A DUTY TO CARE:
MALE PERSPECTIVES ON THEIR ROLE AS CAREGIVERS FOR PERSONS WITH ALZHEIMER'S DISEASE OR RELATED DEMENTIA

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by
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The undersigned, appointed by the dean of the Graduate School, have examined the dissertation entitled

A DUTY TO CARE: MALE PERSPECTIVES ON THEIR ROLE AS CAREGIVERS
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a candidate for the degree of Doctor of Philosophy,

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DEDICATION

This dissertation is dedicated to all those who have supported my academic and professional journey.

First and foremost, my wife, Emily Bueno. You have been my rock, my light, and my fire. You have been my biggest fan and my motivator. Throughout this journey you have acted as a single parent while I was neck deep in schoolwork and still had the energy to lift me up. You are my motivation to be the best person, husband, father, nurse, and researcher I can be. And to my two “study buddies” Alice and Ben. The two main driving forces in pushing me to be the best role model. You both have been very patient and supportive of a busy father, especially the many nights you fell asleep to the glow of the computer screen as your dad worked on his papers. I don’t know how I could have done it without the two of you reminding me why I do the work that I do. I love you three to the moon!

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LIST OF ABBREVIATIONS

AARP	American Association of Retired Persons
ADRD	Alzheimer’s Disease or Related Dementia
CINAHL	Cumulative Index to Nursing and Allied Health Literature
CIT	Caregiver Identity Theory
FCG	Family Caregiver
HRQoL	Health Related Quality of Life
PI	Primary Investigator

FULLFILLING THE CAREGIVER ROLE:
MALE PERSPECTIVES ON THEIR ROLE AS CAREGIVERS FOR PERSONS WITH ALZHEIMER'S DISEASE OR RELATED DEMENTIA

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ABSTRACT

People with Alzheimer's Disease or related dementia (ADRD) require a significant amount of care due to its progressive and chronic nature. Most of the care provided to people with ADRD come from family caregivers (FCGs). The importance of the FCG is significantly increasing as it is estimated that the number of people with ADRD in the U.S. will double by the year 2050. Although caregiving provides many personal, familial, and economic benefits, the progressive and heavy demands of providing care for someone with ADRD places caregivers at risk for negative health outcomes. Most caregiving research has focused on females. Although female caregivers have reported more negative outcomes, men still report significant levels of burden. With the aging population and increased need for caregivers, there is a gap in knowledge exploring the male caregiving experience. Understanding male caregiving experiences can inform clinicians on developing future strategies to tailor support for this underrepresented group. The purpose of this qualitative descriptive study was to explore the experiences of male FCGs of people with ADRD. The Caregiver Identity Theory (CIT) was used to guide the study exploring participants' perception of self-identity within their caregiving relationship and self-identity as a male. Eleven male caregivers, recruited through social media and community resources, were interviewed by telephone or Zoom. Interviews were recorded, transcribed, and analyzed using thematic analysis. Four major themes emerged highlighting males' struggles with the unfamiliar caregiving role and changing identity, their acknowledgement of personal growth and discovery through caregiving, challenges in finding the “right” kind of support, and perceived reshaping of masculinity through the caregiving role. Within each major theme, sub-themes were identified to further exemplify the male caregiving experience. Male caregivers express unique experiences as FCGs suggesting future research is needed to explain gender differences in caregiving and identify additional factors that influence male caregivers’ experiences. Furthermore, findings indicate clinicians should tailor support strategies for male FCGs’ as they fulfill this potentially unfamiliar role.

CHAPTER 1: INTRODUCTION

BACKGROUND

Family caregivers (FCGs) are family members who take on the duties of providing care for another person through sickness or disability (AARP, 2020). Although the term “family” can often mean individuals of kin, some people can be considered family by choice which includes those who may not be directly blood related but share a mutual bond to the person receiving care. Friends and sometimes close neighbors have been considered “family” when referring to the caregiving relationship (Family Caregiving Alliance, n.d.). FCGs are often unpaid and may share the term “informal” caregiver. These FCGs serve an important role in society, especially in the lives of older adults in need of their care. With the expected rise of the older adult population, fueled by the aging baby boomer generation, FCGs will play an even larger role in the health of the country.

According to the American Association of Retired Persons [AARP] and the National Alliance for Caregiving, the prevalence of older adult caregivers in the U.S. significantly increased to 41.8 million people in 2020 up from 34.2 million in 2015 (AARP, 2020). In addition to providing a significant service to caring for the aging adult population, FCGs offer an economic impact in their role. For example, FCGs for people with Alzheimer’s or related dementias (ADRD) accounted for 15.3 billion hours of unpaid caregiving which has an equitable value of $256.7 billion in 2020 (Alzheimer’s Association, 2021). Although older adult caregiving may involve many other types of chronic illness, ADRD is the focus of this study as it is a progressive, age-related disease that presents a higher risk for the aging adult population. Furthermore, it is projected that by 2050, 12.7 million older adults will be diagnosed with Alzheimer's dementia, which is more than double the 6.2 million people with the disease in 2021 (Alzheimer's Association, 2021). The rapid predicted rise of people with ADRD will further increase the need for, and importance of, the FCG role.

Caregiving can be a rewarding role as it can bring comfort and a sense of duty to providing for a loved one. However, caregivers are at risk to develop their own negative health outcomes due to the many responsibilities and demands of providing support for someone with a chronic illness. These health consequences for the caregiver can be further compounded by caring for someone with ADRD since the disease can progressively worsen over a long period of time. Caring for persons with ADRD has been associated with an impact on psychological health with development of stress, anxiety, and depression (Goren et al., 2016; Richardson et al., 2013; Tatangelo et al., 2018). Groups of negative health effects of ADRD caregiving has also been termed as "caregiver burden" for which a tool, the Zarit Burden Interview (ZBI) was developed measuring multiple aspects of the negative caregiving experience that influences feelings of burden (Zarit et al., 1980). This validated tool has become one of the most widely used instruments to measure negative health aspects of caregiving for people with ADRD. It has been translated in various languages used across the world in ADRD caregiving studies. The psychological health consequences of caregiving have also been linked to caregiver physical health. In a study exploring the links between caregiving, the stress biomarker interleukin (IL)-6, and coping self-efficacy, it was found that caregiver stress combined with low coping self-efficacy was significantly related to IL-6. This finding is important because IL-6 is a known biological risk factor for health morbidity and mortality in older adults; it is associated with physical disability, hypertension, subclinical atherosclerosis, and risk for coronary heart disease (Mausbach et al., 2011). Given the important role that ADRD caregivers play in older adult health management and economic benefits, the health consequences of caregiving can result in caregivers needing care themselves, further burdening the current US healthcare system.

The many responsibilities of caregiving can have secondary effects on the lives of caregivers. Caregiving can affect other domains of caregivers' lives, including, responsibilities to other family members, social networks, and, most notably, their jobs. The Alzheimer's Association (2021) has reported that unpaid ADRD caregivers provided care with equitable value over two and half billion dollars, but what may not be included are the costs associated with disruptions in caregivers' work for those employed elsewhere. Moreover, ADRD caregiving has been found to create more work disruptions compared to disruptions experienced by caregivers who care for other types of people. Caregivers for people with ADRD were found to report more instances of absenteeism, leaves of absence, loss of benefits, retiring earlier, or quitting altogether compared to other types of caregivers (Alzheimer's Association, 2021). Even in retirement, additional financial stressors can further impact the health of the caregiver. One study suggested that retired caregivers for people with ADRD compared to employed caregivers were prone to reporting lower health related quality of life (HRQoL), possibly due to being unable to afford paid services such as respite care (Majoni & Oremus, 2017). These findings illustrate the financial impact that caregiving for a person with ADRD has on the individual level.

FCGs provide a critical role but also shoulder a tremendous amount of responsibility which can lead to high levels of burden and negative health outcomes. But the experiences and outcomes of FCGs can vary based on additional factors such as relationship type, time spent caregiving, and caregiver gender. A demographic that is beginning to attract more focus is the male caregiver. Caregiving has traditionally been seen as a female role, evident by the fact that 61% of all caregivers of older adults are women (AARP, 2020). Much of the literature exploring the differences in caregiver health outcomes by gender have found that female caregivers experience higher levels of burden, stress, and anxiety compared to their male counterparts (Avdikou et al., 2019; Del Pino Casado et al., 2017; Glavin & Peters, 2015; Kahn et al., 2016; Prevo et al., 2018). It has also been found that female caregivers report higher levels of anxiety and lower HRQoL (Del Rio Lozano et al., 2017; Perrin et al., 2015). However, it is still important to note that male caregivers endure a significant amount of burden, and stress as well, even if it not at the level experienced by female caregivers. Traditional views on gender, identity, and role expectations are increasingly challenged in today's society in areas such as the workforce and healthcare. With the expected rise in the older adult population, higher risks for chronic age-related diseases, and the consequent need for caregivers, a new look at how gender affects the caregiving role is warranted.

Humans as sentient beings are driven by the uniqueness they provide to the world around them. Consequently, individuals' experience of the world is influenced through the lenses of multiple identities that makes up the sense of self. Some of these identities include cultural, religious, familial, societal, political, and sexual identity. An area of focus of this dissertation is exploring men's view of their caregiver identity and how it is influenced by their gender identity and their relationship identity with the care recipient. How men view their multiple identities within the caregiving realm can positively or negatively affect their experiences. For example, gender identity may influence how men appraise their abilities as a caregiver (Baker et al., 2010). It was also found that there was a reciprocal effect of caregiving on a man's self-identity. One study found that older male caregivers' inability to cope with the demands caring for their spouse impacted their own sense of self and identity as a man. Furthermore, this negative affect on their self-identity as men may explain how some older male caregivers are more hesitant to seek support for their caregiving role (Milligan & Morbey, 2016). Identity plays a significant part in how men shape their experiences as caregivers.

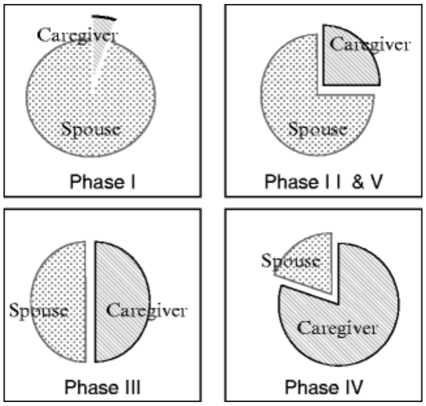
Theoretical Framework

Exploring how identity plays a factor in how men perceive their position as caregivers, the conceptual framework used to guide this dissertation was the caregiver identity theory (CIT) developed by Montgomery et al (2007). The theory attempts to explain the relationship between how an individual providing care balances their dual identities of that of a family member, such as a spouse, and that of a caregiver. The CIT is modeled after three key principles. First, the caregiving role is gained in a systematic process. Secondly, the process itself is dynamic and involves multiple changes over time. This process of evolving identities is illustrated in figure 1.1. Lastly, through the experiences of caregiving, caregivers will also experience a change in their self-identity (Montgomery & Kosloski, 2013). Furthermore, the theory posits that stress and burden are created when a caregivers' perception of their identities as a caregiver and spouse is unbalanced or mismatched (Montgomery et al., 2007; Montgomery & Kosloski, 2012;

Montgomery & Kosloski, 2013). An example of this is when a husband feels their identity as a spouse is overtaken by the increasing responsibilities of being a caregiver due to the increase in needs and demands of their wife's progressive disease.

Figure 1.1

Evolution of Caregiver Identity as Phases over time (Montgomery & Kosloski, 2013)



The original development of the CIT focused on the spousal relationship of caregiving. This dissertation study attempts to expand on the application of this theory to not only of that of a spouse, but other possible relationships involved in ADRD caregiving by men such as a son, grandson, brother, nephew, or friend. This is important to emphasize as more men are fulfilling this caregiver role. Additionally, as younger generations are beginning to take on these caregiving roles, it has been found that younger caregivers tend to be male (AARP, 2020).

Statement of the Problem

The responsibilities of older adult caregiving can place FCGs at risk for developing burden and other negative health effects. Caring for someone with ADRD can present further issues since the disease is progressive and can last over a very long period, with some living with the disease for up to 20 years (Alzheimer's Association, 2021). Although the literature has found that female caregivers of people with dementia reported higher levels of burden, depression and other care-related distress, most studies have been cross-sectional, and the percentage of male caregiver participants have been disproportionally low and may not effectively reflect the current trends in caregiver makeup (Xiong et al., 2020). It is also important to consider that the ADRD caregiving experience is unique and quantitative measures may not illustrate the individual perceptual differences between how men and women engrain their caregiver role within their everyday lives. The few existing qualitative studies on caregiving for persons with ADRD have mainly centered on female caregivers and gaps in the literature include the lack of qualitative studies of the male caregiving experiences caring for a person with ADRD. Furthermore, given the focus on gender differences in caregiving, there is a lack of research exploring the concept of masculinity and its influence on the caregiving experience for male caregivers.

Purpose Statement

The purpose of this qualitative study is to explore the subjective experiences of male family caregivers as they care for a person with ADRD. The study will further investigate how additional factors influence their perception of their role as a caregiver. These factors will include how they see they’re role as a family member (i.e., spouse, child, sibling, etc.) within the caregiving relationship, their perception of support within fulfilling their caregiving duties, and how the concept of masculinity has influenced their perception of being a caregiver. This dissertation will address two aims and the following research questions:

Primary Aim: Explore the perceived experiences of male caregivers caring for a person with ADRD through the role transitions from family member to caregiver.

Research Question 1: How do male caregivers describe their experience as a caregiver throughout their caregiving relationship?

Research Question 2: How do male caregivers describe their experiences related to preparation and resource finding to manage the care needs of persons with ADRD?

Secondary Aim: Describe the male caregivers' perception of masculinity and its influence on their caregiver role.

Research Question: How do male caregivers' views of masculinity influence their perceptions of their role as a caregiver?

Definition of Terms

- **Alzheimer's Disease or Related Dementia (ADRD)** – Dementia is an umbrella term for a collection of diseases that affects the brain. Dementia affects the persons brain which causes changes to the person's thinking, learning, language, problem-solving, and memory that interferes with the person's ability to function. There are different causes of dementia of which Alzheimer's is the most common cause. Alzheimer's disease or Alzheimer's dementia is associated with the accumulation of two types of proteins that accumulates within the brain that contributes to the changes and symptoms of dementia (Alzheimer's Association, 2021).
- **Family Caregiver (FCG)** – Family or friends who take on the responsibilities of providing care for another person through sickness or disability (AARP, 2020).

The term “family” can mean families of kin or from choice to include those who may not be directly blood related but share a relationship to the person receiving care. Family caregivers are often unpaid and may share the term “unpaid or “informal” caregiver.

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CHAPTER II: LITERATURE REVIEW

Gender Differences in Adverse Psychosocial Outcomes Among Family Caregivers: A Systematic Review

Bueno, M.V. & Chase, J. D. (2022). Gender differences in adverse psychosocial outcomes among family caregivers: A systematic review. *Western Journal of Nursing Research* (In Press)

Abstract

This systematic review explores gender differences in adverse psychosocial and role-related outcomes of family caregivers of older adults with chronic illnesses. Data sources for the systematic review included CINAHL, PubMed, PsycINFO, and Google Scholar. Eligible primary research focused on examining gender-based differences in psychological and emotional outcomes (e.g., burden, depression, stress) among family caregivers of an older adult with chronic illness. Sixteen studies were included in the review with most studies using a cross-sectional design and conducted outside of the United States. Studies reported on gender differences in health outcomes such as burden, stress, and anxiety. Women caregivers had overall higher negative outcomes, but men may have more intense difficulty during the initial caregiver transition phase. Resources to address caregiver health should consider the caregiver's gender. As the older adult population grows, more caregiver research is needed and future studies to include more male caregivers.

Keywords

Gender, differences, caregivers, burden, outcomes

Background and Objectives

Advancements in medical technology, research, and treatments have contributed to longer lifespans (Lichtenberg, 2017). Because of a growing older adult population, the rise in risks and prevalence of chronic disease has become a challenge to the United States healthcare system. To address the needs of the increased numbers of older adults with chronic diseases, informal, familial caregivers are providing valuable care to the needs of this growing population. Prevalence of caregiving for an adult over the age of 50 has risen from 14.3% or 34.2 million adults to 16.8% or 41.8 million within the past five years (AARP, 2020). According to the Alzheimer's Association, informal or familial caregivers provide approximately 83% of care to all older adults that equate to $244 billion dollars of economic value in the United States (Alzheimer's Association, 2020). From addressing the physical, emotional, and psychological needs of the chronically ill to the fiscal impact they have on society, caregivers are Invaluable to the health of the growing older adult population.

Despite the positive contributions that caregivers have on populations and society, there are negative sequelae that accompany the caregiving role. Depending on the type and severity of the care recipient's chronic illness, caregivers are at risk to develop their own physical and psychological health issues (AARP, 2020). For example, caregivers of people with Alzheimer's disease or dementias can develop stress, anxiety, and emotional burden due to the caregiving role demands of their loved one (Goren et al., 2016; Richardson et al., 2013; Tatangelo et al., 2018). In addition to psychological and emotional impacts, the risks for negative physical consequences from caregiving can be contributed to the direct physical demands of the care recipient or the decrease attention to caregivers' own health needs. One study found a link between caregivers and an increase in levels of the biomarker interleukin-6 (Mausbach et al., 2011). Interleukin-6 has been known to be associated with an increased risk for morbidity such as cardiovascular disease, diabetes, osteoporosis, arthritis, and overall functional decline (Wennberg et al., 2015). Due to these negative outcomes associated with caregiving, there has been a growing body of research on caregiver health and well-being.

The caregiver role is difficult due to the complexity of multiple factors that could affect how the role is perceived and performed. One such factor that has not gained much attention is how gender and gender roles influence caregivers. This is particularly important in a time where the societal views on gender and gender roles are becoming increasingly reconceptualized, opening up opportunities for more people to fulfill different roles and professions once dominated by a particular gender (Mott et al., 2019). This is especially true for caregiving which has been historically viewed as a feminine role. However, in recent years, as the needs of the aging population continue to rise, and the need for available caregivers increases, men are beginning to fill in those gaps. The percentage of caregivers who are men has risen from 34 percent to almost 40 percent within the last decade (Caregiving.org, 2020). Although the numbers of male caregivers are on the rise, most caregiver research is still heavily focused on women or include a disproportionately low percentage of male participants. For example, a study examining the concept of compassion fatigue in caregivers of a parent with dementia included only daughter caregivers (Day et al., 2014). As the gender distribution within caregivers becomes more balanced, it is important to explore differences between how men and women perceive their caregiver role.

Caregiving can also have secondary factors that can impact the health and wellbeing of informal caregivers. Time needed to provide caregiving activities usually will impede other aspects of life such as family and work. A study in Japan found that caregivers reported significantly higher absenteeism, presenteeism-related impairment, and reduced overall work performance versus non-caregivers (Goren et al., 2016). Impact on work performance can further be influenced by additional variables, such as the caregiver's age and relationship to the care recipient. Disruptions in work and employment can be more evident in caregivers of the "sandwich generation" due to their added responsibilities of balancing work, caregiving for parents and children, spousal relationships, and demands from other aspects of their life (O'Sullivan, 2014). An important aspect for working caregivers and how gender can affect their caregiving role can be related to financial responsibilities. According to a recent Pew Research Center analysis in 2018, women still earned 85% of what men earned in median hourly wages, and it would take an extra 39 days of work for a woman to earn as much as a man (Graf et al., 2019). This disparity in pay can play a part in working caregivers and differences based on gender due to inequities in financial stability, affecting their caregiving role.

Theoretical Model

The Caregiver Identity Theory (CIT) is a useful framework for examining gender differences in caregiving outcomes (Montgomery et al., 2007). Self-identity plays a major role in how people shape their experiences, attitudes, and actions. Each person's self-identity is then divided into more specific identities that develop from their own life experiences and the world around them. In this systematic review, the role of gender identity will be explored and the impact it has on the identity of the caregiver and the overall influence on health outcomes.

The premise of the CIT revolves around the caregiver role developing from an already existing role relationship such as a spouse, child, or other familial link. This existing role can be considered the person's familial identity and the accompanying values and interactions they have with the care recipient as a typical member of the family. As the care recipient's needs begin to increase due to an ongoing illness or health issue, the family member's caregiving tasks begin to increase and their consequent role and identity as a caregiver evolves. The process of shifting identities from the familial role to the caregiver role is said to happen over a series of phases where the caregiver identity slowly begins to overtake the original identity of the family member. Distress develops when the person's self-appraisal of their identity as a caregiver is incongruent with their family role (Montgomery et al., 2007; Montgomery & Kosloski, 2009) (Figure 2.1). For example, a daughter may have begun her caregiving tasks by assisting with minor responsibilities such as banking or grocery shopping. As her parent's needs begin to rise, she may find herself performing caregiving duties that was previously not part of her original role, duties such as bathing, feeding, or other activities of daily living. Additionally, the increase in demands interfere with her other responsibilities, such as those in her roles as a spouse, mother, or friend ((Montgomery et al., 2007). The imbalance of how the daughter viewed her relationship as a child and her emerging identity as a caregiver gives rise to the negative feelings of distress.

