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Determinants of caregiver burden among informal caregivers looking after older adults with Alzheimer's disease in Saudi Arabia.

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DETERMINANTS OF CAREGIVER BURDEN AMONG INFORMAL CAREGIVERS LOOKING AFTER OLDER ADULTS WITH ALZHEIMER'S DISEASE IN SAUDI ARABIA

By

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B. S. W., King Saud University, 2011
M. S. W., Southern Illinois University, 2018

A Dissertation
Submitted to the Faculty of the
Raymond A. Kent School of Social Work and Family Science of the University of Louisville
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for the Degree of

Doctor of Philosophy
In Social Work

Raymond A. Kent School of Social Work and Family Science
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Louisville, Kentucky

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A Dissertation Committee Approved on

April 12, 2022

by the following Dissertation Committee:

Dissertation Chair
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Dr. Stephanie Grace Prost, University of Louisville

Dr. Sharon E. Moore, University of Louisville

Dr. Mark P. Pfeifer, University of Louisville

DEDICATION

This dissertation is dedicated to my beloved father, Ali Al-Shubair, who is living
with Alzheimer's disease in our family home with dignity; I will never forget
your contribution to my life. Thank you for everything!
To my beloved mother, Shamaa Al-Masrouhi, this dream will not come true
without your unwavering love, constant personal sacrifices, and great support in
my educational journey. Thank you for everything you have done for me.
It is more than I can ever repay you!
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completed without your unceasing love, sacrifices, and support.
Thank you for your patience and understanding.
To my siblings, Wafa and Saud, who are soon to be doctors, Dr. Abdulrahman,
Nada, Huda, Abdulaziz, Saad, Reem, Abdulmalek, and the rest of my entire
family; Thank you all for your support and standing by me
in times of prosperity and hardship.
To the joy of my life, my precious daughter, Malak.

I am eternally grateful!

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ABSTRACT

DETERMINANTS OF CAREGIVER BURDEN AMONG INFORMAL CAREGIVERS LOOKING AFTER OLDER ADULTS WITH ALZHEIMER'S DISEASE IN SAUDI ARABIA

Sultan Ali Shubair

April 12, 2022

Caregiver burden in Alzheimer’s Disease (AD) is a significant factor in the deterioration of caregivers’ physical and mental health. Moreover, increased caregiver burden has been associated with the decline in quality of life and the reduced quality of care for the care recipient. However, the level of caregiver burden perceived by informal caregivers of care recipients with AD can be varied with the impact of different factors related to the caregiver, care recipient, and caregiving process. Identifying factors associated with caregiver burden and exploring factors that account for variation in caregiver burden are vital to prevent adverse outcomes of caregiver burden affecting caregivers and care recipients. However, no Saudi studies have identified factors associated with caregiver burden. Additionally, no studies have explored factors that account for variation in caregiver burden in AD among informal caregivers in Arabic countries, specifically in Saudi Arabia.

The purpose of this dissertation was 1) to examine the association between particular factors (i.e., care recipient's age and caregiver's educational level) and caregiver burden and 2) to explore the ability of contextual variables (Socio-demographic factors of care recipients, Socio-demographic factors of caregivers, and caregiving-related factors), primary stressors (i.e., care recipient stage of Alzheimer's), and caregiver's well-being to account for variation in caregiver burden among a sample of Saudi Arabian informal caregivers caring for older adults with AD.

Using the existing literature and the modified stress process model of Conde-Sala et al. (2010) as a conceptual framework, this non-experimental research project leveraged primary data collected via a survey of caregivers of older adults with Alzheimer's in Saudi Arabia. The sample included 182 individuals who completed self-reported online surveys distributed by the Saudi Alzheimer's Disease Association. The data were analyzed using SPSS version 28.0.1. Pearson's product moment correlation coefficient (r), Point biserial correlation coefficients, and hierarchical multiple linear regression analysis were used to answer the research questions.

Caregivers were more likely to experience a higher burden with older male care recipients with severe AD who had fewer years of formal education. Older female caregivers who were married, lived with the care recipient, daughter, had fewer years of formal education, were employed, had low monthly income, provided more hours of care per week, and were unsatisfied with the formal care for care recipients were more likely to experience a greater burden.

All four sets of predictors related to contextual variables (care recipient socio-demographic factors, caregiver socio-demographic factors, caregiving-

related factors), primary stressor (care recipient stage of Alzheimer's), and caregiver well-being accounted significantly for variance in caregiver burden. In particular, care recipient factors, which included care recipient socio-demographic factors (age and educational level), and the primary stressor (care recipient stage of Alzheimer's) were the largest in effect, accounting approximately for 53% of the variation in caregiver burden, followed by caregiver socio-demographic factors (age, educational level, marital status, employment status, monthly income level, and living with the care recipient), caregiving-related factors (hours of care per week and caregiver's perception of formal care for care recipient), and caregiver well-being, each of which accounted for 21%, 3%, and 2%, respectively of the variation in caregiver burden.

The significant individual variable that accounted for the most variance among care recipient factors was the care recipient's age. Among caregiver socio-demographic factors, spousal relationship (being married to the care recipient) represented a more critical individual determinant of caregiver burden than other factors. An increased total number of caregiving hours was identified as a more burdensome individual variable among caregiving-related factors than the caregiver's negative perception of formal care for the care recipient. Decreased caregiver well-being was a significant factor that accounted for increased caregiver burden.

All contextual variables explored in this research, identified as predictors in the modified stress process model of Conde-Sala et al. (2010), accounted significantly for the variation in caregiver burden except the caregiver's age, educational level, and living with the care recipient. The primary stressor (care

recipient stage of Alzheimer's) did not significantly account for the variance in caregiver burden in this research. These findings aligned with the prediction of Conde-Sala et al. (2010) that caregivers-associated variables have more decisive influence on caregiver burden than the primary stressors.

The contribution of this study is a critical extension of existing worldwide knowledge. The finding of this research should be used as scientific evidence of the need to frame health-related policies to assist Saudi caregivers of persons with AD in obtaining more professional help and support to minimize the probability of experiencing an increased burden. Saudi policy makers, healthcare professionals, professional social workers, educators, and researchers should collaborate to improve the informal and formal care provided to the care recipient, which may enhance the quality of life of caregivers and the quality of care for the care recipient. The inclusion of AD in the Saudi Vision 2030, the establishment of Alzheimer's long-term care facilities and Alzheimer's elderly day centers, and international collaboration among governmental and non-governmental institutions are critical steps to address the gap in care and services for this particular population.

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CHAPTER 1

INTRODUCTION

Presently, over 35 million individuals live in Saudi Arabia. The population in the country is diverse, with respect to race, gender, tribe, and age. Although Saudi Arabia's population is growing steadily, its aging population has tripled since 2000. The Saudi General Authority for Statistics reported the aging population (65 and older) to be 3.2% of the total population in the middle of 2020 (Saudi General Authority for Statistics, 2000, 2020). The number of Saudis over 65 is expected to reach 10 million by 2050, which will be 18.4% of the total population (Abusaaq, 2015). This continued growth of the aging population represents significant social, economic, and medical challenges. For instance, chronic diseases such as Alzheimer's disease are anticipated to rise sharply with age (Jaul & Barron, 2017).

The Saudi experts estimate that no less than one hundred and thirty thousand individuals are living with Alzheimer’s disease in the country (Saudi Alzheimer’s Disease Association, 2021). The number of new and existing Alzheimer’s disease cases is expected to escalate in the nation in the coming decades as age is the primary risk factor for developing Alzheimer’s disease (Batum et al., 2015). The growth of older population resulted in greater attention to care for the elderly in recent years by launching various initiatives to enhance their quality of life and raise the support and services provided to them. For instance, social care houses were developed to accommodate and care for elderly citizens who reach 60 or more and cannot care for themselves and have no family or relatives who have the mean for that (Unified National Platform, 2022).

Saudi Arabia follows the global growth of the aging population due to a decrease in birth rate, a decline in fertility rate, better disease prevention, advancement in medical services, and increased life expectancy. The life expectancy of individuals in the country has increased from 51 years in 1969 to 75 years in 2018 (Alshehri et al., 2021). The Saudi government has released a Vision 2030 statement that includes a goal to increase life expectancy from 75 to 80 years by 2030 (Kingdom of Saudi Arabia Vision 2030, 2016). Even though the health of Saudi older adults has improved, smoking, obesity, poor lifestyle, cardiovascular diseases, dyslipidemia, diabetes, cancer still threatens their lives (Alharbi et al., 2020 & Khoja et al., 2018). Although the Saudi government Vision 2030 has included heart disease, diabetes, and cancer as chronic diseases that threaten the elderly's health, cognitive disorders that impact the aging population, such as Alzheimer's disease, are not discussed (Kingdom of Saudi Arabia Vision 2030, 2016).

The Problem

Dementia is a broad term for experiencing numerous symptoms, such as memory loss, language problems, difficulties with problem-solving, and other thinking abilities that negatively influence the individuals' capacities to perform daily life tasks and activities. Common causes of dementia are Cerebrovascular disease, Lewy body disease, Frontotemporal lobar degeneration (FTLD), Parkinson's disease (PD), Hippocampal sclerosis (HS), Mixed pathologies, and Alzheimer's disease. Alzheimer's disease accounts for 60% to 80% of cases, making it the most common cause of dementia (Alzheimer's Association, 2021).

Alzheimer's disease is a form of dementia and a chronic neurodegenerative dementing disorder that influences individuals and results in a loss of cognitive and executive functions. It also impairs individuals' memory, language, computational skills, reasoning, judgment, and social behavior (Arendt et al., 2017). In Saudi Arabia, there are no official data on the prevalence of Alzheimer's disease, but the experts estimated no less than 130,000 Alzheimer's disease cases (Saudi Alzheimer's Disease Association, 2021). Abusaaq (2015) estimated that the risk of developing Alzheimer's disease would increase with the anticipated growth of Saudi Arabia's aging population over 60 to represent 25% of the total population by 2050. He also predicted that the prevalence of Alzheimer's disease would increase with the expected increase in life expectancy from 64 to 82 years next years (Abusaaq, 2015). Moreover, Norton et al. (2014) estimated that the prevalence of Alzheimer's disease worldwide would triple by 2050 (Norton et al., 2014). The Saudi Ministry of Health anticipated the Alzheimer's incidence in Saudi Arabia to double every five years (Ministry of Health, 2021).

Alzheimer's disease typically impacts individuals slowly. Its progression is usually categorized into mild, moderate, and severe stages. In the mild stage, most individuals can function independently in their daily life activities. Still, they are likely to need some help in different activities to be independent and safe due to experiencing memory lapses. In the moderate stage, which is usually the longest stage, individuals require great care to perform routine life tasks due to increased memory lapses. In the late stage, individuals are likely to need around-the-clock care and supervision to perform daily living activities due to losing awareness of their environment and experiencing severe impairment in their cognitive, physical, and communication abilities (Alzheimer's Association, 2021 & Breijyeh & Karaman, 2020).

Due to the progression of the disease, individuals with Alzheimer's rely heavily on informal caregivers for care (Llanque et al., 2016). Informal caregivers are indispensable in the lives of persons with Alzheimer's disease because they provide them with assistance in daily life activities, adherence to treatment recommendations, and managing their behavioral symptoms. Alzheimer's informal caregivers also deal with emotional distress and manage finances (Alzheimer's Association, 2021). Although the economic cost of care provided by informal caregivers of individuals with Alzheimer's daises has not been valued in Saudi Arabia, Abyad (2016) indicated that most of the care provided to persons with Alzheimer's disease in Saudi Arabia comes from informal caregivers. This projection is supported by the cultural and religious belief that caring for the elderly is a family responsibility (Abyad, 2016).

Experts also reported that long-term care, rehabilitation, nursing home care services, and assisted living facilities are extremely rare in Saudi Arabia. However, the few long-term care facilities that exist are not intended for individuals with Alzheimer's diseases and are viewed as places for abandoned the aged (Alshahri, 2009 & Alzheimer's Disease International, 2018). Consequently, attention to the needs of informal caregivers has increased recently in Saudi Arabia, particularly by the establishment of the Saudi Alzheimer's Disease Association, Saudi Elderly Support Organization, "WAQAR," and Friends of Geriatric Patient Charity Association. However, Saudi researchers recommended more formal attention and efforts be made to educate and support informal caregivers socially, emotionally, and financially (Almoajel et al., 2019 & Sharif et al., 2020).

Although caring for individuals with Alzheimer's disease at home is the culturally preferred method in Saudi Arabia (Abyad, 2016), it can be an extremely burdensome experience. This heavy burden is because caregivers cope with Alzheimer's disease burden, deterioration of cognitive, physical, and psychological health, disability, and high dependency of Alzheimer’s patients daily for a long time (Llanque et al., 2016). For these reasons, the caregiver burden literature is overflowing with undesirable outcomes that influence caregivers and care recipients as a result of caregiver burden. For instance, Llanque et al. (2016) conducted a literature review of articles on Alzheimer’s caregiver burden and found that depression, anxiety, irascibility, cognitive disturbance, poor health status, yielding caregiving role, and role entrapment are common consequences of caregiver burden (Llanque et al., 2016). Moreover, studies have revealed that Alzheimer’s informal caregivers are more likely to be vulnerable to physical illness , mental illness , and financial problems than caregivers of persons with other chronic diseases (Alzheimer’s Association, 2021; Ma et al., 2018; Sefcik et al.,2018).

Alzheimer’s caregiving burden has also been correlated with a decline in the life quality of informal caregivers (Dawood, 2016; Schumann et al., 2019; Srivastava et al., 2016;), which may, in turn, influence the quality of care that caregivers can provide to persons with Alzheimer’s disease (Barbe et al., 2018). Moreover, caregiver burden has been linked with an increase in behavioral and psychological symptoms of Alzheimer’s disease, nursing home placements, neglect, abuse, and early death among persons with Alzheimer’s disease (Fang & Yan, 2018; Gaugler et al., 2011; Schulz et al., 2020; Stall et al., 2019; Toot et al., 2017; Wang et al., 2019).

Alzheimer’s caregiver burden is a significant factor for the deterioration of caregivers’ physical and mental health, financial difficulties, a reduction in caregiver quality of life and quality of care for the care recipient, and the care recipients’ early death (Barbe et al., 2018; Llanque et al., 2016; Schulz et al., 2020; Stall et al., 2019). However, the level of caregiver burden perceived by informal caregivers from caring for care recipients with Alzheimer’s disease may vary across informal caregivers due to the impact of different factors related to the caregiver, care recipient, and caregiving process (Andreakou et al., 2016; Isik et al., 2019; Kaizik et al., 2017; Lethin et al., 2020; Reed et al., 2014; Smith et al., 2018).

Thus, identifying informal caregivers at high risk of Alzheimer's caregiver burden is vital to prevent adverse outcomes of Alzheimer's caregiver burden among caregivers and care recipients. However, no studies have identified factors that account for variation in Alzheimer's caregiver burden among informal caregivers in Arabic countries, and more specifically in Saudi Arabia. In the light of the expected increase in the aging population in Saudi Arabia, particularly those with Alzheimer's disease receive care at home, more research, programs, and policies are required to meet the needs of informal caregivers (Amr et al., 2014; Abusaaq, 2015; Abyad, 2016; Alamri, 2020; Batum et al., 2015; Khoja et al., 2018).

Identifying factors that account for variation in Alzheimer's caregiver burden is essential to the social work profession for many reasons. Although the profession of social work aims to improve well-being and meet the needs of everyone, it pays specific attention to the needs of vulnerable populations. In the same way, the current study focuses on building knowledge that would help improve life quality and meet the needs of informal caregivers and their care recipients with Alzheimer's disease.

Additionally, out of respect for the persons' dignity and worth, the social work profession is devoted to assisting persons in addressing their own needs and reaching their full potential. Similarly, the knowledge generated from the current study may be helpful for Alzheimer's informal caregivers who are central to the well-being of the care recipients to reach their fullest potential. Thus, they can take care of themselves and help their care recipient with Alzheimer's appropriately for the longest possible time.

The social work profession also strives to advocate for the end of suffering with and on behalf of clients. Likewise, the current study's findings will be used to inform healthcare professionals and social workers to advocate for services, programs, and policies that end or decrease the suffering of informal caregivers and their care recipients with Alzheimer's disease in Saudi Arabia. Finally, identifying factors, even non-modifiable factors, such as age and gender, which may account for variation in Alzheimer's caregiver burden, is critical to the social work profession to improve the development and design of services and programs that would appeal to all informal caregivers.

The Study Purpose

Using the existing literature and the stress process model of Conde-Sala et al. (2010) as a conceptual framework, this study explored the ability of a set of factors to account for variation in caregiver burden among a sample of Saudi informal caregivers caring for older adults with Alzheimer's disease. Generally, this study identified how contextual variables (care recipient socio-demographic factors, including age, gender, and educational level, caregiver socio-demographic factors, including age, gender, educational level, marital status, employment status, income level, living with the care recipient, and relationship with the care recipient), caregiving-related factors (hours of care per week and caregiver's perception of formal care), primary stressor (stage of AD), and caregiver's well-being account for variation in Alzheimer's caregiver burden.

The Research Questions

The following six questions were formulated to determine the association between specific factors and caregiver burden and assess the ability of a set of factors to account for variation in caregiver burden.

1. What is the relationship between the contextual variables related to the care recipient socio-demographic factors (age, gender, and educational level) and caregiver burden?
2. What is the relationship between the contextual variables related to the caregiver socio-demographic factors (age, gender, educational level, marital status, employment status, income level, Living with the care recipient, and relationship with the care recipient) and caregiver burden?
3. What is the relationship between the contextual variables related to the caregiving-related factors (hours of care per week and caregiver perception of formal care) and caregiver burden?
4. What is the relationship between the primary stressor (stage of AD) and caregiver burden?
5. What is the relationship between caregiver's well-being and caregiver burden?
6. How can care recipient factors, including contextual variables related to the care recipient socio-demographic factors (age and educational level) and the primary stressor (stage of AD), contextual variables related to the caregiver socio-demographic factors (age, educational level, marital status, employment status, income level, living with the care recipient, and relationship with the care recipient), contextual variables related to the caregiving-related factors (hours of care per week and caregiver's perception of formal care), and caregiver's well-being account for variation in caregiver burden?

The Definitions of the Study Terms

Definitions of the study terms used through this research are provided below.

1. **Caregiving:** Hermanns & Mastel-Smith (2015) analyzed the concept of caregiving qualitatively and concluded that caregiving is the process of assisting those (who are unable to help themselves) physically, psychologically, emotionally, spiritually, and socially. Successful implementation of this process requires having particular qualities, skills, knowledge, time, and abilities to emotionally connect with the care recipients (Hermanns & Mastel-Smith, 2015).
2. **Informal caregiver:** the term of *informal caregiver* refers to family members and friends who provide care for other family members, relatives, or friends with chronic diseases, such as Alzheimer's disease. These informal caregivers usually provide care without payment and generally in a home environment (Llanque et al., 2016). In contrast, the term of *formal caregiver* refers to care professionals associated with a formal social service or the healthcare system, whether a volunteer or paid employee.
3. **Care recipient:** the term of care recipient refers to a person with chronic disease, such as Alzheimer's disease, who receives some, great or around-the-clock help and support with daily living activities (National Alliance for Caregiving and AARP, 2009).
4. **Caregiver burden:** Liu et al. (2020) have analyzed caregiver burden literature published in the last ten years and defined the concept of caregiver burden as the level of physical, psychological, emotional, social, and financial strains experienced by a caregiver from providing consistent care for a family member, relative, or friend over time (Liu et al., 2020).

The Dissertation Structure

1. **CHAPTER 1 – INTRODUCTION:** In the first chapter, the researcher provided preliminary background information, clarified the research problem and pointed out the significance of the research, defined the objective of the study and the main research questions, provided operational definitions of the study concepts, and outlined the chapters' contents.
2. **CHAPTER 2 – LITERATURE REVIEW:** In the second chapter, the researchers reviewed, summarized, and evaluated the current state knowledge relevant to the research.
3. **CHAPTER 3 – METHODOLOGY:** In the third chapter, the researcher explained how the theoretical framework of Conde-Sala et al. (2010) was used to guide this study. The researcher also restated the aim of the study and the research questions, described the study design, provided a rationale for the study design, and explained the data collection procedures and the sampling techniques. The researcher also provided a detailed explanation of the study survey instrument, including the validity and reliability of included standardized measures, and an overview of the performed statistical analysis. Ethical considerations related to the research were also discussed in detail in this chapter.
4. **CHAPTER 4 – RESULTS:** The researcher reported the relevant results and briefly assessed them in the fourth chapter.
5. **CHAPTER 5 – DISCUSSION:** In the fifth chapter, the researcher summarized, explained, interpreted, and evaluated the findings and their significance in the light of the current knowledge. Research limitations and implications were also discussed in this chapter.

CHAPTER II

LITERATURE REVIEW

Overview of the Chapter

The purpose of this chapter is three-fold. The first purpose is to present an overview of the literature on Alzheimer's as a problem, including a description of services and social work education, practice, and policy issues related to Alzheimer's in Saudi Arabia. The second purpose is to provide a broad overview of the literature on Alzheimer's caregiving, particularly informal caregiving. The third purpose is to provide a detailed review of the literature on the caregiver burden among informal caregivers of persons with Alzheimer's disease. The researcher reviewed published and unpublished studies to meet these purposes, including master and doctoral dissertations written in English and Arabic.

Literature focusing on Alzheimer's as a problem, Alzheimer's caregiving, and Alzheimer's caregiver burden in the Arab countries, including Saudi Arabia, is limited (Al-Than et al., 2021; Alamri, 2019; Bhalla et al., 2018; El-Metwally et al., 2019; Kane et al., 2020;;; Yaghmour et al., 2019). Thus, it is crucial to look at the literature in western countries, such as the United States, to gain a fuller understanding of Alzheimer's as a problem, informal caregiving, and caregiver burden with respect to Saudi Arabia to understand the need for further Alzheimer's research among the Saudi population.

Alzheimer's Disease as a Problem

Definition and Stages of Alzheimer's Disease

Alzheimer's is a chronic neurodegenerative dementing disorder that primarily impacts older adults. Its characteristics include the loss of cognitive and executive functions. It causes impairments in individuals' memory, language, computational skills, reasoning, judgment, and social behavior (Arendt et al., 2017). Alzheimer's has also been defined as "a fatal, progressive neurodegenerative disorder with clinical manifestations that include acute memory loss, cognitive decline and behavioral changes resulting in social inappropriateness" (Rangachari et al., 2018, p.1653).

Alzheimer's is a form of dementia that progresses slowly and is usually categorized into three stages mild, moderate, and severe stages. In the mild stage, the symptoms of the disease start to appear, including facing difficulties in daily life, losing attention and memory, beginning to lose the ability to recognize the current time and place correctly, experiencing a change in mood, and developing depression. In the moderate stage, Alzheimer's spreads into parts of the cerebral cortex area, leading to increased memory loss, difficulty identifying relatives and friends, a lack of impulse control, and experience of problems with reading, writing, and speaking. In the severe stage, Alzheimer's spreads to the whole cerebral cortex area, leading to progressive impairment in cognitive and executive functional abilities and eventually death (Alzheimer's Association, 2021 & Breijyeh & Karaman, 2020).

Prevalence and Magnitude of Alzheimer's Disease

In the United States, Alzheimer's is the sixth-leading cause of death among everyone and the fifth cause of death among individuals age 65 and older. It is also the primary cause of dementia, disability, and poor health among American older adults 65 and above. Currently, nearly 5.8 million Americans aged 65 and older are diagnosed with Alzheimer's. This number of Alzheimer's cases will escalate rapidly with the estimated increase in the number of older adults in the US aged 65 and older from 58 million in 2021 to 88 by 2050 as aging is the most significant known risk factor for developing Alzheimer's. Presently, one American develops Alzheimer's disease every 65 seconds. By 2050, one American will develop the disease every 33 seconds (Alzheimer's Association, 2021). In the United Kingdom, more than 850,000 were living with AD in 2019. This number is expected to reach to 1.5 million by 2040 (Wittenberg et al., 2019)

For Saudi Arabia, there are no official statistics on the prevalence of Alzheimer's. However, Saudi experts estimate no less than 130,000 Alzheimer's cases in Saudi Arabia (Saudi Alzheimer's Disease Association, 2021). This number of Alzheimer's cases is projected to increase in the country with the estimated increase of the number of Saudis aged 65 or older from 1.5 million in 2017 to 10 million by 2050 (Abusaaq, 2015). Moreover, the incidence of Alzheimer's is expected to double every five years (Ministry of Health, 2021). However, it is significant to note that these statistics do not reflect Alzheimer's actual scope and magnitude since it is underdiagnosed and underreported worldwide, including in Saudi Arabia (Alkhunizan et al., 2018 & Saudi Alzheimer's Disease Association, 2021).

Due to Alzheimer's range and magnitude, it has been recognized as one of the diseases that affect societies worldwide that requires international action to address (World Health Organization, 2008). The United States administration and other countries' governments worldwide have considered Alzheimer's one of the largest and growing public health problems that significantly impact patients, families, communities, and societies, requiring development of national plans to address (Bennett, 2018). Although the Saudi government's Vision 2030 has included heart disease, diabetes, and cancer as chronic diseases in its national health and social care plan, cognitive disorders that face older adults, such as Alzheimer's, are not included in the vision (Kingdom of Saudi Arabia Vision 2030, 2016).

Treatments of Alzheimer's Disease

Scientists have not discovered pharmacological treatment to cure Alzheimer's. However, scientific progress towards understanding Alzheimer's, including developing treatments to slow the progression of the disease, has been made. For instance, several drugs have been developed to slow, maintain, and manage mental and behavioral symptoms of Alzheimer's. Examples include aducanumab, acetylcholinesterase inhibitors, N-methyl D-aspartate antagonists, Antidepressants, and Antipsychotics (Alzheimer's Association, 2021 & Bhushan et al., 2018).

Furthermore, several non-drug interventions have been found to help individuals cope with various physical, emotional, mental, and social challenges associated with Alzheimer's. For instance, several cognitive exercises have been found to enhance mental abilities and functional cognitive task performance for individuals with Alzheimer's. Examples include solving arithmetic problems, reading aloud, remembering images, and performing daily activities (Kallio et al., 2017).

Additionally, several activities have been proven to improve the quality of life of individuals with Alzheimer's and reduce the care needed from their caregivers. Examples include discussing diverse topics, walking, preparing meals, making coffee, and brushing teeth (Hoffmann et al., 2016). Also, several therapeutic techniques have been developed to target the feelings and experiences of individuals with Alzheimer's and enhance their quality of life. Examples include validation therapy and reminiscence therapy (Dourado & Laks, 2016; Takeda et al., 2012).

Causes and Risk Factors of Alzheimer’s Disease

Although experts believe that a failure in human nerve cells may cause Alzheimer’s, they do not yet understand the underlying cause of pathological changes in Alzheimer’s (Alzheimer’s Association, 2021). However, scientists proposed Cholinergic, Amyloid, and Tau hypotheses as causes of Alzheimer’s. According to the Cholinergic Hypothesis, choline acetyltransferase and acetylcholine (ACh) deficits weak individuals’ cognitive and non-cognitive function and cause Alzheimer’s. According to the Amyloid Hypothesis, the accumulation and deposition of amyloid β-peptide (Aβ) in plaques in brain tissue cause Alzheimer’s. According to the Tau hypothesis, an increase of Tau’s phosphorylation leads to the rise of free Tau and loss of microtubules, causing Alzheimer’s. However, there is no currently accepted theory for explaining the pathogenesis of Alzheimer’s (Breijyeh & Karaman, 2020 & Bhushan et al., 2018).

Although scientists worldwide are still trying to discover the leading cause of Alzheimer’s, they have succeeded in identifying multiple factors in individual, familial, and societal/cultural levels that may increase the risk of developing the disease. The risk factors of developing Alzheimer’s at the individual level are researched in Saudi Arabia and the US. However, other factors, such as family, community, and society, have not been studied among the Saudi population.

At the individual level, researchers in the United States have found that increasing age, Apolipoprotein E genotype, and chromosomal sex are fundamental drivers of Alzheimer’s (Riedel et al., 2016). Individuals with pre-existing diseases (e.g., frailty, cancer, carotid atherosclerosis, spontaneous bacterial peritonitis, Hypertension, and type 2 diabetes), hyperhomocysteinemia, high and low body mass, and depression are at increased risk of developing Alzheimer’s (Xu et al., 2015).

Additionally, individuals with Down Syndrome who carry an extra copy of chromosome 21 are at high risk of developing early onset of Alzheimer’s (Wiseman et al., 2015).

Also, head injury may cause over-production of the β-amyloid precursor protein that puts individuals at high risk of developing Alzheimer’s (Li et al., 2017). Women are at increased risk of developing Alzheimer’s than men due to biological (genetic and hormones), psychosocial, and cultural differences, including access to education and occupation (Podcasy & Epperson, 2016). Moreover, women from all races and ethnicities are at high risk of developing Alzheimer’s than men. African Americans, followed by Hispanics, are more vulnerable than White Americans to Alzheimer’s due to limited access to resources (Matthews et al., 2019). Lesbian, gay, bisexual, and transgender (LGBT) also are at high risk of developing Alzheimer’s than others due to social isolation, discrimination, barriers to health care access, limited availability of support for caregivers, and higher rates of certain chronic illnesses than others (Fredriksen-Goldsen et al., 2018).

However, studies conducted to identify risk factors for developing Alzheimer’s in Saudi Arabia are limited. A review of current literature in the country revealed only three studies conducted to identify risk factors for developing Alzheimer’s among Saudis at the individual level. Alhawiti (2016) conducted the first study using the medical record from 2010 to 2015 for three hundred and thirteen patients who were fifty years old. He found that women and individuals with diabetes mellitus, hypertension, lower blood pressure, heart disease, stroke, or cardiovascular disease are at a higher risk of developing Alzheimer’s than others (Alhawiti, 2016).

Using the data of patients with Alzheimer's who received regular care at King Faisal Specialist Hospital and Research Center from 1995 to 2010, Albugami et al. (2018) found that women, older adults, and individuals with cardiovascular disease, hypertension, dyslipidemia, diabetes mellitus, stroke, chronic renal disease, degenerative myelopathy, obesity, epileptic seizure, or depression are at a higher risk of developing Alzheimer's than others (Albugami et al., 2018). Lastly, Alkhunizan et al. (2018) conducted a study that consisted of one hundred and seventy-one patients above age sixty. They found that age, low level of education, smoking, obesity, diabetes, hypertension, and high cholesterol are risk factors for developing Alzheimer's among Saudis (Alkhunizan et al., 2018).

At the familial level, researchers in the United States have found that individuals with parents or siblings with dementia are more likely to develop Alzheimer's (Wolters et al., 2017). Moreover, inherited genetic factors have a broad influence that extends immediate relatives to distant ones (Cannon-Albright et al., 2019). At the community level, researchers in the United States have found that individuals growing up in rural communities are twice as likely to develop Alzheimer's than individuals growing up in urban areas due to limited access to healthcare, exposure to an unknown substance, and socioeconomic factors (Russ et al., 2012).

At the societal level, researchers have found that lack of physical, mental, and social activities and lack of nutrition are risk factors for developing Alzheimer's in the United States, particularly among individuals with low income and limited resources (Isaev et al., 2015; Stępkowski et al., 2015). Additionally, American society's tendency to exclude older adults socially is one of the risk factors contributing to Alzheimer's development and progress (Isaev et al., 2015). It occurs because older adults' social exclusion is associated with low quality of life and poor access to health services and resources, contributing to developing Alzheimer's (Dahlberg & McKee, 2018). Individuals who experience social isolation and loneliness are also at high risk of developing Alzheimer's (Hsiao et al., 2018). Long-term exposure to toxic metals, pesticides, industrial chemicals, and air pollutants resultant from limited environmental policies on a national level that prevent ecological exposures are also associated with Alzheimer's development (Yegambaram et al., 2015).

Consequences of Alzheimer's Disease

In the long term, Alzheimer's has devastating effects on individuals, families, communities, and societies (Alzheimer's Association, 2021). Although studies conducted to define the impact of Alzheimer's at the individual and familial levels are limited in Saudi Arabia, their findings are consistent with the results of studies conducted in the United States. However, there are no studies conducted to define the effects of Alzheimer's on Saudi communities and societies.

At the individual level, researchers in the United States have found that individuals with Alzheimer's are more likely to experience significant depression, low self-esteem, anxiety, apathy, loss of motivation, loss of control, and poor self-care (Boyle et al., 2003; Chau et al., 2016; Lopez et al., 2003). Others found that individuals with Alzheimer's are more likely to face cognitive impacts in areas of memory, language, computational skills, reasoning, and judgment impairments (Arendt et al., 2017). Moreover, individuals with Alzheimer's may experience a decline in their cognitive and physical function, affecting dual-task performance. For instance, bone fracture and falls are common among individuals with Alzheimer's, increasing hospitalization rates (Li, 2016).

In Saudi Arabia, at the individual level, researchers have found that individuals with Alzheimer’s may experience cognitive decline, physical decline, confusion, memory impairment, personality change, visual hallucination, difficulty in performing the usual religious duty, agitation, urine incontinence, and poor oral intake. They may also experience depression, anxiety, apathy, delusions, hallucinations, aberrant motor activity, and sleep disturbance (Amr et al., 2014; Albugami et al., 2018; Ogunniyi et al., 2009).

At the family level, researchers in the United States have found that Alzheimer's is a demanding and frustrating disease for families due to dealing with a wide range of tasks and distressing emotional and behavioral symptoms (Galvin et al., 2020 & Yu et al., 2018). Consequently, families may report various adverse effects related to their physical health, mental health, and financial situations (Alzheimer’s Association, 2021). For instance, a representative national study revealed that almost a third of informal caregivers experience high physical strain (Alzheimer's Association & National Alliance for Caregiving, 2021). Additionally, mental health problems, particularly depression and anxiety, are common among informal caregivers (Ma et al., 2018).

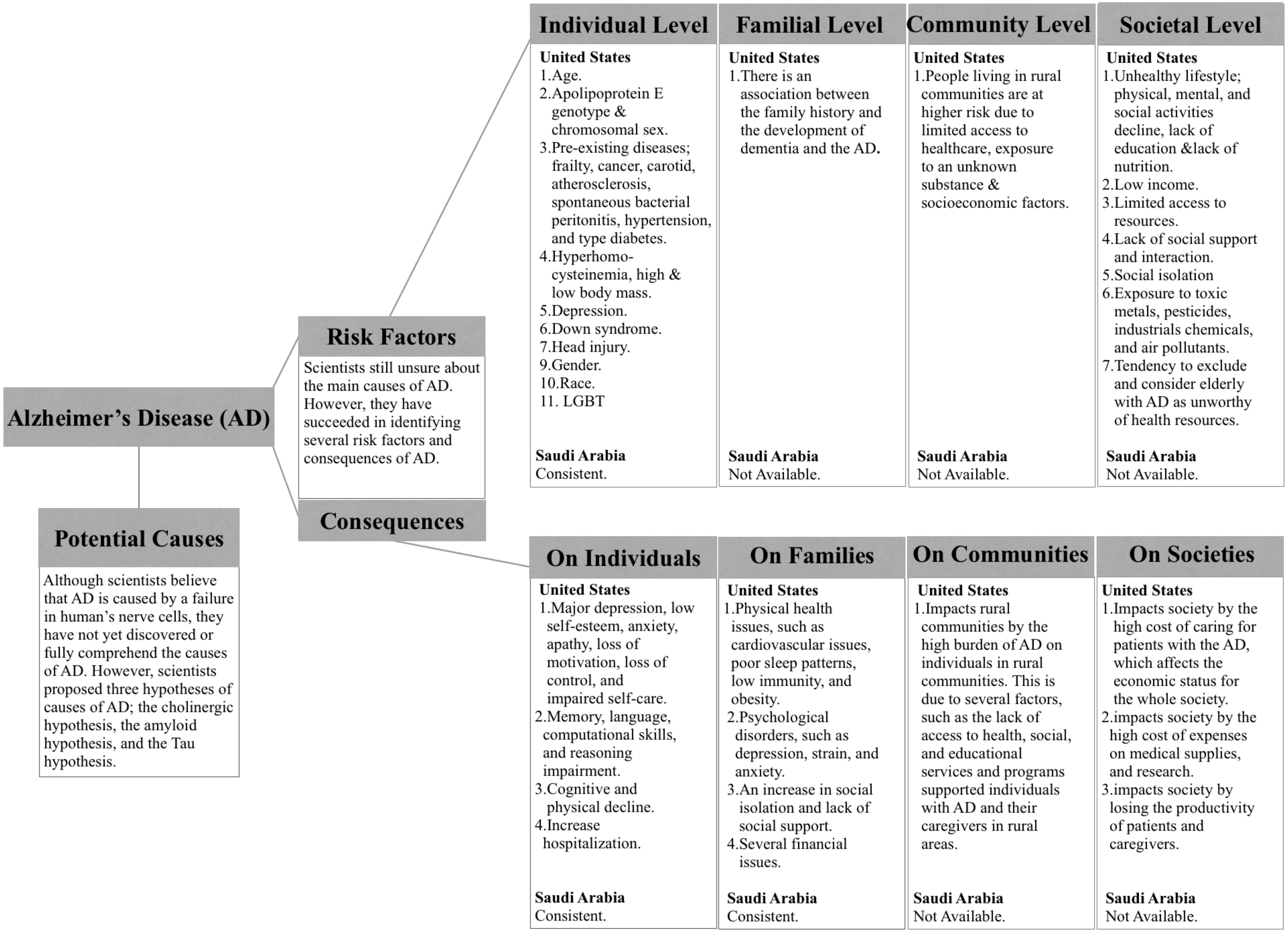
Also, families are more likely to experience financial consequences than the general population in the short and long term. For example, they are more likely to 1) incur high out of pocket expenses for medication, services, and house modification, 2) engage in risky financial behaviors, such as borrowing money, using savings, selling off assets, and taking bank loans, and 3) make accommodations at work, such as reducing hours of work, losing employment benefits, shifting to a part-time position, turning down job offers and quitting work completely to meet caregiving responsibilities (Li et al., 2017; Sefcik et al., 2018). Early death is common among family members who perceive higher strain and poor mental health due to Alzheimer's caregiving responsibilities (Christakis & Allison, 2006; Lwi et al., 2017; Perkins et al., 2013).

At the familial level, researchers in Saudi Arabia have found that physical, psychological, and economic problems are common among families of persons with Alzheimer’s. For instance, most Saudi families face adverse physical effects, such as not having enough time for themselves, suffering from health issues, and having sleeping problems due to caregiving duties. Additionally, most families face negative psychological impacts, such as feeling stressed and fearing the future. Also, more than half of them struggle financially, and they have not received any financial support (Almoajel et al., 2019).

Another study conducted in Saudi Arabia by Alduaij (2018) revealed that informal caregivers face serious psychological, social, and economic problems. However, the most-reported psychological issues are anxiety and the fear of deterioration of the patient’s condition. The most-reported social issues are suffering from a lack of social support from the institutions of society. The most-reported economic issues are the inability to provide a maid or nurse to care for the patient (Alduaij, 2018).

At the community level, researchers in the United States have found that the burden of Alzheimer’s on individuals and families living in American rural communities is higher than the burden on individuals and families living in American urban areas. They suggest that the higher incidence of Alzheimer’s in rural communities is due to the limited access to health, social, and educational services and programs designed to support individuals with Alzheimer’s and their caregivers

(Wiese et al., 2018). A summary of findings on American and Saudi literature related to causes, risk factors, and consequences of AD is shown in Figure 1.



Alzheimer's Disease (AD)

Potential Causes

Although scientists believe that AD is caused by a failure in human's nerve cells, they have not yet discovered or fully comprehend the causes of AD. However, scientists proposed three hypotheses of causes of AD; the cholinergic hypothesis, the amyloid hypothesis, and the Tau hypothesis.

Risk Factors

Scientists still unsure about the main causes of AD. However, they have succeeded in identifying several risk factors and consequences of AD.

Individual Level

United States
1. Age.
2. Apolipoprotein E genotype & chromosomal sex.
3. Pre-existing diseases; frailty, cancer, carotid, atherosclerosis, spontaneous bacterial peritonitis, hypertension, and type diabetes.
4. Hyperhomo-cysteinemia, high & low body mass.
5. Depression.
6. Down syndrome.
7. Head injury.
9. Gender.
10. Race.
11. LGBT

Saudi Arabia
Consistent.

Familial Level

United States
1. There is an association between the family history and the development of dementia and the AD.

Saudi Arabia
Not Available.

Community Level

United States
1. People living in rural communities are at higher risk due to limited access to healthcare, exposure to an unknown substance & socioeconomic factors.

Saudi Arabia
Not Available.

Societal Level

United States
1. Unhealthy lifestyle; physical, mental, and social activities decline, lack of education &lack of nutrition.
2. Low income.
3. Limited access to resources.
4. Lack of social support and interaction.
5. Social isolation
6. Exposure to toxic metals, pesticides, industrials chemicals, and air pollutants.
7. Tendency to exclude and consider elderly with AD as unworthy of health resources.

Saudi Arabia
Not Available.

Consequences

On Individuals

United States
1. Major depression, low self-esteem, anxiety, apathy, loss of motivation, loss of control, and impaired self-care.
2. Memory, language, computational skills, and reasoning impairment.
3. Cognitive and physical decline.
4. Increase hospitalization.

Saudi Arabia
Consistent.

On Families

United States
1. Physical health issues, such as cardiovascular issues, poor sleep patterns, low immunity, and obesity.
2. Psychological disorders, such as depression, strain, and anxiety.
3. An increase in social isolation and lack of social support.
4. Several financial issues.

Saudi Arabia
Consistent.

On Communities

United States
1. Impacts rural communities by the high burden of AD on individuals in rural communities. This is due to several factors, such as the lack of access to health, social, and educational services and programs supported individuals with AD and their caregivers in rural areas.

Saudi Arabia
Not Available.

On Societies

United States
1. Impacts society by the high cost of caring for patients with the AD, which affects the economic status for the whole society.
2. impacts society by the high cost of expenses on medical supplies, and research.
3. impacts society by losing the productivity of patients and caregivers.

Saudi Arabia
Not Available.

Figure 1. A Summary of Findings on American and Saudi Literature Related to Causes, Risk Factors, and Consequences of Alzheimer's Disease.

Services and Social Work in Alzheimer's Disease in Saudi Arabia

This section aims to provide an overview of the current services available and social work education, practice, and policy related to Alzheimer's Disease and informal caregiving. This overview is necessary to identify the need for further research devoted to enhancing services and social work education, practice, and policies related to Alzheimer's disease in Saudi Arabia.

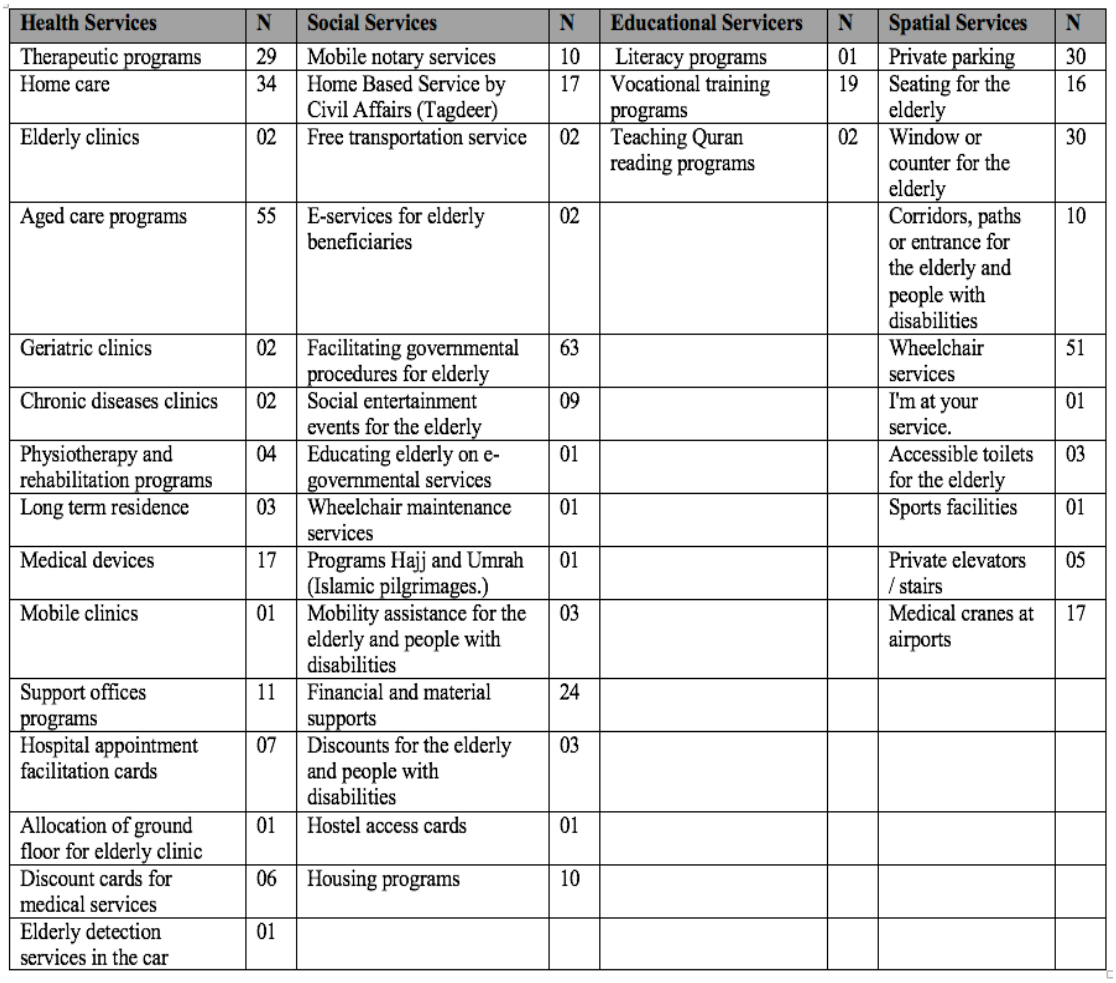
Services for Persons with Alzheimer's and their Families

Article 27 of the Basic Law of Governance states that "The State shall guarantee the right of the citizens and their families in emergencies, sickness, disability, and old age, and shall support the social security system and encourage institutions and individuals to participate in charitable work" (Arabia, S, 1992, p. 6). Recognizing the rights of older adults, Saudi Arabia has introduced various care and services for them in society and care homes to improve their quality of life.

The total number of entities that provide services for older adults, in general, is 319. The majority of these entities are governmental (257), followed by non-profit (46) and private (16). Thus, the level of participation of the non-profit and private sectors is deficient compared to the government sector. More than 40% of the entities are located in only three urban cities: Riyadh, Makkah, and the Eastern region. The primary services for older adults can be divided into health, social, educational and training, and spatial "logistics" services. The total number of sub-services is (42) divided into health services (15), social services (14), educational and training services (3), and spatial services "logistics" (10) (Saudi Elderly Support Organization "WAQAR," 2017). A list of the primary and sub-services for older adults in Saudi Arabia is shown in Table 1.

Table 1

Primary & Sub-Services Provided for Older Adults in Saudi Arabia



Health Services	N	Social Services	N	Educational Servicers	N	Spatial Services	N
Therapeutic programs	29	Mobile notary services	10	Literacy programs	01	Private parking	30
Home care	34	Home Based Service by Civil Affairs (Tagdeer)	17	Vocational training programs	19	Seating for the elderly	16
Elderly clinics	02	Free transportation service	02	Teaching Quran reading programs	02	Window or counter for the elderly	30
Aged care programs	55	E-services for elderly beneficiaries	02			Corridors, paths or entrance for the elderly and people with disabilities	10
Geriatric clinics	02	Facilitating governmental procedures for elderly	63			Wheelchair services	51
Chronic diseases clinics	02	Social entertainment events for the elderly	09			I'm at your service.	01
Physiotherapy and rehabilitation programs	04	Educating elderly on e-governmental services	01			Accessible toilets for the elderly	03
Long term residence	03	Wheelchair maintenance services	01			Sports facilities	01
Medical devices	17	Programs Hajj and Umrah (Islamic pilgrimages.)	01			Private elevators / stairs	05
Mobile clinics	01	Mobility assistance for the elderly and people with disabilities	03			Medical cranes at airports	17
Support offices programs	11	Financial and material supports	24				
Hospital appointment facilitation cards	07	Discounts for the elderly and people with disabilities	03				
Allocation of ground floor for elderly clinic	01	Hostel access cards	01				
Discount cards for medical services	06	Housing programs	10				
Elderly detection services in the car	01						

* Source: Saudi Elderly Support Organization “WAQAR” (2017). Directory of elderly services in the kingdom of Saudi Arabia. Available from https://waqar.org.sa/uploads/files/bfa5361_1592544386.pdf

Table 1 shows a variation in the size of the availability of sub-services within the four primary services. The elderly care and home care programs represent approximately 50% of the health services, while the other 13 health sub-services share the additional 50%. Facilitating governmental procedures for the elderly and home-based service by Civil Affairs (Tagdeer) account for about 54% of the social services, while the other 12 social sub-services share 46%. In terms of educational services, vocational training programs control over 86% of services in this sector, which includes only 3sub-services. For the fourth sector, “spatial or logistical services," wheelchair provision and window or counter allocation for the elderly account for about 49% of spatial services, which include ten sub-services in total (Saudi Elderly Support Organization "WAQAR," 2017).

In terms of the distribution and spread of sub-services across the cities of Saudi Arabia, they are very disparate. 40% of all the sub-services do not repeat in more than three different cities, where only eight sub-services are in one city. 5 sub-services in two cities, and four sub-services in other cities. Only six sub-services are available in all 13 cities of Saudi Arabia. 72% of the total services in Saudi Arabia are approved under a governmental regulation or administrative decision. 22 % are provided based on personal estimates or considerations, causing these services to be blocked or not offered as their officials change (Saudi Elderly Support Organization "WAQAR," 2017).

Regarding the bodies that provide services to older adults in general, the government sector is dominated by 81%, followed by the non-profit sector by 15%, and the private sector participates by only about 4%. These figures show how limited the participation of the private sector is, followed by the non-profit sector in providing services to the elderly despite the large size of private and non-profit sectors in Saudi Arabia (Saudi Elderly Support Organization "WAQAR," 2017). For the agencies that provide services to older adults with Alzheimer's and their families, there is only one non-profit agency, the Saudi Alzheimer's Disease Charity Association.

Founded in 2009, the main branch of the Saudi Alzheimer's Disease Charity Association is located in Riyadh, and it serves all 13 regions in Saudi Arabia. The association's primary objectives are increasing public awareness of Alzheimer's, enhancing health and living standards, and supporting and assisting individuals with

Alzheimer’s and their caregivers. The association provides consultation for informal caregivers and activates strategic partnerships between charitable entities. It also encourages research related to Alzheimer’s and planning to establish a database of information and statistics related to Alzheimer's disease. The associations also cooperate with regional and international Alzheimer’s associations to enhance the services and support for individuals with Alzheimer’s and their families (Saudi Alzheimer’s Disease Association, 2021).

