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Social Support of Caregiver Sons of Parents With Dementia

Ralph Callanta Pascual
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Walden University

College of Social and Behavioral Sciences

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Walden University
2021

Abstract

Social Support of Caregiver Sons of Parents With Dementia

by

Ralph Pascual

MA, Pacific Oaks College, 2000

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Human and Social Services

Walden University

November 2021

Abstract

Despite the growing number of male caregivers, few researchers have examined social supports for caregiver sons of parents with dementia. The purpose of this qualitative interpretative phenomenological study was to contribute to the empirical literature on the social support of caregiver sons of aging parents with dementia. The research question centered on the lived experience of social support of caregiver sons of parents with dementia. The theoretical framework was the social role theory. The sample consisted of eight caregiver sons of parents with dementia. Participants were interviewed using semi-structured, researcher-developed questions. The results were generated from coding and thematizing processes, which yielded the following five themes: unprepared for caregiving, family and friends are the main social supports, the sons cannot do it by themselves, the sons do it for love, and lessons learned from being a caregiver son. This study provides a better understanding of difficulties experienced in caregiving roles, social supports accessed, coping strategies, reasons for becoming a caregiver, and lessons learned as caregivers. Policymakers and advocates may use study findings to refine existing tools, resources, and supports for son caregivers. Caregivers may benefit by learning about others' caregiving, learning, and growing experiences and comparing those experiences to their own.

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Dedication

I dedicate this research to my mom, whose passing last year left a permanent scar in my heart. She was my number one cheerleader. I am sure she continues to cheer me on from heaven's sidelines. She would say, "That's my son!"

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Thank you to the faculty at Walden University, especially Dr. Barbara Benoiel, for her tireless support, taking me under her wing, and guiding me throughout the dissertation journey. Thank you to the caring men who dared to be vulnerable by participating in this study. Their stories were awe-inspiring, and I assured them I heard their words loudly and clearly.

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Chapter 1: Introduction to the Study

Men have increasingly taken on the role of family caregiver. Researchers have suggested a cultural shift where more women have come to fill executive positions (Francoeur et al., 2019). In contrast, over the same period, some men have undertaken roles in the home traditionally occupied by women (Family Caregiver Alliance, 2018). Additionally, researchers have indicated that there is a trend among baby boomers where their families have become more geographically dispersed with smaller families (Hicks et al., 2018). Shrinking and geographically separated families add to the need of immediate and extended family caregivers to care for older adult relatives with chronic illness (Wolff et al., 2016).

The need for male family caregivers is from a multitude of complex situational factors: shifting career goals for women, the trend of shrinking and dispersed family, and the sheer number of older adults who require care (Hicks et al., 2018). In the United States, during 2017 alone, 66% of the 6.6 million older adults who received care in the community relied mainly on the help of family members (Riffin et al., 2017). This may be why the number of male family caregivers who take care of their older parents with chronic health conditions has been on the rise (Sharma et al., 2016).

Although caregivers in general may be somewhat at risk of physical and mental stress just by the nature of their position, those caregivers who aid older adults with cognitive impairments such as dementia face a higher rate of negative psychological implications (Edwards et al., 2017). For example, a qualitative study by Riffin et al. (2017) showed that regardless of gender, family caregivers who provided care for family members with dementia were at a high risk of suffering from social

isolation. Currently, little is known about the roles and experiences of sons as caregivers for their parents who suffer from dementia (Grigorovich et al., 2016). Those in the caregiver system may use this knowledge to address son caregivers' needs. I begin Chapter 1 by presenting background information, the purpose of the study, problem statement, and research question. I then discuss the theoretical framework, methodology, definitions, assumptions, scope and delimitations, limitations, and significance of the study. The chapter closes with a summary and a preview of Chapter 2.

Background

Social isolation represents a pressing issue for family caregivers. Riffin et al. (2017) found that regardless of gender, family caregivers who provided care for family members with dementia were at a high risk of suffering from social isolation. Male family caregivers have drastically increased in number; in Mexico alone 37% of caregivers are men (Riffin et al., 2017). Although the number of male caregivers in the family have increased in recent years, researchers have been slow to reflect this increase. Accius (2017) concluded that despite a sizable increase in the population of male caregivers, this population remained understudied, except for some studies focusing on husbands as male caregivers to their older spouses (see Spindelov et al., 2017; Wallroth, 2016). Women still dominate as family caregivers and the subject of primary research (Riffin et al., 2017).

The need for male caregivers is apparent due to the sheer number of older adults, but what also must be recognized, according to experts, is that male caregivers undergo a different experience than that of women which warrants a different set of tools and resources to aid their family duty (Edwards et al., 2017; Giesbrecht et al.,

2016). Schwartz and McInnis-Dittrich (2015) concluded that despite the increase in male caregivers, male-specific social support and resources are lacking. The missing information on the needs and social support for male caregivers, specifically those tending to family members with dementia, constituted the gap of knowledge that I sought to fulfill in conducting this study. This study was needed to understand the experiences of son caregivers working with dementia relatives to build a corpus of research that could be translated into a clinical and interventional medium that may supply son caregivers with the supportive tools they need to succeed and thrive.

Problem Statement

Regarding societal and gender norms, women remain the predominate caregivers for older family members (Riffin et al., 2017). Notwithstanding, this U.S. societal and cultural reality has started to shift, and a considerable number of women have taken up positions in the once male-dominated workplace (Wallroth, 2016). As a result, the availability of daughters who could once supply care for elder parents has now diminished. Sons, when needed, play the role of primary caregiver when a daughter is not available (Wallroth, 2016). Despite the growing number of male caregivers (Wallroth, 2016), few researchers have examined examining the social support for caregiving sons of parents with dementia (Giesbrecht et al., 2016). This gap in the literature means there may be an inadequate understanding of how to provide appropriate support to caregiving sons.

The percentage of male caregivers for older adults has already grown significantly (Sharma et al., 2016). Like women, men have transcended gender stereotype by becoming caregivers of older adult parents who may suffer debilitating consequences from chronic conditions (Accius, 2017; Spindelov et al., 2017). Recent

gender—specific research on caregiving—shows that men typically have unique caregiving experiences, challenges, and support needs compared to women (Giesbrecht et al., 2016). Further studies of family caregivers are female-focused, and the studies about male caregivers are focused on male husbands who care for their older spouses (Grigorovich et al., 2016). Giesbrecht et al. (2016) studied the implications of the gap in current research on male caregivers, agreeing more research was needed.

The issue only gains greater importance when considering the risks that male and female caregivers face, such as the feeling of social isolation that family caregivers may experience when aiding family members with dementia (Riffin et al., 2017). Schwartz and McInnis-Dittrich (2015) acknowledged that given the increase in male family caregivers, future researchers should identify the support and resources male caregivers need. Schwartz and McInnis-Dittrich's call for research further showed the need for research on the support needed by male caregivers who tended to family members, specifically those with dementia, possibly placing family caregivers at a heightened need for resources and support.