The CIT emphasizes the importance of balancing the identities of caregiver and familial role to reduce the risk of developing distress. A factor that plays an integral part in the development of one’s identity is gender. The differences of how men and women see themselves in their respective familial role may play a part in the development of negative outcomes as they transition further into the caregiver identity. Examining existing research through the lens of the CIT can facilitate understanding of how gender and the differences in gender may play a role in the identity transitions of the caregiver.

Existing literature reviews exploring caregivers and health outcomes have had diverse foci. One review investigated the general impact caregiving has on the various types of caregivers of older adults and concluded there is a negative effect of caregiving on health and further differentiates the intensity of the effect on subcategories. These subcategory findings found a higher negative effect for females, married caregivers, and those who provide more intensive activities (Bom et al., 2019). In a more recent literature review, authors explored gender differences in caregiving outcomes for caregivers of persons with dementia (Xiong et al., 2020). Consistent with the previous review, among caregivers of persons with dementia, female caregivers had significantly higher levels of burden. Additionally, gender perspectives may contribute to differences between the genders, such as male caregivers seeking help earlier in the caregiving process and recognizing the importance of time for themselves (Xiong et al., 2020). The authors of this review did acknowledge that the most relevant limitation was that most studies lacked methodological rigor which could be attributed to the only recent interest in sex and gender-based analyses in caregiving. Current research and reviews have mostly focused on caregivers of older adults with dementia, but what has not been explored are caregivers for older adults with other chronic diseases and the possible differences in psychological and emotional health outcomes based on gender.

The purpose of this systematic review is to explore the role of gender and gender differences in caregiving outcomes among caregivers of adults with diverse chronic illnesses, expanding beyond past reviews that focused only on dementia. Additionally, this review will explore current research inclusion of male caregivers for people with chronic illness as their population is expected to rise. Chronic illness will be defined as disease processes that are progressive and develop over a longer period of time and require assistance from a caregiver for management of the disease. Examples of chronic long-term illnesses include, but not limited to, heart failure, diabetes, cancer, Parkinson’s disease, Alzheimer’s disease and related dementias, and multiple sclerosis. Findings from this paper will add to the body of knowledge related to gender-related differences and the influences of role transitions in psychological and emotional health outcomes of caregivers caring for older adults with a chronic illness.

Research Design and Methods

The Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guided the reporting and conduct of this systematic review. A review protocol does not exist for this review.

Eligibility Criteria

Eligible studies were published between 2010 and 2020. Caregivers in the studies must identify as the primary caregiver of the older adult with chronic illness, or in other words, provide the majority of care throughout the progression of the disease. Although “older adult” age criteria may vary slightly among studies, for this review, older adults are considered those 60 and older. Informal or familial caregivers were characterized as those who identified as spouse, partner, children, grandchildren, niece, or nephew. Also included in the search were other caregivers who were neighbors, friends, or individuals that the person with chronic disease who has a close working relationship that fills the caregiver role. In addition to assisting with activities of daily living (ADLs), these responsibilities include buying groceries, managing medical appointments, providing transportation, and communicating with medical professionals to understand disease management, or can be designated as the family member to notify for problems (AARP, 2020). Outcomes that were included in this review involve aspects in health-related determinants which will include emotional, and psychological effects from the caregiving role. Psychological and emotional health will involve psychosocial outcomes such as stress, anxiety, and burden. To be excluded in this review are caregivers who have specific training or work in a professional caregiving role or provide paid caregiving services (e.g., nurse, nursing assistant).

Search Strategy

The following databases were used: CINAHL, PubMed, and PsycINFO. Google Scholar was also searched to identify additional articles potentially not captured by main databases. Utilizing these databases, literature was limited to studies conducted from January 2010 up to 2020, published in English, with the end date of September 30, 2020. Discussions around gender and gender roles in society are constantly changing, with examples of an increased focus on gender equality and gender identity in various aspects of the US; thus, a look at the most recent decade was chosen. The strategy used to search the databases included entering initial key terms of “gender”, “differences”, “informal”, “caregiving”, “burden”, and “outcomes” in various combination. Combination terms were also used for relationship context such as “informal” “AND” “caregiving” and "gender" "AND" "differences". Exclusion terminology included "children" OR "adolescents" in titles to limit findings to adult or older adult care recipients. Further searches were done with the addition of terms such as "chronic illness" with multiple combinations of key terms to yield the studies to be included in the review. Bibliographic and author searches were conducted to supplement the initial search databases.

Initial search of the databases yielded 437 articles. These articles were then screened by title and abstract and excluded 401 articles due to limited to no report on gender difference analysis; articles focused on children, adolescents, or youth; articles were a review or meta-analysis; care recipient suffered from an acute illness; and additional articles found unrelated to caregivers of older adults. This resulted in 36 full-text articles that were screened for eligibility. Further assessment of these articles concluded in exclusion of 20 articles due to following reasons: articles focused on gender of care recipients; caregivers of patients with mental illness; articles focused on disorders of consciousness; orthopedic illness; patients on hospice or terminally ill; and outcomes measured were not in area of interest. Figure 2.2 details the search strategy diagram for articles included in the final review (N=16). Although caregiving within these specific situations are also important, certain aspects of caregiving for these populations can pose significant differences in outcomes compared to caregiving for more prevalent medical chronic illnesses. In a cross-sectional comparative study comparing caregiver burden in caregivers for medical patients versus caregivers for psychiatric patients, it was found that there was a significant difference in caregiver burden between the two groups (Mital, et al., 2017).

Data Extraction and Synthesis

The following data were extracted independently by the main author from each article: author and year published, purpose of study, location of study, research method, sample size and percentages of each gender, relationship of caregiver, outcome variables measured, key findings, and limitations. Risk of bias assessment was not conducted due to the diversity of observational studies included in the review. However, a synthesis table that depicts the levels of evidence across studies included in this review is provided in Table 2.1.

Results

Table 2.2 depicts characteristics of the 16 articles included in this review. Most articles utilized cross-sectional designs as their research methodology (n=11). Majority of the studies found were conducted outside of the United States (n=12), mainly in Europe and other North American countries.

Sample Characteristics

All articles included caregivers of older adults with physical or cognitive needs or caregiving for an adult with chronic illness such as multiple sclerosis (n=1), cancer (n=1), Alzheimer's disease or dementia (n=4), while the remaining 10 studies did not focus on a specific chronic disease, but caregivers provided generalized support to an older adult needing caregiving assistance. Most studies implemented a cross-sectional design (n=11), whereas three studies were longitudinal observational, one a cohort study, and one study was a quantitative secondary analysis. Additionally, the percentages of male participants included in gender difference studies were disproportionate to their female counterparts. In the included studies, males ranged between 28 to 43 percent of all participants.

In exploring the relationship of caregiver and care recipient, five articles compared outcomes based on gender between caregiver spouses or partners versus adult children caregivers. Five articles explored differences on outcomes based on gender of only spousal caregivers. Two articles studied differences between additional caregiving relationships such as siblings and parents. The remaining four articles did not specify the relationship type between caregiver and care receiver.

Only four out of the sixteen studies that met criteria were conducted in the US. Few other studies were conducted in other parts of North America, with one study conducted in Canada and another study done in Mexico. The remaining ten studies were conducted in Europe in countries such as the Netherlands, Spain, United Kingdom, France, Germany, Finland, and Greece.

Outcome Measurements

Across multiple studies, there are varying outcome measures used to explore the effects of caregiving. The most popular measure was the Zarit Burden Interview (ZBI) which was used in four of the sixteen studies. However, studies included varying types of scales to measure caregiver outcomes such as the Robinson’s Caregiver Strain Index or the Subjective Burden Scale (Del-Pino-Casado et al., 2017; Friedemann & Buckwalter, 2014). When exploring a specific outcome such as depression, studies used differing types of depression scales for measurement such as the EQ-5D-5L (Del Rio Lozano et al., 2017), Hospital Anxiety and Depression Scale (HADS) (Ketcher et al., 2020), PHQ-9 Depressive symptoms scale (Perrin et al., 2015), Geriatric Depression Scale (GDS) (Pöysti et al., 2012), and the Center for Epidemiologic Studies Depression scale (CES-D) (Zwar et al., 2020). Studies that included outcomes such as shame, anxiety, role strain, and cognitive functioning used diverse tools, with some outcomes limited to use in a single study.

Gender Differences in Caregiver Outcomes

Psychosocial Outcomes

The main psychological outcomes based on gender differences were burden, anxiety, depression, and quality of life. Female caregivers experience higher levels of burden compared to men (Avdikou et al., 2019; Del Pino Casado et al., 2017; Glavin & Peters, 2015; Kahn et al., 2016; Prevo et al., 2018). In addition to feeling more burden, female caregivers experience higher levels of anxiety and report lower quality of life when caring for their loved one (Del Rio Lozano et al., 2017; Perrin et al., 2015). However, some studies found additional negative outcomes for female caregivers that are not commonly identified in the literature. Female caregivers were found to have higher levels of internal and external shame (Avdikou et al., 2019), primary and secondary role strain (Polenick & DePasquale, 2017), self-esteem (Perrin et al., 2015), and caregiver stigma (Kahn et al., 2016).

Role-related Outcomes

Another aspect that can differ between genders is how caregiving affects role-related areas in their life such as individual, family, and work life. For male caregivers, although level of burden may be lower compared to women, they may react more negatively in transitioning to the caregiver role or during severe changes in the needs of the care recipient (Polenick & DePasquale, 2017; Zwar et al., 2018). In comparison, female caregivers’ depressive symptoms may not increase when transitioning into the caregiving role (Zwar et al., 2020).

For men, caregiving involved higher risks for negative effects in marital, work, and family relationships (Glavin & Peters, 2015; Polenick & DePasquale, 2017). Male caregivers reported that being unemployed and belonging to a lower socioeconomic class was associated in reporting poorer quality of life (Del Rio Lozano et al., 2017). Lastly, only one study found differences in the type of resources utilized between the genders to assist with their caregiving role. Women were found to use more government and outside the home resources, such as family caregiving allowances (more commonly known as paid family leave in the US), respite care services, and counseling, while men preferred more direct care assistance, such as paid help and instrumental help (Del Rio Lozano et al., 2017).

Relationship to care recipient

In addition to differences in gender, kinship, or the type of familial relationship between caregiver and care recipient may influence caregiver outcomes. Comparing spousal and adult children caregivers, adult children reported higher levels of burden (Del-Pino-Casado et al., 2017; Friedemann & Buckwalter, 2014; Kahn et al., 2016; Reed et al., 2014). In further exploring the combination of gender and kinship and caregiving outcomes, one study found that the largest proportion of burden were found among spousal females and adult child males (Friedemann & Buckwalter, 2014). Although these findings illustrate how kinship can also affect gender differences in caregiving, studies that focus on kinship and gender included small percentages of male adult children caregivers. In a study exploring caregiver stigma and burden, male adult children only accounted for 13% of all adult child caregivers (Kahn et al., 2016). In another study focusing on effects of familial caregiver gender and effects on role perception, workload, burden, and family help, male adult child caregivers comprised 15% of all adult child participants (Friedmann & Buckwalter, 2014).

Discussion

We investigated gender differences in outcomes related to caregiving among caregivers of older adults with chronic illness. Findings from this study revealed a lack of research focusing on comparing psychosocial and emotional outcomes between male and female caregivers as it relates to informal caregivers of older adults with chronic illness. Further research is increasingly important as the older adult population continues to grow and the subsequent increase in need for caregivers to care for them. Additionally, societal views of gender and sex have recently garnered more attention across interdisciplinary fields. There have been previous literature reviews focusing on gender differences and health outcomes in caregivers. However, past reviews concentrated on spousal relationships and care recipients with dementia (Arbel et al., 2019) or psychiatric outcomes only (Yee & Schulz, 2000). This review adds to the growing body of caregiver research by including a broader perspective of caregivers of older adults with diverse chronic illnesses across different relationship roles. Additionally, this review is the first to explore the existing literature with the lens of the CIT for differences in psychosocial and emotional health outcomes between genders and the effect of role transitions throughout the caregiving relationship.

Our study findings suggest gender plays an important factor in caregiving and caregiver psychosocial and emotional outcomes. One of the major findings from this review was that female caregivers had greater negative caregiving outcomes compared to males overall, but in certain situations, men experience higher levels of burden. In particular, the immediate phase of transitioning into the caregiver role was found to be more burdensome for men compared to women (Polenick & DePasquale, 2017; Zwar et al., 2018). The CIT could explain the reason for this difference since the theory describes a mismatch in identities as the caregiver moves through the phases of identity change. As caregiving has traditionally been a feminine role that influences societal views of gendered responsibilities, it could be theorized that women have been indoctrinated with the caregiver identity from an early age. Having been accustomed to caregiving activities early on, women may not be affected with increased caregiving demands during the immediate phase of becoming a primary caregiver of their older family member. Societal gender role is an important source of developing masculine versus feminine identities when it comes to domestic tasks. Whereas tasks such as cooking, shopping, cleaning, and caregiving are considered non-masculine, men spend more time on “male” tasks such as home repair or lawn and garden care. As men are tasked to becoming a caregiver in later life, they must generate new understandings about self and what it means to be a man (Hellström et al., 2017). Employing concepts from the CIT, future studies should explore how the role of societal gender norms and tasks such as caregiving can affect caregivers later in life and identify interventions to mitigate the mismatch in identities during the transition in the caregiving role.

There are additional factors that may affect differences in caregiving outcomes between men and women that may not be directly measured or accounted for consistently across the instruments used to measure caregiving consequences. The approach to the caregiving role and certain caregiving activities may pose different challenges depending on the caregiving relationship. As caregivers, women are more involved in direct caregiving tasks as men may be uncomfortable with hands-on personal care that they find uncomfortable, particularly for those without prior experience including childcare (Lanzito, 2017). This could explain the larger overall burden for women but may also explain the more intense struggle in the early phases of caregiving for men as they learn new skills and build up the comfort for sensitive tasks. Additional evidence shows the differences between genders in consequences during the early transition of becoming a caregiver. It was found that during the early phases, men reported higher feelings of loneliness and depressive symptoms despite increasing their networking size (Zwar et al., 2020). A possible explanation is that men approach caregiving challenges using a problem-focused coping compared to emotion-focused coping which women tended to use more often. This type of male coping can make men detached from their social network and increase the feelings of isolation from lower quality relationships (Lopez-Anuarbe & Kohli, 2019; Zwar et al., 2020). To better explore these contributing factors, more longitudinal studies could help explain these differences over time.

Although the findings support that more women endure negative caregiving outcomes and at increased severity, future research should include more male caregivers to increase the strength of the findings. As more men enter caregiving roles in both personal and professional fields, this increase in number should also be reflected in research. Multiple studies found that gender differences may also be influenced by the relationship of the caregiver to care recipient. The effect of the familial relationship is difficult to determine because very few studies included caregivers who were adult male children. This is an important aspect to discuss as the reconceptualization of traditional gender roles is being seen in younger generations, especially millennials, including increasing percentages of men as caregivers. Compared to the overall percentage of male caregivers in the US at 40%, millennial male caregivers are higher than average at 47% and higher than any other generational groups (AARP, 2020). The expansion of caregiving roles to younger generations and the differences in the gendered makeup of this increasing population could direct future research on exploring dyadic relationships and caregiving outcomes. Future studies should include culturally diverse participants that can further the understanding of how culture and ethnicity influence gender roles as they relate to men in the caregiving role. Although male caregivers do not appear to suffer as severe consequences in the caregiving role as females, there is a dearth of literature examining the male caregiving lived experiences. Thus, future qualitative research is needed to address this knowledge gap.

In addition to identifying gender differences in caregiving outcomes, we found methodological weaknesses across the extant body of literature in this area. Outcome measurements have been found to be inconsistent in studies exploring gender differences in caregiving outcomes. When measuring caregiver burden, the ZBI appears to be the most consistent instrument used, but when exploring caregiver depression, five different instruments were found to measure this specific outcome. One possible reason for this is that gender-related caregiving studies are few and only recently has the interest in this population gained popularity. As momentum gains, future studies should incorporate consistent types of measurement instruments to assist in comparing outcomes. Another methodological weakness is the findings of mostly cross-sectional study designs in research examining gender differences in caregiving for older adults with chronic conditions. Although cross-sectional designs allow exploratory comparisons, these designs lack the ability to determine causal inferences that truly discriminate gender as a predictor of poorer psychological and emotional health outcomes. Additionally, cross-sectional designs are unable to examine longitudinal changes in outcomes. When considering the CIT and the mismatch of changing identities over time as a contributor to negative outcomes, longitudinal and prospective research designs would be a better fit for application of the theory.

Since caregiving may affect genders differently and across different types of psychological and psychosocial outcomes, findings from this review suggest that assessment of caregiver burden, providing resources, and developing support for caregivers should not use the “one size fits all” approach. How society and gender norms portray masculinity and femininity can affect strategies men and women use to seek help for their own emotional and psychological struggle within their caregiving roles. Healthcare professionals tasked to address caregiver health should tailor recommendations and create individualized plans that can address the specific needs of men or women. One of the main difficulties in developing a tailored plan to support male caregivers is assessing the need for support for male caregivers. Men are found to have far less health-seeking behaviors than women and are less likely to ask for help for their own mental health (Parent et al.,2018; Staiger et al., 2020). Another contributor to health-seeking behaviors is the reluctance for men to share emotions due to the idea of restrictive emotionality (Tsan et al., 2011). The reluctance for men to share emotions has been attributed to the idea of restrictive emotionality. Restrictive emotionality can influence how men develop attitudes towards psychotherapy types of support, wherein men who are emotionally conflicted due to gender roles have more negative feelings towards psychotherapy because they will be perceived as feminine (Tsan et al., 2011). In a study exploring barriers to participation in support groups for people living with HIV, men voiced being uncomfortable with mixed-gender support groups and advocated for men-only types of groups (Madiba & Canti-Sigaga, 2012). Although support groups can offer many psychological benefits for caregivers, men may not be as comfortable to be open about their emotions in these types of environments. Even when men access caregiving support, men may favor assistance in a more private setting, while women have less reservations in asking for help from multiple supportive care resources for the care recipient (Del Rio Lozano et al., 2017). It is important for healthcare providers to use a holistic approach with the consideration of the caregiver's gender when assessing the need and tailoring supportive resources. In doing so, healthcare providers are acknowledging that each caregiver has unique experiences and contributing to person-centered care.

Due to the differences in types of resources sought, it is important to consider the person's gender in recommending types of services. Only one article in this review mentioned these differences in support utilization; therefore, additional research is warranted to explore what type of support services are more effective by gender. In addition to exploring effectiveness of the types of support services by gender, timing of these interventions would be important, as the intensity of negative outcomes differ between men and women with their evolution into the caregiving role. An interesting finding in a few studies suggest that male caregivers experience more negative feelings in the early stages of caregiver transition and this could mean that male caregivers prefer a more stable and routine role (Polenick & DePasquale, 2017; Zwar et al., 2018). Since male caregivers may have higher burden in the earlier stages of role transition, earlier interventions and resources could prove more effective. Although this finding is encouraging, there is still a lack of robust completed research to strengthen this evidence and thus further exploration is warranted.

Limitations

This study has some important limitations. Only one author screened articles to be included in this review which would introduce the risk of not capturing more robust studies. Generalizability, especially among US caregiving populations, can be difficult given the lack of diverse geographical settings in included studies. Several studies stated that due to location and demographics, cultural and demographical differences may not be reflective of more diverse populations outside of the area studies were conducted (Ketcher et al., 2020; Perrin et al., 2015; Prevo et al., 2018). Similarly, inclusion of only literature in English would exclude studies done in countries where other factors such as ethnicity, culture, and religion have increased influence on gender roles and caregiving. Overall, these findings are promising in exposing factors that affect the health of the growing population of informal, familial caregivers and encourages future studies to add to and strengthen the current evidence included in this review.

The context of gender can have different interpretations, varying from identity, roles, or biological sex. Unfortunately, differences in meaning and application across studies were not discussed in detail in any of the included articles. Gender was typically used within the studies to identify participants’ sex as either male or female. Only two of the studies acknowledged an identification of alternative gender identity, reporting in their study that less than 1% of dyads reporting as same-sex couples, so authors assumed all couples were heterosexual (Swinkels et al., 2019a; Swinkels et al., 2019b). The assumption brings to light an issue of the lack of literature inclusive of lesbian, gay, bisexual, transgender, queer plus (LGBTQ+) populations in gendered caregiver studies. Issues concerning gender and gender roles is especially important to this population of caregivers and unique concerns may pose additional problems for these caregivers. In addition to negative outcomes already mentioned, the LGBTQ+ caregiver may face additional influences on health outcomes, such as family factors, service providers' readiness to work with LGBTQ+ clients, fear of accessing services, and reluctance to disclose orientation (Croghan et al., 2013). Additionally, methods used within this review could have further limited the findings. These methods included use of only five databases and inclusion/exclusion criteria that may have excluded caregivers with more diverse backgrounds in age, culture, religion, and societal norms. Finally, because this study focused on observed gender differences in adverse psychosocial outcomes, we did not closely examine the construct of resiliency. Resiliency can impact outcomes related to stress, coping, and lowering burden levels (Isac et al., 2021). An important next step in this work would be to explore the moderating or mediating role of resiliency in these observed differences. Even in considering these limitations, findings from this review are promising and call for further exploration in gendered caregiver research.