While governmental and private attention to meet the needed services for older adults has enhanced in recent years, more efforts are still required to address the gap in health, social, educational, and training services specialized for older adults with Alzheimer’s and their informal caregivers, particularly long-term care, rehabilitation centers (Al-shahri, 2009; Abyad, 2017; Dementia Innovation Readiness Index, 2018). A critical step to address the gap in services for this particular population is discussing Alzheimer’s in the Saudi government Vision 2030 (Kingdom of Saudi Arabia Vision 2030, 2016) as a chronic disease that threatens the nation’s health. Developing an international plan is also significant to address the challenges associated with the expected increase in older adults with chronic diseases, such as Alzheimer’s disease.

Social Work Policy, Practice & Education in Alzheimer’s

The social work profession worldwide plays a significant role in addressing the physical, psychological, emotional, spiritual, social, and financial issues associated with Alzheimer’s (Chen et al., 2019; Glasby & Thomes, 2018; Justine, 2015). However, the social work profession is still in a unique position in Saudi Arabia that makes it difficult to be effectively involved in Alzheimer’s caring process. Examples of current policy, social work practice, and teaching issues concerning Alzheimer’s in Saudi Arabia are presented below.

1. **Recognition of the social work profession:** There is a lack of recognition of social work as a profession in the country associated with an absence of policy that limits social work jobs to qualified social workers who are professionally trained. Therefore, most of those doing social work jobs and providing care and services for individuals with Alzheimer’s in educational, social, health, and mental health institutions and organizations are non-professionals with no degree in social work and without Alzheimer’s care training (Albardisi, 2016).
2. **Involvement with other professionals:** Hospital social workers are employed in the hospitals to play an active role with multidisciplinary care teams that include physicians, nurses, caregivers, and other non-physician health care providers to extend effective care and services for individuals with Alzheimer’s and their carers (Chen et al., 2019; Fazio et al., 2018; Koskas et al., 2018). However, medical professionals underestimate the importance of involving social workers in Alzheimer’s cases because they believe that Alzheimer’s disease is a medical problem that does not require attention from hospital social workers. Nevertheless, the involvement and participation of knowledgeable, trained, and skilled social workers are needed to best support and assist individuals with Alzheimer’s and their families with psychological, emotional, spiritual, social, economic, and adjustment issues that are associated with the disease (Alahmadi, 2010; Albrithen & Yalli et al., 2016).

3. **The right to self-determination:** One of the issues concerning health care providers, including social workers in Saudi Arabia, is contention surrounding treatment decisions for individuals with Alzheimer's by informal caregivers and health care providers. This problem presents a threat to the right of self-determination of individuals with Alzheimer's, particularly those with severe Alzheimer's. Moreover, it impacts the quality of care and causes moral distress to social workers (Almoallem et al., 2020).
4. **Distribution of services and resources:** One of the challenges facing healthcare providers, including nurses and Saudi social workers, is the unequal distribution of services and resources. This issue presents a significant concern in Saudi Arabia since access to resources is limited to Saudis living in urban cities such as Riyadh, Makkah, and the Eastern region. This limited access to resources puts Saudi social workers in a difficult position when attempting to provide resources for individuals with Alzheimer's and their families, particularly those living in rural areas and those with illegal residency (Alkabba et al., 2012).
5. **Matching the market demand of social workers:** With the estimated growing number of the aging Saudi population, including those with Alzheimer’s, the demand for social workers who are specialized in providing care and services to older adults with chronic diseases, such as Alzheimer’s disease, will increase (Abusaaq, 2015). However, Saudi social work departments across the country failed short to address this demand due to several factors. The first factor is the limited number of Saudi social work faculty specializing in gerontology. Additionally, an

accredited gerontology program does not exist for those who desire to specialize in caring and to serve older adult populations with chronic diseases, such as Alzheimer’s disease. Moreover, few graduate students concentrate on gerontology and Alzheimer’s research due to the limited number of Saudi social work faculty specializing in gerontology (Ibrahim et al., 2020).

6. **Using outdated and insensitive cultural sources in teaching**: There is a lack of scientific knowledge that discusses social problems associated with chronic diseases, such as Alzheimer’s disease in Saudi Arabia (Alamri, 2020; Efrosini et al., 2016). This fact increases the tendency to utilize outdated sources and foreign contents that are not sensitive to Saudi culture. This impacts the learning outcomes and the development of a foundation for gerontology social work education that fits the unique Saudi culture and addresses the spreading social problems associated with chronic diseases, such as Alzheimer’s disease (Abdullatif, 2014).
7. **Lack of internship opportunities for social work students:** In general, there is a lack of internship opportunities for social work students in the country. It is due to the increase of social work students, the limited health and social institutions that can accommodate them, and the lack of experienced supervisors (Ibrahim et al., 2020). Finding internship opportunities for social work students who desire to specialize in Alzheimer’s care is more challenging, particularly with the limited number of organizations serving and supporting the older adults population with Alzheimer’s disease and their families.

Alzheimer’s Caregiving

Definition of Caregiving

Due to the loss of cognitive and executive functions and impairments in memory, language, computational skills, reasoning, judgment, and social behavior (Arendt et al., 2017), persons with Alzheimer's disease rely on others for caregiving (Llanque et al., 2016). Caregiving is the process of assisting those (who are unable to help themselves) physically, psychologically, emotionally, spiritually, and socially. Caregiving for persons with Alzheimer's disease is facilitated by acquiring knowledge about the disease and obtaining particular skills, such as compassion, communication skills, observation, interpersonal skills, initiative, time management, and emotional connection with the care recipients (Hermanns & Mastel-Smith, 2015).

Distinction Between Formal and Informal Caregivers

Some persons with Alzheimer's disease rely on formal caregivers. However, the majority of them rely on informal caregivers. The term formal caregivers refers to care professionals associated with a care service or healthcare system, whether a volunteer or paid employee. In contrast, the term informal caregivers refers to persons who provide care for other family members, relatives, or friends with chronic diseases. Typically, those informal caregivers provide care without payment and generally in a home environment (Llanque et al., 2016).

Prevalence and Demographic Background of Informal caregivers

Informal caregivers in the United States provide 83% of all assistance to the elderly. Nearly half of these provide care for the elderly with Alzheimer's disease and other forms of dementia. The number of informal caregivers of persons with Alzheimer's disease in the United States who provide unpaid care and assistance exceeds 16 million (Alzheimer's Association, 2021). Nearly 67% of them are women. Approximately a third of them are 65 and over. More than 60% of them are married and have long-term relationships with their partners. Also, more than 50% of them care for a parent or in-law with Alzheimer’s. Over half of them are white, followed by (10%) black/African American. Hispanic/Latino represents (8%) of informal American caregivers, followed by (5%) Asians. Also, nearly 40% of them have a college degree or higher. Almost (67%) of them live in the community with the care recipient (Freedman & Spillman, 2014; Fisher et al., 2011; Langa et al., 2005; Rabarison et al., 2018).

In Saudi Arabia, there is no official data on the number of informal caregivers providing care for persons with Alzheimer’s disease. Though, Saudi experts project that most of the care provided to Saudi persons with Alzheimer’s also comes from informal caregivers. This projection is supported by the cultural and religious belief that caring for the elderly is a family responsibility (Abyad, 2016). With the predictable increase in the prevalence of Alzheimer’s, the number of Saudi families caring for older adults with Alzheimer’s is expected to grow, as well (Alshammari et al., 2017; Amr et al., 2014). There has not been a comprehensive study with a direct purpose to describe characteristics of informal caregivers of persons with Alzheimer’s in Saudi Arabia. However, Saudi studies whose primary purpose was something other than describing caregivers showed that most informal caregivers of persons with Alzheimer’s are women, 50 years or less, married, caring for parents, with a university degree and above, employed, with low levels of income, provide care most of the time, and live with the care recipient (Almoajel et al., 2019; Alqahtani et al., 2018; Alfakhri et al., 2018; Alhazzani et al., 2017; Khusaifan et al., 2017).

Caregiving Duties in Alzheimer's Disease

The informal caregivers provide many services and care to their care recipients. For instance, they provide their care recipients support with activities of daily living (ADLs). ADLs include bathing, grooming, dressing, feeding, toileting, cleaning, and mobility. The informal caregivers also help with instrumental daily living activities (IADLs). IADLs include maintaining the house, shopping for groceries and other necessities, preparing meals, providing transportation, arranging hospital appointments, and managing money and other legal affairs (Alzheimer's Association, 2021). Additionally, the informal caregivers of persons with Alzheimer's ensure that their care recipients adhere to treatment recommendations. They also assist them in taking their medications properly. Finally, they help manage behavioral symptoms of Alzheimer's such as aggression, anger, anxiety, agitation, emotional distress, and physical and verbal outbursts (Alzheimer's Association, 2021).

Distinction Between Alzheimer's Caregiving and Caregiving for Persons with other Chronic Diseases

Although it can be argued that caring for persons with other chronic diseases such as cancer, heart disease, and diabetes is somewhat similar to caring for persons with Alzheimer's disease, caregiving for someone with Alzheimer's disease presents unique challenges for informal caregivers. According to a systemic review of articles from 1990 to September 2012 on life expectancy and mortality in Alzheimer's disease, older adults 65 and above may live 4 to 8 years after being diagnosed with Alzheimer's. Moreover, some of them may live with Alzheimer's disease for 20 years (Todd et al., 2013). The long-living duration of Alzheimer's from diagnosis to death is associated with a long time of disability and dependency, contributing significantly to Alzheimer’s burden, particularly on informal caregivers (Alzheimer’s Association, 2021).

Indeed, researchers have developed Disability-Adjusted Life Years (DALYs), which measures and compares the burden of different diseases on a population by considering the number of years of life lost due to premature mortality and the number of years lived with disability. According to the most recent Global Burden of Diseases measurement, Alzheimer’s disease is a very burdensome disease for care recipients and their caregivers. In terms of Causes of Disability-Adjusted Life-Years (DALYs), Alzheimer’s was the 12th most burdensome disease or injury in the US in 1990. By 2016, Alzheimer’s disease rose to the sixth most burdensome disease or injury in the US (Alzheimer’s Association, 2021).

Years of Life lost (YLLs) is a component of DALYs that measures early death by taking into account the frequency of deaths and the age at which it happens. Alzheimer’s disease rose from the 7th highest disease or injury in the United States in 1990 to the fourth in 2016 in terms of YLLs. Years lived with disability (YLDs) is another component of DALYs that measures the burden of living with a disease or disability in the number of years. In terms of YLDs, Alzheimer’s disease has risen from the 23rd disease or injury in the United States in 1990 to the 19th in 2016 (Alzheimer’s Association, 2021 & Mokdad et al., 2018).

The rank change for the 25 leading causes of DALYs, YLLs, DALYs in the US from1990 to 2016 are presented in Table 2.

Table 2

Years of Life Lost (YLLs), Years of Life with Disability (YLDs), and Disability Adjusted Life Years (DALYs) Rank Change for the 25 Leading Causes of Death, Disability, and Injury in the US, 1990-2016

Diseases and Injuries	**YLLs Rank** 1990/2016		**Diseases and Injuries**	**YLDs Rank** 1990/2016		**Diseases and Injuries**	**DALYs Rank** 1990/2016	
Ischemic heart disease	1	1	Low back pain	1	1	Ischemic heart disease	1	1
Tracheal, bronchus, and lung cancer	2	2	Major depressive disorder	2	2	Lung cancer	2	2
Chronic obstructive pulmonary disease	4	3	Diabetes mellitus	8	3	COPD	4	3
Alzheimer disease and other dementias	7	4	Other musculoskeletal disorders	4	4	Diabetes	6	4
Colon and rectum cancer	6	5	Migraine	3	5	Low back pain	3	5
Motor vehicle road injuries	3	6	Neck pain	6	6	Alzheimer disease	12	6
Lower respiratory infections	8	7	Anxiety disorders	5	7	Opioid use disorders	11	7
Diabetes	12	8	Opioid use disorders	7	8	Other musculoskeletal	8	8
Intracerebral hemorrhage	13	9	Age-related and other hearing loss	9	9	Major depression	7	9
Ischemic stroke	11	10	Falls	11	10	Migraine	9	10
Breast cancer	10	11	Chronic obstructive pulmonary disease	12	11	Neck pain	17	11
Self-harm by other specified means	16	12	Osteoarthritis	14	12	Ischemic stroke	10	12
Self-harm by firearm	14	13	Acne vulgaris	10	13	Falls	21	13
Pancreatic cancer	17	14	Dermatitis	13	14	Anxiety disorders	14	14
Opioid use disorders	52	15	Ischemic stroke	18	15	Motor vehicle road injury	5	15
Chronic kidney disease due to diabetes mellitus	35	16	Schizophrenia	17	16	Age-related hearing loss	22	16
Hypertensive heart disease	26	17	Edentulism and severe tooth loss	19	17	Colorectal cancer	16	17
Physical violence by firearm	15	18	Alcohol use disorders	15	18	Lower respiratory infection	19	18
Cirrhosis and other chronic liver diseases due to alcohol use	27	19	Alzheimer disease and other dementias	23	19	Intracerebral hemorrhage	20	19
Other cardiovascular and circulatory diseases	18	20	Rheumatoid arthritis	25	20	Breast cancer	18	20
Neonatal preterm birth complications	9	21	Asthma	16	21	Diabetes CKDc	38	21
Endocrine, metabolic, blood, and immune disorders	37	22	Other mental and substance use disorders	20	22	Self-harm by other means	28	22
Other neoplasms	24	23	Dysthymia	22	23	Alcohol use disorders	26	23
Cirrhosis and other chronic liver diseases due to hepatitis C	30	24	Bipolar disorder	21	24	Osteoarthritis	31	24
Non-Hodgkin lymphoma	32	25	Psoriasis	24	25	Acne vulgaris	23	25

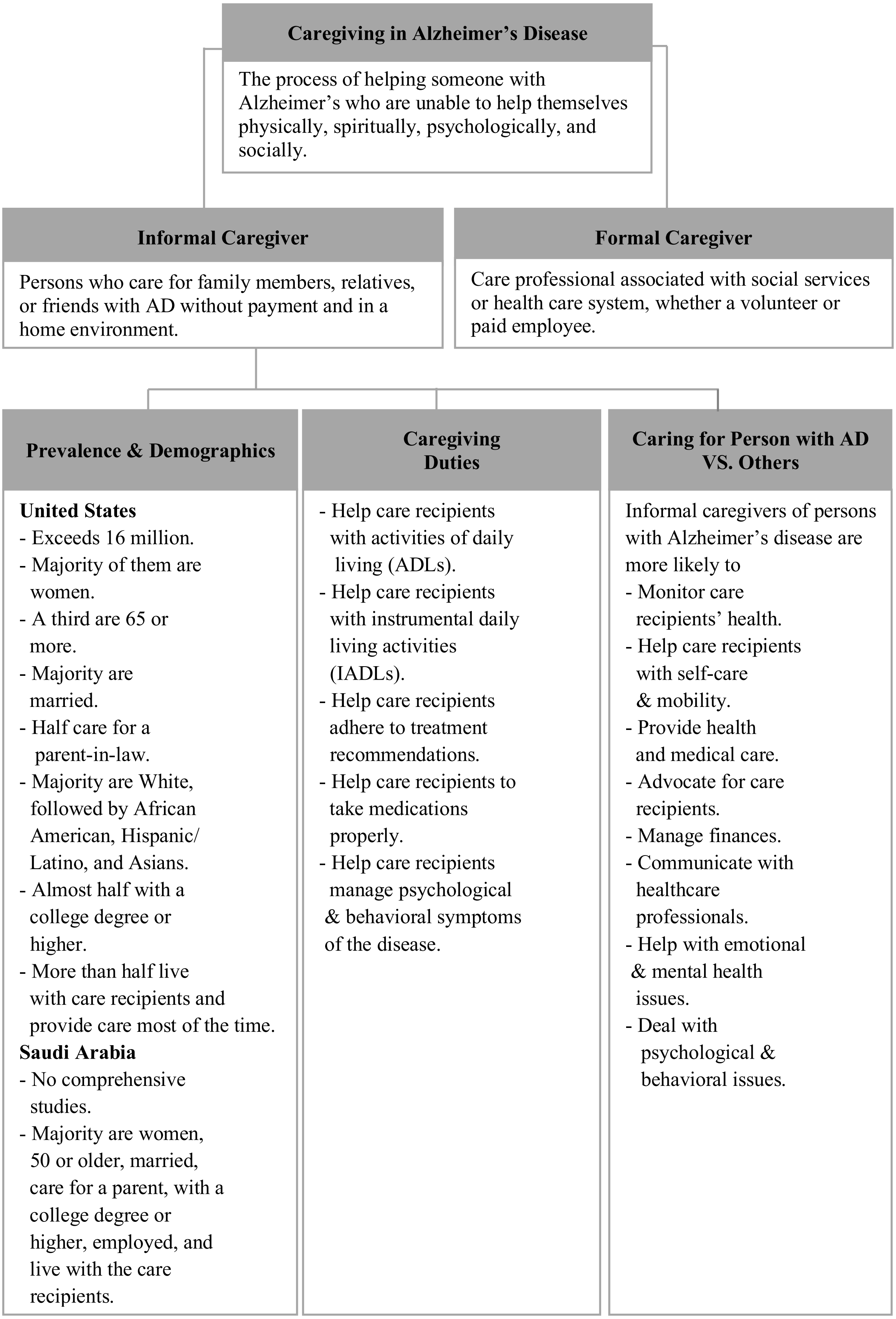
*Source: Mokdad et al. (2018). The state of US health, 1990-2016: burden of diseases, injuries, and risk factors among US states. *Jama*, 319 (14), 1444-1472.

Additionally, based on a national representative quantitative online survey with 1248 informal American caregivers of for older adults, informal caregivers for persons with Alzheimer’s are more likely to monitor the care recipients’ health than informal caregivers of persons with cancer, mobility, and mental/emotional health issues (National Alliance for Caregiving & AARP Public Policy institute, 2020). Another national representative survey with 1739 informal American caregivers of persons with disabilities found that informal caregivers of persons with Alzheimer’s disease are more likely than informal caregivers of older adults without Alzheimer’s disease to assist with self-care and mobility (85% against versus 71%) and provide health and medical care (63% against versus 52%) (Wolff et al., 2016).

Also, based on a national representative study, which included 1,335 informal caregivers, informal caregivers of persons with Alzheimer’s disease are more likely than informal caregivers of persons without alzheimer’s to 1) advocate for care recipients (65% versus 46%), 2) manage finances of care recipients (68% versus 50%), 3) communicate with health and medical care professionals (80% versus 59%), 4) help with emotional, spiritual, and mental health issues (41% versus 16%), and 5) deal with behavioral problems (15% versus 4%) (Alzheimer’s Association, 2021 & National Alliance for Caregiving, 2020).

Though some debate exists regarding the disparate burden of caregivers of persons who care for those with Alzheimer’s compared to caregivers of persons with other conditions, it can be argued based on the previous findings that caregiving for persons with Alzheimer’s disease is more demanding and frustrating than caring for persons without Alzheimer’s disease or with other chronic diseases. Caring for persons with Alzheimer's disease presents more challenges for informal caregivers than caring for persons with other chronic conditions such as cancer, heart disease, and diabetes due to coping with Alzheimer's burden, the deterioration of cognitive and physical health, disability, and dependency of the care recipient for a long time (Llanque et al., 2016).

A summary of Findings on American and Saudi literature related to Alzheimer’s caregiving is shown in Figure 2.



Caregiving in Alzheimer's Disease

The process of helping someone with Alzheimer's who are unable to help themselves physically, spiritually, psychologically, and socially.

Informal Caregiver

Persons who care for family members, relatives, or friends with AD without payment and in a home environment.

Formal Caregiver

Care professional associated with social services or health care system, whether a volunteer or paid employee.

Prevalence & Demographics

United States

- Exceeds 16 million.
- Majority of them are women.
- A third are 65 or more.
- Majority are married.
- Half care for a parent-in-law.
- Majority are White, followed by African American, Hispanic/ Latino, and Asians.
- Almost half with a college degree or higher.
- More than half live with care recipients and provide care most of the time.

Saudi Arabia

- No comprehensive studies.
- Majority are women, 50 or older, married, care for a parent, with a college degree or higher, employed, and live with the care recipients.

Caregiving Duties

- Help care recipients with activities of daily living (ADLs).
- Help care recipients with instrumental daily living activities (IADLs).
- Help care recipients adhere to treatment recommendations.
- Help care recipients to take medications properly.
- Help care recipients manage psychological & behavioral symptoms of the disease.

Caring for Person with AD VS. Others

Informal caregivers of persons with Alzheimer's disease are more likely to

- Monitor care recipients' health.
- Help care recipients with self-care & mobility.
- Provide health and medical care.
- Advocate for care recipients.
- Manage finances.
- Communicate with healthcare professionals.
- Help with emotional & mental health issues.
- Deal with psychological & behavioral issues.

Figure 2. A Summary of Findings on American and Saudi Literature Related to Alzheimer's Caregiving.

Caregiver Burden among Caregivers of Persons with Alzheimer’s

Within the caregiving journey, informal caregivers of persons with Alzheimer’s disease may experience various positive feelings of caregiving. The positive aspects of Alzheimer’s caregiving have been defined as positive emotions evolving from 1) self and social affirmation of playing a successful role in caregiving, 2) conscious and successful use of various cognitive strategies (e.g., reviewing goals, making choices, being grateful, and using humor) to deal with the demanding caregiving situation and 3) having intrinsic motivation towards caregiving (e.g., providing care out of love; Yu et al., 2018).

A systematic critical review of 41 articles on positive aspects of caregiving in Alzheimer’s disease revealed that positive aspects of caregiving generally covers four domains: an increased sense of personal achievement and life satisfaction, an increased sense of personal growth and purpose in life, an increase of mutuality between caregivers and care recipients, and an improvement in family unity and functionality (Galvin et al., 2020). Although there can be benefits and rewards of caregiving, it can be a demanding and frustrating process that may lead to caregiver burden due to dealing with a wide range of caregiving tasks and distressing emotional and behavioral symptoms of care recipients (Alzheimer’s Association, 2021; Christakis & Allison, 2006; Lwi et al., 2017; Ma et al., 2018; Perkins et al., 2013).

Caregiver Burden and Relevant Concepts

Liu et al. (2020) have analyzed caregiver burden literature published in the last ten years and defined caregiver burden as the level of physical, mental, emotional, social, and financial strains experienced by an informal caregiver from providing day-to-day care for a family member, relative, or friend (Liu et al., 2020).

Llanque et al. (2016) analyzed the relevant concepts of caregiver burden in caring for individuals with Alzheimer’s and found that caregiver burden has been considered a dimension of caregiver well-being. Stress, distress, tension, overload, and burnout have been used in the literature to represent caregiver burden. The most common synonym of caregiver burden utilized by researchers is caregiver stress. Caregiver stress can be subjective and objective. Subjective stress is the cognitive and emotional reactions perceived by caregivers. Objective stress is the obligations assumed by caregivers. While caregiver stress is frequently used in the literature, it still refers to the caregiver burden experienced by caregivers (Llanque et al., 2016).

Existing Theoretical Models of Caregiver Burden

Researchers have used several theoretical models to define and explore caregiver burden (Gérain & Zech, 2019). Given et al. (1999) theorized that caregiver burden is a severe response perceived by caregivers due to the increase and the severity of care demands. As care demands increase and become a challenge for caregivers, they respond by adapting or modifying their care strategies, such as accepting help and joining a support group to meet the care recipient's increased needs and reduce the caregiving burden. Caregivers who fail to alter the care strategies to meet caregiving challenges are more likely to experience caregiver burden (Papastavrou et al., 2007). Therefore, a disconnect between knowledge and skills and increased care demands may result in a burden.

In the two-factor model of caregiving appraisal and psychological well-Being, Lawton et al. (1991) treated caregiver burden as the negative outcome of providing care for individuals with Alzheimer’s disease that resulted from stressors and caregiver demands, which consume a caregiver’s resources. On the other hand, they considered caregiver satisfaction as the positive outcome of providing care for individuals with Alzheimer's disease. They also postulated that caregiver satisfaction would have only a minor effect in alleviating the negative impact. Conversely, experiencing caregiver burden would not diminish the positive impact completely (Wilson-Genderson et al., 2009).

However, in the general stress theories, the most common theories used to study caregiver burden (Papastavrou et al., 2007), caregiver burden has been conceptualized in diverse ways. Pearlin et al. (1990) considered caregiver burden (overload) as a primary stressor anticipated to be influenced by background variables (e.g., sociodemographic factors of caregiver and care recipients). In turn, caregiver burden is expected to influence outcomes such as depression and anxiety directly. Additionally, caregiver burden is expected to indirectly influence outcomes via secondarily role strains (e.g., job-caregiving conflict) and secondary intrapsychic strains (e.g., mastery). Different outcomes experienced by caregivers are explained by coping and social support (Chappell & Reid, 2002). The Stress Process Model is shown in Figure 3.

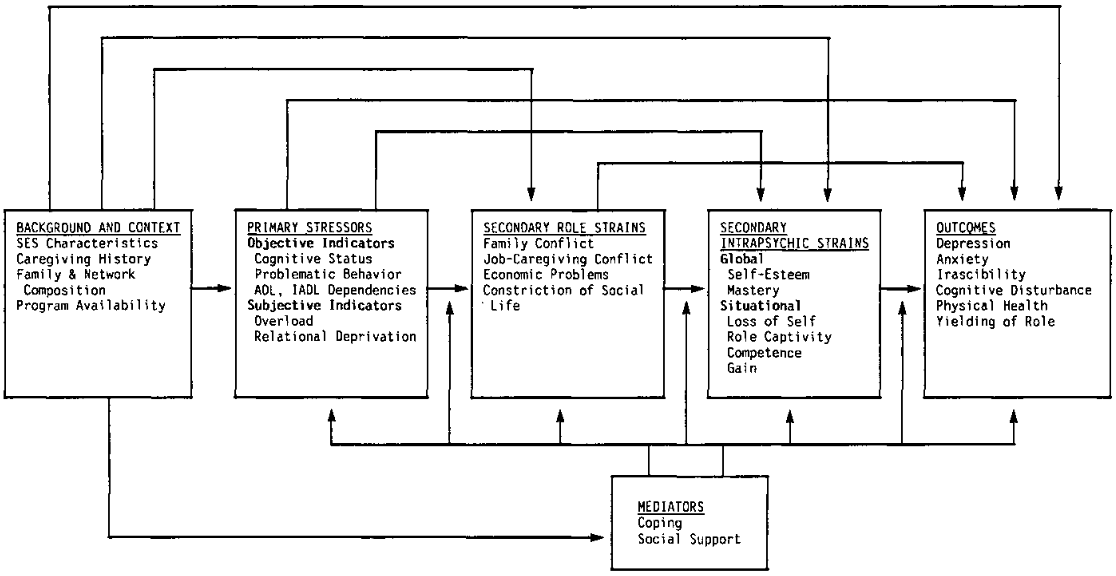


Figure 3. The Stress Process Model of Pearlin et al. (1990).
*Source: Pearlin et al. (1990). Caregiving and the stress process: an overview of concepts and their measures. *The Gerontologist*, 30(5), 583–94.

Conde-Sala et al. (2010) incorporated the studies of Pearlin et al. (1990) and Schulz and Martire (2004) into a theoretical framework and intervention that aims to highlight the multidimensional nature of predictors of caregiver burden and related interventions. According to Conde-Sala et al. (2010), caregiver burden is one of the symptoms experienced by those who care for persons with Alzheimer's disease (Conde-Sala et al., 2010).

Kim et al. (2012) modified the theoretical framework of Conde-Sala et al. (2010). According to the modified model, caregiver burden is influenced by 1) Contextual variables include socio-demographic factors of care recipients, socio-demographic factors of caregivers, and caregiving-related factors, 2) Primary stressors include patient symptomatology and disease progressions, and 3) Secondary stressors include family conflicts, difficulties at work, and financial difficulties.

Social support, social resources, treatments, and interventions are expected to alleviate the burden experienced by caregivers (Kim et al., 2012). Therefore, Conde-Sala et al. (2010) support the importance of looking into variables associated with the care recipients and caregivers when researching factors that account for caregiver burden among caregivers of persons with Alzheimer's disease. However, they indicated that variables associated with caregivers have more decisive influence on caregiver burden than variables associated with the patients (Conde-Sala et al., 2010; Kim et al., 2012). The Stress Process Model of Conde-Sala et al. (2010) is shown in Figure 4.

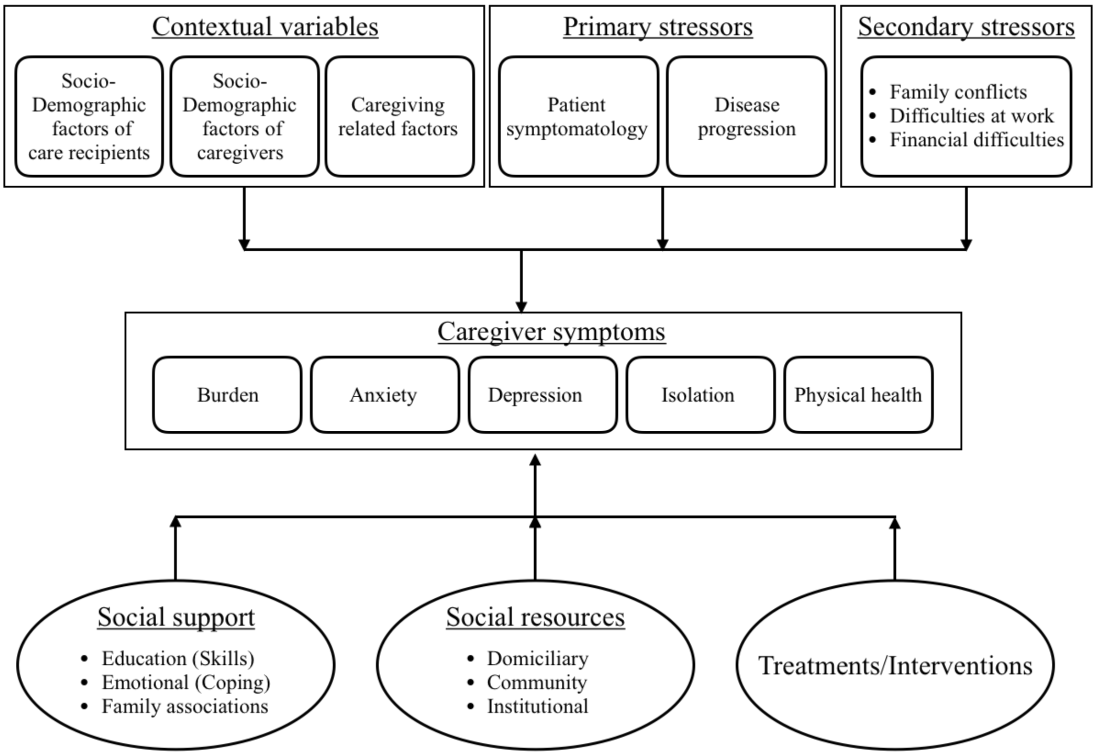


Figure 4. The Stress Process Model of Conde-Sala et al. (2010).
*Source: Kim, H., Chang, M., Rose, K., & Kim, S. (2012). Predictors of caregiver burden in caregivers of individuals with dementia. *Journal of Advanced Nursing*, 68(4), 846–55. https://doi.org/10.1111/j.1365-2648.2011.05787.x

Determinants of Caregiver Burden

A determinant is a term that has been used in literature to refer to a factor that accounts for variance in caregiver burden (Abdollahpour et al., 2012; Campbell et al., 2008; Lindt et al., 2020; Park et al., 2015). Identifying factors that account for variation in caregiver burden among caregivers of persons with Alzheimer’s is essential for minimizing the deleterious consequences of caregiver burden on informal caregivers and care recipients, personalizing support and intervention for caregivers, and enhancing the quality of caregiving (Kim et al., 2012; Rodríguez-González et al., 2021; Scott, 2013).

This researcher found no studies that identified care recipient or caregiver factors that account for variance in caregiver burden among informal caregivers of persons with Alzheimer’s in Saudi Arabia. However, researchers in the United States and worldwide have identified several factors that contribute to Alzheimer’s caregiver burden. For instance, Kim and Park (2019) categorized factors accounting for variance in Alzheimer’s caregiver burden into care recipients and caregiver factors (Kim & Park, 2019).

First: Care Recipient Characteristics as Factors of Caregiver Burden

Care recipient factors can be grouped into socio-demographic, psychological, and disease-related factors (Chiao et al., 2015).

1. **Socio demographic factors:** Levels of education for care recipients have been found to account for variation in caregiver burden. There is a relationship between caring for persons with Alzheimer’s with low levels of education and increased caregiver burden. A possible explanation for this finding is that caregivers need to assess care recipient needs which requires clear communication. Caregivers of persons with a low level of education may experience difficulty communicating with the patients, which may increase the burden (Chiao et al., 2015 & Fried et al., 2005). A significant correlation has also been found between a high level of caregiver burden and caring for persons with Alzheimer’s who are at least 80 years old (Rodríguez-González et al., 2021).
2. **Psychological factors:** Functional status, the prevalence of behavioral disturbances, and levels of neuropsychiatric symptoms have been found to contribute to caregiver burden. There is a direct association between a high level of caregiver burden and caring for persons with Alzheimer’s with a high prevalence of behavioral problems, and a high level of neuropsychiatric symptoms (Chiao et al., 2015; Kim & Park, 2019; Reed et al., 2020; Rodríguez-González et al., 2021).

3. **Disease-related factors:** The severity, type, and duration of the illness have been identified as predictors of caregiver burden. There is a relationship between a high level of caregiver burden and caring for persons with severe Alzheimer’s and a long duration of the illness (Chiao et al., 2015 & Kim & Park, 2019). There is also an association between caregiver burden and caring for persons with Alzheimer’s with low well-being (Lethin et al., 2020).

Second: Caregivers Characteristics as Factors of Caregiver Burden

Researchers have classified caregivers factors that account for variation in caregiver burden into three groups: socio-demographic, psychological, and caregiving-related factors (Chiao et al., 2015).

1. **Socio-demographic factors**: Income level, gender, age, educational levels, living with the care recipient, ethnicity, and relationship with the care recipients have been identified as predictors of caregiver burden. Female caregivers are more likely to experience caregiver burden compared to male caregivers. Caregivers with low income are at increased risk of increased caregiver burden than those with a high-income level. Caregivers with low educational levels are more likely to report a care burden than those with higher educational levels. This is because the low educational level of caregivers is negatively influencing health literacy in Alzheimer's care. Living with the care recipient has been associated with caregiver burden. Compared to other ethnic groups, non-Hispanic Caucasian caregivers are more likely to report a high caregiver burden. There is also an association between being an adult or older adult caregiver and being a spouse or adult-child caregiver and a high caregiver

burden (Almeida et al., 2019; Chiao et al., 2015; Häikiö et al., 2020; Tsai et al., 2021). Generally, the caregiver burden is higher among adult-child caregivers than among spouse caregivers (Conde-Sala et al., 2010). Caregivers with poor health status are also expected to experience a high caregiver burden than those with better health status. There is also an association between being an unemployed caregiver and experiencing caregiver burden (Rodríguez-González et al., 2021; Socci et al., 2021).

2. **Psychological factors:** Mental health status, the prevalence of depressive symptoms, level of religious coping skills, the degree of self-sufficiency for symptom management, and levels of anxiety, aggression, and authoritarianism have been identified as predictors of caregiver burden. There is a predictive relationship between caregiver burden and poor mental health, high prevalence of depressive symptoms, spiritual struggle, low self-sufficiency for symptom management, severe anxiety, high aggressive behavior, and high authoritarianism of caregivers (Chiao et al., 2015 & Kim & Park, 2019).
3. **Caregiving-related factors:** Caregiving load and level of family function have been found to account for variation in caregiver burden. There is a significant relationship between caregiver burden, a heavy caregiving load, and poor family functioning (Chiao et al., 2015). Additionally, duration of care and coping strategies have been identified as predictors of caregiver burden. Caring for persons with Alzheimer's for a long time and not using positive coping strategies, such as exercising and talking to a professional counselor, are associated with higher caregiver burden (Kim et al., 2012; Kim & Park, 2019). The level of care provision and perception of quality

of formal care provided to persons with Alzheimer's have been associated with caregiver burden. Informal caregivers who devote more hours of care and negatively perceive the quality of formal care provided to their care recipients report higher caregiver burden (Lethin et al., 2020 & Park et al., 2018). The well-being of caregivers has also been defined as a predictor of caregiver burden. Informal caregivers with diminished well-being negatively impact caregiving competence and experience, which is associated with a high caregiver burden (Quinn et al., 2019; Lethin et al., 2020).

Best Predictor Factors of Caregiver Burden

Researchers in the US and worldwide have studied multidimensional predictors of caregiver burden and identified the most significant predictors of caregiver burden. Conde-Sala et al. (2010) argued that caregiver factors have more decisive effects on caregiver burden than care recipient factors (Conde-Sala et al., 2010). However, Kim et al. (2011) found that disease-related factors (e.g., the functional decline of care-recipients) are the most significant predictors that explain differences in caregiver burden, followed by caregiver socio demographic factors (co-residence, spousal status, and gender), and caregiving related factors (number of hours of caregiver and the use of positive coping strategies, such as praying and looking for helpful information (Kim et al., 2012).

Van der Lee et al. (2014) found that behavioral difficulties of care recipients contribute to caregiver burden more than cognitive disorders and lack of ability to self-care. Caregiver’s competencies (e.g., feeling competent and having higher self-efficacy), positive coping styles (e.g., emotional disclosure and positive thinking), and personality traits (e.g., extraversion and agreeableness) are the best factors that predict decreased caregiver burden. Neuroticism and higher expressed emotion (e.g., anger and hostility) are the best factors that predict increased caregiver burden (Van der Lee et al., 2014).

Kim and Park (2019) identified problematic behavior followed by cognitive impairment, severe stage of the disease, and lack of ability to perform daily life functions as the most decisive care recipient factors associated with increased caregiver burden. Well-being (low) followed by relationship (unhealthy) with the care recipient, educational level (low), length of caring (spend longer time), level of income (low), age (older), occupational status (unemployed), and religion (none) have been identified as the most decisive caregiver factors associated with increased caregiver burden (Kim & Park, 2019). Lindt et al. (2020) also found that time of caring (spend longer time), the dependency of the care recipient (high dependency), gender of caregiver (female), and kinship with the care recipient (child) are the most significant factors that explain caregiver burden (Lindt et al., 2020).

Consequences of Caregiver Burden

Consequences are the factors found in the literature resulting from caregiver burden (Walker & Avant, 2005). Researchers in the US have found that caregiver burden has consequences for both caregivers and care recipients (Bastawrous, 2013; Mittleman et al., 2007; Pearlin et al., 1990; Thornton et al., 2004; Winslow, 1997). For instance, Liu et al. (2020) categorized the consequences of caregiver burden on caregivers and their care recipients into three dimensions:

1. **A decrease in care quality**: a reduction in the quality of care provided to care recipients occurs when caregivers experience caregiver burden without appropriate emotional support and resources. It can be explained by research evidence that the quality of care for care recipients is

influenced by the physical and mental status of caregivers and their perception of the care recipients' condition (Liu et al., 2020).

2. **A decrease in quality of life:** there is an association between caregiver burden and decreased quality of life of caregivers. Caregivers who experience caregiver burden have limited time to attend to their own needs and perform their daily activities, negatively impacting their quality of life. The effect of caregiver burden on caregivers' quality of life differs depending on the stage of the disease. Decreasing caregiver burden would enhance their quality of life (Liu et al., 2020).
3. **A decline in physical and psychological health:** caregivers spend a significant time and effort caring for their care recipients, which leads them to neglect to devote time to caring for themselves even when they are sick. Because of the lack of time in caring for themselves, caregivers experience several health issues (e.g., heart problems, hypertension, and physical fatigue) and several psychological problems (e.g., depression, anger, anxiety, and guilt;) (Liu et al., 2020).

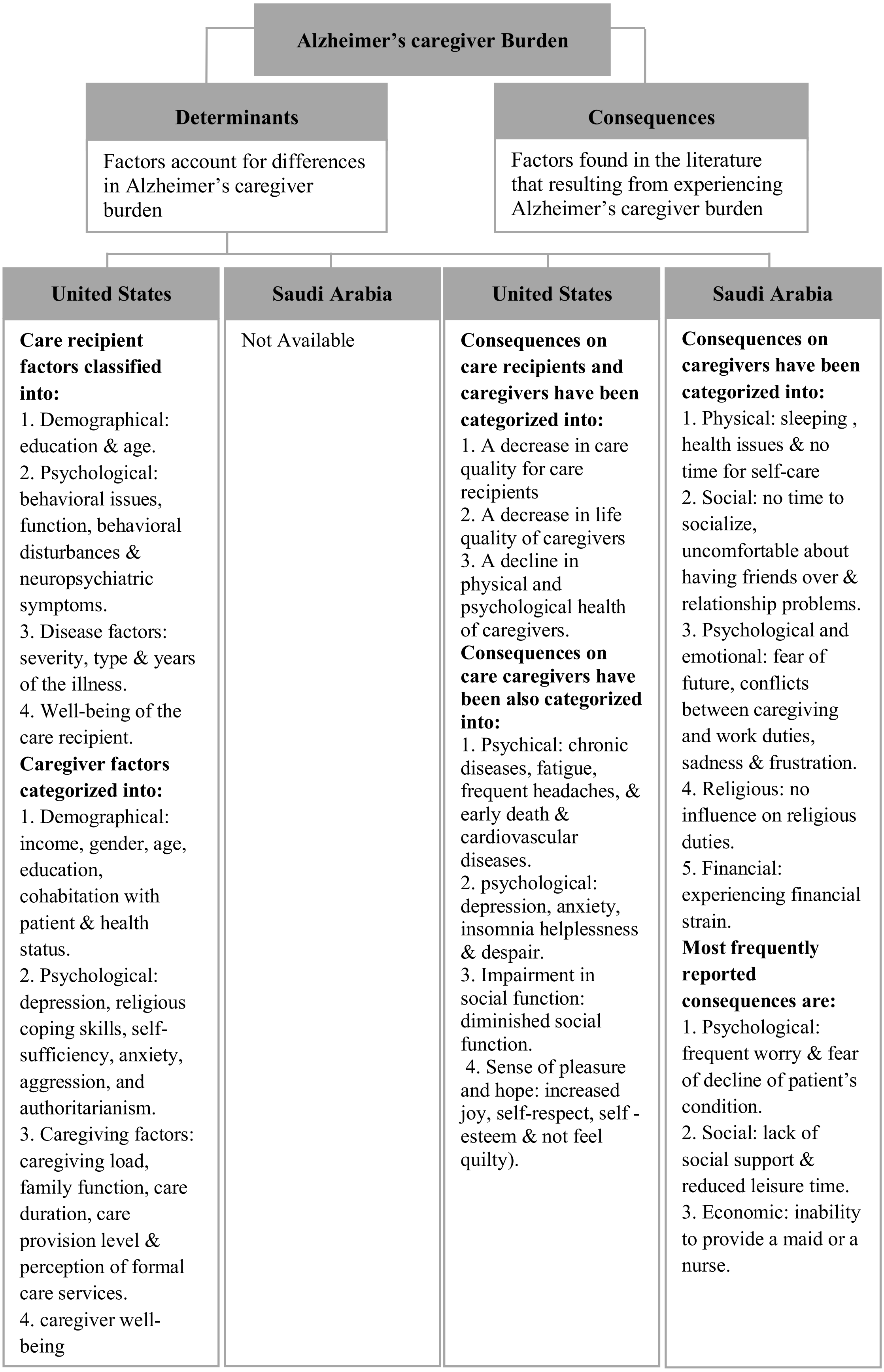
Ghezeljeh et al. (2020) categorized consequences of caregiver burden among caregivers of individuals with Alzheimer’s into four dimensions:

1. **The physical disease of caregivers:** Caregivers who experience a high caregiver burden are more likely to develop chronic diseases, have physical problems, and experience fatigue. They are also at increased risk of developing cardiovascular diseases and experiencing frequent headaches and nausea. Caregivers who experience increased caregiver burden are also at high risk of mortality (Ghezeljeh et al., 2020).

2. **The psychological disease of caregivers:** Increased caregiver burden might lead to depression, anxiety, helplessness, insomnia, despair, a sense of loneliness, and aggressive behaviors (Ghezeljeh et al., 2020).
3. **Impairment in social function:** Diminished social function is common among caregivers who experience caregiver burden. It is due to relationship disruptions among patients and families, a sense of loneliness, increased obligations and workload, the occurrence of problems related to domestic affairs, losing friends, quitting job, and reduced time for daily activities for a long time (Ghezeljeh et al., 2020).
4. **Sense of pleasure and hope**: despite the negative consequences, caring for persons with Alzheimer's may bring joy and hope for caregivers and make them feel that they have done the right thing and should not feel guilty. Caregiving may also increase self-respect, improve self-esteem, and result in personal adequacy and a sense of assurance (Ghezeljeh et al., 2020).

Researchers in Saudi Arabia also reported several consequences of caregiver burden on caregivers of persons with Alzheimer's. Almoajel et al. (2019) found that caregivers of persons with Alzheimer's faced physical, emotional, psychological, social, religious, and financial consequences of caregiver burden. Regarding physical consequences, caregivers have experienced sleeping difficulty, health problems, and limited time for self-care. Regarding psychological and emotional consequences, caregivers have experienced fear of the future, conflicts between caring for their relatives and meeting family or work responsibilities, and sadness and frustration (Almoajel et al., 2019). Regarding social consequences, caregivers indicated that they have been uncomfortable about having friends over, have experienced relationship problems with other relatives and friends, and have found no time to socialize due to caregiving duties. In terms of financial consequences, caregivers reported experiencing financial strain due to caring for their relatives in addition to the rest of their expenses. Regarding religious consequences, most caregivers considered caregiving a religious duty, and it did not influence their performance in the worship (Almoajel et al., 2019).

Alduaij (2018) has found that the most frequently reported consequences of caregiver burden by Saudi caregivers are psychological consequences, followed by social consequences and economic consequences. The most commonly reported psychological consequences are a constant worry for the care recipient and fearing deterioration of the care recipient’s condition. The most frequently reported social consequences are the lack of social support from community institutions and reduced leisure time due to caregiving duties. The most commonly reported economic consequence is the inability to provide a maid or nurse to care for the patient (Alduaij, 2018). A summary of findings on American and Saudi literature related to the determinants and consequences of Alzheimer’s caregiver burden is presented in Figure 5



Alzheimer's caregiver Burden

Determinants

Factors account for differences in Alzheimer's caregiver burden

Consequences

Factors found in the literature that resulting from experiencing Alzheimer's caregiver burden

United States	Saudi Arabia	United States	Saudi Arabia
Care recipient factors classified into: 1. Demographical: education & age. 2. Psychological: behavioral issues, function, behavioral disturbances & neuropsychiatric symptoms. 3. Disease factors: severity, type & years of the illness. 4. Well-being of the care recipient. **Caregiver factors categorized into:** 1. Demographical: income, gender, age, education, cohabitation with patient & health status. 2. Psychological: depression, religious coping skills, self-sufficiency, anxiety, aggression, and authoritarianism. 3. Caregiving factors: caregiving load, family function, care duration, care provision level & perception of formal care services. 4. caregiver well-being	Not Available	**Consequences on care recipients and caregivers have been categorized into:** 1. A decrease in care quality for care recipients 2. A decrease in life quality of caregivers 3. A decline in physical and psychological health of caregivers. **Consequences on care caregivers have been also categorized into:** 1. Psychical: chronic diseases, fatigue, frequent headaches, & early death & cardiovascular diseases. 2. psychological: depression, anxiety, insomnia helplessness & despair. 3. Impairment in social function: diminished social function. 4. Sense of pleasure and hope: increased joy, self-respect, self - esteem & not feel quilty).	**Consequences on caregivers have been categorized into:** 1. Physical: sleeping , health issues & no time for self-care 2. Social: no time to socialize, uncomfortable about having friends over & relationship problems. 3. Psychological and emotional: fear of future, conflicts between caregiving and work duties, sadness & frustration. 4. Religious: no influence on religious duties. 5. Financial: experiencing financial strain. **Most frequently reported consequences are:** 1. Psychological: frequent worry & fear of decline of patient's condition. 2. Social: lack of social support & reduced leisure time. 3. Economic: inability to provide a maid or a nurse.

Figure 5. A Summary of Findings on American and Saudi Literature Related to Consequences and Determinants of Alzheimer's Caregiver Burden.

Key Findings of the Review of the Current Literature in Alzheimer’s Caregiver burden and the Remaining Questions

This review aimed to summarize Alzheimer’s disease research literature in Saudi Arabia and the United States, particularly research studies addressing caregiver burden among informal caregivers caring for those with Alzheimer’s disease. The key findings are summarized as follows. Caregiving can be a rewarding experience for informal caregivers that increases their sense of personal achievement and life satisfaction, personal growth and purpose in life, mutuality between caregivers and care recipients, and improves family unity and functionality (Galvin et al., 2020). Nevertheless, caregiving can be a demanding and frustrating process that increases the probability of experiencing caregiver burden (Alzheimer’s Association, 2021; Christakis & Allison, 2006; Lwi et al., 2017; Ma et al., 2018; Perkins et al., 2013).

Caregiver burden has been defined as the level of physical, mental, emotional, social, and financial strains experienced by an informal caregiver from providing regular care for a family member, relative, or friend (Liu et al., 2020). Caregiver burden has been considered as a dimension of caregiver well-being. Terms such as stress, distress, overload, tension, and burnout have been used in the literature to represent caregiver burden. Caregiver stress is the most common term that has been utilized in the literature to refer to the burden experienced by caregivers (Llanque et al., 2016).

Several conceptual frameworks have been used to define and explore Alzheimer’s caregiver burden. Examples include the theory of caregiving demands (Given et al.,1999), the two-factor model of caregiving appraisal and psychological well-Being (Lawton et al., 1991), the stress process model (Pearlin et al., 1990), and the modified stress process model (Conde-Sala et al., 2010 & Kim et al., 2012).

However, the stress process model of Pearlin et al. (1990), which has been modified by Conde-Sala et al. (2010), and Kim et al. (2012), is the most widely applied theoretical model in research studies related to Alzheimer's caregiver burden. Specifically, stress process models have been used to identify and explore possible predictors of Alzheimer's caregiver burden (Gérain & Zech, 2019; Kim et al., 201; Park et al., 2015;).

Caregiver burden has several consequences on care recipients and caregivers (Bastawrous, 2013; Mittleman et al., 2007; Pearlin et al., 1990; Thornton et al., 2005; Winslow, 1997). Examples of consequences of caregiver burden found in the US literature include a decrease in care quality provided to the care recipients, a reduction in life quality of caregivers, a decline in the physical and psychological health of caregivers, and diminished social function of caregivers (Ghezeljeh et al., 2020 & Liu et al., 2020). Examples of consequences of caregiver burden found in the Saudi literature are physical (e.g., sleeping, health issues & no time for self-care), social (e.g., no time to socialize, uncomfortable about having friends over & relationship problems), psychological and emotional (e.g., fear of future, conflicts between providing care and work duties, sadness & frustration), religious (e.g., no influence on religious duties), and financial (e.g., experiencing financial strain & inability to provide a maid or a nurse) (Almoajel et al., 2019 & Alduaij, 2018). While caregiver burden has several negative consequences on both care recipients and caregivers, some caregivers may experience a sense of pleasure and hope (e.g., increased joy, self-respect, self -esteem & not feeling guilty) (Ghezeljeh et al., 2020).