Purpose of the Study

The purpose of this qualitative interpretative phenomenological study was to contribute to the empirical literature on the phenomenon of the social support of caregiver sons of aging parents with dementia. The number of U.S. men serving as caregivers for older family members has been on the rise since baby boomers have started having smaller families that have become more geographically separated (Wallroth, 2016). Additionally, many women who once may have been caregivers to the older members of their families have moved into the white-collar workforce to

become heads of the household, and men who once worked in white-collar jobs now stay at home as homemakers (Spendelov et al., 2017). Hence, there is urgency for family caregivers as the shrinking family has led to reduced family support (Accius, 2017; Hicks et al., 2018).

Given the considerable influx of men who have become caregivers for the older members of their family, the primary body of literature on the subject remains centered on female caregivers or spousal male caregivers (Grigorovich et al., 2016). Although bountiful data exist for female caregivers in the United States, there is a paucity of research for male caregivers. This lack of information has led to a limited understanding of males as caregivers for older family members. Therefore, these male caregivers are at risk of not being afforded the support and resources needed (Schwartz & McInnis-Dittrich, 2015).

Being a caregiver, regardless of gender, is burdensome. The role of a caregiver is a tough one; as many studies have shown, the costs are not just financial but also, psychological, emotional, and social (Kent et al., 2016). Additionally, the toll on the caregiver is heavy when they expend so much energy caring for a loved one and then experience the death of that individual (Do et al., 2015). The difficulties of being a caregiver show that researchers should study male caregivers' experiences and hardships to supply them with the support and resources required. This study may contribute to the empirical literature on what facilitates or hinders sons in caring for their aging parents with dementia, sons' experiences in obtaining assistance and support, and son caregivers' health.

Research Question

I sought to answer the following research question: What is the lived experience of the social support of son caregivers of parents with dementia?

Theoretical Framework

The theoretical framework for the study was Eagly and Wood's (2012) social role theory (SRT). Eagly and Wood posited that gender stereotypes perpetuated through individuals' exposure and perceptions of stereotypes in others. The basis of the SRT is that individuals witness gender in others, thus creating a template for the norms of how individuals should act and who they should be (Eagly & Wood, 2012). Eagly and Wood (2012) inferred that all societal roles for men and women were due to psychological differences between the sexes due to evolutionary biology.

These main differences between men and women include the notable size and strength of men, in contrast to the women's heightened ability to nurse children or gestalt those in need of care (Eagly & Wood, 2012). These differences have led to women having increased efficiency at caregiving, while men seem better suited for other work (Eagly & Wood, 2012). Culture promotes gender stereotyping: Women are assigned attributes of nurturing and domestic tasks, and men receive archetypes of assertiveness, leadership, and independence (Eagly & Wood, 2012). Although people enact a specific social role, they also carry out the gender role in which it was modeled on. Eagly and Wood (2012) also noted how gender roles were biosocial, reverberating in hormonal fluctuations, social self-regulation, and social self-regulation related to the expectation of others pertaining to gender norms. Eagly and Wood postulated that gender roles were not only biosocial but also psychosocial.

Gendered expectations may lead to self-fulfilling prophecies and the societal idea that male caregivers are unrealistic. Due to dementia's progressive nature, caregivers of family members with dementia are at an increased risk of stress, depression, and other chronic illnesses (Wang et al., 2019). The self-care management of these caregivers may sustain their ability to care for their loved ones. Self-care means knowing how to take care of oneself and the aging parent (Wang et al., 2019). Self-care also involves knowing how and where to obtain help from the community and from relatives and friends when needed. A large part of self-care entails understanding of one's feelings about caregiving, possibly helping one cope with the role (Wang et al., 2019). According to Orem et al. (1995), every person has the capacity to self-care and handles their and others' health. One may sustain oneself while committing to caring for another person using self-care activities on an ongoing basis. Using Eagly and Wood's (2012) SRT for the theoretical analysis of gender roles in the context of sons who care for parents with dementia showed a comprehensive view of how gender and social roles are interlaced.

Nature of the Study

The nature of this study's method was qualitative. Its design was interpretative phenomenology following Sundler et al.'s (2019) design. Researchers use this design to glean insights into how a participant, in the context of their environment, makes sense of a given phenomenon (Matua & Van Der Wal, 2015). The design of the study included using semi structured interviews with participants to collect their experiences and the meaning they gave those experiences, as sons who were caregivers to aging parents. I conducted the interviews remotely due to COVID-19 restrictions (Centers for Disease Control and Prevention [CDC], 2019). The qualitative phenomenological

method was appropriate for this research in identifying the meaning participants gave their lived experiences of being caregivers to aging parents (see Matua & Van Der Wal, 2015).

Seidman (2012) stated that interviews were a primary mode of inquiry of qualitative studies. Semi structured interviews were the mode of data gathering for this study. These interviews were useful for getting the story behind the phenomenon of social supports of participants (see Seidman, 2012). I used the interviews to obtain in-depth information on the topic of social supports for son caregivers of aging parents. Collecting participants' first-hand accounts using semi structured interviews provided comparable data for the sake of organization, allowing participants to articulate their lived experiences as family dementia caregivers in their own way. This process produced an organized yet diverse array of qualitative experiences that I analyzed for patterns and consistencies between participants. The interviews elicited thick data to explore and analyze the experience of male caregivers caring for older adult parents with dementia.

Definitions

Dementia: The American Psychiatric Association's (2013) *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; DSM-5) deemed dementia a stigmatizing term; the rough translation in Latin is "loss of mind." "Neurocognitive disorders, major or mild" (American Psychiatric Association, 2013, p. 20) have now replaced the term. However, the American Psychiatric Association (2013) acknowledged that the term remains widely used. The use of the term dementia is not forbidden "where the term is standard" (American Psychiatric Association, 2013, p. 20). For this study, the standard and commonly used term dementia was used.

Formal caregiver: A formal caregiver is defined as a caregiver—anyone who treats and provides care to an individual who may be older or ill—who has undergone training and, most importantly, is being paid to supply care to the person (Lewis, 2014). For example, formal caregivers can include nursing home staff, hospice nurses, and paid at-home nurses. Therefore, family and friends who help, regardless of whether they receive payment, are not considered formal caregivers.

Informal caregivers: In this study, informal caregivers referred to individuals, mainly sons, involved in providing care to an older and/or ill family member. In this study, the focus was on dementia in older parents (see Lewis, 2014). Because informal caregivers can be close friends or even immediate family, they may be entrusted to take on tasks that are primarily non-care-related such as sorting financial assets, obtaining legal assistance, and coordinating other life and family affairs, financial or not. Informal caregivers may not have the formal training of formal, professional caregivers; nevertheless, they still can be a lifeline to ill and older adult family members. Informal family members also may not be paid but see their tasks as a noble duty of mutual family reciprocity (Lewis, 2014).