Conclusion

Family caregivers provide numerous benefits to society and the individuals they care for. As recipients of care can vary greatly in their disease and overall needs to thrive, so do caregivers differ in how they are affected by the role in various aspects of their lives. The growing population of caregivers deserves increased attention on how to address their needs based on demographical differences. Since nursing professionals are in constant interactions among individuals with chronic disease, they are in prime position to assess and address the needs of the growing diversity of caregivers. Overall literature on gender in caregiving is still minimal, especially in the growing population of male caregivers. To help address this gap, future direction in research can explore the experiences of male caregivers and the unique challenges that face their adoption of the caregiving role. This synthesis of the literature, presented in the context of the CIT, indicates that differences do exist between male and female caregiver outcomes; however, additional research is needed to further explore how nurses are able to support caregivers based on differences in genders.

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Table 2.1

Levels of evidence adopted from Melnyk, B.M. & Fineout-Overholt, E. (2015). Box 1.3: Rating system for the hierarchy of evidence for intervention/treatment questions" in Evidence-based practice in nursing & healthcare: A guide to best practice (3rd ed.) (pp. 11). Philadelphia, PA: Wolters Kluwer Health.

	Level I	Level II	Level III	Level IV	Level V	Level VI	Level VII
Swinkels et al., (2019a)				X			
Ketcher et al., (2020)				X			
Reed et al., (2018)				X			
Zwar et al., (2018)				X			
Zwar et al., (2020)				X			
Avdikou et al., (2019)						X	
Del-Pino-Casado et al., (2017)						X	
Del Rio Lozano et al., (2017)						X	
Friedmann & Buckwalter, (2014)						X	
Glavin & Peters, (2015)						X	
Kahn et al., (2016)						X	
Perrin et al., (2015)						X	
Polenick & DePasquale, (2017)						X	
Pöysti et al., (2012)						X	
Prevo et al., (2018)						X	
Swinkels et al., (2019b)						X	

Note: Level I = Systematic review or meta-analysis; Level II=Randomized controlled trial; Level III= Controlled trial without randomization; Level IV= Case-control or cohort study; Level V= Systematic review of qualitative or descriptive studies; Level VI= Qualitative or descriptive study; Level VII= Expert opinion or consensus

Table 2.2

Literature table

Reference & Purpose			Subjects	Variables	Results	
Author(s)	Purpose & Location	Research Method	Sample #	Outcome Variable(s)	Key Findings	Limitations
Avdikou, K., Stefanatos, C., Tsatali, M., Gouva, M., & Tsolaki, M. (2019).	Investigate the differences between male and female caregivers for patients with dementia in experienced shame, hostility and aggression. Greece	Cross-sectional	N = 55 Female = 34 (62%) Male = 21 (38%) Spouses & children	• Other As Shamer Scale (OAS) • Experience of Shame Scale (ESS) • Symptom checklist-90-revised (SCL-90-R)	• Significant finding of higher levels of external and internal shame among women suggest existence in gender differences in caregiving.	• Sample size relatively small • Certain variables such as age of the caregiver, severity of dementia, and relation of the caregiver and recipient were not controlled.
Del-Pino-Casado, R., Pastor-Bravo, M.D., Palomino-Moral, P.A., & Frias-Osuna, A. (2017).	To analyze gender differences in intensity of care, care recipient needs and subjective burden, as well as the moderating effects of kinship on the relationship between gender and subjective burden. Jaén, Spain	Cross-sectional	N = 200 Female = 100 (50% Male = 100 (50%) Spouse = 87 (43.5%) Offspring = 96 (48%) Other = 17 (8.5%)	• Subjective burden – Robinson's Caregiver Strain Index • Objective burden – (Barthel Index) • Pfeiffer's Short Portable Mental Status Questionnaire (SPMSQ) • Cumming's Neuropsychiatric Inventory (NPI)	• Overall subjective burden higher in females, wives compared to husbands, and offspring compared to spouses. • Culture did not play a factor in differences of subjective burden between genders.	• Limitation of cross-sectional design.
Del Rio Lozano, M., Garcia-Calvente, M.M., Calle-Romero,	Analyze gender differences in health-related	Cross-Sectional	N = 610 Male = 265 (43%)	• Health-related quality of life (HRQoL) using the 5	• Men and women differed in types of supportive care	• Study did not include information about cognitive or

J., Machon-Sobrado, M., & Larrañaga-Padilla, I. (2017).	quality of life (HRQoL) and associated factors between informal male and female caregivers in Spain. Granada & Gipuzkoa, Spain		Female = 345 (57%) Spouse/Partner = 230 (37.7%) Child = 245 (40.2%) Parent = 78 (12.8%) Other = 57 (9.3%)	dimensions of EQ-5D-5L	utilized. More men used paid help and home and instrumental help while women used FCA, day care, and respite care more. • More women compared to men had poorer HRQoL (37% versus 43%).	behavioral issues of care recipients. These issues may affect how caregivers rate their HRQoL. • Only caregivers who utilized health or social services were included.
Friedemann, M.L., & Buckwalter, K.C. (2014).	To describe and contrast family caregivers and explore the effect of gender and family relationship on the caregiver's role perception, workload, burden, and family help. South Florida, United States	Cross-Sectional	N= 533 Spouses Men = 61 (29%) Women = 147 (71%) Children Men = 48 (15%) Women = 277 (85%)	• Caregiver: Age, health, burden, obligation, spirituality, norm discrepancy, number tasks, family help number tasks, family help hours, community services. • Relative: Age, ADL/IADL, cognitive status, problem behavior.	• Overall, male caregivers reported involvement in fewer caregiving tasks. Male spousal caregivers scored significantly higher in obligation to care but lesser burden. Male adult children caregivers reported smaller norm discrepancy but larger proportion of burden.	• Inability to recruit caregivers of other minority demographics. • Although sufficient for analysis, smaller proportion of male caregivers were included.
Glavin, P., & Peters, A. (2015).	Examine social distribution and mental health of those providing unpaid care to a family member or relative. Investigated gender differences in the association between	Cross-sectional	N = 5667 Men = 2306 (41%) Women = 3361 (59%) Relationship not specified	• Psychological distress • Mastery • Frequency of caregiving • Family-to-work conflict	• Women reported higher levels of psychological distress than non-caregivers and women more affected by caregiving demands. • Work-family conflict fully	• Lacked information detailing types of activities caregivers were engaged in. • Caregiving measure did not specify the care recipient whether they were parents or spouses.

	caregiving frequency and mental health. Canada			• Work-to-family conflict	explained the association between caregiving and distress among men.	
Kahn, P.V., Wishart, H.A., Randolph, J.S., & Santulli, R.B., (2016).	Examine the relationship of caregiver stigma and caregiver burden in a sample of both adult child and spousal caregiver in the United States. Additionally, study compares the degree of caregiver stigma and burden experienced by caregivers based on kinship and gender. New Hampshire, United States	Cross-sectional	N= Spouse (n=59) Men = 21 (35.6%) Women = 38 (64.4%) Adult child (n=23) Men = 3 (13%) Women = 20 (87%)	•Zarit Burden Interview (ZBI) Short form • Modified Family Stigma in Alzheimer's Disease Scale (FS-ADS-C) – 18-item caregiver section measuring stigma. Likert-type scale of 1-5, reflecting the extent to which they felt the item applied to them. Higher scores reflect greater stigma.	• Female caregivers reported higher stigma and more burden compared to males. • Adult children caregivers experienced significantly greater stigma and burden compared to spouses.	• Disproportionately low number of males among the adult child caregiver sample. • Small but statistically significant difference between mail and telephone responders for FS-ADS-C score. • FS-ADS-C tool had to be modified to accommodate spousal caregivers affecting validity.
Ketcher, D., Trettevik, R., Vadaparampil, S.T., Heyman, R.E., Ellington, L., & Reblin, M. (2020)	Identify differences in amount of caregiving provided between genders, how gender influences caregiver outcomes (stress, burden, anxiety, and depression), and explore how caregiver gender influence coping styles.	Quantitative secondary analysis	N = 88 Male = 25 (28%) Female = 63 (72%) Spouses only	• Hospital Anxiety and Depression Scale (HADS) • Perceived Stress Scale • Caregiver Burden Scale •Duke Social Support and Stress Scale (DUSOCS)	• No significant gender differences in caregiving tasks, caregiver burden, coping, communication, social support, or preparedness for caregiving. • Female spouse caregivers reported significantly higher levels of perceived	• Secondary analysis did not allow to capture variables such as role change, utilization of support resources, and social identity. • Study did not have enough power to assess if some measures explained or altered the effect

	United States			• Coping Self-Efficacy Scale (CSE) • Communication and Attitudinal Self-Efficacy Scale for Cancer (CASE) • Preparedness subscale of the Family Care Inventory • Couples Satisfaction Index (CSI)	stress, depression, and anxiety.	of gender on outcome measures. • Sample only consisted of heterosexual, racially-homogenous, and mostly mid-life to older adults from a single institution which may not be generalizable.
Perrin, P.B., Panyavin, I., Paredes, A.M., Aguayo, A., Macias, M.A., Rabago, B., Picot, S.J.F. & Arango-Lasprilla, J.C. (2015).	Examine gender differences in mental health, health-related quality of life, and social support in a group of MS caregivers. Guadalajara, Mexico	Cross-sectional	N = 81 Men = 27 (33%) Women = 54 (67%) Spouse = Men (55.6%), Women (14.8%) Parent = Men (11.1%), Women (63.0%) Sibling = Men (18.5%), Women = (9.3%)	•PHQ-9 •Satisfaction with Life Scale (SWLS) •Rosenberg Self-Esteem Scale (RSES) •State-Trait Anxiety Inventory (STAI) •Zarit Burden Interview (ZBI) •Interpersonal Support Evaluation List-Short Version (ISEL-12) •Short Form Health Status Survey (SF-36)	• Overall, women reported significant higher anxiety, lower self-esteem and lower perceived social support. Additionally, women had worse functioning on mental health and social support variables.	• Only collected in one city in Mexico and could not generalize to other countries in Latin America or the US. • Does not consider change over time and lack of information if societal gender norms had an effect on outcomes.

Polenick, C.A., & DePasquale, N. (2017).	Examine the associations among caregivers' background characteristics, primary caregiving stressors, and secondary role strains. United States	Cross-sectional	N = 367 Husbands = 149 (40%) Wives = 218 (60%)	• Secondary role-strain • Negative caregiving relationship quality • Care-related family disagreements	• Wives reported more primary stressors, secondary role strain, and higher negative caregiving relationship quality. • Husbands at higher risks for marital and familial issues when care recipient has higher care needs or partner has dementia.	• Cross-sectional analyses difficult to determine causality. • Study did not include spouses with high levels of stress.
Pöysti, M.M., Laakkonen, M.L., Strandberg, T., Savikko, N., Tilvis, R.S., Eloniemi-Sulkava, U., & Pitkälä, K.H. (2012).	Compared the characteristics and burden of male and female spousal caregivers of patients with dementia. Finland	Cross-sectional	335 Husband-wife dyads Male = 128 (38%) Female = 207 (62%)	• Zarit Burden Interview Scale (ZBI) • Geriatric Depression Scale (GDS)	• Female caregivers experienced significantly higher burden and higher points in the GDS depression scale.	• Cross-sectional design.
Prevo, L., Hajema, K., Linssen, E., Kremers, S., Crutzen, R., & Schneider, F. (2018).	Explore the characteristics and needs of adult and senior informal caregivers reporting a low or high burden, as well as the contributions made by these characteristics to perceiving a high burden. Limburg, Netherlands	Cross-sectional	Adult caregivers N = 3067 Male = 935 (30.5%) Female = 2132 (69.5%) Senior caregivers N = 1936 Male = 941 (48.6%) Female = 995 (51.4%)	• Background demographic variables. • Three relationship factors: Type of support, recipient of the care provided, and duration of care. • Physical and mental health status.	• Risk factors for perceiving a high burden: female gender, aged 40-54 years, being widowed, providing emotional support, providing many hours of care, low sense of mastery, presence of depressive symptoms, and severe loneliness.	• Cross-sectional difficult to prove causality. • Voluntary participation and self-reports on measurements increase risk of bias. • Instruments to measure Quality of life and perceived burden scales used not validated.

			Relationship not specified	• Assessment of caregivers' social roles. • Coping indicators. • Needs of caregivers.		• Issue with generalizability since population sample only from the Netherlands.
Reed, C., Belger, M., Dell'Agnello, G., Wimo, A., Argimon, J.M., Bruno, G., Dodel, R., Haro, J.M., Jones, R.W., & Vellas, B. (2014).	Explore the associations between patient and caregiver characteristics and clinical factors, and subjective caregiver burden in adult-child and spousal caregivers participating in the GERAS study. France, Germany, and United Kingdom	Observational cohort study.	N= 1390 Adult-child n= 405 (82.5% female) Spouse n = 985 (41.6% female)	•Zarit Burden Interview (ZBI)	• In spouses, females found to have greater burden. • Although offspring caregivers provide less time on all caregiving aspects, they report a higher level of burden compared to spousal caregivers but report higher HRQoL.	• Sampling method of community-dwelling AD patients may not represent the full spectrum of caregiver burden. • Reporting bias in the caregiver assessment of patient behavioral symptoms and HRQoL. •HRQoL tool not well measured by EQ-5D. •Adult-child caregiver mostly female compared to spouses.
Swinkels, J.C., van Groenou, M.I.B., de Boer, A., & van Tilburg, T.G. (2019a).	Examines to what degree and why partner-caregiver burden changes over time in spousal men and women. Netherlands	Longitudinal, observational	N= 722 Partner Male = 279 (39%) Female = 443 (61%)	• Self-rated burden scale from 0-100 • Hours of caregiving • Care provided by other informal caregivers	• Impact of physical functioning on burden is higher for male caregivers. •Impact of relational problems on burden is small for male caregivers compared	• Two measurement points may not be representative as the development of burden can be non-linear. Burden can be exponential or irregular.

				•Perceived social support •Fulfillment	with female caregivers. •Fulfillment lowered burden for male caregivers but not for female caregivers.	• No information about the duration of caregiving. • Period of 1 year may be too short to notice changes.
Swinkels, J., van Tilburg, T., Verbakel, E. & van Groenou, M.B. (2019b).	Examine gender differences in the experienced burden of partner caregivers using the stress-appraisal model. Netherlands	Cross-sectional	N = 1,611 Partner Male = 700 (43%) Female = 911 (57%)	•Experienced burden on scale from 0-100 •Hours of caregiving •Other caregivers – help from other informal caregivers •Secondary stressors	• Greater care needs of recipient husbands contributed to higher level of secondary stressor in women spouses. • Male caregivers' experienced burden directly and positively associated with secondary stressors and hours of caregiving and only indirectly with wife's need for care.	• Sampling and data collection amongst the 30 projects varied. • Study was not a longitudinal design and so unable to determine if gender differences in burden do indeed vary over time or care intensity.
Zwar, L., König, H.H., & Hajek, A. (2018).	Investigate the influence of different caregiving types on cognitive functioning of caregivers aged 65 years and older longitudinally and to look at potential gender differences. Germany	Longitudinal, observational	N = 6079-6560 observations Female = 45% Relationship not specified	• Cognitive functioning Digital symbol test (DST)	• Positive association of looking after someone with cognitive functioning in both men and women but men might struggle more with transitioning into the caregiving role.	• Low response rates for the cohorts for certain years and some issues with attrition. • Caregiver and care recipient characteristics not fully explored for influential affects.

Zwar, L., König, H.H., & Hajek, A. (2020).	Investigate association between transitioning into the role of informal caregiver and psychosocial outcomes loneliness, social isolation, network size, and depressive symptoms. Second purpose to investigate gender differences in these outcomes. Germany	Longitudinal, observational	N= 547 Female = 298 (54%) Male = 249 (46%). Relationship not specified	• Bude and Lantermann Social isolation instrument • De Jong Gierveld Loneliness Scale Short Form • Network size • Center for Epidemiologic Studies Depression Scale (CES-D)	• Only male caregivers experienced increased network size, increased depressive symptoms and loneliness when transitioning into caregiving. • No increase in depressive symptoms in women transitioning into caregiving, possibly due to their network being more adequate at the start of caregiving role.	• Low response rates but similar to response rates in other German surveys. • Sample was assessed in a 3-year interval thus difficult to compare caregivers in different caregiving durations. • Not all influential characteristics of care situation was included.

Figure 2.1

Caregiver Identity Theory adopted from Montgomery & Kosloski (2013)

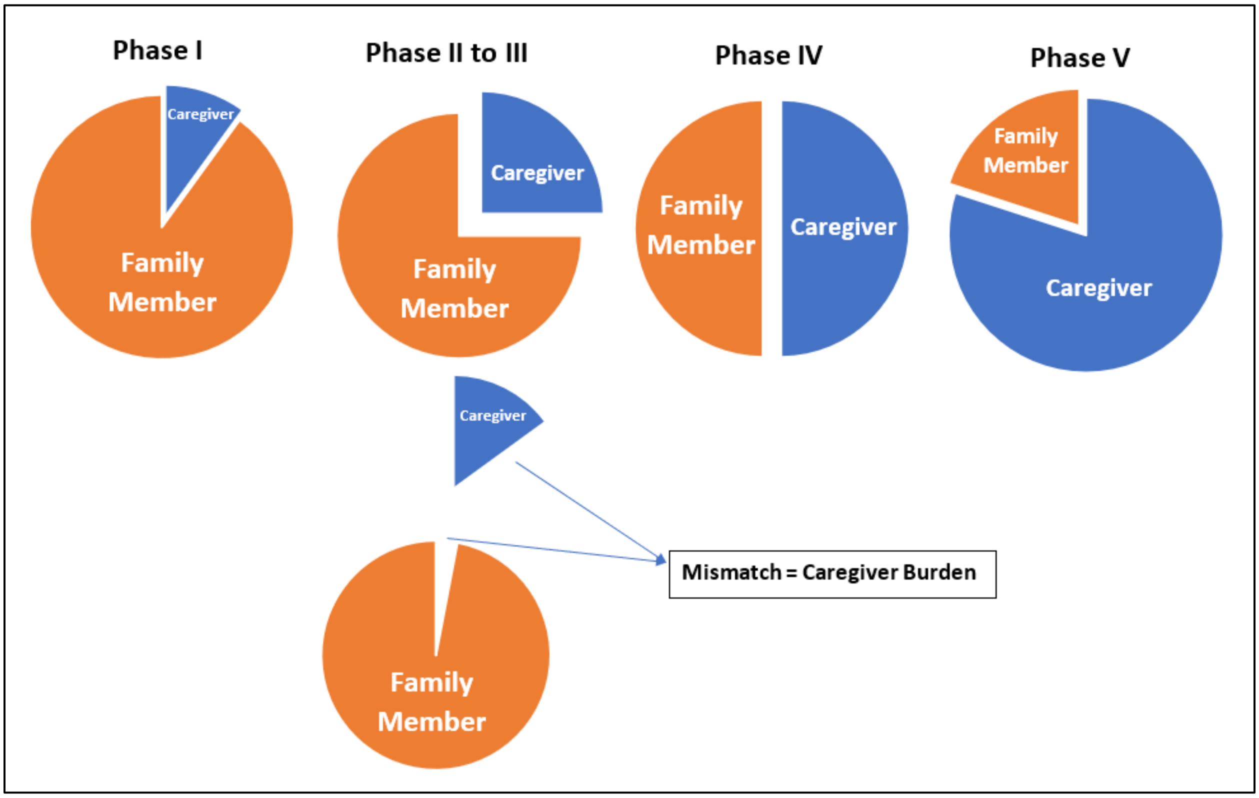
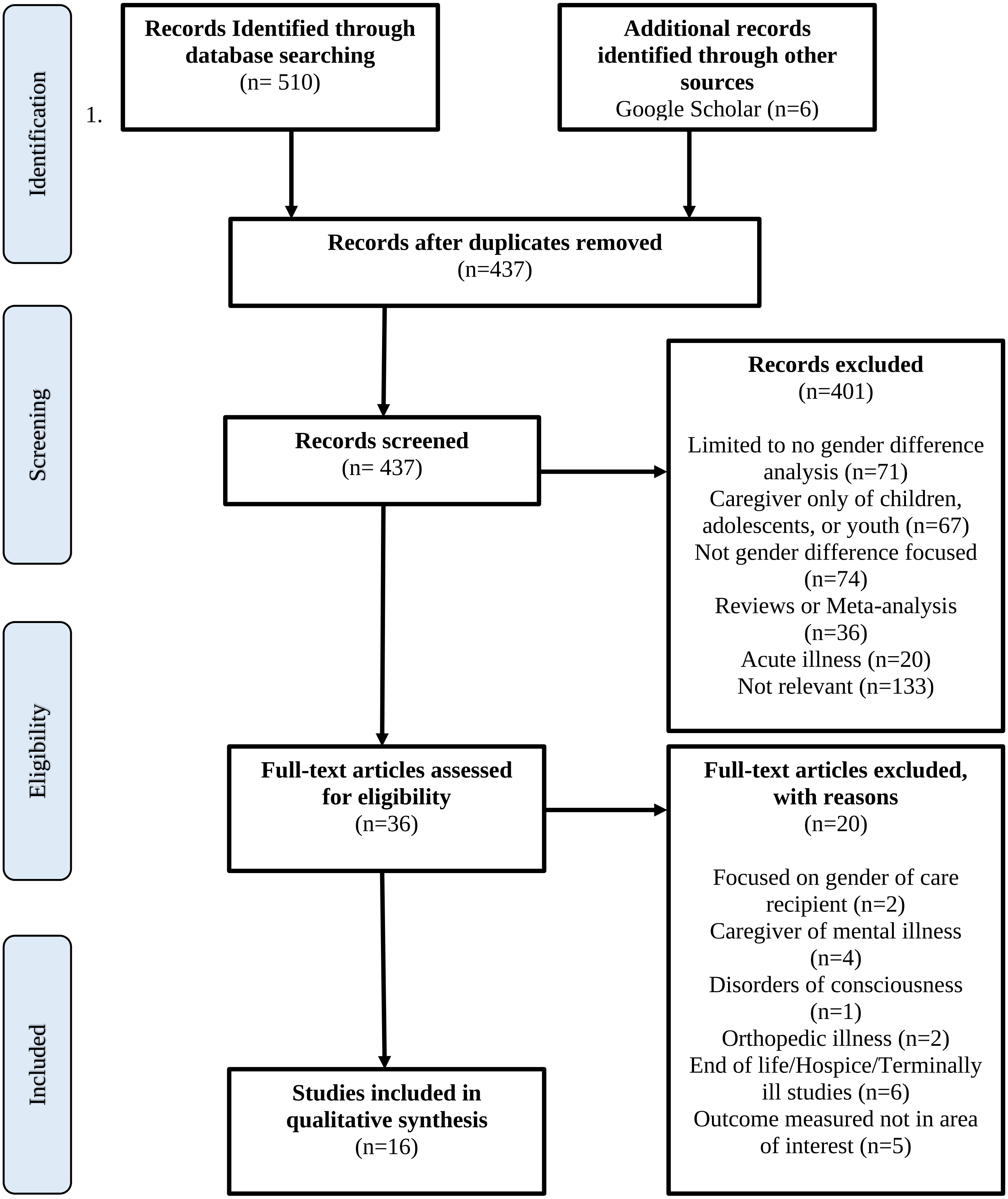


