly agree. Total scores range from 5 - 35. Higher scores indicate increased quality of life. The scale has consistently generated Cronbach alphas of .88 - .89 in HRS analysis. Total scale scores were also categorized into low (5 - 14), moderate (15 - 25), and high levels (26 - 35) for additional analysis (Løvereide & Hagell, 2016).

Data Management

After creating an account, data was downloaded from the HRS study website. The demographic and leave-behind data sets were merged. Data from participants not identifying as a caregiver and not completing the surveys were removed. Caregivers who were not given a weight because they did not qualify according to HRS guidelines were also removed. If more than one value was missing from a survey, that data was removed. Missing values were replaced with mean of continuous data and mode of categorical data. Caregivers with missing demographic values were included for pair-wise analysis. The total number of cases included for analysis were 591. Outliers were not removed because the weighted sample is large, making outliers less likely to affect results (Newsom, 2022).

Data Analysis

Demographic data was analyzed using IBM Statistical Package for the Social Sciences (SPSS version 28). Univariate analysis was conducted to determine frequencies and/or measures of central tendency. Frequencies are reported using the unweighted N and the weighted percent.

Relationships among the variables were explored using bivariate general linear modeling (GLM) and crosstabs with chi-square analysis as well as multivariate linear regression analysis (Y1= caregiver burden, Y2 = spirituality, Y3 = QOL). Bivariate analysis using GLM was conducted by first exploring the relationships between the variables of interest (caregiver burden, spirituality, and QOL), then by exploring the relationships between caregiver burden with each of the demographics and QOL with each of the demographics. Attitude toward providing care for more than one year was also included in bivariate analysis to determine if there were statistically significant relationships with any demographics or with the three variables of interest.

General linear modeling requires data to be normally distributed with homogeneity of variance (Kim, 2012). To determine if the assumption of normal distribution was met, data dispersion was analyzed for skewness and kurtosis. The data was assumed to have met the requirement of homogeneity because clustering and stratification of the original sample ensures homogeneity of variance and more accurate representation of the sample (Sharma, 2017). GLM also requires the dependent variable to be continuous (Kim, 2012). Total scale scores were used in GLM analysis to meet this requirement.

Once correlations were established among the variables using GLM, an SEM was built and tested using AMOS software version 28. SEM uses a theory-based path diagram to analyze multivariate data to determine relationships among multiple variables in a single analysis (Hoyle & Smith, 1994). SEM was the most appropriate method to answer the research question because the variables of interest were complex, abstract, and multifaceted. These types of concepts can be analysed using SEM because SEM accounts for errors in measurement (Sturgis, 2019). SEM can also test theoretical models depicting relationships between concepts and show multiple and interconnected relationships in one analysis (Jain & Chetty, 2021).

Structural equation modeling was conducted in a step-by-step process. The first step was model specification testing. A model depicting significant relationships among the concepts and demographics was entered into the software. Path analysis was then conducted to validate each relationship. The path coefficients represent the strength of the influence one variable has on another. This allowed for comparisons to be made and for direct, indirect, and total effects to be determined (Wang, 2022). The next step was to analyze goodness of fit. Several tests were run simultaneously to evaluate the how well the model fit the data. These included: Chi-square testing, which should have a p -value $> .05$, Comparative Fit Index (CFI), Bollen's Incremental Fit Index (IFI), Bentler-Bonnett Normed Fit Index (NFI), Tucker-Lewis Index (TLI), which should all be $> .9$; the Parsimony Comparative Fit Index (PCFI), which should be $> .5$; and the Root Mean Square Error of Approximation (RMSEA), which should be $< .08$ (Sharif, 2021). Non-significant results were removed, and the final model was analyzed for significant paths and goodness of fit.

Summary

Cross-sectional data from a large, well-established national data set was analyzed in accordance with expected ethical principles. Data was analyzed using structural equation modeling to best capture the relationships among caregiver burden, spirituality, and quality of life. While there are limitations with secondary data analysis, justification for concept measurement has been made. Additionally, a large, heterogenous caregiving sample may make the findings more generalizable.

Chapter 4: Results

Analysis was conducted to answer the following research question:

Among older adult informal caregivers of other adults, does caregiver burden have a different effect on quality of life in those who are spiritual vs those who are not spiritual?

The hypothesis was:

Spirituality will moderate the effect of caregiver burden on quality of life resulting in higher quality of life outcomes in informal older adult caregivers living in the U.S.

Aim 1: To determine the prevalence of caregiver burden in a nationally representative sample of older adult informal caregivers.

Aim 2: To investigate the relationships among caregiver burden, spirituality, and quality of life in a nationally representative sample of older adult informal caregivers.

This chapter reports findings from univariate, bivariate, and multivariate data analysis as well as SEM. IBM SPSS was used to analyze frequencies and measures of central tendency for demographics and total scale scores, crosstab analysis using chi-square test for independence, and general linear modeling. SPSS AMOS was used for SEM that was constructed based on results from GLM. Unless otherwise stated, all analysis in SPSS was conducted with the complex samples feature using an analysis plan utilizing the strata, clusters, and individual weights provided by the HRS (HRS, 2019).

Demographic Analysis

Demographics variables are shown in table 1. Both weighted and non-weighted variable results are shown. The sample mean age was 66.32 years ($SD = 7.84$) with the largest age category being 54 - 64 ($n = 241, 46.8\%$). More caregivers were female ($n = 368, 53.1\%$) than male ($n = 223, 46.9\%$). Caregivers were predominantly White ($n = 399, 81.5\%$) and non-

Hispanic (n = 516, 91.2%) with Mexican Americans (n = 45, 5.1%) making up the largest Hispanic population. Black caregivers accounted for 11.5% (n = 145) of this sample. Most caregivers were married (n = 378, 68.7%) and most lived with a spouse or partner (n = 400, 72.4%), while 12.8% (n = 83) lived alone. Most caregivers had at least a high school education or general education diploma (GED). Educational attainment included no degree (n = 66, 9.6%), high school diploma or GED (n = 290, 47.1%), any amount of undergraduate education (n = 150, 30.1%), and master's or professional degree (n = 64, 12.9%). Additionally, 22.5% (n = 126) of caregivers provided care for more than a year and found it to be *somewhat upsetting*, while 9.6% (n = 51) provided care for more than a year and found it to be *very upsetting*. However, 49.3% (n = 292) provided care for more than a year found it to be *not upsetting*.

Psychometric Properties

To measure scale reliability, factor analysis was conducted for each instrument in both the total HRS population and in the caregiving population, respectively. The Perceived Stress Scale measuring caregiver burden yielded Cronbach's alphas of .847 and .866. The spirituality scale yielded Cronbach's alphas of .933 and .941. The Satisfaction with Life scale measuring QOL yielded Cronbach's alphas of .878 and .869. All scales have good reliabilities with alphas greater than .8 (Schweizer, 2011).

Dispersion

The data was assessed for normal distribution by analyzing skewness and kurtosis. It is generally considered acceptable that the absolute values of skewness not be greater than two and kurtosis not be over seven (Ryu, 2011). The variables of interest in this study show skewness between +2 and -2 and kurtosis < 7 and are therefore acceptable for analysis (see table 2).

Additionally, kurtosis values of less than 10, indicate a platykurtic curve, which confirmed fewer extreme outliers in this data set (Chirchiglia, 2020).

Descriptive Statistics

Descriptive statistics were conducted to address Aim 1 (Table 2). Perceived stress scale scores measured caregiver burden and produced a mean score of 23.48(SD = 6.54). Among this caregiver population, 48.5% (n = 284) scored as having low levels of caregiver burden, 48% (n = 289) scored as having moderate caregiver burden, and 3.5% (n = 18) scored as having high levels of caregiver burden. This analysis met aim 1, which was to determine the prevalence of caregiver burden in this population of older adult caregivers.

The majority of the population scored as being spiritual on the spirituality scale with a mean score of 19.16 (SD = 6.25), median of 22, and mode of 24. The decision was made to transform this variable to avoid possible ceiling effect. The variable was dichotomized using the median score of 22 (Mitchell et al., 2020). Those scoring 23 and above (n = 289, 44.7%) were categorized as being highly spiritual. Those scoring 22 and below (n = 302, 55.3%) were categorized as being not highly spiritual. For the purpose of this dissertation, spirituality refers to those who are *highly spiritual*.

Quality of life was measured using the Satisfaction with Life Scale. The total mean score was 24.27 (SD = 7.36). When categorized, the majority of caregivers scored as having high QOL (n = 285, 50.7%), while 236 (n = 36.8%) scored as having moderate QOL, and 70 (12.5%) scored as having low QOL.

Bivariate Analysis

Spearman Rank Correlations

Spearman's rank correlation was conducted to examine the relationships between caregiver burden, spirituality, QOL, and attitude toward providing care for more than one year (table 3). There was a negative correlation between caregiver burden and spirituality ($\rho = -.09, p = .026$). There also was a negative correlation between caregiver burden and QOL ($\rho = -.479, p = <.001$). Negative correlations were found between attitude toward providing care for more than one year and spirituality ($\rho = -.100, p = .015$) and QOL ($\rho = -.185, p = <.011$). There was positive correlation between spirituality and QOL ($\rho = .125, p = .002$). There was also a positive correlation between attitude toward providing care for more than one year and caregiver burden ($\rho = .252, p = <.001$).

Bivariate Linear Regression Analysis (GLM)

Bivariate analysis was conducted using GLM to explore relationships among all variables. Each variable of interest (caregiver burden, spirituality, and QOL) was tested with each of the other two. Caregiver burden and QOL were also each tested with every individual demographic and with attitude toward providing care for more than one year. In all GLM models, the most frequent occurrence of each categorical variable was used as the referent category, therefore each outcome was compared with the most frequent occurrence.

Caregiver burden was measured by the Perceived Stress Scale (PSS). Higher scores indicated higher caregiver burden while lower scores indicated lower burden. In this study, caregiver burden had no statistically significant correlations with gender, race, Hispanicity, education, and living alone (table 4). Some relationships were statistically significant, however. Caregivers who were aged 75 - 85 had lower PSS scores ($B = -2.641, t = -3.365, p = .001$)

compared with those under age 65. Caregivers who have never been married ($B = 2.425, t = 2.582, p = .012$) and those who were separated or divorced ($B = 1.633, t = 1.924, p = .059$) had higher PSS scores compared with those who were married. Caregivers who were highly spiritual had lower PSS scores ($B = -1.689, t = -2.337, p = .023$) compared with those who were not highly spiritual. Caregivers who reported that providing care for more than a year was *very upsetting* ($B = 9.549, t = 7.517, p = <.001$) and *somewhat upsetting* ($B = 3.883, t = 4.974, p = <.001$) had higher PSS scores than those who provided care for more than a year but found it to be *not upsetting*. See table 4 for full results.

Quality of life was measured using the Satisfaction with Life Scale (SWLS). See table 5. Higher scores indicated higher QOL while lower scores indicated reduced QOL. Gender, age, education, and spirituality yielded no statistically significant results. Analysis did show that race, Hispanicity, marital status and living alone were significant predictors of QOL. Black caregivers scored lower on the SWLS as compared with White caregivers ($B = -3.401, t = -3.382, p = .001$). Mexican American caregivers scored higher on the SWLS when compared with non-Hispanic caregivers ($B = 3.075, t = 2.767, p = .025$). Caregivers who were separated or divorced scored lower on SWLS as compared with married caregivers ($B = -5.383, t = -4.775, p = <.001$). Caregivers who live alone scored lower on the SWLS than those who do not live alone ($B = -3.599, t = -2.296, p = .025$). Additionally, those with high burden ($B = 12.84, t = -6.786, p = <.001$) and with moderate burden ($B = -5.851, t = -8.311, p = <.001$) scored lower on SWLS than caregivers with low burden. Furthermore, those caregivers who reported providing care for more than a year and reported that it was *very upsetting* scored lower on the SWLS than those who said it was *not upsetting* ($B = -6.234, t = -4.59, p = <.001$). There were no statistically significant

findings between the SWLS scores in those providing care for more than a year and said it was *somewhat upsetting* and *not upsetting*.