Social role theory (SRT): Eagly and Wood (2011) defined the SRT as showing how gender stereotypes perpetuated throughout society by people facing such stereotypes. Researchers can use the SRT to study how people are influenced by the roles of others. Researchers can use the SRT to study gender being witnessed in others, where the onlooker places their beliefs on others pertaining to how they should act (Eagly & Wood, 2012). Eagly and Wood (2012) proposed that societal roles for men and women occurred due to different psychological and physiological specializations between genders due to evolutionary biology. This evolutionist

perspective has shown that human consciousness, in contrast to that of animals, has subconsciously taken consideration of these dissimilarities. As such, the SRT—starting with psychological differences—developed from a psychosocial conception of social construction of roles showing gendered roles as constituted by others.

Assumptions

The primary assumption of the study was that gender permeated into the social sphere of the son–parent caregiver family dynamic (see Hicks et al., 2018). I gathered data pertaining to the social support experiences of male caregivers of parents with dementia. I assumed that the participants were honest and that their responses did not skew the findings for whatever reason. Additionally, I assumed that as the researcher, I would put personal biases aside by using epoché to allow the voice of the participant to speak for themselves (see Hicks et al., 2018).

Participants' experiences as sons who care for their parents with dementia cannot be generalized to all male caregivers. However, this limitation did not negate all consistencies found within the sample evidence that might exist in the broader population. Although the experience of participant was unique, some aspects of their experiences might be generalizable to the larger population.

Scope and Delimitations

I restricted the study to male caregivers of parents with dementia. My research interest entailed understanding how sons managed the social gender role of caregiver for aging parents with dementia. The position of a caregiver takes a toll, not just physically, financially, and temporally regarding available time but also socially and emotionally (Kent et al., 2016). A caregiver also must deal with the idea that the parent will eventually pass (Do et al., 2015). Finally, the caregiver deals with a parent

who has not only grown old but also has a debilitating cognitive impairment, such as dementia, making even the simplest tasks complicated. Male caregivers may struggle due to these factors, as the role is not considered a traditionally male role (Hicks et al., 2018). Self-care and social support come into play as coping strategies for the caregiver (Hicks et al., 2018). Thus, I limited the study focus to coping strategies used by male caregivers of parents with dementia.. Although researchers have shown male caregivers to be on the rise in different parts of the world, such as Mexico (Nance et al., 2018), the participants were restricted to the United States.

Limitations

A limitation of the study was its limited sample size. This limitation was partially offset by the thickness of the data produced by in-depth interviewing of the participants (see Seidman, 2012). Another limitation of the data was that participants were probably less likely to disclose personal information during an interview with a stranger (see Seidman, 2012). Thus, I ensured that the participants felt comfortable by assuring them that their data would remain confidential. Furthermore, I remained flexible in allowing the participants to choose the platform, time, and date of the interview. Another limitation was that COVID-19 pandemic and related safety concerns (CDC, 2019) prevented me from conducting in-person interviews as social distancing continued to be enforced throughout the United States. This limitation might have been offset as I conducted the interviews instead either via Zoom, FaceTime, telephone, or email. Using phone and email interviews presented another limitation, as I could not observe the body language or other nonverbal cues of participants during the interview.

Significance

The need for this study was underlined by the paucity of research on the social support available to male caregivers (see Grigorovich et al., 2016). Particularly, the experience of son caregivers of parents with dementia has been overlooked. As a result, the current caregiving system does not have adequate resources to address the needs of son caregivers (Grigorovich et al., 2016). This study may provide insight into the perspectives of son dementia caregivers, showing the needs of these caregivers. However, the needs of one male dementia family caregiver may differ from another.

I described the phenomenon of the social support of sons providing care for parents who have dementia. As such, the intent in undertaking this study was not to discount the efforts and contributions of female caregivers. Society remains male-oriented as women continue to face many inequalities (Schwartz & McInnis-Dittrich, 2015). Rather, studying sons' experiences as caregivers for a parent with dementia is a step toward ensuring that interventions and practices match sons' needs.

Gender-sensitive research on caregiving point to men as having unique caregiving experiences, challenges, and support needs compared to women (Giesbrecht et al., 2016). Yet, researchers of the caregiver literature have overlooked the experiences of men as caregivers. Consequently, the caregiver system is unprepared to address son caregivers' needs adequately because little is known about their roles and experiences with their older adult parents who suffer from dementia (Grigorovich et al., 2016).

Summary

Shrinking and geographically separated families add to the need of immediate and extended family caregivers to tend to older family members with chronic illnesses

(Wolff et al., 2016). In 2017, 66% of the 6.6 million older adults in the United States who received care in the community relied on the help of family members (Riffin et al., 2017). This finding may be why the number of male family caregivers who take care of their older parents with chronic health conditions has risen (Sharma et al., 2016). Accius (2017) concluded that despite a sizable increase in the population of male caregivers, their population remains understudied. Yet, women still dominate as family caregivers and are the primary subject of research (Riffin et al., 2017).

Researchers contend that male caregivers undergo a different experience that warrants a different set of tools and resources to aid their family duties (Edwards et al., 2017; Giesbrecht et al., 2016). Schwartz and McInnis-Dittrich (2015) concluded that despite the increase in male caregivers, male-specific support and resources were lacking. The missing data on the needs and resources for male caregivers, specifically tending to family members with dementia, constituted the gap of knowledge that I sought to fulfill. Edwards et al. (2017) used data from the 2009 Behavioral Risk Factors Surveillance System (BRFSS) to compare male and female caregivers and found that men were more ready to report a lack of social support.

The number of male caregivers around the world is on the rise. A study from Mexico reported that 37% of that nation's caregivers were now men (Nance et al., 2018). Despite this finding, studies on caregivers remain concerned with women as caregivers (e.g., Riffin et al., 2017). This gap of knowledge should be addressed because, as Riffin et al. (2017) concluded, family caregivers who provide care for relatives with dementia are at heightened risks for suffering social isolation. Schwartz and McInnis-Dittrich (2015) stated that despite the major increase in the number of male caregivers, male-specific support and resources remained deficient. Currently,

all data available about male caregivers include self-help skills as modes of coping (Spendelov et al., 2017).

In Chapter 2, I present a more in-depth analysis of the issue of coping resources for male family caregivers. I review the available literature in relation to how the issue has changed over time. Chapter 2 also includes an analysis of existing literature in relation to the theoretical framework of this study. I used this review as a method of inquiry based on previous studies to ensure a minimal margin of error and greater validity of results. I used data collection methods shown to work in the past.