Several factors may account for variation in Alzheimer's caregiver burden. Researchers in the US have identified care recipient factors, such as low educational level, age (old age), high functional impairment, high prevalence of behavioral problems, high level of neuropsychiatric symptoms, severe Alzheimer's, long duration of the illness, and low well-being as factors that contribute to caregiver burden. Caregiver factors, such as gender (female), low-income level, low educational level, living with the patient, ethnicity (non-Hispanic Caucasian), age (young adulthood/old age), relationship with the patient (children/spouses), poor health status, poor mental health status, severe depression, spiritual struggle, low self-sufficiency, severe anxiety, aggressive behavior, high authoritarianism, heavy caregiving load, poor family functioning, caregiving for a long time, not using positive coping strategies, diminished well-being have been identified as factors that increase the likelihood of caregiver burden (Chiao et al., 2015; Kim & Park, 2019; Lethin et al., 2020; Reed et al., 2020; Rodríguez-González et al., 2021).

However, researchers in the United States have argued that caregiver factors are the factors that have more decisive effects on experiencing caregiver burden than care recipient factors (Conde-Sala et al., 2010). Other researchers have identified disease-related factors, followed by caregiver socio-demographic factors and caregiving-related factors, as the most significant predictors of caregiver burden (Kim et al., 2012). While care recipient, caregiver, and caregiving and disease-related factors account for differences in Alzheimer’s caregiver burden have been addressed in the US literature, no studies have explored this research area in Arabic countries, including in Saudi Arabia.

In the light of the estimated growth of the number of Saudi older adults aged 65 or older from 1.3 million in 2020 to 10 million by 2050 and the expected increase of the incidence of Alzheimer’s in the country, research that contributes to our understanding of the correlates of care burden and what factors contribute to variation in care burden is highly critical and needed (Amr et al., 2014; Abusaaq, 2015;; Abyad, 2016; Alamri, 2019; Batum et al., 2015 Khoja et al., 2018). Research studies in these areas are significant for many reasons. Alzheimer’s caregiver burden is a substantial factor for the decline of caregivers’ physical and mental health, economic difficulties, the decline in quality of life, reduction of quality of care for the care recipient, and the care recipients’ early death (Barbe et al., 2018; Llanque et al., 2016; Schulz et al., 2020; Stall et al., 2019). Thus, identifying factors that contribute to Alzheimer’s caregiver burden will assist in alleviating Alzheimer’s caregiver burden and preventing its adverse outcomes on caregivers and care recipients. Therefore, identifying factors that shape Alzheimer’s caregiver burden is significant not only for increasing the life quality of caregivers but the care recipient’s quality of life, as well (Dufournet et al., 2019; Fang & Yan, 2018; Gainey & Payne, 2006; Schulz et al., 2020; Stall et al., 2019; Toot et al., 2017; Wang et al., 2019).

Identifying factors that account for variation in Alzheimer's caregiver burden among Saudi informal caregivers is also relevant to social workers. Social workers will benefit from such knowledge and will be better able to identify those at high risk of Alzheimer's caregiver burden and provide them with the support they need. Recognizing which factors are more related to Alzheimer's caregiver burden will also assist social workers in utilizing culturally relevant research to detect Alzheimer's caregiver burden. Additionally, the knowledge generated from the current study will help social workers effectively assist informal caregivers of persons with Alzheimer's who are central to the well-being of the care recipients.

Also, researchers have suggested personalizing support and intervention to reduce Alzheimer’s caregiver burden (Conde-Sala et al., 2010). Therefore, identifying non-modifiable factors (e.g., age and gender) that account for variation in

Alzheimer’s caregiver burden will help social workers ensure the personalization of services, support, and intervention programs provided to informal caregivers of persons with Alzheimer’s. The identification of factors accounting for caregiver burden will also aid in developing policy and practice. The knowledge generated from the current research will also be used to inform healthcare professionals and social workers to advocate for services, programs, and policies that end or decrease the suffering of informal caregivers and their care recipients with Alzheimer’s in Saudi Arabia.

In Saudi Arabia, in contrast to the US, there has been scarce research on Alzheimer’s as a problem, Alzheimer’s caregiving, and Alzheimer’s caregiver burden experienced by informal caregivers of persons with Alzheimer’s (Abyad, 2017; Alamri, 2019; Bhalla et al., 2018; El-Metwally et al., 2019; El Masri et al., 2021; Karam & Itani, 2013; Kane et al., 2020). Moreover, no research focuses on identifying factors that account for variation in Alzheimer’s caregiver burden among Saudi informal caregivers. Thus, there is an urgent need to conduct studies in this area to shape adequate policy and social work practice for Saudi informal caregivers of persons with Alzheimer’s.

CHAPTER III

METHODOLOGY

Overview of the Chapter

The conceptual framework of the stress process model of Conde-Sala et al. (2010), which was used to guide the study, is explained in this chapter. Additionally, the research design for this study, including data collection elements, sampling techniques, study instruments, validity and reliability issues, and planned statistical analysis methods are discussed. The method applied to consider the ethical issues are also discussed in detail in this chapter.

Conceptual Framework

The study used the stress process model of Conde-Sala et al. (2010), which has been modified by Kim et al. (2012) to investigate factors that account for variance in Alzheimer's caregiver burden (Kim et al., 2012). The model was developed by Conde-Sala et al. (2010) via incorporating the stress studies of Pearlin et al. (1990) and Schulz and Martire (2004). The multidimensional nature of predictors of caregiver burden factors and interventions was highlighted in the model. Caregiver burden, anxiety, depression, isolation, and decline of physical health were treated as symptoms of caregiver stress. According to the model, caregiver burden is one of the symptoms of caregiver stress that is influenced by:

1. Contextual variables (socio-demographic factors of care recipients, socio-demographic factors of caregivers, and caregiving-related factors).

2. Primary stressors (patient symptomatology and disease progression).
3. Secondary stressors (family conflicts, difficulties at work, and financial difficulties).

Therefore, this study used the modified stress process model of Conde-Sala et al. (2010) to explore the ability of contextual variables (sociodemographic factors of care recipients, sociodemographic factors of caregivers, and caregiving related factors), a primary stressor factor (disease progression), and caregiver's well-being to account for variance in caregiver burden among caregivers of persons with Alzheimer's in Saudi Arabia. Other factors that may account for variation in experiencing Alzheimer's caregiver burden, such as secondary stressors (family conflicts, difficulties at work, and financial difficulties), were not included in this study to reduce the amount of time required for completing the survey.

Acquiring information on the primary stressor (patient symptomology) by patient self-report can be problematic since a significant percentage of care recipients with Alzheimer's may have mental problems that make it difficult or impossible for them to answer the study survey accurately (Rodríguez-González et al., 2021). Using proxy ratings (caregivers, nurses, and physicians) in this matter may not be feasible since some proxy raters may overestimate or underestimate patients' symptoms (Loewenstein et al., 2001; Puntillo et al., 2012; Roydhouse et al., 2021; Römhild et al., 2018).

To avoid these problematic issues, this study did not explore symptomology as a factor that may account for differences in caregiver burden. Lastly, other caregiver symptoms (Anxiety, depression, isolation, and physical health) and the effectiveness of social support, social resources, and treatment/treatment to alleviate caregiver symptoms were not explored since this study was devoted to exploring factors that account for differences in caregiver burden. The focused areas of the study are highlighted in the model shown in Figure 6.

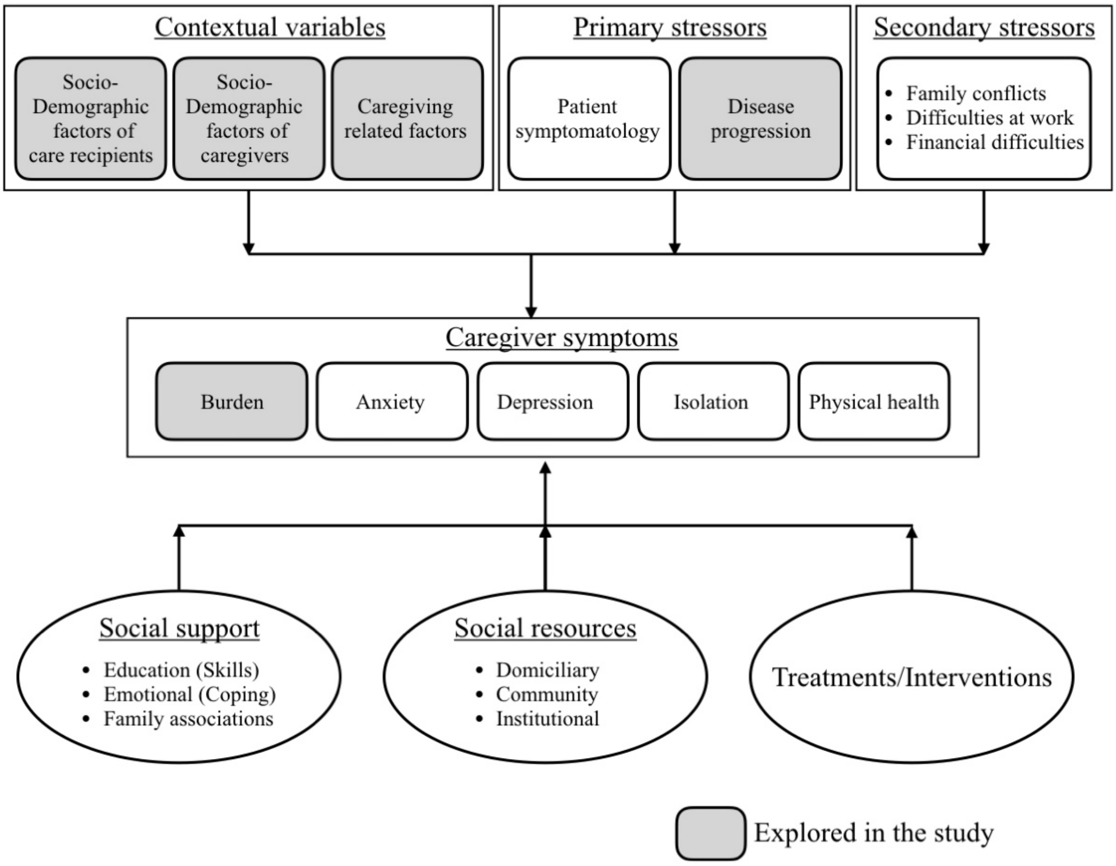


Figure 6. The Modified Stress Process Model of Conde-Sala et al. (2010)
*Source: Kim, H., Chang, M., Rose, K., & Kim, S. (2012). Predictors of caregiver burden in caregivers of individuals with dementia. Journal of Advanced Nursing, 68(4), 846–55. https://doi.org/10.1111/j.1365-2648.2011.05787.x

Research Design

This study is non-experimental, particularly a cross-sectional correlation design with primary data collection using self-reported online surveys. This method has been used to answer the research questions for this type of study in the United States and worldwide (Kim et al., 2012; Lethin et al., 2020; Park et al., 2015; Rodríguez-González et al., 2021; Tsai et al., 2021). Therefore, this method is suitable for this type of study since no methodologically sound research has examined factors that account for variation in Alzheimer's caregiver burden in Saudi Arabia. Therefore, this study will be conducted using a quantitative research method to answer the following questions formulated to determine the association between specific factors and Alzheimer's caregiver burden and assess the ability of a set of factors to account for variation in Alzheimer's caregiver burden.

Research Questions

1. What is the relationship between the contextual variables related to the care recipient socio-demographic factors (age, gender, and educational level) and caregiver burden?
2. What is the relationship between the contextual variables related to the caregiver socio-demographic factors (age, gender, educational level, marital status, employment status, income level, Living with the care recipient, and relationship with the care recipient) and caregiver burden?
3. What is the relationship between the contextual variables related to the caregiving-related factors (hours of care per week and caregiver perception of formal care) and caregiver burden?
4. What is the relationship between the primary stressor (stage of AD) and caregiver burden?
5. What is the relationship between caregiver's well-being and caregiver burden?
6. How can care recipient factors, including contextual variables related to the care recipient socio-demographic factors (age and educational level) and the primary stressor (stage of AD), contextual variables related to the caregiver socio-demographic factors (age, educational level, marital status, employment status, income level, living with the care recipient, and

relationship with the care recipient), contextual variables related to the caregiving-related factors (hours of care per week and caregiver's perception of formal care), and caregiver's well-being account for variation in caregiver burden?

Data Collection Procedures

The survey administration and its methodology used elements of the Social Media Networks Method proposed by Kayam and Hirsch (2012) to enhance response rates and survey completion, which are explained below.

1. An online-based survey using the free of charge Google Forms tool (docs.google.com) was designed to gather survey data through an electronic device (e.g., iPad, computer, or smartphone) that connects to the internet. Respondents accessed a smartphone, tablet, computer, or other suitable devices to complete the survey. In addition to its online availability, Google Forms is an attractive and user-friendly tool for conducting a survey with no affiliation with any website and requires no login information from respondents. Thus, potential respondents can access the survey with an invitation link without revealing any identified information. Google Forms provided a method of assessing the visual appearance of the survey content for ensuring ADA compliance and accessibility. Google Forms offered enterprise-grade security features that include data encryption and continuous network monitoring with ISO27001 certification that is FedRAMP authorized to meet the highest standards for SaaS providers set by the U.S. Government.
2. A preamble that contains an explanation of study purpose, benefits and risks, and contact and background information on the researcher, study

committee, and the research institution was included on the first page of the survey. This provided respondents with an option to reach the researcher for additional questions or comments.

3. To reach informal caregivers of persons with Alzheimer's in Saudi Arabia, the researcher first reached the Saudi Alzheimer's Disease Association, which provides services and support to informal caregivers of persons with Alzheimer's. The researcher contacted the association via email and phone call and asked for their assistance in sharing the link for the self-report survey. Thus, potential respondents were recruited by invitation, embedding a single reusable link to the online survey.
4. To improve participation and ensure that the target sample is reached, the Saudi Alzheimer's Disease Association published the invitation on its official account on social media (WhatsApp) instead of (Twitter), which includes 330 caregivers of persons with AD.
5. The invitation was published once a week for four weeks to encourage joining the study. After clicking the link, respondents were sent to an initial page with the attached preamble. After reading the preamble, using the advance button at the bottom of the page to move to the first question marks respondents' consent to start the survey, including using and sharing study data outside Saudi Arabia. Respondents could start and stop their responses to complete the survey at another time. However, respondents must return to the previous link to reinitiate their responses in the survey. Once the survey is initiated, it takes approximately 5 minutes to complete.

6. Each page with questions and the initial page with the preamble contains an advance button that allows respondents to navigate the survey. This allowed the respondents to revisit questions and change their previous responses or advance if they decided not to respond to the questions presented.
7. The number of questions per page was varied depending on the wordiness of the questions and instructions presented to respondents. The ultimate goal of varying the number of questions that appear per page was to improve the clarity of the survey questions and reduce any unnecessary burden on respondents.

Sampling Techniques

The researcher conducted a cross-sectional study using self-reported online surveys to explore the ability of a set of factors to account for variation in Alzheimer's caregiver burden in a sample of Saudi informal caregivers. Unpaid informal caregivers who provide care for a family member, relative, and friends with Alzheimer's disease were invited to participate in the study who are between the ages of 18 to 65 years old through an invitation sent by the Saudi Alzheimer's Disease Association.

Unpaid informal caregivers often do not choose to take on the role of caregiver and lack the critical information and resources to deal with caregiving challenges; thus, they are more likely to experience increased caregiver burden than paid and professional caregivers (Alzheimer's Association, 2021; Brugnera et al., 2019; Shakiba et al., 2020). Therefore, paid and professional caregivers were excluded from the study. Children (individuals under 18) and older adults above 65 years old also provide care for persons with AD. However, they are not the focus of this study; thus, they were excluded from the study. Participating in the study requires access to the internet and a suitable device to complete the survey. Therefore, individuals with no access to the internet or suitable devices were excluded from the study. The aim was to recruit approximately 200 informal caregivers of persons with Alzheimer's disease, which are required to perform the planned statistical analyses. 184 informal caregivers submitted the self-reported online surveys.

Measures

Existing caregiver burden literature and consult with researchers and practitioners were used to design the study survey. The study variables were selected using the stress process model of Conde-Sala et al. (2010) and the current literature on Alzheimer's caregiver burden. Since research on Alzheimer's caregiver burden is scarce in Saudi Arabia, the present study variables can be used as baseline information and a reference for future studies. Other related variables to Alzheimer's caregiver burden will be included in future studies. Information regarding the collected data is provided in detail below.

Several different types of questions were utilized during the survey to gather certain types of data from respondents (See Appendix A for the English version and Appendix B for the Arabic version). General demographic questions were asked of respondents. Demographic questions consist of the care recipient's age (Number of years), gender (Female or Male), education (Number of completed years in formal education), stage of AD (Early stage, Middle stage, or Late stage), and caregiver's age (Number of years), gender (Female or Male), education (Number of completed years in formal education), marital status (Married, Single, Separated, Divorced, or Widowed) employment status (Employed or Unemployed), income (Monthly income by Saudi Riyal_ 1 US Dollar equals 3.75 Saudi Rials), living the care recipient (Live with the care recipient or Not live with the care recipient), relationship to the care recipient (Type of relationships, such as daughter, son, etc.), hours of care per week (Number of hours of care per week), and perception of formal care provided to the care recipients with Alzheimer's (Satisfied with formal care provided to the care recipient or Dissatisfied with the formal care provided to the care recipient).

Several standardized scales were included in the survey to assess caregiver burden and caregiver well-being thoroughly. The abridged Arabic version of the Zarit Burden Interview (ZBI-A; Bachner, 2013) was used to measure caregiver burden. An exploratory factor analysis of the ZBI-A supported the factor structure of the full ZBI Scale. Concurrent validity of the ZBI-A was supported by finding a significant negative correlation with caregiver well-being and a significant positive correlation with depression and emotional exhaustion (Bachner et al., 2013). The test-retest reliability of the ZBI-A was found to be 0.97, and the internal consistency was found to be $\alpha = 0.83$ (Alshammari et al., 2019).

The ZBI-A consists of 12 items about caregiver experience related to the relationships' burden, loss of control over life, finance, social and family life, and emotional well-being domains. The measure includes questions like "Do you feel strained when you are around your relative?" and "Do you feel you should be doing more for your relative?" Respondents are asked to rate the frequency of these experiences on a 5- point Likert scale from 0 (Never) to 4 (Nearly always), which are summed for a global score. Scores range between 0-48, with a 0-10 score representing no burden to mild burden, a 10-20 representing mild to moderate burden, and >20 score representing high burden (Bachner, 2013).

The Arabic version of the 5-item World Health Organization Well Being Index (WHO-5-A) for Sibai et al. (2009) will be used to assess the well-being of caregivers. The qualitative face validity was supported via extensive translation and pilot testing. Construct validity for the scale was tested and supported using a principal axis factor analysis method. The Kaiser–Meyer–Olkin (KMO) values of the scale were found to be range between 0.753 to 0.792 with significant levels of Bartlett's test of sphericity. The test-retest reliability and internal consistency reliability for the WHO-5-A were tested and were both found to be 0.877 (Abdulameer et al., 2019).

The WHO-5-A consists of five statements that assess both positive and negative aspects of well-being. These statements are associated with positive mood, vitality, and general interests. The measure includes statements like "I have felt cheerful in good spirits" and "My daily life has been filled with things that interest me." Respondents are asked to rate the frequency of these feelings in the last two weeks on a 6-point Likert scale from 0 (at no time) to 5 (all of the time), which are summed for a global score. Scores range between 0 to 25, with 0 representing worst possible and 25 representing best possible well-being. Percentage score ranges from 0 to 100 can be obtained by multiplying the raw score by 4. A 0 score represents the worst possible well-being while a 100 score represents the best possible well-being (Regional Office for Europe WHO, 1988).

Reliability and Validity of the Standardized Measures

The internal consistency of the Arabic version of the 5-item World Health Organization Well Being Index (WHO-5-A) and the abridged Arabic version of the Zarit Burden Interview (ZBI-A) was evaluated using Cronbach's alpha coefficient. The reliability analysis showed a Cronbach's alpha of 0.81 for WHO-5-A and a Cronbach's alpha of 0.88 for ZBI-A in this sample (Table 3), which is good (George & Mallery, 2003).

Table 3

The Cronbach's Alpha Reliability for the Standardized Measures

Measure	No. of Items	Cronbach's alpha	N of Cases
WHO-5-A	5	0.81	182
ZBI-A	12	0.88	182

The construct validity was evaluated by determining the correlation between the standardized measures (WHO-5-A and ZBI-A) and other variables they are expected to be correlated with.

1. **Construct validity of the WHO-5-A.** Well-being has been significantly associated with caregiver burden (Schumann et al., 2019; Srivastava et al., 2016; Dawood, 2016). Therefore, the researcher hypothesized that there would be a significant relationship between the caregiver's well-being (measured by WHO-5-A) and the caregiver burden. A Pearson r coefficient was calculated to determine the relationship between WHO-5-A and caregiver burden —see SPSS results in Table 4. The hypothesis was supported, indicating a significant relationship between the WHO-5-A and the caregiver burden (r = -0.637, P = < .001). Thus, the WHO-5-A measures the underlying construct that it is supposed to measure.

Table 4

Correlations

		TotalWHO_5Score	CaregiverBurdenScore
TotalWHO_5Score	Pearson Correlation	1	-.637**
	Sig. (2-tailed)		<.001

	N	182	182
CaregiverBurdenScore	Pearson Correlation	-.637**	1
	Sig. (2-tailed)	<.001	
	N	182	182

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

The Results for the Relationship between WHO-5-A and Caregiver Burden

2. **Construct validity of the ZBI-A.** Caregiver burden has been significantly associated with the duration of care (Kim et al., 2012; Kim & Park, 2019). Therefore, the researcher hypothesized that there would be a significant relationship between the caregiver burden (measured by ZBI-A) and the hours of care per week. A Point-biserial correlation coefficient was calculated to determine the relationship between ZBI-A and the hours of care per week -see SPSS results in Table 5. The hypothesis was supported, indicating a significant relationship between the ZBI-A and the hours of care per week (^{r}pbi = -0.671, *P* = < .001). Thus, the ZBI-A measures the underlying construct that it is supposed to measure.

Table 5

The Results for the Relationship between ZBI-A and hours of care per week

Correlations			
		TotalZBI_AScore	Hoursofcareperweek
TotalZBI_AScore	Pearson Correlation	1	.671**
	Sig. (2-tailed)		<.001
	N	182	182
Hoursofcareperweek	Pearson Correlation	.671**	1
	Sig. (2-tailed)	<.001	
	N	182	182

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

Data Analysis

Descriptive statistics (Range, percentage, mean, standard deviation, and frequency) were used to describe the study sample and measures. The internal consistency of the standardized measures (the ZBI-A and the WHO-5-A) was evaluated using Cronbach's alpha coefficient. The construct validity was evaluated using correlational analyses between standardized measures and other variables they are expected to be correlated with. The correlations between ZBI-A scores and continuous variables were analyzed using the Pearson coefficient (*r*). The correlations between ZBI-A scores and categorical variables and those with a non-normal distribution were analyzed by using Point biserial, Phi/Cramer's V, or Eta correlation coefficients.

The ability of factors to account for variation in caregiver burden was tested using the hierarchical multiple linear regression. The care recipient factors including the contextual variables related to the care recipient socio-demographic factors (age, gender, and educational level) and the primary stressor (stage of AD) were entered into Block 1, followed by contextual variables related to the caregiver socio-demographic factors (age, educational level, marital status, employment status, income level, and living with the care recipient) in Block 2 and the contextual variables related to the caregiving-related factors (weekly hours of care and caregiver's perception of formal care) in the Block 3. The caregiver's well-being factor was entered into the Block 4. Assumptions of linearity, normality, homoscedasticity for the hierarchical multiple linear regression were assessed. Other factors that may impact the analysis, such as sample size, multicollinearity, and outliers, were also evaluated. Statistical analyses were conducted using SPSS version 28.0.1.

Ethical Considerations

The Saudi Alzheimer's Disease Association approved the study (See Appendix C) and the Institutional Review Board (IRB) at the University of Louisville (See Appendix D). A preamble that includes the nature and terms of the study appeared as the initial item in the online study survey. After reading the consent, participants were required to check a box at the bottom of the preamble stating the following, "I do not have any questions regarding the risks and benefits of the study, and by answering survey questions, I agree to participate in this study, including the use and sharing of study data outside Saudi Arabia." The data were encrypted and stored on an encrypted flash drive stored in a locked, secure location with careful protection on confidentiality. Only the researcher and the co-investigators have access to the data.

CHAPTER IV

RESULTS

Overview of the Chapter

Findings related to determinants of caregiver burden among 182 informal caregivers caring for individuals with Alzheimer's disease in Saudi Arabia are reported. Correlations between Alzheimer's caregiver burden and contextual variables (care recipient socio-demographics, caregiver socio-demographics, and caregiving-related factors), primary stressor (stage of AD), and caregiver's well-being are presented. Findings related to the ability of contextual variables, primary stressors, and caregiver's well-being to account for variation in Alzheimer's caregiver burden are also reported.

Survey Response Rate

The study entailed informal caregivers caring for individuals with Alzheimer's disease in Saudi Arabia. Using self-reported online surveys, respondents were asked to provide information on their care recipient's age, gender, educational level, stage of AD and caregiver's age, gender, educational level, marital status, employment status, income level, living with the care recipient, relationship with the care recipient, weekly hours of care, and perception of formal care for the care recipient. The abridged Arabic version of the Zarit Burden Interview (ZBI-A) was included in the online survey to assess caregiver burden, while the Arabic version of the 5-item World Health organization Well Being Index (WHO-5-A) was included to assess caregivers' well-being.

The Saudi Alzheimer's Disease Association published the self-reported online surveys on its official account on social media (WhatsApp), which includes 330 caregivers of persons with AD. A total of 184 online surveys were returned, resulting in a 55% response rate. Of those, two responses were excluded because the online questionnaire was returned empty. If respondents have not agreed to participate in the research, Google Forms returned their questionnaire empty. Thus, 182 responses were used to perform the final statistical analysis. Data inspection was performed to ensure data accuracy and avoid systematic bias when reporting findings. The data inspection included checking missing values, linearity, normality, homoscedasticity, sample size, multicollinearity, and outliers. Some of the study variables were recategorized based upon lack of representation in some of the initial groups (See Appendix E).

Overview of the Analytical Approach

Q1. What is the relationship between the contextual variables related to the care recipient socio-demographic factors (age, gender, and educational level) and caregiver burden?

Q2. What is the relationship between the contextual variables related to the caregiver socio-demographic factors (age, gender, educational level, marital status, employment status, income level, living with the care recipient, and relationship with the care recipient) and caregiver burden?

Q3. What is the relationship between the contextual variables related to the caregiving-related factors (hours of care per week and caregiver perception of formal care) and caregiver burden?

Q4. What is the relationship between the primary stressor (stage of AD) and caregiver burden?

Q5. What is the relationship between caregiver's well-being and caregiver burden?

Q6. How can care recipient factors, including contextual variables related to the care recipient socio-demographic factors (age and educational level) and the primary stressor (stage of AD), caregiver factors, including contextual variables related to the caregiver socio-demographic factors (age, educational level, marital status, employment status, income level, living with the care recipient, and relationship with the care recipient), contextual variables related to the caregiving-related factors (hours of care per week and caregiver's perception of formal care), and caregiver's well-being account for variation in caregiver burden?

Description of the Study Sample

The sample comprised 182 informal caregivers of persons with Alzheimer's disease in Saudi Arabia. The mean age of care recipients was 77.28 (SD =7.98), and ranged from 59 to 90 years. Over half were female (63.2%) and with no formal education (55.5%). Of those receiving care (57.7%) were in severe stage of AD while (42.3%) were in non-severe stage of AD. The mean age of caregivers was 43.88 (SD = 9.14), and ranged from 27 to 64 years. More than half were female (64.8%) and had 14 or more years of education (54.9%). Over half were married (53.3%) and employed (58.8%). The majority had an income less than 10000 Saudi Riyal per month (66.5%), live with their care recipients (58.2%), and spent 31 or more hours of care per week (52%). Of those who had a familial relationship with the care recipient (56.6%) were daughter of the care recipient and (43.4%) were other relatives. The majority (64.3%) were unsatisfied with the formal care provided to their loved ones with Alzheimer's. The mean caregiver well-being score was 13.75 (SD = 5.75), and ranged between 0 and 25. The mean caregiver burden score was 21.76 (SD = 10.41), and ranged between 4 and 46. The majority of caregivers reported high burden (46.7%), followed by moderate burden (42.9%), and mild burden (10.4%). The complete demographical profiles of the informal caregivers and their care recipients are shown in Table 6.

Table 6

Demographic Characteristics of Informal caregivers and their Care Recipients with Alzheimer's Disease

Variables	(*n* = 182)
Description of the persons with Alzheimer's (N = 182)	
Age (Years)	
Mean (*SD*)	77.28 (7.979)
Range	59-90
Gender, *n* (%)	
Female	115 (63.2)
Male	67 (36.8)
Educational level, *n* (%)	
Did not obtain any formal education	101 (55.5)
Obtained a formal education	81 (44.5)
Stage of AD, n (%)	
Non-severe stage	77 (42.3)
Severe stage	105 (57.7)
Description of the informal caregivers (*N* = 182)	
Age (Years)	
Mean (*SD*)	43.88 (9.140)
Range	27-64
Gender, *n* (%)	
Female	118 (64.8)
Male	64 (35.2)
Educational level, *n* (%)	
<14 years	82 (45.1)
≥14 years	100 (54.9)
Marital status, *n* (%)	
Non-married	85 (46.7)
Married	97 (53.3)
Employment status, *n* (%)	

Unemployed	75 (41.2)
Employed	107 (58.8)
Income level, *n* (%)	
<10000 Saudi Riyal per month	121 (66.5)
≥10000 Saudi Riyal per month	61 (33.5)
Living with the care recipient, *n* (%)	
Not living with the care recipient	76 (41.8)
Living with the care recipient	106 (58.2)
Hours of care per week, *n* (%)	
< 31 hours of care per week	86 (47.3)
≥ 31 hours of care per week	96 (52.7)
Relationship with the care recipient, *n* (%)	
A daughter of the care recipient	103 (56.6)
Other relatives	79 (43.4)
Perception of formal care for care recipient, *n* (%)	
Dissatisfied with the formal care for care recipient	117 (64.3)
Satisfied with the formal care for care recipient	65 (35.7)
Caregiver's well-being (Score)	
Mean (*SD*)	13.75 (5.747)
Range	0-25
Caregiver Burden (Score)	
Mean (*SD*)	21.76 (10.406)
Range	04-46
Burden Level level, *n* (%)	
(0-10) Mild burden	19 (10.4)
(10-20) Moderate burden	78 (42.9)
(>20) High burden	85 (46.7)

Correlation Analyses

Results of study questions (1 to 5) regarding correlations of contextual variables (care recipient socio-demographic factors, including age, gender, and educational level, caregiver socio-demographic factors, including age, gender, educational level, marital status, employment status, income level, living with the care recipient, and relationship with the care recipient, and caregiving-related factors, including hours of care per week and caregiver's perception of formal care), the primary stressor (stage of the AD), and caregiver's well-being to caregiver burden are presented below.

Study Question 1:

What is the relationship between the contextual variables related to the care recipient's socio-demographic factors (age, gender, and educational level) and Alzheimer's caregiver burden?

First Part of Question 1: What is the relationship between the care recipient's age and the caregiver burden?

Null: There is no relationship between the care recipient's age and the caregiver burden.

Predicted: There is a relationship between the care recipient's age and the caregiver burden.

A *Pearson r* coefficient was calculated to determine the relationship between the care recipient's age and the caregiver burden. The results indicated that there was a highly significant strong positive correlation between the care recipient's age and the caregiver burden ($r = .658$, $P = < .001$). Thus, the null hypothesis of no relationship between the care recipient's age and the caregiver burden was rejected and the alternative hypothesis was accepted.

Second Part of Question 1: What is the relationship between the care recipient's gender and the caregiver burden?

Null: There is no relationship between care recipient's gender and the caregiver burden.

Predicted: There is a relationship between care recipient’s gender and the caregiver burden.

A Point-biserial correlation coefficient was calculated to determine the relationship between the care recipient’s gender (1= Female, 2= Male) and the caregiver burden. The results indicated that there was a significant weak positive correlation between the care recipient’s gender and caregiver burden (${}^{r}pbis = 0.173$, $P = .019$). Thus, the null hypothesis of no relationship between the care recipient’s gender and the caregiver burden was rejected and the alternative hypothesis was accepted.

Third Part of Question 1: What is the relationship between the care recipient’s educational level and the caregiver burden?

Null: There is no relationship between the care recipient’s educational level and the caregiver burden.

Predicted: There is a relationship between the care recipient’s educational level and the caregiver burden.

A Point-biserial correlation coefficient was calculated to determine the relationship between the care recipient’s educational level (1= did not obtained any formal education, 2= Obtained formal education) and caregiver burden. The results indicated that there was a highly significant weak negative correlation between the care recipient’s educational level and the caregiver burden (${}^{r}pbis = -0.30$, $P = .<001$). Thus, the null hypothesis of no relationship between the care recipient’s educational level and the caregiver burden was rejected and the alternative hypothesis was accepted.

Study question 2:

What is the relationship between the contextual variables related to the caregiver's socio-demographic factors (age, gender, educational level, marital status, employment status, income level, Living with the care recipient, and relationship with the care recipient) and Alzheimer's caregiver burden?

First Part of Question 2: What is the relationship between the caregiver's age and the caregiver burden?

Null: There is no relationship between caregiver's age and the caregiver burden.

Predicted: There is a relationship between caregiver's age and the caregiver burden.

A *Pearson r* coefficient was calculated to determine the relationship between the caregiver's age and the caregiver burden. The results indicated that there was a highly significant moderate positive correlation between the caregiver's age and caregiver burden (r = 0.416, P = .<001). Thus, the null hypothesis of no relationship between the caregiver's age and the caregiver burden was rejected and the alternative hypothesis was accepted.

Second Part of Question 2: What is the relationship between the caregiver's gender and the caregiver burden?

Null: There is no relationship between caregiver's gender and the caregiver burden.

Predicted: There is a relationship between caregiver's gender and the caregiver burden.

A Point-biserial correlation coefficient was calculated to determine the relationship between the caregiver's gender (1= Female, 2= Male) and the caregiver burden. The results indicated that there was a highly significant weak negative correlation between the caregiver's gender and caregiver burden ($^{r}pbis = -0.201$, $P = .007$). Thus, the null hypothesis of no relationship between the caregiver's gender and the caregiver burden was rejected and the alternative hypothesis was accepted.

Third Part of Question 2: What is the relationship between the caregiver's educational level and the caregiver burden?

Null: There is no relationship between the caregiver's educational level and the caregiver burden.

Predicted: There is a relationship between the caregiver's educational level and the caregiver burden.

A Point-biserial correlation coefficient was calculated to determine the relationship between the caregiver's educational level (1= Less than 14 years of education, 2= 14 or more years of education) and the caregiver burden. The results indicated that there was a highly significant moderate negative correlation between the caregiver's educational level and the caregiver burden ($^{r}pbis = -0.452$, $P = <.001$). Thus, the null hypothesis of no relationship between the caregiver's educational level and the caregiver burden was rejected and the alternative hypothesis was accepted.

Forth Part of Question 2: What is the relationship between the caregiver's marital status and the caregiver burden?

Null: There is no relationship between the caregiver's marital status and the caregiver burden.

Predicted: There is a relationship between the caregiver's marital status and the caregiver burden.

A Point-biserial correlation coefficient was calculated to determine the relationship between the caregiver's marital status (1= Non married, 2= Married) and the caregiver burden. The results indicated that there was a highly significant strong positive correlation between the caregiver's marital status and the caregiver burden ($^{r}pbis = 0.679$, $P = <.001$). Thus, the null hypothesis of no relationship between the caregiver's marital status and the caregiver burden was rejected and the alternative hypothesis was accepted.

Fifth Part of Question 2: What is the relationship between the caregiver's employment status and the caregiver burden?

Null: There is no relationship between the caregiver's employment status and the caregiver burden.

Predicted: There is a relationship between the caregiver's employment status and the caregiver burden.

A Point-biserial correlation coefficient was calculated to determine the relationship between the caregiver's employment status (1= Unemployed, 2= Employed) and the caregiver burden. The results indicated that there was a highly significant moderate postitive correlation between the caregiver's employment status and the caregiver burden ($^{r}pbis = 0.342$, $P = <.001$). Thus, the null hypothesis of no relationship between the caregiver's employment status and the caregiver burden was rejected and the alternative hypothesis was accepted.

Sixth Part of Question 2: What is the relationship between the caregiver's income level and the caregiver burden?

Null: There is no relationship between the caregiver's income level and the caregiver burden.

Predicted: There is a relationship between the caregiver's income level and the caregiver burden.

A Point-biserial correlation coefficient was calculated to determine the relationship between the caregiver's income level (1= Less than 10000 Saudi Riyal per month, 2= 10000 Saudi Riyal and above per month]) and the caregiver burden. The results indicated that there was a highly significant strong negative correlation between the caregiver's income level and the caregiver burden ($^{r}pbis$ = -0.549, P = <.001). Thus, the null hypothesis of no relationship between the caregiver's income level and the caregiver burden was rejected and the alternative hypothesis was accepted.

Seventh Part of Question 2: What is the relationship between the caregiver's living with the care recipient and the caregiver burden?

Null: There is no relationship between the caregiver's living with the care recipient and the caregiver burden.

Predicted: There is a relationship between the caregiver's living with the care recipient and the caregiver burden.

A Point-biserial correlation coefficient was calculated to determine the relationship between the caregiver's living with the care recipient (1=Not living with the care recipient, 2= Living with the care recipient) and the caregiver burden. The results indicated that there was a highly significant moderate positive correlation between the caregiver's living with the care recipient and the caregiver burden ($^{r}pbis$ = 0.294, P = <.001). Thus, the null hypothesis of no relationship between the caregiver's living with the care recipient and the caregiver burden was rejected and the alternative hypothesis was accepted.

Eighth Part of Question 2: What is the relationship between the caregiver's relationship with the care recipient and the caregiver burden?

Null: There is no relationship between the caregiver's relationship with the care recipient and the caregiver burden.

Predicted: There is a relationship between the caregiver’s relationship with the care recipient and the caregiver burden.

A Point-biserial correlation coefficient was calculated to determine the relationship between the caregiver’s relationship with the care recipient (1= A daughter of the care recipient, 2= Other relatives) and the caregiver burden. The results indicated that there was highly significant weak negative correlation between the caregiver’s relationship with the care recipient and the caregiver burden (${}^{r}pbis = -0.20$, $P = .007$). Thus, the null hypothesis of no relationship between the caregiver’s relationship with the care recipient and the caregiver burden was rejected and the alternative hypothesis was accepted.

Study question 3:

What is the relationship between the contextual variables related to the caregiving-related factors (hours of care per week and caregiver’s perception of formal care) and caregiver burden?

First Part of Question 3: What is the relationship between the hours of care per week and the caregiver burden?

Null: There is no relationship between the hours of care per week and the caregiver burden.

Predicted: There is no relationship between the hours of care per week and the caregiver burden.

A Point-biserial correlation coefficient was calculated to determine the relationship between the hours of care per week (1=Less than 31 hours of care per week, 2= 31 or more hours of care per week) and the caregiver burden. The results indicated that there was a highly significant strong positive correlation between the hours of care per week and the caregiver burden (${}^{r}pbis = 0.690$, $P = <.001$). Thus, the null hypothesis of no relationship between the hours of care per week and the caregiver burden was rejected and the alternative hypothesis was accepted.

Second Part of Question 3: What is the relationship between the caregiver's perception of formal care and the caregiver burden?

Null: There is no relationship between the caregiver's perception of formal care and the caregiver burden.

Predicted: There is a relationship between the caregiver's perception of formal care and the caregiver burden.

A Point-biserial correlation coefficient was calculated to determine the relationship between the caregiver's perception of formal care (1= Unsatisfied with the formal care, 2= Satisfied with the formal care) and the caregiver burden. The results indicated that there was a highly significant moderate negative correlation between the caregiver's perception of formal care and the caregiver burden ($^{r}pbis = -0.423$, $P = <.001$). Thus, the null hypothesis of no relationship between the caregiver's perception of formal care and the caregiver burden was rejected and the alternative hypothesis was accepted.

The summary of results of correlations analyses for questions 1 to 5 are shown in Table 7. Appendix F shows all results of the correlational analyses for questions one, two, three, four, and five.

Study question 4:

What is the relationship between the primary stressor (stage of AD) and caregiver burden?

Null: There is no relationship between the stage of AD and the caregiver burden.

<u>Predicted:</u> There is a relationship between the stage of AD and the caregiver burden.

A Point-biserial correlation coefficient was calculated to determine the relationship between the stage of AD (1= Non-severe stage, 2= Severe stage) and the caregiver burden. The results indicated that there was a highly significant moderate positive correlation between the caregiver's the stage of AD and the caregiver burden ($^{r}pbis = 0.365$, $P = <.001$). Thus, the null hypothesis of no relationship between the stage of AD and the caregiver burden was rejected and the alternative hypothesis was accepted.

Study question 5:

What is the relationship between caregiver's well-being and Alzheimer's caregiver burden?

<u>Null:</u> There is no relationship between the caregiver's well-being and the caregiver burden.

<u>Predicted:</u> There is a relationship between the caregiver's well-being and the caregiver burden.

A Pearson r correlation coefficient was calculated to determine the relationship between the caregiver's well-being (Scores) and the caregiver burden. The results indicated that there was a significant strong negative correlation between the caregiver's well-being and the caregiver burden ($r = -.637$, $P = < .001$). Thus, the null hypothesis of no relationship between the caregiver's well-being and the caregiver burden was rejected and the alternative hypothesis was accepted.

<u>Table 7</u>

<u>Summary of Results of Correlations Analyses for Questions 1 to 5</u>

Variables	Caregiver Burden Score
Age_CR	r = .66, P = < .001
Gender_CR	$^{r}pbis$ = .17, P = .019
Educational level-CR	$^{r}pbis$ = -.30, P = < .001
Stage of AD	$^{r}pbis$ = .37, P = < .001
Age_CG	r = .42, P = < .001
Gender_CG	$^{r}pbis$ = -.20, P = .007
Educational level_CG	$^{r}pbis$ = -.45, P = <.001
Marital status_CG	$^{r}pbis$ = .68, P = <.001
Employment status_CG	$^{r}pbis$ = .34, P = <.001
Income level_CG	$^{r}pbis$ = -.55, P = <.001
Living with the care recipient _CG	$^{r}pbis$ = .29, P = <.001
Hours of care per week	$^{r}pbis$ = .69, P = <.001
Relationship with the care recipient	$^{r}pbis$ = -.20, P = .007
Caregiver’s perception of formal care	r = -.42, P = < .001
Caregiver’s well-being	r = -.64, P = < .001

CR = Care Recipient, CG = Caregiver, AD = Alzheimer’s Disease

Prediction Analyses

First: Results of Pre-Analyses

1.1 Missing Values:

No missing values were identified in the dataset for this study.

1.2 Selecting the most important predictors of caregiver burden (DV):

Table 7 shows that all 15 predictors variables (IVs) correlated significantly with caregiver burden (DV). Based upon these bivariate correlations, twelve predictors: care recipient’s age, care recipient’s educational level, stage of AD, caregiver’s age, caregiver’s educational level, caregiver’s marital status, caregiver’s employment status, caregiver’s income level, living with the care recipient, hours of care per week, caregiver’s perception of formal care, and caregiver's well-being had the highest correlations with caregiver burden (above 0.2). The other three predictors: the care recipient's gender, caregiver's gender, and the relationship with the care recipient, had the lowest correlations with caregiver burden (under 0.2).

To ensure the selection of the strongest predictors, a simple linear regression analysis was performed using each factor independently to account for variation in caregiver burden. Based on the linear regression results (Table 8), the twelve predictors (had the correlations with caregiver burden above 0.2) contributed significantly about 8% to 46% of caregiver burden. The other three predictors (had the correlations with caregiver burden under 0.2) contributed significantly only about 3% or 4% of caregiver burden. Based on the results of the bivariate correlations and the multiple linear regression, care recipient's age, care recipient's educational level, stage of AD, caregiver's age, caregiver's educational level, caregiver's marital status, caregiver's employment status, caregiver's income level, living with the care recipient, hours of care per week, caregiver's perception of formal care, and caregiver's well-being, which were the strongest predictors than the others were included in the hierarchical multiple regression analysis to enhance the prediction of caregiver burden. Although the care recipient's gender, caregiver's gender, and the relationship with the care recipient have been identified as possible factors that may account for variation in caregiver burden by the stress process model of Conde-Sala et al. (2010), they were dropped to enhance the prediction .

Table 8

Summary of Results of Simple Linear Regression Analyses for each Predictors

Predictors	R^2	*F* for

	Adjusted	R^2 Adjusted
Age_CR	0.43	137.51**
Gender_CR	0.03	5.57*
Educational level-CR	0.08	18.26**
Stage of AD	0.13	27.71**
Age_CG	0.17	37.64**
Gender_CG	0.04	7.54**
Educational level_CG	0.20	46.11**
Marital status_CG	0.46	154.20**
Employment status_CG	0.11	23.90**
Income level_CG	0.30	77.71**
Living with the care recipient _CG	0.08	17.06**
Hours of care per week	0.47	163.62**
Relationship with the care recipient	0.04	7.51**
Caregiver's perception of formal care	0.17	39.18**
Caregiver's well-being	0.40	122.94**

CR = Care Recipient, CG = Caregiver, AD = Alzheimer's Disease, $^*P < 0.05$, $^{**}P < 0.01$.

1.3 Checking the Assumptions of the Hierarchical Multiple Regression:

1.3.1 Sample size assumption:

Three predictors out of fifteen were dropped, driven by the results of the bivariate correlations and the linear regression analysis. As a rule of thumb, 15 cases per predictor is recommended to ensure enough power (Lawson et al., 2019). Twelve predictors were included in the multiple regression. Thus, at least 180 cases were required to meet the sample size assumption. There were 182 cases per predictor, and therefore this assumption has been met.

1.3.2 Outliers:

Casewise Diagnostics was used when running the multiple regression to detect outliers with three or more standard deviations away from the mean. No cases with extreme outliers were found.

1.3.3 Multicollinearity assumption:

Predictors should not highly correlate with each other (Lawson et al., 2019). A correlation matrix was constructed among all the study variables based on Pearson r, Point biserial or Phi/Cramer’s V correlation coefficients (Table 9) to check this assumption. The only high correlation (above 0.65) found between predictors was the correlation between caregiver’s gender and the relationship with the care recipient (0.82). The caregiver’s gender and the relationships with the care recipient predictors were dropped early to improve the prediction. After running the regression, the multicollinearity assumption was rechecked by looking at each predictor’s Variance Inflation Factors (VIF). VIF statistics for all predictors were less than 4, indicating no multicollinearity situation (Lawson et al., 2019).

Table 9

Results of Correlations among all Predictor Variables

	Caregiver Burden	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
1. Age_CR	0.66**	-														
2. Gender_CR	0.17*	0.18**	-													
3. Educational Level_CR	-0.30**	-0.20**	0. 10	-												
4. Stage of AD	0.37**	0.34**	0.08	-0.29**	-											
5. Age_CG	0.42**	0.39**	0.00	-0.17*	0.26**	-										
6. Gender_CG	-0.20**	-0.12	0.11	0.01	-0.02	-0.14*	-									
7. Educational level_CG	-0.45**	-0.40**	-0.06	0.01	-0.19**	-0.35**	0.16*	-								
8. Marital status_CG	0.68**	0.53**	0.22**	-0.20**	0.22**	0.31**	-0.16*	-0.33**	-							
9. Employment status_CG	0.34**	0.22**	0.15*	-0.17*	0.07	0.20**	0.03	-0.06	0.27**	-						
10. Income level_CG	-0.55**	-0.45**	-0.11	0.02	-0.22**	-0.22**	0.26**	0.34**	-0.48**	-0.16*	-					
11. Living with the CR	0.29**	0.29**	-0.00	-0.07	0.34**	0.20**	-0.05	-0.14*	0.08	0.02	-0.23**	-				
12. Relationship with the CR	-0.20**	-0.15*	0.16*	0.02	-0.08	-0.14*	0.82**	0.13*	-0.15*	-0.03	0.22**	-0.02	-			
13. Hours of care per week	0.69**	0.61**	0.22**	-0.15*	0.26**	0.33**	-0.32**	-0.50**	0.53**	0.24**	-0.52**	0.25**	-0.22**	-		
14. Perception of formal care	-0.42**	-0.33**	-0.05	0.09	-0.13	-0.17*	0.27**	0.24**	-0.28**	0.15*	0.23**	-0.09	0.27**	-0.31**	-	
15. Caregiver's well-being	-0.64**	-0.55**	-0.03	-0.25**	-0.26**	-0.37**	0.21**	0.34**	-0.52**	-0.09	0.45**	-0.31**	0.19	-0.56**	0.31**	-

* $p < 0.05$, ** $P < 0.01$, CR = Care Recipient , CG, Caregiver.

1.3.4 Homoscedasticity assumption:

This assumption was assessed by examining the scatterplot of the standardized residual values versus the predicted standardized values. The scatterplot in Figure 7 shows that the variation for each value of the study predictors and the amount of variability of predicted values is not about the same, indicating heteroscedasticity. Breusch-Pagan test was performed to ensure the presence of heteroscedasticity. The result was significant (<.001), indicating heteroscedasticity (Breusch & Pagan, 1979)

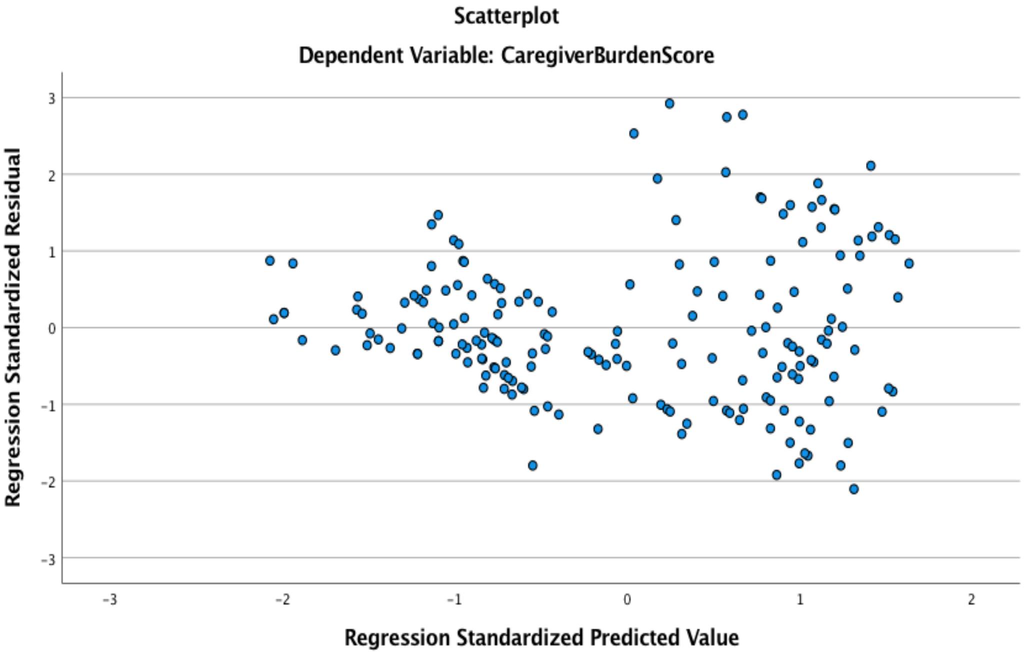


Figure 7. The Scatterplot of Standardized Residuals Versus the Predicted Values-1

To meet the assumption of homoscedasticity, the predicted variable (caregiver burden score) was transformed using log function to meet the assumption of homoscedasticity (Carroll et al., 1988). The scatterplot in Figure 8 shows that the variation for each value of the study predictors and the amount of variability of predicted values is about the same after this procedure, indicating homoscedasticity. Breusch-Pagan test was performed again to ensure the absence of heteroscedasticity. The result was insignificant (0.07), indicating homoscedasticity (Breusch & Pagan, 1979).