Independence Test Using Chi-square Test

The variables of interest were analyzed with each other and with each demographic to determine frequencies and correlations. In crosstab analysis of the three variables of interest (tables 6-8), caregiver burden and QOL displayed a significant relationship ($\chi^2 = 103.827, p = <.001$). Although not statistically significant ($\chi^2 = 8.776, p = .096$), caregivers who have high caregiver burden were more likely to be not highly spiritual ($n = 11, 4.9\%$) than highly spiritual ($n = 7, 1.9\%$). Additionally, among the highly spiritual, 54.3% ($n = 158$) had low levels of caregiver burden compared with 43.8% ($n = 126$) of those not highly spiritual. No significant relationship was shown between QOL and spirituality.

Levels of caregiver burden did not show significant correlations with any demographics, but education approached significance ($\chi^2 = 4.716, p = .057$) (table 9). Those caregivers with any undergraduate education were more likely to have low caregiver burden ($n = 92, 61\%$). Those with no degree were more likely to have moderate caregiver burden ($n = 46, 69.2\%$).

Crosstab analysis between spirituality and each demographic variable yielded non-significant results with gender, Hispanicity, marital status, and living alone (table 10). Significant results revealed these female caregivers were more highly spiritual than males ($\chi^2 = 27.214, p = <.001$). Race was also significant ($\chi^2 = 35.311, p = <.001$). Black ($n = 97, 72.4\%$) and other minority ($n = 31, 66.9\%$) caregivers were more highly spiritual than White caregivers ($n = 174, 39.2\%$). Age was also associated with spirituality ($\chi^2 = 12.648, p = .011$). Older caregivers were more likely to be highly spiritual with 70.5% ($n = 22$) of 85 - 95 years old being highly spiritual versus 38.6% ($n = 106$) of caregivers under 65. Education was also significant ($\chi^2 = 21.259, p =$

.005). The higher the degree attainment, the less likely caregivers were to be highly spiritual. Caregivers with a graduate or professional degree (n = 36, 70.7%) and those with any amount of undergraduate education (n = 88, 64.6%) were more likely to be not highly spiritual.

Crosstab analysis between QOL and each demographic variable yielded non-significant results with gender, Hispanicity, age and education (table 11). Race ($\chi^2 = 13.274, p = .023$), marital status ($\chi^2 = 48.742, p = .002$), and living alone ($\chi^2 = 13.636, p = .040$) were all correlated with QOL. White caregivers (n = 204, 52.2%) and those of “other” races (n = 27, 61.1%,) were more likely to have high QOL. Black caregivers were more likely to have moderate QOL (n = 68, 40.3%). Those caregivers who were married (n = 202, 57.1%) and who were not living alone (n = 249, 52.6%) had the highest QOL in their respective demographics. Compared with other marital statuses, caregivers who were separated or divorced had the highest percent of low QOL scores (n = 29, 30.4%).

Attitude toward providing care for a loved one for more than a year was shown to be significantly associated with both caregiver burden ($\chi^2 = 91.312, p = <.001$) and QOL ($\chi^2 = 35.821, p = .004$) (table 12). Among caregivers with high caregiver burden, 59.1% (n = 7) have provided care for more than a year and reported it as being *very upsetting*. In contrast, among caregivers with low caregiver burden, 60.2% (n = 167) provided care for at least a year but found it to be *not upsetting*. Additionally, the lowest percentage of those with high caregiver burden (n = 1, 2.1%) were found in those who have been providing care for less than a year. Likewise, the lowest percentage of those with high QOL (n = 9, 4.4%) was found in those who have been caregiving for more than a year and find it to be *very upsetting*. Furthermore, caregivers with the highest QOL were those who provided care for more than a year but found it to be *not upsetting*. No significant relationship was established between attitudes toward helping and spirituality.

Multivariate Linear Regression Analysis

GLM with Caregiver Burden, Spirituality, and QOL

Multivariate linear regression analysis was conducted to further analyze the relationships among the variables (caregiver burden, spirituality, and QOL; Aim 2) and to prepare for building a structural equation model (SEM). Based upon the findings of the bivariate linear regression analysis, several GLMs were conducted. The first set of GLMs tested the main effect of caregiver burden, as measured by PSS scores, and spirituality on QOL, as measured by the SWLS (table 13), followed by a model testing both main and interaction effects (table 14). The second set of GLMs tested the main effect of spirituality and QOL on caregiver burden (table 13) followed by a model testing both main and interaction effects (table 15).

Results yielded a significant main effect of PSS scores on SWLS scores in the main effects model ($B = -.540, t = -10.626, p = <.001$) as well as in the interaction model ($B = -.587, t = -8.752, p = <.001$). Spirituality had no main effect, and there was no interaction effect between PSS scores and spirituality.

The models using caregiver burden as the dependent variable, testing the main effects of SWLS scores and spirituality as well as their interaction effect yielded both significant main and interaction effects. Those caregivers who are highly spiritual had lower PSS scores than those who are not highly spiritual ($B = -4.848, t = -1.245, p = .009$). Additionally, those caregivers with higher SWLS scores had lower PSS scores ($B = -.529, t = -10.333, p = <.001$). However, the interaction effect between spirituality and SWLS scores raised burden scores ($B = .151, t = 2.068, p = .043$).

GLM with All Predictors

Based on results from the bivariate linear regression analysis, GLM was conducted using caregiver burden (PSS scores) as the outcome variable and its significant predictors (spirituality, age, marital status, and attitude toward providing care for more than one year) as independent variables (table 16). All predictors remained significant, except for age ($p = .451$). In this model, highly spiritual caregivers had lower PSS scores ($B = -1.499, t = -2.177, p = .033$). Higher PSS scores were found in those never married ($B = 2.765, t = 2.640, p = .011$) and those who were separated or divorced ($B = 2.177, t = 2.763, p = .008$) compared with those who are married. Additionally, compared with caregivers who provided care for more than one year and found it to be *not upsetting*, higher PSS scores were found in those who found it to be *somewhat upsetting* ($B = 4.03, t = 5.375, p < .001$) and *very upsetting* ($B = 9.405, t = 7.902, p < .001$).

GLM was also conducted using QOL (SWLS scores) as the outcome variable and its significant predictors (caregiver burden, race, Hispanicity, marital status, living alone status, and attitude toward providing care for more than one year) as independent variables (table 17). In the model, living alone ($p = .351$) was not significant. Caregiver burden, race, Hispanicity, marital status, and attitude toward providing care for more than one year were significant. Caregivers with PSS scores indicating a high burden ($B = -10.843, t = -6.490, p < .001$) and a moderate burden ($B = -5.024, t = -7.232, p < .001$) all had lower SWLS scores. Caregivers who were Black ($B = -3.237, t = -3.425, p = .001$) also scored lower on the SWLS compared with White caregivers, as did caregivers who are separated or divorced ($B = -4.373, t = -3.945, p < .001$) compared with married caregivers. Additionally, those who found caregiving for greater than one year to be *very upsetting* ($B = -3.776, t = -3.701, p < .001$) had lower SWLS scores than those

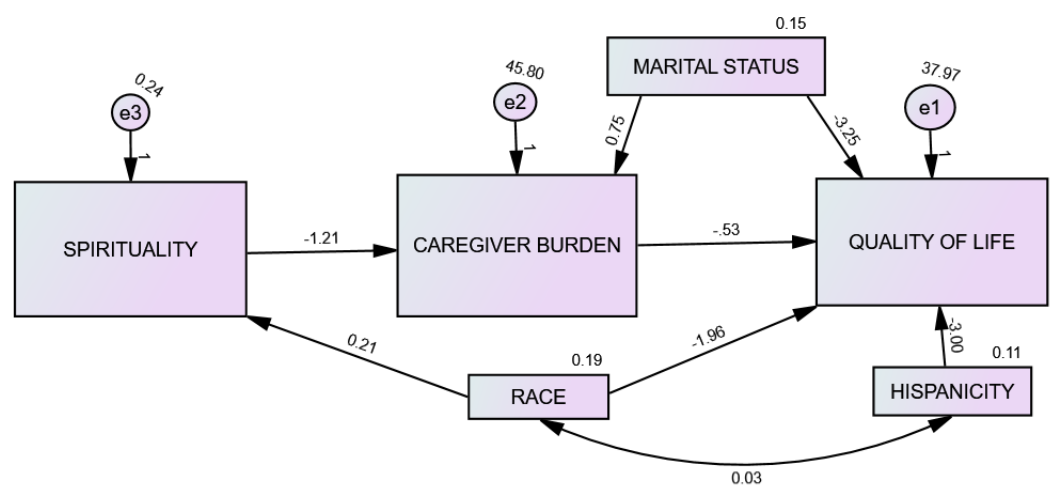
who found it to be *not upsetting*. Hispanic caregivers other than those of Mexican decent had higher SWLS scores ($B = 3.102, t = 2.511, p = .015$).

Structural Equation Modeling

Bivariate and multivariate analysis showed that marital status, race, Hispanicity, and caregiver burden were predictors of QOL. Spirituality and marital status were predictors of caregiver burden. Among those demographics, race was correlated with spirituality. A structural equation model (figure 1) was built using IBM SPSS AMOS software to reflect those relationships.

Figure 1

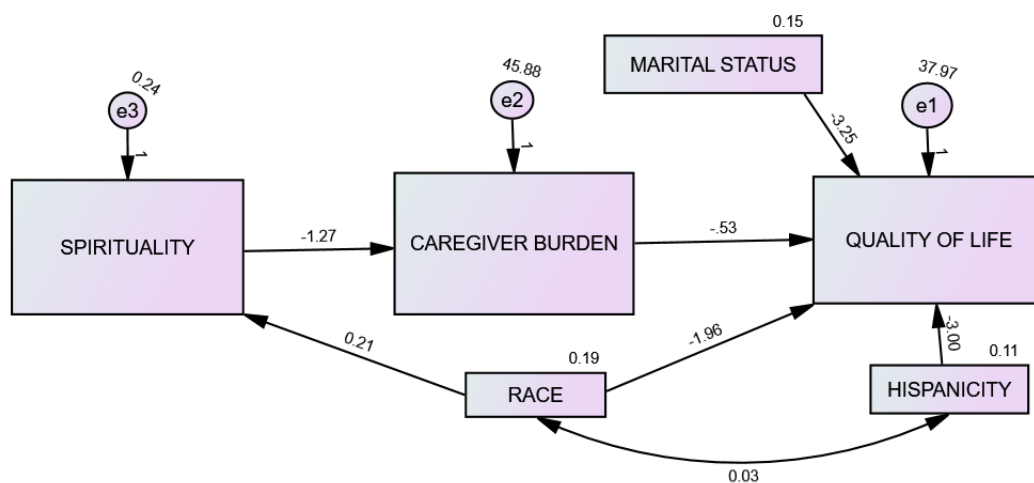
Model 1



Path analysis showed that marital status to caregiver burden ($p = .303$) was not significant in this model (table 18). Results significant to the model include: spirituality to caregiver burden ($B = -1.208$, $SE = .557$, $CR = -2.2167$, $p = .030$), caregiver burden to QOL ($B = -.528$, $SE = .037$, $CR = -14.134$, $p = .000$), marital status to QOL ($B = -3.253$, $SE = .664$, $CR = -4.897$, $p = .000$), race to spirituality ($B = .209$, $SE = .047$, $CR = 4.450$, $p = .000$), race to QOL ($B = -1.965$, $SE = .601$, $CR = -3.270$, $p = .001$), and Hispanicity to QOL ($B = -2.999$, $SE = .781$, $CR = -3.839$, $p = .000$). Additionally, Hispanicity and race covaried ($B = .027$, $SE = .006$, $CR = 4.579$, $p = .000$).