Chapter 2: Literature Review

Introduction

Studies indicate a cultural shift among women with some achieving nontraditional, executive career positions; similarly, certain men have undertaken nonorthodox roles in the home that were once traditionally occupied by women. Additionally, researchers have indicated that baby boomers' families have become more geographically dispersed, with less children than before (Hicks et al., 2018). Shrinking and geographically separated families underline the need of immediate and extended family caregivers to care for older relatives with chronic illness (Wolff et al., 2016). There is especially a need for men to assume caregiving roles.

The relatively recent increased need for male family caregivers is not just the result of a single cause. The situation is complex and has many layers of causality, such as the shifting of traditional gender and class roles, the ecological trend of shrinking and separating families, and the rapid medical advancements in the last decade that have led to a greater number of older adults who require care (Hicks et al., 2018). In the last 10 years, an increasing number of U.S. older adults have been cared for by a male family member, such as a son, available to take up the task (Hicks et al., 2018). The problem is that most research to date focuses exclusively on female family caregivers in the United States. This issue has led to a limited understanding of the experiences of men who care for aging parents (Nance et al., 2018).

The findings of this study showed the lived experiences of the social support of caregiver sons, specifically family dementia caregivers. The findings showed how caregiver sons' needs could be addressed by established systems of caregiver resources and support. This study may help the well-being of male caregivers, expand

the knowledge regarding them, and lead to safer and better patient and family care. Sharma et al. (2016) concluded that although various findings were conflicting between male and female caregivers caring for older adults, specifically those with dementia, there were far more similarities than differences. However, researchers must still acknowledge that less is known about the needs of male caregivers. Sharma et al. demonstrated the need for the current study. Eagly and Wood's (2012) study was also a key cornerstone of the current research. The authors' SRT, which holds that gender stereotypes perpetuate through individuals being exposed to them and perceiving them in others, served as the theoretical framework of the current study.

Literature Search Strategy

The Internet yields vast results of data on the topic of caregivers. There is less literature on male caregivers, with even fewer results on male caregivers caring for their relatives with dementia. I searched Google Scholar, Sage, and EBSCOhost using the following keywords in various combinations: *male family caregivers*, *family caregivers with dementia*, and *male family caregivers for aging parents with dementia*. The primary body of research cited (90%) was from the last five years (2015-2019), but certain older seminal work (about 10%), such as research on the SRT (Eagly & Wood, 2012) conducted outside of this time range, was used due to its relevance.

Theoretical Framework

The SRT, the theoretical framework selected for this study, is premised on gender norms defining how men and women behave in the roles that society dictates for them (Eagly & Wood, 2012). The SRT is a means of exploring the differences between men and women in social settings. Biologists propose sex-related differences

stemming from differences in chromosomes and differentiated hormones as sources of behavioral differences (Eagly & Wood, 2012). SRT researchers posit that gender stereotypes perpetuate through individuals being exposed to them and perceiving them in others.

These main differences between genders are the notable size and strength of men in contrast to the women's heightened ability to nurse children or gestate those in need of care (Eagly & Wood, 2012). Such differences have led to an increased ability for women to be more efficient at caregiving, while men seem better suited for general work (Eagly & Wood, 2012). Culture promotes gender stereotyping: Women are assigned attributes of nurturance and domestic tasks, and men are defined by archetypes of assertiveness, leadership, and independence. Although people enact specific social roles, they also carry out the gender role on which it is modeled = (Eagly & Wood, 2012). Eagly and Wood (2012) also noted how gender roles were biosocial, reverberating in hormonal fluctuations, social self-regulation, and social self-regulation.

Supporters of the SRT posit that men and women assume caregiving responsibilities based on societal expectations. Western societies assign and encourage caregiving behaviors of nurturance for women, while men are assigned traits of assertiveness, leadership, and independence (Eagly et al., 2000). Societal gender expectations create self-fulfilling prophecies, and the result is that men are rarely primary caregivers.

Social role theorists have described factors that drive gendered behavior in varying ethnic and socioeconomic contexts (Swinkels et al., 2017). Social, cultural, individual, and physical factors influence gender role beliefs (Swinkels et al., 2017).

For instance, differences in physical strength and size between men and women predisposed allocation of labor. Men are more likely to have greater upper body strength that may influence them to take certain physical actions that women might not be predisposed to performing. Hormonal fluctuations function differently between men and women, and such differences influence individual actions within a given context (Swinkels et al., 2017). As such, researchers have integrated both perceptions and real physical differences in the SRT. The SRT includes psychological and biological factors that have social implications for individuals.

Social Role Theory and the Literature

A combination of gender role beliefs and observed physical sex differences contributes to gender stereotypes (Swinkels et al., 2017). These stereotypes lead people to believe that certain female and male behaviors are socially appropriate (Eagly & Wood, 2012). People may attach specific attributes to individuals based on their genders. A variety of factors influence gendered behavior, including socialization and gender stereotyping (Lee & Tang, 2015). Certain personality traits are promoted and encouraged, and specific types of behavior are supported among individuals of different genders (Swinkels et al., 2017). Consequently, the performance of specific roles using gender-expected behaviors may show how people act in each context. However, researchers have not denied the role of differentiated hormonal responses as a means of explaining behavior under different conditions (Lee & Tang, 2015). A second factor explaining behavior is self-standards or the internalized gender roles that people integrate and use to regulate their behaviors in response to their environments. The last factor shows behavior as being regulated in response to expectations (Eagly & Wood, 2012; Lee & Tang, 2015).

Gendered expectations could lead to self-fulfilling prophecies and the circulation of the idea that male caregiving is not possible in practice. Due to dementia's progressive nature, caregivers of a family member with dementia are at an increased risk of stress, depression, and other chronic illnesses (Wang et al., 2019). The self-care management of these caregivers is what helps sustain their ability to care for their loved one. Self-care means knowing how to take care of oneself as well as the aging parent (Wang et al., 2019). Self-care also involves knowing how and where to obtain help from the community, relatives, and friends when needed.

A large part of self-care entails understanding of one's feelings about caregiving, which can help one cope with the role (Wang et al., 2019). According to Orem et al. (1995), every person can practice self-care and handle their and others' health. One should sustain oneself while committing to caring for another person using self-care activities on an ongoing basis. Thus, I used Eagly and Wood's (2012) SRT as the theoretical analysis of gender roles to show the totalized view of how gender and social roles were independently interlaced.

Researchers of the SRT integrate multiple factors to establish a connection from larger societal and environmental influences on actual individual behavior. Gender role beliefs and attributed social roles interact with biological factors to influence behavior (Eagly & Wood, 2012). This influence manifests internally and externally, with internalized expectations guiding how people behave and internalized expectations responding to external expectations and conditions. Therefore, the SRT is an attempt to account for multiple factors that come together to influence actual gender differentiated behavior under varying circumstances.

Gupta et al. (2019) examined sex-role stereotypes within both high- and low-growth entrepreneurship by conducting gender characterizations using the SRT as a framework. The researchers tested group-level stereotypes and found that men were more commonly associated with high-growth entrepreneurship. Another category, social entrepreneurship, was equally associated with both men and women. This third category of entrepreneurship, which was less understood than low and high entrepreneurship, led to less established role stereotypes. Findings indicated that societal norms and expectations influence roles that, in turn, led to self-fulfilling prophecies (Gupta et al., 2019).