Figure 2.2

PRISMA Diagram



CHAPTER III: RESEARCH METHODOLOGY

In 2019, more than 16 million Americans were family caregivers (FCGs) for people with Alzheimer's disease or related dementias (ADRD), providing an estimated 18.6 billion hours of unpaid care[4]. Family caregivers (FCG) who provide care for people with chronic illness often suffer negative health effects due to demands of their caregiving role (Family Caregiving Alliance, n.d.; AARP & National Alliance for Caregiving, 2020; Sambasivam et al., 2019). In the past five years, there was a significant decrease in the number of caregivers who considered their health to be *excellent* or *very good*, with a subsequent increase in in caregivers who reported their health to be *fair* or *poor* (AARP & National Alliance for Caregiving, 2020). FCG for people with Alzheimer's disease or related dementias (ADRD) can be especially impacted due to slow, chronic decline in mental, emotional, and physical abilities of the person suffering the disease (Alzheimer's Association, 2021; Ankri et al., 2005). The resulting caregiver burden can increase FCG stress, anxiety, and depression (Reed et al., 2014). Differences within demographics of the FCG can also influence health outcomes. With the continued growth of the older adult population and increased risk for age related diseases such as ADRD, it is important to understand the consequences of caregiving faced by FCG to better anticipate and address their health needs.

Caregiver health outcomes differ by sex, with females having increased risk for developing negative psychological and psychosocial outcomes in the caregiving role (Del-Pino-Casado et al., 2017; Del Rio Lozano et al., 2017; Glavin & Peters, 2015; Kahn et al., 2016; Perrin et al., 2015; Pöysti et al., 2012; Prevo et al., 2018; Reed et al., 2014). However, male caregivers may develop significant amounts of burden more during the early phases of transitioning into the caregiver role (Polenick & DePasquale, 2017; Zwar et al., 2018). Approximately 39% of all caregivers are male and are more often younger (age 18-49) (AARP & National Alliance for Caregiving, 2020) compared to their female counterparts. Caregivers aged 18 to 49 who care for a person with ADRD often experience higher-intensity care situations that compound risk for poorer outcomes (AARP & National Alliance for Caregiving, 2020). Thus, caregiver gender is an important factor to consider as generation Z transitions into adulthood and more potential male caregivers enter the caregiving population (AARP & National Alliance for Caregiving, 2020). Because caregiving is still considered a predominately female role with activities perceived as feminine (Björk, 2015), the concept of masculinity can influence male caregivers' perceptions of their caregiving experiences. Traditional hegemonic masculinity, or the idea of power, authority, control, and actions believed to be what men should do, is a major influence in men's perceptions of their role in caring relationships (Leung et al., 2019). Assuming a traditionally feminine role such as a caregiver can be viewed as "unmasculine" and may influence health outcomes of the male caregiver (Leung et al, 2019). Despite the differences between sex and caregiver outcomes, there is a lack in current literature exploring the subjective experiences of male caregivers caring for persons with ADRD. Since gender may play a role in perceived caregiver burden, exploring the subjective experiences of male caregivers is vital to understanding unique encounters and how healthcare professionals can anticipate and provide individualized supportive care resources to mitigate negative health outcomes.

This study used a qualitative descriptive methodology to explore male caregivers' perceptions of their role as caregivers of persons ADRD and provided insight on the subjective experiences contributing to observed differences in health outcomes by gender. This study can assist future research and practice in anticipating potential health consequences of men in caregiving roles and the individualization of caregiver support. Moreover, findings from this study will help guide future research on exploring further differences based on male caregiver demographics (e.g., age, kinship, ethnicity, culture, and religion) and discovering effective resources to address and mitigate negative caregiver outcomes.

Primary Aim: Explore the perceived experiences of male caregivers caring for a person with ADRD through the role transitions from family member to caregiver.

- **Research Question 1:** How do male caregivers describe their experience as a caregiver throughout their caregiving relationship?
- **Research Question 2:** How do male caregivers describe their experiences related to preparation and resource finding to manage the care needs of persons with ADRD?

Secondary Aim: Describe the male caregivers' perception of masculinity and its influence on their caregiver role.

- **Research Question:** How do male caregivers view masculinity within their role as a caregiver?

RESEARCH PLAN

1. Significance

Growing Older Adult Population

In the United States, one of the fastest growing populations is the older adult, which is attributed to the aging Baby Boomer generation (United States Census Bureau, 2020).

Between 2008 and 2018, the number of Americans aged 60 and older has increased from 54.1 million to 72.8 million, which is a growth of 34%. This number is projected to increase to 94.7 million by the year 2060 (Administration for Community Living, 2019). Additionally, Americans' life expectancy is also projected to increase by about six years from the average age of 79.7 in 2017, to 85.6 by 2060 (Hunter et al., 2017). The continued growth of the older adult population and increasing life expectancy increases the need to effectively manage chronic and age-related illnesses.

Alzheimer's Disease and Related Dementias and Family Caregiving

Risk for Alzheimer's disease and related dementia (ADRD), an age-related illness, will increase due to the exponential growth of the older adult population. The annual number of new cases of Alzheimer's disease will double by the year 2050 (Alzheimer's Association, 2021). ADRD is a chronic, progressive disease that demands significant time and resources to manage effectively. Most of the care provided to older adults with ADRD come from family caregivers (FCG) which include family, friends, and neighbors (AARP & National Alliance for Caregiving, 2020). In 2019, there were 16 million American FCG providing 18.6 billion hours of unpaid care for a person with ADRD (Alzheimer's Association, 2021). The demands of caregiving can have a negative impact on the FCG's overall health due to physical, emotional, financial, and psychosocial challenges in their role. These negative outcomes contribute to caregiver burden and can lead to an increase in stress, anxiety, and depression for the FCG (Reed et al., 2014).

Gender Differences in Family Caregiver Outcomes

Individual FCG demographics can play a factor in FCGs' perceived burden and risks for negative health outcomes associated with the caregiver role. However, some demographic variables, such as gender, have not been fully explored in relation to differences in health outcomes between men and women in the FCG role. It is important to note that the term “gender” within caregiver studies is used synonymously with biological sex, thus differentiating it from the term “gender identity.” For example, the majority of current literature on gender differences in caregiving outcomes suggest that female FCGs report higher overall levels of burden (Del-Pino-Casado et al., 2017; Del Rio Lozano et al., 2017; Glavin & Peters, 2015; Kahn et al., 2016; Perrin et al., 2015; Pöysti et al., 2012; Prevo et al., 2018; Reed et al., 2014). However, some studies have found that male FCGs develop significantly higher amounts of burden during the early phases of the FCG role (Polenick & DePasquale, 2017; Zwar et al., 2018). These findings suggest that caregiving outcomes may vary for different genders depending on the point in time during the caregiving relationship. Moreover, although differences in psychological and psychosocial outcomes have been found between men and women FCGs, a common limitation within the research is the disproportionate number of male caregivers who participate in caregiving studies. Approximately 39% of all adult caregivers are male (AARP and National Alliance for Caregiving, 2020) and male FCG make up a third of caregivers for people with ADRD (Alzheimer’s Association, 2021). Compared to the general caregiver population, male caregivers are often younger (18-49). As societal gender roles are reconstructed and we see more men and women crossing into typical masculine versus feminine roles, we will see a rise in male caregivers. Additionally, with generation Z entering adulthood, we can anticipate a rise in younger male caregivers entering the caregiver population (AARP & National Alliance for Caregiving, 2020). Younger caregivers for the ADRD population experience higher-intensity care situations that increases the risk for poorer health outcomes (AARP & National Alliance for Caregiving, 2020).

Several gaps in the literature exist concerning gender differences in caregiving. A major gap is that men are underrepresented in FCG research. Existing studies include a lower, disproportionate number of male participants. For example, the limited available qualitative studies exploring subjective caregiving experiences have mainly focused on female FCGs. Additionally, most of the existing literature exploring gender differences in FCGs have been conducted outside of the US and may not be representative of the diverse backgrounds, family caregiving structures, or male caregiving perspectives compared to other countries. An examination of male FCGs in the US is needed to better understand the male perspectives in entering a role that is traditionally viewed as feminine and to identify specific supportive resources to mitigate the risk of developing negative health consequences in this emerging group of FCGs.

2. Innovation

This study sought to increase our understanding of how masculinity and gender influence a role that has been predominantly female. As gender roles in society are being challenged and reconstructed, research in how gender affects the caregiving experience is needed to address differences in health outcomes. To date, this is the only study to utilize the CIT conceptual model to investigate the subjective experiences of male FCGs to help explain the differences in perceived burden throughout the role transitions during the caregiving relationship of a person with ADRD. Findings from this study will help evaluate current standards of practice providing support for caregivers of persons with ADRD and refine individualized support with consideration to the FCG’s gender.

Examples of studying more effective resources for male FCGs would be comparing outcomes of gender mixed support groups versus male only support groups, or effectiveness of tailored support for areas that male FCGs find more burdensome. Furthermore, the results of the study could then propel future research in exploring other factors that influence male FCG identities such as age, race, culture, and religion.

3. Approach

Study Design

To address the aims of this study, we used a qualitative descriptive methodology (Sandelowski, 2010; Neergaard et al., 2009). The use of qualitative descriptive method is fitting to the purpose of the study by providing a voice to male FCGs and using their own language to describe their experiences (Neergaard et al., 2009). Emphasis was given on participants' direct quotes and provided to allow for low-interference interpretations of meanings and allow the words to speak for themselves. A qualitative descriptive approach offers a broader review of events provided by those who experience them only achieved by researchers staying close to the data and the surface meaning of words compared to other types of qualitative methods (Sandelowski, 2000).

Study Sampling

Participants were recruited using a multifaceted approach. Participant recruitment was conducted by partnering with two local Alzheimer's Associations. The PI is a current volunteer community educator for the Alzheimer's Association of Orange County. The second organization that was approached is the Alzheimer's Orange County organization. A recruitment online survey was created using the secure REDCap tool that included the study's information and aims that interested participants can submit contact information for the PI to contact. A link to the survey was included in each organization's website, advertised during their online education webinars, organization's Facebook pages, and community outreach programs. Partnership with the Alzheimer's Association of Orange County as a recruitment source was discussed and supported by the organization. Additionally, an application was included and accepted for inclusion of this proposed study to the Alzheimer's Association TrialMatch® service. TrialMatch® is a national service that matches individuals with dementia, caregivers, and healthy volunteers to clinical and research studies based on user-provided information (Alzheimer's Association, n.d.). The study recruitment survey link was also shared via the PI's personal social media platforms such as Facebook, LinkedIn, Twitter, and Instagram and users in the PI's personal network were encouraged to share the study information as well. All interested participants were contacted and screened by the PI for eligibility. Convenience and snowball sampling were used to obtain a sample of 11 male FCGs who identify as a caregiver for a person diagnosed with ADRD. In previous male caregiver qualitative studies, number of participants included to provide rich data varied between six to thirteen (Bamgboje-Ayodele et al., 2020; Hellström et al., 2017; Oldertrøen et al., 2019; Williams et al., 2017) with one study able to reach data saturation by the 11th interview, where no new information is found with further analysis (Hendricks-Lalla & Pretorius, 2020).

Inclusion/Exclusion Criteria

Male FCGs included in this study was identified as being biologically male at birth and who identify as male during the caregiving relationship. This distinction is important to specify as the terms gender and sex can often be interchanged but have different meaning. Inclusion as a caregiver can be determined by the participant having provided caregiving activities such as assisting with activities of daily living (e.g., hygiene, dressing, eating, mobility), instrumental activities of daily living (e.g., transportation, shopping, laundry, housekeeping activities, finances), providing medical/nursing tasks (e.g., medication management, wound care, use of medical equipment), or coordinating care or services for the care recipient. Additionally, male FCG participants must have been over the age of 18, English speaking, and able to provide verbal consent.

Procedures

Initial IRB approval (IRB# 2058682) was obtained from the University of Missouri prior to recruitment of participants. Once eligible male FCGs were identified, the PI scheduled and conducted telephone or Zoom interviews with each participant. Verbal informed consent was obtained prior to data collection. All male FCGs were assigned a random participant ID to de-identify any data. All interviews were recorded and transcribed using a professional transcription service. Transcribed interviews were reviewed by research team for accuracy and then uploaded into the qualitative analysis program Dedoose® only accessible by the research team. Electronic data files were stored on a password protected computer that meets security requirements of the University of Missouri. A $20 incentive in the form of a gift card will be offered and mailed to caregivers who participate and complete the interview.

Data Collection

Data were collected using 30-45 minute semi-structured interviews. Demographic data (e.g., age, race/ethnicity, employment status) and caregiving relationship characteristics (e.g., relationship to care recipient, years in caregiver role, average hours per week providing care) were collected at the start of the interview and recorded on an excel spreadsheet. A semi-structured interview guide was used that was developed in agreement between the PI and co-investigators (Appendix A). Examples of interview questions and follow-up prompts to address the specific aims of this study are presented in table 3.1.

Table 3.1

Specific Aims and Examples of Representative Interview Questions (Full Interview Guide in Appendix A)

Primary Aim: Explore the perceived experiences of male caregivers caring for a person with ADRD through the role transitions from family member to caregiver.

1. Could you think back when your X (wife, parent, sibling, aunt/uncle, friend) was first showing signs that led up to the diagnosis of Alzheimer's Disease or related dementia. What was your initial reaction?
    - Probe: What was your understanding of the potential needs of your X in terms of the disease progressing?
    - Probe: How did you see yourself as a caregiver at the beginning stages of ADRD?
      Probe: What kinds of expectations did your X have for you as their caregiver?
2. As your X's care needs begin/began to increase, how do/did you see your relationship with your X change?
    - Probe: How did you see your role as a (husband, son, brother, nephew, friend) change over time?
    - Probe: Did you begin seeing yourself more as a caregiver than a (husband, son, brother, nephew, friend)?

Secondary Aim: Describe the male caregivers' perception of masculinity and its influence on their caregiver role.

1. Since the caregiver role and caregiving activities are or has been seen as a typical female role, being a man, did that affect how you saw yourself as a (husband, son, brother, nephew, friend) and as a caregiver?

- Probe: Did you have any reservations or hesitancy in becoming a caregiver?
- Probe: How do you think your thoughts on masculinity affected your role as a caregiver?

2. How can you explain how masculinity influences your perceptions of the caregiving role?

- Probe: What are your thoughts on men being caregivers?
- Probe: Can you think of specific examples in your life that has helped shape these ideas or perceptions?
- Probe: How has your views on masculinity and being a caregiver changed or not changed?

Data Analysis

Descriptive statistics were used to summarize demographic characteristics of each male FCG participant. Qualitative data were analyzed using thematic analysis with the support of Dedoose software. Thematic analysis is a method where data are analyzed and organized based on recurring patterns (themes). Additionally, thematic analysis is a method that works to reflect the individual meanings within the data, but also extends the application of these meanings to a larger, social context (Braun & Clarke, 2006). The PI and co-investigator independently read and re-read the first four to five interviews and developed thematic codes from transcribed excerpts. Researchers then met to discuss and compare codes and segments for agreement. A codebook was created documenting the agreed upon thematic codes and then applied to the remaining interviews during analysis. Thematic codes were categorized based on their relation to each of the study aims. Codes related to the overall lived experiences of male caregivers throughout the caregiving relationship were applied to the primary aim of exploring their perceived experiences caring for a person with ADRD during their transitions from family member to caregiver. Codes related to male and masculine identities were applied to the secondary aim of describing male caregivers' perception of masculinity and its influence on their caregiver role. The research team met bi-weekly to discuss codes and thematic categories in subsequent interviews until all participant interviews were coded or data saturation was met, where no new or additional information were found.

Study Rigor

To ensure rigor in qualitative analysis, Guba and Lincoln's framework was used to established *trustworthiness* in conducting the research (Vaismoradi et al., 2013). *Trustworthiness* in qualitative research is the recontextualization of reliability and validity found in quantitative research to address the criticisms of non-empirical work (Morse, 2018). Guba and Lincoln's framework for rigor includes four strategies to strengthen the findings of qualitative research: *Credibility, transferability, dependability,* and *confirmability*. Each strategy further delineates into specific actions during qualitative research to strengthen rigor. Table 3.2 describes actions conducted during this study to ensure methodological trustworthiness (Krefting, 1991).

Table 3.2

Strategies used to ensure rigor and trustworthiness based on Guba and Lincoln's framework (Krefting, 1991).

Category	Strategy	Action
Credibility – Confidence in the truth of the findings in the context in which the study was conducted.	Reflexivity, triangulation	PI will conduct reflexive journaling to examine own beliefs and biases during research. Two researchers will independently analyze data and compare coding results; research team will meet monthly to discuss thematic coding and analysis.
Transferability – Findings fit into contexts outside of the study situation by degree of similarities or goodness of fit	Comparison of sampling to demographic data, dense descriptions	Sampling techniques (e.g., partnering with local organization, social media, and networking) to achieve the most diverse participant pool as possible to reflect demographic variability; providing dense background information about participants and the research context.
Dependability – Consistency of findings within the context of study technique and design	Audit trail, triangulation	PI will record all team meetings and keep notes on all decisions made during analysis. Two researchers will independently analyze data and compare coding results; research team will meet bi-weekly to discuss thematic coding and analysis.
Confirmability – Neutrality of findings and conditions of research free of influence of other	Reflexivity, audit trail, triangulation, member checking	PI will conduct reflexing journaling to examine own beliefs and biases during the collection and analysis of data. PI will keep notes of team meetings and all decision-making processes.

biases, motivations, and perspectives.		Initial analysis of data will be conducted independently between researchers and then compared during bi-weekly meetings. PI will conduct an additional interview after final analysis to confirm findings with an additional participant who meets criteria for the study.