Model fit testing showed a satisfactory model fit (table 19) was achieved with several fit testing indices > 0.9 . NFI was .906, IFI was .929, , and CFI was .927. RMSEA was $< .08$ at .059. However, TLI was .843, and the PCFI was not $> .5$ (.455). See table 18. Chi-square results were large and significant (χ^2 of 26.858, $p = .000$, $DF = 7$, $PCMIN/DF = 3.873$), but large sample sizes make this test less reliable in SEM (Sharif, 2021). Non-significant results were removed from the model, and the model was revised. Figure 2.

Figure 2

Final Model

In the final model, spirituality to caregiver burden ($B = -1.267$, $SE = .558$, $CR = -2.271$, $p = .023$), caregiver burden to QOL ($B = -.528$, $SE = .037$, $CR = -14.152$, $p = .000$), marital status to QOL ($B = -3.253$, $SE = .664$, $CR = -4.902$, $p = .000$), race to spirituality ($B = .209$, $SE = .047$, $CR = 4.450$, $p = .000$), race to QOL ($B = -1.965$, $SE = .601$, $CR = -3.270$, $p = .001$) and Hispanicity to QOL ($B = -2.999$, $SE = .781$, $CR = -3.839$, $p = .000$) all remained significant.

Model fit testing on the revised model revealed a better model fit (table 21) with fit testing indices > 0.9 . NFI was .902, IFI was .929, TLI was .862, and CFI was .927. RMSEA was $< .08$ at .065, PCFI = .494 and a χ^2 of 27.902 ($p = .000$, $DF = 8$, $PCMIN/DF = 3.488$).

This structural equation model does not support the hypothesis that spirituality would moderate the effect of caregiver burden on quality of life resulting in higher quality of life outcomes in informal older adult caregivers living in the U.S. It did, however, show that spirituality influenced QOL through caregiver burden. The model also showed that in these caregivers, marital status, race, and Hispanicity affected QOL independent of other variables and demographics.

Conclusion

Data on informal caregivers participating in the nationally representative Health and Retirement Study was examined using Spearman's rank correlation, GLM, crosstab with independent chi-square analysis, and SEM to examine the relationships among caregiver burden, spirituality, and QOL. Demographic categories and attitude toward providing care for more than one year were also included for descriptive purposes and to determine if length of care contributed to caregiver burden. Attitude toward providing care for more than a year was correlated with caregiver burden. Results of GLM and SEM revealed that spirituality influenced QOL through caregiver burden. Marital status, race, and Hispanicity also independently predicted QOL in the final SEM.

Chapter 5 will include discussion of these results. The discussion will include implications to nursing practice and as well as to policy. Limitations of this study and suggestions for future research will be presented.

Chapter 5: Discussion

The purpose of this research was to study the relationships among caregiver burden, spirituality, and QOL in a nationally representative sample of older adult informal caregivers participating the Health and Retirement Study (HRS). The specific aims that guided the study were as follows:

Aim 1: To determine the prevalence of caregiver burden in a nationally representative sample of older adult informal caregivers.

Aim 2: To investigate the relationships among caregiver burden, spirituality, and quality of life in a nationally representative sample of older adult informal caregivers.

The major topics of this chapter include an overview of the study; discussion of findings related to the literature; research, practice, and policy implications; contribution to the knowledge base of nursing; as well as strengths and limitations.

Overview of the Study

As the US population age increases and more people are diagnosed with complex illnesses, the number of older adults caring for other adults is increasing in frequency. Consequently, a growing number of informal caregivers may be facing caregiver associated problems such as poorer physical and mental health and increased financial strain (Bialon & Coke, 2012; Saleh et al., 2022). Caregiver burden is associated with poor QOL and has been recognized as a health concern by government agencies, healthcare providers, and caregiver advocacy groups (CDC, 2021; NINR, 2016; NAC & AARP, 2020). However, spirituality has been shown in some studies to moderate the effect of caregiver burden on QOL (Colgrove et al., 2007; Taha et al., 2021). The theory of self-transcendence was utilized to explore relationships

among caregiver burden, spirituality and QOL in a nationally representative sample of older adult informal caregivers living in the contiguous U.S.

Crosstab analysis and GLM was conducted to investigate relationships among caregiver burden, spirituality, and QOL as well as demographics to prepare for structural equation modeling (SEM). Once relationships among variables were determined, a model was tested using path analysis and goodness of fit testing (fig. 1). Non-significant relationships were removed from the model. A final model depicting spirituality influencing QOL through caregiver burden was tested and showed goodness of fit (fig. 2).

Findings of the Study

Demographics: Caregiver Prevalence, Gender Race/ Ethnicity

Demographic analysis showed that caregiver characteristics in this study differ from those in another large nationally representative study that included participants with a larger age range (NAC & AARP, 2020). Caregivers in both studies were predominantly White, but this study had a larger percent of White caregivers (n = 399, 81.5%) as compared with the NAC & AARP (2020) who reported White caregivers make up 61% of the caregiving population. This discrepancy most likely reflects demographics of older U. S. adults who are predominantly White (Shaeffer, 2019). The NAC & AARP (2020) also specifically targeted Hispanic and Asian American caregivers for sampling purposes and report that 17 % of caregivers are Hispanic or Latino, 5% are Asian American, and 3% are other or multi-racial. In the HRS, Hispanic and Asian American caregivers fall under *other race* and account for just 7% (n = 46) of those in the 2020 wave who identified as providing care to another adult. This discrepancy could be due to potential underrepresentation of Hispanic and Asian American caregivers in this HRS study population. It may also be that due to immigration policies and tight family dynamics as well as

expectations in Hispanic culture (Cadet et al., 2020), Hispanic HRS participants were less likely to identify as being a caregiver and would then not be included in this study.

Caregivers in both studies were also predominantly female. The NAC & AARP (2020) report females make up 61% of all caregivers ages 18 and above. The percentage of female caregivers (n=368, 53.1%) was smaller in this study, possibly because participants in this study are retired, which may allow more men to assume a caregiving role. Another difference is reflected in education. Caregivers in this study are less educated than caregivers in the NAC & AARP (2020) study. In this sample, 47.1% (n = 290) of caregivers had a high school diploma or GED while 50% of NAC & AARP participants had at least some college or technical school education. This too is likely reflective of the age of participants, as fewer baby Boomers sought post-secondary education as compared with later generations (Knickman & Snell, 2002).

This study also found that overall, participants were more likely to be spiritual, but less likely to be highly spiritual. Older caregivers, female caregivers, ethnic minority caregivers, and less-educated caregivers were more likely to be highly spiritual. These findings are similar to results from a previous study of younger caregivers (M = 48.9, SD11.69) that found non-Hispanic Whites were less spiritual than ethnic minorities, males were less spiritual than females, and higher education was negatively associated with spirituality while age was positively associated with spirituality (La et al., 2020).

Racial disparities were also described. In this study, Black caregivers had lower QOL than White caregivers. Despite this, race was not significantly associated with caregiver burden. This is consistent with the literature that shows that despite having to provide increased intensity of care and having fewer resources, Black caregivers have more positive attitudes about caregiving and display less caregiver burden (Cohen, 2017; Fabius, 2020). This may be

attributed to cultural appraisals of caregiving and religiosity (Fabius, 2020). Future research using SEM to investigate relationships among caregiver burden, attitudes toward caregiving, and QOL among different races could provide important insights that may contribute to development of interventions unique to these populations. In contrast, another study found that while overall QOL scores among Black caregivers of cancer patients were consistent with those of the general caregiving population, emotional well-being scores were lower (Ellis et al., 2021). Prospective studies could further explore these relationships.

Study Aims

Aim 1

Aim one in this study was to determine the prevalence of caregiver burden in this population of older adult caregivers. Frequency analysis found that just over half of the caregivers scored as having moderate (48%, n = 289) or high (3.5 %, n = 18) levels of caregiver burden. These results vary from a study of caregivers aged 18 and older that found 28% of family caregivers reported moderate stress, and 36% reported high stress (NAC & AARP, 2020). It may be that younger caregivers, who are still working, experience more stress due increased life demands of juggling a job and perhaps children, where older retired caregivers do not. Morrison et al. (2020) studied QOL in caregivers of patients with dementia and found that younger caregivers had lower QOL compared with older caregivers. Additionally, length of time caregiving was a factor. Among all caregivers, 22.5% (n = 126) provided care for more than a year and found caregiving to be *somewhat upsetting* while 9.6% (n = 51) found it to be *very upsetting*. Caregivers that reported being “*upset*” scored significantly higher on the burden scale than those who provided care but found it to be *not upsetting*. Kim et al. (2012) studied spousal caregivers of cancer patients and

found that caregivers who had provided care for 5 years had lower QOL than caregivers whose loved ones were in remission or who had passed.

Aim 2

Aim two was to investigate the relationships among caregiver burden, spirituality, and QOL in this study sample. This study confirmed an inverse relationship between caregiver burden and QOL that was reported in other studies. Taha et al. (2021) investigated relationships among spirituality, caregiver burden, QOL, demographics, and depressive symptoms in parents of adolescents with spina bifida and found caregivers with higher levels of caregiver burden reported lower QOL. Additionally, both Taha et al. (2021) and Colgrove et al. (2007), who studied spousal caregivers of patients with cancer, found spirituality to have a moderating effect between caregiver burden and QOL. In this study there was no moderating effect of spirituality between caregiver burden and QOL, thus the null hypothesis was accepted. However, an earlier study looking at the role of spirituality in HRS caregivers in the 2004 to 2014 waves found that higher intrinsic religiosity may buffer the physical effects of caregiver burden in high intensity spousal caregivers (>14 hours of care per week; Koumoutzis & Mehri, 2020). This study is the first to find that, in this population of older adult caregivers in the HRS 2020 wave, spirituality was a predictor of lower caregiver burden, which was a predictor of increased QOL. These relationships were established through GLM and confirmed through path analysis in SEM (Fig. 2).

The relationships among caregiver burden, spirituality, and QOL are also supported by the theory of self-transcendence which suggests that individuals can transcend (through spirituality) vulnerable situations (like caregiving) to achieve better well-being (QOL). Acton (2000) reported that spiritual connections helped caregivers of dementia patients cope with the

challenges of caregiving. In this study, caregivers who were highly spiritual had lower caregiver burden/ PSS (caregiver burden) scores ($p = .023$). Lower caregiver burden /PSS scores were correlated with higher QOL/SWLS scores ($p = <.001$). The study conclusion, therefore, is that spirituality influenced QOL through caregiver burden in this population. As supported by the theory of self-transcendence, spirituality (the means of transcendence) can lessen caregiver burden (a vulnerable state) potentially leading to improved QOL (well-being). This influence of spirituality on QOL through caregiver burden supports the idea that spiritual interventions could be effective in both reducing caregiver burden and improving QOL. Kim et al. (2015) found that among participants in the National Quality of Life Survey for Caregivers, spirituality was a psychological pathway of beneficial effects. Studies show that caregivers are receptive to spiritual interventions and even expect spiritual care (Glueckauf et al., 2022, Selman et al., 2018).