The SRT was the foundation of this study. Social role theorists posit that gender and culture are one, as they have an effect resulting from the synergized totality and pervade individuals' decision-making outcomes (Eagly & Wood, 2012). In this sense, the SRT includes different elements of culture and gender. Culture and gender are perceived as separate notions, insofar as each constitute the totality of the subject. Madsen and McGarry (2016) noted that few women filled the role of college athletic coaches. The authors explored the career plans of female student athletes, showing what factors influenced career decisions. Data collected from the study indicated that women felt pressured to fill traditional gender roles. Student athletes believed that careers in sports were masculine and held negative views of their female coaches. These stereotypes concerning roles affected their decisions to pursue stereotypically feminine careers.

A second study showed the restraint that girls felt on their college and career aspirations. Shapiro et al. (2015) noted that women occupied few top leadership roles in Fortune 500 companies. Data indicated that girls performed well academically

when compared to boys but lost ground once in the professional arena. Research conducted among middle school girls showed that even by middle school, students started considering their future careers. The study data also indicated that gendered messages began to influence thoughts about future careers.

Researchers have applied the SRT to understand how gender-role orientation and career/family role salience have influenced an individual identifying with their organizations and their intentions to leave those organizations. Liu and Ngo (2017) surveyed employees from three large companies across China. Following the analysis of the data, the researchers found that masculinity was associated with role salience or the importance that individuals assigned to their career roles. In contrast, femininity was associated with family role salience. These findings indicated that masculine and feminine qualities were associated with stereotypical roles of work and family, respectively. In turn, career role salience was associated with lower intentions to leave. The findings indicated that regarding work, feminine employees needed additional support to increase their career role saliency, thereby reducing their intentions to leave.

Researchers have also used the SRT to explore gender and volunteering in professional associations. Fyall and Gazley (2015) hypothesized that the roles women and men filled when volunteering would fall along gendered lines. The researchers collected data from 12,722 volunteers across 23 different organizations and found that gender influenced volunteer behavior. Women were less likely to participate in specific volunteer activities linked to professional associations. This reluctance to participate in such roles declined as women became older; however, the disparity in

participation at earlier ages showed how role stereotypes influenced how women conducted themselves.

The SRT indicates that women are associated with communal roles that emphasize the good of the group. Researchers of corporate social performance based on this assumption investigated the relationship between gender diverse boards and corporate actions that had societal benefits (Francoeur et al., 2019). This exploration of the relationship between diverse boards and corporate social performance accounted for multiple stakeholders who might benefit for company actions. The study findings indicated that when corporate boards were gender diversified, there were improvements in corporate actions that benefited the least powerful stakeholders to which the company might be accountable, including the environment and community. The findings indicated some support that gender diversifying improved communal qualities that led to actions benefiting others.

In the SRT, researchers aim to understand how roles are associated with males and females. Masculinity was associated with stronger career saliency (Liu & Ngo, 2017), participation in professional associations (Fyall & Gazley, 2015), and high performing entrepreneurship (Gupta et al., 2019). Such findings indicate an association between men and work roles, including higher performance in those work roles. Women felt constrained in their career choices and began contemplating career roles that fit feminine stereotype as early as middle school (Madsen & McGarry, 2016; Shapiro et al., 2015). These findings indicated that men and women were associated with different careers, and consistent with SRT, they internalized those stereotypes and contemplate careers consistent with the stereotypes.

The SRT was applicable to the current study because it helped to explain the predominant roles that women choose, with the theory indicating that such choices were due to a complicated interaction between internal and external factors that worked to constrain the most likely sets of choices an individual will make. As Chappell et al. (2014) found after conducting a qualitative study in British Columbia using structured interviews, gender plays into social roles and the identity people create for themselves. Data indicate that men are either at higher risk, less risk, or less likely reporting the impact of caregiver burden. Thus, I explored males who cared for their parents with dementia. The SRT shows that the men's roles, as defined by environmental, psychological, and biological factors, affect their decisions to care for older adult parents (Gilbert et al., 2018).

Traditionally, societal expectations dictate that women fill the role of caregivers and tend to dominate such roles (Riffin et al., 2017). Consistent with this finding, female caregivers outnumber their male counterparts, although the total number of male caregivers is on the rise (Sharma et al., 2016). From the perspective of the SRT, the decision to enter a role typically associated with females may derive from societal expectations, internalized expectations, and biological impulses. Females may enter these roles given this combination of factors, therefore leading to the question regarding why men choose to enter these traditionally female roles and how they manage those roles. I attempted to answer this question by exploring male caregivers' experiences.

Literature Review Related to Key Concepts

Precursor

In 2017, 66 % of the 6.6 million older adults who receive care in the community rely mainly on the help of family members (Riffin et al., 2017). This finding may be why the number of male family caregivers to parents with chronic health conditions has risen (Sharma et al., 2016). A qualitative study by Riffin et al. (2017) showed that regardless of gender, family caregivers who provided care for family members with dementia were at a high risk from suffering from social isolation.

Male family caregivers have drastically increased. In Mexico, 37% of caregivers are men. Although male caregivers in the family have increased in number during the last five years, researchers have been slow to reflect this finding. Accius (2017) concluded that despite sizable increase in the population of male caregivers, they remained understudied. In lieu of the notable increase in male caregivers, women still dominate as family caregivers and the subject of primary research (Riffin et al., 2017). This finding may be due to the lack of research on family male caregivers and because the selected data on male family caregivers focus on husbands who care for their spouses (Spendelow et al., 2017; Wallroth, 2016).

The need for male caregivers exists, as the numbers show. In addition, male caregivers have different experiences, warranting a different set of tools and resources to aid their family duties (Edwards et al., 2017; Giesbrecht et al., 2016). Schwartz and McInnis-Dittrich (2015) concluded that despite the increase in male caregivers, male-specific support and resources were lacking.

Current Situation

In times of need and throughout a multitude of cultures, families have lent a hand to one another as a fulfillment of a reciprocal social pact. As people begin to age, they reach a state of debilitation. This growth continues until a point is reached where they require assistance to navigate through daily tasks. Families in developed nations, such as the United States, fall into the role of assisting older adult family members who cannot function independently anymore (Wolff et al., 2016).

Given the increasing medical advancement, among other factors, there has been a growth in the U.S. older adult population. The number of adults aged 65 and older has swiftly grown (Edwards et al., 2017). Of the older adults who have physical chronic illnesses and severe cognitive impairments, many live at home (Roth et al., 2015). For example, 66% of the 6.6 million older adults who need daily care rely chiefly on help from family members (Riffin et al., 2017).