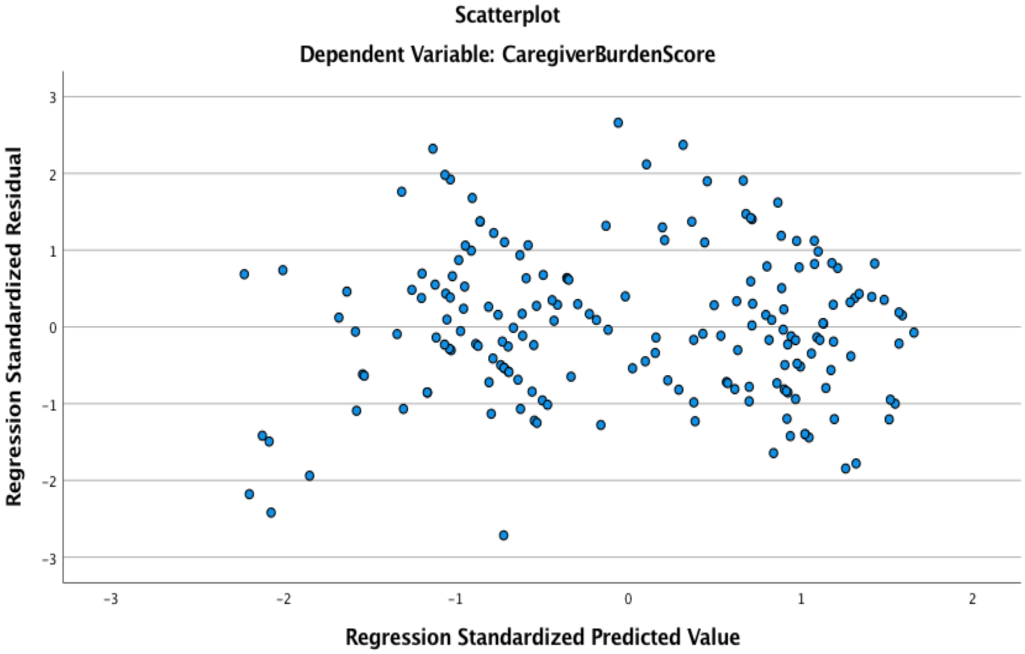


Figure 8. The Scatterplot of Standardized Residuals Versus the Predicted Values-2

1.3.5 Linearity assumption:

Before running the hierarchical multiple regression, scatterplots of the relationship between each predictor and caregiver burden were produced. The Scatterplots appear linear. After running the regression, the linearity assumption was rechecked by examining the normal probability plot (Normal P-P Plot), which indicated linearity. The Normal P-P Plot is shown in Figure 9.

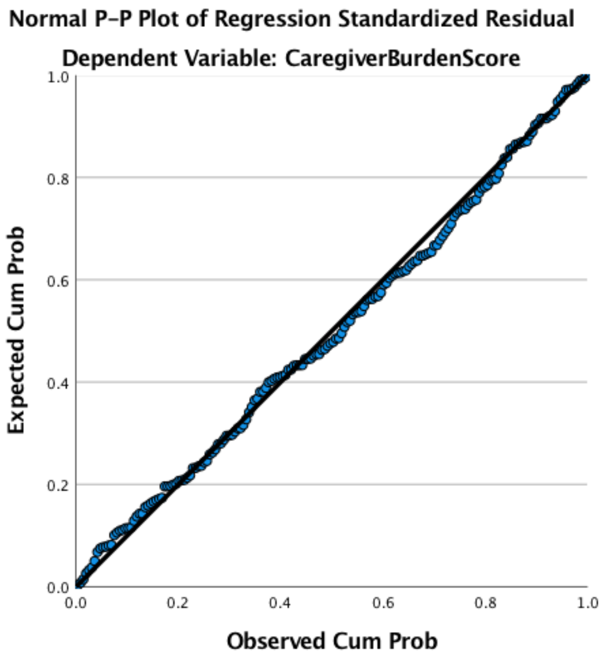


Figure 9. The Normal Probability Plot of the Hierarchical Multiple Regression

1.3.6 Normality assumption:

The shape of distribution of residuals was inspected by looking at the histogram of standardized residuals, which indicated normality. The Histogram of Residuals is shown in figure 10.

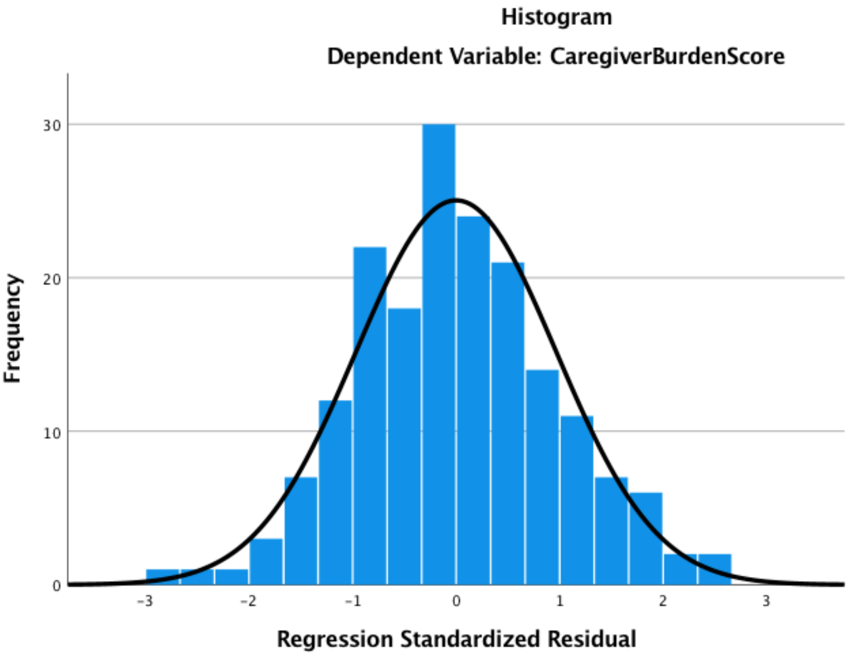


Figure 10. The Histogram of Residuals of the Hierarchical Multiple Regression

Second: Results of Hierarchical Multiple Linear Regression

Study question 6:

How can care recipient factors, including contextual variables related to the care recipient socio-demographic factors (age and educational level) and the primary stressor (stage of AD), contextual variables related to the caregiver socio-demographic factors (age, educational level, marital status, employment status, income level, living with the care recipient, and relationship with the care recipient), contextual variables related to the caregiving-related factors (hours of care per week and caregiver's perception of formal care), and caregiver's well-being account for variation in caregiver burden?

This question was examined by performing a hierarchical multiple regression using caregiver burden score as the dependent variable and the other twelve variables as predictors. The predictor variables explored in this study have been categorized into two broad sets- contextual variables and the primary stressors in the stress process model of Conde-Sala et al. (2010). In this analysis, the predictor variables were categorized into four sets (care recipient-related factors, caregiver-related factors, caregiving-related factors, and caregiver well-being) to determine the amount of variance in caregiver burden accounted by each set.

On block 1 of the hierarchical multiple regression, care recipient-related factors (care recipient socio-demographic factors, including age and educational level and the primary stressor_ stage of AD) accounted for 53.3% of the variance in caregiver burden ($R^2 = 0.53$, adjusted $R^2 = 0.52$, $F(3,178) = 67.77$, $P = <.001$). When the caregiver-related factors, including caregiver socio-demographic factors (age, educational level, marital status, employment status, income level, and living with the care recipient) were entered on block 2, they uniquely accounted for an additional 21.9% of the variance in caregiver burden ($R^2_{\text{change}} = 0.22$, F_{change} (6,172) = 25.26, P = <.001).

When the caregiving-related factors (Hours of care and caregiver's perception of formal care) were entered on block 3, they uniquely account for additional 2.8% of the variance in caregiver burden ($R^2_{\text{change}} = 0.03$, F_{change} (2,170) = 10.90, P = <.001). Lastly, when the caregiver's well-being was entered on block 4, it uniquely accounted for an additional 1.5% of the variance in caregiver burden score after controlling for all the other predictors ($R^2_{\text{change}} = 0.02$, F change (1,169) = 12.23, P = <.001). In total, all four blocks of the study variables accounted for 79.5% of variance in caregiver burden score, $R^2_{\text{change}} = 0.80$, adjusted $R^2 = 0.78$, F(12,169) = 54.57, P = <.001.

When predictors were examined individually using the standardized beta coefficients, eight of the twelve predictors accounted significantly for the variance in caregiver burden. Marital status accounted for the most variance in caregiver burden score (B = 0.22, P = <0.01, β = 0.21), followed by caregiver's well-being (B = -0.02, P = <0.01, , β =- 0.17), caregiver's employment status (B = 0.17, P = <0.01, β = 0.16), caregiver's income level (B = - 0.17, P = <0.01, β = -0.16), care recipient's age (B = 0.01, P = <0.01, β = 0.15), hours of care per week (B = 0.14, P = <0.05, β = 0.13), caregiver's perception of formal care (B = -0.12, P = <0.01, β = -0.11), and care recipient's educational level (B = -0.12, P = <0.01, β = -0.11). Stage of AD, caregiver age, caregiver's educational level, and living with the care recipient did not significantly account for the variance in caregiver burden.

The Summary of results of hierarchical multiple regression analysis is shown in Table 10. Appendix G shows all results of the hierarchical multiple regression analysis.

Table 10

The Summary of Results of Hierarchical Multiple Regression Analysis

Variables	R^2 Change	F for R^2 change	B	Std. Error	β
Block 1	0.53	67.77^{**}			
Age_CR			0.01^{**}	0.00	0.15
Educational level_CR			-0.12^{**}	0.04	-0.11
Stage of AD			0.09	0.04	0.08
Block 2	0.21	25.26^{**}			
Age_CG			0.00	0.00	0.07
Educational level_CG			-0.05	0.05	-0.05
Marital status_CG			0.22^{**}	0.05	0.21
Employment status_CG			0.17^{**}	0.04	0.16
Income Level_CG			-0.17^{**}	0.05	-0.16
Living with the CR			0.08	0.04	0.08
Block 3	0.03	10.90^{**}			
Hours of care per week			0.14^{*}	0.06	0.13
Perception of formal care			-0.12^{**}	0.04	-0.11
Block 4					
Caregiver well-being	0.02	12.23^{**}	-0.02^{**}	0.00	-0.17
Total R^2	0.80	54.57^{**}			

CR = Care recipient, CR = Caregiver, AD = Alzheimer's Disease, $*P < 0.05$, $**P < 0.01$.

This chapter provided results for determinants of caregiver burden among 182 informal caregivers caring for individuals with Alzheimer's disease in Saudi Arabia are reported in this chapter. In the following chapter, findings will be summarized, explained, interpreted, and evaluated for their significance in the light of the current knowledge. Research limitations and implications for social work and future research will also be discussed in the next chapter.

CHAPTER V

DISCUSSION

Overview of the Chapter

This study aimed to examine the association between particular factors (i.e., care recipient's age and caregiver's educational level) and caregiver burden among a sample of Saudi Arabian informal caregivers caring for older adults with Alzheimer's disease. This study also explored the ability of a set of factors (i.e., care recipient stage of Alzheimer's and caregiver's well-being) to account for variation in Alzheimer's caregiver burden. A summary, explanation, and interpretation of findings are provided considering existing knowledge. Contributions, implications, recommendations for social work policy, practice, education, and future research, strengths, and limitations of this study are also discussed.

Using the existing literature and the stress process model of Conde-Sala et al. (2010) as a conceptual framework, this non-experimental study leveraged primary data collected via a survey of caregivers of older adults with Alzheimer's in Saudi Arabia. The sample included 182 individuals who completed self-reported online surveys distributed by the Saudi Alzheimer's Disease Association. Respondents completed an online survey with 31 items (Chapter III). The following section includes a discussion of the study findings related to the study's six questions : (1) What is the relationship between contextual variables related to the care recipient socio-demographic factors (age, gender, and educational level) and caregiver burden?; (2) What is the relationship between contextual variables related the caregiver factors (age, gender, educational level, marital status, employment status, income level, living with the care recipient, and relationship with the care recipient) and caregiver burden?; (3) What is the relationship between contextual variables related to the caregiving-related factors (hours of care per week and perception of formal care) and the Alzheimer's caregiver burden? (4) What is the relationship between the primary stressor (stage of AD) and caregiver burden?; (5) What is the relationship between caregiver's well-being and caregiver burden?; and (6) How will care recipient factors, including contextual variables related to the care recipient socio-demographic factors (age and educational level) and the primary stressor (stage of AD), caregiver factors, including contextual variables related to the caregiver socio-demographic factors (age, educational level, marital status, employment status, income level, and living with the care recipient), contextual variables related to the caregiving-related factors (hours of care per week and caregiver's perception of formal care), and caregiver's well-being account for variation in caregiver burden?

Summary of Key Findings

The results of this study strengthen our understanding of the association between a set of predictors and caregiver burden among informal caregivers of older adults with Alzheimer's disease in Saudi Arabia. The knowledge generated from this study adds to the limited but growing empirical knowledge base related to the prediction of caregiver burden among informal caregivers. General demographic information and information regarding caregiver burden and caregiver well-being were collected to describe the study sample and answer the research questions. Demographic queries related to the care recipient's age, gender, educational level, stage of AD and caregiver’s age, gender, educational level, marital status, employment status, income level, living the care recipient, relationship to the care recipient, hours of care per week, and perception of formal care provided to the care recipients with Alzheimer’s were included. The standardized 12-Item Abridged Arabic version of the Zarit Burden Interview and the Arabic version of the 5-Item World Health Organization Well Being Index were included to thoroughly assess caregiver burden and caregiver well-being (Appendix A).

The mean age of older adults with Alzheimer's disease was 77.28 years. Most were female with no formal education and had a severe AD stage. Informal caregivers were predominantly female between the ages of 27 and 64 years. More than half were non-married and had 14 or more years of education. Over half were employed and had an income of less than 10000 Saudi Riyal per month. The majority were daughters who were living with their care recipients. More than half spent 31 or more hours of care per week and were unsatisfied with the formal care for the care recipients. The mean caregiver well-being score was 13.75 on a scale of 25, and the mean caregiver burden score was 21.76 on a scale of 48.

Pearson r and Point-biserial correlations were used to determine if significant relationships existed between care recipient demographic factors (age, gender, and educational level), caregiver demographic factors (age, gender, educational level, marital status, employment status, income level, living with the care recipient, and relationship with the care recipient), caregiver well-being, primary stressor (stage of AD), caregiving-related factors (hours of care per week and caregiver’s perception of formal care) and caregiver burden. The results from the correlational analyses revealed significant relationships between the care recipient’s demographic factors (age, gender, and educational level), caregiver’s demographic factors (age, gender, educational level, marital status, employment status, income level, living with the care recipient, and relationship with the care recipient), caregiver's well-being, primary stressor (stage of AD), caregiving-related factors (hours of care per week and caregiver's perception of formal care) and caregiver burden.

Hierarchical multiple linear regression was used to determine if the care recipient socio-demographic factors (age, educational level, and stage of AD), caregiver socio-demographic factors (age, educational level, marital status, employment status, income level, and living with the care recipient), caregiving-related factors (hours of care per week and caregiver's perception of formal care), and caregiver's well-being accounted significantly for variation in caregiver burden. The results from regression revealed that the overall model with all twelve predictors was statistically significant.

The care recipient factors, including contextual variables related to the socio-demographic factors (age and educational level) and the primary stressor (stage of AD) accounted for the greatest variation in caregiver burden, followed by contextual variables related to the caregiver socio-demographic factors (age, educational level, marital status, employment status, income level, and living with the care recipient), contextual variables related to the caregiving-related factors (hours of care per week and caregiver's perception of formal care), and caregiver's well-being. The significant individual predictor that accounted for the most variance was marital status. This was followed by caregiver's well-being, employment status, income level, care recipient's age, hours of care per week, caregiver's perception of formal care, and care recipient's educational level. Stage of AD, the caregiver age, caregiver's educational level, and living with the care recipient did not significantly account for the variance in caregiver burden.

Interpretation of Care Recipient Socio-Demographic Data

The findings of this study showed that 41.8% of care recipients with Alzheimer’s disease were between the ages of 76 and 85, 63.2% were women, and 55.5% had no formal education. These findings align with the results of previous studies about care recipients with Alzheimer’s disease in Saudi Arabia: the age of more than a third of 172 Saudi care recipients with AD ranged from 76 to 85 years (Almoajel et al., 2019), the majority of 110 Saudi care recipients with AD were women (Alfakhri et al., 2018), and 3) more than half of 418 Saudi care recipients with AD had no formal education (Albugami, 2018).

These results are also consistent with findings of previous studies in the US and are expected as the risk of Alzheimer’s increases with advancing age. Also, the risk of Alzheimer’s disease is higher among women rather than men due to the likelihood of reaching an older age of increased risk of Alzheimer’s. Too, risks are also highest among persons without formal education due to its link to the lower socioeconomic status which may limit the access to a healthy environment, and health promoting lifestyles, and medical care, which are critical to the prevention of AD (Alzheimer’s Association, 2021; Podcasy & Epperson, 2016; Riedel et al., 2016).

Interpretation of Caregiver Socio-Demographics Data

The findings of the current study showed that 77% of caregivers of persons with AD were between the ages of 27 and 50, 64.8% were women, 54.9% held a university degree or above, 53.3% were married, 57.7% cared for a relative with severe AD, 58.8% were employed, 66.5% had a low level of income_less than 10000 Saudi Riyal per month, 58.2% lived with their care recipient, 52% spent 31 or more hours of care per week, and 43.4% were daughters of the care recipient.

These findings are in accordance with the results of previous studies about caregivers of persons with Alzheimer’s disease in Saudi Arabia, which reported that most of the 122 caregivers were women and between the ages of 27 and 50 (Khusaifan et al., 2017), the majority of 141 caregivers were daughters, married and held a university degree or above (Alduaij, 2018), most of 110 caregivers were employed and had a low level of income (less than 10000 Saudi Riyal per month; Alqahtani et al., 2018), and the majority of 222 caregivers cared for a relative with severe AD, lived with their care recipient, spent 31 or more hours of care per week (Alfakhri et al., 2018).

These results also correspond to findings of previous studies in the United States that have shown that caregivers who live in the community with the care recipient are usually less than 65 years old, women, have a college degree or higher, are married and employed, have a low household income, provide care most of the time, and provide care to a family member (Alzheimer's Association, 2022; Freedman & Spillman, 2014; Fisher et al., 2011; Langa et al., 2005; Rabarison et al., 2018). Additionally, the findings of this study showed that the caring role for persons with Alzheimer's in Saudi society is often falling to women, which is similar to the results reported in an earlier study that included 172 caregivers of persons with AD (Almoajel et al., 2019).

Interpretation of Caregiving-Related Data

This study also revealed that 64.3% of caregivers were unsatisfied with the formal care and services for the care recipients. The finding cannot be compared to earlier Saudi findings as no studies have focused on Alzheimer’s caregivers’ stratification with formal care and services provided to the care recipients. However, this result is similar to the findings of Lethin et al. (2020), who reported that the majority of 1223 informal caregivers of persons with AD in eight European countries were unsatisfied with the formal care and services provided to their loved ones with AD.

The finding of this study regarding caregivers' well-being—that 57% had a low level of well-being—is in agreement with results reported by the American Alzheimer's Association, which indicated that caregivers of persons with Alzheimer's disease tend to have a low level of well-being due to increased caregiver burden (Alzheimer's Association, 2022). However, no previous studies in the Arab region, including Saudi Arabia, have evaluated the well-being of caregivers of persons with Alzheimer's.

Lastly, one of the salient findings of this study is that 89.7% of caregivers of this population had a moderate or severe level of burden. This finding confirmed the finding of a previous study in Saudi Arabia by Alshammari et al. (2017), which reported that the majority of 315 caregivers included in the study experienced a moderate or severe burden. The finding of this study regarding caregiver burden—that majority of caregivers had a moderate or severe level of burden—is also in accordance with the results of Kim et al. (2012), who reported that most of the 302 American caregivers of persons with AD included in the study experienced moderate or severe levels of burden.

Discussion of Results of Correlation Analyses

As no research has been conducted to identify factors associated with caregiver burden among Saudi informal caregivers of persons with Alzheimer's disease, findings from the current study were compared to studies worldwide. Firstly, the results of the first research question showed that informal caregivers were more likely to experience a higher burden with older male care recipients with AD who had fewer years of formal education. These findings are critical and are affirmed the following findings of previous studies focused on investigating the factors related to increased burden among non-Saudi caregivers of individuals with Alzheimer's living at home.

The first significant association identified in the results of question 1 was between the increased age of the care recipient and increased burden. This result is comparable to the finding of an earlier correlational study that included 148 Spanish caregivers of persons with AD, which showed that caregivers caring for older care recipients with AD are more likely to experience increased burden. This result was expected since older care recipients are heavily dependent on caregivers. A high level of dependency on caregivers has been associated with an increased caregiver burden (Rodríguez-González et al., 2021).

The second significant association identified in the results of question 1 was between being a caregiver of a male care recipient and increased burden. This result is similar to the finding of a previous systematic review of fifteen quantitative studies that examined the factors related to increased burden among caregivers of persons with AD by Quinn et al. (2009), who found caregivers for a male care recipient are more likely to experience a high burden. This result was anticipated since most caregivers of male care recipients are daughters or sons who are culturally expected to undertake the caregiving responsibility regardless of the quality of their relationship with their parents. The poor quality of the pre-caregiving relationship between caregiver and care recipient is related to experiencing a high caregiver burden (Quinn et al., 2009).

The third significant association identified in the results of question 1 was between the lower level of formal education of the care recipient and increased burden. This result is in accordance with an earlier systematic review of twenty-one articles published between 2003 and 2012 identified the factors related to the burden on the informal caregivers of people with AD living in the community, which showed that caregivers for a care recipient with a lower level of formal education are more likely to experience an increased burden (Chiao et al., 2015). This is because caregivers perceived a degree of difficulty communicating with care recipients with lower formal education. An unmet desire for caregiver-patient communication is associated with increased caregiver burden (Fried et al., 2005).

Additionally, the results of the second research question showed that informal caregivers who were older, female, married, living with the care recipient, daughters, had fewer years of formal education, were employed, and had a low monthly income were more likely to experience a greater burden. These findings are also in agreement with the following findings of previous studies focused on exploring the factors related to increased burden among non-Saudi informal caregivers of individuals with AD.

The first significant association identified in the results of question 2 was between the increased age of the caregiver and increased burden. This result is parallel to the finding of a previous study that assessed the burden of 237 informal Spanish caregivers of individuals with AD, which indicated that older caregivers are more likely than younger caregivers to experience increased burden (Serrano-Aguilar et al., 2006). This result can be explained by the fact that older caregivers are at a higher risk of experiencing physical health problems compared to younger caregivers. The deterioration of physical health may increase the probability of experiencing a high caregiver burden (Kim et al., 2012).

The second significant association identified in the results of question 2 was between being a female caregiver and increased burden. This result is in agreement with the finding of an earlier correlational study that examined the relationship between caring for individuals with AD and burden among 784 American caregivers, which reported that female caregivers are more likely than male caregivers to experience increased burden (Yeager et al., 2010). This result was projected as social support for women caregivers is limited compared to men caregivers. Moreover, women caregivers are less likely to seek outside support due to caregiving responsibilities (Sharma et al., 2016).

The third significant association identified in the results of question 2 was between being a married caregiver and increased burden. This result is similar to the finding of a Korean study that explored the burden among 157 primary caregivers of persons diagnosed with AD, which showed that married caregivers are at higher risk of an increased burden than non-married caregivers (Hong et al., 2008). This result can be attributed to the fact that spouse caregivers are expected to care for husbands or wives in Saudi traditional culture, even if they are not prepared for this role.

The fourth significant association identified in the results of question 2 was between living with the care recipient and increased burden. This result is comparable to the finding of a previous Spanish study that identified trajectories of burden among 330 caregivers in the context of AD and the factors associated with them, which showed that caregivers who live with their care recipients are more likely to experience increased care burden compared to caregivers who do not live with their care recipient (Conde-Sala et al., 2014). This result was expected since caregivers who live with the care recipient tend to feel more responsible and provide more hours of care than those who do not live with the care recipient (Carretero et al., 2009; Kim et al., 2012).

The fifth significant association identified in the results of question 2 was between being a daughter caregiver and increased burden. This result is comparable to the finding of a previous cross-sectional analytic study that identified and compared the factors associated with burden among 251 Spanish caregivers of persons with AD, which showed that a daughter caregiver is more likely to experience an increased burden than spouse caregivers. This is because the daughters of the care recipient with AD may consider caring for their parents as an additional task that changes their lifestyle and increases the burden. In contrast, spouse caregivers are committed to caring for their husbands or wives as part of their marriage, which could be related to a decreased burden (Conde-Sala et al., 2010).

The sixth significant association identified in the results of question 2 was between the lower level of formal education of caregivers and increased burden. This result is in accordance with the finding of a prior systematic review by Chiao et al. (2015), who found that caregivers with a lower level of education are more likely to experience increased burden (Chiao et al., 2015). This result may be attributed to the fact that caregivers with lower educational attainment tend to have lower scores on health literacy than those with higher educational attainment (Almeida et al., 2019). The low level of health literacy among caregivers of persons with AD has been identified as a predictor of experiencing increased caregiver burden (Häikiö et al., 2020).

The seventh significant association identified in the results of question 2 was between being employed and increased caregiver burden. This result is comparable to the finding of an earlier correlational study conducted by Rodríguez-González et al.

(2021), who found that employed caregivers are at high risk of experiencing an increased burden than unemployed caregivers. This result was expected since employed caregivers are more likely to have difficulty balancing between demands of work and caregiving, which is associated with an increased caregiver burden (Socci et al., 2021).

The eighth significant association identified in the results of question 2 was between low monthly income and increased caregiver burden. This result is similar to the finding of a previous systematic review by Chiao et al. (2015), who found that informal caregivers with low monthly income are more likely to experience a high burden than caregivers with high monthly income. This result was expected since informal caregivers with low monthly income may have less access to supportive resources like home health care aides, which is related to increased caregiver burden (Tsai et al., 2021).

Also, the results of the third research question showed that informal caregivers who provided more hours of care per week and were unsatisfied with the formal care for care recipients were more likely to experience a greater burden. These findings are important and are in agreement with the following findings of previous studies that explored the factors associated with caregiver burden among non-Saudi informal caregivers of individuals with AD.

The first significant association identified in the results of question 3 was between caregivers' negative perception of formal healthcare services provided to the care recipients and increased burden. This result is consistent with the finding of an earlier study that identified factors associated with burden among 1223 caregivers in eight European countries, which showed that caregivers who are unsatisfied with the formal care for patients are more likely to experience a high burden (Lethin et al., 2020). This result was anticipated since caregivers' negative perception of formal healthcare services related to the unmet health needs of care recipients with Alzheimer's disease. The unmet health needs of care recipient contributes to an increased caregiver burden (Park et al., 2018).

The second significant association identified in the results of question 3 was between providing more hours of care per week and increased burden. This result is in agreement with the finding of a previous systemic review on caregiver burden in AD by Chiao et al. (2015), who reported that informal caregivers who devoted more hours to providing care for their care recipients are more likely to experience a higher caregiver burden than those who provide fewer hours of caregiving (Chiao et al., 2015). This result may be attributed to the fact that devoting more hours to caregiving is associated with caregivers' decreased physical and psychological well-being. Diminished caregiver well-being contributes to increasing caregiver burden (Conde-Sala et al. 2010).

Also, the results of the fourth research question showed a significant association between caring for a person with a severe stage of AD and increased caregiver burden. This result is parallel to the findings of a systematic review of twenty-four studies and a meta-analysis of eleven studies that investigated variables related to burden among caregivers of persons with AD, which reported that informal caregivers for care recipients with severe AD are more likely to experience increased burden than informal caregivers for care recipients with non-severe AD (Kim et al., 2019). This result can be attributed to the caregiver burden being more likely to escalate as Alzheimer's disease progresses due to increased care recipient dependency on caregivers (Koca et al., 2017).

Lastly, the results of the fifth research question showed a significant association between decreased caregiver well-being and increased caregiver burden. This result is consistent with the finding of the systemic review of studies on caregiver burden in AD, which showed that caregivers with a lower level of well-being are more likely to experience increased burden (Chiao et al., 2015). This result can be explained by the fact that the lower well-being of caregivers has been associated with low caregiving competence and perceiving fewer positive aspects of caregiving. Decreased competence of caregivers and reduced positive aspects of caregiving have been linked to experiencing an increased burden (Quinn et al., 2019).

Discussion of Results of Hierarchical Multiple Regression for Question (6)

This study is the first of its kind in the Arab region and Saudi Arabia to investigate the ability of sets factors to account for variation in caregiver burden among informal caregivers of persons with Alzheimer's. Therefore, the results will be compared to the previous findings in the US and worldwide.

All four sets of predictors, including care recipient factors (contextual variables related to the care recipient socio-demographic factors and the primary stressor_ stage of AD), caregiver factors (contextual variables related to the caregiver socio-demographic factors), contextual variables related to the caregiving related factors, and caregiver well-being accounted significantly for variance in caregiver burden. In particular, care recipient factors, including contextual variables related to the care recipient socio-demographic factors and the primary stressor were the largest in effect, accounting approximately for 53% of the variation in caregiver burden, followed by caregiver factors, including contextual variables related to the caregiver socio-demographic factors), contextual variables related to the caregiving-related factors, and caregiver well-being, each of which accounted for 21%, 3%, and 2% of the variation in caregiver burden. These results affirmed the findings of Conde-Sala et al. (2010), Kim et al. (2011), and Park et al. (2015), who found that care recipient factors accounted for more variance of caregiver burden in Alzheimer’s disease than caregiver factors and caregiving related factors.

One of the notable findings of this study is that the care recipient's age represented a more burdensome individual variable among care recipient factors, which also includes educational level and stage of AD. In earlier studies (Abreu et al., 2020; Gallagher et al., 2011; Lindt et al., 2020; Peña-Longobardo & Oliva-Moreno, 2015), increased age of the care recipient has been associated with the high level of dependency of the patients on informal caregivers, which was cited as one of the most vital predictors of caregiver burden among those caring for older adults with Alzheimer's disease.

In this analysis, the stage of AD did not account for variation in caregiver burden. Previous studies have identified patient unawareness of cognitive problems (Anosognosia) as a more critical predictor of caregiver burden than the stage severity of AD (Baptista et al., 2019; Rymer et al., 2002; Seltzer et al., 1997). This is due to the fact that impaired insight in patients is related more strongly to higher behavioral dysfunction, depression, anxiety, and a worse rate of personal care and judgment than the stage of AD, which contributes to an increased caregiver burden than other factors (Ala et al., 2020; Kelleher et al., 2016; Van der Lee et al., 2014).

Another salient finding of this study is that marital status of caregiver (being married) represented a more critical determinant of caregiver burden than other caregiver factors, including caregiver’s age, educational level, employment status, income level, and living with the care recipient. This result is in agreement with the findings of the previous studies (Kim et al., 2011; Park et al., 2015), and it could be explained by the fact that married caregivers are more likely to experience depression, age-related chronic disease, and caregiving difficulties, which may lead to increased caregiver burden (Connell et al., 2001; Joling et al., 2010; Tremont et al., 2006).

In contrast to previous studies (Allegri et al., 2006; Adelman et al., 2014; Springate & Tremont, 2014; Tsai et al., 2021; Van der Lee et al., 2014), caregiver age, educational level, and living with the care recipient did not account for variation in caregiver burden in this study. However, the influence of the caregiver's age, educational level, and living with the care recipient on the caregiver burden should be investigated further since there may be aspects related to these findings that did not come to light in the current study. For instance, older caregivers are at high risk of experiencing increased caregiver burden due to the projected decline in physical health with aging (Conde-Sala et al., 2014). Additionally, caregivers' low educational level is associated with low health literacy, which has been linked to a greater experience of caregiver burden (Almeida et al., 2019). Also, caregivers who live with the care recipient provide more hours of care, which contributes to an increased caregiver burden (Conde-Sala et al., 2014 & Kim et al., 2012).

In this study, an increased total number of caregiving hours was identified as a more burdensome individual variable among caregiving-related factors than the caregiver's negative perception of formal care for the care recipient. Comparing caregiver burden with caregiving hours per week, the increased burden was observed in the caregiver group who spent more than 31 hours of care per week. This finding is consistent with the result reported by Park et al. (2015). Higher hours of care are usually related to the care recipient's high dependency level: a greater decline in patient function is related to the increased hours of care and increased caregiver burden (Reed et al., 2020). Moreover, caregivers who spend more time on caregiving tend to be isolated from their support systems, which increases their caregiver burden (Han et al., 2014; Park et al., 2015; Yurtsever et al., 2013).

Decreased caregiver well-being was a significant predictor of increased caregiver burden. This is similar to the findings of previous studies; caregivers with diminished well-being among those caring for persons with Alzheimer's disease is associated with lower quality of life and increased caregiver burden (Serrano-Aguilar et al., 2006; Kim et al., 2012; Lethin et al., 2017; Lynch et al., 2018; Lethin et al., 2020).

Contribution of the Study

A recent review of research in the field of geriatrics from Saudi Arabia between the years 1980 to 2018 revealed that common issues related to geriatric health conditions, such as Alzheimer's disease and dementia, had yet to be addressed (Alamri, 2019). In the current review of literature related to Alzheimer's caregiver burden, no research has been conducted in Saudi Arabia regarding the relationship between caregiver burden and (contextual variables, including care recipient factors, caregiver factors, and caregiving-related factors, the primary stressor_ stage of AD, and caregiver's well-being). Moreover, no study has been conducted to identify the factors that account for variation in caregiver burden among Saudi informal caregivers of persons with Alzheimer's disease. Therefore, the contribution of this study is a critical extension of existing worldwide knowledge related to these critical research areas.

The information generated from this study might be also valuable to policy, practice, education, and research. For instance, this study provided further knowledge regarding the characteristics of Saudi persons with Alzheimer's disease and their informal caregivers, who are at high risk of caregiver burden. This descriptive information helps inform policy makers, practitioners, educators, and researchers about the burdens of Alzheimer’s disease and caregiving in the region, thus this study sets the stage for further assessment of the need for additional research, healthcare services, support, programs and policies for this particular population.

More importantly, this study is the first of its kind in Saudi Arabia to examine the ability of multidimensional factors to account for variation in Alzheimer’s caregiver burden; thus, it can be used by researchers as an initial reference to identify the variation in caregiver burden in Alzheimer’s disease based on international data.

Implications for Policy, Practice, Education.

With the cognitive and functional decline of Saudi persons with Alzheimer’s disease, most of them rely on informal caregivers who do not choose to be caregivers and provide care without payment or appropriate in a home environment (Abyad, 2016). Although there can be benefits and rewards of caregiving, it can be a demanding and frustrating process that increase the possibility of experiencing caregiver burden due to dealing with a wide range of caregiving tasks and distressing emotional and behavioral symptoms of care recipients (Alzheimer’s Association, 2021; Christakis & Allison, 2006; Ma et al., 2018; Lwi et al., 2017; Perkins et al., 2013). These facts alone highlight the importance of supporting informal caregivers of persons with Alzheimer's disease.

Generally, the findings of the study are applicable to policy makers, practitioners, and educators. Identification of factors that account for caregiver burden is essential for early prevention, which may enhance the quality of life of caregivers and the quality of care they provide to their care recipient. For example, policymakers can use the findings of this study as scientific evidence of the need to construct policies to assist Saudi caregivers of persons with AD in obtaining more professional help and support. This may minimize the probability of experiencing increased caregiver burden, particularly among those at higher risk.

Additionally, the findings of this study offer an indication for the Ministry of Health, the Ministry of Human Resources and Social Development, and governmental and non-governmental institutions in Saudi Arabia about the urgent need to collaborate to develop and improve the delivery of the informal and formal health and social care provided to the care recipient with AD and their caregivers. The focus of this international collaboration should be on the inclusion of AD in the Saudi Vision 2030, establishment of long-term care facilities, increasing the participation of private organizations, and increasing in-home hours for home health care, in-home training and education, monetary compensation, and community social support resources, which may play a vital role in supporting caregivers of persons with AD and alleviating caregiver burden.

Also, the knowledge in this study can be used by home healthcare providers, including social workers in Saudi Arabia, to formulate assessment tools that identify caregivers who are at high risk of caregiver burden and design health-oriented interventions, such as respite care that benefit foremost caregivers with risk factors of caregiver burden. The information about risk factors of caregiver burden in this study may also be used by Saudi healthcare professionals, including social workers, to devise evidenced-based training and educational programs to prepare caregivers of persons with AD for the required level of care and caregiving tasks, which may help minimize caregiver burden.

More specifically, several non-modifiable care recipient factors (i.e., older age, male gender, and severe stage of AD) and caregiver factors (i.e., older age., female gender, and being married) were associated with increased caregiver burden. These crucial findings have implications for care providers and policy makers. Older female caregivers who are married and provide care for male older adults with severe AD should be carefully considered and evaluated by care providers, particularly home and hospital social workers and clinical psychologists, for evidence of high burden. Social and health policy-makers should consider these groups of caregivers in planning and delivering resources and interventions to promote quality of life and health and alleviate the burden.

Modifiable factors (i.e., higher hours of care per week and lower level of well-being) were associated with increased caregiver burden. These results have major implications for the development of respite care services and recommendations to improve the well-being of caregivers of persons with AD in Saudi Arabia. Ensuring access to respite care services, such as personal care, companionship, home health aide, and maid services, can reduce hours of care per week, which may alleviate their burden. Providing respite care services can also allow caregivers to physically and mentally relax, spend time with other relatives, and care for themselves, which may improve caregiver well-being and thus decrease burden.

The findings of this study can be also valuable to further education, particularly social work education in Saudi Arabia the area of understanding the caregiver burden and Alzheimer's disease by using the existing theoretical models, such as the stress process models of Pearlin et al. (1990) and Conde-Sala et al. (2010). The study methodology and findings can also be used as an educational guide for teaching social work students approaches for investigating the caregiver burden experienced by informal caregivers. The findings of this study can also be helpful to increase the empathy and awareness of social work students about the needs of caregivers of persons with Alzheimer’s disease and advocate for designing specific services to meet the needs of informal caregivers.

Study Strengths, Limitations, and Future Directions

Research related to the caregiving of persons with Alzheimer's disease in Saudi Arabia, such as the caregiver burden experienced by informal caregivers, is scarce. This current study provided insights that help address the gap in caregiver burden research not yet discussed in the Saudi literature. Importantly, this is the first Saudi study exploring the ability of a set of the care recipient, caregiver, and caregiving-related factors to account for variation in caregiver burden. The predictor factors explored in this study were selected and categorized using the stress process model of Conde-Sala et al. (2010). Exemplary articles were reviewed extensively, and conceptual and empirical aspects were integrated to develop this stress model.

This study is also the first Saudi study that determined the association between caregiver burden and diverse factors related to care recipients with Alzheimer's disease and their informal caregivers in Saudi Arabia. None of the previous Saudi studies have examined these relationships. This study is also the first of its kind in Saudi Arabia to assess the informal caregiver burden and caregiver's well-being of persons with Alzheimer's disease using standardized scales (Zarit Burden Interview and 5-item World Health Organization Well Being Index). Also, the data was collected in this study by using the elements of the Social Media Networks Method proposed by Kayam and Hirsch (2012), which were recommended to enhance response rates and survey completion. For instance, this study used an online survey and partnered with the Alzheimer's Disease Association in Saudi Arabia to improve caregivers' participation in the study.

In spite of its strength, the current study also has its limitations. The first limitation is using a cross-sectional design to conduct this study. Data obtained by a cross-sectional design does not provide a chance to identify the changes over time in Alzheimer's caregiver burden. Therefore, longitudinal designs are recommended in future research to evaluate the actual ability of care recipient, caregiver, and caregiving-related factors, which were explored in this study, to account for variation in caregiver burden among Saudi informal caregivers of persons with Alzheimer's disease over time.

Additionally, this study only recruited a convenience sample of informal caregivers who received care services and support from Riyadh's Saudi Alzheimer's Association. Convenience sampling is not representative of the general population and can lead to several biases, thus the findings of this study cannot be generalized to Saudi informal caregivers of persons with AD beyond this study. Researchers should identify caregiver burden predictors based on nationwide data sample to improve the generalizability of the findings. Random sampling is also recommended to eliminate sample bias and enhance generalizability in future research.

Also, the paid and professional caregivers, caregivers under the age of 18, and older adults caregivers age 65 or older were not the focus of this study. These individuals should be included in future research, particularly adult children and older adults caregivers of persons with AD who may be at higher risk of experiencing caregiver burden. This study used an online-based survey; therefore, caregivers with no access to the internet or suitable devices were not represented in this study. Using other survey methods, such as an in-person survey, is recommended in future research to ensure the inclusion of caregivers excluded in this study. However, an in-person survey is high in cost and may limit the sample size due to the limited size of interviewing staff.

The stress process theoretical framework of Conde-Sala et al. (2010) consisted of multiple factors that highlighted the multidimensional nature of predictors of caregiver burden. Exploring all predictor factors from a model of this scale and scope will be a daunting task for the researcher and a high burden for the study respondents. Thus, not all factors that have been identified as essential predictors of caregiver burden in the stress process model of Conde-Sala et al. (2010) were included in this study. The factors explored in this study are limited to sociodemographic characteristics of the care recipient, sociodemographic characteristics of caregivers, and caregiving-related factors. Thus, future research should focus on other complex factors that have been identified in the stress process model of Conde-Sala et al. (2010) as factors that account for variation in experiencing caregiver burden, such as patient symptomology and secondary stressors (family conflicts, difficulties at work, and financial difficulties).

Moreover, the findings of this study showed the importance of future research to explore several factors that may account for variation in caregiver burden and are not identified in the stress process model of Conde-Sala et al. (2010). For instance, the quality of the pre-caregiving relationship between caregivers and care recipients with AD, the degree of difficulty communicating with the care recipient, caregivers' health literacy, and access to home health care services may account for variation in caregiver burden, thus they should be explored in future research. Also, few factors explored in this study were intervenable, such as hours of care per week and caregiver well-being. Other modifiable factors, such as poor family function, coping skills, self-efficacy, self-esteem, and sense of competence, which may account for variation in

Alzheimer's caregiver burden, should be explored in future studies to recommend possible interventions that might benefit caregivers (Yoon et al., 2014 & Kim et al., 2012).

This study used hierarchical multiple linear regression analysis with a notion that caregiver burden in AD is influenced directly by care recipient, caregiver, caregiving-related- factors, and caregiver well-being. However, the assessment of the findings of this study provided insights for future research to use path analysis since they may be direct and indirect relationships and interaction effects among the sociodemographic care recipient, sociodemographic caregiver, caregiving related-factors, and caregiver well-being, which may increase caregiver burden.

Lastly, this quantitative study cannot provide in-depth information about the unique experiences of caregiver burden among Saudi informal caregivers. Qualitative data may be helpful for researchers to identify the areas in caregiver burden that should be the focus of future quantitative studies. Thus, qualitative studies exploring the lived experience of informal caregivers of persons with AD are recommended to provide in-depth personal insight related to caregiver burden experience in AD.

Conclusion

This chapter included an analysis of the quantitative data collected from informal caregivers of persons with Alzheimer's disease in Saudi Arabia. This study is the first of its kind that explored the ability of multidimensional predictors related to care recipient and caregivers factors, caregiving related factors, stage of Alzheimer's, and caregiver well-being to account for variation in caregiver burden using the existing literature and the stress process model of Conde-Sala et al. (2010) as a conceptual framework. This study is non-experimental study leveraged primary data collected via a survey of caregivers of older adults with Alzheimer’s in Saudi Arabia. .

The sample included 182 individuals who completed self-reported online surveys distributed by the Saudi Alzheimer's Disease Association. Respondents completed an online survey which included 31 items.

Data were analyzed using the SPSS version 28.0.1. The collected data were coded and entered by the researcher. Descriptive statistics (Range, percentage, mean, standard deviation, and frequency) were used to describe the study sample and measures. The ability of predictors to account for variation in experiencing caregiver burden was tested using the hierarchical multiple linear regression analysis. Assumptions of linearity, normality, homoscedasticity for the hierarchical multiple linear regression analysis were assessed. Other factors that may impact the analysis, such as sample size, multicollinearity, and outliers, were also evaluated.

The correlation analyses revealed significant relationships between the care recipient's demographic factors (age, gender, and educational level), caregiver's demographic factors (age, gender, educational level, marital status, employment status, income level, Living with the care recipient, and relationship with the care recipient), caregiver's well-being, primary stressor (stage of AD), caregiving-related factors (hours of care per week and caregiver's perception of formal care) and the caregiver burden. The overall prediction model with all twelve predictors accounted for variance in caregiver burden. The care recipient socio-demographic factors accounted significantly for the most variance in caregiver burden, followed by caregiver socio-demographic factors, caregiving-related, and caregiver well-being. The significant individual predictor that accounted for the most variance was marital status, followed by caregiver well-being, employment status, income level, care recipient's age, hours of care per week, caregiver's perception of formal care, and care recipient's educational level.

Additional research is needed to explore other complex factors that may account for variation in caregiver burden among this population, such as patient symptomology and secondary stressors (family conflicts, difficulties at work, and financial difficulties). Modifiable factors, such as poor family function, self-efficacy, and sense of competence, should be explored in future research to recommend possible interventions that might benefit caregivers. A collaborative effort among policy makers, healthcare professionals, professional social workers, educators, and researchers is recommended to improve the informal and formal care provided to the care recipient, such as more in-home hours for home health care, more in-home training and education, and more financial and social support for caregivers, which may enhance the quality of life of caregivers, quality of care for the care recipient, and decrease caregiver burden.

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APPENDICES

Appendix A

Questionnaire of Caregiver Burden among Family Caregivers Looking After Older Adults with Alzheimer's Disease

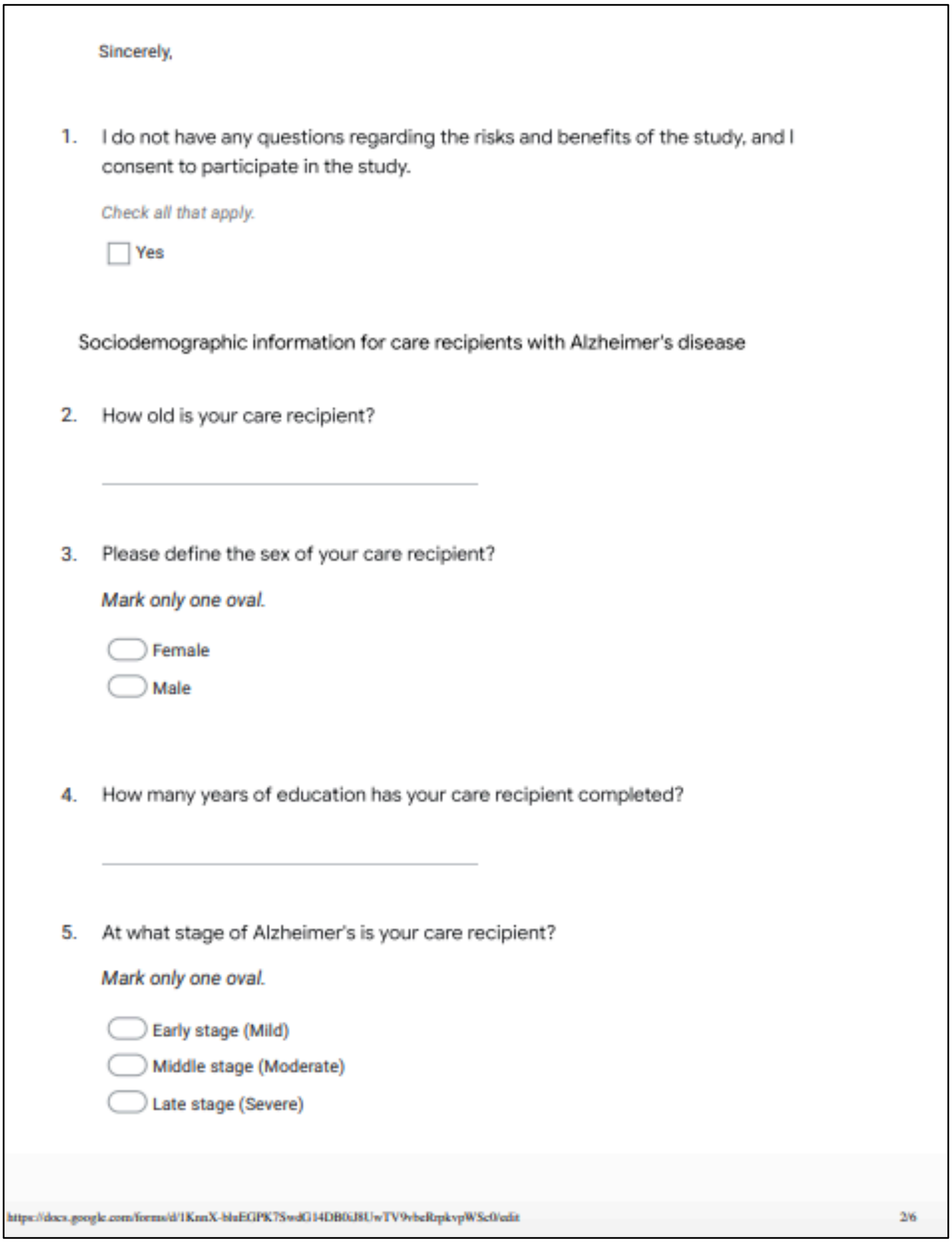
Dear AD Caregiver,

You were invited to participate in the study because you were recognized as an informal caregiver for someone with Alzheimer's who is between the ages of 18 and 65. You will be asked to answer questions in the attached survey about your experience with caregiver burden. Mr. Sultan Shubair conducts this study under the supervision of Drs. Thomas Richard Lawson and Stephanie Grace Prost with the Kent School of Social Work at the University of Louisville. The risks to participants in the current study are minimal. Some questions may present some discomfort in answering them. However, none of the questions are intended to elicit such a feeling. The information collected may not benefit you directly. However, the information learned in this study may be helpful to others. The current survey will gather demographic information, including your care recipient's age, gender, education level, stage of AD and your age, gender, education level, marital status, occupational status, monthly income, living situation, kinship with the care recipient, and duration of care. You will also be asked to rate your satisfaction with the formal care provided to your care recipient. In addition, the survey will ask questions about your experience with the caregiving burden and your quality of life. The researchers will use the information in this study to examine the ability of a set of factors as predictors of Alzheimer's caregiver burden.