Taha et al. (2020) found a positive correlation between spirituality and QOL in parents under the age of 65 caring for adolescents with spina bifida. This present study did not find a significant relation between spirituality and QOL in this group of older caregivers. This could be explained by this population's stage of development. More than half of the caregivers in this study were over the age of 65 (64 - 95, $M = 66.32$, $SD = 7.84$) and are in Erikson's developmental stage of Ego Integrity versus Despair, which begins around age 65. In this developmental stage, older adults are evaluating their lives for meaning and how they feel about that meaning (Hearn et al., 2012). Spirituality can give meaning and purpose to life, but even those who are not highly spiritual are reflecting on meaning in their lives as part of this developmental stage. They are balancing successes and failures and arriving on a spectrum between integrity, or acceptance, and despair (Hearn et al., 2012). Life satisfaction comes with

achieving ego integrity. The literature is sparse regarding a potential relationship, but it may be that SWLS scores in this study were influenced by the psychosocial reflection taking place in this population, as these caregivers reflected on the meaning in their lives separate from spirituality. Quality of life, then, was less dependent upon the meaning received from spirituality because meaning was gained otherwise in the life review. Spirituality was still important in this population, however, as it gives meaning to the caregiving experience and was correlated with decreased caregiver burden (Hebert, 2006; Koenig et. al, 2016).

Contribution to the Knowledge Base of Nursing

The findings of this study contribute to the discipline of nursing by exploring the human-environment-health relationship, which is central to nursing knowledge (Smith, 2019), as it relates to older adult caregivers. This study was about health and well-being in the caregiving context. Quality of life was the standard by which well-being was compared. Studies have shown that good QOL, which includes spiritual well-being, influences overall health (Shattuck & Muehlenbein, 2018; WHO, 1998). By exploring the relationships between caregiver burden, spirituality, and QOL, overall health in older adults who care for other adults can be better understood.

Implications of Findings for Further Research

Research findings from this study exposed areas where further research could offer more insight. Data was not available for attitudes toward caregiving in those providing care for less than a year. Future studies could investigate differences in attitudes between new caregivers and those who have been providing care for longer periods of time. Further research should also take into consideration the impact of income and familial relationships on caregiver burden. Cross-sectional and longitudinal studies including these factors could give further insight into attitudes

toward and patterns of caregiver burden over time and whether these additional factors affect caregiver burden, spirituality, or QOL. Further research should also evaluate improvement of QOL in those experiencing caregiver burden who are not spiritual and in those for whom spiritual interventions are not appropriate. Additionally, more research is needed to determine if there is a relationship between ego integrity and QOL (Kleijn, 2018).

Implications of Findings for Nursing Practice

The NINR has called for nurses to improve caregiver QOL (2016). Bivariate analysis showed that race, Hispanicity, marital status, and living alone were correlated with QOL, and that age and marital status were correlated with caregiver burden. Caregivers who were separated or divorced had higher burden and lower QOL. Those never married also had higher caregiver burden, and Black caregivers had lower QOL. Special consideration should be given to caregivers who fall within these categories. Educational or other interventions targeting those individuals could be implemented during inpatient or home health visits. Caregivers could be included in patient care plans, and referrals to appropriate services such as community or faith programs could be made. This study demonstrated that spirituality affects QOL through caregiver burden. Thus, by supporting spirituality, nursing interventions may improve QOL.

This study demonstrated a relationship between spirituality and caregiver burden. Research shows that families desire and even expect spiritual care, especially in hospice or oncology settings (Batstone et al., 2020; Hennessy et al., 2020). Additionally, nursing scholars recognize the importance of providing spiritual care, which is inherent in nursing care (Hawthorne & Goren, 2020; Willis & Leone-Sheehan, 2019). However, research shows that nurses are not comfortable speaking with patients and their caregivers about spiritual matters primarily because they are not settled about their own spirituality (Cooper et al., 2021; Selman et

al., 2018). Nurses could become more comfortable with spirituality by completing self-assessments to understand their own spirituality and where they are on their own spiritual journeys. Nurses could also become trained in providing spiritual care. Continuing education programs are available as well as scholarly literature promoting spiritual care. Additionally, referrals to chaplain services should be encouraged for more specialized care.

Implications of Findings for Policy

Findings from this study laid the foundation for future research and could inform stakeholders and policy makers. This study showed that spirituality influences quality of life through caregiver burden. Spiritual interventions can be easy, low-cost ways, based on individual's preference, to potentially ease caregiver burden. Therefore, policy makers at various levels could be influenced to draft, support and implement policies incorporating or encouraging spiritual interventions or behavior. At the local level, nurses in community positions such as in faith communities, home health organizations, and health departments could support and implement policies to promote spirituality in their prospective communities. At the organizational level, organizations and advocacy groups could be led to advocate for more spiritual support and resources for their constituents.

Strengths and Limitations

The observations were taken from a large, nationally representative data set. It would be difficult to impossible for this researcher to recruit and collect data from such a large number of participants, 591 (weighted n= 10,785,655) in this case. Furthermore, a large number is necessary for model convergence when there are many indicators per variable. Large sample sizes are also needed to increase power. Wolf et al. (2013) found that larger samples are required for models with more than two constructs, in mediating models, in latent variable models, in

models with high levels of bias and/or measurement error, and in models where factor loadings may be either weak or very strong. Therefore, using a secondary data set with a large sample size actually reduces many of the limitations that could be encountered in a primary study with fewer participants. The Health and Retirement Study HRS was conducted with rigor and has been widely used by researchers in a variety of disciplines. The use of HRS data for this SEM was justified. Another benefit of the study was to test the interaction effect of spirituality on caregiver burden and QOL to confirm the relationship among variables based on self-transcendence theory. The results could be used to develop faith-based interventions to reduce caregiver burden and promote caregiver quality of life.

Limitations for this study include threats to internal validity common in secondary data analysis and cross-sectional studies. Results could not be interpreted in terms of causality. Additionally, the data was self-reported, so there is a risk of over or under reporting of behaviors. It is also possible that responses to the survey questions were inaccurate due to social desirability bias or lack of clarity in explanations or interpretations. Another common limitation of secondary data analysis, as in this in this study, is instrumentation. However, SEM accounts for measurement error, especially in large sample sizes. Furthermore, the sample is nationally representative and therefore heterogenous. Heterogeneity enhances external validity which increases generalizability (Shadish et al., 2002).

Conclusion

Findings in this study demonstrated that spirituality influenced QOL through caregiver burden in this population. Findings underscore the importance of addressing the spiritual needs of caregivers. The NINR has called for nurses to improve caregiver QOL and nursing assessment should include a holistic approach that addresses the spiritual needs of this

population. A thorough assessment of the caregivers' spiritual needs can alert health care providers to initiate interventions to foster spirituality. Addressing spirituality in caregivers may result in improved quality of life.

References

- Acton, G. J., & Wright, K. B. (2000). Self-transcendence and family caregivers of adults with dementia. *Journal of Holistic Nursing, 18*(2), 143–158.
- Applebaum, A. (2022). There is nothing informal about caregiving. *Palliative and Supportive Care, 20*(5), 621-622. doi:10.1017/S1478951522001092
- Bajjani-Gebara, J., Hinds, P., Insel, K., Reed, P., Moore, K., & Badger, T. (2019). Well-being, self-transcendence, and resilience of parental caregivers of children in active cancer treatment: Where do we go from here? *Cancer Nursing, 42*(5), 52.
<https://doi.org/10.1097/NCC.0000000000000662>
- Batstone, E., Bailey, C., & Hallett, N. (2020). Spiritual care provision to end-of-life patients: A systematic literature review. *Journal of Clinical Nursing, 29*(19-20), 3609–3624.
<https://doi.org/10.1111/jocn.15411>
- Bennett, J. A. (2000). Mediator and moderator variables in nursing research: Conceptual and statistical differences. *Research in Nursing & Health, 23*(5), 415–420.
- Bialon, L. N., & Coke, S. (2012). A study on caregiver burden: Stressors, challenges, and possible solutions. *The American Journal of Hospice & Palliative Care, 29*(3), 210–8.
<https://doi.org/10.1177/1049909111416494>
- Cadet, T., Burke, S. L., Nedjat-Haiem, F., Bakk, L., Naseh, M., Grudzien, A., O’Driscoll, J., & Alcide, A. (2020). Timing of immigration effects asset change among Hispanic caregivers of older family members. *Journal of Family and Economic Issues, 42*(3), 561–572. <https://doi.org/10.1007/s10834-020-09719-3>

Centers for Disease Control (2021). *Supporting caregivers*. Alzheimer's Disease and Healthy Aging. Retrieved December 29, 2022.

<https://www.cdc.gov/aging/publications/features/supporting-caregivers.htm>

Chirchiglia, D., Chirchiglia, P., & Latorre, D. (2020). An update of the imaging and diagnostic techniques in use for the preservation of eloquent areas in brain tumor surgery - An opinion paper. *Interdisciplinary Neurosurgery: Advanced Techniques and Case Management*, 20. <https://doi.org/10.1016/j.inat.2019.100611>

Choi, S., & Seo, J. Y. (2019). Analysis of caregiver burden in palliative care: An integrated review. *Nursing Forum*, 54(2), 280–290. <https://doi.org/10.1111/nuf.12328>

Chwalisz, K. (1996). The perceived stress model of caregiver burden: Evidence from spouses of persons with brain injuries. *Rehabilitation Psychology*, 41(2), 91–114.

<https://doi.org/10.1037/0090-5550.41.2.91>

Chwalisz, K., & Kisler, V. (1995). Perceived stress: A better measure of caregiver burden. *Measurement and Evaluation in Counseling and Development*, 28(2), 88–98.

Cohen, S. A., Cook, S. K., Sando, T. A., Brown, M. J., & Longo, D. R. (2017). Socioeconomic and demographic disparities in caregiving intensity and quality of life in informal caregivers: A first look at the national study of caregiving. *Journal of Gerontological Nursing*, 43(6), 17–24.

Cohen, S., Kamarck, T., & Mermelstein, R. (1983). A global measure of perceived stress. *Journal of Health and Social Behavior*, 24(4), 385–396.

Colgrove, L. A. A., Kim, Y., & Thompson, N. (2007). The effect of spirituality and gender on the quality of life of spousal caregivers of cancer survivors. *Annals of Behavioral Medicine*, 33(1), 90–98. https://doi.org/10.1207/s15324796abm3301_10

- Cooper, K. L., Luck, L., Chang, E., & Dixon, K. (2021). What is the practice of spiritual care? A critical discourse analysis of registered nurses' understanding of spirituality. *Nursing Inquiry*, 28(2), 12385. <https://doi.org/10.1111/nin.12385>
- Dionne-Odom, J. N., Azuero, A., Taylor, R. A., Dosse, C., Bechthold, A. C., Currie, E., Reed, R. D., Harrell, E. R., Engler, S., Ejem, D. B., Ivankova, N. V., Martin, M. Y., Rocque, G. B., Williams, G. R., & Bakitas, M. A. (2022). A lay navigator-led, early palliative care intervention for African American and rural caregivers of individuals with advanced cancer (project cornerstone): Results of a pilot randomized trial. *Cancer*, 128(6), 1321–1330. <https://doi.org/10.1002/cncr.34044>
- Dunn, S. L., Arslanian-Engoren, C., DeKoekkoek, T., Jadack, R., & Scott, L. D. (2015). Secondary data analysis as an efficient and effective approach to nursing research. *Western Journal of Nursing Research*, 37(10), 1295–307. <https://doi.org/10.1177/0193945915570042>
- Ellis, K. R., Oh, S., Hecht, H. K., & Northouse, L. (2021). Symptom distress and quality of life among black Americans with cancer and their family caregivers. *Psycho-Oncology*, 30(8), 1356–1365. <https://doi.org/10.1002/pon.5691>
- Fabius, C. D., Wolff, J. L., Kasper, J. D., & Meeks, S. (2020). Race differences in characteristics and experiences of black and white caregivers of older Americans. *The Gerontologist*, 60(7), 1244–1253. <https://doi.org/10.1093/geront/gnaa042>
- Family Caregiver Alliance (2022). *Definitions*. <https://www.caregiver.org/resource/definitions-0/>
- Ferrell, B. R., Kravitz, K., Borneman, T., & Friedmann, E. T. (2018). Family caregivers: A qualitative study to better understand the quality-of-life concerns and needs of this population. *Clinical Journal of Oncology Nursing*, 22(3), 286–294.