Regarding societal and gender norms, women remain the predominate caregivers for older family members (Riffin et al., 2017). The idea of caregiving as a traditional male role was so strongly rooted in U.S. culture that male caregivers did not win the right to receive the same Social Security benefits as female caregivers until the 1975 *Weinberger v. Weidenfeld* case argued by Ruth Bader Ginsberg (Brinkley, 2019). Notwithstanding, this societal and cultural reality has started to shift, and many women have positions in the once male-dominated workplace (Wallroth, 2016). As a result, the availability of daughters who can supply care for older adult parents has now diminished. Sons, when needed, play the role of primary caregiver when a daughter is unavailable (Wallroth, 2016).

The percentage of male caregivers for older adults has grown significantly (Sharma et al., 2016). Considering women transcending the gender stereotype and taking up historically male-dominated roles, men have done so by caregiving older adult parents who may suffer from the debilitating symptoms of chronic conditions (Accius, 2017; Spindelov et al., 2017). Recent gender-specific research on caregiving denoted men face unique caregiving experiences, challenges, and support needs compared to women (Giesbrecht et al., 2016). Studies of family caregivers are female-focused, and the studies that exist for male caregivers are focused on male husbands who care for their older adult spouses (Grigorovich et al., 2016). Conclusions have been reached based on research by Giesbrecht et al. (2016) who noted the negative implications resulting from the gap in current research on male caregivers.

When noting the risks common to both genders, such as feelings of social isolation when caring for family members with dementia, the need to study the experiences of male caregivers become more pronounced (Riffin et al., 2017). Schwartz and McInnis-Dittrich (2015) acknowledged that given the increase in male family caregivers as response to the situational demand, studies must be conducted to recognize the support and resources male caregivers need. This finding further underlines the need for research to be conducted on male caregivers who tend to family members, specifically those with dementia. This condition puts family caregivers at a heightened risk and may result in the male caregiver to require additional resources and support. This support can only come because of a discourse created by filling the gaps where knowledge on this topic is scarce.

Dementia

Dementia refers to the loss of cognitive functioning (National Institute on Aging, 2019a). As dementia progresses, there is a loss of numerous functions including the ability to think, remember, or reason through daily problems. This impact on cognitive functioning also includes behavioral changes (Livingston et al., 2017). As these behavioral changes become more severe, a person may struggle to handle the average daily routine. Dementia is also associated with a loss in language skills, a decline in visual perception, and an inability to focus or pay attention to external stimuli. People may struggle to maintain control of their emotions as well. Dementia progresses over several stages (Livingston et al., 2017). At the earliest stage, a person's functions are only lightly impacted, but by the latest stages of dementia, people become dependent on others to help them in their day-to-day routine.

Even the very earliest stages of dementia manifest noticeable symptoms, such as memory loss regarding recent events, confusion, an inability to concentrate, and some behavioral changes (Singh-Manoux et al., 2017). Some behavioral changes may include increased apathy and depression, as well as withdrawal from performing everyday tasks. Individuals lose their initiative and interest in engaging with activities they previously enjoyed. The subtlety and complexity of dementia symptoms makes an early diagnosis difficult. A dementia diagnosis requires positive results along multiple dimensions (National Institute on Aging, 2019a). Various screening services and genotyping tests are available to help diagnose the disease (National Institute on Aging, 2019a).

Caregivers and Disease Management

The National Institute on Aging (2019b) suggested that behavioral management was among the first treatments for dementia. A person with dementia exhibits certain behaviors disturbing to family and friends who knew a “different” person before dementia onset. Behavioral management may consist of many different approaches. First, one should assess what behaviors a person can no longer control and what tasks they can no longer fulfill. For instance, a person may no longer be able to drive, requiring a caregiver to take over those duties. Caregivers may need to apply certain techniques to help those with dementia continue to assert what functions they still have (National Institute on Aging, 2019b). For instance, individuals may feel apathetic and may not want to make choices. A caregiver can help by limiting their choices and removing the feeling of being overwhelmed, thereby encouraging a more positive behavior.

Behavioral management suggests not arguing with individuals that have symptoms of dementia. Caregivers may get angry or frustrated with someone who has dementia (National Institute on Aging, 2019b). This issue can lead to arguments when a caregiver feels they cannot control the behavior of the care receiver. Arguing leads to even greater frustration for the person with dementia, developing poor outcomes for both caregiver and care receiver. One way of easing difficulties for individuals with dementia may entail setting regular schedules. Eliminating environmental distractions and determining ways that dementia sufferers may harm themselves all work together to ease the lives of those who have dementia and make caregiving easier.

Researchers suggested several approaches to caring for those with dementia (National Institute on Aging, 2019b). Psychological therapies for dementia include validation, cognitive, and music therapy. Validation therapy helps individuals feel greater acceptance, despite dealing with a progressive disease. Cognitive stimulation is meant to stimulate a person's cognitive processes to help them to remember who they are and what they are doing. Finally, music therapy can help people with dementia feel more relaxed, which can be conducive to improved behavior and communication.

Caregivers of those with dementia must monitor the patient's medication closely (Singh-Manoux et al., 2017). There are several drugs recommended for dementia based on the progression of the disease. The primary forms of dementia medication stall its progression. Other medications address secondary symptoms arising from dementia, including aggression and depression. This second class of medication treats behavioral and psychological symptoms. Finally, anti-psychotic medications are prescribed as needed (Singh-Manoux et al., 2017).

Caregivers must understand the requirements for dementia medication management (National Institute on Aging, 2019b). Caregivers should understand dementia medication management and the effect that the medication have on the patient. Complications may arise from taking multiple medicines that may have contra-indications and influence each other chemically. Caregivers should maintain a list of medication and understand the importance of monitoring the medicine to ensure the health and safety of those they are caring for. Furthermore, some researchers have found that gender, as a social position, can either work with or in opposition to the way caregivers tend to those with dementia (O'Connor et al., 2010).

Caregiver Characteristics

Samus et al. (2018) described dementia caregivers as a heterogeneous group. Most caregivers (60%) are female, and 80% handle only one patient. The average dementia caregiver is 49 years old, female, and responsible for a parent, while approximately 10% of caregivers are responsible for a spouse. Ten percent of dementia caregivers are 75 years of age or older, 26% are 65 and 74 years of age, 41% are between the ages of 50 and 64, 17% are between the ages of 35 and 49, and 16% are under the age of 35. The burden for older adult caregivers and the likelihood of maladaptation diminish their ability to provide proper care for themselves.

Data from the Alzheimer's Impact Movement and Alzheimer's Association (2019) indicated that almost a quarter of those providing care were "sandwich" (para. 2) caregivers; individuals who had to care for someone with dementia but were the child or grandchild of that person. In 2018, researchers estimated that 16.3 million family members and friends generated 18.5 billion hours of unpaid care for those who had Alzheimer's and other manifestations of dementia. One in three Alzheimer's caregivers had to provide help to individuals with bathing, showering, feeding, or going to the toilet. Researchers indicated that dementia caregivers had more responsibilities than those providing care for other types of disorders. Dementia caregivers handled helping with a wider variety of activities and provided an average of 28 hours of work per week helping those with dementia (National Alliance for Caregiving, 2015). Many (67%) reported performing medical and nursing tasks with no training or preparation for such roles.