To assist with validity and reliability of study findings, after qualitative themes and subthemes were developed, a member check interview was completed with a 12th participant. Member checking, also called respondent or participant validation, is considered a “gold standard” in qualitative research used to validate, verify, and assess the researcher’s interpretation of the data (Motulsky, 2021). The twelfth participant used for member checking met study inclusion criteria but was also a close relative to the PI and the main influence for conducting the study having been a male caregiver for a spouse with ADRD. The participant confirmed the developed themes and sub-themes and did not report any additional themes for the study.

Importance of the Knowledge to be Gained

FCGs provide a vital role to the health of individuals living with chronic disease, as well as the economic health of the US. With the anticipated rise in older adult population and those with chronic diseases, more FCGs will be relied upon to meet their health needs. As caregiving can have a significant impact on the FCG’s health, it is important to explore factors that can influence the development of negative outcomes and interventions to prevent or lessen its impact on caregiver health. Although female caregivers have significantly higher risk for negative health outcomes, male caregivers are underrepresented in caregiving research. Additionally, current literature is lacking in information on the subjective experiences of male caregivers, especially for those who care for ADRD. Findings from this study can help strengthen the understanding the unique experiences of male FCGs. Furthermore, findings can guide future research into evaluating current practices in caregiver support and investigating more effective interventions for this caregiver demographic.

Chapter Summary

This chapter described the qualitative research methodology, conceptual framework, study approach, plan for data collection and analysis, and protection of human subjects. Additionally, the potential benefits and importance of knowledge to be gained from the study were discussed.

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CHAPTER IV

A Duty to Care: Male Perspectives on the Caregiver Role for Persons with Alzheimer's or Dementia

Bueno, M.V., & Chase, J.D. (2022). A Duty to Care: Male Perspectives on the Caregiver Role for Persons with Alzheimer's or Dementia. *Journal of Family Nursing.* (in preparation).

Abstract

The population of family caregivers (FCGs) of persons with Alzheimer's Disease and related Dementias (ADRD) is growing, as is the proportion of males taking on this traditionally female role. Caregiving research has mainly centered around women due to historic roles, resulting in a knowledge gap regarding male caregiving experiences. The purpose of this qualitative descriptive study was to explore the experiences of male FCGs of people with ADRD. Eleven male caregivers were recruited and interviewed by telephone or Zoom/videoconferencing. Data were analyzed using ~~general~~ thematic analysis. Four major themes emerged highlighting males' struggles with the unfamiliar caregiving role and changing identity; their acknowledgement of personal growth and discovery through caregiving; their challenges in finding the "right" kind of support; and their perceived reshaping of masculinity through the caregiving role. Findings indicate researchers and clinicians should develop tailored support to address male FCGs' unique needs and experiences in the caregiving role.

A looming issue facing the health of the US is the growing older adult population driven by the aging baby boomer generation. An aging population presents various concerns including economic, social, and familial challenges that significantly impacts the population and individual family units. This is due to the higher risk and incidence for chronic illnesses, especially age-related diseases such as Alzheimer's disease and related dementias (ADRD) (Eifert et al., 2016; Power et al., 2019). ADRD is a chronic, progressive disease that can be challenging to manage as the disease involves cognitive impairment, immobility and falls, nutrition deficits, swallowing disorders and associated aspiration pneumonia, and behavioral disturbances. Behavioral changes alone can be difficult to address as families and health professionals may need to deal with the person with ADRD's agitation, aggression, depression, and hallucinations (Reuben et al., 2019). As the incidence of ADRD is expected to grow, this will be a more significant issue families and healthcare will need to address.

One segment of society that is offsetting some of the challenges stemming from an older population are family caregivers (FCGs). Although the term "family" can mean individuals of kin, some people can also be considered family by choice which includes those who may not be directly blood related but share a mutual bond to the person receiving care. These FCGs, who are mostly unpaid, providing care for people with chronic illness often suffer negative health effects due to demands of their caregiving role (Family Caregiving Alliance, n.d.; AARP & National Alliance for Caregiving, 2020; Sambasivam et al., 2019). In the past five years, there was a significant decrease in the number of caregivers who considered their health to be *excellent* or *very good*, with a subsequent increase in in caregivers who reported their health to be *fair* or *poor* (AARP

& National Alliance for Caregiving, 2020). The resulting caregiver burden can increase FCG stress, anxiety, and depression (Reed et al., 2014). FCGs caring for people with ADRD will be increasingly impacted within this caregiving environment. In 2022, more than 11 million Americans were FCGs for people with ADRD, providing an estimated 6 billion hours of unpaid care (Alzheimer's Association, 2022). Furthermore, caregivers aged 18 to 49 who care for a person with ADRD often experience higher-intensity care situations that compound risk for poorer outcomes (AARP and National Alliance for Caregiving, 2020). This could be due to younger caregivers having to balance multiple responsibilities in addition to caregiving such as work, family, and social needs. Other differences within demographics of the FCG can also influence health outcomes. With the continued growth of the older adult population and increased risk for age related diseases such as ADRD, it is important to understand the consequences of caregiving faced by FCG to better anticipate and address their health needs.

Gender Differences in Caregiving Experiences

Caregiver health outcomes differ by sex, with females having increased risk for developing negative psychological and psychosocial outcomes in the caregiving role (Del-Pino-Casado et al., 2017; Del Rio Lozano et al., 2017; Glavin & Peters, 2015; Kahn et al., 2016; Perrin et al., 2015; Pöysti et al., 2012; Prevo et al., 2018; Reed et al., 2014). However, male caregivers may develop significant amounts of burden more during the early phases of transitioning into the caregiver role (Polenick & DePasquale, 2017; Zwar et al., 2018). Approximately 39% of all caregivers are male and are more often younger (age 18-49) (AARP and National Alliance for Caregiving, 2020) compared to their female counterparts. Caregivers aged 18 to 49 who care for a person with ADRD often experience higher-intensity care situations that compound risk for poorer outcomes (AARP and National Alliance for Caregiving, 2020). Thus, caregiver gender is an important factor to consider as generation Z (born 1997 and after) transitions into adulthood and more potential male caregivers enter the caregiving population (AARP and National Alliance for Caregiving, 2020). Because caregiving is still considered a predominately female role with activities perceived as feminine (Björk, 2015), the concept of masculinity can influence male caregivers' perceptions of their caregiving experiences. Traditional hegemonic masculinity, or the idea of power, authority, control, and actions believed to be what men should do, is a major influence in men's perceptions of their role in caring relationships (Leung et al., 2019). Assuming a traditionally feminine role such as a caregiver can be viewed as "unmasculine" and may influence health outcomes of the male caregiver (Leung et al, 2019).

A possible explanation for gender differences in caregiving for older adults with ADRD is that life experiences and familial expectations play a role in self-identity and role transition. A framework that addresses this concept and what guided this study's approach is the Caregiver Identity Theory (CIT) (Figure 4.1). The CIT posits that the caregiving role evolves from an existing role relationship, usually within the familial role such as a spouse or child. As the needs of the care recipient increases, the relationship between the caregiver and care recipient change. Caregivers not only change in their behaviors due to the increase in responsibilities, but they also change how their see their identity within the relationship (Montgomery & Kosloski, 2009). The CIT further explains that caregiver burden develops when the FCG's perceived identities of being a caregiver and a family member are incongruent within the relationship (Montgomery &

Kosloski, 2009). Since gender plays a major role in an individual's identity, exploring male FCGs understanding of masculinity and gendered expectations' influence on their changing identities as a family member and caregiver is important. Additionally, the original development of the CIT focused on the spousal relationship of caregiving and so this study attempts to expand on the application of this theory to not only of that of a spouse, but other possible relationships involved in ADRD caregiving by men such as a son, grandson, brother, nephew, or friend.

Despite gender differences in caregiving, and the challenges involved with caring for persons with ADRD, there is a lack in current literature exploring the subjective experiences of male caregivers caring for persons with ADRD. Quantitative approaches may not fully capture the caregiving experiences of men because quantitative instruments may result in underreported levels of burden (Lopez-Anuarbe & Kohli, 2019). Additionally, men may be less likely to report their negative feelings, less comfortable in sharing their emotions, or may not be familiar with quantifying their caregiving experience (Lopez-Anuarbe & Kohli, 2019). A qualitative approach using semi-structured interviews can build trust and explore male FCG's subjective experiences to better understand how they perceive their role as a caregiver, the effect of masculinity on caregiver perceptions, and the associated negative outcomes that accompany the caregiver role. Male caregivers also offer a unique perspective of how they juggle their responsibilities of providing care and provide insights of self-identity in the context of what it is to be a man in today's modern society.

Purpose Statement

The purpose of this qualitative descriptive study was to explore the experiences of male caregivers caring for a person with ADRD during the role transitions from family member to caregiver and to describe the male caregivers' perception of masculinity and its influence on their caregiver role. The aims of this study address a gap in understanding of the subjective experiences of male caregivers for persons with ADRD. This study was guided by the following research questions:

Research Question 1: How do male caregivers describe their experience as a caregiver throughout their caregiving relationship?

Research Question 2: How do male caregivers describe their experiences related to preparation and resource finding to manage the care needs of persons with ADRD?

Research Question 3: How do male caregivers view masculinity within their role as a caregiver?

Methods

This study used a qualitative descriptive methodology (Sandelowski, 2010; Neergaard et al., 2009). The use of qualitative descriptive method is fitting to the purpose of the study by providing a voice to male FCGs and using their own language to describe their experiences (Neergaard et al., 2009). Emphasis was given on participants' direct quotes and provided to allow for low-interference interpretations of meanings and allow the participants' words to speak for themselves. A qualitative descriptive approach offers a comprehensive review of events provided by those who experience them which is only achieved by researchers staying close to the data and the surface meaning of words compared to other types of qualitative methods (Sandelowski, 2000).

Setting and Recruitment

IRB approval was obtained prior to participant recruitment. Recruitment then began using a multifaceted approach. A REDCap online survey was created for recruitment and screening which was provided in the advertisement of the study. The study partnered with two local Alzheimer's Associations where the study could be advertised through their multiple outreach programs and support groups. An application was also completed and accepted for inclusion on the Alzheimer's Association TrialMatch® service. TrialMatch® is a national service that matches individuals with dementia, caregivers, and healthy volunteers to clinical and research studies based on user-provided information (Alzheimer's Association, n.d.). Additionally, the study was advertised through multiple social media applications such as Facebook, LinkedIn, Twitter, and Instagram via the PI's personal network and dementia caregiver interest groups within the respective applications. Convenience and snowball sampling was used to recruit participants until data saturation was achieved.

Eligibility

To be included in this study, male FCGs should identify as being biologically male at birth and who identify as male during the caregiving relationship. This distinction is important to specify as the terms gender and sex can often be interchanged but have different meaning. To be considered as a caregiver, participants must have provided caregiving activities such as assisting with activities of daily living (ADL) (e.g., hygiene, dressing, eating, mobility), instrumental activities of daily living (IADL) (e.g., transportation, shopping, laundry, housekeeping activities, finances, providing medical/nursing tasks (e.g., medication management, wound care, use of medical equipment), or coordinating care or services for a person with ADRD. Additionally, male

FCG participants identified as over the age 18, English speaking, and able to provide verbal consent. PI screened all interested participants to meet eligibility criteria for inclusion in the study.

Study Procedures

Eligible participants were notified, and interviews were scheduled to conducted by Zoom or telephone based on participant preference. Participants were informed that if Zoom was used, they could choose to not share video if they felt more comfortable during the interview. After verbal consent, demographic data (e.g., age, race/ethnicity, employment status) and caregiving relationship characteristics (e.g., relationship to care recipient, years in caregiving role, shared caregiving responsibilities, average hours per week providing care) were collected. Semi-structured interviews were then conducted and double recorded using the Zoom application and a digital recorder in the event of data loss.

Data Collection

A semi-structured interview guide that addressed the aims of the study was used. Interview questions were created using the CIT as a guide as well as themes surrounding hegemonic masculinity (Hunter, 2017). Guidance from experts in the field of caregiving and family science research were sought and provided clarity and depth in question development. Example interview questions are provided in Table 4.1. All interviews were transcribed using a professional transcription service and reviewed by the PI for accuracy. Transcribed interviews were uploaded into the qualitative analysis program Dedoose® and only accessible by the research team. A $20 incentive in the form of an electronic gift card was provided and emailed to participants after the completion of the interview.

Data Analysis

Descriptive statistics was used to summarize demographic and caregiving relationship of each male FCG participant. Qualitative data were analyzed using thematic analysis with the support of Dedoose software. In thematic analysis, data are analyzed and organized based on recurring patterns or themes to illustrate participant experiences (Vaismoradi et al., 2013; Vaismoradi & Snelgrove, 2019). Additionally, thematic analysis emphasizes the individual meanings within the data, but also extends the application of these meanings to a larger, social context (Braun & Clarke, 2006). The research team independently read and re-read the first four to five interviews and developed initial thematic codes from early transcribed interviews, then met to discuss and compare codes and segments for agreement. A codebook was created documenting the evolving thematic codes and the research team met bi-weekly to discuss application of thematic codes to the remaining interviews until thematic saturation was met. Pseudonyms were then given to each participant for anonymity when reporting the results.

To ensure rigor in qualitative analysis, Guba and Lincoln's framework was utilized to established *trustworthiness* in analysis of qualitative data (Krefting, 1991). This framework includes four strategies to strengthen the findings of qualitive research: *Credibility, transferability, dependability,* and *confirmability* (Table 4.2). A member check interview was also completed with a 12th participant who met study eligibility to validate thematic findings and verify interpretation of the data. The 12th participant used for member checking was also a close relative to the PI and the main influence for conducting the study having been a male caregiver for a spouse with ADRD.

Results

A total of 11 male FCGs were included in this study. Four participants cared for a spouse, three participants cared for a parent, three participants cared for a grandparent, and one participant cared for a brother with ADRD. Seven male FCGs have been in the caregiver role for one to five years with the remaining participants having been a caregiver for six to ten years. Racial background of participants included five who identified as white, four Asian, one African American, and one of Hispanic or Latino background. Full caregiver demographic and relationship characteristics are provided in Table 4.3.

Thematic analysis resulted in three major themes that addressed the first aim of exploring the male FCG experiences within their changing roles of family member to caregiver: (1) *Male Caregivers Struggle with the Unfamiliar Role and Changing Identity as a Caregiver,* (2) *Caregiving Provides Personal Growth and Discovery,* and (3) *Men are Challenged to Find the "Right" Kind of Support as Caregivers*. One main theme emerged that addressed the second study aim of exploring men's perception of masculinity and its influence on their caregiver role: *Reshaping Masculinity Through the Caregiver Role.* Additional sub-themes were identified for each major theme and an overview of all themes with representative quotes are outlined in Table 4.4.

Male Caregiver Struggle with the Unfamiliar Role and Changing Identity as a Caregiver

Male FCGs described their difficulties in their ability to fulfill their role as caregiver in multiple aspects such as physically, mentally, emotionally, and financially. Additionally, their caregiving responsibilities left men to question their changing role and inter-personal identities as the needs for care of their loved one with ADRD became increasingly demanding. Some of these perceptions of difficulty within their role could be attributed to the lack of prior experiences in any prior caregiving role.

Negative Perceptions/Experiences of the Caregiving Role

Caregiving for a person with ADRD can be difficult due to the challenges posed by the progressive, often lengthy disease process. In this study participants detailed similar negative experiences as found in prior studies such as helping with ADLs and IADLs. But because of this long, arduous role of being a caregiver, men found that they were losing a sense of self as they began losing other aspects of their personal, professional, and social lives.

> And I think what everyone can fall prey to is that you give up so much. Like I said, I don't have many friends anymore. I don't have men I hang out with and just do men things. I have work colleagues that I talked to at work, but we just talk. We're not doing anything. (***Nicholas, spouse, 50-59y)***

Change in Familial/Relationship Identity

When male FCGs were asked about how they see their familial identity within the context of caregiving for someone with ADRD, some expressed the difficulty of losing their familial relationship as their caregiver role has engulfed most of their interactions. One participant describes the feeling of total transition outside of their spousal relationship into caregiving, and that the identity of being a husband is only a formality but not in connection. Another participant described seeing his relationship change as being more of a job rather than that of a grandson.

> It's tough. It's tough because as a grandson, it was like, oh, come over to visit, and now it’s, come over to almost work, or I mean, I don’t necessarily think of it as work. I don’t know. I try not to necessarily think of it as a quote, unquote, ‘job,’ but sometimes it’s easier for me, personally, to disconnect the relationship, and it makes me sad that I have to disconnect that relationship between being a grandchild and being a caregiver. ***(Abel, grandson, 18-29y)***

Much of this challenge in shifting self-identity from family member to caregiver can be attributed to the disease process of ADRD itself where loss of the ability to recognize the FCG affected the relationship. As described by the following participant, he describes the loss of familial identity related to losing the familiar interactions and recognition when caring for his father.

> I see myself more as a carer than a son now…I do feel that the role of a son and a caregiver has been quite one in the same. I don’t see them as a separation although, of recent times [they are separating]?, because I’m losing my relationship with my father. When I say I’m losing my relationship, what I’m saying is I don’t seem to have a relationship other than going in [to be a caregiver]. Because I can try and talk to him, I can try to elicit some kind of conversations, we can reminisce about the past…I don’t get a response from him because his ability to talk has gone and his ability to communicate has been severed. (***Harrison, son, 40-49y)***

Unknown Expectations

An element of the challenge for the participants is the lack of preparation for their new role as caregivers. Many of the male FCGs expressed their lack of knowledge of what ADRD was and the disease process itself and thus were unaware of what to expect in their caregiving role.

> I had little idea from the pot burning on the stove repeatedly, but I did not expect it would be a medical emergency such as this. And I was completely out of my element because I didn't have any training. (***Kingston, grandson, 30-39y)***

The unknown expectations combined with the lack of experiences in any prior caregiving encounters or responsibilities contributed to negative feelings of self-doubt and lack of confidence in their caregiving role. As described by one participant, recurring concern of being an effective caregiver for his brother with ADRD was attributed to the lack of prior experiences and knowledge.

> Will I be good enough to do this, am I good enough for you now? Will I be able to do this now? That was a question that keep popping up in my head. (***Walker, brother, 18-29y)***

Caregiving Provides Personal Growth and Discovery

Despite the challenges face by the unfamiliar caregiving role, men find how the positive aspect of caregiving help them find new personal characteristics which allow them to become better versions of themselves. Furthermore, male FCGs did express improvement in other self-characteristics (e.g., patience, empathy, and compassion) and inter-familial connections (. relationship with parents, siblings, and friends) during their role as caregivers.

"See Life Differently"/Change in Perspective

Although caregiving for ADRD may be challenging in many aspects of the role and the progression of the disease, male FCGs voiced how their experience as caregivers taught them valuable skills that not only helped them care for their loved one but may help in other relationships. One FCG shared how the patience he learned through caring for his grandfather helped him become more selfless and attentive to others. Additionally, he saw how becoming more patient could eventually help him in future relationships.

> Not necessarily that I want to brag, but I think it has taught me a lot of precious skills, and it also has upped my patience and wanting to be a father someday and have a family. I think it has taught me patience and having to work around other people, and it's just not about you, necessarily, anymore. ***(Abel, grandson, 18-29y)***

Compassion

Another trait that some male FCGs began to see in themselves as they cared for their loved one was compassion. Even if this compassion was not outwardly acknowledged, compassionate care for their loved one was demonstrated through the growth of their relationship with the person with ADRD and the caregiving activities provided even as the disease further progressed. Being a compassionate type of person was something that some male FCGs did not see in themselves which was brought about by their caregiver role as one FCG shared.

> I don't know if I'm embedded with such qualities but this particular situation with my brother, it does make me to maybe bring out those qualities. I never saw myself like someone who has compassion or cared so much for people. (***Walker, brother, 18-29y)***

Acceptance

A common sentiment shared by male FCGs is that of acceptance. Although they may not have had prior experience, or felt they had inadequate preparation for caregiving responsibilities, many of the FCGs were able to acknowledge these feelings as part of the growth process in providing the best care possible.

> And then accepting my own imperfection, that's not easy to do. I'm going to mess up, I'm going to screw up and I'm not perfect, and I need to know how to deal with those imperfections as they come up. I still do. (***Reginald, spouse, 70-79y)***

Similarly, control is an important concept among male FCGs, and it was important for them to accept that they had none especially caring for someone with ADRD. One caregiver shared his idea of the importance of control and acceptance:

> Wow. For me, I would love a lot [of control], but I'm learning I cannot have that. I have to accept that. But to answer your question, in my perfect world, it would be total control. (***Graham, son, 60-69y)***

Men are Challenged to Find the "Right" Kind of Support

The third major theme that emerged surrounding male FCGs' perceptions of the type of support they required in their role as caregivers, was *difficulty in finding the right kind of support* to address their needs. Male FCGs also voiced reluctance in seeking support, preferring to rely on their own self-support. For the men who did look for support from others, they found comfort in more familiar types of support such as family or other men in similar situations, rather than formal support?