- Ferrell, B., & Wittenberg, E. (2017). A review of family caregiving intervention trials in oncology. *Ca: A Cancer Journal for Clinicians*, *67*(4), 318–325.
<https://doi.org/10.3322/caac.21396>
- Fetzer Institute. (2003). Brief multidimensional measure of religiousness/spirituality: 1999. In N. W. Group (Ed.), *Multidimensional measurement of religiousness/spirituality for use in health research: A report of the Fetzer Institute/National Institute on Aging Working Group* (2nd ed., pp. 85-88). Kalamazoo, MI: John E. Fetzer Institute.
- Freeman, B. (2015). *Compassionate person-centered care for the dying: An evidence-based palliative care guide for nurses*. Springer Publishing Company, LLC.
- Giovannetti, A. M., Covelli, V., Sattin, D., & Leonardi, M. (2015). Caregivers of patients with disorder of consciousness: Burden, quality of life and social support. *Acta Neurologica Scandinavica*, *132*(4), 259–269. <https://doi.org/10.1111/ane.12392>
- Glueckauf, R. L., Kazmer, M. M., Nowakowski, A. C. H., Wang, Y., Thelusma, N., Williams, D., McGill-Scarlett, C., Lampe, N. M., Norton-Brown, T., Davis, W. S., Sharma, D., & Willis, F. B. (2022). African American Alzheimer's caregiver training and support project 2 (acts2) pilot study: Outcomes analysis. *Rehabilitation Psychology*, *67*(4), 437–448.
<https://doi.org/10.1037/rep0000470>
- Gonçalves, J. P., Lucchetti, G., Menezes, P. R., & Vallada, H. (2015). Religious and spiritual interventions in mental health care: A systematic review and meta-analysis of randomized controlled clinical trials. *Psychological Medicine*, *45*(14), 2937–49.
<https://doi.org/10.1017/S0033291715001166>

- Hawthorne, D. M., & Gordon, S. C. (2020). The invisibility of spiritual nursing care in clinical practice. *Journal of Holistic Nursing*, 38(1), 147–155.
<https://doi.org/10.1177/0898010119889704>
- Health and Retirement Study (2019). Sampling weights revised for tracker 2.0 and beyond
https://hrs.isr.umich.edu/sites/default/files/biblio/wghtdoc_0.pdf
- Health and Retirement Study (2008, December 1). *Design History*.
<https://hrs.isr.umich.edu/sites/default/files/biblio/DesignHistory.pdf>
- Health and Retirement Study (2017). Aging in the 21st century: Challenges and opportunities for Americans. University of Michigan.
<https://hrsonline.isr.umich.edu/sitedocs/databook/?page=1>
- Health and Retirement Study, 2020 HRS Early Core public use dataset. Produced and distributed by the University of Michigan with funding from the National Institute on Aging (grant number NIA U01AG009740). Ann Arbor, MI, (2020)
- Hearn, S., Saulnier, G., Strayer, J., Glenham, M., Koopman, R., & Marcia, J. E. (2012). Between integrity and despair: Toward construct validation of Erikson's eighth stage. *Journal of Adult Development*, 19(1), 1–20.
- Hebert, R. S., Weinstein, E., Martire, L. M., & Schulz, R. (2006). Religion, spirituality and the well-being of informal caregivers: A review, critique, and research prospectus. *Aging & Mental Health*, 10(5), 497–520.
- Hennessy, N., Neenan, K., Brady, V., Sullivan, M., Eustace-Cooke, J., & Timmins, F. (2020). End of life in acute hospital setting— A systematic review of families' experience of spiritual care. *Journal of Clinical Nursing*, 29(7-8), 1041–1052.
<https://doi.org/10.1111/jocn.15164>

- Hodge, D. R., & Sun, F. (2012). Positive feelings of caregiving among Latino Alzheimer's family caregivers: Understanding the role of spirituality. *Aging & Mental Health, 16*(6), 689–98. <https://doi.org/10.1080/13607863.2012.678481>
- Hoyle, R. H., & Smith, G. T. (1994). Formulating clinical research hypotheses as structural equation models: A conceptual overview. *Journal of Consulting and Clinical Psychology, 62*(3), 429–40.
- Huang, Y., Nagao, C., Michelle Santos, K., & Werchowsky, M. (2021). Asian-American caregivers: Factors that influence caregiver burden...American Occupational Therapy Association (AOTA) INSPIRE 2021 (Virtual), April 6-30, 2021. *American Journal of Occupational Therapy, 75*(Sup2), 1.
<https://doiorg.wvu.idm.oclc.org/10.5014/ajot.2021.75S2-RP270>
- Ilesanmi, R. E., Hanson, V. F., Dabou, E. A. R., & Mathias, C. A. (2021). Perceived stress and burden of caregiving among nurses in the United Arab Emirates during the COVID-19 pandemic. *Medical & Clinical Research, 615-623*.
- Institute for Social Research (2020). *Health and retirement study core: Questionnaire on your everyday life and well-being*. (Early V1.0) [Data set]. University of Michigan.
<https://hrsdata.isr.umich.edu/data-products/public-survey-data>
- Jain, R., & Chetty, P. (2021, Aug 03). *Understanding the application of structural equation modelling (SEM)*. Knowledge Tank; Project Guru.
<https://www.projectguru.in/understanding-the-application-of-structural-equation-modelling-sem/>
- Kim, F. N. (2012). Statistical assumptions of substantive analyses across the general linear model: A mini-review, 3. <https://doi.org/10.3389/fpsyg.2012.00322>

- Kim, Y., Carver, C. S., Shaffer, K. M., Gansler, T., & Cannady, R. S. (2015). Cancer caregiving predicts physical impairments: Roles of earlier caregiving stress and being a spousal caregiver. *Cancer, 121*(2), 302–310. <https://doi-rg.wvu.idm.oclc.org/10.1002/cncr.29040>
- Kim, Y., Spillers, R. L., & Hall, D. L. (2012). Quality of life of family caregivers 5 years after a relative's cancer diagnosis: Follow-up of the national quality of life survey for caregivers. *Psycho-Oncology, 21*(3), 273–281. <https://doi.org/10.1002/pon.1888>
- Kleijn, G., Lissenberg-Witte, B. I., Bohlmeijer, E. T., Steunenberg, B., Knipscheer-Kuijpers, K., Willemsen, V., Becker, A., Smit, E. F., Eeltink, C. M., Bruynzeel, A. M. E., van der Vorst, M., de Bree, R., Leemans, C. R., van den Brekel, M. W. M., Cuijpers, P., Verdonck-de Leeuw, I. M., & van Wouwe, J. P. (2018). The efficacy of life review therapy combined with memory specificity training (lrt-mst) targeting cancer patients in palliative care: A randomized controlled trial. *Plos One, 13*(5).
- Koenig, H. G., Nelson, B., Shaw, S. F., Saxena, S., & Cohen, H. J. (2016). Religious involvement and adaptation in female family caregivers. *Journal of the American Geriatrics Society, 64*(3), 578–583. <https://doi.org/10.1111/jgs.13929>
- Knickman, J. R., & Snell, E. K. (2002). The 2030 problem: Caring for aging baby boomers. *Health Services Research, 37*(4), 849-884.
- Koumoutzis, A., & Mehri, N. (2020). The impact of caregiving intensity and religiosity on spouse caregivers' health and mortality in the United States (2004–2014). *Innovation in Aging, 4*(Suppl 1), 514.
- Krause, N. (2003). Religious meaning and subjective well-being in late life. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences, 58*(3), 160–70.

- La, I. S., Johantgen, M., Storr, C. L., Cagle, J. G., Zhu, S., & Ross, A. (2020). Spirituality among family caregivers of cancer patients: The spiritual perspective scale. *Research in Nursing & Health, 43*(4), 407–418.
- Lapid, M. I., Atherton, P. J., Kung, S., Clark, M. M., Sloan, J. A., Whitford, K. J., Hubbard, J. M., Gentry, M. T., Miller, J. J., & Rummans, T. A. (2022). A feasibility study of virtual group therapy to improve quality of life of cancer caregivers. *Journal of Psychosocial Oncology, 40*(6), 854–867. <https://doi.org/10.1080/07347332.2021.2000550>
- Lapid, M. I., Atherton, P. J., Kung, S., Sloan, J. A., Shahi, V., Clark, M. M., & Rummans, T. A. (2016). Cancer caregiver quality of life: Need for targeted intervention. *Psycho-Oncology, 25*(12), 1400–1407. <https://doi.org/10.1002/pon.3960>
- Lalani, N., Duggleby, W., & Olson, J. (2018). Spirituality among family caregivers in palliative care: An integrative literature review. *International Journal of Palliative Nursing, 24*(2), 80–91. <https://doi.org/10.12968/ijpn.2018.24.2.80>
- Libre Texts (August 21, 2021). 2.2: *Concepts, constructs, and variables*. Social Sciences. [https://socialsci.libretexts.org/Bookshelves/Social_Work_and_Human_Services/Social_Science_Research_-_Principles_Methods_and_Practices_\(Bhattacharjee\)/02%3A_Thinking_Like_a_Researcher/2.02%3A_Concepts_Constructs_and_Variables#:~:text=Constructs%20are%20conceptualized%20at%20the,forth%20between%20these%20two%20planes](https://socialsci.libretexts.org/Bookshelves/Social_Work_and_Human_Services/Social_Science_Research_-_Principles_Methods_and_Practices_(Bhattacharjee)/02%3A_Thinking_Like_a_Researcher/2.02%3A_Concepts_Constructs_and_Variables#:~:text=Constructs%20are%20conceptualized%20at%20the,forth%20between%20these%20two%20planes).
- Liu, Z., Heffernan, C., & Tan, J. (2020). Caregiver burden: A concept analysis. *International Journal of Nursing Sciences, 7*(4), 438–445. <https://doi.org/10.1016/j.ijnss.2020.07.012>
- Lorenzo-Seva, U., Calderon, C., Ferrando, P. J., Beato, C., Ghanem, I., Castelo, B., Carmona-Bayonas, A., Hernández, R., & Jiménez-Fonseca, P. (2019). Psychometric properties and

- factorial analysis of invariance of the satisfaction with life scale (swls) in cancer patients. *Quality of Life Research*, 28(5), 1255–1264. <https://doi.org/10.1007/s11136-019-02106-y>
- Løvereide, L., & Hagell, P. (2016). Measuring life satisfaction in Parkinson's disease and healthy controls using the Satisfaction with Life Scale. *Plos One*, 11(10), e0163931.
- Mioshi, E., Bristow, M., Cook, R., & Hodges, J. R. (2009). Factors underlying caregiver stress in frontotemporal dementia and Alzheimer's disease. *Dementia and Geriatric Cognitive Disorders*, 27(1), 76–81. <https://doi.org/10.1159/000193626>
- Mitchell, U. A., Gutierrez-Kapheim, M., Nguyen, A. W., Al-Amin, N., & Sands, L. P. (2020). Hopelessness among middle-aged and older blacks: The negative impact of discrimination and protecting power of social and religious resources. *Innovation in Aging*, 4(5). <https://doi.org/10.1093/geroni/igaa044>
- Morrison, B., Phillips, B. N., Jones, J. E., Przybelski, R., & Huck, G. (2020). The impact of risk and resistance factors on quality of life in caregivers of individuals with dementia. *Clinical Gerontologist* 43(5):585–97.
- National Institute of Nursing Research (US). (2016). *The NINR strategic plan: Advancing science, improving lives: A vision for nursing science*. https://www.ninr.nih.gov/sites/files/docs/NINR_StratPlan2016_reduced.pdf
- Newsom, J. T. (2022). Univariate quantitative methods. Portland State University. https://web.pdx.edu/~newsomj/uvclass/ho_outlier%20and%20sample%20size.pdf
- Nolan, S., Saltmarsh, P., & Leget, C. (2011) Spiritual care in palliative care: Working towards an EAPC Task Force. *European Journal of Palliative Care*. 18(2):86–9.