Given the many roles that a caregiver plays and the diversity of their responsibilities, these individuals ranked higher on the burden of care index (National

Alliance for Caregiving, 2017). The situation for these caregivers also tended to be chronic. As an example, researchers noted that cancer caregivers tended to be in similar high burden situations (Kent et al., 2016). However, the important distinction between cancer and dementia caregivers was that cancer caregivers tended to provide care for brief periods, during periods of increased severity (Kent et al., 2016).

Dementia caregivers, on the other hand, tended to provide high-burden care over longer periods of more than five years, placing them at particular risk of suffering from distress and burden (National Alliance for Caregiving, 2017).

Researchers noted that the overall picture of caregivers in the United States was diverse (Pendergrass et al., 2015); dementia caregivers also identified with this trend (Alzheimer's Impact Movement & Alzheimer's Association, 2019). Dementia caregivers differed in their responsibilities (National Alliance for Caregiving, 2017). Dementia caregivers often worked longer hours and needed to perform intensive duties for which they were not prepared, including nursing. As such, dementia caregivers might be as demographically diverse as other caregivers but faced increased burdens.

Male Caregivers and the Similarities and Dissimilarities of Gender

There must be an inquiry into how gender plays into the experience of caregivers to reach a greater understanding about the self-help of male caregivers. Pillemer et al. (2017) noted that the major body of prior data investigating burden in relation to dementia caregiving did not show gender differences in relation to burden and depression in dementia caregiving. The researchers sought to understand what role gender played in relation to the burden caregivers carry when caring for individuals with dementia. Furthermore, the researchers clarified that in lieu of the

surge of male caregivers, other researchers had neglected this issue while remaining focused on female caregivers. Although only assumptions can be drawn from the few studies on male caregivers, these studies indicate that men approach caregiving differently and that the male experience of caregiving is much less known than that of women (Sharma et al., 2016). Given that little is known, as Sharma et al. (2016) stated, conflicting conclusions have been drawn about male caregivers—the gap in knowledge that I explored. Nevertheless, before I conducted research in line with the hypothesis, the available data from prior research were consulted. Sourcing older studies, Sharma et al. (2016) noted that although gender did impact caregiving based on the total duration of caregiving, gender did not have an impact.

Pillemer et al. (2017) used the Zarit Burden Interview (ZBI) to measure level of burden among caregivers and levels of impact. In this instance, specifically depression was assessed using the Epidemiologic Studies Depression scale. The researchers broke burden down into the impact of caregiving on the caregivers' lives, guilt, frustration/embarrassment, and the four facets of depression they outlined: depressed affect, somatic activity, positive affect, and interpersonal feelings. The results of burden and impact scores indicated that both were significantly higher in females. The conclusions of the research showed the dissimilarities of the experience for caregivers based on gender and how that knowledge can be used to optimize the life quality of the caregiver experience. The researchers also showed that women experienced a greater burden while providing care to dementia patients. Although this finding may be the case for most women, it may indicate social gender conditions shown from a skewed data collection method. This finding may also be related to the

SRT. This difference of experience between male and female caregivers was the same hypothesis I assumed as part of the gendered social conception of roles.

Research based on the SRT indicates tension may be at the level of the perceived male role when taking up a role traditionally considered feminine, such as caregiving (Eagly & Wood, 2012). Bartlett et al. (2016) analyzed the male perspective of caregiving for those with dementia. The researchers indicated that such tension existed, finding a strong correlation between masculine tension and the feminine nature of the act of giving care to someone (Bartlett et al., 2016). In one study, male caregivers identifying as masculine had trouble maintaining contact with their male friends due to the perceived role they took up as caregivers (Bartlett et al., 2016). In another study, Bartlett et al. (2016) highlighted that the conflict that male caregivers experienced was a gender role conflict and was deemed more significant than gender identity as they struggled to construct themselves in the role of caring. This finding also shows why men may be so reluctant to reach out to support services and concurrently why men need services and resources made readily available. In contrast and in accordance with the findings of Riffin et al. (2017), Bartlett et al. (2016) noted that masculine men might feel isolated when in the role of caregiver if other looked down on them as out of place in the position of caregiver. In conclusion, Bartlett et al. declared that for male caregivers, the reported experience was variable and diverse. Male caregivers, who feel out of place due to their assumed gendered social roles, may feel this way out of the nature of the situation. For example, Hicks et al. (2018) showed that family members who lived at home with a relative who had a chronic illness or disability might feel underutilized or even marginalized.

Riffin et al. (2017) highlighted the need for the development of tools and resources that would meet the requirements of the male family caregiver, specifically male caregivers aiding family members with dementia. Further, Edwards et al. (2017) utilized data from the 2009 BRFSS and found that, in contrast to female caregivers, male caregivers were more ready to report a lack of social support.

Just by nature of the role a caregiver must assume, one faces a multitude of challenges that deviate from the juncture of the caregiver experience and whose impact end up in separate categories of variables. For example, Giesbrecht et al. (2016) proposed that within the world of the caregiver, being a male was only one factor that defined the caregiver experience. Other factors comprised the caregiver experience involving psychological capacity, cultural influences, socioeconomic status, housing status, social connectedness, relationship to the care recipient, and the care of the recipient's health and mental capacity (Giesbrecht et al., 2016).

Similarly, Sharma et al. (2016) studied the challenges of caregivers and noted that caregivers experienced multiple burdens. The data indicated that older male caregivers who cared for those with dementia consistently experienced a higher level of a multiple burdens (Sharma et al., 2016). Sharma et al. (2016) called this dynamic psychosocial affect by the neologism they termed as "a multidimensional response" (p. 10), stating that influences existed individually yet in correlation with many other factors. Regarding coping strategies, Schwartz and McInnis-Dittrich (2015) reported that depending on how male caregivers sensed their roles in relation to their genders, traditional roles of masculinity would lead to suppressed coping methods, while a less masculine, more feminine approach allowed for more open coping strategies (Eagly &

Wood, 2012). This finding showed the complexity of gender and the validity and aptitude of the SRT for the nature of this study.

Researchers have established that caregivers who treat their older adult parents and relatives generally view the effort they put forth as an active act of love. In a qualitative study, Gilbert et al. (2018) found that it was this feeling of love and respect that helped carry caregivers through the difficulty of the task. Furthermore, the love and respect that results from the social sphere and the sense of universal duty, the caregiver's task is elevated to a transcendental level as a labor of love. This love and respect, although generally inherent to most modern cultures in the family social structure, is a coping strategy, although it may not formerly be treated as such. Gilbert et al. found that while many caregivers face many hardships, it was love and respect, particularly in relation to caring for older relatives that provide the driving force to help sustain caregivers through their experience.