Hesitant to Seek or Engage in Self-Support

A common theme among male FCGs was the lack of attention to finding support for themselves as they deal with the challenging responsibilities of being a caregiver. Many of the participants attributed this lack of attention for themselves because they reserved any free time they had for themselves. In one situation, one FCG detailed that due to the intense caregiving situation with his father who had ADRD, any free time was spent just to recover, away from other people.

> There’s a degree of apathy...There’s a degree of laziness because sometimes when I have a spare two hours, rather than get up and go and meet new people, sometimes I just want to go upstairs and just crash in my bed. So, there is a degree of because I physically... I’m just tired and I don’t want to talk to anybody, and I just want to be left alone. (***Harrison, son, 40-49y)***

Some men expressed that the hesitancy to find support for themselves was due to bad prior experiences with available resources. A common resource for FCGs is support groups to help people in similar situations deal with challenges caring for people with ADRD. But as this participant explains, traditional support groups may not be the kind of support needed for men in these caregiving situations.

> I was told, basically, “You’re too fucked up asshole! You’re too fucked up for us. We only provide these cookie cutter programs for namby-pamby people. You really need more help, so I recommend you go through all these hoops, jump through all these hoops, be on the phone, wait for an hour, blah, blah, blah, and all that stuff.” And I just said, “Oh, fuck this. Fuck this!” I work so hard to relying on myself that... And in my life, I’ve had situations where I reached out for help and

> it doesn't come or the help that does provide is just so shitty that I regret asking for help. (***Silas, son, 60-69y)***

Seeking Support from Familiar Places

To support them in their caregiving tasks and the skills needed to provide care, male FCGs utilized the common pathways of information such as the internet and professional organizations to help ADRD FCGs. But when the male FCGs sought emotional and social support for their own health, they preferred them from people whom they were most comfortable with like family, friends, and just themselves. One FCG commented how the opportunity to spend time with friends doing once familiar activities, and the ability to have some respite time alone gave him the release needed from the challenges of caregiving.

> And I went camping for two nights with a buddy of mine. And I can tell you that weekend was in some ways I feel like it saved my life…So, I got my car and I had all my windows down. And so, I'm driving home and I had music playing on the radio. And I started just singing out loud. And I decided don't even get on the freeway, just drive home like surface street, and it took me like three hours to get home even though we're only an hour away. And it just felt like I'm actually having a life, I'm actually doing something I wanted to do! (***Nicholas, spouse, 50-59y)***

For the participants that did seek outside help from formal support groups, they preferred the familiarity of being around other men in similar situations and thus chose to seek help from male only support groups. One FCG, Silas, who joined a male only support group after participating in other support groups, voiced how men may approach problems differently than women and that traditional groups can lack that male viewpoint.

> But on the other hand, based on what I observe in the different caregiver support groups, meaning all men's caregiver support group versus the local ones and the local ones, I'm the only guy. Everyone else is either they're taking care of their husband or they're taking care of their mother, but they're all female. And some of these women, I mean, I give them credit, but some of them it's like, 'Excuse me, this is not that difficult. You're making it more difficult than it is and how come you're not taking advantage of all the information that's being provided to you? (***Silas, son, 60-69y)***

Lack of Support in Caregiving

Although male FCGs did seek support, some expressed that there is a general lack of support for male FCGs and are left to struggle on their own. Some men expressed that they were commended for fulfilling the caregiver role since it was not typical for a man to be a caregiver. But within that praise of being a caregiver, there was also a sense that because they were a man, they were strong enough to be able to do this on their own.

> And some friends, but I think usually with friends and stuff, it usually gets to, "Oh, you do that. Oh, good for you," and that's the end of the conversation. They don't want to know the details of it. So, it stops there. ***(Abel, grandson, 18-29y)***

One participant even explains that he expected caregiving support from family, but these expectations were not met and contributed to his sense of burden providing care.

> Imagine if my father was on fire, okay, and he's there and he's on fire, and there's me running to him, okay? I would expect the rest of my family to run with me,

> but it's almost as if they're standing and watching at the periphery, watching me trying to put the flame out. And it's almost as if society has taught me that, "No, your family will run with you," so I go in with that expectation but, in reality, I'm just running on my own. So therefore, that is the single hardest thing, being constantly let down… (***Harrison, son, 40-49y)***

Reshaping Masculinity Through the Caregiver Role

In terms of how views of masculinity helped shape the FCGs' approach to their caregiving role and vice versa, the men described how masculinity brought physical and emotional strengths to the caregiving role and consequently, how their view on masculinity has been reshaped by fulfilling the role of caregiver. Additionally, men expressed how societal views of caregiving and who's best suited to provide care should change as they believed men can provide the same level of care as women.

A Man's Duty in Caregiving

A common theme that male FCGs expressed is that the caregiving role is encompasses what it means to be man. They expressed how it is the duty of the man to be the protector, the safe haven for their family member in need, therefore making the caregiving role a natural fit for men. The men who were spousal caregivers attributed their fulfilling the caregiving role as them keeping their promise of being a husband. Overall, male FCGs felt that their masculine attributes of strength and resilience was made for being a caregiver, especially for someone with ADRD.

> I think masculinity is being able to be strong even if you feel weak or even having that breakdown and recovering from it, because that's what you do. It's not just winning the football game. It's not dominating in the football game play after play

> and then grinding the other team into the dust. It’s being down 21 points and still win somehow coming up in the last quarter, even though your best player broke his leg and somehow winning the game because you found the strength within yourself, and you did it. (***Nicholas, spouse, 50-59y)***

Intimacy & Sexuality

An interesting finding was that although sexuality and intimacy were not specifically asked in relation to masculinity, when asked about masculinity within their role as caregivers, spousal caregivers shared how caregiving for their wife with ADRD changed their sexual/intimate relationship. Male spousal caregivers viewed sex and intimacy as a significant aspect of their relationship with their wives, prior to their wives’ acquisition of ADRD. The significant role that intimacy and sexuality played in defining their relationship with their wives affected how they viewed their role as a husband concurrent to their caregiving role. Two FCGs shared:

> So, I’m not a traditional, historically-defined husband any longer. Even intimacy goes, you can’t have sex anymore after a certain point that you reach with a woman who becomes a child. (***Reginald, spouse, 70-79y)***
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> As a man, to me? Between me and my ex-wife, no sex relationship at all. Okay? She has dementia, she doesn’t know anything at all... because when I met her, I noticed that, okay? She doesn’t have any desire of sex at all. (***Larry, spouse, 70-79y)***

Caregiving Gives New Meaning to Masculinity

Men expressed how their experience as caregivers has redefined their ideas of masculinity and runs counter to what is seen in society or how they were socialized to experience gender. This is further expressed by male FCGs wanting their masculinity to be self-defined rather than having definitions imposed on them by surrounding forces (e.g., society, culture, historical context). Due to the caregiving role, male FCGs questioned the way masculinity is currently defined in society. They believed men and society must be able to adapt to the changing views and responsibilities of what is typically seen as masculine. These adaptations involve areas of physical responsibilities, expression of emotions, and loss of situational control.

> So as a caregiver, as a man we've learned along the way to protect a woman, certainly make something easier for her... And then as I said earlier, why we're not defining this by today's culture because I don't agree with today's culture in terms of the way things are done. So as a male, taking care of your spouse, or if that's your profession, taking care of a woman and doing it in a way that brings dignity back to a situation. (***Dawson, spouse, 70-79y)***

Another caregiver who is involved in a men-only support group share how men can feel ok with the uncomfortable feeling of being inadequate and find comfort in expressing those feelings.

> There is no book about this, just like parenting, and sometimes especially with the new members, you can tell they kind of found a good place, let's say with the group, but then I can see them, not really sure what to ask, and so sometimes, you just have to give them permission. It's like, "You know what, I'm glad you're here, sometimes you don't know even what to ask," and they're like, "Yeah, that's right," you know, and that's fine, "but keep coming back…"
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> (***Graham, son, 60-69y)***

Men Bring Unique Abilities to Caregiving

Ultimately, the male FCGs expressed that their ability to be a caregiver is no different and that they are able to provide the same level of care as their female counterparts. However, some male FCGs expressed a belief that men can provide unique abilities to the caregiving role in terms of physical capabilities and emotional aptitude but emphasized that the best outcomes would be that both genders can learn from each other and bring the strength of both genders to the caregiving role.

> I think the input of a man and the viewpoint of a man in the aspect of caregiving can be very useful, but without saying, “Women can’t do that,” you know what I mean? But I think when you combine the two together, it has the best outcome in anything… it just brings about so many more ideas and insights that you wouldn’t normally have. ***(Abel, grandson, 18-29y)***

Discussion

Findings from this qualitative study provide insight to the subjective experiences of men as they recounted their transition to the caregiver role for a family member with ADRD. Furthermore, this study undertook a unique approach by exploring how masculinity influences male FCGs’ self-identity as both men and as caregivers in a historically female role. Prior caregiving studies for people with ADRD illustrated the high burden that is experienced by FCGs and the differences between men and women; however, the subjective experiences of male caregivers had not been well understood.

Within our study, we were able to see through the eyes of the male caregiver as they attempt to bridge their competing roles of a caregiver and that of a husband, brother, son, or grandson. Most of the men in our study have had no prior experience in any caregiving role or lacked the knowledge of what the disease process entailed which led to the theme of struggle in the unfamiliar transition into the caregiver role. The men in the study voiced that they were not prepared for the physical, emotional, and psychological challenges that caring for someone with ADRD would bring. Also, the lack of knowledge of encompassing ADRD contributed to the unknown expectations of the caregiving responsibilities. Through the lens of the CIT, the male caregiver's struggles highlighted how, without prior experiences or expectations around caregiving, a man's self-identity goes through a drastic change in the initial stages of role transition. Additionally, the transition of having to balance the dual roles of being a husband, son, grandson, or brother with that being a caregiver attributed to negative feelings of self-doubt and difficulty fulfilling the role. This finding is similar to prior research demonstrating that men had a higher intensity in burden during the initial stages of becoming a caregiver compared their female counterparts (Polenick & DePasquale, 2017; Zwar et al., 2018). This aligns with the popular concept of society's influence on the believed gendered social roles whereas men were not expected to play a major role in caregiving. These beliefs include responsibilities that women were mostly in charge when it came to child rearing or caring for an aging parent or grandparent (Mott et al., 2019). These struggles highlight a need for improving awareness, education, and training for male caregivers, especially during the early phases of becoming a caregiver.

Our findings have illustrated the additional challenges faced by male FCGs to support them in their caregiving role. Challenges encompass both internal and external factors that affect how men see their own need for support and the types of support available to them. Internally, the men exhibited the idea of self-reliance as a driving force for hesitancy in seeking or utilizing available support for their own health. Although this is not an uncommon finding among men's health-seeking behaviors, it still displays an importance to help male FCGs understand the benefits of finding emotional and mental health support for themselves. It is vital for male FCGs to be aware of the types of external avenues available to them to address their own health early and often as prior studies have shown the effectiveness of informal and formal support on mental and emotional health (Worrall et al., 2018) and gender specific support (Gwyther et al., 2019). Even then, current available resources may not be sufficient to properly meet the needs of male FCGs. As found in this study, male FCGs prefer and look towards more familiar sources as a form of support such as family and friends. But when male FCGs do seek external resources for caregiving support, they prefer and find comfort in the familiarity of being around other men. Given the difficulty in conducting research on male caregivers due to the aforementioned finding that men are less likely than women to seek help for themselves, some of the participants in this study were recruited through a men's only support group for those involved with the care of someone with ADRD. As one participant voiced their experience of being the only male in a previous support group, men only support groups could be the answer to providing male FCGs a more attractive and effective way to express their feelings and obtain the help they need for themselves. Although men-only support groups are available, they are still limited in the number compared to other types of support groups. Additionally, there is a lack of research on the actual effectiveness of specialized support groups compared to other types of support resources.

Despite the negative aspects experienced by male FCGs, the caregiving role does provide positive and transformative opportunities for men. Through the role of caregiving, the male FCGs were appreciative of learning and developing new emotional skills in providing care needed for their family member with ADRD. In early studies, when problems or distressing circumstances arise, men tend to focus on finding solution or "problem-focus" type of coping whereas women are more inclined to an "emotional-focused" form of coping (Folkman & Lazarus, 1980; Tamres et al., 2002). Patience and acceptance were characteristics that men acknowledged were very important in caring for someone with ADRD where there is no solution or "fix" to the disease. The men had to learn to accept the fact that they did not have all the answers while caregiving and be happy with providing the best care they possibly could. But most intriguingly, they were becoming more aware of the emotional adaptation that was happening. In a society where men feel they must curb their emotions or display a type of "manliness" at all times, a sense of compassion and compassionate care was brought upon the experiences of caregiving. Instilling compassion in men through caregiving can be an important driver to help liberate them from feelings of suffering and isolation generated by having a "me"-only mindset (Adams & Frauenheim, 2020).

Masculinity is interwoven in all aspects of the male caregiving experience of providing care for someone with ADRD. Traditional hegemonic masculinity, a concept defined as men conforming to socially dominant roles represented by strength and power, shapes ideas that men should be more involved in work that are more productive than in unpaid positions (Hunter et al., 2017). Therefore, some of the struggles experienced by the male FCGs may have been due to the competing identities and the constructs of masculinity where caregiving is socially viewed as a more feminine position (Björk, 2015; Leung et al., 2019). Masculine influences on caregiving are also seen especially concerning men seeking support for themselves. The present study's findings have echoed previous studies of resistance in help-seeking behaviors among men relative to mental health. Prior literature found that masculine norms and attitudes towards mental health issues play a major role in why men do not seek help for themselves (Parent et al., 2018; Staiger et al., 2020). Evidence also suggests men preferred to address their mental health challenges on their own and voiced a socialized belief that men should avoid feelings, appear strong and never cry (Staiger et al., 2020).

An emerging trend observed among participants in this study was how they disagreed with the current socialized norms of what it means to be a man and voiced that men should not be ashamed to share their feelings or appear vulnerable. Since participants in this study varied widely in age and caregiving relationships, these findings could be a positive movement of changing views on masculine social norms. Participants described how social masculine ideas affected the male FCGs' perception and experience of their caregiving role; however, they were also transparent and openly candid in their sharing of emotions and struggles surrounding their familial and social lives. For example, an interesting finding associated with masculinity was the mention of sex and intimacy among the spousal caregivers. Given that these topics were voiced when asked about their views on masculinity illustrates intimacy as an important aspect of male FCG's view of their conflicting identities as a husband and caregiver and should be an area of focus to be addressed when supporting male spousal caregivers.

Limitations

This study does have some limitations. There was a lack in racial diversity in participants as most were White or Asian with only one participant each of African American and Latino/Hispanic backgrounds. This is notably important as perceptions of masculinity can be influenced by ethnicity and culture which could alter the caregiving experience. Additionally, geographic location of participants was not explored as this may alter what resources for support were available for caregivers and thus influencing their perception of self-support in their caregiving role. Similarly, this study was conducted during the COVID-19 pandemic which impacted social activities and resources available. Lastly, this study did not include men who identified as LGBTQ+. This exclusion is important to note during a time where gender identity is a major topic in US social issues, but prior studies have shown that caregivers within this population face unique problems based on their gender identity and future male FCG studies should focus on that population separately (Croghan et al., 2013).

There are additional factors that could have influenced the male FCGs' participation and openness in this study that should be noted. Since interviews were done remotely, and participants were not required to share their video if conducted via Zoom, the physical disconnect, and anonymity may have allowed them to be more comfortable in providing their responses. Furthermore, all interviews were conducted by the PI who is also male and may have also played a part in how comfortable the participants were at sharing their experiences and feelings. Although these factors may have affected how open and honest the participants were in the interviews, these could be valuable considerations in future research and development of supportive resources for male FCGs. Meanwhile the recruitment strategy involved social media and local organizations who provide caregiving resources such as training and support groups. Thus, participants in this study may have already been utilizing support resources and may have a biased view of help-seeking behaviors and more open view of masculinity’s role in caregiving.

Implications for Nursing Practice and Research

Nurses and other healthcare professionals are in prime position to address the needs of male FCGs. When educating and addressing management of client health at home, it should be essential to include into the plan of care of people with ADRD to focus on assessing the health of the FCG as well. Healthcare professionals should not assume that caregiving responsibilities will be undertaken by the women in the family and that education and caregiving support be emphasized to familial men as well. Since men’s health-seeking behaviors are different than women’s and since men may be more reluctant to seek help for themselves, future research should explore strategies to reduce the stigma for seeking help and types of support resources that would better fit what male FCGs are looking for. This idea may be one of the more challenging approaches as social masculinity ideologies have shaped men’s help-seeking behaviors. Researchers must find strategies to help men increasingly view finding mental and emotional help for themselves acceptable in today’s society. Additionally, future studies should explore further differences in experiences of male FCGs based on demographics such as race, culture, geography, and sexual orientation. If male FCGs are not adequately supported in their role as caregivers and their physical, mental, and emotional health to prevent negative health outcomes, they too will eventually need their own caregivers.

Conclusion

Results of this study provide only a small window into the experiences of male caregivers for a person with ADRD but fills a research gap of understanding the rich views of the inner thoughts and feelings that encompass the struggles and rewards of an unfamiliar role. Although quantitatively, men may not report as high of a total burden compared to women in caregiving for an older adult with ADRD, their experiences still highlight the need for tailored support and should not be overlooked. Given that men in caregiving research have not been a popular focus and that there is a disproportionate number of them that participate in this type of research, there is still a large gap of knowledge to uncover about this population. As it is projected that the US older adult population will continue to significantly rise, it is vital to address the growing needs of all caregivers so they may be able to provide the care for older adults to achieve the best quality of life.

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Table 4.1

Specific Aims and Examples of Representative Interview Questions (Full Interview Guide in Appendix A)

Primary Aim: Explore the perceived experiences of male caregivers caring for a person with ADRD through the role transitions from family member to caregiver.

3. Could you think back when your X (wife, parent, sibling, aunt/uncle, friend) was first showing signs that led up to the diagnosis of Alzheimer's Disease or related dementia. What was your initial reaction?
    - Probe: What was your understanding of the potential needs of your X in terms of the disease progressing?
    - Probe: How did you see yourself as a caregiver at the beginning stages of ADRD?
      Probe: What kinds of expectations did your X have for you as their caregiver?
4. As your X's care needs begin/began to increase, how do/did you see your relationship with your X change?
    - Probe: How did you see your role as a (husband, son, brother, nephew, friend) change over time?
    - Probe: Did you begin seeing yourself more as a caregiver than a (husband, son, brother, nephew, friend)?

Secondary Aim: Describe the male caregivers' perception of masculinity and its influence on their caregiver role.

3. Since the caregiver role and caregiving activities are or has been seen as a typical female role, being a man, did that affect how you saw yourself as a (husband, son, brother, nephew, friend) and as a caregiver?

- Probe: Did you have any reservations or hesitancy in becoming a caregiver?
- Probe: How do you think your thoughts on masculinity affected your role as a caregiver?

4. How can you explain how masculinity influences your perceptions of the caregiving role?

- Probe: What are your thoughts on men being caregivers?
- Probe: Can you think of specific examples in your life that has helped shape these ideas or perceptions?
- Probe: How has your views on masculinity and being a caregiver changed or not changed?

Table 4.2

Strategies used to ensure rigor and trustworthiness based on Guba and Lincoln's framework (Krefting, 1991).

Category	Strategy	Action
Credibility – Confidence in the truth of the findings in the context in which the study was conducted.	Reflexivity, triangulation	PI will conduct reflexive journaling to examine own beliefs and biases during research. Two researchers will independently analyze data and compare coding results; research team will meet monthly to discuss thematic coding and analysis.
Transferability – Findings fit into contexts outside of the study situation by degree of similarities or goodness of fit	Comparison of sampling to demographic data, dense descriptions	Sampling techniques (e.g., partnering with local organization, social media, and networking) to achieve the most diverse participant pool as possible to reflect demographic variability; providing dense background information about participants and the research context.
Dependability – Consistency of findings within the context of study technique and design	Audit trail, triangulation	PI will record all team meetings and keep notes on all decisions made during analysis. Two researchers will independently analyze data and compare coding results; research team will meet bi-weekly to discuss thematic coding and analysis.
Confirmability – Neutrality of findings and conditions of research free of influence of other	Reflexivity, audit trail, triangulation, member checking	PI will conduct reflexing journaling to examine own beliefs and biases during the collection and analysis of data. PI will keep notes of team meetings and all decision-making processes.

biases, motivations, and perspectives.		Initial analysis of data will be conducted independently between researchers and then compared during bi-weekly meetings. PI will conduct an additional interview after final analysis to confirm findings with an additional participant who meets criteria for the study.