- O'Connor, S. (2020). Secondary data analysis in nursing research: A contemporary discussion. *Clinical Nursing Research, 29*(5), 279-284.
- Pavot, W., & Diener, E. (1993). Review of the Satisfaction with Life Scale. *Psychological Assessment, 5*(2), 164–172.
- Pristavec, T., & Luth, E. A. (2020). Informal caregiver burden, benefits, and older adult mortality: A survival analysis. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences, 75*(10), 2193–2206.
- Ravyts, S. G., & Dzierzewski, J. M. (2020). Sleep disturbance, mental health symptoms, and quality of life: A structural equation model assessing aspects of caregiver burden. *Clinical Gerontologist, 1-10*, 1–10.
<https://doi.org/10.1080/07317115.2020.1783042>
- Reed, P. G. (1991). Toward a nursing theory of self-transcendence: Deductive reformulation using developmental theories. *ANS. Advances in Nursing Science, 13*(4), 64–77.
- Reed, P. G. (1992). An emerging paradigm for the investigation of spirituality in nursing. *Research in Nursing & Health, 15*(5), 349–57.
- Reed, P. G. (2018). Theory of self-transcendence. In M.J. Smith & P.R. Liehr (eds.), *Middle range theory of nursing* (pp.119-145). New York: Springer.
- Reinhard, S., Feinberg, L. F., Houser., A. Choula, R., Evans, M., & Public Policy Institute. (2019, November 14). *Valuing the invaluable 2019 update: Charting a path forward*. AARP Public Policy Institute.
- Rogers, L. Q., McAuley, E., Anton, P. M., Courneya, K. S., Vicari, S., Hopkins-Price, P., Verhulst, S., Mocharnuk, R., & Hoelzer, K. (2012). Better exercise adherence after

- treatment for cancer (beat cancer) study: Rationale, design, and methods. *Contemporary Clinical Trials*, 33(1), 124–37. <https://doi.org/10.1016/j.cct.2011.09.004>
- Runquist, J., & Reed, P. (2007). Self-transcendence and well-being in homeless adults. *Journal of Holistic Nursing*, 25(1), 5–13.
- Ryu, E. (2011). Effects of skewness and kurtosis on normal-theory based maximum likelihood test statistic in multilevel structural equation modeling. *Behavior Research Methods*, 43(4), 1066–1074. <https://doi.org/10.3758/s13428-011-0115-7>
- Saleh, Z. M., Salim, N. E., Nikirk, S., Serper, M., & Tapper, E. B. (2022). The emotional burden of caregiving for patients with cirrhosis. *Hepatology Communications*, 6(10), 2827–2835. <https://doi.org/10.1002/hep4.2030>
- Schaeffer, K. (2019, July 30). *The most common age among whites in U. S. is 58 – more than double that of racial and ethnic minorities*. Pew Research Center. <https://www.pewresearch.org/short-reads/2019/07/30/most-common-age-among-us-racial-ethnic-groups/>
- Schweizer, K. (2011). On the changing role of Cronbach's α in the evaluation of the quality of a measure. *European Journal of Psychological Assessment*, 27(3), 143–44.
- Selman, L. E., Brighton, L. J., Sinclair, S., Karvinen, I., Egan, R., Speck, P., Powell, R. A., Deskur-Smielecka, E., Glajchen, M., Adler, S., Puchalski, C., Hunter, J., Gikaara, N., Hope, J., & InSpirit Collaborative (2018). Patients' and caregivers' needs, experiences, preferences and research priorities in spiritual care: A focus group study across nine countries. *Palliative Medicine*, 32(1), 216–230. <https://doi.org/10.1177/0269216317734954>

- Shadish, W., Cook, T., & Campbell, D. (2002). *Experimental and quasi-experimental designs for generalized causal inference*. Belmont, CA: Wadsworth Cengage Learning
- Sharif, S. P. (2021). [Video]. *SEM with AMOS: From zero to hero (18:) Model fit assessment*.
<https://www.youtube.com/watch?v=7aHCo9kaIwI>
- Sharma, G. (2017). Pros and cons of different sampling techniques. *International Journal of Applied Research*, 3(7), 749-752.
- Shattuck, E. C., & Muehlenbein, M. P. (2018). Religiosity/spirituality and physiological markers of health. *Journal of Religion and Health*, 59(2), 1035–1054.
<https://doi.org/10.1007/s10943-018-0663-6>
- Simpson, G. K., Anderson, M. I., Jones, K. F., Genders, M., & Gopinath, B. (2020). Do spirituality, resilience and hope mediate outcomes among family caregivers after traumatic brain injury or spinal cord injury? A structural equation modelling approach. *NeuroRehabilitation*, 46(1), 3-15.
- Smith, M. (2019). Regenerating nursing's disciplinary perspective. *Advances in Nursing Science*, 42(1), 3–16. <https://doi.org/10.1097/ANS.0000000000000241>
- Sturgis, P. (2019). *Structural equation modeling*. Geek's Lesson. National Center for Research Methods <https://www.youtube.com/watch?v=Flqbo8J3li4>
- Swartz, K., & Collins, L. G. (2019). Caregiver care. *American Family Physician*, 99(11), 699–706.
- Taha, A. A., Eisen, A. M., Abdul-Rahman, H. Q., Abdul-Rahman, T. Q., La, S., Hanes, D., & Zouros, A. (2021). Spirituality and quality of life among parents of adolescents with spina bifida. *Western Journal of Nursing Research*, 43(8), 742–750.
<https://doi.org/10.1177/0193945920976407>

- Teresi, J. A., Ocepek-Welikson, K., Toner, J. A., Kleinman, M., Ramirez, M., Eimicke, J. P., Gurland, B. J., & Siu, A. (2017). Methodological issues in measuring subjective well-being and quality-of-life: Applications to assessment of affect in older, chronically and cognitively impaired, ethnically diverse groups using the feeling tone questionnaire. *Applied Research in Quality of Life*, *12*(2), 251–288.
- The National Alliance for Caregiving and AARP. (2020). *Caregiving in the U.S. 2020*. <https://www.aarp.org/content/dam/aarp/ppi/2020/05/full-report-caregiving-in-the-united-states.doi.10.26419-2Fppi.00103.001.pdf>
- Tkatch, R., Bazarko, D., Musich, S., Wu, L., MacLeod, S., Keown, K., Hawkins, K., & Wicker, E. (2017). A pilot online mindfulness intervention to decrease caregiver burden and improve psychological well-being. *Journal of Evidence-Based Complementary & Alternative Medicine*, *22*(4), 736–743. <https://doi-org.wvu.idm.oclc.org/10.1177/2156587217737204>
- Wang, K. (2022). *Health Research Statistics II Lecture 11: Structural equation modeling* [PowerPoint slides].
- Whitehead, B. R., & Bergeman, C. S. (2012). Coping with daily stress: Differential role of spiritual experience on daily positive and negative affect. *The Journals of Gerontology*, *67*(4), 456–456. <https://doi.org/10.1093/geronb/gbr136>
- Willis, D. G., & Leone-Sheehan, D. M. (2019). Spiritual knowing: Another pattern of knowing in the discipline. *Advances in Nursing Science*, *42*(1), 58–68. <https://doi.org/10.1097/ANS.0000000000000236>
- Wolf, E. J., Harrington, K. M., Clark, S. L., & Miller, M. W. (2013). Sample size requirements for structural equation models: An evaluation of power, bias, and solution

propriety. *Educational and Psychological Measurement*, 76(6), 913–934.

<https://doi.org/10.1177/0013164413495237>

World Health Organization. (1998). *Whoqol user manual: Programme on mental health*. World Health Organization.

World Health Organization Quality of Life Group. (1998) The world health organization quality of life assessment (whoqol): Development and general psychometric properties. *Social Science & Medicine*, 46(12), 1569.

Appendix A: Tables

Table 1. *Demographics and Attitude toward Providing Care for more than One Year*

| Category | Unweighted N | Weighted M(SD) or % |
|--|--------------|---------------------|
| Age (years) | | 66.32(7.84) |
| 54-64 | 241 | 46.8% |
| 65-74 | 203 | 37.1% |
| 75-84 | 116 | 13.6% |
| 85-95 | 31 | 2.5% |
| Gender | | |
| Male | 223 | 46.9% |
| Female | 368 | 53.1% |
| Race | | |
| White/ Caucasian | 399 | 81.5% |
| Black or African American | 145 | 11.5% |
| Other | 46 | 7.0% |
| Hispanicity | | |
| Hispanic, Mexican | 45 | 5.1% |
| Hispanic, Other | 29 | 3.7% |
| Not Hispanic | 516 | 91.2% |
| Marital Status | | |
| Married | 378 | 68.7% |
| Separated/ Divorced | 105 | 15.9% |
| Widowed | 72 | 8.1% |
| Never Married | 35 | 7.3% |
| Living Arrangements | | |
| Living with spouse/ partner | 400 | 72.4% |
| Living with unrelated adult | 8 | 1.5% |
| Living with relative | 96 | 13.2% |
| Living alone | 83 | 12.8% |
| Other/ unknown | 4 | 0.2% |
| Education | | |
| No Degree | 66 | 9.6% |
| High School Diploma or GED | 290 | 47.1% |
| Any Amount of Undergraduate Education | 150 | 30.1% |
| Master's Degree or Professional Degree | 64 | 12.9% |
| Attitude Toward Providing Care > 1Year | | |
| No, it didn't happen | 115 | 18.6% |
| Yes, very upsetting | 51 | 9.6% |
| Yes, somewhat upsetting | 126 | 22.5% |
| Yes, but not upsetting | 292 | 49.3% |

Table 2. *Scale Scores*

| Measure | Unweighted N | % | M(SD) | Skewness/ Kurtosis |
|--------------------------|--------------|-------|-------------|-----------------------|
| Caregiver Burden Total | | | 23.48(6.54) | .326/ .027 |
| Low | 284 | 48.5% | | |
| Medium | 289 | 48% | | |
| High | 18 | 3.5% | | |
| Spirituality Total Score | | | 19.16(6.25) | -1.339/ .549 |
| Highly (23 & above) | 289 | 44.7% | | |
| Not Highly (22 & below) | 302 | 55.3% | | |
| Quality of Life Total | | | 24.27(7.36) | -.702/ -.174 |
| Low | 70 | 12.5% | | |
| Moderate | 236 | 36.8% | | |
| High | 285 | 50.7% | | |

Table 3. *Unweighted Spearman Correlations of Study Variables and Attitude*

| Variable | 1 | 2 | 3 | 4 |
|--|---------|--------|---------|----|
| 1 CG Burden Level | -- | | | |
| 2 Spirituality | -.092* | -- | | |
| 3 QOL | -.479** | .125** | -- | |
| 4 Attitude Toward Providing Care > 1 Year | .252** | -.100* | -.185** | -- |