The survey will take approximately 5 minutes to complete. Please find a private and safe location to complete the survey to ensure the privacy of your responses. Data collected using Google Forms is protected. Google Forms' platform provides enterprise-grade security features that include data encryption and continuous network monitoring with ISO 27001 certification that is FedRAMP authorized to meets the highest standards for SaaS providers set by the U.S. Government. Data used in any analyses will be coded and stored on an encrypted flash drive that will be stored in a locked, secure location.

Individuals from the Kent School of Social Work, the Institutional Review Board (IRB), the Human Subjects Protection Program Office (HSPPO), and other regulatory agencies may inspect these records. However, in all other respects, the data will be held in confidence to the extent permitted by law. Should the data be published, your identity will not be disclosed. Taking part in this study is voluntary. By clicking on the statement below, you agree to take part in this research study. You do not have to answer any questions that make you uncomfortable. You may choose not to take part at all. If you decide to be in this study, you may stop taking part at any time.

If you have any questions, concerns, or complaints about the research study, please don't hesitate to contact Mr. Sultan Shubair at +966541444843 or sashub01@louisville.edu OR Dr. Thomas Richard Lawson at thomas.lawson@louisville.edu or Dr. Stephanie Grace Prost at s0pros01@louisville.edu.



Sincerely,

1. I do not have any questions regarding the risks and benefits of the study, and I consent to participate in the study.

Check all that apply.

☐ Yes

Sociodemographic information for care recipients with Alzheimer's disease

2. How old is your care recipient?

____

3. Please define the sex of your care recipient?

Mark only one oval.

○ Female
○ Male

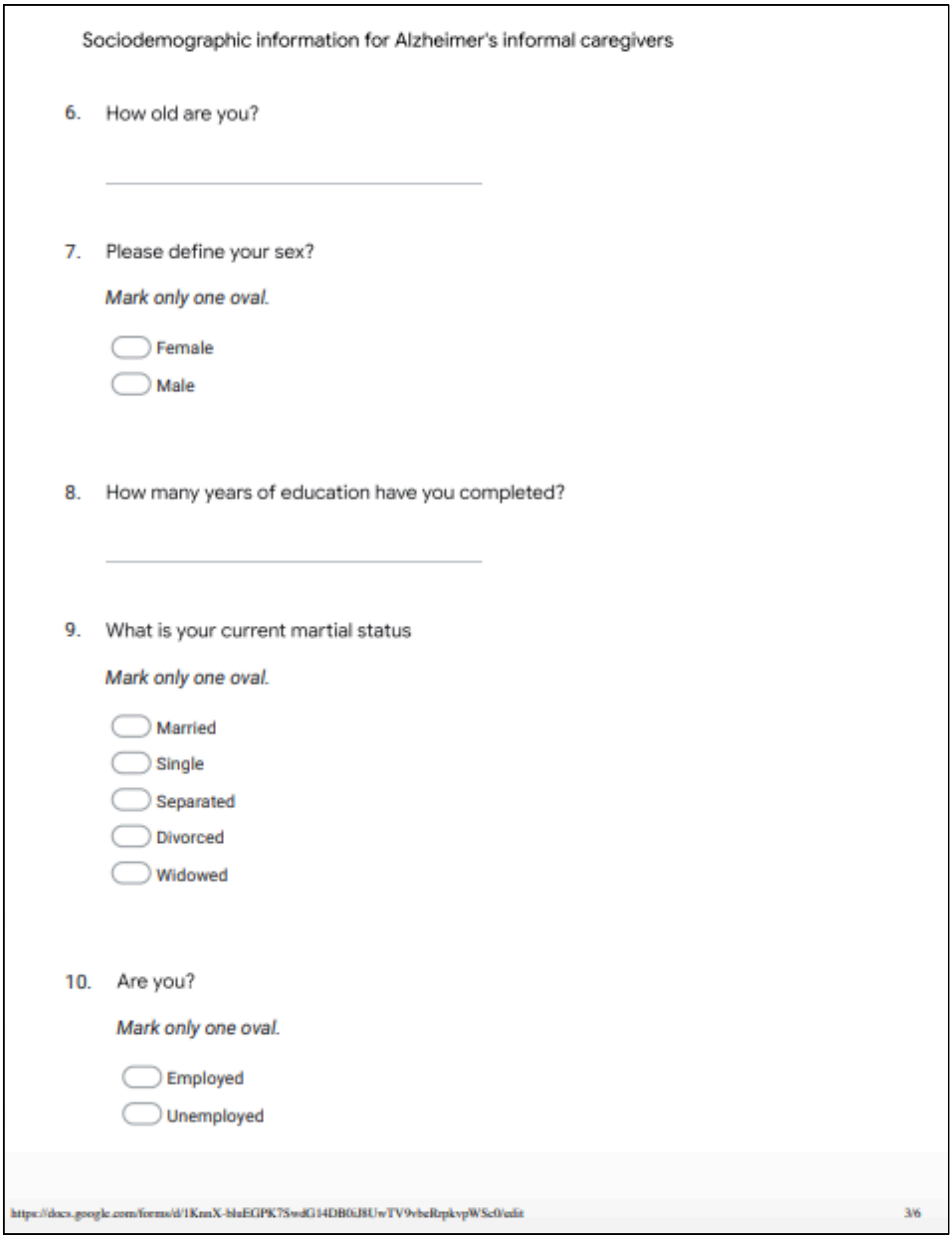
4. How many years of education has your care recipient completed?

____

5. At what stage of Alzheimer's is your care recipient?

Mark only one oval.

○ Early stage (Mild)
○ Middle stage (Moderate)
○ Late stage (Severe)



Sociodemographic information for Alzheimer's informal caregivers

6. How old are you?

____

7. Please define your sex?

Mark only one oval.

○ Female
○ Male

8. How many years of education have you completed?

____

9. What is your current martial status

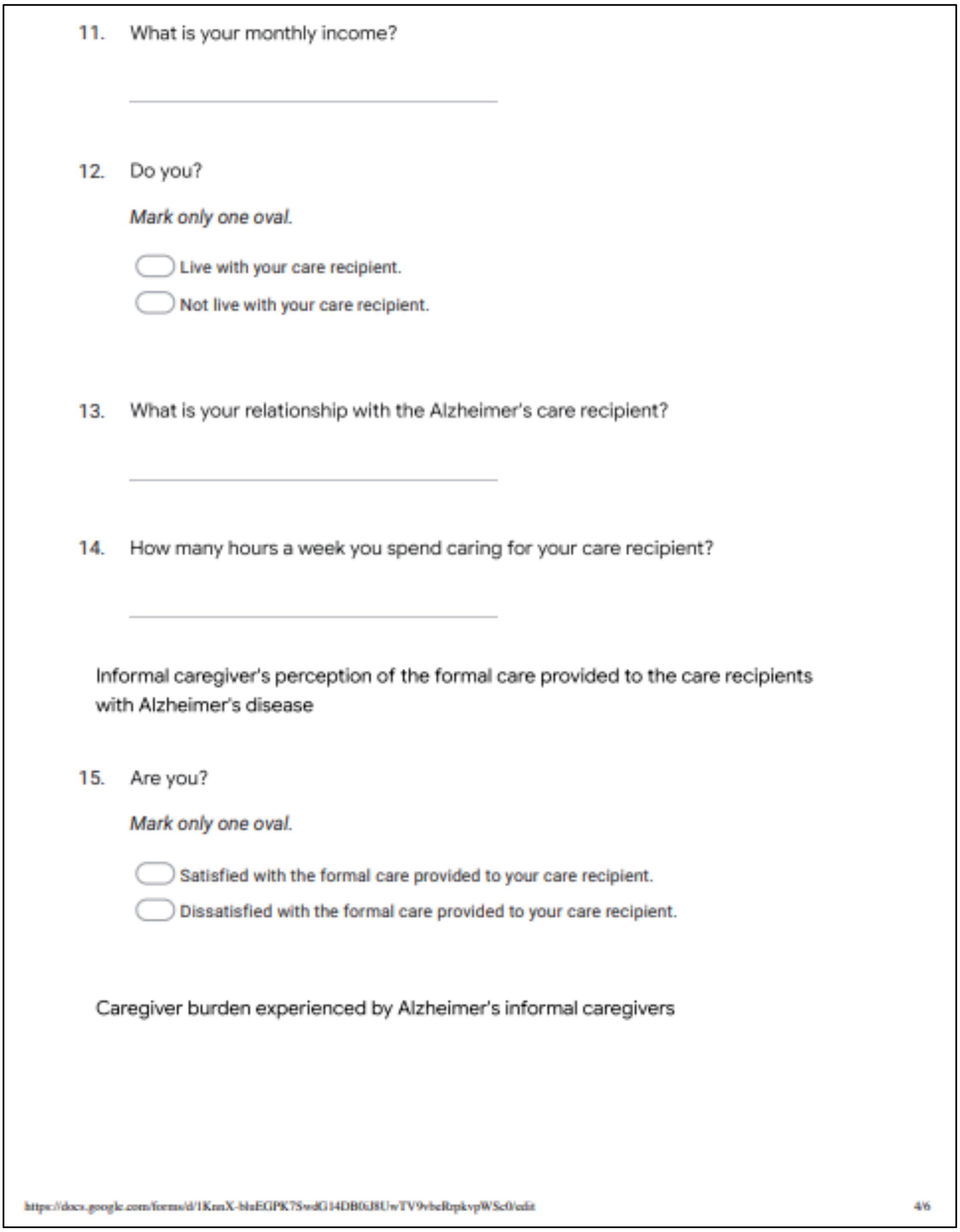
Mark only one oval.

○ Married
○ Single
○ Separated
○ Divorced
○ Widowed

10. Are you?

Mark only one oval.

○ Employed
○ Unemployed



11. What is your monthly income?

12. Do you?

Mark only one oval.

○ Live with your care recipient.
○ Not live with your care recipient.

13. What is your relationship with the Alzheimer's care recipient?

14. How many hours a week you spend caring for your care recipient?

Informal caregiver's perception of the formal care provided to the care recipients with Alzheimer's disease

15. Are you?

Mark only one oval.

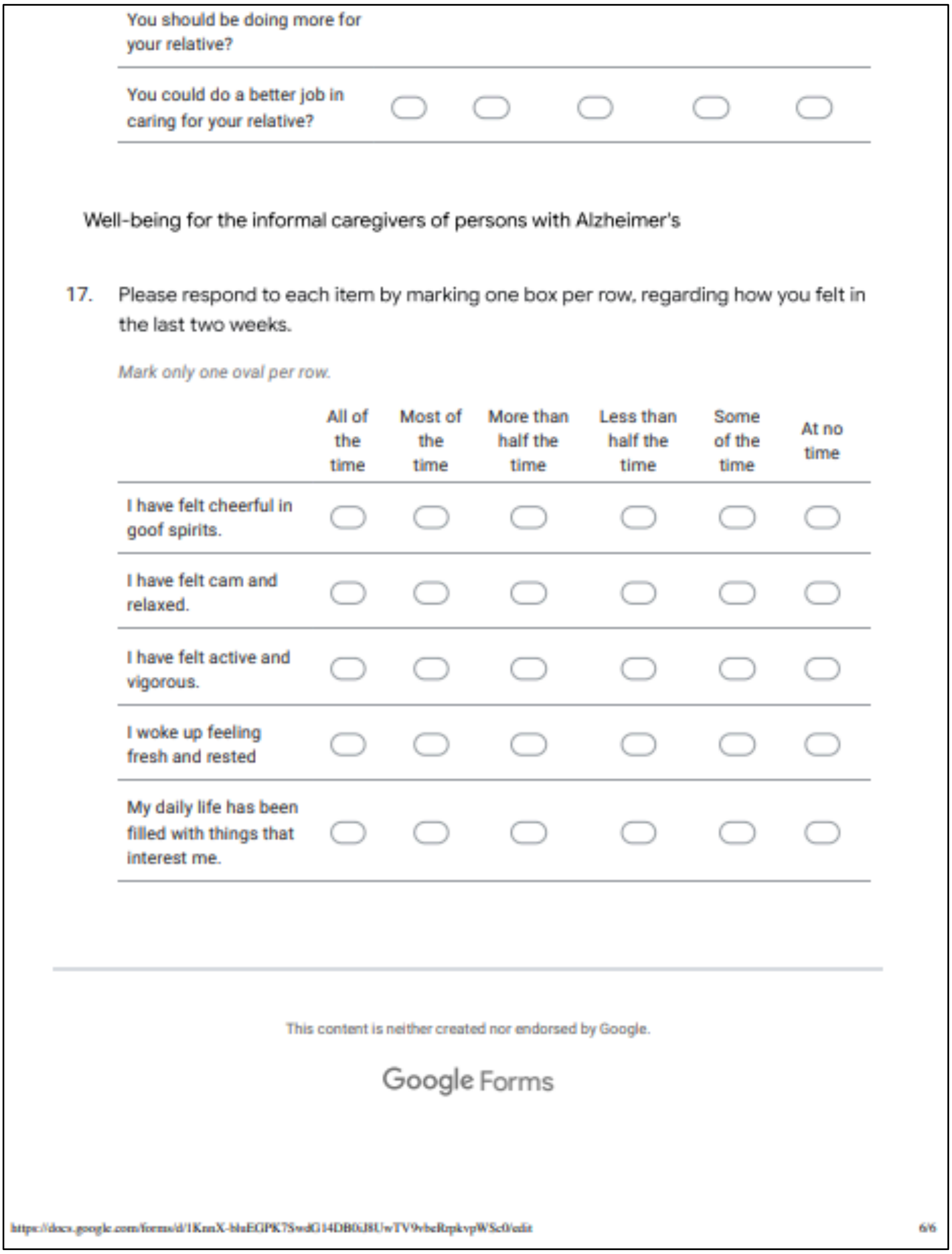
○ Satisfied with the formal care provided to your care recipient.
○ Dissatisfied with the formal care provided to your care recipient.

Caregiver burden experienced by Alzheimer's informal caregivers

16. Do you feel

Mark only one oval per row.

	"Never" (0)	"Rarely" (1)	"Sometimes" (2)	"Quite frequently" (3)	"Nearly always" (4)
That because of the time you spend with your relative that you do not have enough time for yourself?	○	○	○	○	○
Stressed between caring for your relative and trying t meet other responsibilities (work/family)?	○	○	○	○	○
Angry when you are around your relative?	○	○	○	○	○
That your relative currently affects your relationship with family members or friends in a negative way?	○	○	○	○	○
Strained when you are around your relative?	○	○	○	○	○
That your health has suffered because if your involvement with your relative?	○	○	○	○	○
That you do not have as much privacy as you would like because of your relative?	○	○	○	○	○
That your social life has suffered because you are caring for your relative?	○	○	○	○	○
That you have lost control of your life since your relative's illness?	○	○	○	○	○
Uncertain about what to do about your relative?	○	○	○	○	○



You should be doing more for your relative?					
You could do a better job in caring for your relative?	○	○	○	○	○

Well-being for the informal caregivers of persons with Alzheimer's

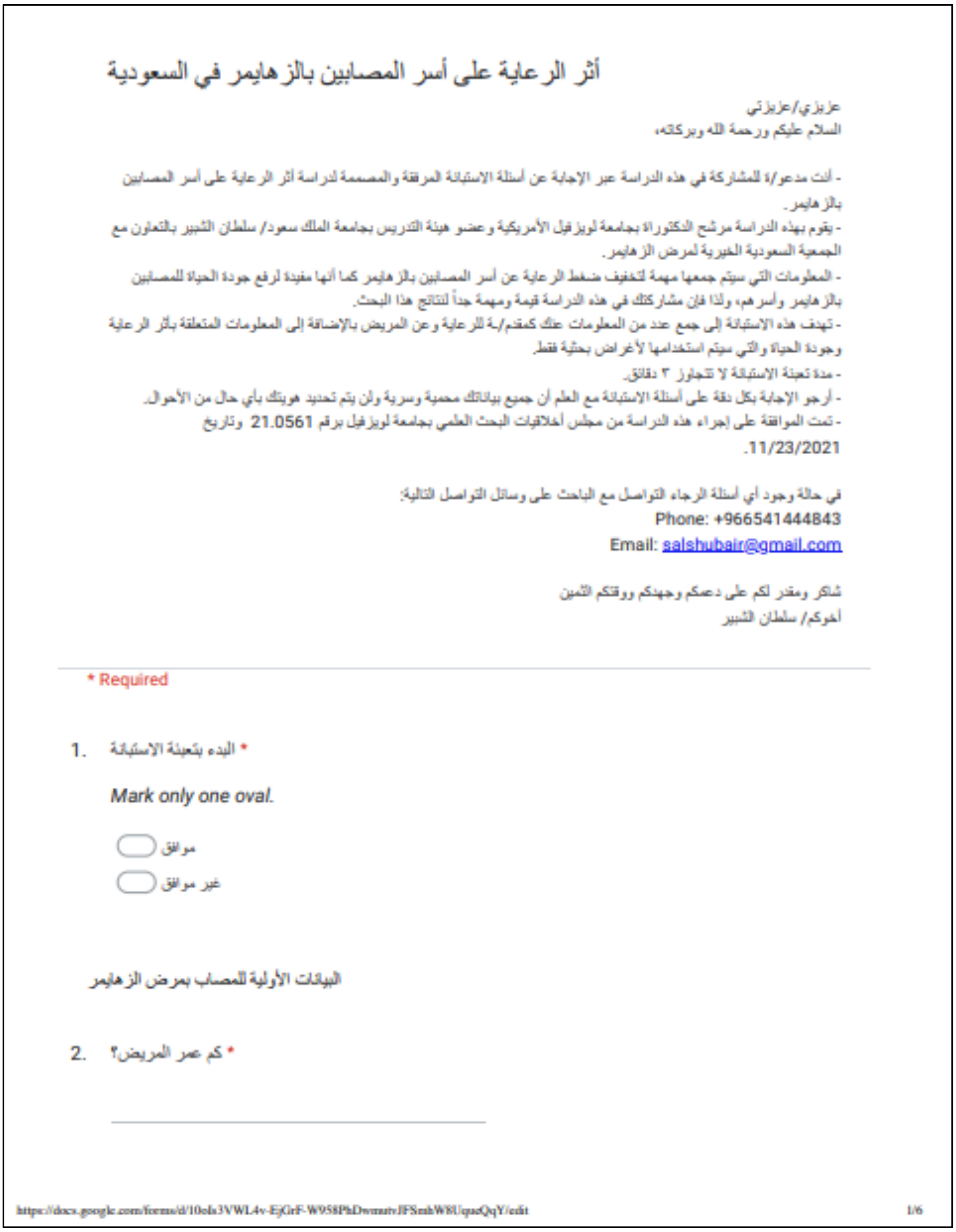
17. Please respond to each item by marking one box per row, regarding how you felt in the last two weeks.

Mark only one oval per row.

	All of the time	Most of the time	More than half the time	Less than half the time	Some of the time	At no time
I have felt cheerful in goof spirits.	○	○	○	○	○	○
I have felt cam and relaxed.	○	○	○	○	○	○
I have felt active and vigorous.	○	○	○	○	○	○
I woke up feeling fresh and rested	○	○	○	○	○	○
My daily life has been filled with things that interest me.	○	○	○	○	○	○

Google Forms

Appendix B



أثر الرعاية على أسر المصابين بالزهايمر في السعودية

عزيزي/عزيزتي
السلام عليكم ورحمة الله وبركاته،

- أنت مدعو/ة للمشاركة في هذه الدراسة عبر الإجابة عن أسئلة الاستبانة المرفقة والمصممة لدراسة أثر الرعاية على أسر المصابين بالزهايمر.
- يقوم بهذه الدراسة مرشح الدكتوراة بجامعة لويزفيل الأمريكية وعضو هيئة التدريس بجامعة الملك سعود/ سلطان الشبير بالتعاون مع الجمعية السعودية الخيرية لمرض الزهايمر.
- المعلومات التي سيتم جمعها مهمة لتخفيف ضغط الرعاية عن أسر المصابين بالزهايمر كما أنها مفيدة لرفع جودة الحياة للمصابين بالزهايمر وأسرهم، ولذا فإن مشاركتك في هذه الدراسة قيمة ومهمة جداً لنتائج هذا البحث.
- تهدف هذه الاستبانة إلى جمع عدد من المعلومات عنك كمقدم/ـة للرعاية وعن المريض بالإضافة إلى المعلومات المتعلقة بأثر الرعاية وجودة الحياة والتي سيتم استخدامها لأغراض بحثية فقط.
- مدة تعبئة الاستبانة لا تتجاوز ٣ دقائق.
- أرجو الإجابة بكل دقة على أسئلة الاستبانة مع العلم أن جميع بياناتك محمية وسرية ولن يتم تحديد هويتك بأي حال من الأحوال.
- تمت الموافقة على إجراء هذه الدراسة من مجلس أخلاقيات البحث العلمي بجامعة لويزفيل برقم 21.0561 وتاريخ 11/23/2021.

في حالة وجود أي أسئلة الرجاء التواصل مع الباحث على وسائل التواصل التالية:
Phone: +966541444843
Email: salshubair@gmail.com

شاكر ومقدر لكم على دعمكم وجهدكم ووقتكم الثمين
أخوكم/ سلطان الشبير

* Required

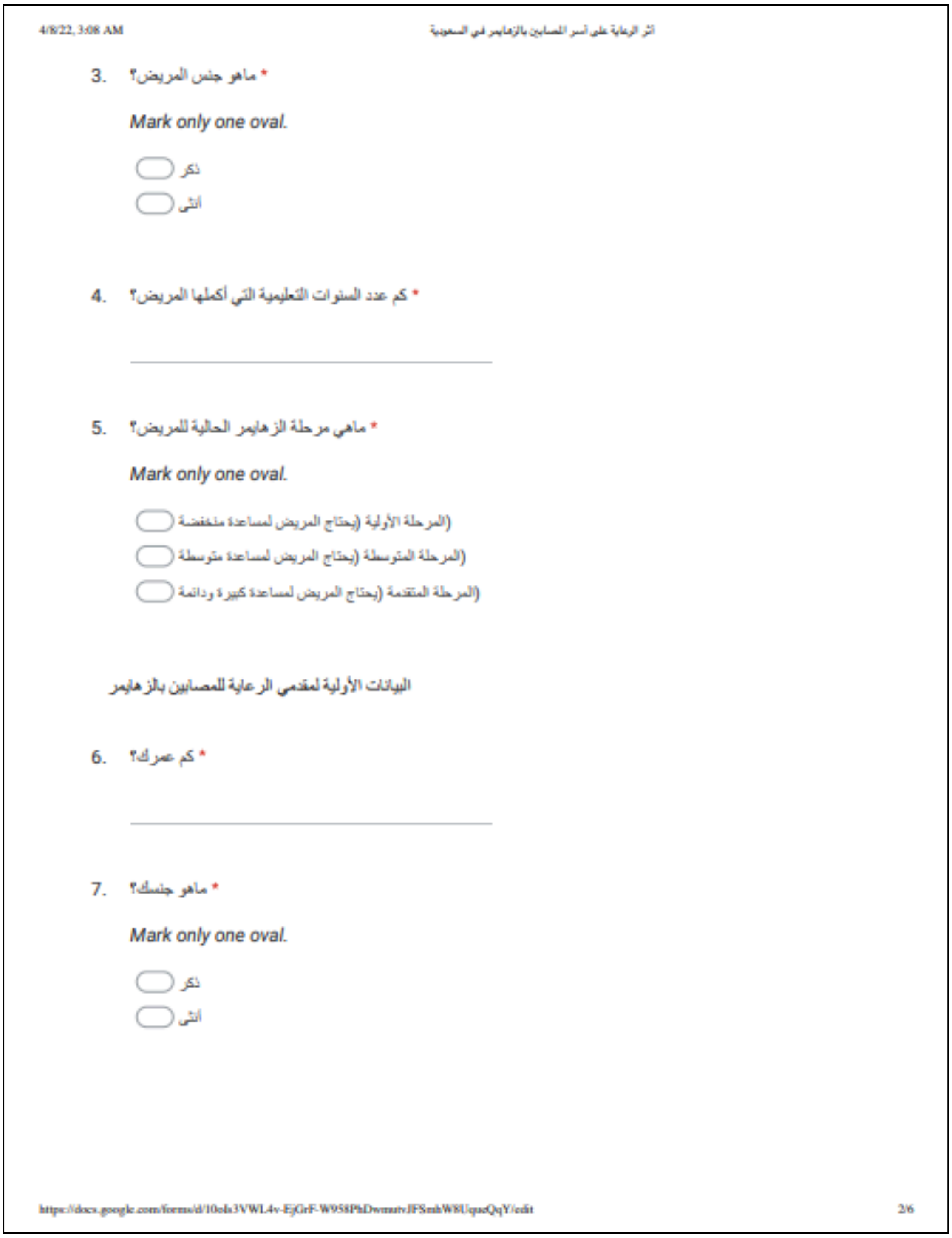
1. البدء بتعبئة الاستبانة *

Mark only one oval.

○ موافق
○ غير موافق

البيانات الأولية للمصاب بمرض الزهايمر

2. كم عمر المريض؟ *



4/8/22, 3:08 AM اثر الرعاية على أسر المصابين بالزهايمر في السعودية

3. ماهو جنس المريض؟ *

Mark only one oval.

○ ذكر
○ أنثى

4. كم عدد السنوات التعليمية التي أكملها المريض؟ *

____

5. ماهي مرحلة الزهايمر الحالية للمريض؟ *

Mark only one oval.

○ المرحلة الأولية (يحتاج المريض لمساعدة منخفضة)
○ المرحلة المتوسطة (يحتاج المريض لمساعدة متوسطة)
○ المرحلة المتقدمة (يحتاج المريض لمساعدة كبيرة ودائمة)

البيانات الأولية لمقدمي الرعاية للمصابين بالزهايمر

6. كم عمرك؟ *

____

7. ماهو جنسك؟ *

Mark only one oval.

○ ذكر
○ أنثى

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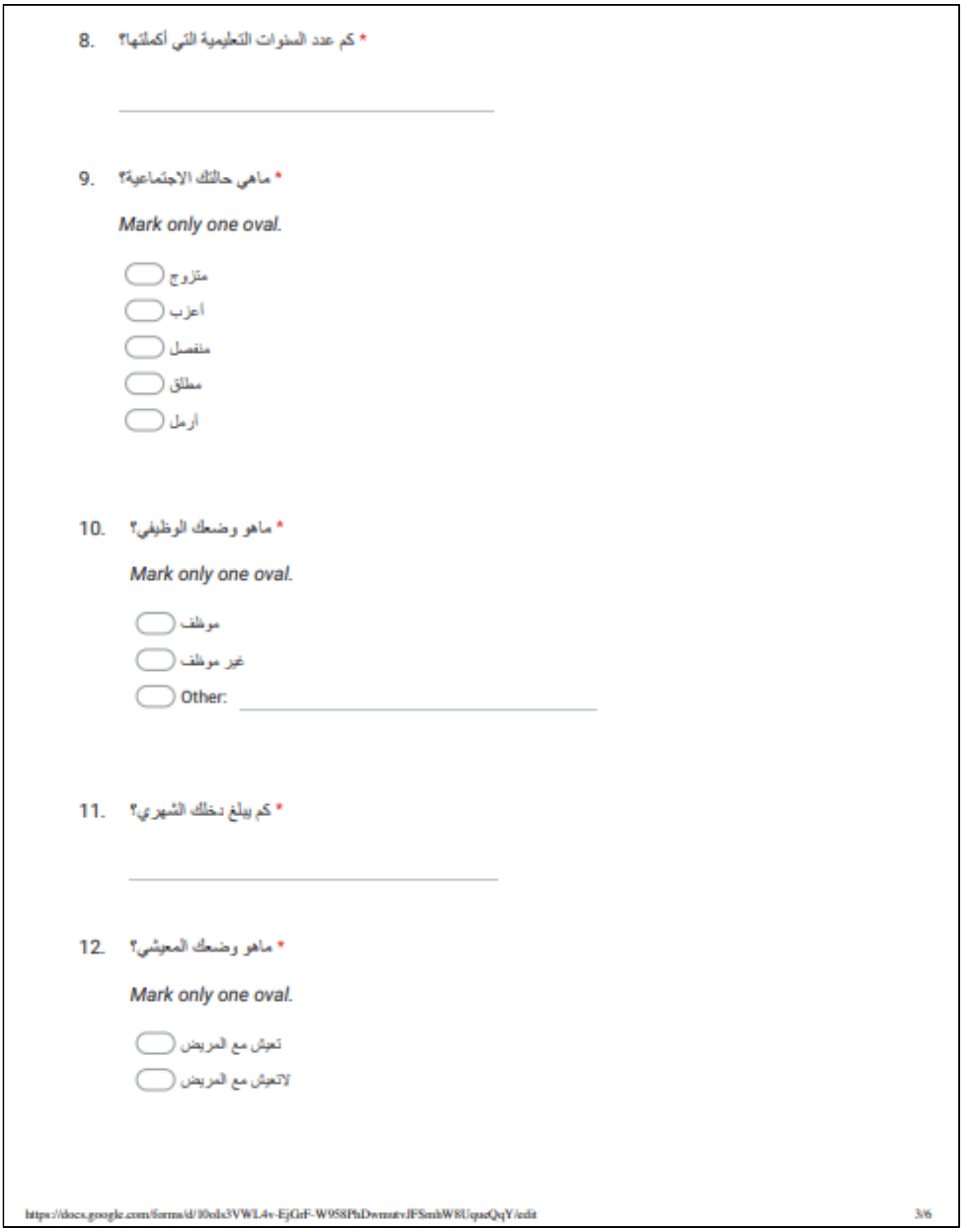

8. * كم عدد السنوات التعليمية التي أكملتها؟

____

9. * ماهي حالتك الاجتماعية؟

Mark only one oval.

○ متزوج
○ أعزب
○ منفصل
○ مطلق
○ أرمل

10. * ماهو وضعك الوظيفي؟

Mark only one oval.

○ موظف
○ غير موظف
○ Other: ______________________________

11. * كم يبلغ دخلك الشهري؟

____

12. * ماهو وضعك المعيشي؟

Mark only one oval.

○ تعيش مع المريض
○ لاتعيش مع المريض

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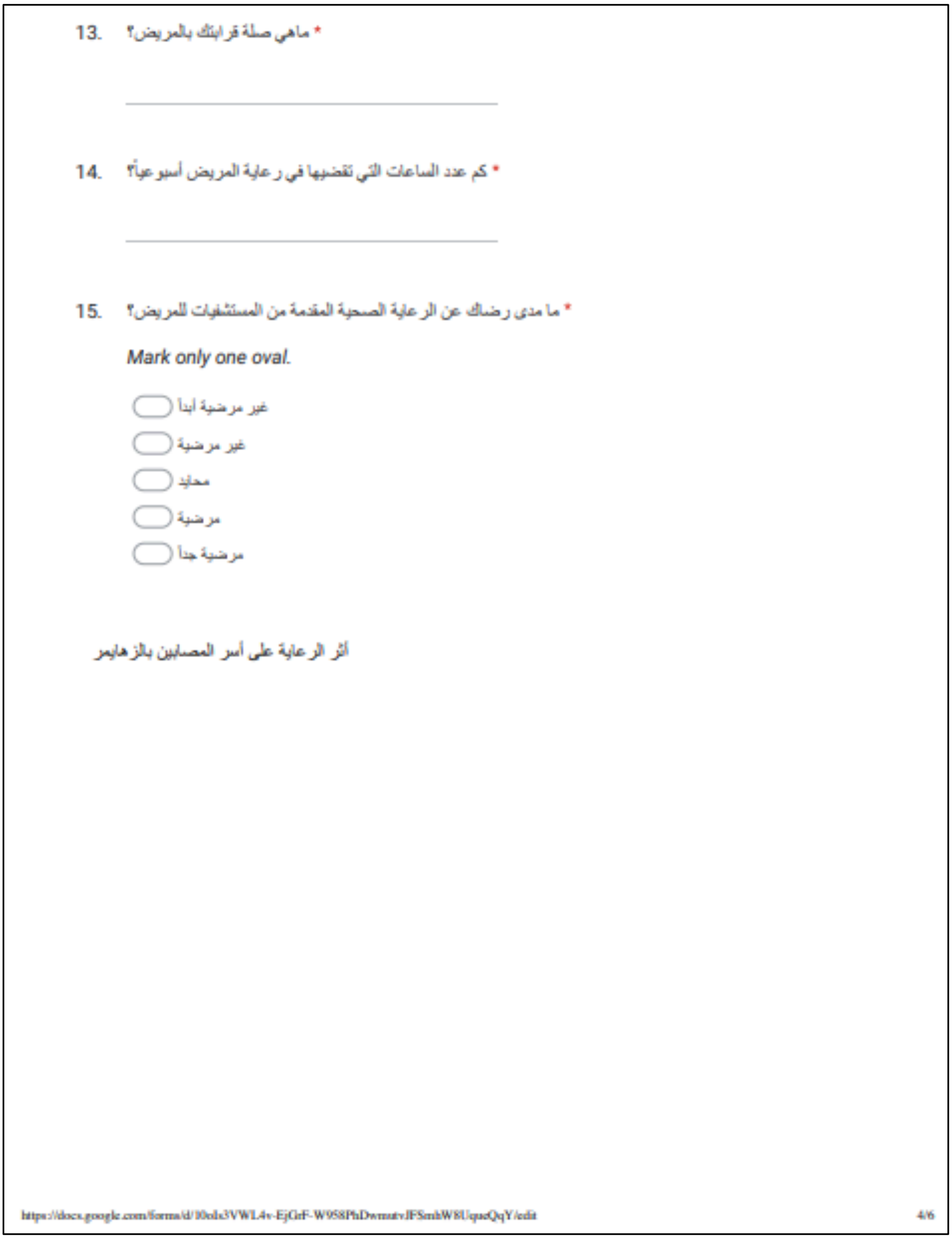

13. ماهي صلة قرابتك بالمريض؟ *

14. كم عدد الساعات التي تقضيها في رعاية المريض أسبوعياً؟ *

15. ما مدى رضاك عن الرعاية الصحية المقدمة من المستشفيات للمريض؟ *

Mark only one oval.

- ○ غير مرضية أبدا
- ○ غير مرضية
- ○ محايد
- ○ مرضية
- ○ مرضية جدا

أثر الرعاية على أسر المصابين بالزهايمر

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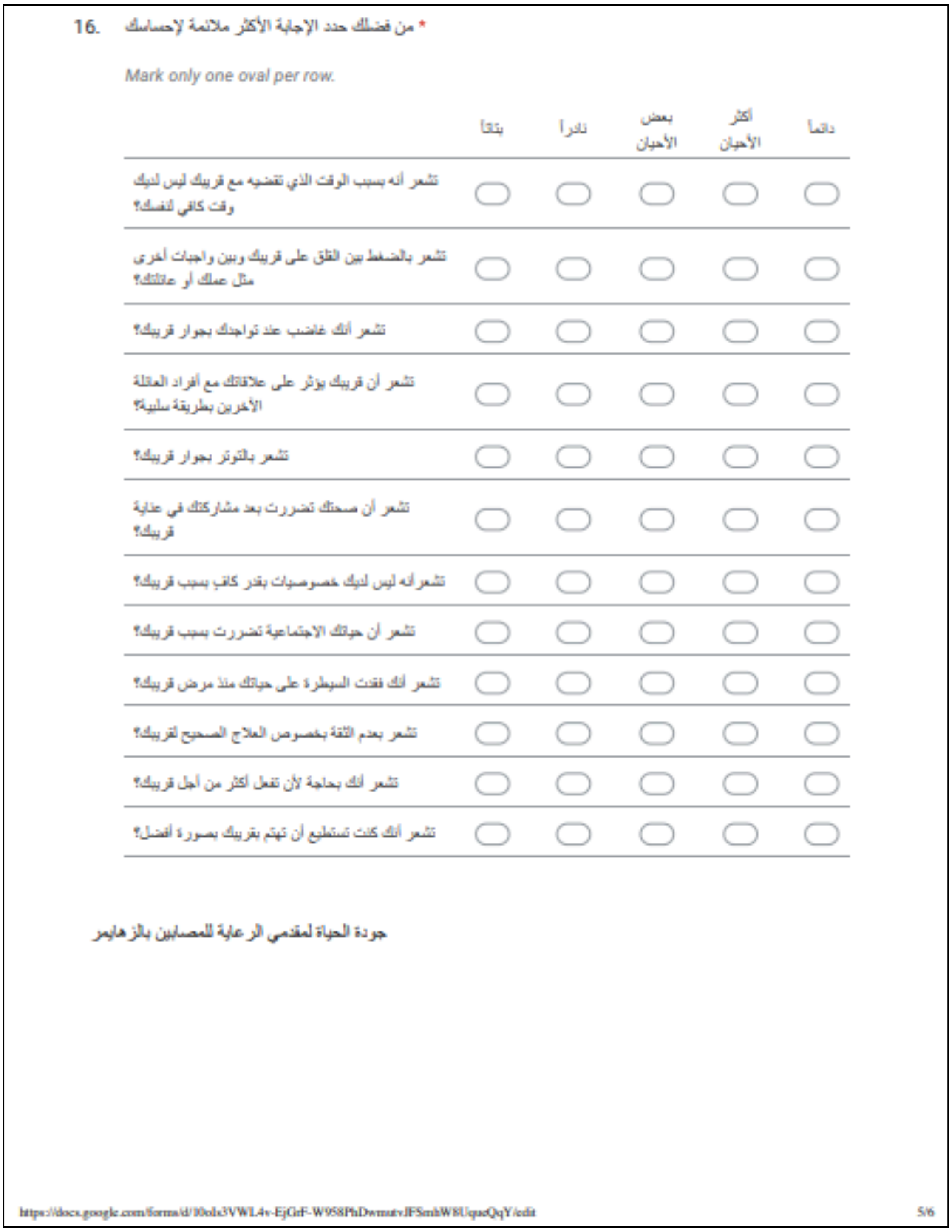

16. من فضلك حدد الإجابة الأكثر ملائمة لإحساسك *

Mark only one oval per row.

دائما	أكثر الأحيان	بعض الأحيان	نادرا	بتاتا	
○	○	○	○	○	تشعر أنه بسبب الوقت الذي تقضيه مع قريبك ليس لديك وقت كافي لنفسك؟
○	○	○	○	○	تشعر بالضغط بين القلق على قريبك وبين واجبات أخرى مثل عملك أو عائلتك؟
○	○	○	○	○	تشعر أنك غاضب عند تواجدك بجوار قريبك؟
○	○	○	○	○	تشعر أن قريبك يؤثر على علاقاتك مع أفراد العائلة الأخرين بطريقة سلبية؟
○	○	○	○	○	تشعر بالتوتر بجوار قريبك؟
○	○	○	○	○	تشعر أن صحتك تضررت بعد مشاركتك في عناية قريبك؟
○	○	○	○	○	تشعر أنه ليس لديك خصوصيات بقدر كاف بسبب قريبك؟
○	○	○	○	○	تشعر أن حياتك الاجتماعية تضررت بسبب قريبك؟
○	○	○	○	○	تشعر أنك فقدت السيطرة على حياتك منذ مرض قريبك؟
○	○	○	○	○	تشعر بعدم الثقة بخصوص العلاج الصحيح لقريبك؟
○	○	○	○	○	تشعر أنك بحاجة لأن تفعل أكثر من أجل قريبك؟
○	○	○	○	○	تشعر أنك كنت تستطيع أن تهتم بقريبك بصورة أفضل؟

جودة الحياة لمقدمي الرعاية للمصابين بالزهايمر

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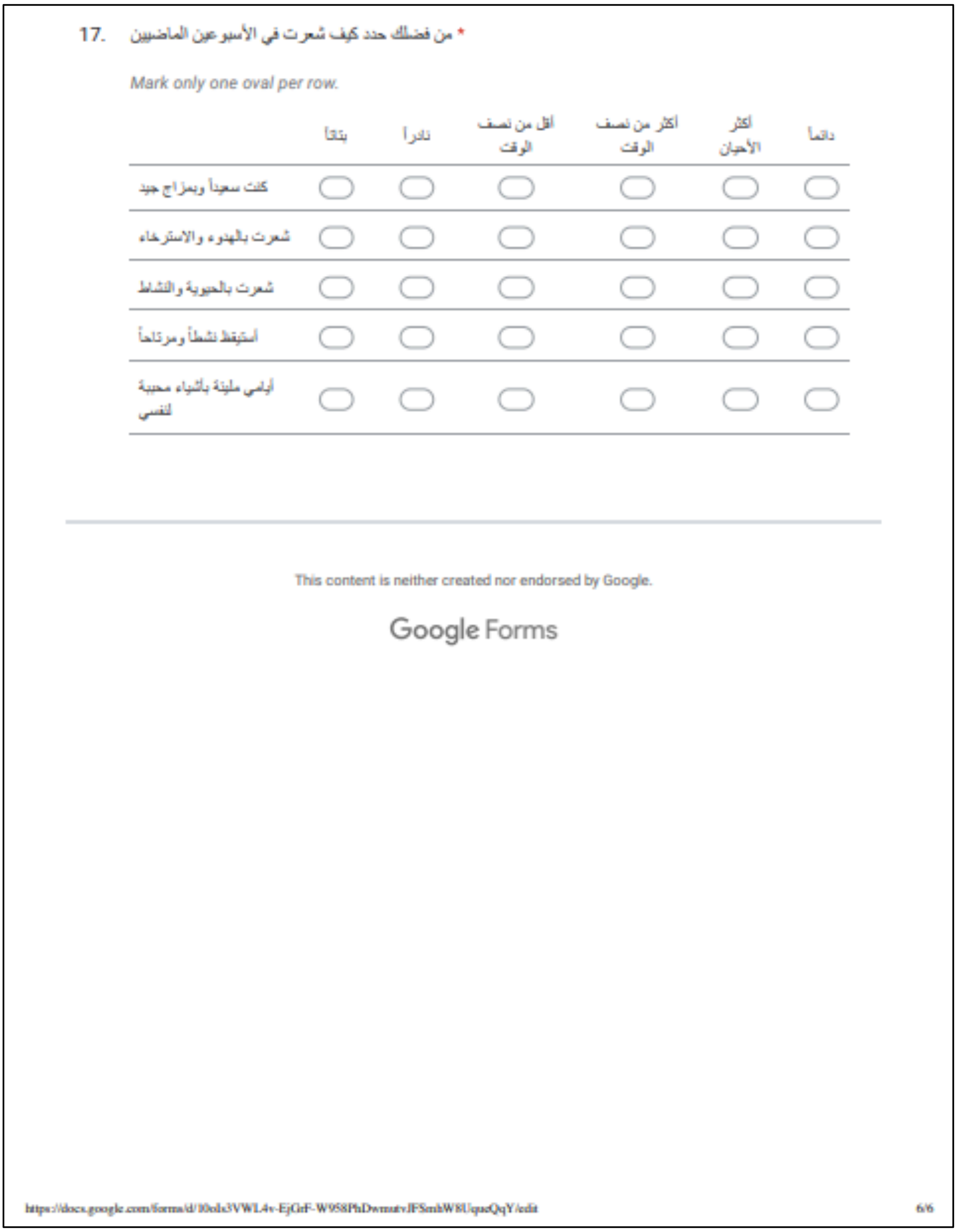

17. * من فضلك حدد كيف شعرت في الأسبوعين الماضيين

Mark only one oval per row.

دائما	أكثر الأحيان	أكثر من نصف الوقت	أقل من نصف الوقت	نادرا	بتاتا	
○	○	○	○	○	○	كنت سعيداً وبمزاج جيد
○	○	○	○	○	○	شعرت بالهدوء والاسترخاء
○	○	○	○	○	○	شعرت بالحيوية والنشاط
○	○	○	○	○	○	أستيقظ نشطاً ومرتاحاً
○	○	○	○	○	○	أيامي مليئة بأشياء محببة لنفسي

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Appendix C

Approval from the Saudi Alzheimer's Disease Association

الجمعية السعودية
الخيرية لمرض الزهايمر
SAUDI ALZHEIMER'S DISEASE ASSOCIATION

الرقم:ج.ز/٤٢/٢٣٢
التاريخ:١٤٤٣/٠٢/٢٩هـ
الموافق:٢٠٢١/١٠/٠٦م

الموضوع: موافقة على نشر الاستبيان

إن جمعيتكم الجمعية السعودية الخيرية لمرض ألزهايمر هي الأولى من نوعها التي تعنى بالمصابين بمرض ألزهايمر في الخليج تحت مظلة ودعم وزارة الموارد البشرية والتنمية الاجتماعية ومسجلة برقم (٤٩١)، ومن أهم أهدافها الرئيسية المتمثلة برفع مستوى الوعي الصحي والنفسي والاجتماعي هو دعم الأبحاث والدراسات المتعلقة بمرض ألزهايمر، والتعاون مع الباحثين في المجال الطبي والنفسي والاجتماعي لما يعود بالنفع ومصلحة هذا الوطن الغالي.

إشارةً إلى خطابكم بتاريخ ٢٩-٠٦-٢٠٢١م، بشأن موضوع الدراسة أدناه، وبعد الاطلاع على تفاصيل الاستبيان كاملاً فإننا نفيدكم بسرية بيانات المستفيدين لدينا ولا يمكن الاطلاع عليها إلا من قبل الجمعية ومن خلالنا سيتم إرسال الاستبيان لقاعدة البيانات، ولذا نفيدكم بموافقة الجمعية السعودية الخيرية لمرض ألزهايمر على التعاون مع الباحث من خلال نشر وتعميم الاستبيان البحثي المصمم لغرض الدراسة بناءً على طلبه، حيث أنه يحتوي على أسئلة وبيانات عامة لا تتضمن معلومات شخصية/سرية للمرضى أو مقدمي الرعاية ضمن المرفقات المرسلة من خلالكم.

عنوان الدراسة:	**محددات عبء الرعاية الذي يواجه مقدمي الرعاية لمرضى ألزهايمر في المملكة العربية السعودية.**
عينة الدراسة:	**الأسر التي تقدم الرعاية لمرضى ألزهايمر.**
الجامعة:	**لويزفل/ الولايات المتحدة الأمريكية**
أسم الباحث:	**سلطان بن علي الشبير**

هذا ولكم جزيل الشكر والتقدير،،،

المرفقات:
- **الاستبيان البحثي**

رنا المرعي
المدير التنفيذي

أعضاء الجمعية مقدمي الرعاية المتطوعين
مسجلة بوزارة الموارد البشرية والتنمية الاجتماعية برقم (٤٩١)
Ministry of Labor and Social DevelopmentNo (491)

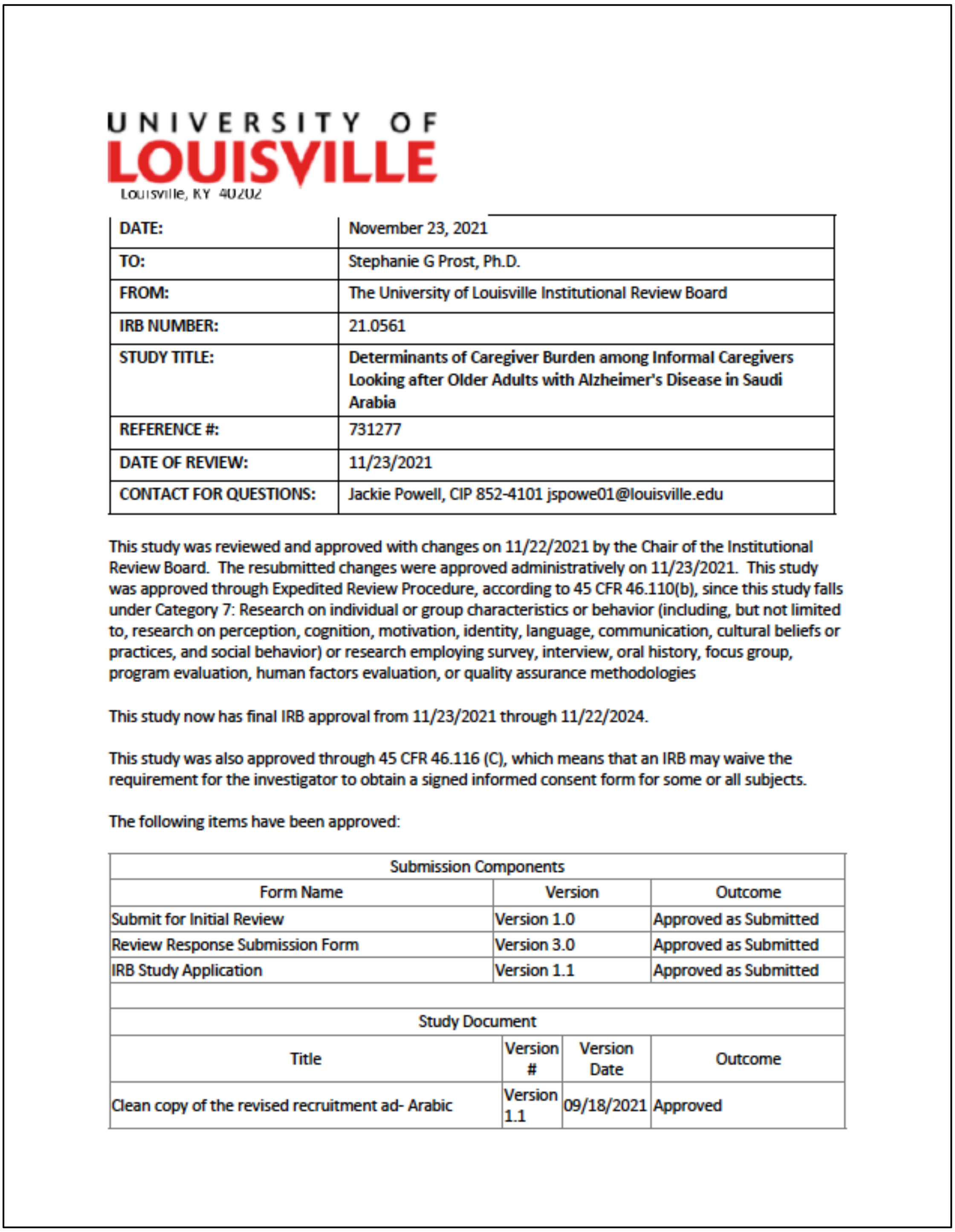
@Saudialzheimer
@Saudialzheimer
Saudialzheimer

www.alz.org.sa

ص.ب ١٤٩١٩ الرياض ١١٤٣٤ المملكة العربية السعودية
P.O.BOX 14919 Riyadh 11434 Kingdom of Saudi Arabia
T: +966112143838/+966114100112 F: +966112170904

Appendix D

IRB Approvals from the University of Louisville



UNIVERSITY OF
LOUISVILLE
Louisville, KY 40202

DATE:	November 23, 2021
TO:	Stephanie G Prost, Ph.D.
FROM:	The University of Louisville Institutional Review Board
IRB NUMBER:	21.0561
STUDY TITLE:	**Determinants of Caregiver Burden among Informal Caregivers Looking after Older Adults with Alzheimer's Disease in Saudi Arabia**
REFERENCE #:	731277
DATE OF REVIEW:	11/23/2021
CONTACT FOR QUESTIONS:	Jackie Powell, CIP 852-4101 jspowe01@louisville.edu

This study was reviewed and approved with changes on 11/22/2021 by the Chair of the Institutional Review Board. The resubmitted changes were approved administratively on 11/23/2021. This study was approved through Expedited Review Procedure, according to 45 CFR 46.110(b), since this study falls under Category 7: Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies

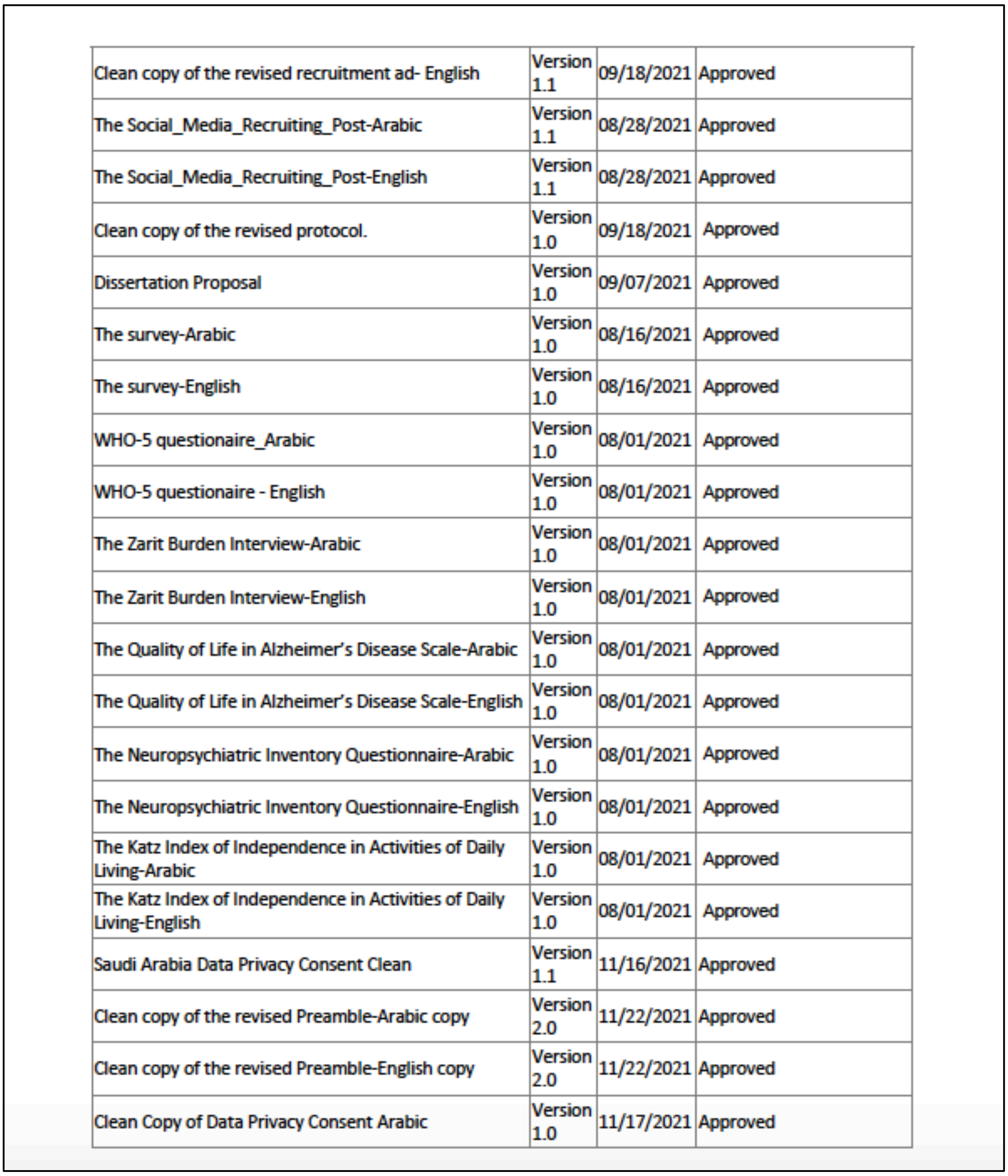
This study now has final IRB approval from 11/23/2021 through 11/22/2024.