Table 4.3

Male Family Caregiver Characteristics

Caregiver Pseudonyms	Age Range	Race	Employment Status	Relationship to person with ADRD	Years Caregiving	Average Hours Caregiving/week
Walker	18-29	African American	Part-time	Brother	1-5	21-30
Nicholas	50-59	White	Full-time	Spouse	1-5	30+
Harrison	40-49	Asian	Unemployed	Son	6-10	30+
Dawson	70-79	White	Retired	Spouse	6-10	30+
Larry	60-69	Asian	Full-time	Spouse	6-10	21-30
Kingston	30-39	Asian	Full-time	Grandson	1-5	30+
Silas	60-69	White	Unemployed	Son	6-10	11-20
Reginald	70-79	Hispanic/ Latino	Retired	Spouse	1-5	30+
Graham	60-69	Asian	Part-time	Son	1-5	11-20
Jesse	30-39	White	Unemployed	Grandson	1-5	30+
Abel	18-29	White	Unemployed	Grandson	1-5	11-20

Table 4.4

Overview of Themes, Sub-themes, & Representative Quotes

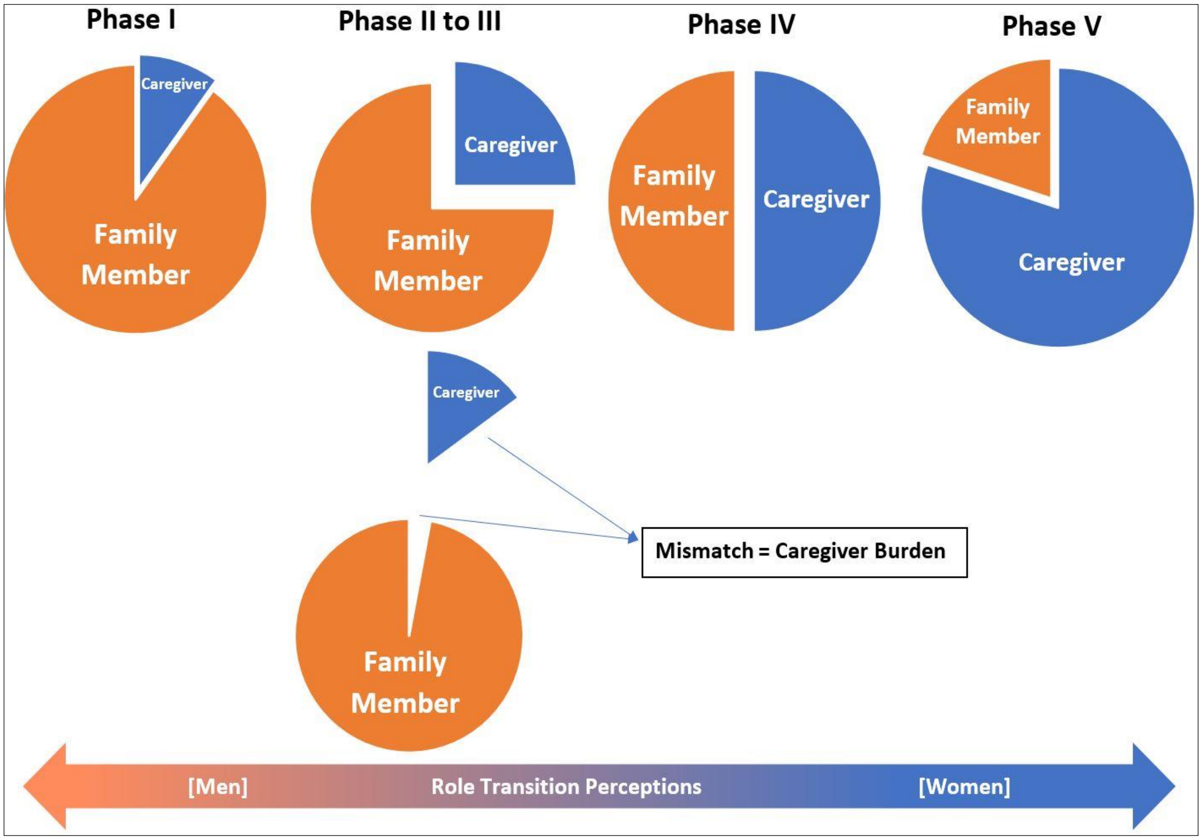
Main Theme	Sub-theme	Representative Quote
Male caregiver struggle with the unfamiliar role and changing identity as a caregiver	***Negative Perceptions/Experiences of the Caregiving Role***	"I hate to…Okay, I just have to say it, there's no way to say it. If she becomes a human vegetable, if she comes to that, if she digresses to that state, that is going to be extremely emotionally hard for me and physically hard for me to be able to visit her and to do anything with her." (***Silas, son, 60-69 y)***
	Change in Familial/Relationship Identity	"Well, it's not a conflict. It's really just a complete transition at this point. I'm in the role I'm in because I'm a husband. But I'm not her husband anymore other than on paper. I mean, it's not a romantic relationship. It's a caregiver relationship and one I'm obligated to because I'm married to her. And I do love her. But the love is, one, it's like residual love for the woman I married but that's not who am I taking care of. She's not there anymore." (***Nicholas, spouse, 50-59 y)***
	Unknown Expectations	"No, when I first heard he had Alzheimer's, I had no idea what it really entailed but because, like most diseases, if it doesn't affect you, you don't really look into it." (***Harrison, son, 40-49 y)***
Caregiving Provides Personal Growth and Discovery	***"See Life Differently"/Change in Perspective***	"But part of how I worked through it was by taking full ownership of all the harm I did. And so, since we're talking frankly, basically, within the first week of the diagnosis, we were sitting there one day and I said to her, 'I'm sorry that I wasn't there for you when you were finding something was wrong that I was too wrapped up in what I was feeling to see that you needed my help. And I wasn't maybe there for you like I should be. And I'm sorry. And I promise you, I'll be there for you from now on. And you can trust me" (***Nicholas, spouse, 50-59 y)***
	Compassion	"I'm no doctor, but I suspect it's a combination of that new medication and me being there to encourage her,

		and I think that effort has improved our relationship fantastically.” (***Silas, son, 60-69 y)***
	Acceptance	“…some people are just much more resistant to acknowledging and accepting what it is and wanting to adapt, find ways of adapting to it, which requires you to change. You’re the only one that could change. She’s going to change with the disease, but you’re the only one that can change in response to what you’re going to do to deal with it and to help her out, and how to take care of yourself in the process.” ***(Reginald, spouse, 70-79 y)***
Men are Challenged to Find the “Right” Kind of Support	***Hesitant to Seek or Engage in Self-Support***	“No. I haven’t sought support since for myself. I am support, I guess…So, all through high school, all my friends and stuff would ask me why they were having these problems or in their relationship or whatever it may be. Now I could tell them what they should do, and I won’t listen to my own self.” (***Jesse, grandson, 30-39 y)***
	Seeking Support from Familiar Places	“As far as family support, my brother and his family live in Seattle, so not to much contact there. But through the course of the disease, I would manage to get up and spend some time with my brother and his family with [wife]. And they were very sweet to her. And my mom and dad were awesome in terms of support.” (***Dawson, spouse, 70-79 y)***
	Lack of Support in Caregiving	“I mean, I think it’s something that jumps on a lot of people, and a lot of people don’t know, or they feel like they’re alone. And I think that’s the scariest part is when people feel like they’re alone and they don’t have anyone to reach out to about anything, and this is just their life now, and they have no other option or nobody to reach out to because no one’s going to understand.” (***Abel, grandson, 18-29 y)***

Reshaping Masculinity Through the Caregiver Role	***A Man's Duty in Caregiving***	"It goes back as far as just the core tenets of what it's like to be a family man, is being able to provide any care, means, or items necessary to make sure that your family ends up being successful." (***Kingston, grandson, 30-39 y)***
	Intimacy & Sexuality	"As a man, to me? Between me and my (then) wife, no sex relationship at all. Okay? She has dementia, she doesn't know anything at all…because when I met her, I noticed that, okay? She doesn't have any desire of sex at all.?" (***Larry, spouse, 60-69 y)***
	Caregiving Gives New Meaning to Masculinity	"Express your feelings. Don't feel like you're alone. I think the aspect of being alone impacts men even more because they're afraid to express their feelings or afraid to ask for help or not wanting to ask for help. And I just think if helps available, and it is, you should be willing to, man or woman, you should be willing to reach out and ask for that help because doing something like this alone is extremely difficult." (***Abel, grandson, 18-29 y)***
	Men Bring Unique Abilities to Caregiving	"It's a choice that I make to think there's something manly, I guess, or a man quality, think that I know I'm going to make a better decision…I guess most men probably think that they're going to make, if they had to put the bet, they're probably going to make the more logical decision whatever situation they're in." (***Jesse, grandson, 30-39 y)***

Figure 4.1

Caregiver Identity Theory and Gender Role Perceptions Adopted from Montgomery & Kosloski (Montgomery & Kosloski, 2009).



CHAPTER V: DISCUSSION, LIMITATIONS, AND RECOMMENDATIONS

Family caregivers (FCGs) provide a necessary role for maintaining the health and quality of life of people suffering from Alzheimer's disease or related dementia (ADRD). The stress and challenges of being a FCG for someone with ADRD can bring upon detrimental health consequences due to its long term and demanding role (Goren et al., 2016; Richardson et al., 2013; Tatangelo et al., 2018). There are several factors that can affect the differences in caregiving experiences, and one understudied area is gender. Family caregiving has traditionally been held as a female role and the literature is reflective in that men are underrepresented in caregiving studies. Although female caregivers are found to have a higher overall level of caregiving burden (Avdikou et al., 2019; Del Pino Casado et al., 2017; Glavin & Peters, 2015; Kahn et al., 2016; Prevo et al., 2018), male caregivers still experience significant levels of burden; however, little is known about their subjective experiences. Using the Caregiver Identity Theory (CIT) as a framework, this qualitative descriptive study addressed the research aims that explored the subjective experiences of men as they managed their familial and caregiving roles and how men viewed masculinity's influence on their caregiving role while caring for a person with ADRD. This chapter will summarize the findings of this study, limitations, and recommendations for future research and implications for professional and community practice.

Additional experiences guided this dissertation study. The literature review conducted on gender differences on caregiving burden on older adults with chronic illness (Chapter 2) revealed the scarcity of studies focusing on the detailed experiences of men in caregiving roles. The quantitative studies that were observed also showed a pattern of imbalance in the number of male participants included in studies illustrating a need for this population to be further investigated. The literature review findings prompted this dissertation’s focus to further explore the research problem of understanding the male caregiving experience caring for an older adult with chronic illness, and more specifically, ADRD. An additional activity that influenced this dissertation work was conducting a secondary qualitative analysis study of qualitative interview data from two parent qualitative studies that explored the experiences of FCGs managing the needs of older adults during post-acute home health care (Chase et al., 2019; Chase et al., 2020). The secondary qualitative analysis mainly focused on the data from male FCGs and found themes surrounding the challenges men faced in the coordination of care, lack of preparation for the caregiving role, and masculinity (Bueno, 2021). Given that the parent studies did not look at specific gender related themes, the findings of the secondary analysis helped guide the development of interview questions for the current study to illicit the negative and positive caregiving experiences. Furthermore, these research activities with a focused view on gender and gender differences prompted a closer look at the concept of masculinity within the male caregiver’s identity which this dissertation explored.

Prior studies have exemplified the consequences of caregiving for older adults and differences found between genders; but this study provided a look at the deeper meaning of what it means to be a male FCG. The first aim of this dissertation study explored the overall caregiving experience for male FCGs caring for a person with ADRD. The themes of *negative perceptions/experiences of the caregiving role, change in familial/relationship identity,* and *unknown expectations* emerged that addressed the first research question about how men described their experience throughout the caregiving relationship. The men within this study detailed how they struggled with seeing their role of husband, son, grandson, or brother transition to more of that of a caregiver as their responsibilities for care increased. Much of this difficulty was due to the lack of knowledge surrounding the disease and not knowing what to expect as one caregiver mentioned he only thought it was something "old people got." This highlights the issue that the male FCGs did not understand the disease and what to expect as ADRD progresses, leading to the challenge of learning how to take care of their loved one. The caregiving experience for male FCGs were not all negative. Within their experiences, the male FCGs found positive aspects received as caregivers. Positive sub-themes emerged of *"see life differently"/change perspective, compassion,* and *acceptance* that exemplified the major theme of *caregiving provides personal growth and discovery*. These themes encompassed how men were able to learn or be more aware of their own emotions. For some men, even if it was not a verbalized expression of emotional growth, it was exemplified through their actions and ability to be more understanding of the physical and mental changes that were happening with their family member with ADRD. Lastly, as their roles evolved along with the challenge of keeping up with changing needs of their loved ones, male FCGs' growth involved acceptance of the perceived imperfections being a male caregiver. These perceptions included the acknowledgement of not being in complete control of their caregiving situation and that they or have done the best job of being a caregiver as possible.

To address the second research question regarding how men describe their experience related to preparation and resource finding, findings have presented the internal and external factors contributing to the lack of preparation for being a male FCG and perceptions around the types of preferred support and the resources available and accessed. For their role as a caregiver, male FCGs expressed the lack of life experiences related to caregiving that would have prepared them for this role. Through the lens of the CIT, this could be a possible explanation of the difficulty in the early phases of role transition where social gender norms didn't see a major expectation for men to fulfill caregiving roles whether it be in child rearing or caring for an aging parent. This was a similar finding in the literature review where men had a higher intensity in burden during the initial stages of becoming a caregiver compared their female counterparts (Polenick & DePasquale, 2017; Zwar et al., 2018). The responses from the male FCGs echoed the feeling of being unprepared for the physical, emotional, and psychological challenges that caring for someone with ADRD. These struggles indicate a need for improving awareness, education, and training for male caregivers, especially in the early phases of role transition to becoming a caregiver. In terms of the male FCGs perception of the need for support in the caregiving role, sub-themes included *hesitant to seek or engage in support for themselves, seeking support from familial places,* and *lack of support in caregiving.* Male FCGs exhibited the idea of self-reliance as a driving force for hesitancy in seeking or utilizing available support for their own health. Although this is not an uncommon finding among men's health-seeking behaviors, it still displays an importance to help male FCGs understand the benefits of finding emotional and mental health for themselves. In conjunction with education on the potential to be in a long-term caregiving role due to ADRD's slow, progressive nature, it is vital for male FCGs to be aware of the types of external avenues available to them to address their own health early and often.

Even then, current available resources may not be sufficient to properly meet the needs of male FCGs. As found in this study, male FCGs prefer and look towards more familiar sources as a form of support such as family and friends. But when male FCGs do seek external resources for caregiving support, they prefer and find comfort in the familiarity of being around other men. Given the difficulty in conducting research on male caregivers due to the finding that men are less likely than women to seek help for themselves, some of the participants in this study were recruited through a men's only support group for those involved with the care of someone with ADRD. As one participant voiced their experience of being the only male in a previous support group, men only support groups could be the answer to providing male FCGs a more attractive and effective way to express their feelings and obtain the help they need for themselves. Although men only support groups are available, they are still limited in the number compared to other types of support groups. Additionally, there is a lack in research on the effectiveness of specialized support groups compared to other types of support resources.

The last aim of this study was to describe the male caregivers' perception of masculinity and its influence on their caregiver role. The major theme that emerged for this aim was *reshaping masculinity through the caregiver role* with sub-themes of *a man's duty in caregiving, intimacy & sexuality, caregiving gives new meaning to masculinity*, and *men bring unique abilities to caregiving.* Masculinity was found to be interwoven in all aspects of the male caregiving experience of providing care for someone with ADRD. Regarding identity and the caregiving role, traditional hegemonic masculinity, a concept defined as men conforming to socially dominant roles represented by strength and power, shapes ideas that men should be more involved in work that are more productive than in unpaid positions (Hunter et al., 2017). Therefore, some of the challenges perceived by the male FCGs may have been due to the competing caregiver and male familial identities and the constructs of masculinity where caregiving is socially viewed as a more feminine position (Björk, 2015; Leung et al., 2019). Masculine influences on caregiving are also seen especially concerning men seeking support for themselves and the comfortability of sharing their emotions with others. Findings have echoed previous studies of resistance in help-seeking behaviors among men associated with masculine norms and attitudes towards mental health issues that play a major role in why men do not seek help for themselves (Parent et al., 2018; Staiger et al., 2020). Findings also echoes a previous study where men preferred to address their mental health challenges on their own and voiced a socialized belief that men should avoid feelings, appear strong and never cry (Staiger et al., 2020). Even with the socialized views on masculinity, participants in this study expressed how they disagreed with these social gender norms of what it means to be a man and voiced that men should not be ashamed to share their feelings or appear vulnerable. An interesting finding was the mention of sex and intimacy among the spousal caregivers when asked about masculinity in general. Given that these topics were voiced without specific questions addressing these concepts, responses illustrate that intimacy was an important aspect of their view of their conflicting identities between being a husband and a caregiver and should be an area of focus when supporting male spousal caregivers. These themes show that caregiving and masculinity is a “two-way” relationship and have some influence on each other. Given that participants’ ages varied widely but had similar views on the reshaping of masculinity through their caregiving role, provides a positive outlook of how caregiving can evolve and change the narrative of what it means to be a man in today's society.

Limitations

This dissertation did have some limitations. Lack in racial and cultural diversity of the participants could have affected themes surrounding masculinity and the caregiving experience. Considering identity was a focus of this study, cultural and ethnic influences play major factors in role expectations and self-identity, inclusion of more caregivers of African American and Hispanic/Latino backgrounds would strengthen the findings. Other demographic information such as geographic location of participants was not a focus of this study and not recorded which may lead to differing experiences of the perception and availability of what kinds of resources participants had access to. Similarly, the COVID-19 pandemic may have also impacted social activities and available resources Given these limitations, there was confidence in the findings as data saturation was met and findings provide general insight on the overall male caregiving experience. Future research is needed to explore the influence of these specific factors for male FCGs

There were some limitations presented by study methodology as well. The passive recruitment strategy of using social media and local organizations who provide caregiving resources such as training and support groups, interested participants could have already been utilizing support resources and thus may have a more positive help-seeking behaviors already and a more open view of masculinity's role in caregiving. Since interviews were done remotely, and participants were not required to share their video if conducted via Zoom, the physical disconnect, and anonymity may have allowed male FCGs to be more comfortable in providing their responses. Furthermore, all interviews were conducted by the PI who is also male and may have also influenced how comfortable the participants were at sharing their experiences and feelings. Although these factors may have affected how open and honest the participants were in the interviews, these could in fact be helpful clues to developing the types of supportive resources that male FCGs may prefer which future research is warranted.

Future Implications

As previously mentioned, future studies should include more participants of diverse ethnic and cultural backgrounds and studies addressing the specific needs of certain populations. Factors such as culture and ethnicity are important concepts to consider as these play major roles in a person's self-identity and practices when it comes to caregiving. For example, concepts surrounding filial piety expectations differed between Asian Americans and Caucasian Americans and played a role in the attitudes of individuals towards caring for aging parents (Lim et al., 2022). Broadening the understanding behind diverse types of male FCGs would help add to the body of knowledge to support male FCGs in their caregiving role.

Since most of the previous quantitative literature exploring gender differences in caregiving outcomes for older adults used cross-sectional designs, planned future studies should implement longitudinal designs to observe the experiences of burden over time. This would be helpful when looking at caregiving for people with ADRD as the disease can progressively get worse and care needs increase. Additionally, combining longitudinal designs with the CIT framework would provide clarity regarding the changing perceptions of role identity between men and women as the needs of their care recipients change.

An important topic to note related to self-identity is that this study did not include men who identified as LGBTQ+. This exclusion is important to note during a time where gender identity is a major topic in US social issues. Prior studies have shown that caregivers within this population face unique problems based on their gender identity; therefore, future male FCG studies should focus on that population separately (Croghan et al., 2013).

Healthcare professionals and organizations are tasked to address the growing needs of FCGs and supporting unique and diverse populations of caregivers including male FCGs. It is essential to include into the plan of care of people with ADRD to focus on assessing the health and well- being of all FCGs involved in their care. Professionals should not assume that caregiving responsibilities will be undertaken by the women in the family and that education and assessing the need for caregiving support be emphasized to familial men as well. Increasing the awareness of men entering caregiving roles should also be accompanied by early education and consistent training to help support them in providing the care needed for family members with ADRD.

Since evidence suggests that men's health-seeking behaviors differ than women and that they may be more reluctant to seek help for themselves (Parent et al., 2018; Staiger et al., 2020), strategies should be developed to reduce the stigma for seeking help, being emotionally vulnerable, and open to utilization of support resources for male FCGs. This idea may be one of the more challenging approaches as masculine and social influences are threaded in multiple aspects of men's lives. While men may not be proactive in addressing their own mental and emotional health, a possible strategy would be to meet men where they are rather than wait for them to come forward. One such strategy could be providing caregiving education and resource information at providers' offices at the initial diagnosis of ADRD or the provider visits leading up to it. Decreasing the social stigma and encouraging men to seek help is a challenging but a needed approach to engage male FCGs to improve their overall health.