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

Table 4. *Bivariate GLM with Caregiver Burden as Outcome*

| | Wald F (sig) | <i>B</i> | <i>t</i> | <i>p</i> |
|---|----------------------------|----------|----------|----------|
| Age | 3.679 (<i>p</i> = .017) | | | |
| 85-95 | | -1.085 | -.888 | .378 |
| 75-84 | | -2.641 | -3.365 | .001 |
| 65-74 | | -1.199 | -1.222 | .227 |
| Ref. = 54-64 | | | | |
| Gender | 1.120 (<i>p</i> = .294) | | | |
| Male | | -.775 | -1.058 | .294 |
| Ref. = Female | | | | |
| Race | .793 (<i>p</i> = .457) | | | |
| Black | | -.816 | -1.260 | .213 |
| Other | | -.723 | -.559 | .578 |
| Ref. = White | | | | |
| Hispanicity | .047 (<i>p</i> = .954) | | | |
| Mexican | | -.238 | -.183 | .855 |
| Other | | .389 | .244 | .808 |
| Ref. = Non-Hispanic | | | | |
| Marital Status | 2.849 (<i>p</i> = .045) | | | |
| Never Married | | 2.425 | 2.582 | .012 |
| Separated/ Divorced | | 1.633 | 1.924 | .059 |
| Widowed | | .435 | .264 | .793 |
| Ref. = Married | | | | |
| Education | 1.954 (<i>p</i> = .131) | | | |
| No Degree | | 1.439 | 1.112 | .271 |
| Any Undergraduate Education | | -1.514 | -1.912 | .061 |
| Graduate or Professional | | -1.590 | -1.097 | .277 |
| Ref. = High School Diploma or GED | | | | |
| Lives Alone | .077 (<i>p</i> = .783) | | | |
| Yes | | .237 | .277 | .783 |
| Ref. = Does Not Live Alone | | | | |
| Spirituality | 5.459 (<i>p</i> = .023) | | | |
| Highly Spiritual | | -1.689 | -2.337 | .023 |
| Ref. = Not Highly Spiritual | | | | |
| Attitude Toward Providing Care > 1Year | 20.795 (<i>p</i> = <.001) | | | |
| No, it didn't happen | | 1.162 | 1.187 | .240 |
| Yes, very upsetting | | 9.549 | 7.517 | <.001 |
| Yes, somewhat upsetting | | 3.883 | 4.974 | <.001 |
| Ref. = Yes, but not upsetting | | | | |

Table 5. *Bivariate GLM with Quality of Life as Outcome*

| | Wald F (sig) | B | t | p |
|--|----------------------------|---------|--------|-------|
| Age | | | | |
| 85-95 | | 1.694 | 1.127 | .264 |
| 75-84 | | 1.380 | 1.595 | .116 |
| 65-74 | | -.175 | -.34 | .815 |
| Ref. = 54-64 | | | | |
| Gender | .072 (<i>p</i> = .789) | | | |
| Male | | .190 | .269 | .789 |
| Ref. = Female | | | | |
| Race | 6.994 (<i>p</i> = .002) | | | |
| Black | | -3.401 | -3.382 | .001 |
| Other | | 1.429 | .933 | .355 |
| Ref. = White | | | | |
| Hispanicity | 4.565 (<i>p</i> = .014) | | | |
| Mexican | | 3.075 | 2.767 | .008 |
| Other | | 2.980 | 1.668 | .101 |
| Ref. = Non-Hispanic | | | | |
| Marital Status | 9.687 (<i>p</i> = <.001) | | | |
| Never Married | | -3.830 | -1.809 | .076 |
| Separated/ Divorced | | -5.383 | -4.775 | <.001 |
| Widowed | | -.334 | -1.325 | .190 |
| Ref. = Married | | | | |
| Education | .477 (<i>p</i> = .699) | | | |
| No Degree | | 1.125 | .630 | .531 |
| Any Undergraduate Education | | .801 | .891 | .377 |
| Graduate or Professional | | 1.738 | 1.044 | .301 |
| Ref. = High School Diploma or GED | | | | |
| Lives Alone | 5.271 (<i>p</i> = .025) | | | |
| Yes | | -3.599 | -2.296 | .025 |
| Ref. = Does Not Live Alone | | | | |
| Caregiver Burden | 42.415 (<i>p</i> = <.001) | | | |
| High | | -12.840 | -6.786 | <.001 |
| Moderate | | -5.851 | -8.311 | <.001 |
| Ref. = Low | | | | |
| Spirituality | 2.566 (<i>p</i> = .114) | | | |
| Highly Spiritual | | 1.122 | 1.602 | .114 |
| Ref. = Not Highly Spiritual | | | | |
| Attitude Toward Providing Care > 1Year | 7.216 (<i>p</i> = <.001) | | | |
| No, it didn't happen | | -.355 | -.291 | .772 |
| Yes, very upsetting | | -6.234 | -4.590 | <.001 |
| Yes, somewhat upsetting | | -1.427 | -1.577 | .120 |
| Ref. = Yes, but not upsetting | | | | |

Table 6. *Crosstabs Caregiver Burden as Dependent with Unweighted N & Weighted %*

| | Low Caregiver Burden | Moderate Caregiver Burden | High Caregiver Burden | χ^2 , <i>p</i> -value |
|--------------------|-------------------------|------------------------------|-----------------------------|----------------------------|
| Quality of Life | | | | 103.827, <i>p</i> = <.001 |
| Low | 10, 7.5% | 53, 81.8% | 7, 10.8% | |
| Moderate | 81, 38% | 149, 57% | 6, 4.9% | |
| High | 193, 66.2% | 87, 33.1% | 5, 0.7% | |
| Spirituality Total | | | | 8.776, <i>p</i> = .096 |
| Highly | 158, 54.3% | 137, 43.8% | 7, 1.9% | |
| Not Highly | 126, 43.8% | 152, 51.3% | 11, 4.9% | |
| Total | 284, 48.5% | 289, 48% | 18, 3.5% | |

Table 7. Crosstabs Spiritual Level as Outcome with Unweighted N & Weighted %

| | Highly Spiritual | Not Highly Spiritual | χ^2 , p-value |
|------------------|------------------|----------------------|--------------------|
| Quality of Life | | | 2.069, $p = .575$ |
| Low | 27, 40.4% | 43, 59.6% | |
| Moderate | 115, 42.3% | 121, 57.7% | |
| High | 160, 47.6% | 125, 52.4% | |
| Caregiver Burden | | | 8.776, $p = .096$ |
| Low | 158, 50.1% | 126, 49.9% | |
| Moderate | 137, 40.8% | 152, 59.2% | |
| High | 7, 23.7% | 11, 76.3% | |
| Total | 302, 44.7% | 289, 55.3% | |

Table 8. Crosstabs with QOL as Dependent with Unweighted N & Weighted %

| | Low QOL | Moderate QOL | High QOL | χ^2 , p-value |
|------------------|-----------|--------------|------------|----------------------|
| Caregiver Burden | | | | 103.827, $p = <.001$ |
| Low | 10, 1.9% | 81, 28.9% | 193, 69.2% | |
| Moderate | 53, 21.3% | 149, 43.8% | 87, 34.9% | |
| High | 7, 38% | 6, 51.3% | 5, 10.7% | |
| Spirituality | | | | 2.069, $p = .575$ |
| Not Highly | 27, 11.3% | 115, 34.8% | 160, 53.9% | |
| Not Highly | 43, 13.5% | 121, 38.4% | 125, 48.1% | |
| Total | 70, 12.5% | 236, 36.8% | 285, 50.7% | |

Table 9. *Caregiver Burden X Demographic Frequencies with Unweighted N & Weighted %*

| Demographic | Levels of Caregiver Burden | | | χ^2 , p-value |
|------------------------|----------------------------|------------|----------|--------------------|
| | Low | Moderate | High | |
| Gender | | | | 2.505, p=.569 |
| Male | 114, 51.3% | 104, 46.1% | 5, 2.6% | |
| Female | 170, 46% | 185, 49.6% | 13, 4.4% | |
| Race | | | | 5.056, p=.315 |
| White | 191, 47.5% | 195, 48.8% | 13, 3.7% | |
| Black | 71, 52.4% | 73, 47% | 1, 0.6% | |
| Other | 22, 56.4% | 20, 36.5% | 4, 7% | |
| Hispanicity | | | | 4.861, p=.347 |
| Mexican | 17, 44.5% | 28, 55.5% | 0, 0% | |
| Other | 14, 62.6% | 12, 29.9% | 3, 7.5% | |
| Not Hispanic | 253, 48.4% | 248, 48% | 15, 3.6% | |
| Lives Alone | | | | 1.686, p=.527 |
| Yes | 42, 45.2% | 40, 53.2% | 1, 1.5% | |
| No | 242, 49% | 249, 47.2% | 17, 3.8% | |
| Marital Status | | | | 17.171, p=.176 |
| Married | 189, 51.8% | 178, 45% | 11, 3.2% | |
| Separated/ Divorced | 46, 38.1% | 56, 59% | 3, 2.7% | |
| Widowed | 37 54.5% | 32, 36.1% | 3, 9.3% | |
| Never Married | 12, 33.8% | 22, 63.9% | 1, 2.3% | |
| Age | | | | 13.683, p=.166 |
| 54-64 | 103, 42.8% | 129, 54.2% | 9, 3.1% | |
| 65-74 | 98, 50.2% | 98, 44.7% | 7, 5.1% | |
| 75-84 | 68, 62.9% | 47, 36% | 1, 1.1% | |
| 85-95 | 15, 52.8% | 15 44.4% | 1, 2.7% | |
| Education | | | | 4.716, p=.057 |
| No Degree | 19, 28.8% | 46, 69.2% | 1, 2% | |
| HS Diploma or GED | 130, 44.9% | 149, 50.2% | 11, 4.9% | |
| Any Undergraduate | 92, 61% | 54, 37% | 4, 2% | |
| Graduate/ Professional | 36, 49.5% | 26, 46.3% | 2, 4.3% | |

Table 10. *Spiritual Level X Demographic Frequencies with Unweighted N & Weighted %*

| Demographic | Highly Spiritual | Not Highly Spiritual | χ^2 , <i>p</i> -value |
|-----------------------------------|------------------|----------------------|----------------------------|
| Age | | | 12.648, <i>p</i> = .011 |
| 54-64 | 106, 38.6% | 135, 61.4% | |
| 65-74 | 104, 46.5% | 99, 53.5% | |
| 75-84 | 70, 56.2% | 46, 43.8% | |
| 85-95 | 22, 70.5% | 9, 29.5% | |
| Gender | | | 27.214, <i>p</i> = <.001 |
| Male | 89, 33.4% | 134, 66.6% | |
| Female | 213, 54.7% | 155, 45.3% | |
| Race | | | 35.311, <i>p</i> = <.001 |
| White | 174, 39.2% | 225, 60.8% | |
| Black | 97, 72.4% | 48, 27.6% | |
| Other | 31, 66.9% | 15, 33.1% | |
| Hispanicity | | | .537, <i>p</i> = .817 |
| Mexican | 25, 50.8% | 20, 49.2% | |
| Other | 12, 47.9% | 17, 52.1% | |
| Not Hispanic | 265, 44.5% | 251, 55.5% | |
| Lives Alone | | | 4.154, <i>p</i> = .135 |
| Yes | 40, 55.6% | 43, 44.4% | |
| No | 262, 43.1% | 246, 56.9% | |
| Marital Status | | | 4.004, <i>p</i> = .483 |
| Married | 198, 42.8% | 180, 57.2% | |
| Separated/ Divorced | 42, 43.7% | 63, 56.3% | |
| Widowed | 40, 53.8% | 32, 46.2% | |
| Never Married | 21, 54.7% | 14, 45.3% | |
| Education | | | 21.259, <i>p</i> = .005 |
| No Degree | 43, 57.9% | 23, 42.1% | |
| HS Diploma or GED | 157, 50.9% | 133, 49.1% | |
| Undergraduate Education (Any Amt) | 62, 35.4% | 88, 64.6% | |
| Graduate or Professional Degree | 28, 29.3% | 36, 70.7% | |
| Ref. = High School Diploma or GED | | | |