This study was also approved through 45 CFR 46.116 (C), which means that an IRB may waive the requirement for the investigator to obtain a signed informed consent form for some or all subjects.

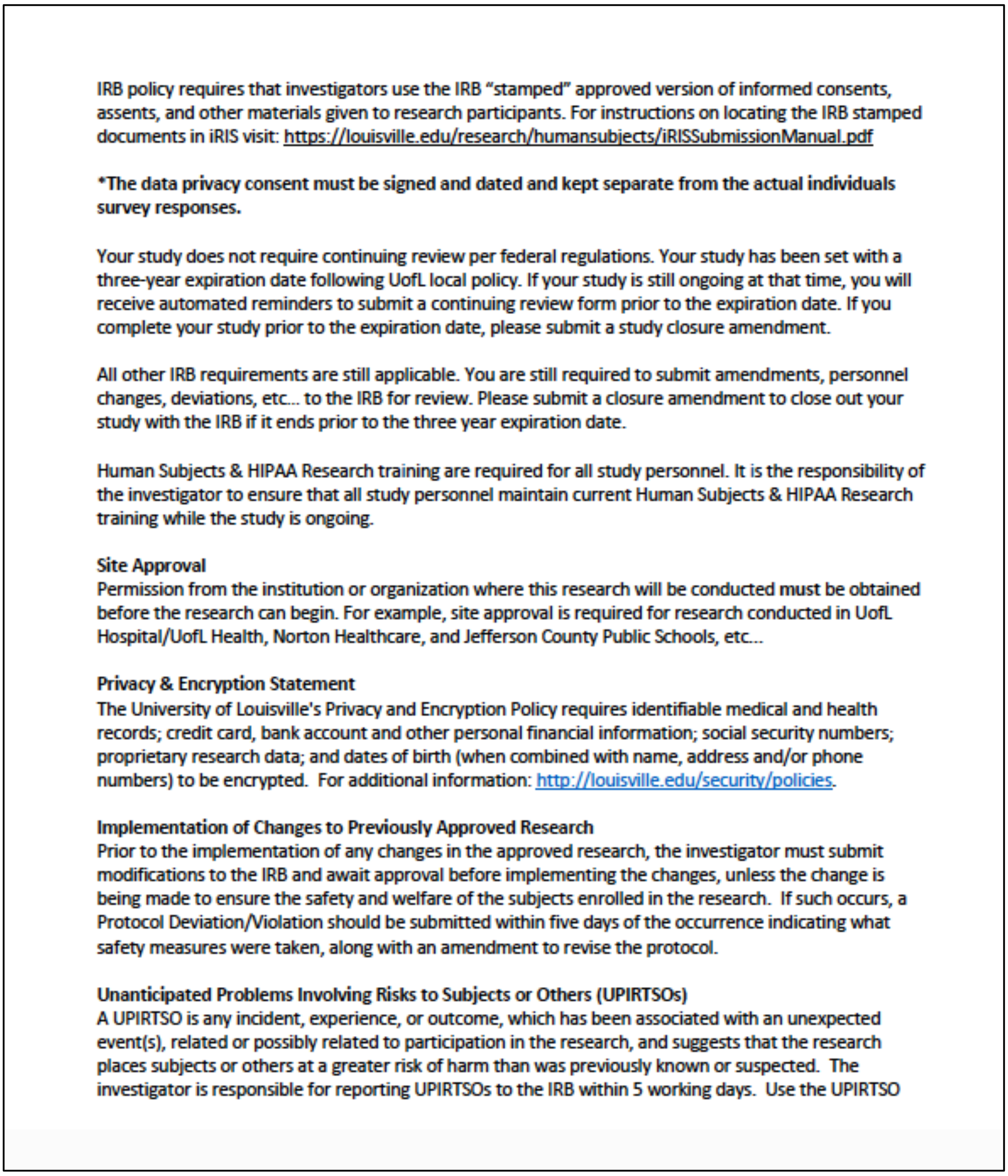
The following items have been approved:

Submission Components		
Form Name	Version	Outcome
Submit for Initial Review	Version 1.0	Approved as Submitted
Review Response Submission Form	Version 3.0	Approved as Submitted
IRB Study Application	Version 1.1	Approved as Submitted

Study Document			
Title	Version #	Version Date	Outcome
Clean copy of the revised recruitment ad- Arabic	Version 1.1	09/18/2021	Approved



Clean copy of the revised recruitment ad- English	Version 1.1	09/18/2021	Approved
The Social_Media_Recruiting_Post-Arabic	Version 1.1	08/28/2021	Approved
The Social_Media_Recruiting_Post-English	Version 1.1	08/28/2021	Approved
Clean copy of the revised protocol.	Version 1.0	09/18/2021	Approved
Dissertation Proposal	Version 1.0	09/07/2021	Approved
The survey-Arabic	Version 1.0	08/16/2021	Approved
The survey-English	Version 1.0	08/16/2021	Approved
WHO-5 questionaire_Arabic	Version 1.0	08/01/2021	Approved
WHO-5 questionaire - English	Version 1.0	08/01/2021	Approved
The Zarit Burden Interview-Arabic	Version 1.0	08/01/2021	Approved
The Zarit Burden Interview-English	Version 1.0	08/01/2021	Approved
The Quality of Life in Alzheimer's Disease Scale-Arabic	Version 1.0	08/01/2021	Approved
The Quality of Life in Alzheimer's Disease Scale-English	Version 1.0	08/01/2021	Approved
The Neuropsychiatric Inventory Questionnaire-Arabic	Version 1.0	08/01/2021	Approved
The Neuropsychiatric Inventory Questionnaire-English	Version 1.0	08/01/2021	Approved
The Katz Index of Independence in Activities of Daily Living-Arabic	Version 1.0	08/01/2021	Approved
The Katz Index of Independence in Activities of Daily Living-English	Version 1.0	08/01/2021	Approved
Saudi Arabia Data Privacy Consent Clean	Version 1.1	11/16/2021	Approved
Clean copy of the revised Preamble-Arabic copy	Version 2.0	11/22/2021	Approved
Clean copy of the revised Preamble-English copy	Version 2.0	11/22/2021	Approved
Clean Copy of Data Privacy Consent Arabic	Version 1.0	11/17/2021	Approved



IRB policy requires that investigators use the IRB "stamped" approved version of informed consents, assents, and other materials given to research participants. For instructions on locating the IRB stamped documents in iRIS visit: https://louisville.edu/research/humansubjects/iRISSubmissionManual.pdf

***The data privacy consent must be signed and dated and kept separate from the actual individuals survey responses.**

Your study does not require continuing review per federal regulations. Your study has been set with a three-year expiration date following UofL local policy. If your study is still ongoing at that time, you will receive automated reminders to submit a continuing review form prior to the expiration date. If you complete your study prior to the expiration date, please submit a study closure amendment.

All other IRB requirements are still applicable. You are still required to submit amendments, personnel changes, deviations, etc… to the IRB for review. Please submit a closure amendment to close out your study with the IRB if it ends prior to the three year expiration date.

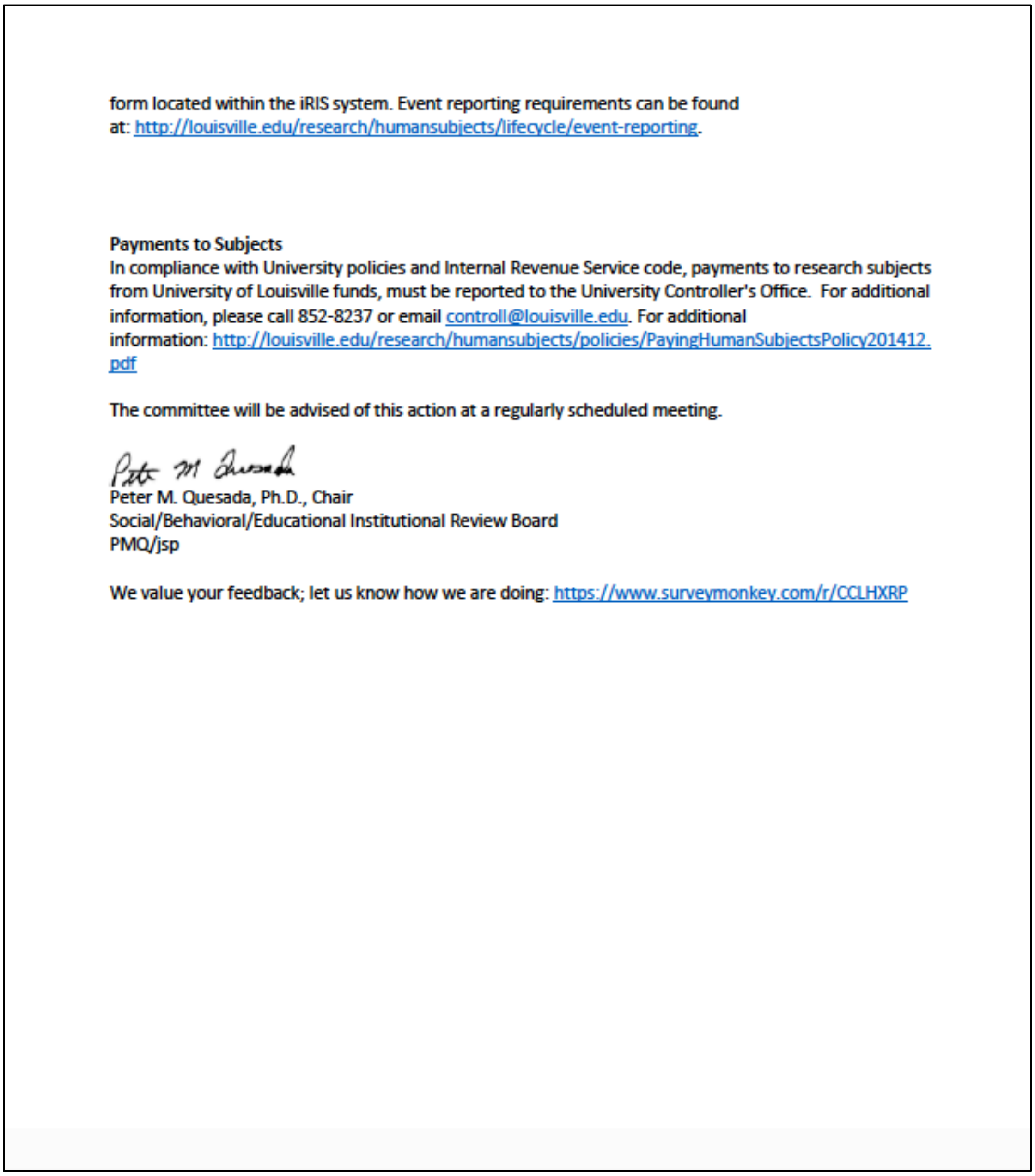
Human Subjects & HIPAA Research training are required for all study personnel. It is the responsibility of the investigator to ensure that all study personnel maintain current Human Subjects & HIPAA Research training while the study is ongoing.

Site Approval
Permission from the institution or organization where this research will be conducted must be obtained before the research can begin. For example, site approval is required for research conducted in UofL Hospital/UofL Health, Norton Healthcare, and Jefferson County Public Schools, etc…

Privacy & Encryption Statement
The University of Louisville's Privacy and Encryption Policy requires identifiable medical and health records; credit card, bank account and other personal financial information; social security numbers; proprietary research data; and dates of birth (when combined with name, address and/or phone numbers) to be encrypted. For additional information: http://louisville.edu/security/policies.

Implementation of Changes to Previously Approved Research
Prior to the implementation of any changes in the approved research, the investigator must submit modifications to the IRB and await approval before implementing the changes, unless the change is being made to ensure the safety and welfare of the subjects enrolled in the research. If such occurs, a Protocol Deviation/Violation should be submitted within five days of the occurrence indicating what safety measures were taken, along with an amendment to revise the protocol.

Unanticipated Problems Involving Risks to Subjects or Others (UPIRTSOs)
A UPIRTSO is any incident, experience, or outcome, which has been associated with an unexpected event(s), related or possibly related to participation in the research, and suggests that the research places subjects or others at a greater risk of harm than was previously known or suspected. The investigator is responsible for reporting UPIRTSOs to the IRB within 5 working days. Use the UPIRTSO



form located within the iRIS system. Event reporting requirements can be found at: http://louisville.edu/research/humansubjects/lifecycle/event-reporting.

Payments to Subjects
In compliance with University policies and Internal Revenue Service code, payments to research subjects from University of Louisville funds, must be reported to the University Controller's Office. For additional information, please call 852-8237 or email controll@louisville.edu. For additional information: http://louisville.edu/research/humansubjects/policies/PayingHumanSubjectsPolicy201412.pdf

The committee will be advised of this action at a regularly scheduled meeting.

Peter M. Quesada, Ph.D., Chair
Social/Behavioral/Educational Institutional Review Board
PMQ/jsp

We value your feedback; let us know how we are doing: https://www.surveymonkey.com/r/CCLHXRP

Appendix E

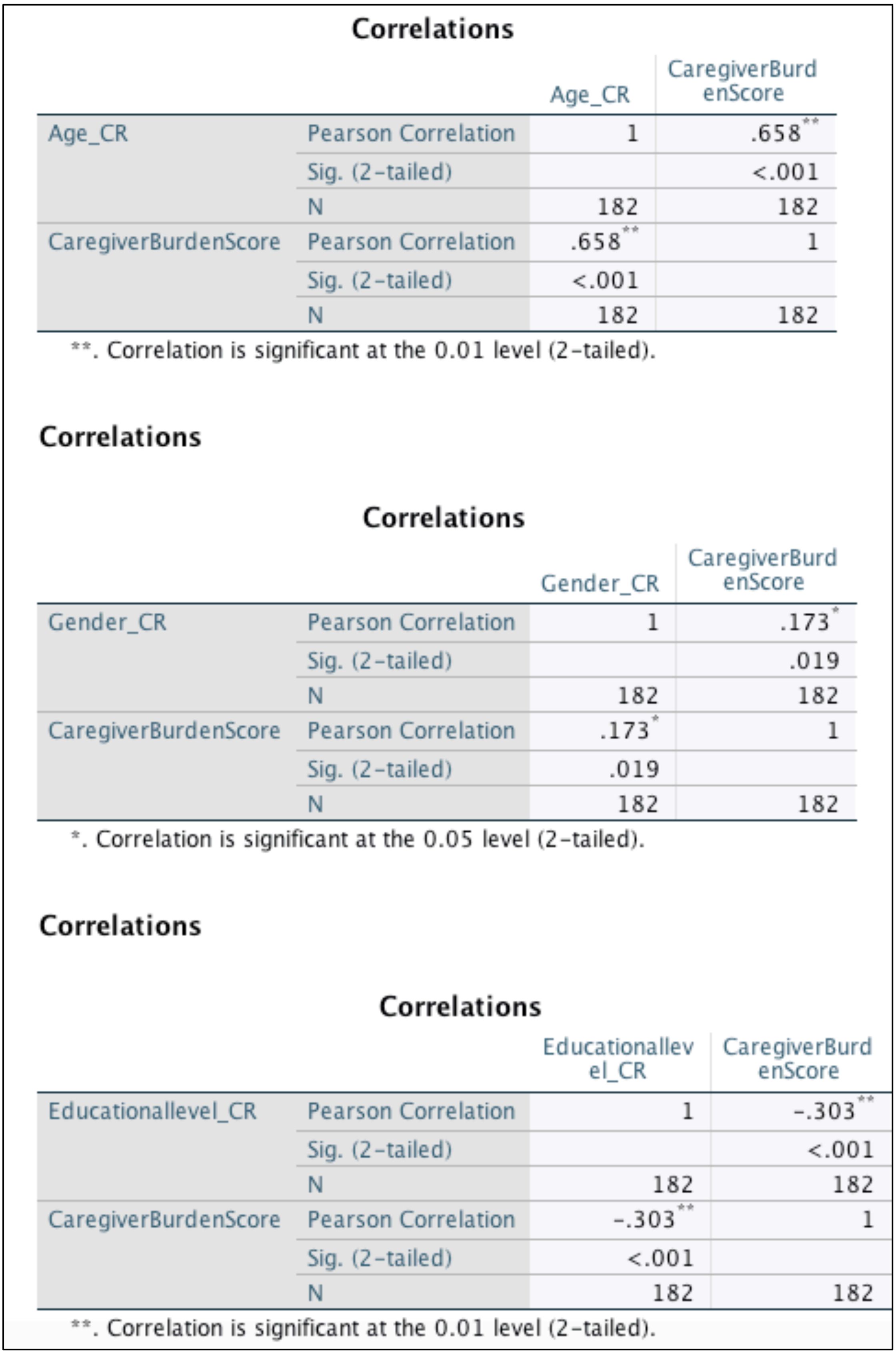
Recategorization of Some of the Study Variables

Initial categorization	**(*n* = 182)**	**Recategorization**	**(*n* = 182)**
Care recipient factors (N = 182)			
Educational level, *n* (%)		**Educational level, *n* (%)**	
No formal education	101 (55.5)	Did not obtain any formal education	101 (55.5)
<14 years of formal education	58 (31.9)	Obtained a formal education	81 (44.5)
≥14 years of formal education	23 (12.6)		
Stage of AD, *n* (%)		**Stage of AD, *n* (%)**	
Mild stage	22 (12.1)	Non-severe stage	77 (42.3)
Moderate stage	55 (30.2)	Severe stage	105 (57.7)
Severe stage	105 (57.7)		
Caregiver factors (N = 182)			
Marital status, *n* (%)		**Marital status, *n* (%)**	
Single	76 (41.8)	Married	97 (53.3)
Married	97 (53.3)	Non-married	85 (46.7)
Separated	03 (1.6)		
Divorced	04 (2.2)		
Widowed	02 (1.1)		
Employment status, *n* (%)		**Employment status, *n* (%)**	
Public employee	72 (39.6)	Employed	107 (58.8)
Private employee	29 (15.9)	Unemployed	75 (41.2)
Self-employed	06 (3.3)		
Retired	07 (3.8)		
Unemployed	68 (37.4)		
Monthly income, *n* (%)		**Monthly income, *n* (%)**	
Less than 2000 SR	65 (35.7)	<10000 Saudi Riyal per month	121 (66.5)
2000 to 3999 SR	31 (17.0)	≥10000 Saudi Riyal per month	61 (33.5)
4000 to 5999 SR	06 (3.3)		
6000 to 7999 SR	08 (4.4)		
8000 to 9999 SR	11 (6.0)		
10000 SR and above	61 (33.5)		
Hours of care per week, *n* (%)		**Hours of care per week, *n* (%)**	
1-10	29 (15.9)	< 31 hours of care per week	86 (47.3)
11-20	51 (28.0)	≥ 31 hours of care per week	96 (52.7)
21-30	06 (3.3)		
31-40	39 (21.4)		
41+	57 (31.3)		
Relationship with the care recipient, *n* (%)		**Relationship with the care recipient, *n* (%)**	
Daughter	103 (56.6)	A daughter of the care recipient	103 (56.6)
Son	62 (34.1)	Other relatives	79 (43.4)

Granddaughter	03 (1.6)
Grandson	01 (0.5)
Daughter-in-law	01 (0.5)
Niece	05 (2.7)
Sister	01 (0.5)
Wife	05 (2.7)
Husband	01 (0.5)

Appendix F

Results of Correlation Analyses (Research Questions 1-5)



Correlations

		Age_CR	CaregiverBurdenScore
Age_CR	Pearson Correlation	1	.658**
	Sig. (2-tailed)		<.001
	N	182	182
CaregiverBurdenScore	Pearson Correlation	.658**	1
	Sig. (2-tailed)	<.001	
	N	182	182

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

Correlations

Correlations

		Gender_CR	CaregiverBurdenScore
Gender_CR	Pearson Correlation	1	.173*
	Sig. (2-tailed)		.019
	N	182	182
CaregiverBurdenScore	Pearson Correlation	.173*	1
	Sig. (2-tailed)	.019	
	N	182	182

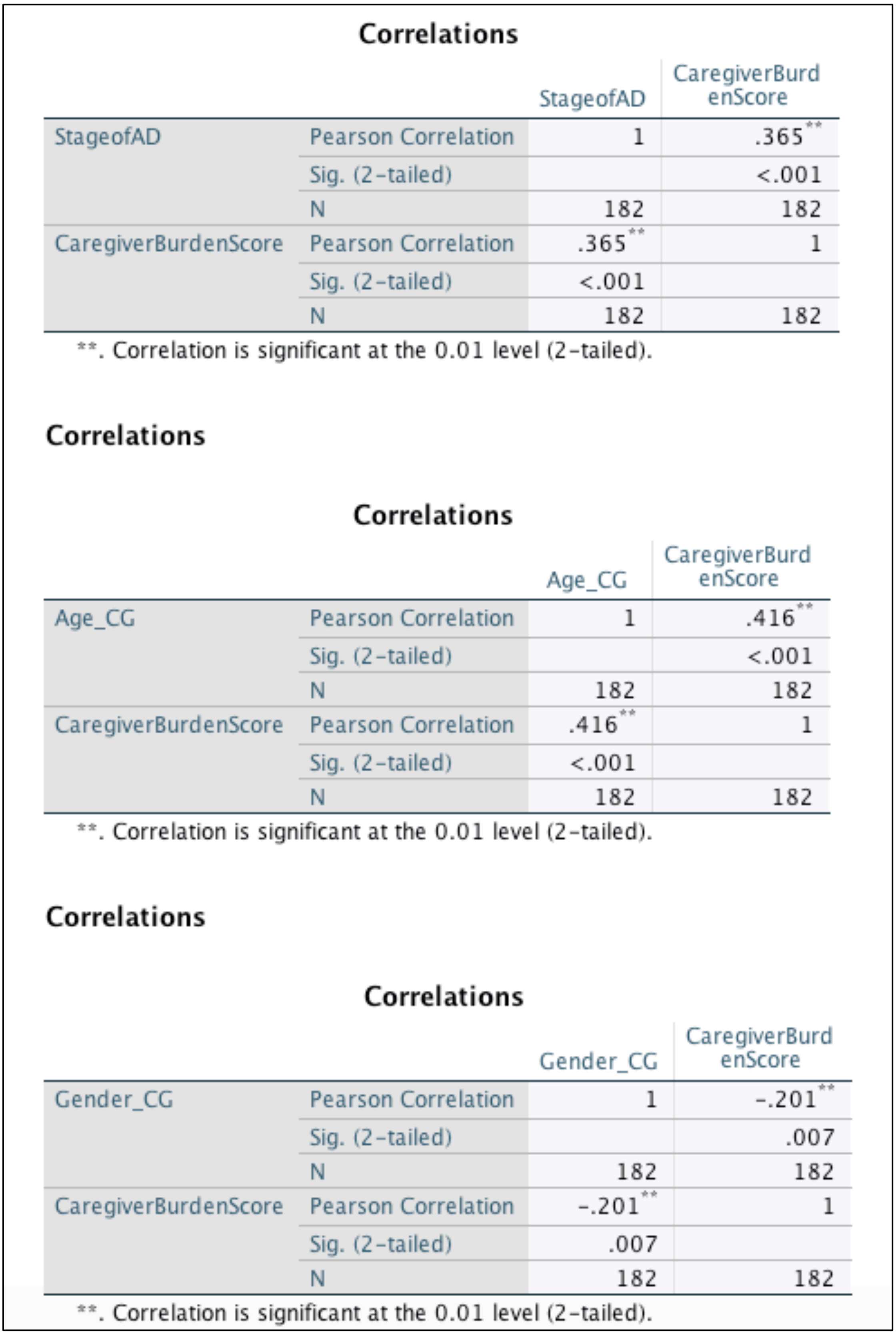
*. Correlation is significant at the 0.05 level (2-tailed).

Correlations

Correlations

		Educationallevel_CR	CaregiverBurdenScore
Educationallevel_CR	Pearson Correlation	1	-.303**
	Sig. (2-tailed)		<.001
	N	182	182
CaregiverBurdenScore	Pearson Correlation	-.303**	1
	Sig. (2-tailed)	<.001	
	N	182	182

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



Correlations

		StageofAD	CaregiverBurdenScore
StageofAD	Pearson Correlation	1	.365**
	Sig. (2-tailed)		<.001
	N	182	182
CaregiverBurdenScore	Pearson Correlation	.365**	1
	Sig. (2-tailed)	<.001	
	N	182	182

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

Correlations

Correlations

		Age_CG	CaregiverBurdenScore
Age_CG	Pearson Correlation	1	.416**
	Sig. (2-tailed)		<.001
	N	182	182
CaregiverBurdenScore	Pearson Correlation	.416**	1
	Sig. (2-tailed)	<.001	
	N	182	182

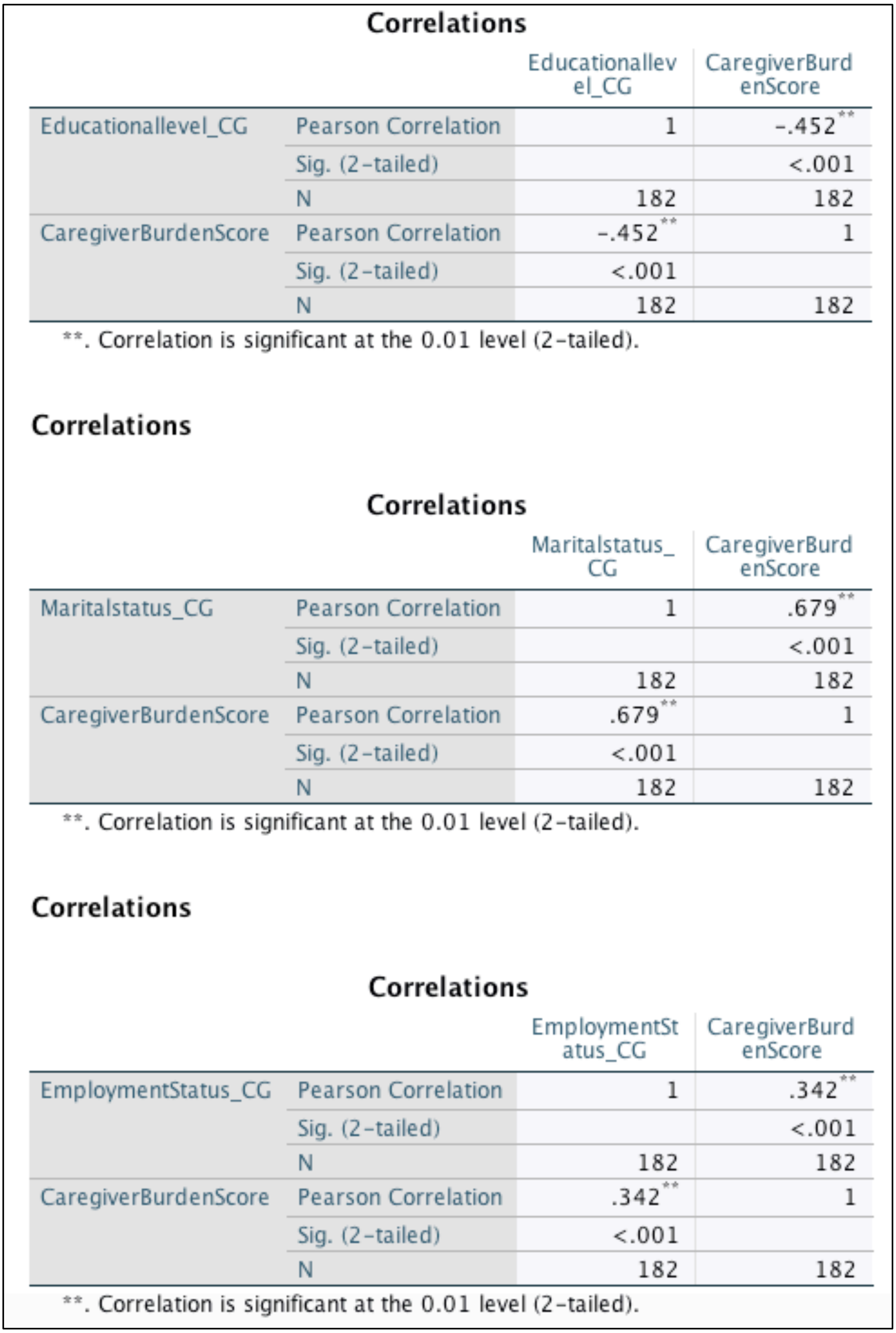
**. Correlation is significant at the 0.01 level (2-tailed).

Correlations

Correlations

		Gender_CG	CaregiverBurdenScore
Gender_CG	Pearson Correlation	1	-.201**
	Sig. (2-tailed)		.007
	N	182	182
CaregiverBurdenScore	Pearson Correlation	-.201**	1
	Sig. (2-tailed)	.007	
	N	182	182

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



Correlations

		Educationallevel_CG	CaregiverBurdenScore
Educationallevel_CG	Pearson Correlation	1	-.452**
	Sig. (2-tailed)		<.001
	N	182	182
CaregiverBurdenScore	Pearson Correlation	-.452**	1
	Sig. (2-tailed)	<.001	
	N	182	182

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

Correlations

Correlations

		Maritalstatus_CG	CaregiverBurdenScore
Maritalstatus_CG	Pearson Correlation	1	.679**
	Sig. (2-tailed)		<.001
	N	182	182
CaregiverBurdenScore	Pearson Correlation	.679**	1
	Sig. (2-tailed)	<.001	
	N	182	182

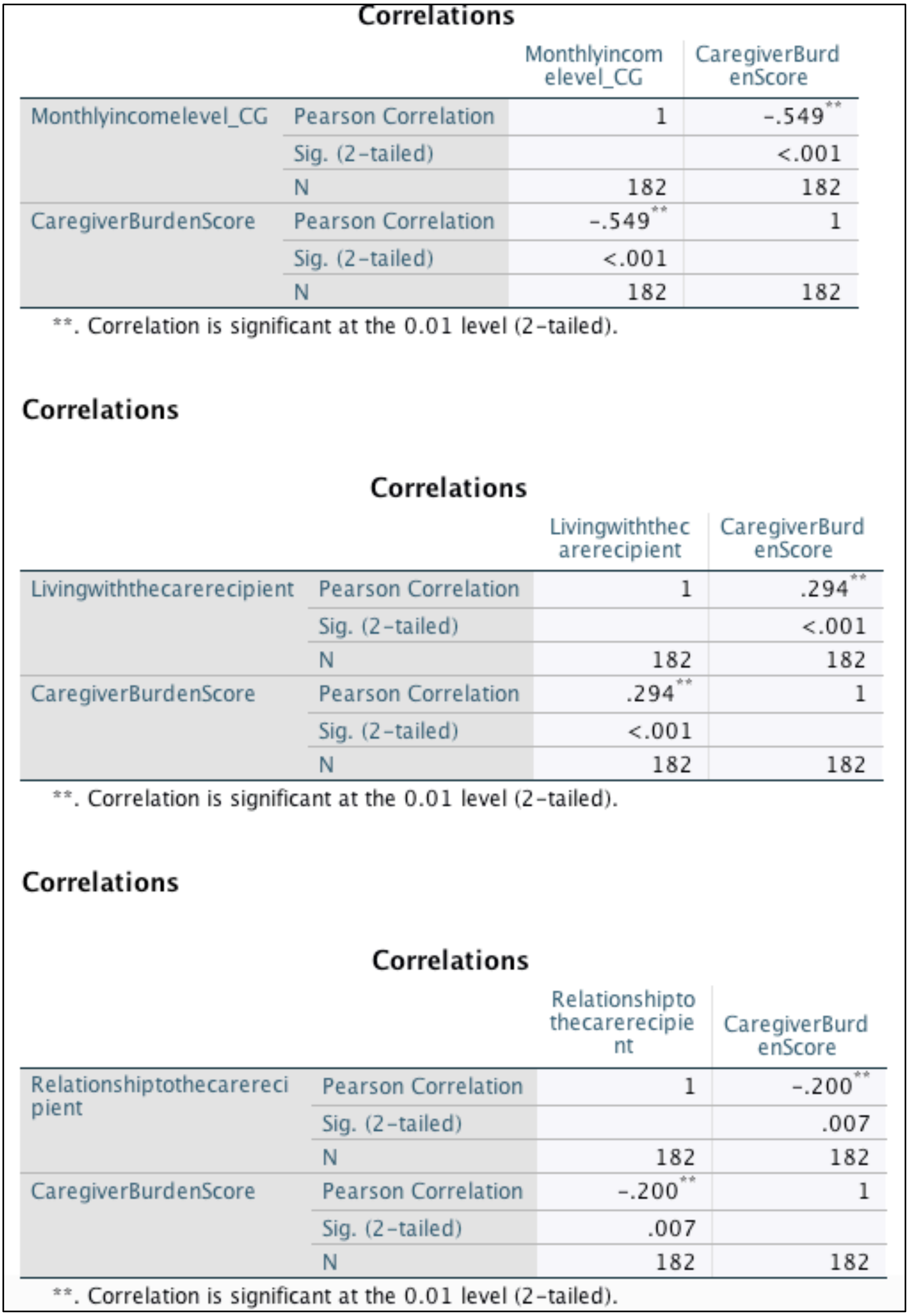
**. Correlation is significant at the 0.01 level (2-tailed).

Correlations

Correlations

		EmploymentStatus_CG	CaregiverBurdenScore
EmploymentStatus_CG	Pearson Correlation	1	.342**
	Sig. (2-tailed)		<.001
	N	182	182
CaregiverBurdenScore	Pearson Correlation	.342**	1
	Sig. (2-tailed)	<.001	
	N	182	182

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



Correlations

		Monthlyincomelevel_CG	CaregiverBurdenScore
Monthlyincomelevel_CG	Pearson Correlation	1	-.549**
	Sig. (2-tailed)		<.001
	N	182	182
CaregiverBurdenScore	Pearson Correlation	-.549**	1
	Sig. (2-tailed)	<.001	
	N	182	182

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

Correlations

Correlations

		Livingwiththecarerecipient	CaregiverBurdenScore
Livingwiththecarerecipient	Pearson Correlation	1	.294**
	Sig. (2-tailed)		<.001
	N	182	182
CaregiverBurdenScore	Pearson Correlation	.294**	1
	Sig. (2-tailed)	<.001	
	N	182	182

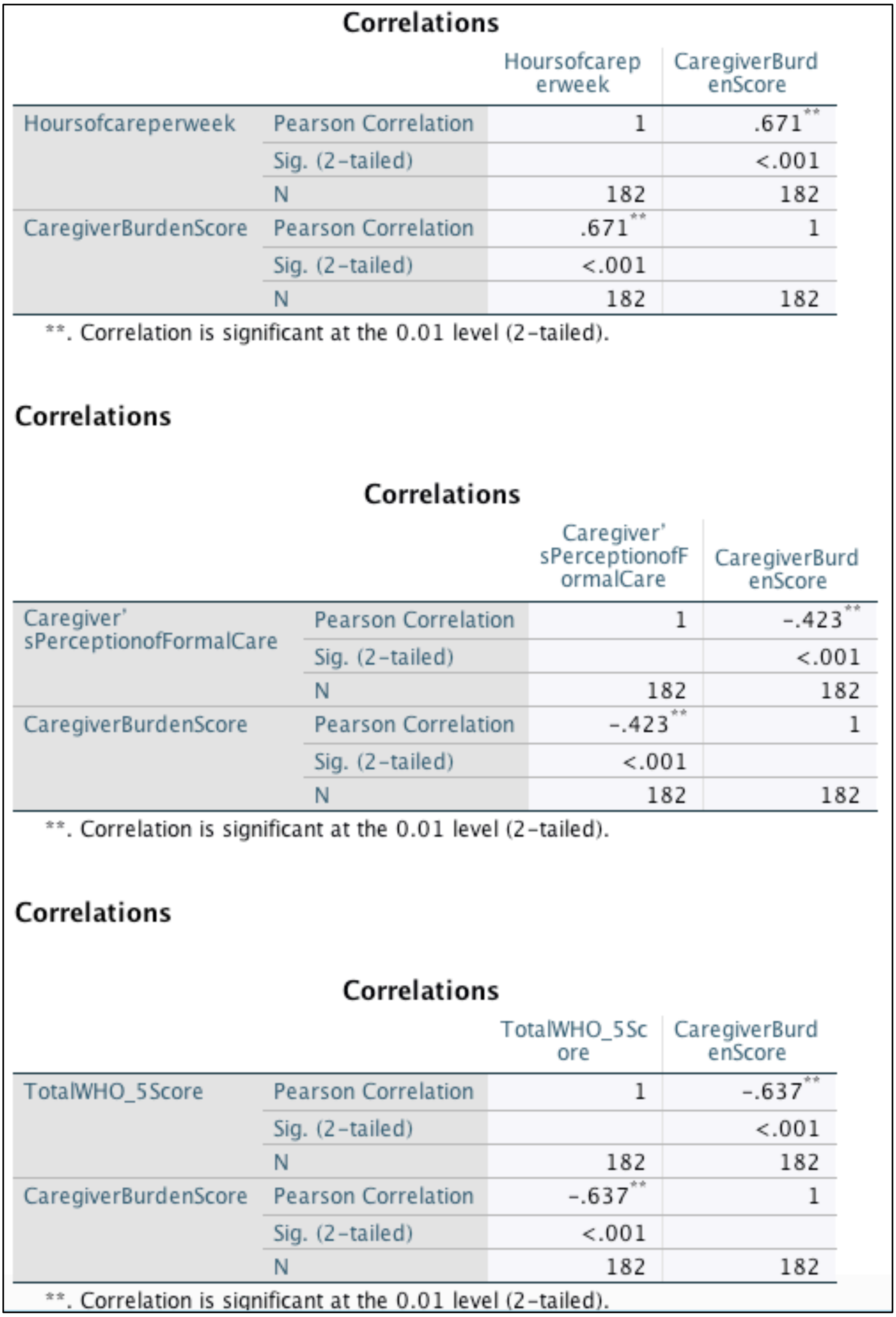
**. Correlation is significant at the 0.01 level (2-tailed).

Correlations

Correlations

		Relationshiptothecarerecipient	CaregiverBurdenScore
Relationshiptothecarerecipient	Pearson Correlation	1	-.200**
	Sig. (2-tailed)		.007
	N	182	182
CaregiverBurdenScore	Pearson Correlation	-.200**	1
	Sig. (2-tailed)	.007	
	N	182	182

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



Correlations

		Hoursofcareperweek	CaregiverBurdenScore
Hoursofcareperweek	Pearson Correlation	1	.671**
	Sig. (2-tailed)		<.001
	N	182	182
CaregiverBurdenScore	Pearson Correlation	.671**	1
	Sig. (2-tailed)	<.001	
	N	182	182

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

Correlations

Correlations

		Caregiver'sPerceptionofFormalCare	CaregiverBurdenScore
Caregiver'sPerceptionofFormalCare	Pearson Correlation	1	-.423**
	Sig. (2-tailed)		<.001
	N	182	182
CaregiverBurdenScore	Pearson Correlation	-.423**	1
	Sig. (2-tailed)	<.001	
	N	182	182

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

Correlations

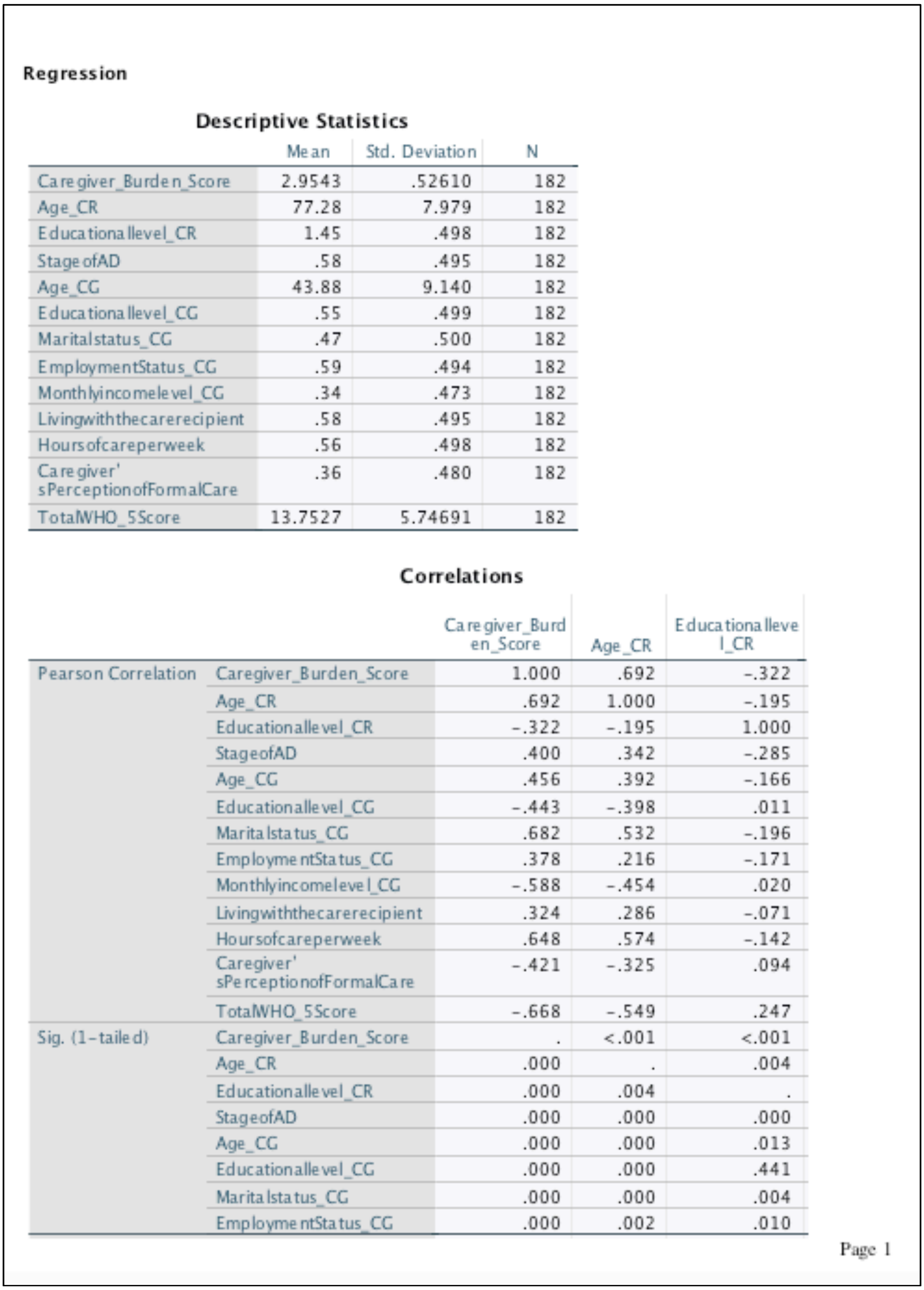
Correlations

		TotalWHO_5Score	CaregiverBurdenScore
TotalWHO_5Score	Pearson Correlation	1	-.637**
	Sig. (2-tailed)		<.001
	N	182	182
CaregiverBurdenScore	Pearson Correlation	-.637**	1
	Sig. (2-tailed)	<.001	
	N	182	182

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

Appendix G

Results of the Hierarchical Multiple Regression Analysis (Research Question 6)



Regression

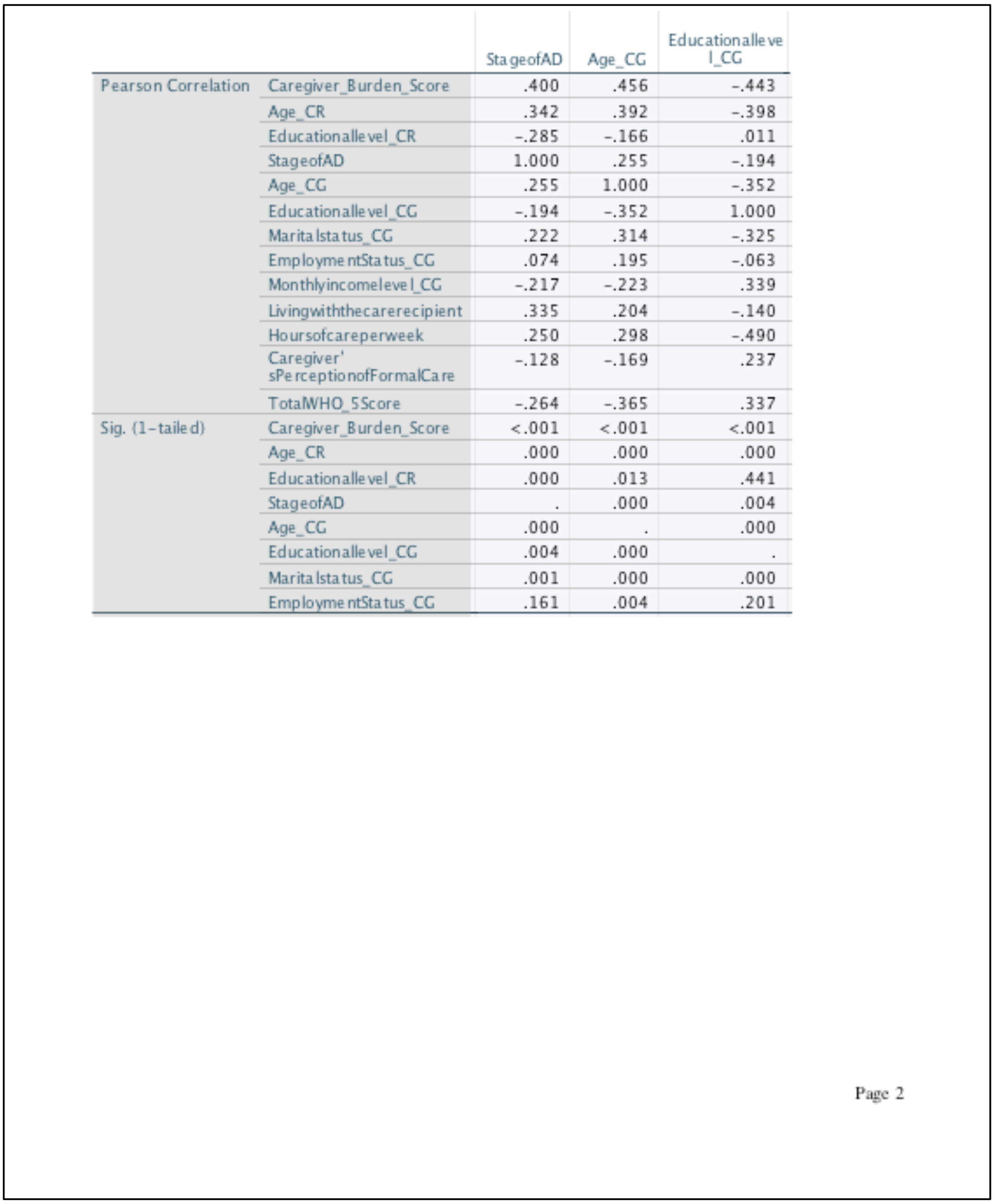
Descriptive Statistics

	Mean	Std. Deviation	N
Caregiver_Burden_Score	2.9543	.52610	182
Age_CR	77.28	7.979	182
Educationallevel_CR	1.45	.498	182
StageofAD	.58	.495	182
Age_CG	43.88	9.140	182
Educationallevel_CG	.55	.499	182
Maritalstatus_CG	.47	.500	182
EmploymentStatus_CG	.59	.494	182
Monthlyincomelevel_CG	.34	.473	182
Livingwiththecarerecipient	.58	.495	182
Hoursofcareperweek	.56	.498	182
Caregiver'sPerceptionofFormalCare	.36	.480	182
TotalWHO_5Score	13.7527	5.74691	182