Conclusion

Findings form this dissertation provide only a small glimpse into the experiences of male caregivers for a person with ADRD but adds to the body of knowledge a rich, in-depth personal views of the thoughts and emotions that encompass the struggles and rewards of being a male FCG. Additionally, this study takes a unique approach in exploring the concept of masculinity and it's influences on the caregiving experience for men. Although quantitative studies have found that men may not report as high of an overall burden compared to women in caregiving for an older adult with ADRD, this dissertation study provides an in-depth description of how men experience their caregiving roles through their stories. Furthermore, this study adds to the growing body of caregiving knowledge and highlights the need for developing tailored resources to support male FCGs. Given that men in caregiving research have not been given an equal focus, there is still a large gap of knowledge to uncover about this population. Male FCGs are fulfilling a critical role that may be foreign and unfamiliar and supporting them is increasingly important. Expanding awareness of their unique physical, mental, and emotional needs early is a vital step in improving the health of all ADRD caregivers.

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APPENDIX A

INTERVIEW GUIDE
INDIVIDUAL INTERVIEWS

Introduction:

Thank you for interest in participating in this study. My name is Mike Bueno and I am a PhD student conducting a qualitative study about caregiving. The purpose of this study is to explore your experience as a man providing care or help to your family member with Alzheimer's disease or related dementia. I am also interested in your perceptions of masculinity as it pertains to your role in providing care or help to your loved one with Alzheimer's disease or related dementia.

1. Could you think back when your X (wife, partner, parent, sibling, aunt/uncle, cousin, friend) was first showing signs that led up to the diagnosis of Alzheimer's Disease or related dementia. What was your initial reaction?
    a. Probe: What was your understanding of the potential needs of your X in terms of the disease progressing?
    b. Probe: How did you see yourself as a caregiver at the beginning stages of ADRD?
    c. Probe: What kinds of expectations did your X have for you as their caregiver?

2. Could you describe how your relationship was with your X over the course of time?
    a. Probe: What did your interactions looked like before or earlier in the diagnosis compared to now?
    b. Probe: How did you experience your role as a (husband, son, brother, nephew, friend) within that relationship?
    c. Probe: What were your jobs/responsibilities within your role as a (husband, son, brother, nephew, friend)?

3. As your X's care needs begin/began to increase, how do/did you feel (or think) about your relationship?
    a. Probe: How did you experience your role as a (husband, son, brother, nephew, friend) as needs increased?
    b. Probe: Could you describe your interactions now with X and how it compared to earlier or before the diagnosis?
    c. Probe: Did you begin seeing yourself more as a caregiver than a (husband, son, brother, nephew, friend)?

4. Throughout your life, what sort of things influence or have influenced how you experienced your caregiver role?

    a. Probe: What experiences helped you feel familiar to the caregiving role or caregiving activities?

   b. Probe: What parts of your upbringing or life at this point do you feel you wished you had to prepare you for your role as a caregiver?
   c. Probe: What kinds of values or beliefs were instilled in you from an early age to adulthood that impacted your experience as a caregiver?
   d. Probe: What sort of things helped you or didn't help you prepare to be a caregiver?

5. As you provide care or provided care to your X, what are some of the main things you thought about?
   a. Probe: What part of your role as a caregiver did you find most difficult?
   b. Probe: What part of your role as a caregiver did you feel most rewarding?
   c. Probe: What do you think contributed to making the role difficult/comfortable?

6. During your time providing care to your X, what kind of support or resources do/did you utilize to help with caregiving activities?
   a. Probe: (If they did not seek support) Why not?
   b. Probe: What types of resources do/did you find most helpful in your role as a caregiver?
      Probe: What kinds of support or resources do you wish were more available?

7. I want to know about your experience sharing your feelings or emotions. What has that experience been like for you most of your life? How have you experienced sharing your feelings and emotions now during your time providing care or assistance to X? **(Restrictive emotionality)**
   a. Probe: With whom did you share these feelings or emotions with?
   b. Probe: (if not) What prevented you from sharing your feelings or emotions?

– **Section Transition:** Ok, now I want to examine your experience as a caregiver specifically through the lens of gender or in other words, what it is like being a man/male.

8. First, can you tell me what your views are on masculinity and what it means to you?
   a. Probe: How would you define what it means to be successful as a male?
   b. Probe: How important is it to you to be in control of situations? Probe: How would you describe the idea of men sharing their feelings with others?

9. Can you explain how masculinity influences your perceptions of the caregiving role?
   a. Probe: What are your overall thoughts on men being caregivers?

    b. Probe: What was your experience in maintaining control over your caregiving situation?
    c. Probe: During your experience, how would you define your relationship with X in terms of closeness or expressing your feelings of affection towards them?
    d. Probe: In what ways do you think being a man/being male in this role has mattered?

10. Since the caregiver role and caregiving activities are or has been seen as a typical female role, being a man, how did that affect how you saw yourself?
    a. Probe: How does the caregiving role affect how you saw yourself as a (husband, son, brother, nephew, friend)?
    b. Probe: Did you have any reservations or hesitancy in becoming a caregiver?
    c. Probe: How do you think your thoughts on masculinity have affected your role as a caregiver?

11. Is there anything additional that you would like to share that was not discussed?

12. (Snowball Sampling Question) Would you know anyone that is also a male caregiver of someone with ADRD who you think would fit this study’s purpose?

APPENDIX B

Recruitment Script Included in the Redcap Screening Survey

Welcome to the Male Family Caregivers for a Person with Alzheimer's disease or Dementia Study Survey!

Hi. My name is Mike Bueno and I'm a PhD candidate at the University of Missouri Sinclair School of Nursing. Our research team is conducting a study of male caregivers of people with dementia. We are looking for men over the age of 18 who provide **unpaid** caregiving activities or assist with help for a family member, friend, or neighbor who has Alzheimer's disease or a related dementias. Related dementias include frontotemporal dementia, vascular dementia, or dementia with Lewy Bodies.

Examples of caregiving activities or assistance include, but are not limited to:

Activities of daily living (ADL): Hygiene (Bathing, toileting), dressing, eating, functional mobility

Instrumental activities of daily living (IADL): Transportation, shopping, laundry, housekeeping, finances

Medical/Nursing tasks: Medication management, wound care, use of medical equipment

Coordinating care or health care services: Provider appointments, home health services, home and/or outpatient therapies

Study Purpose: The purpose of this study is to explore the experience of men who provide **unpaid** care to people with Alzheimer's disease or a related dementia. We want to understand male caregivers' thoughts on masculinity and how it influences their views on men in caregiving roles or providing caregiving activities.

The study will involve participating in a recorded interview over the phone or Zoom that will last approximately 30-45 minutes. You will receive a $20 e-gift card to thank you for your time in participating in this study. If you are male, over the age of 18, and provide care or assistance for someone with Alzheimer's disease or related dementias, please consider taking part in this study.

The information you provide is **confidential**. No identifying information will be shared. Study participation is voluntary. You are free to decline answering any questions that you do not feel comfortable answering.

Are you interested in participating? If so, please complete the brief eligibility survey at https://showmeportal.missouri.edu/redcap/surveys/ ACCESS Code: **JFXP4RW7L** or use the QR code below. Someone from the research team will contact you for further information as soon as possible.

Please share the link or QR code to this study with friends, family, or colleagues you think might also be interested!

Need more info? Email mvb8m3@mail.missouri.edu or call/text: (707)853-5513

Michael V. Bueno MSN, RN CNL
University of Missouri Doctoral Student
(707)853-5513
mvb8m3@mail.missouri.edu

APPENDIX C

Social Media Recruitment Script

Facebook/LinkedIn Post

Hi. My name is Mike Bueno and I'm a PhD candidate at the University of Missouri Sinclair School of Nursing. I am conducting a study to explore male caregivers' experiences providing unpaid care for a loved one with Alzheimer's disease or related dementias (e.g., frontotemporal dementia, vascular dementia, or dementia with Lewy Bodies). This study will improve our understanding on masculinity and how it influences male caregivers' views on their caregiving roles and activities.

If you are male, over the age of 18, and provide care or assistance for someone with Alzheimer's disease or related dementia, please consider taking part in this study. The study will involve participating in a recorded interview that will approximately last 30-45 minutes. You will be given a $20 e-gift card to thank you for your time in participating in this study.

For more information or if you are interested in participating, please visit this link https://showmeportal.missouri.edu/redcap/surveys/ and then enter this code **JFXP4RW7L** to complete a brief eligibility survey. You may also access the survey using the QR code below.

I am also asking you to please distribute this survey to your friends, family, or colleagues who may be interested in this study. This survey may provide valuable insights on the experiences of being a male caregiver and provide information that may help in the development of future interventions to address caregiver health.

Twitter/Instagram

Are you male, over the age of 18, and provide care for someone with Alzheimer's or related dementia, please consider taking part in this study. The study will involve an interview that will last 30-45 minutes. For more information, please visit this link https://showmeportal.missouri.edu/redcap/surveys/ CODE: **JFXP4RW7L** or scan this QR code

APPENDIX D

Study Consent Form

Consent with Waiver of Documentation for Participation in a Research Study

Project Title: Fulfilling the caregiving role: Male perspectives on their role as caregivers for persons with Alzheimer's disease or related dementias.
Principal Investigator Name: Michael V. Bueno
IRB Assigned Project Number: 2058682

Key Information About the Study

You are being asked to participate in a research study. The purpose of the research study is to explore the experiences of men providing care or help for someone with Alzheimer's disease or a related dementia. Additionally, we want to explore how the idea of masculinity influences the perceptions of men towards the role of a caregiver as they provide care or help for someone with Alzheimer's disease or dementia. You are being asked to participate in an interview that will ask questions about your experience providing care or help to your family member with Alzheimer's disease or related dementia. We will also be collecting some demographic details such as age, race/ethnicity, education level, employment status and caregiving characteristics such as relationship to family member with Alzheimer's or dementia, amount of time in the caregiver role, living arrangement with care recipient, and shared caregiving responsibilities. There are no direct benefits in participating in the study, but information learned from this study may help future men in similar caregiving situations. Possible benefits include. There is minimal risk expected when participating in this study. However, there is a potential risk to negative emotional or psychological effects if sharing unpleasant memories or experiences, but you can choose not to answer the question or choose to stop participation in the study at any time.

We are inviting you to take part in this research if you are male, over 18, English is your primary language, and that you identify as a caregiver or having provided care or help to a family member, friend, or neighbor with Alzheimer's disease or related dementia. The definition of a caregiver or the types of help provided involve assisting with activities of daily living (e.g., hygiene, dressing, eating, mobility), instrumental activities of daily living (e.g., transportation, shopping, laundry, housekeeping, finances), providing medical/nursing tasks (e.g., medications, wound care, use of medical equipment), or coordinating care or services.

Please read this form carefully and take your time. Let us know if you have any questions before participating. The research team can explain words or information that you do not understand. Research is voluntary and you can choose not to participate. If you do not want to participate or choose to start then stop later, there will be no penalty or loss of benefits to which you are otherwise entitled.

Purpose of the Research

You are being asked to participate in this study because you are male and have indicated that you provide or have provided care to a family member with Alzheimer's disease or a related dementia. The purpose of the study is to explore the unique experiences of men who provide have provided different aspects of care for a family member with Alzheimer’s disease or related dementia. Additionally, the study intends to explore how you perceive the concept of masculinity and its influence on the activities you do providing care for your family member.

What will happen during the study?
If you decide to participate in this study, we will ask you to participate in a one-to-one recorded phone or Zoom interview for approximately 30-45 minutes. If the interview is done over Zoom, you are not required to share your video during the interview if you choose not to. We will ask you to share, as much as you are comfortable and willing, about your experiences providing care/help for a family member with Alzheimer’s or dementia. We will also ask you about your insights on masculinity as it pertains to your role providing care for your family member. We will be audio recording and transcribing the interview for analysis purposes only and will only be accessible by the research team. You must give us permission to use the audio recordings we take of you during the study.
Your participation is expected to last only for the time we are conducting the interview which will be approximately 30-45 minutes.

What are the expected benefits of the study?
You may or may not personally benefit as a result of your participation in the study. However, information learned from the study will help us improve our understanding of the experiences of men providing caregiving activities for someone with Alzheimer’s disease or dementia and may help other people in the future who are in similar situations.

What are the possible risks of participating in this study?
There are minimal risks expected when taking part in this study. There are some that we know about and some may not know about yet. Some risks from being in this study include psychological or emotional distress from the interview questions, or breach of confidentiality. To help lower these possible risks, you do not have to answer any question you are uncomfortable with and are free to stop or leave the study at any time without consequences or repercussions. To help lower the risk of breach of confidentiality, all possible measures to keep all data collected from you to be secure and only accessible by the primary and co-investigator.
We will tell you about any new information we learn that may affect your decision to continue to participate in this study. If you’re concerned by any of these risks, please discuss these with the investigator (Michael Bueno).

What other choices do I have if I don’t want to be in this study?
You are not required to be in this study and participation is 100% voluntary. You can simply choose not to participate. You may also decide to stop or leave the study at any time without consequence.

Will I receive compensation for taking part in this study? 3 MU IRB Consent with Waiver of Documentation Template - April 1, 2021 **MU IRB Office Use Only** IRB Approval Date: July 7, 2021

You will be compensated for taking part in this study. For your time and effort, you will receive a $20 electronic gift card sent to you at your preferred email.

Will information about me be kept private?

The research team is committed to respecting your privacy and keeping your personal information confidential. We will make every effort to protect your information to the extent allowed by law. When the results of this research are shared, we will remove all identifying information so it will not be known who provided the information and replace any names with pseudonyms when reporting this study. We might publish articles about this study or talk about it at research conferences. If we do, will not use your name, names that you mention, or any confidential information. Your information will be kept as secure as possible to prevent your identity from being disclosed.

We might collect information from you that indicate the possibility of neglect/elder abuse. One or more of the study staff are mandated reporters. This means that they are required by law to report any of these findings to the appropriate state agencies. These agencies include the California Department of Social Services, Adult Protective Services (APS).

Who do I contact if I have questions or concerns?

If you have questions about this study or experience a research-related injury, you can contact the University of Missouri researcher Michael Bueno at (707) 853-9612.

If you have questions about your rights as a research participant, please contact the University of Missouri Institutional Review Board (IRB) at 573-882-3181 or muresearchirb@missouri.edu. The IRB is a group of people who review research studies to make sure the rights and welfare of participants are protected.

If you want to talk privately about any concerns or issues related to your participation, you may contact the Research Participant Advocacy at 888-280-5002 (a free call) or email muresearchrpa@missouri.edu.

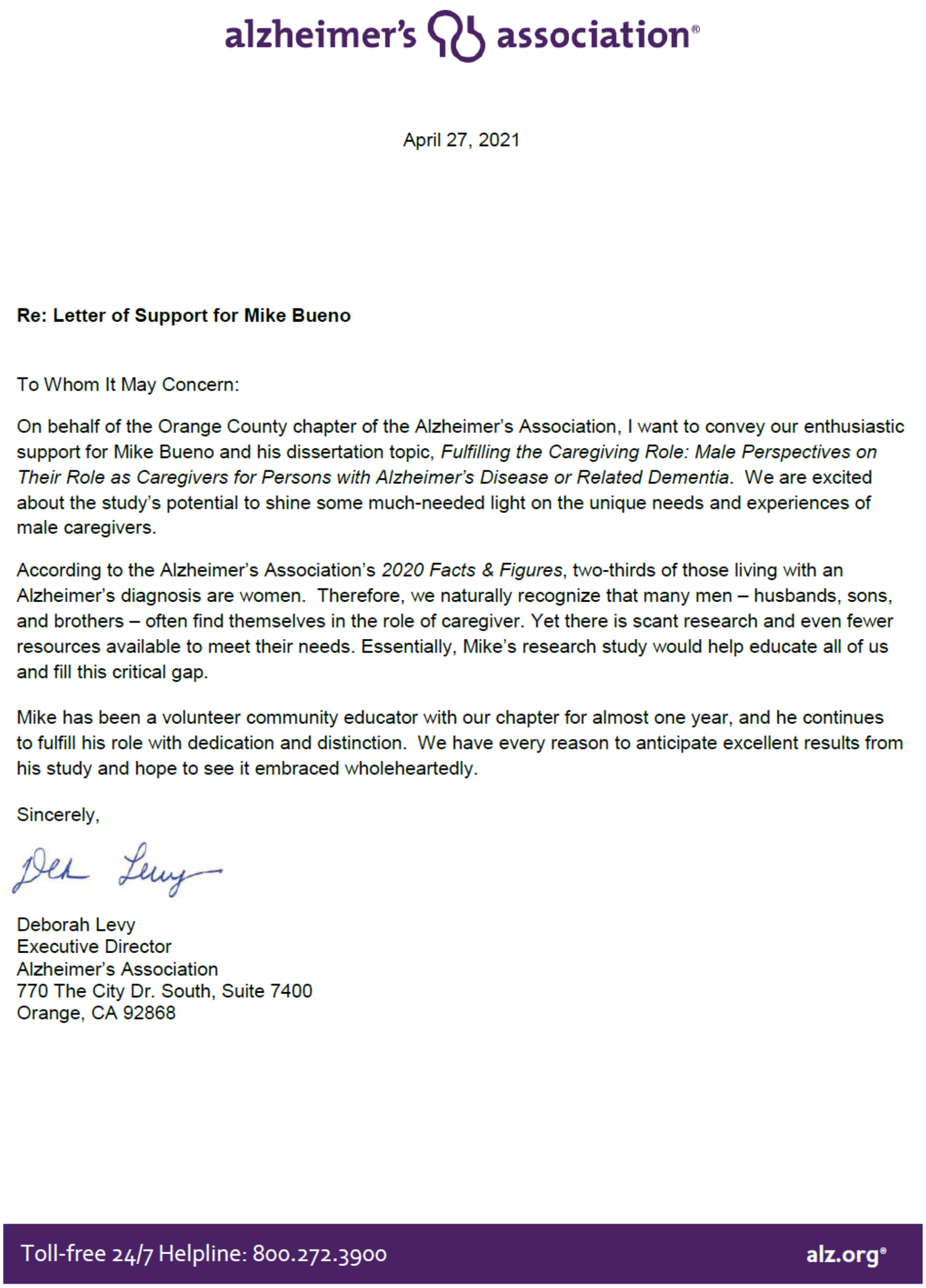
Do I get a copy of this consent?

You can ask the researcher to provide you with a copy of this consent for your records, or you can save a copy of this consent if it has already been provided to you.

We appreciate your consideration to participate in this study.

APPENDIX E

Letter of Support



alzheimer's association®

April 27, 2021

Re: Letter of Support for Mike Bueno

To Whom It May Concern:

On behalf of the Orange County chapter of the Alzheimer's Association, I want to convey our enthusiastic support for Mike Bueno and his dissertation topic, *Fulfilling the Caregiving Role: Male Perspectives on Their Role as Caregivers for Persons with Alzheimer's Disease or Related Dementia*. We are excited about the study's potential to shine some much-needed light on the unique needs and experiences of male caregivers.

According to the Alzheimer's Association's *2020 Facts & Figures*, two-thirds of those living with an Alzheimer's diagnosis are women. Therefore, we naturally recognize that many men – husbands, sons, and brothers – often find themselves in the role of caregiver. Yet there is scant research and even fewer resources available to meet their needs. Essentially, Mike's research study would help educate all of us and fill this critical gap.

Mike has been a volunteer community educator with our chapter for almost one year, and he continues to fulfill his role with dedication and distinction. We have every reason to anticipate excellent results from his study and hope to see it embraced wholeheartedly.

Sincerely,

Deb Levy

Deborah Levy
Executive Director
Alzheimer's Association
770 The City Dr. South, Suite 7400
Orange, CA 92868

Toll-free 24/7 Helpline: 800.272.3900 alz.org®

VITA

Michael Vincent Bueno was born in Dagupan, Philippines and immigrated to the United States at the age of one. He grew up in the San Francisco, bay area where he attended college at Sonoma State University and obtained a Bachelor of Science in Nursing. After graduation, he started his nursing career at Hungtingon Hospital in Pasadena, California working on the telemetry/medical-surgical unit where he gained experience as a telemetry nurse and relief charge nurse. Additionally, he held positions as a preceptor for numerous nursing students and new graduate nurses where he found the passion to teach.

In 2012, he and his wife moved to Orange County California to start a new position as a telemetry nurse at the University of California, Irvine Medical Center, and then as a acute dialysis nurse at the same institution. With this continued passion for teaching, he went back to school and obtained a Master's degree in Nursing Education from the California State University, Fullerton. With a new career goal to teach, he obtained a positions as a nursing instructor for Concordia Unvirsity Irvine, and then as an instructor and interim program director at the University of San Francisco, Orange County Campus. He is currently employed as a Health Sciences Assistant Clinical Professor for the Sue and Bill Gross School of Nursing at the University of California, Irvine.

Michael decided to pursue his PhD in 2018 at the University of Missouri's Sinclair School of Nursing to further his education and solidify his career path as a nursing professor and researcher. His research interests include improving the health of caregivers for older adults with chronic conditions, such as Alzheimer's disease and related dementia. Future research goals include further addressing the needs of underrepresented caregiving populations such as male caregivers, caregivers of color, and other caregivers of diverse demographic backgrounds.