Table 11. *Quality of Life X Demographic Frequencies with Unweighted N & Weighted %*

| Demographic | Levels of Quality of Life | | | $\chi^2, p\text{-value}$ |
|------------------------|---------------------------|------------|------------|--------------------------|
| | Low | Moderate | High | χ^2/ sig |
| Gender | | | | 2.419, $p = .461$ |
| Male | 23, 10.4% | 90, 36.4% | 110, 53.2% | |
| Female | 47, 14.3% | 146, 37.2% | 175, 48.5% | |
| Race | | | | 13.274, $p = .023$ |
| White | 40, 10.7% | 155, 37.1% | 204, 52.2% | |
| Black | 23, 23.6% | 68, 40.3% | 54, 36.1% | |
| Other | 6, 8.6% | 13, 30.3% | 27, 61.1% | |
| Hispanicity | | | | 5.773, $p = .153$ |
| Mexican | 2, 2.1% | 17, 33.4% | 6, 64.4% | |
| Other | 2, 5.6% | 8, 31.0% | 19, 63.4% | |
| Not Hispanic | 65, 12.9% | 211, 37.4% | 40, 49.7% | |
| Lives Alone | | | | 13.636, $p = .040$ |
| Yes | 16, 24.9% | 31, 37.5% | 36, 37.6% | |
| No | 54, 10.7% | 205, 36.7% | 249, 52.6% | |
| Marital Status | | | | 48.742, $p = .002$ |
| Married | 26, 7.2% | 150, 35.7% | 202, 57.1% | |
| Separated/ Divorced | 29, 30.4% | 42, 40.3% | 34, 29.3% | |
| Widowed | 8, 16.4% | 30, 39.9% | 34, 43.7% | |
| Never Married | 7, 19.6% | 14, 36.4% | 14, 44% | |
| Age | | | | 10.59, $p = .133$ |
| 54-64 | 38, 15.9% | 92, 32.9% | 111, 51.1% | |
| 65-74 | 22, 11.6% | 85, 39.2% | 96, 49.2% | |
| 75-84 | 7, 4% | 48, 44.1% | 61, 51.9% | |
| 85-95 | 3, 7.8% | 11, 34.3% | 17, 57.9% | |
| Education | | | | 7.827, $p = .629$ |
| No Degree | 6, 15.9% | 23, 27.2% | 37, 56.9% | |
| HS Diploma or GED | 42, 14.9% | 117, 35.7% | 131, 49.5% | |
| Any Undergraduate | 14, 8.5% | 60, 42.5% | 76, 49% | |
| Graduate/ Professional | 6, 12.5% | 26, 33.6% | 32, 3.9% | |

Table 12. Crosstabs of Attitude Toward Providing Care > 1Year and Variables of Interest

| | Attitude Toward Providing Care for More Than 1Year | | | | χ^2 , <i>p</i> -value |
|----------------------|--|------------------------|-------------------------|---------------------|----------------------------|
| | No, it didn't happen | Yes, but not upsetting | Yes, somewhat upsetting | Yes, very upsetting | |
| CG Burden Level | | | | | 91.312, <i>p</i> = <.001 |
| Low | 60, 18.1% | 167, 60.2% | 45, 17.8% | 10, 3.9% | |
| Moderate | 54, 20.3% | 122, 41.3% | 74, 26.7% | 34, 11.7% | |
| High | 1, 2.1% | 3, 8% | 7, 30.8% | 7, 59.1% | |
| QOL Level | | | | | 35.821, <i>p</i> = .004 |
| Low | 13, 23% | 27, 39.2% | 16, 15.4% | 14, 22.4% | |
| Moderate | 40, 14.8% | 105, 44.5% | 57, 28.3% | 28, 12.4% | |
| High | 62, 20.2% | 160, 55.2% | 53, 20.2% | 9, 4.4% | |
| Spirituality | | | | | 7.029, <i>p</i> = .251 |
| Highly Spiritual | 68, 23.1% | 153, 48% | 55, 20.6% | 23, 8.2% | |
| Not Highly Spiritual | 47, 14.9% | 139, 50.4% | 71, 24% | 28, 10.7% | |

Table 13. Multivariate GLM Testing Main Effects of Spirituality and Caregiver Burden on QOL and of Spirituality and QOL on Caregiver Burden

| Outcome | Wald F (sig) | <i>B</i> | <i>t</i> | <i>p</i> |
|-----------------------------|----------------------------|----------|----------|----------|
| QOL | 60.788 (<i>p</i> = <.001) | | | |
| Caregiver Burden | | -.540 | -10.626 | <.001 |
| Highly Spiritual | | .211 | .319 | .750 |
| Ref. = Not Highly Spiritual | | | | |
| Caregiver Burden | 78.688 (<i>p</i> = .000) | | | |
| QOL | | -.461 | -11.275 | <.001 |
| Highly Spiritual | | -1.172 | -1.752 | .085 |
| Ref. = Not Highly Spiritual | | | | |

Table 14. *Multivariate GLM Testing Main and Interaction Effects on QOL*

| Model | R^2 | Wald F (sig) | B | t | p |
|--------------------------------|-------|------------------------|--------|--------|-------|
| Model Effects | .256 | 40.998 ($p = <.001$) | | | |
| Spirituality | | | -2.386 | -.967 | .338 |
| Caregiver Burden | | | -.587 | -8.752 | <.001 |
| Spirituality* Caregiver Burden | | | .112 | .963 | .340 |

Table 15. *Multivariate GLM Testing Main and Interaction Effects on Caregiver Burden*

| | R^2 | Wald F (sig) | B | t | p |
|--------------------|-------|------------------------|--------|---------|-------|
| Model Effects | .267 | 53.090 ($p = <.001$) | | | |
| Spirituality | | | -4.848 | -1.245 | .009 |
| QOL | | | -.529 | -10.333 | <.001 |
| Spirituality * QOL | | | .151 | 2.068 | .043 |

Table 16. *Multivariate GLM Testing Main Effects of Significant Variables on Caregiver Burden*

| Model | R^2 | Wald F (sig) | B | t | p |
|--|-------|------------------------|--------|--------|-------|
| Model Effects | .260 | 12.758 ($p = <.001$) | | | |
| Age | | .892 ($p = .451$) | | | |
| 65-74 | | | -.242 | -.283 | .778 |
| 75-84 | | | -1.401 | -1.569 | .122 |
| 85-95 | | | -.750 | -.666 | .508 |
| Ref. = 54-64 | | | | | |
| Marital Status | | 3.761 ($p = <.016$) | | | |
| Never Married | | | 2.765 | 2.640 | .011 |
| Separated/ Divorced | | | 2.177 | 2.763 | .008 |
| Widowed | | | 1.177 | 1.046 | .300 |
| Ref. = Married | | | | | |
| Spirituality | | 4.741 ($p = <.033$) | | | |
| Highly Spiritual | | | -1.499 | -2.177 | .033 |
| Ref. = Not Highly Spiritual | | | | | |
| Attitude Toward Providing Care > 1 Year | | 24.148 ($p = <.001$) | | | |
| No, it didn't happen | | | .998 | 1.001 | .321 |
| Yes, very upsetting | | | 9.405 | 7.902 | <.001 |
| Yes, somewhat upsetting | | | 4.030 | 5.375 | <.001 |
| Ref. = Not Highly Spiritual | | | | | |

Table 17. *Multivariate GLM Testing Main Effects of Significant Variables on QOL*

| Model | R^2 | Wald F (sig) | B | t | p |
|---|-------|------------------------|---------|--------|-------|
| Model Effects | .327 | 12.445 ($p = <.001$) | | | |
| Caregiver Burden | | 33.106 ($p = <.001$) | | | |
| High | | | -10.843 | -6.490 | <.001 |
| Moderate | | | -5.024 | -7.232 | <.001 |
| Race | | 5.897 ($p = .005$) | | | |
| Other Race | | | -.247 | -.173 | .863 |
| Black | | | -3.237 | -3.425 | .001 |
| Ref. = White | | | | | |
| Hispanicity | | 3.513 ($p = .036$) | | | |
| Mexican | | | 1.956 | 1.640 | .106 |
| Other Hispanic | | | 3.102 | 2.511 | .015 |
| Ref. = Non-Hispanic | | | | | |
| Marital Status | | 5.189 ($p = .003$) | | | |
| Never Married | | | -2.045 | -1.115 | .269 |
| Separated/ Divorced | | | -4.373 | -3.945 | <.001 |
| Widowed | | | -1.403 | -.948 | .347 |
| Ref. = Married | | | | | |
| Lives Alone | | .883 ($p = .351$) | -1.397 | -.940 | .351 |
| Attitude Toward Providing Care > 1Year | | 5.207 ($p = .003$) | | | |
| No, it didn't happen | | | .721 | .701 | .486 |
| Yes, very upsetting | | | -3.776 | -3.701 | <.001 |
| Yes, somewhat upsetting | | | -.647 | -.791 | .432 |
| Ref. = Yes, but not upsetting | | | | | |

Table 18. *Model 1 Path Analysis Results*

| | <i>B</i> | <i>SE</i> | <i>CR</i> | <i>p</i> |
|------------------------------------|----------|-----------|-----------|----------|
| Spirituality to Caregiver Burden | -1.208 | .557 | -2.167 | .030 |
| Marital Status to Caregiver Burden | .751 | .729 | 1.030 | .303 |
| Caregiver Burden to QOL | -.528 | .037 | -14.134 | .000 |
| Marital Status to QOL | -3.253 | .664 | -4.897 | .000 |
| Race to Spirituality | .209 | .047 | 4.450 | .000 |
| Race to QOL | -1.965 | .601 | -3.270 | .001 |
| Hispanicity to QOL | -2.999 | .781 | -3.839 | .000 |
| Hispanicity covariance with Race | .027 | .006 | 4.579 | .000 |

Table 19. *Model 1 Fit Indices*

| Model | NFI | IFI | TLI | CFI | PCFI | RMSEA | χ^2 (<i>p</i>) | DF | PCMIN/DF |
|---------|------|------|------|------|------|-------|---------------------------|----|----------|
| Model 1 | .906 | .929 | .843 | .927 | .432 | .069 | 26.858 (<i>p</i> = .000) | 5 | 3.837 |

Table 20. *Model 2 Path Analysis Results*

| | <i>B</i> | <i>SE</i> | <i>CR</i> | <i>p</i> |
|----------------------------------|----------|-----------|-----------|----------|
| Spirituality to Caregiver Burden | -1.267 | .558 | -2.271 | .023 |
| Caregiver Burden to QOL | -.528 | .037 | -14.152 | .000 |
| Marital Status to QOL | -3.253 | .664 | -4.902 | .000 |
| Race to Spirituality | .209 | .047 | 4.450 | .000 |
| Race to QOL | -1.965 | .601 | -3.270 | .001 |
| Hispanicity to QOL | -2.999 | .781 | -3.839 | .023 |

Table 21. *Final Model Fit Indices*

| | NFI | IFI | TLI | CFI | PCFI | RMSEA | χ^2 (<i>p</i>) | DF | PCMIN/DF |
|-------------|------|------|------|------|------|-------|---------------------------|----|----------|
| Final Model | .902 | .928 | .862 | .927 | .494 | .065 | 27.902 (<i>p</i> = .000) | 8 | 3.488 |