Correlations

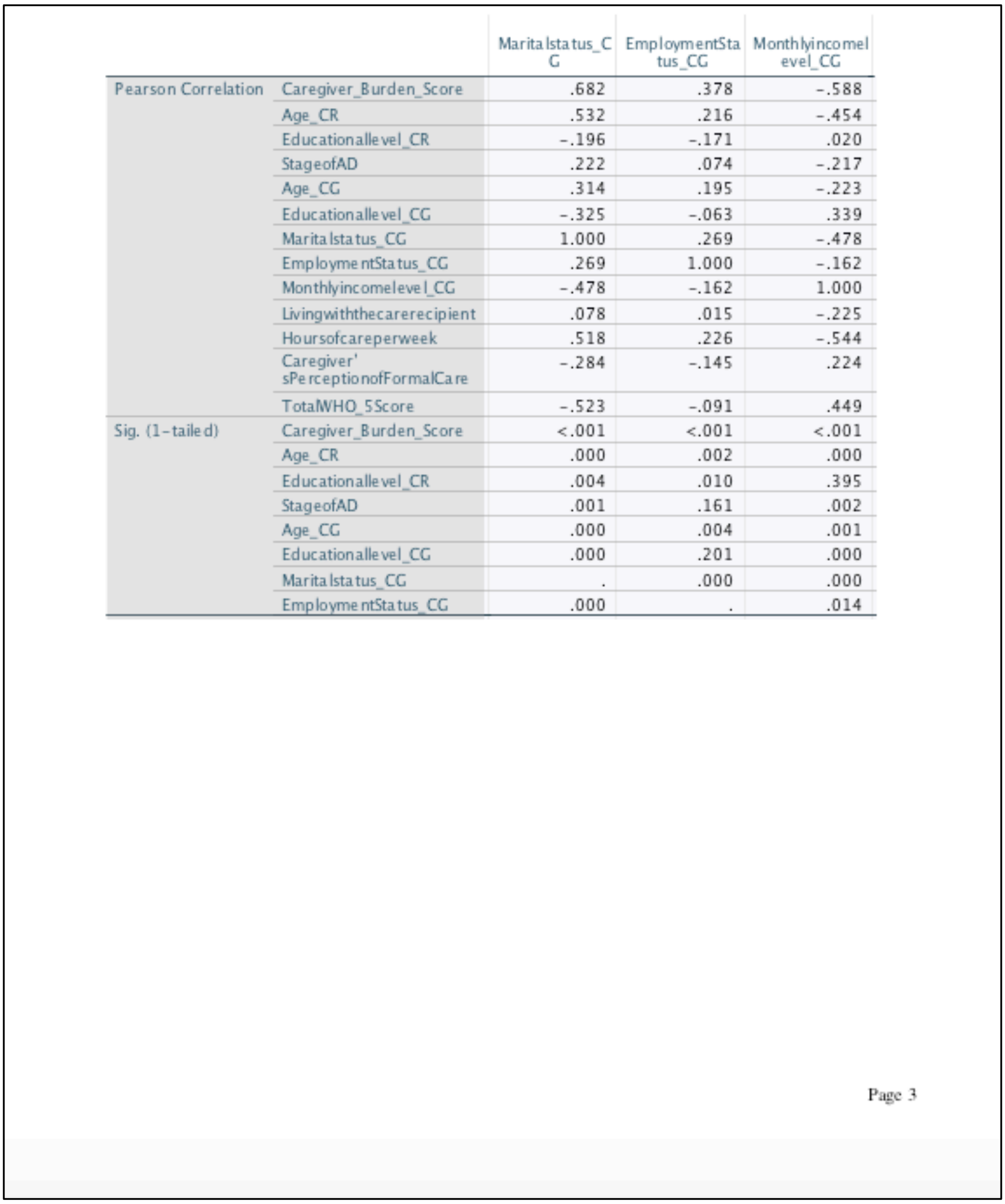
		Caregiver_Burden_Score	Age_CR	Educationallevel_CR
Pearson Correlation	Caregiver_Burden_Score	1.000	.692	-.322
	Age_CR	.692	1.000	-.195
	Educationallevel_CR	-.322	-.195	1.000
	StageofAD	.400	.342	-.285
	Age_CG	.456	.392	-.166
	Educationallevel_CG	-.443	-.398	.011
	Maritalstatus_CG	.682	.532	-.196
	EmploymentStatus_CG	.378	.216	-.171
	Monthlyincomelevel_CG	-.588	-.454	.020
	Livingwiththecarerecipient	.324	.286	-.071
	Hoursofcareperweek	.648	.574	-.142
	Caregiver'sPerceptionofFormalCare	-.421	-.325	.094
	TotalWHO_5Score	-.668	-.549	.247
Sig. (1-tailed)	Caregiver_Burden_Score	.	<.001	<.001
	Age_CR	.000	.	.004
	Educationallevel_CR	.000	.004	.
	StageofAD	.000	.000	.000
	Age_CG	.000	.000	.013
	Educationallevel_CG	.000	.000	.441
	Maritalstatus_CG	.000	.000	.004
	EmploymentStatus_CG	.000	.002	.010

Page 1



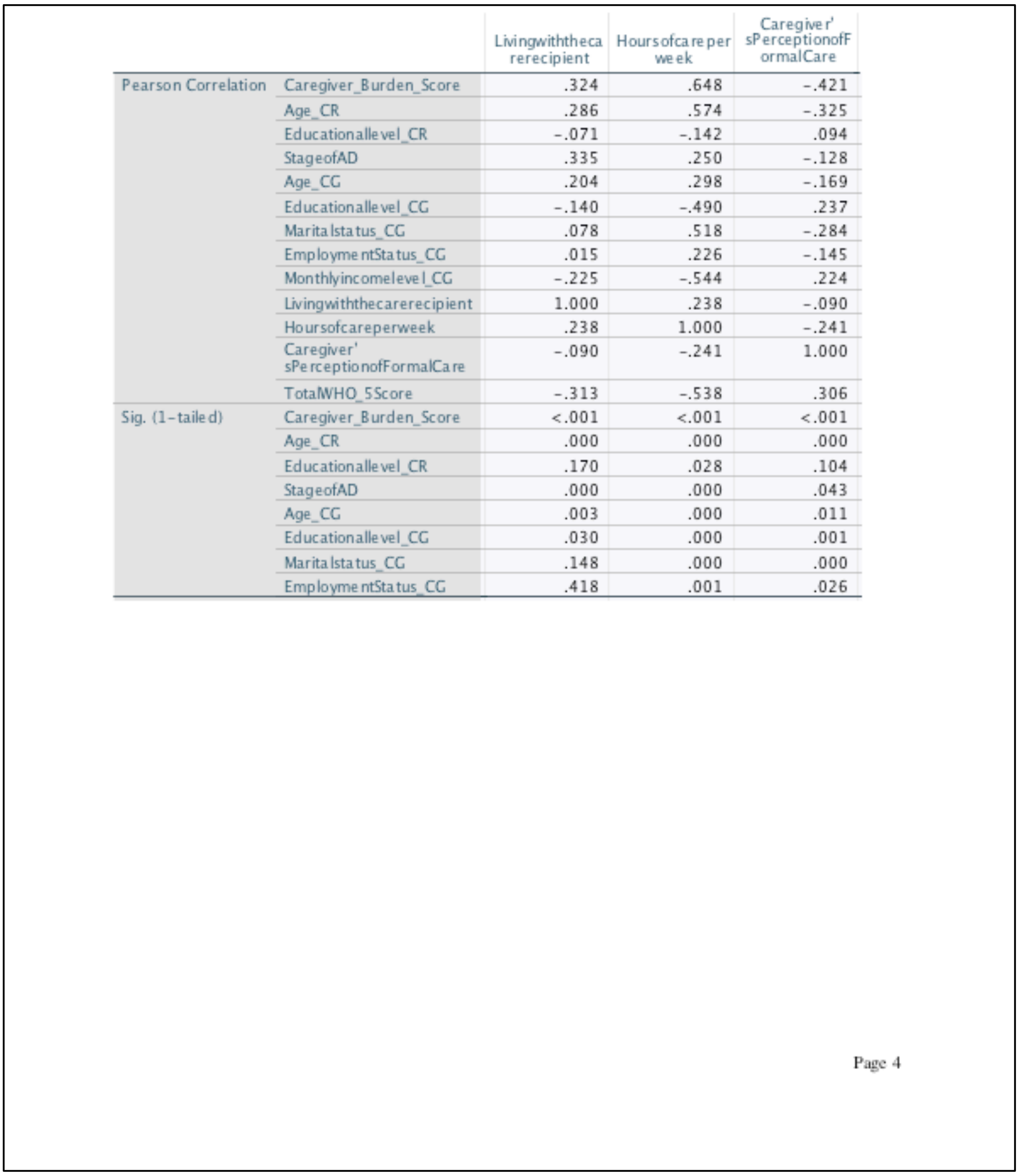
		StageofAD	Age_CG	Educationallevel_CG
Pearson Correlation	Caregiver_Burden_Score	.400	.456	-.443
	Age_CR	.342	.392	-.398
	Educationallevel_CR	-.285	-.166	.011
	StageofAD	1.000	.255	-.194
	Age_CG	.255	1.000	-.352
	Educationallevel_CG	-.194	-.352	1.000
	Maritalstatus_CG	.222	.314	-.325
	EmploymentStatus_CG	.074	.195	-.063
	Monthlyincomelevel_CG	-.217	-.223	.339
	Livingwiththecarerecipient	.335	.204	-.140
	Hoursofcareperweek	.250	.298	-.490
	Caregiver'sPerceptionofFormalCare	-.128	-.169	.237
	TotalWHO_5Score	-.264	-.365	.337
Sig. (1-tailed)	Caregiver_Burden_Score	<.001	<.001	<.001
	Age_CR	.000	.000	.000
	Educationallevel_CR	.000	.013	.441
	StageofAD	.	.000	.004
	Age_CG	.000	.	.000
	Educationallevel_CG	.004	.000	.
	Maritalstatus_CG	.001	.000	.000
	EmploymentStatus_CG	.161	.004	.201

Page 2



		Maritalstatus_CG	EmploymentStatus_CG	Monthlyincomelevel_CG
Pearson Correlation	Caregiver_Burden_Score	.682	.378	-.588
	Age_CR	.532	.216	-.454
	Educationallevel_CR	-.196	-.171	.020
	StageofAD	.222	.074	-.217
	Age_CG	.314	.195	-.223
	Educationallevel_CG	-.325	-.063	.339
	Maritalstatus_CG	1.000	.269	-.478
	EmploymentStatus_CG	.269	1.000	-.162
	Monthlyincomelevel_CG	-.478	-.162	1.000
	Livingwiththecarerecipient	.078	.015	-.225
	Hoursofcareperweek	.518	.226	-.544
	Caregiver'sPerceptionofFormalCare	-.284	-.145	.224
	TotalWHO_5Score	-.523	-.091	.449
Sig. (1-tailed)	Caregiver_Burden_Score	<.001	<.001	<.001
	Age_CR	.000	.002	.000
	Educationallevel_CR	.004	.010	.395
	StageofAD	.001	.161	.002
	Age_CG	.000	.004	.001
	Educationallevel_CG	.000	.201	.000
	Maritalstatus_CG	.	.000	.000
	EmploymentStatus_CG	.000	.	.014

Page 3



		Livingwiththecarerecipient	Hoursofcareperweek	Caregiver'sPerceptionofFormalCare
Pearson Correlation	Caregiver_Burden_Score	.324	.648	-.421
	Age_CR	.286	.574	-.325
	Educationallevel_CR	-.071	-.142	.094
	StageofAD	.335	.250	-.128
	Age_CG	.204	.298	-.169
	Educationallevel_CG	-.140	-.490	.237
	Maritalstatus_CG	.078	.518	-.284
	EmploymentStatus_CG	.015	.226	-.145
	Monthlyincomelevel_CG	-.225	-.544	.224
	Livingwiththecarerecipient	1.000	.238	-.090
	Hoursofcareperweek	.238	1.000	-.241
	Caregiver'sPerceptionofFormalCare	-.090	-.241	1.000
	TotalWHO_5Score	-.313	-.538	.306
Sig. (1-tailed)	Caregiver_Burden_Score	<.001	<.001	<.001
	Age_CR	.000	.000	.000
	Educationallevel_CR	.170	.028	.104
	StageofAD	.000	.000	.043
	Age_CG	.003	.000	.011
	Educationallevel_CG	.030	.000	.001
	Maritalstatus_CG	.148	.000	.000
	EmploymentStatus_CG	.418	.001	.026

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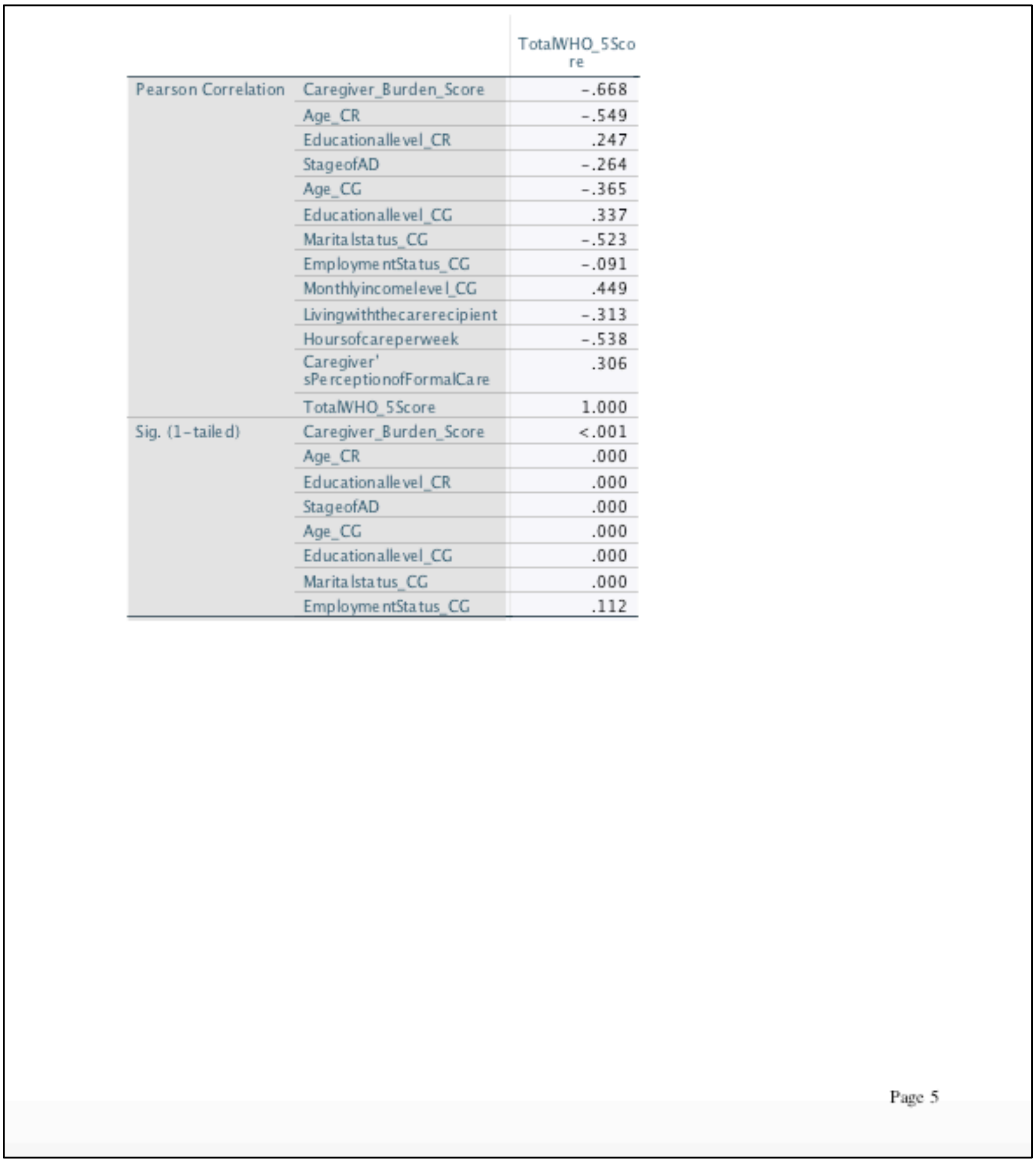
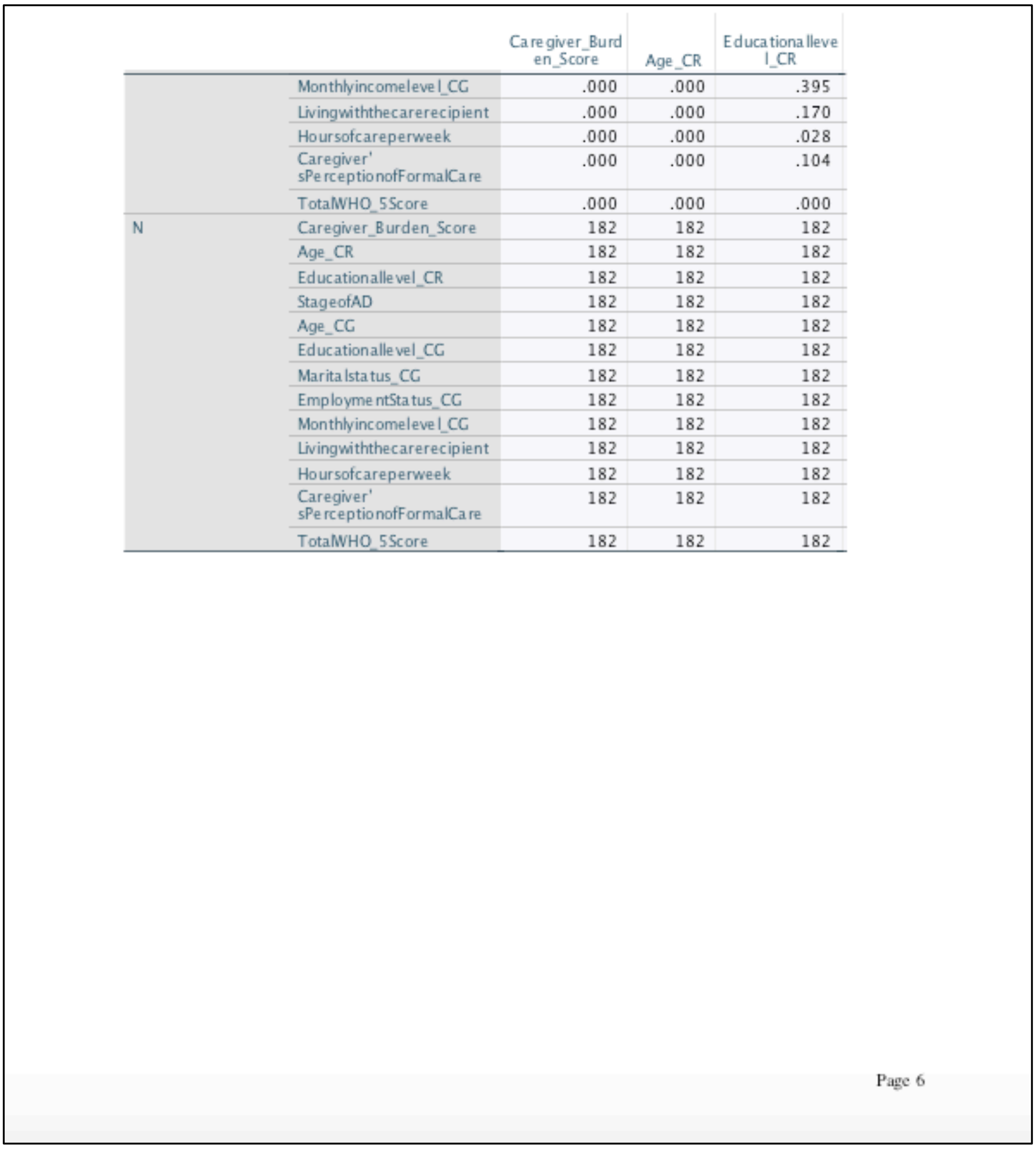
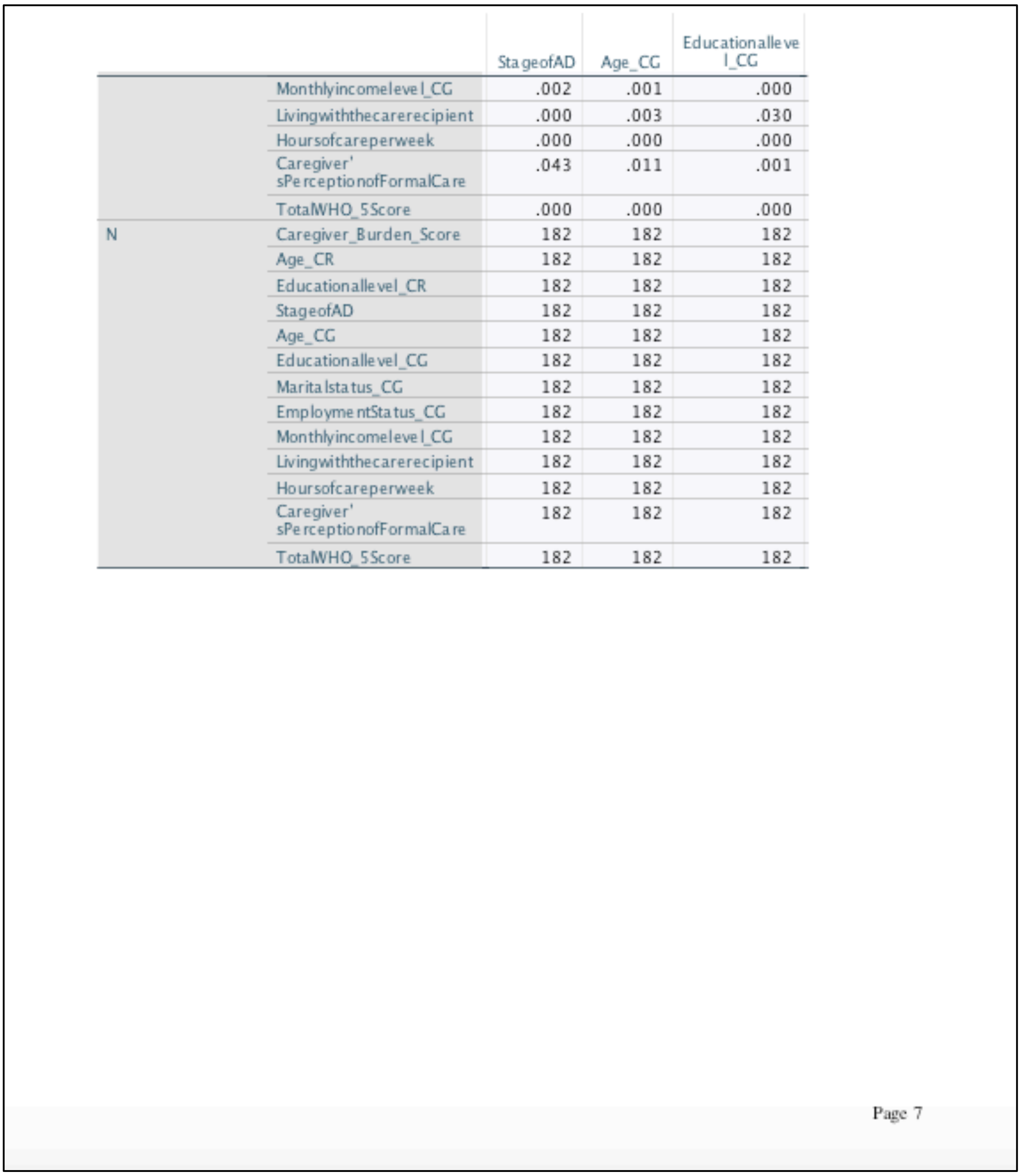


		TotalWHO_5Score
Pearson Correlation	Caregiver_Burden_Score	-.668
	Age_CR	-.549
	Educationallevel_CR	.247
	StageofAD	-.264
	Age_CG	-.365
	Educationallevel_CG	.337
	Maritalstatus_CG	-.523
	EmploymentStatus_CG	-.091
	Monthlyincomelevel_CG	.449
	Livingwiththecarerecipient	-.313
	Hoursofcareperweek	-.538
	Caregiver'sPerceptionofFormalCare	.306
	TotalWHO_5Score	1.000
Sig. (1-tailed)	Caregiver_Burden_Score	<.001
	Age_CR	.000
	Educationallevel_CR	.000
	StageofAD	.000
	Age_CG	.000
	Educationallevel_CG	.000
	Maritalstatus_CG	.000
	EmploymentStatus_CG	.112

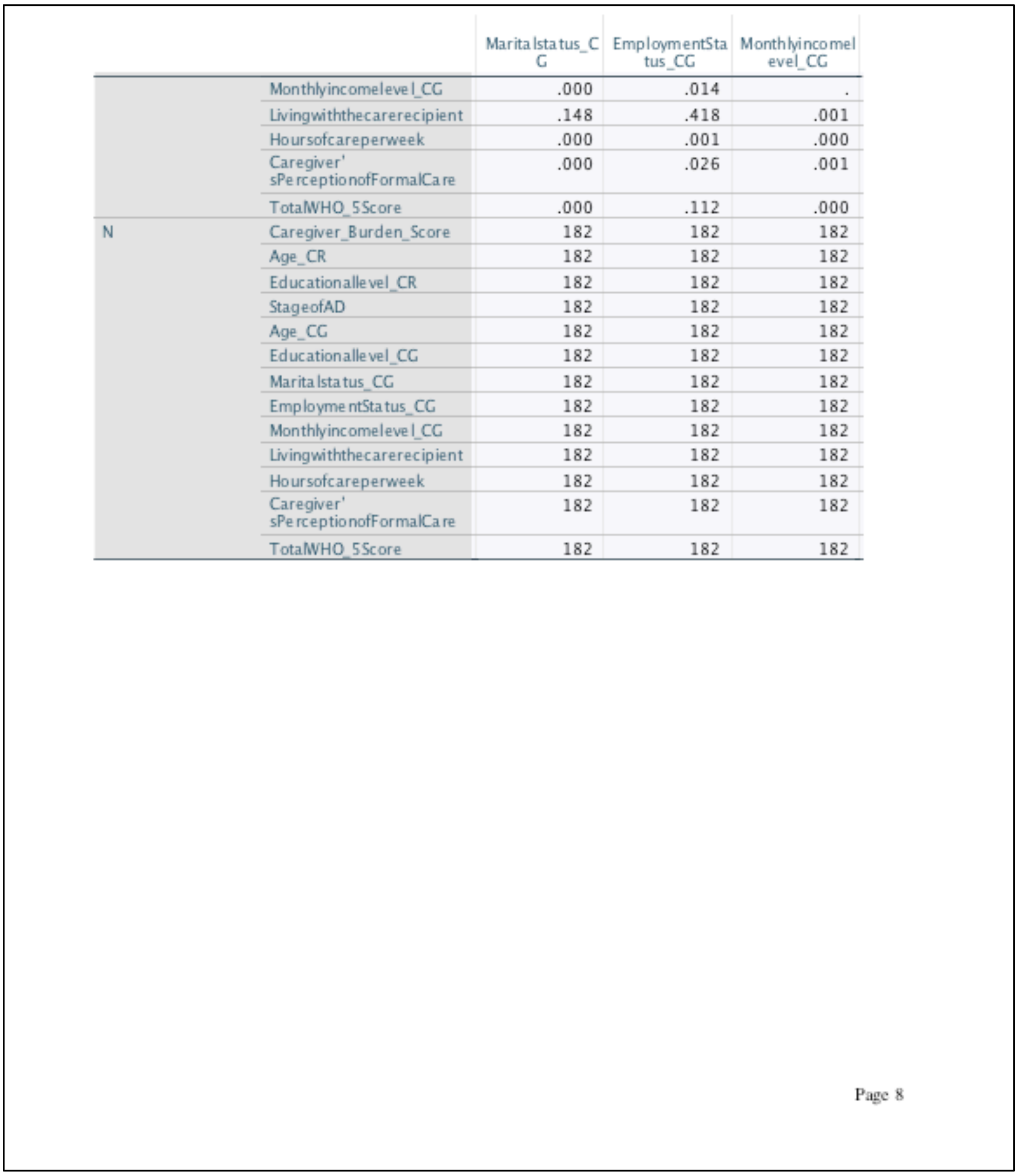
Page 5



		Caregiver_Burden_Score	Age_CR	Educationallevel_CR
	Monthlyincomelevel_CG	.000	.000	.395
	Livingwiththecarerecipient	.000	.000	.170
	Hoursofcareperweek	.000	.000	.028
	Caregiver'sPerceptionofFormalCare	.000	.000	.104
	TotalWHO_5Score	.000	.000	.000
N	Caregiver_Burden_Score	182	182	182
	Age_CR	182	182	182
	Educationallevel_CR	182	182	182
	StageofAD	182	182	182
	Age_CG	182	182	182
	Educationallevel_CG	182	182	182
	Maritalstatus_CG	182	182	182
	EmploymentStatus_CG	182	182	182
	Monthlyincomelevel_CG	182	182	182
	Livingwiththecarerecipient	182	182	182
	Hoursofcareperweek	182	182	182
	Caregiver'sPerceptionofFormalCare	182	182	182
	TotalWHO_5Score	182	182	182



		StageofAD	Age_CG	Educationallevel_CG
	Monthlyincomelevel_CG	.002	.001	.000
	Livingwiththecarerecipient	.000	.003	.030
	Hoursofcareperweek	.000	.000	.000
	Caregiver'sPerceptionofFormalCare	.043	.011	.001
	TotalWHO_5Score	.000	.000	.000
N	Caregiver_Burden_Score	182	182	182
	Age_CR	182	182	182
	Educationallevel_CR	182	182	182
	StageofAD	182	182	182
	Age_CG	182	182	182
	Educationallevel_CG	182	182	182
	Maritalstatus_CG	182	182	182
	EmploymentStatus_CG	182	182	182
	Monthlyincomelevel_CG	182	182	182
	Livingwiththecarerecipient	182	182	182
	Hoursofcareperweek	182	182	182
	Caregiver'sPerceptionofFormalCare	182	182	182
	TotalWHO_5Score	182	182	182



		Maritalstatus_CG	EmploymentStatus_CG	Monthlyincomelevel_CG
	Monthlyincomelevel_CG	.000	.014	.
	Livingwiththecarerecipient	.148	.418	.001
	Hoursofcareperweek	.000	.001	.000
	Caregiver'sPerceptionofFormalCare	.000	.026	.001
	TotalWHO_5Score	.000	.112	.000
N	Caregiver_Burden_Score	182	182	182
	Age_CR	182	182	182
	Educationallevel_CR	182	182	182
	StageofAD	182	182	182
	Age_CG	182	182	182
	Educationallevel_CG	182	182	182
	Maritalstatus_CG	182	182	182
	EmploymentStatus_CG	182	182	182
	Monthlyincomelevel_CG	182	182	182
	Livingwiththecarerecipient	182	182	182
	Hoursofcareperweek	182	182	182
	Caregiver'sPerceptionofFormalCare	182	182	182
	TotalWHO_5Score	182	182	182

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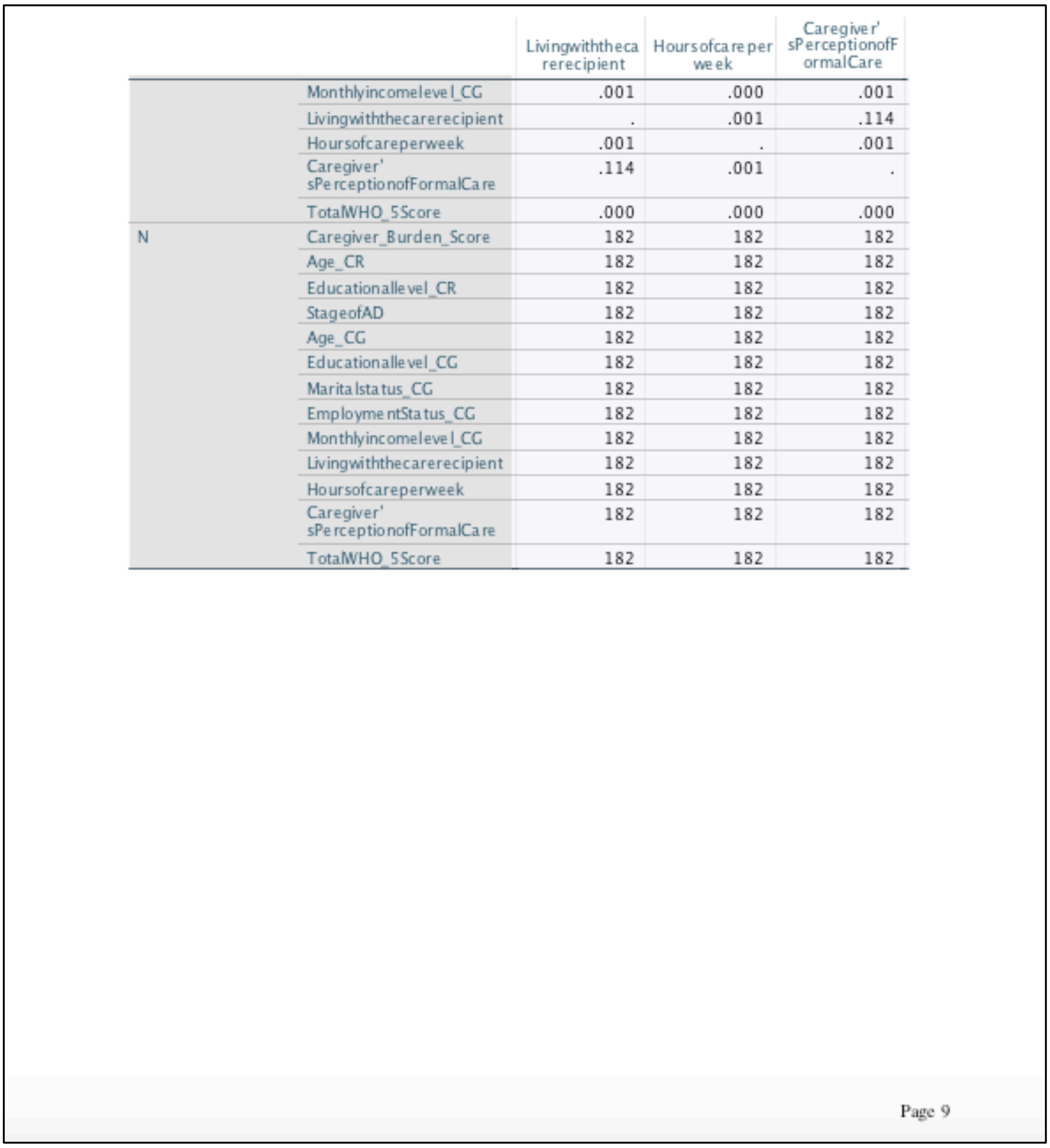

		Livingwiththecarerecipient	Hoursofcareperweek	Caregiver'sPerceptionofFormalCare
	Monthlyincomelevel_CG	.001	.000	.001
	Livingwiththecarerecipient	.	.001	.114
	Hoursofcareperweek	.001	.	.001
	Caregiver'sPerceptionofFormalCare	.114	.001	.
	TotalWHO_5Score	.000	.000	.000
N	Caregiver_Burden_Score	182	182	182
	Age_CR	182	182	182
	Educationallevel_CR	182	182	182
	StageofAD	182	182	182
	Age_CG	182	182	182
	Educationallevel_CG	182	182	182
	Maritalstatus_CG	182	182	182
	EmploymentStatus_CG	182	182	182
	Monthlyincomelevel_CG	182	182	182
	Livingwiththecarerecipient	182	182	182
	Hoursofcareperweek	182	182	182
	Caregiver'sPerceptionofFormalCare	182	182	182
	TotalWHO_5Score	182	182	182

		TotalWHO_5Score
	Monthlyincomelevel_CG	.000
	Livingwiththecarerecipient	.000
	Hoursofcareperweek	.000
	Caregiver'sPerceptionofFormalCare	.000
	TotalWHO_5Score	.
N	Caregiver_Burden_Score	182
	Age_CR	182
	Educationallevel_CR	182
	StageofAD	182
	Age_CG	182
	Educationallevel_CG	182
	Maritalstatus_CG	182
	EmploymentStatus_CG	182
	Monthlyincomelevel_CG	182
	Livingwiththecarerecipient	182
	Hoursofcareperweek	182
	Caregiver'sPerceptionofFormalCare	182
	TotalWHO_5Score	182

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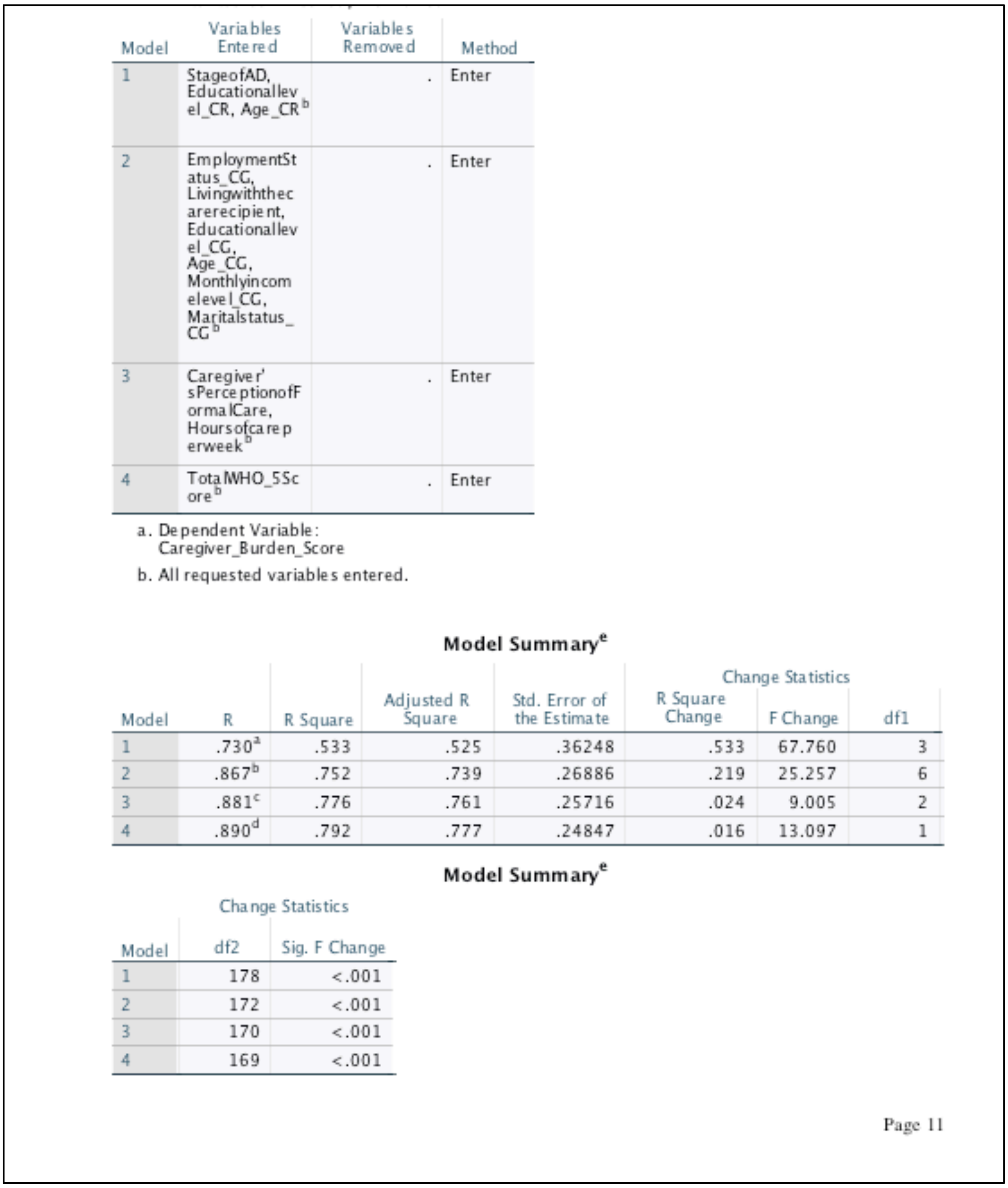

Model	Variables Entered	Variables Removed	Method
1	StageofAD, Educationallevel_CR, Age_CR[b]	.	Enter
2	EmploymentStatus_CG, Livingwiththecarerecipient, Educationallevel_CG, Age_CG, Monthlyincomelevel_CG, Maritalstatus_CG[b]	.	Enter
3	Caregiver'sPerceptionofFormalCare, Hoursofcareperweek[b]	.	Enter
4	TotalWHO_5Score[b]	.	Enter

a. Dependent Variable: Caregiver_Burden_Score

b. All requested variables entered.

Model Summary[e]

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics		
					R Square Change	F Change	df1
1	.730[a]	.533	.525	.36248	.533	67.760	3
2	.867[b]	.752	.739	.26886	.219	25.257	6
3	.881[c]	.776	.761	.25716	.024	9.005	2
4	.890[d]	.792	.777	.24847	.016	13.097	1

Model Summary[e]

Model	Change Statistics	
	df2	Sig. F Change
1	178	<.001
2	172	<.001
3	170	<.001
4	169	<.001

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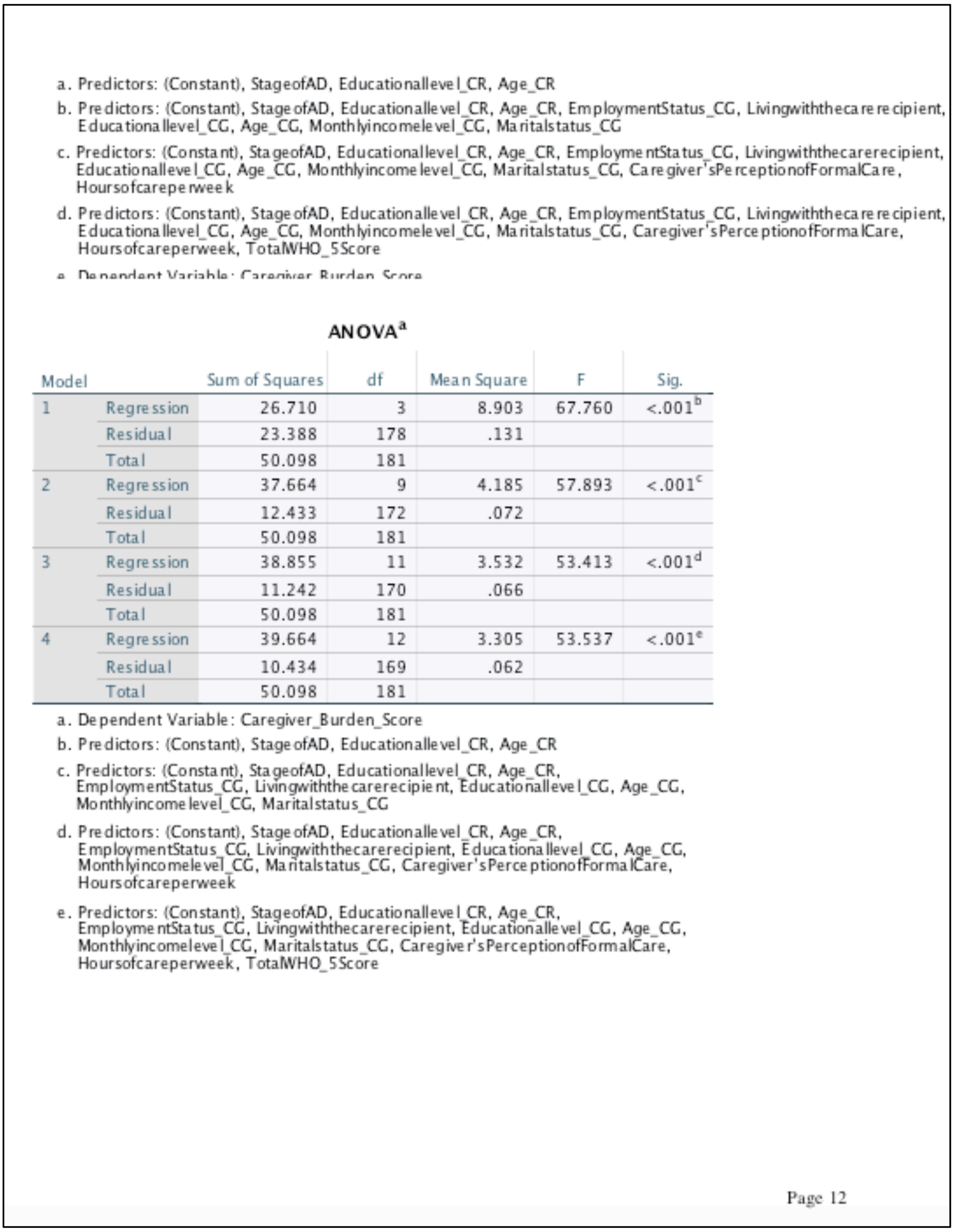


a. Predictors: (Constant), StageofAD, Educationallevel_CR, Age_CR

b. Predictors: (Constant), StageofAD, Educationallevel_CR, Age_CR, EmploymentStatus_CG, Livingwiththecarerecipient, Educationallevel_CG, Age_CG, Monthlyincomelevel_CG, Maritalstatus_CG

c. Predictors: (Constant), StageofAD, Educationallevel_CR, Age_CR, EmploymentStatus_CG, Livingwiththecarerecipient, Educationallevel_CG, Age_CG, Monthlyincomelevel_CG, Maritalstatus_CG, Caregiver'sPerceptionofFormalCare, Hoursofcareperweek

d. Predictors: (Constant), StageofAD, Educationallevel_CR, Age_CR, EmploymentStatus_CG, Livingwiththecarerecipient, Educationallevel_CG, Age_CG, Monthlyincomelevel_CG, Maritalstatus_CG, Caregiver'sPerceptionofFormalCare, Hoursofcareperweek, TotalWHO_5Score

e. Dependent Variable: Caregiver_Burden_Score

ANOVA[a]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	26.710	3	8.903	67.760	<.001[b]
	Residual	23.388	178	.131		
	Total	50.098	181			
2	Regression	37.664	9	4.185	57.893	<.001[c]
	Residual	12.433	172	.072		
	Total	50.098	181			
3	Regression	38.855	11	3.532	53.413	<.001[d]
	Residual	11.242	170	.066		
	Total	50.098	181			
4	Regression	39.664	12	3.305	53.537	<.001[e]
	Residual	10.434	169	.062		
	Total	50.098	181			

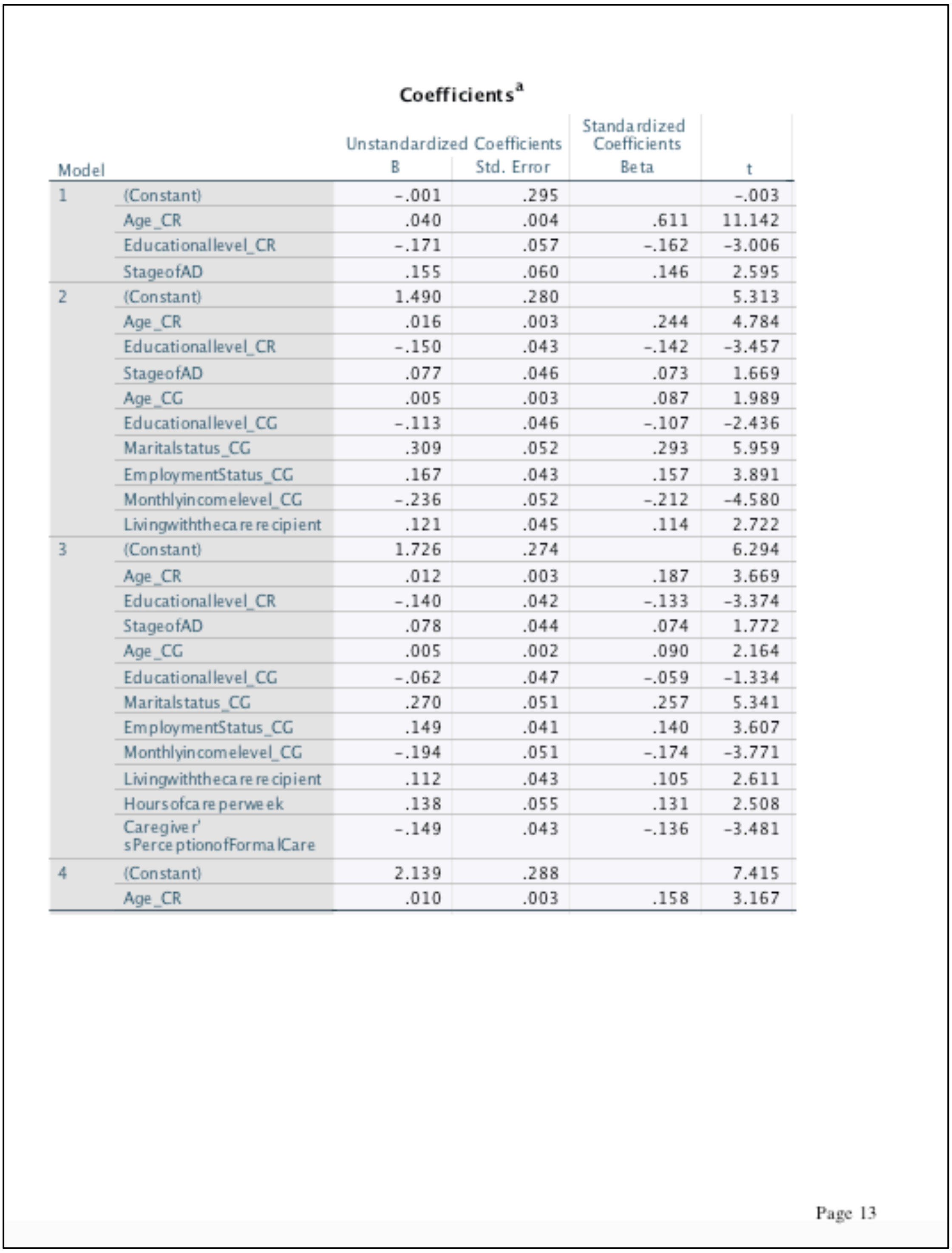
a. Dependent Variable: Caregiver_Burden_Score

b. Predictors: (Constant), StageofAD, Educationallevel_CR, Age_CR

c. Predictors: (Constant), StageofAD, Educationallevel_CR, Age_CR, EmploymentStatus_CG, Livingwiththecarerecipient, Educationallevel_CG, Age_CG, Monthlyincomelevel_CG, Maritalstatus_CG

d. Predictors: (Constant), StageofAD, Educationallevel_CR, Age_CR, EmploymentStatus_CG, Livingwiththecarerecipient, Educationallevel_CG, Age_CG, Monthlyincomelevel_CG, Maritalstatus_CG, Caregiver'sPerceptionofFormalCare, Hoursofcareperweek

e. Predictors: (Constant), StageofAD, Educationallevel_CR, Age_CR, EmploymentStatus_CG, Livingwiththecarerecipient, Educationallevel_CG, Age_CG, Monthlyincomelevel_CG, Maritalstatus_CG, Caregiver'sPerceptionofFormalCare, Hoursofcareperweek, TotalWHO_5Score



Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients	
		B	Std. Error	Beta	t
1	(Constant)	-.001	.295		-.003
	Age_CR	.040	.004	.611	11.142
	Educationallevel_CR	-.171	.057	-.162	-3.006
	StageofAD	.155	.060	.146	2.595
2	(Constant)	1.490	.280		5.313
	Age_CR	.016	.003	.244	4.784
	Educationallevel_CR	-.150	.043	-.142	-3.457
	StageofAD	.077	.046	.073	1.669
	Age_CG	.005	.003	.087	1.989
	Educationallevel_CG	-.113	.046	-.107	-2.436
	Maritalstatus_CG	.309	.052	.293	5.959
	EmploymentStatus_CG	.167	.043	.157	3.891
	Monthlyincomelevel_CG	-.236	.052	-.212	-4.580
	Livingwiththecarerecipient	.121	.045	.114	2.722
3	(Constant)	1.726	.274		6.294
	Age_CR	.012	.003	.187	3.669
	Educationallevel_CR	-.140	.042	-.133	-3.374
	StageofAD	.078	.044	.074	1.772
	Age_CG	.005	.002	.090	2.164
	Educationallevel_CG	-.062	.047	-.059	-1.334
	Maritalstatus_CG	.270	.051	.257	5.341
	EmploymentStatus_CG	.149	.041	.140	3.607
	Monthlyincomelevel_CG	-.194	.051	-.174	-3.771
	Livingwiththecarerecipient	.112	.043	.105	2.611
	Hoursofcareperweek	.138	.055	.131	2.508
	Caregiver' sPerceptionofFormalCare	-.149	.043	-.136	-3.481
4	(Constant)	2.139	.288		7.415
	Age_CR	.010	.003	.158	3.167

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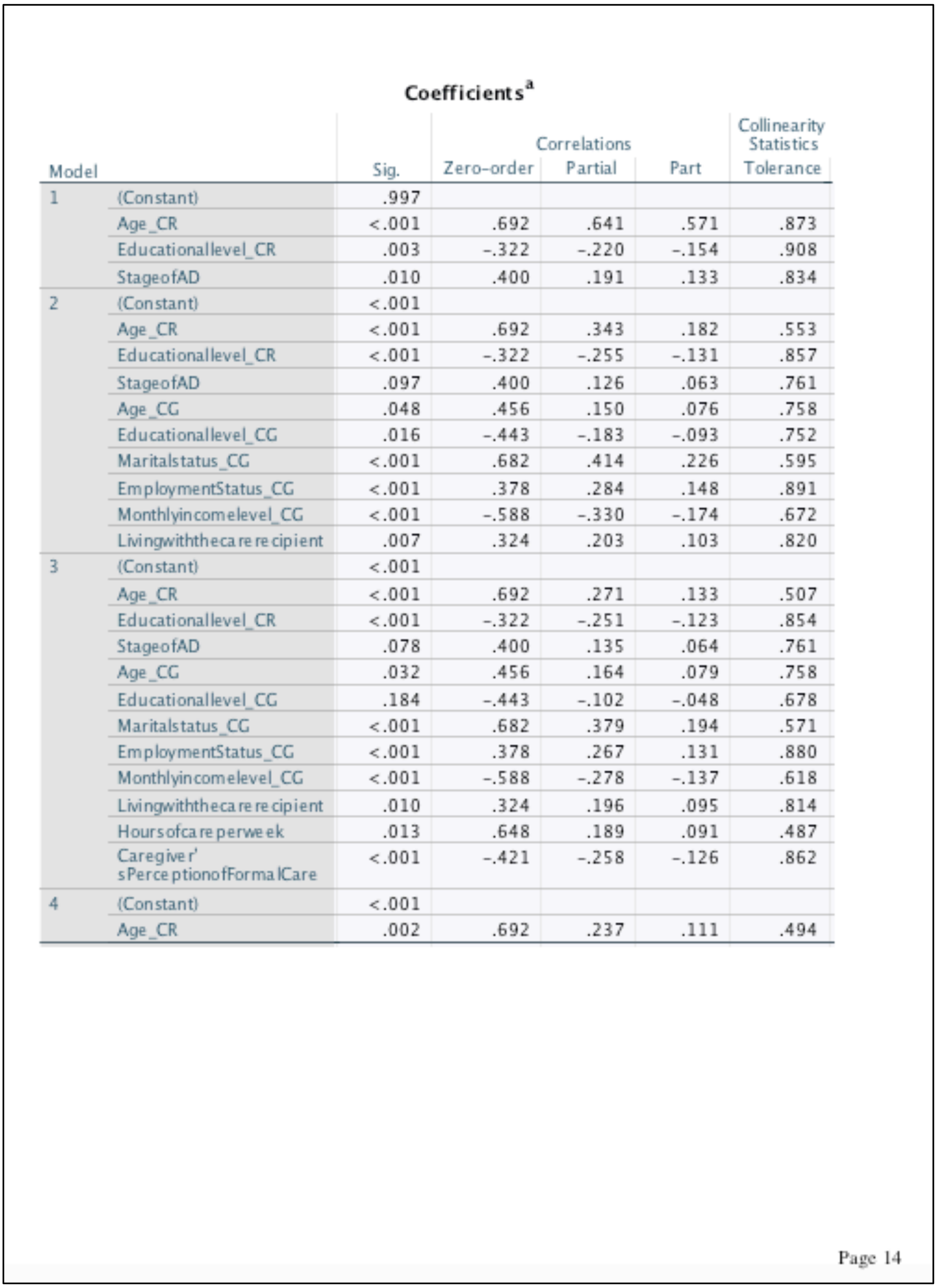
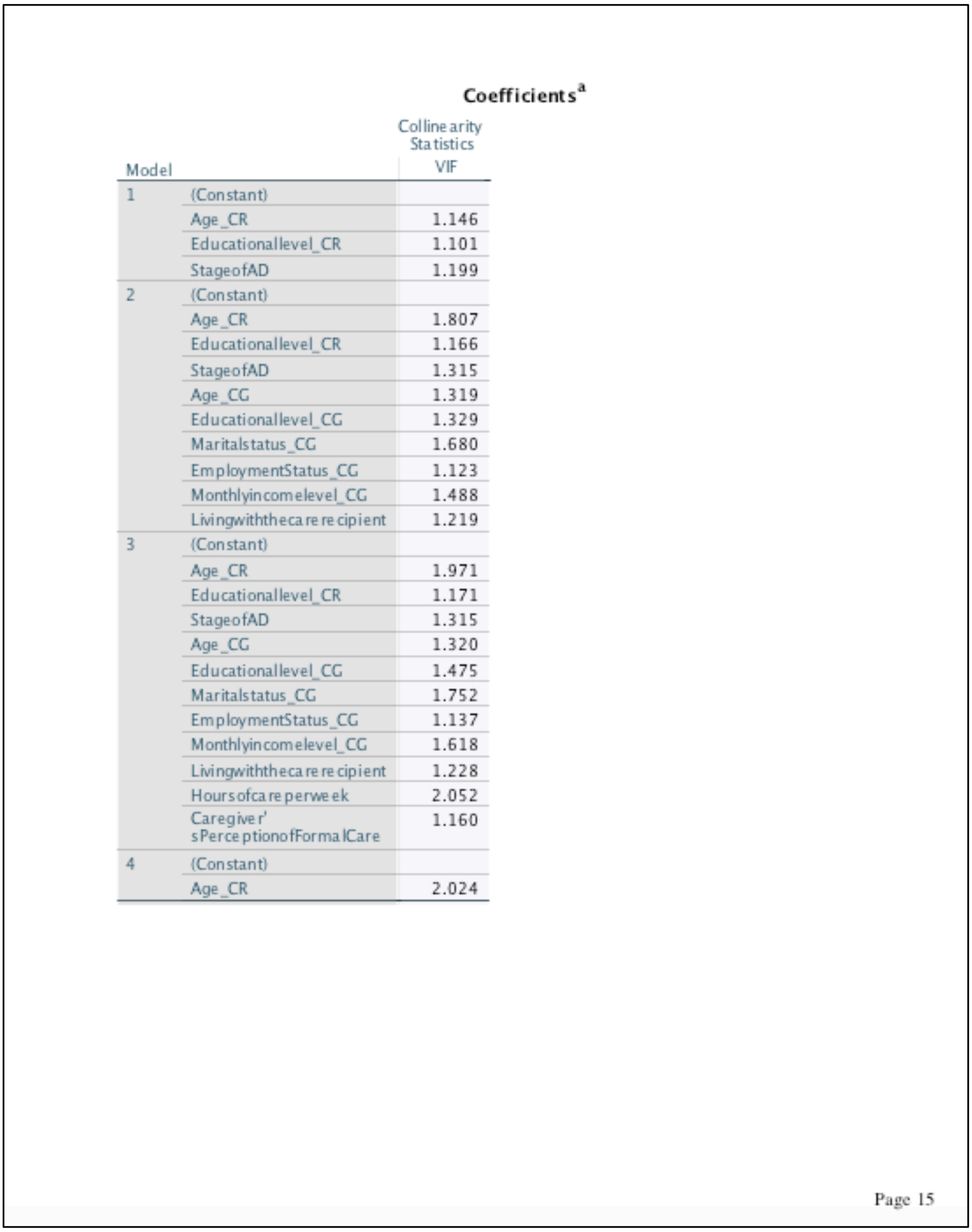


Coefficients[a]

Model		Sig.	Correlations			Collinearity Statistics
			Zero-order	Partial	Part	Tolerance
1	(Constant)	.997				
	Age_CR	<.001	.692	.641	.571	.873
	Educationallevel_CR	.003	-.322	-.220	-.154	.908
	StageofAD	.010	.400	.191	.133	.834
2	(Constant)	<.001				
	Age_CR	<.001	.692	.343	.182	.553
	Educationallevel_CR	<.001	-.322	-.255	-.131	.857
	StageofAD	.097	.400	.126	.063	.761
	Age_CG	.048	.456	.150	.076	.758
	Educationallevel_CG	.016	-.443	-.183	-.093	.752
	Maritalstatus_CG	<.001	.682	.414	.226	.595
	EmploymentStatus_CG	<.001	.378	.284	.148	.891
	Monthlyincomelevel_CG	<.001	-.588	-.330	-.174	.672
	Livingwiththecarerecipient	.007	.324	.203	.103	.820
3	(Constant)	<.001				
	Age_CR	<.001	.692	.271	.133	.507
	Educationallevel_CR	<.001	-.322	-.251	-.123	.854
	StageofAD	.078	.400	.135	.064	.761
	Age_CG	.032	.456	.164	.079	.758
	Educationallevel_CG	.184	-.443	-.102	-.048	.678
	Maritalstatus_CG	<.001	.682	.379	.194	.571
	EmploymentStatus_CG	<.001	.378	.267	.131	.880
	Monthlyincomelevel_CG	<.001	-.588	-.278	-.137	.618
	Livingwiththecarerecipient	.010	.324	.196	.095	.814
	Hoursofcareperweek	.013	.648	.189	.091	.487
	Caregiver'sPerceptionofFormalCare	<.001	-.421	-.258	-.126	.862
4	(Constant)	<.001				
	Age_CR	.002	.692	.237	.111	.494



Coefficients[a]

Model		Collinearity Statistics
		VIF
1	(Constant)	
	Age_CR	1.146
	Educationallevel_CR	1.101
	StageofAD	1.199
2	(Constant)	
	Age_CR	1.807
	Educationallevel_CR	1.166
	StageofAD	1.315
	Age_CG	1.319
	Educationallevel_CG	1.329
	Maritalstatus_CG	1.680
	EmploymentStatus_CG	1.123
	Monthlyincomelevel_CG	1.488
	Livingwiththecarerecipient	1.219
3	(Constant)	
	Age_CR	1.971
	Educationallevel_CR	1.171
	StageofAD	1.315
	Age_CG	1.320
	Educationallevel_CG	1.475
	Maritalstatus_CG	1.752
	EmploymentStatus_CG	1.137
	Monthlyincomelevel_CG	1.618
	Livingwiththecarerecipient	1.228
	Hoursofcareperweek	2.052
	Caregiver'sPerceptionofFormalCare	1.160
4	(Constant)	
	Age_CR	2.024

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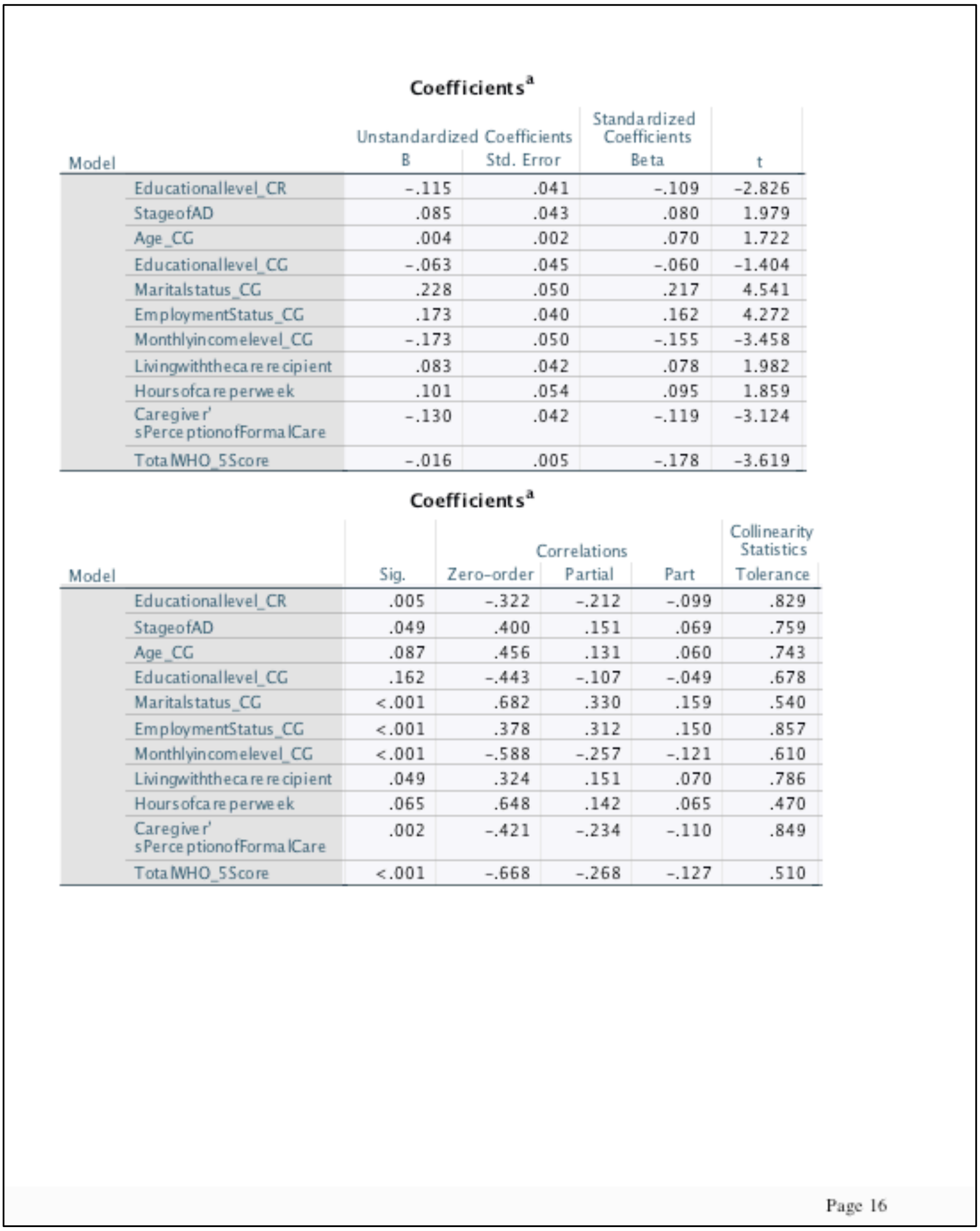

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients	
		B	Std. Error	Beta	t
	Educationallevel_CR	-.115	.041	-.109	-2.826
	StageofAD	.085	.043	.080	1.979
	Age_CG	.004	.002	.070	1.722
	Educationallevel_CG	-.063	.045	-.060	-1.404
	Maritalstatus_CG	.228	.050	.217	4.541
	EmploymentStatus_CG	.173	.040	.162	4.272
	Monthlyincomelevel_CG	-.173	.050	-.155	-3.458
	Livingwiththecarerecipient	.083	.042	.078	1.982
	Hoursofcareperweek	.101	.054	.095	1.859
	Caregiver'sPerceptionofFormalCare	-.130	.042	-.119	-3.124
	TotalWHO_5Score	-.016	.005	-.178	-3.619

Coefficients[a]

Model			Correlations			Collinearity Statistics
		Sig.	Zero-order	Partial	Part	Tolerance
	Educationallevel_CR	.005	-.322	-.212	-.099	.829
	StageofAD	.049	.400	.151	.069	.759
	Age_CG	.087	.456	.131	.060	.743
	Educationallevel_CG	.162	-.443	-.107	-.049	.678
	Maritalstatus_CG	<.001	.682	.330	.159	.540
	EmploymentStatus_CG	<.001	.378	.312	.150	.857
	Monthlyincomelevel_CG	<.001	-.588	-.257	-.121	.610
	Livingwiththecarerecipient	.049	.324	.151	.070	.786
	Hoursofcareperweek	.065	.648	.142	.065	.470
	Caregiver'sPerceptionofFormalCare	.002	-.421	-.234	-.110	.849
	TotalWHO_5Score	<.001	-.668	-.268	-.127	.510

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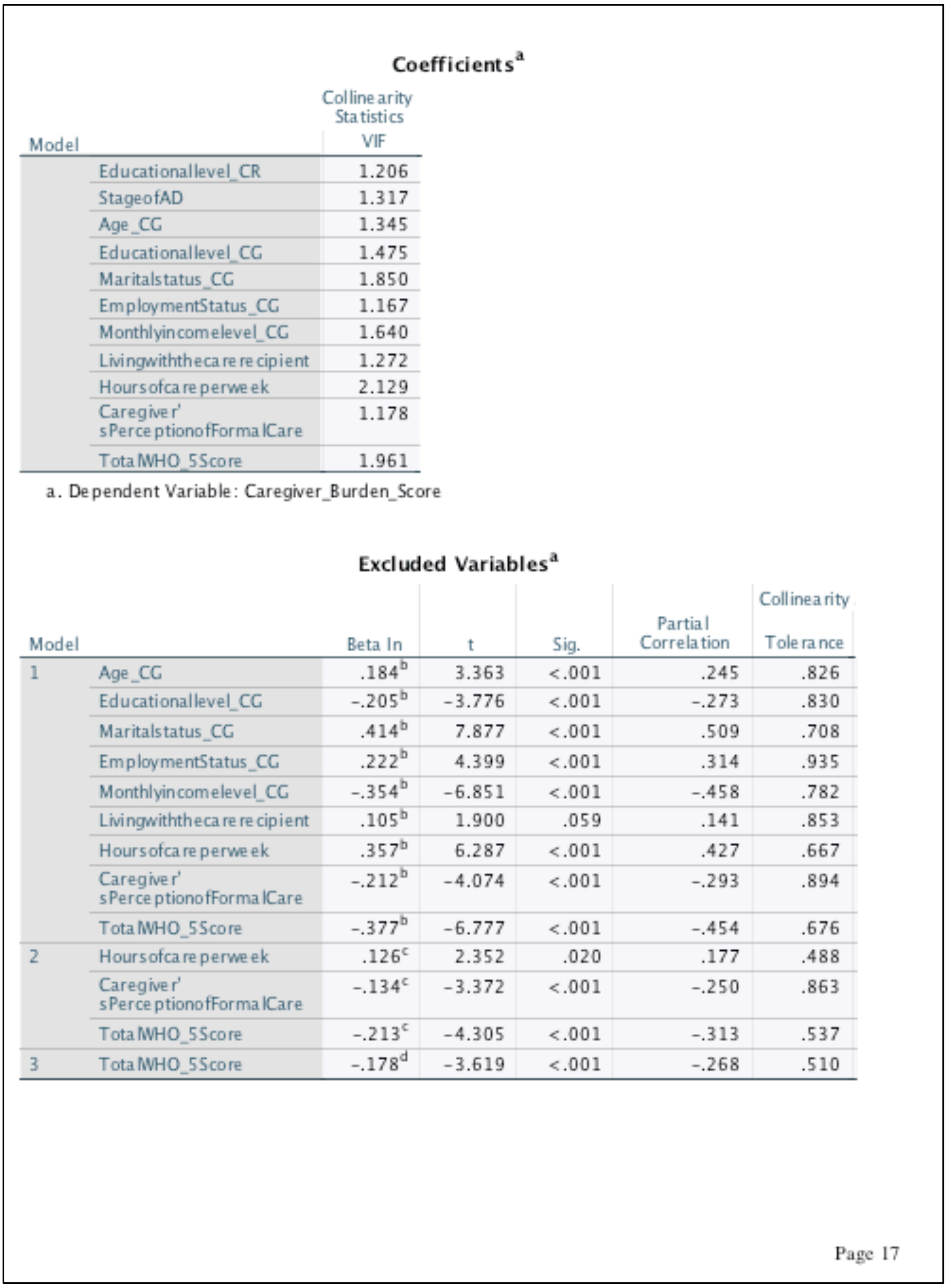


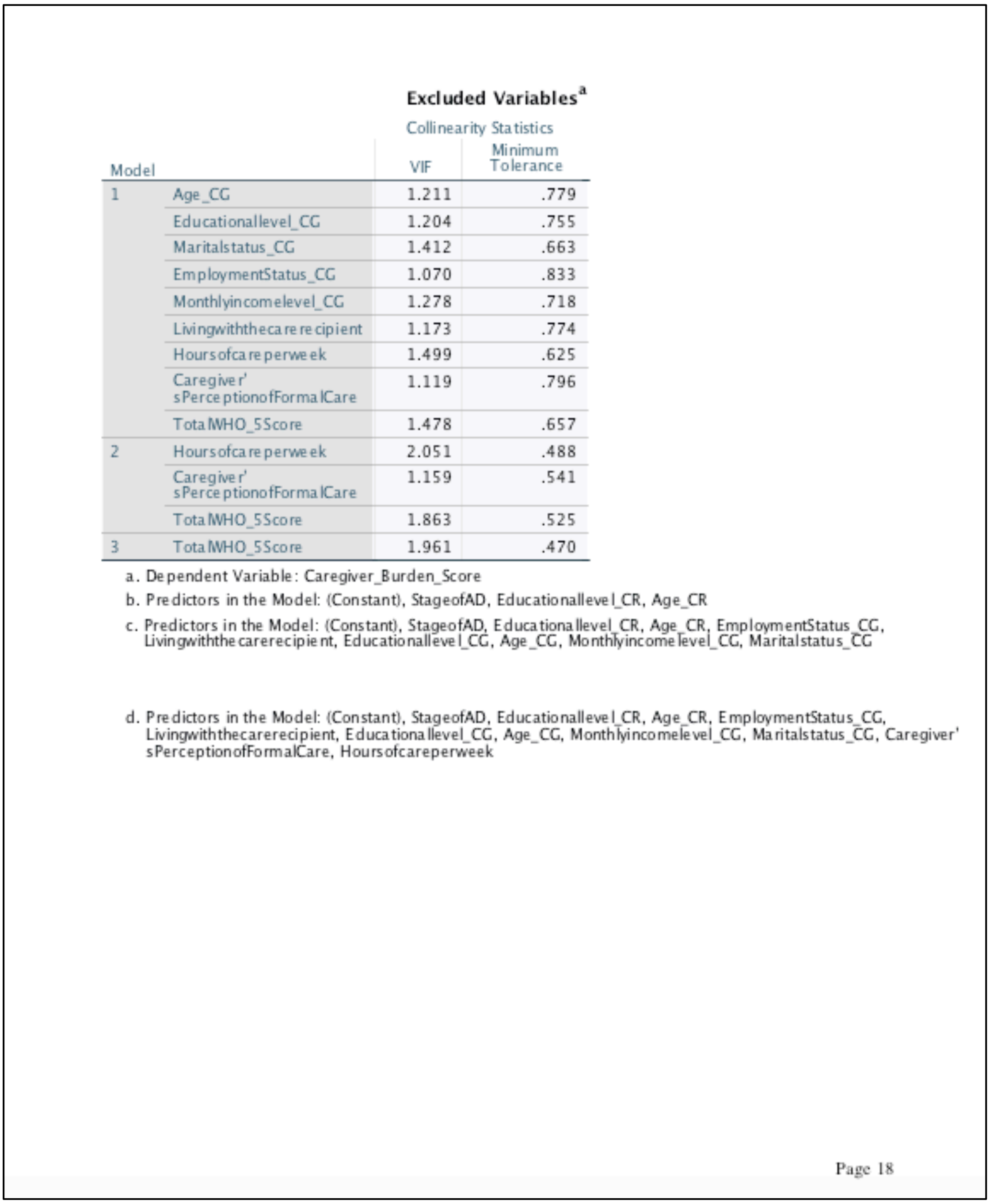
Coefficients[a]

Model		Collinearity Statistics
		VIF
	Educationallevel_CR	1.206
	StageofAD	1.317
	Age_CG	1.345
	Educationallevel_CG	1.475
	Maritalstatus_CG	1.850
	EmploymentStatus_CG	1.167
	Monthlyincomelevel_CG	1.640
	Livingwiththecarerecipient	1.272
	Hoursofcareperweek	2.129
	Caregiver'sPerceptionofFormalCare	1.178
	TotalWHO_5Score	1.961

a. Dependent Variable: Caregiver_Burden_Score

Excluded Variables[a]

Model		Beta In	t	Sig.	Partial Correlation	Collinearity Statistics
						Tolerance
1	Age_CG	.184[b]	3.363	<.001	.245	.826
	Educationallevel_CG	-.205[b]	-3.776	<.001	-.273	.830
	Maritalstatus_CG	.414[b]	7.877	<.001	.509	.708
	EmploymentStatus_CG	.222[b]	4.399	<.001	.314	.935
	Monthlyincomelevel_CG	-.354[b]	-6.851	<.001	-.458	.782
	Livingwiththecarerecipient	.105[b]	1.900	.059	.141	.853
	Hoursofcareperweek	.357[b]	6.287	<.001	.427	.667
	Caregiver'sPerceptionofFormalCare	-.212[b]	-4.074	<.001	-.293	.894
	TotalWHO_5Score	-.377[b]	-6.777	<.001	-.454	.676
2	Hoursofcareperweek	.126[c]	2.352	.020	.177	.488
	Caregiver'sPerceptionofFormalCare	-.134[c]	-3.372	<.001	-.250	.863
	TotalWHO_5Score	-.213[c]	-4.305	<.001	-.313	.537
3	TotalWHO_5Score	-.178[d]	-3.619	<.001	-.268	.510



Excluded Variables[a]

Model		Collinearity Statistics VIF	Collinearity Statistics Minimum Tolerance
1	Age_CG	1.211	.779
	Educationallevel_CG	1.204	.755
	Maritalstatus_CG	1.412	.663
	EmploymentStatus_CG	1.070	.833
	Monthlyincomelevel_CG	1.278	.718
	Livingwiththecarerecipient	1.173	.774
	Hoursofcareperweek	1.499	.625
	Caregiver'sPerceptionofFormalCare	1.119	.796
	TotalWHO_5Score	1.478	.657
2	Hoursofcareperweek	2.051	.488
	Caregiver'sPerceptionofFormalCare	1.159	.541
	TotalWHO_5Score	1.863	.525
3	TotalWHO_5Score	1.961	.470

a. Dependent Variable: Caregiver_Burden_Score

b. Predictors in the Model: (Constant), StageofAD, Educationallevel_CR, Age_CR

c. Predictors in the Model: (Constant), StageofAD, Educationallevel_CR, Age_CR, EmploymentStatus_CG, Livingwiththecarerecipient, Educationallevel_CG, Age_CG, Monthlyincomelevel_CG, Maritalstatus_CG

d. Predictors in the Model: (Constant), StageofAD, Educationallevel_CR, Age_CR, EmploymentStatus_CG, Livingwiththecarerecipient, Educationallevel_CG, Age_CG, Monthlyincomelevel_CG, Maritalstatus_CG, Caregiver'sPerceptionofFormalCare, Hoursofcareperweek

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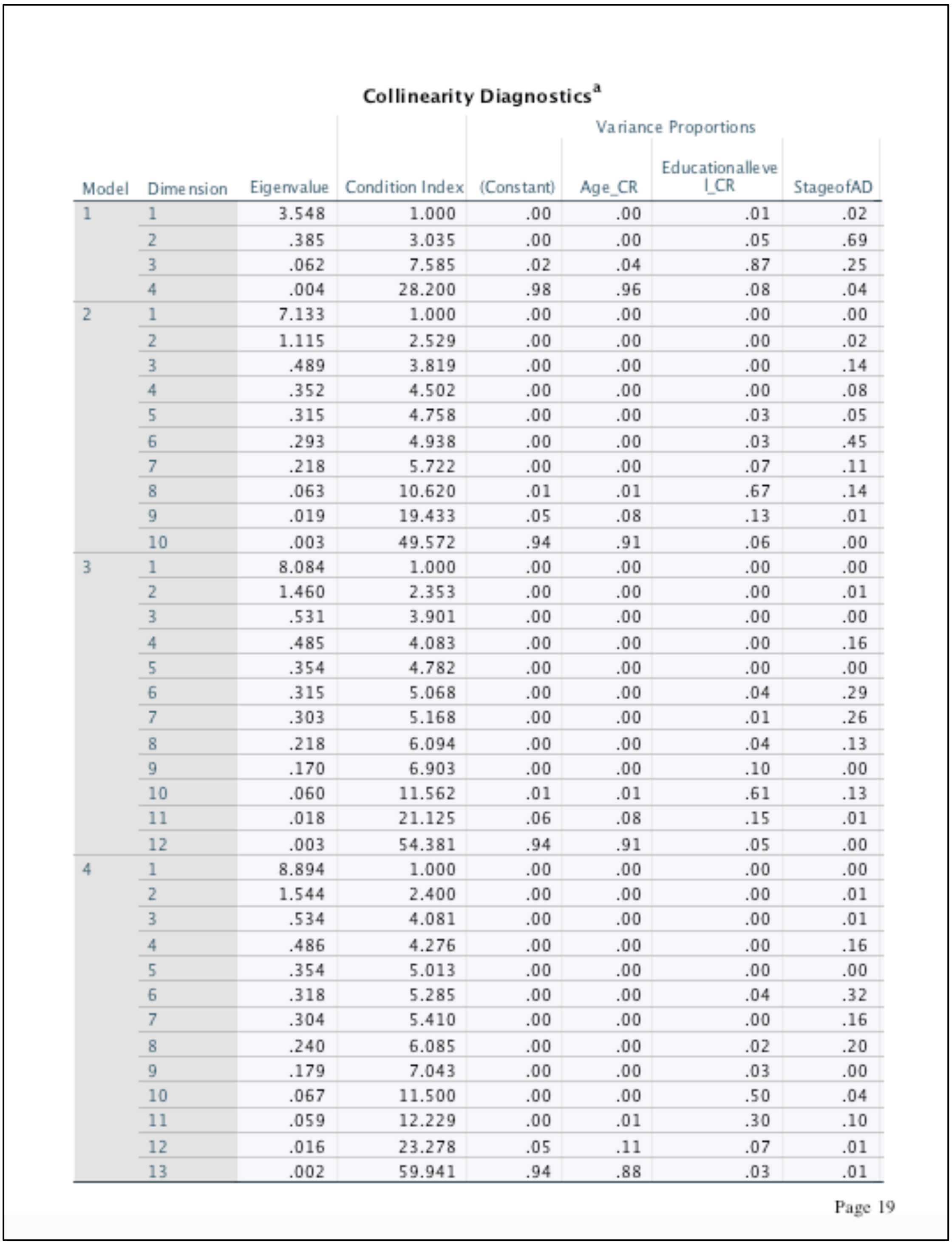
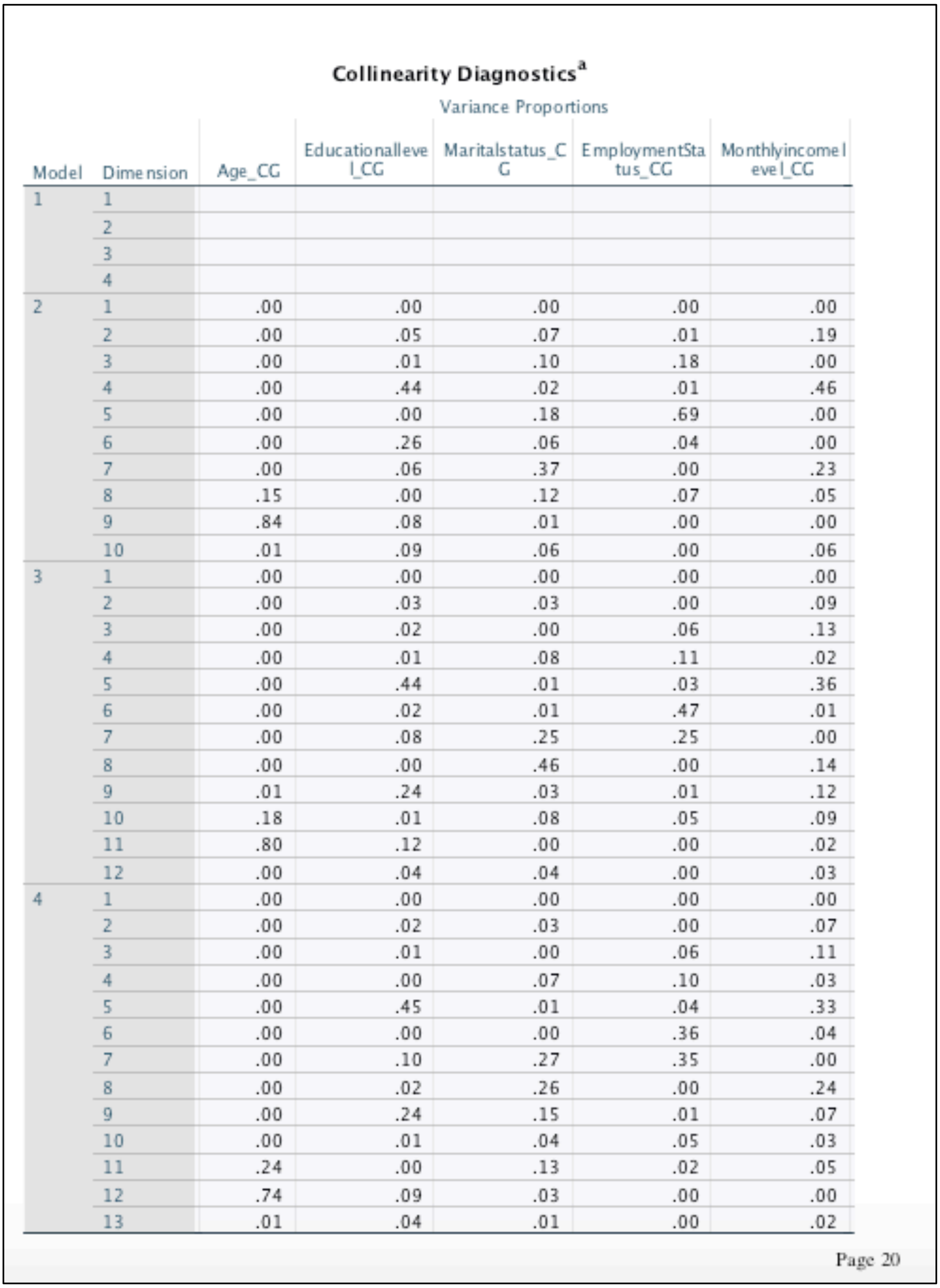


Collinearity Diagnostics[a]

				Variance Proportions			
Model	Dimension	Eigenvalue	Condition Index	(Constant)	Age_CR	Educationallevel_CR	StageofAD
1	1	3.548	1.000	.00	.00	.01	.02
	2	.385	3.035	.00	.00	.05	.69
	3	.062	7.585	.02	.04	.87	.25
	4	.004	28.200	.98	.96	.08	.04
2	1	7.133	1.000	.00	.00	.00	.00
	2	1.115	2.529	.00	.00	.00	.02
	3	.489	3.819	.00	.00	.00	.14
	4	.352	4.502	.00	.00	.00	.08
	5	.315	4.758	.00	.00	.03	.05
	6	.293	4.938	.00	.00	.03	.45
	7	.218	5.722	.00	.00	.07	.11
	8	.063	10.620	.01	.01	.67	.14
	9	.019	19.433	.05	.08	.13	.01
	10	.003	49.572	.94	.91	.06	.00
3	1	8.084	1.000	.00	.00	.00	.00
	2	1.460	2.353	.00	.00	.00	.01
	3	.531	3.901	.00	.00	.00	.00
	4	.485	4.083	.00	.00	.00	.16
	5	.354	4.782	.00	.00	.00	.00
	6	.315	5.068	.00	.00	.04	.29
	7	.303	5.168	.00	.00	.01	.26
	8	.218	6.094	.00	.00	.04	.13
	9	.170	6.903	.00	.00	.10	.00
	10	.060	11.562	.01	.01	.61	.13
	11	.018	21.125	.06	.08	.15	.01
	12	.003	54.381	.94	.91	.05	.00
4	1	8.894	1.000	.00	.00	.00	.00
	2	1.544	2.400	.00	.00	.00	.01
	3	.534	4.081	.00	.00	.00	.01
	4	.486	4.276	.00	.00	.00	.16
	5	.354	5.013	.00	.00	.00	.00
	6	.318	5.285	.00	.00	.04	.32
	7	.304	5.410	.00	.00	.00	.16
	8	.240	6.085	.00	.00	.02	.20
	9	.179	7.043	.00	.00	.03	.00
	10	.067	11.500	.00	.00	.50	.04
	11	.059	12.229	.00	.01	.30	.10
	12	.016	23.278	.05	.11	.07	.01
	13	.002	59.941	.94	.88	.03	.01



Collinearity Diagnostics[a]

Model	Dimension	Variance Proportions				
		Age_CG	Educationallevel_CG	Maritalstatus_CG	EmploymentStatus_CG	Monthlyincomelevel_CG
1	1					
	2					
	3					
	4					
2	1	.00	.00	.00	.00	.00
	2	.00	.05	.07	.01	.19
	3	.00	.01	.10	.18	.00
	4	.00	.44	.02	.01	.46
	5	.00	.00	.18	.69	.00
	6	.00	.26	.06	.04	.00
	7	.00	.06	.37	.00	.23
	8	.15	.00	.12	.07	.05
	9	.84	.08	.01	.00	.00
	10	.01	.09	.06	.00	.06
3	1	.00	.00	.00	.00	.00
	2	.00	.03	.03	.00	.09
	3	.00	.02	.00	.06	.13
	4	.00	.01	.08	.11	.02
	5	.00	.44	.01	.03	.36
	6	.00	.02	.01	.47	.01
	7	.00	.08	.25	.25	.00
	8	.00	.00	.46	.00	.14
	9	.01	.24	.03	.01	.12
	10	.18	.01	.08	.05	.09
	11	.80	.12	.00	.00	.02
	12	.00	.04	.04	.00	.03
4	1	.00	.00	.00	.00	.00
	2	.00	.02	.03	.00	.07
	3	.00	.01	.00	.06	.11
	4	.00	.00	.07	.10	.03
	5	.00	.45	.01	.04	.33
	6	.00	.00	.00	.36	.04
	7	.00	.10	.27	.35	.00
	8	.00	.02	.26	.00	.24
	9	.00	.24	.15	.01	.07
	10	.00	.01	.04	.05	.03
	11	.24	.00	.13	.02	.05
	12	.74	.09	.03	.00	.00
	13	.01	.04	.01	.00	.02

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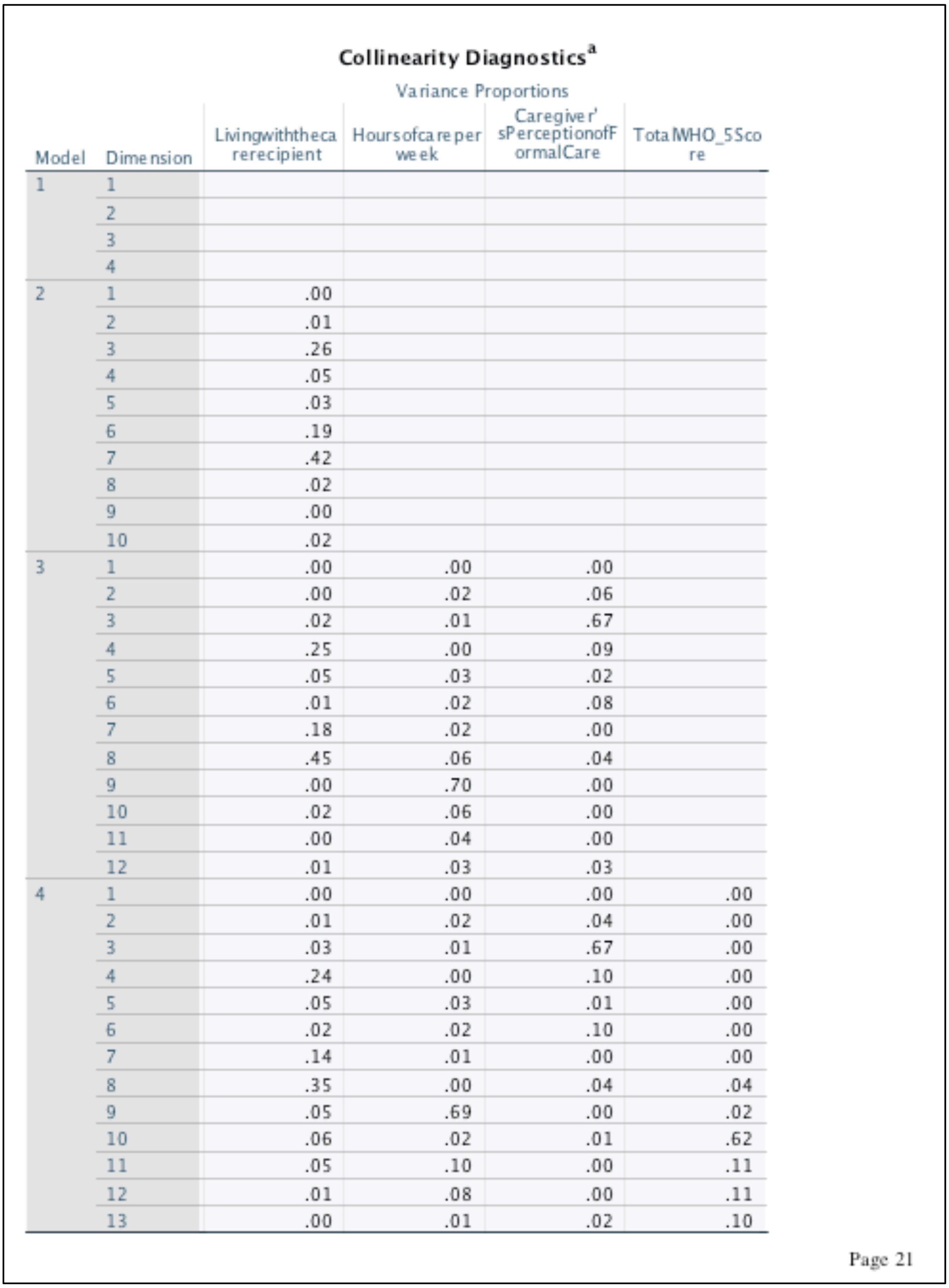
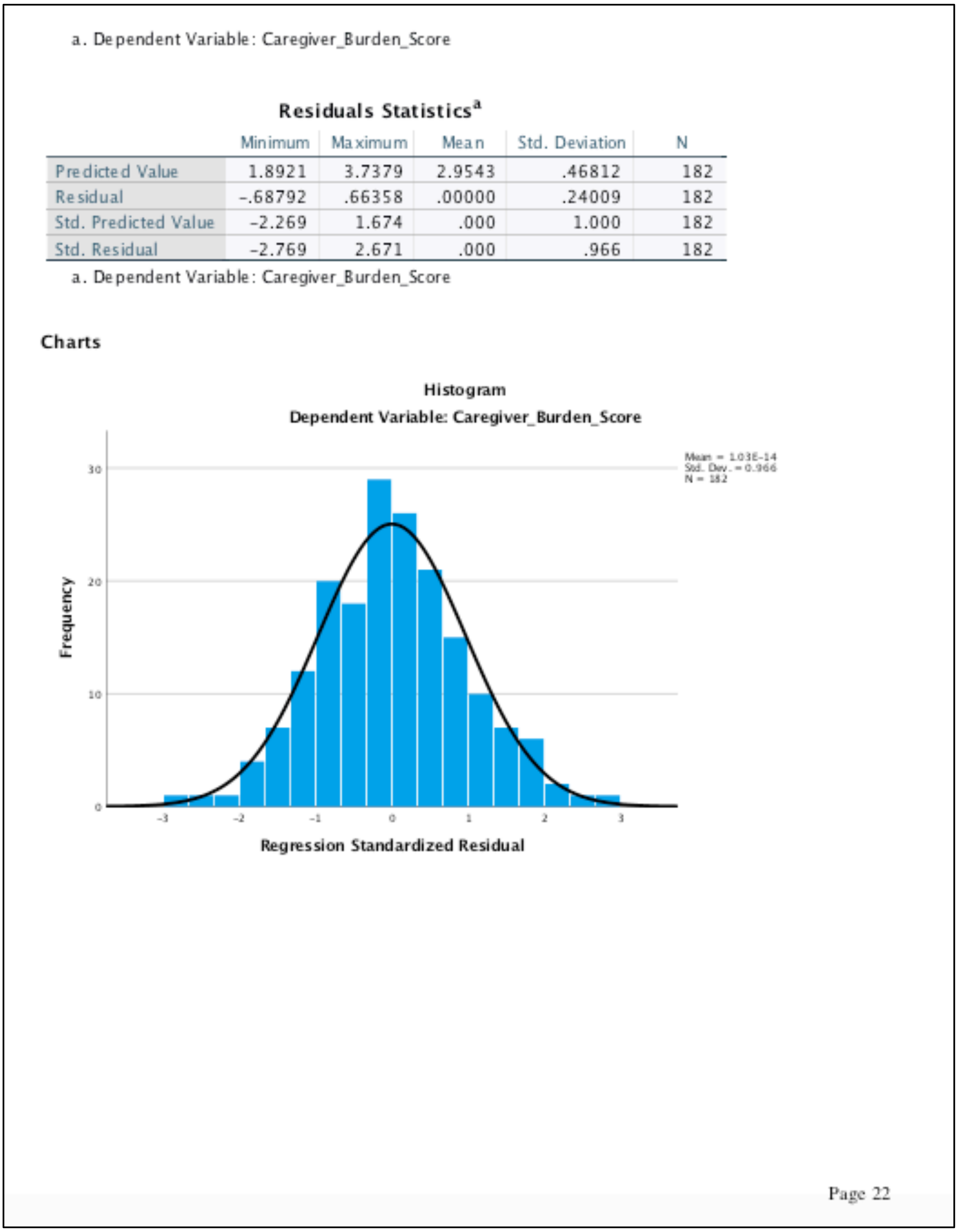


Collinearity Diagnostics[a]

		Variance Proportions			
Model	Dimension	Livingwiththecarerecipient	Hoursofcareperweek	Caregiver'sPerceptionofFormalCare	TotalWHO_5Score
1	1				
	2				
	3				
	4				
2	1	.00			
	2	.01			
	3	.26			
	4	.05			
	5	.03			
	6	.19			
	7	.42			
	8	.02			
	9	.00			
	10	.02			
3	1	.00	.00	.00	
	2	.00	.02	.06	
	3	.02	.01	.67	
	4	.25	.00	.09	
	5	.05	.03	.02	
	6	.01	.02	.08	
	7	.18	.02	.00	
	8	.45	.06	.04	
	9	.00	.70	.00	
	10	.02	.06	.00	
	11	.00	.04	.00	
	12	.01	.03	.03	
4	1	.00	.00	.00	.00
	2	.01	.02	.04	.00
	3	.03	.01	.67	.00
	4	.24	.00	.10	.00
	5	.05	.03	.01	.00
	6	.02	.02	.10	.00
	7	.14	.01	.00	.00
	8	.35	.00	.04	.04
	9	.05	.69	.00	.02
	10	.06	.02	.01	.62
	11	.05	.10	.00	.11
	12	.01	.08	.00	.11
	13	.00	.01	.02	.10



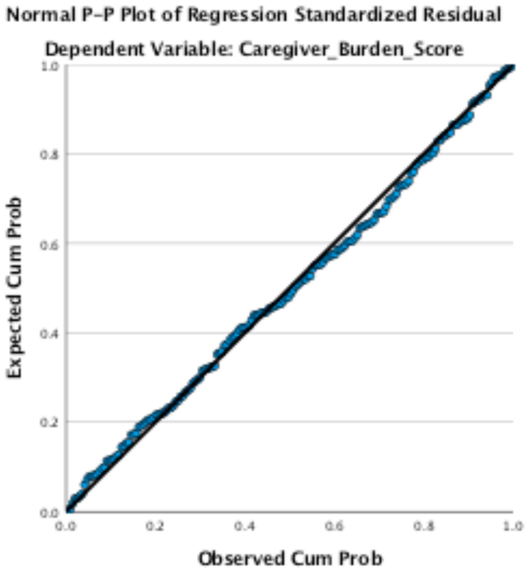
a. Dependent Variable: Caregiver_Burden_Score

Residuals Statistics[a]

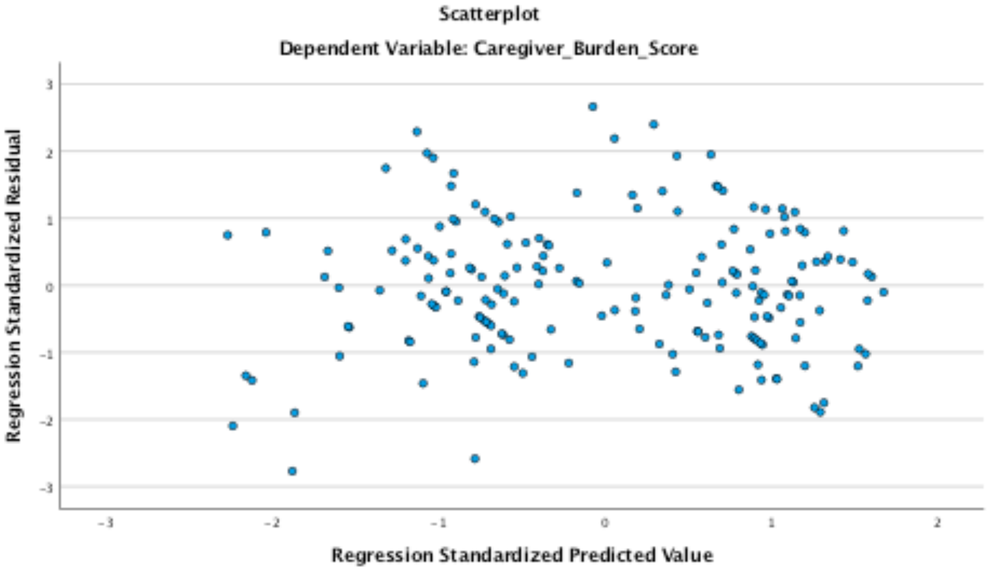
	Minimum	Maximum	Mean	Std. Deviation	N
Predicted Value	1.8921	3.7379	2.9543	.46812	182
Residual	-.68792	.66358	.00000	.24009	182
Std. Predicted Value	-2.269	1.674	.000	1.000	182
Std. Residual	-2.769	2.671	.000	.966	182

a. Dependent Variable: Caregiver_Burden_Score

Charts


Normal P-P Plot of Regression Standardized Residual

Dependent Variable: Caregiver_Burden_Score


Scatterplot

Dependent Variable: Caregiver_Burden_Score