Sharma et al. (2016) conducted a literature review and found that gender in correlation with the SRT framework played a big role in the formation of social roles and thus caregiving. Regarding family caregiving and gender, Sharma et al. postulated that male caregivers might be less skillful or willing to express their stressors and the state of their well-being because of the gender expectation of males to not become caregivers. This finding may have resulted in a report bias, where men are less willing to report the impact of the caregiver-burden in contrast to the high caregiver-burden of women. Although Sharma et al. noted this point, it would need further validation. Several researchers have pointed to this possibility, especially when considering the way Eagly and Wood's (2012) SRT functions.

Caregiver Burden

Caregiver burden refers to stressors, as perceived by caregivers, associated with tending to the needs of loved ones in home care situations (Cheng, 2017). The level of perceived caregiver burden is a significant predictor for negative outcomes of the care situation—for the caregivers and the one receiving care (Samus et al., 2018). Caregiver burden is a chronic form of stress resulting in negative psychological, behavioral, and physiological outcomes that can affect the daily lives of caregivers. Caregivers include family members and friends, and these individuals endure specific forms of stress, distinguishing them from professional healthcare providers (Hicks et al., 2018).

Bartlett et al. (2016) noted that one study found that male caregivers of those with dementia experienced lower levels of caregiver burden. However, researchers have also demonstrated that because of how gender constitutes social roles, males who perceive themselves as masculine may resist the temptation of reporting caregiver burden (Broughton et al., 2011). Moreover, caregiver burden increases over time as dementia patients lose functioning, experience personality changes, and require greater care to ensure their safety and well-being (Cheng, 2017). The length of time that an individual is affected by the disease is not the only factor that is associated with increased burden. Rather, the intensity of symptoms experienced by a person is associated with increased ratings of caregiver burden. Caregiver burden may be impacted by how long the patient has had dementia as well as the severity of symptoms. More severe symptoms are associated with higher ratings of burden, even if the patient has the disease for a shorter period. Over time, caregiver burden tends to

disrupt the lives of caregivers including sleep deprivation, among other negative outcomes (Cheng, 2017).

Caregiver Well-Being

Long-term caregiver burden for dementia patients was associated with increasing levels of depression (Schulz & Monin, 2018). Researchers suggested that intrusive thoughts and compassion played a role in causing depression among those who provide care (Schulz & Monin, 2018). Researchers worked to understand better the relationship between caregiving and psychological maladaptation. Researchers found that when caregivers perceived physical suffering occurring within a person with dementia, there was a resulting influence that increased the likeliness of depression (Schulz & Monin, 2018). Intrusive thoughts mediated this relationship between perceptions of physical suffering and depression. As such, increasing numbers of intrusive thoughts increased the likeliness of depression.

Cheung et al. (2015) described a multicomponent intervention for enhancing the well-being of dementia caregivers. The intervention includes 12 sessions conducted individually with dementia caregivers and covers issues that included caregiver well-being, caring for a recipient's problem behavior, and general safety. A quantitative study of 201 family dyads indicated that the intervention significantly increased caregiver well-being. Dementia caregivers felt more positive about caregiving and experienced a reduction in depressive symptoms, subjective burden, caregiving risks, and improvements in behavioral problems that those with dementia experience. Therefore, the results indicated that such a multicomponent approach could help to improve multiple aspects of the dementia caregiver process.

Users of multiple psychosocial interventions improved dementia caregiver well-being (Pendergrass et al., 2015). A meta-analysis of quantitative studies using 82 validated assessments indicated that psychosocial interventions improved caregiver depressive symptoms, feelings of burden, self-efficacy beliefs, emotional distress, and general quality of life. The researchers indicated that these caregiver interventions were effective at reducing several symptoms associated with burden, although the researchers noted that few programs existed that used psychosocial interventions.

Outcomes of Male Caregivers

Interventions meant to help dementia caregivers do not have equal outcomes. Researchers indicated that such interventions were less effective for African Americans and Hispanics versus their White caregiver counterparts (Graham-Phillips et al., 2016). Researchers performed randomized controlled trials among 323 caregiving families who were taking care of individuals with dementia, with the intervention used characterized by nine in-home sessions of 90 minutes each and accompanied by three telephone sessions of 30 minutes each. The session's design aided to reduce caregiver burden and depression (Graham-Phillips et al., 2016). The researchers also hoped to alleviate caregivers' self-care and improve the social support of those caregivers. Although this intervention was successful, researchers found that Whites received the most in-home sessions. Hispanics and African Americans received fewer sessions with African Americans receiving the least number of sessions (Graham-Phillips et al., 2016). The findings indicated that interventions might not be equally applied due to conditions rooted in demographic background, possibly reducing the effectiveness of these interventions.

Although interventions designed to address caregiver burden were somewhat diverse, it remained a challenge to capture the true scope of diversity for caregivers. Some interventions were intended to address disruptive thoughts (Schulz & Monin, 2018), while others were rooted in previously established best practices, such as those located in *Resources for Enhancing Alzheimer's Caregiver Health* (Cheung et al., 2015). The latter intervention was like an intervention used by Graham-Phillips et al. (2016). However, researchers noted that although interventions were generally effective at improving caregiver well-being (Pendergrass et al., 2015), the effectiveness of these interventions might hinge on demographic characteristics (Graham-Phillips et al., 2016). As such, the interventions design should accommodate caregivers' unique characteristics.

The Relationship Between Gender, Well-Being, Caregiver Burden, and Support

Focused on the well-being of caregivers are strategies for mitigating the negative impact of stressors, sometimes also known as self-help or self-care strategies. Sharma et al. (2016) defined the caregiver's burden as a "multidimensional response" (p. 10). The burden of the caregiver cannot be reduced to some essentialist, single determinate factor, but rather it is a plethora of culturally contingent factors, in combination with some cross-cultural consistencies, such as the guarantee of psychological stress, even if the act is driven by love (Giesbrecht et al., 2016). Sharma et al. (2016) cited prior data that prevalent stress-coping theories about female caregiver indicated that females more commonly reported stressors most likely due to the trend of females being more willing to perceive, report, and cope with stressors. Additionally, many researchers have found women to have higher level of mental and psychological strain, a greater caregiver burden and higher levels of psychological

distress while delivering care (Sharma et al., 2016). Although a decisive conclusion can be postulated about the well-being and stress levels of female and male caregivers, some researchers have suggested otherwise and presented conflicting results (Sharma et al., 2016).

Firstly, other researchers have investigated the stress levels of male and female caregivers—which may pertain to caregiver well-being, given strategies of self-help and self-coping are used to mitigate the stress—and shown no differences between male and female caregiver stress levels (Sharma et al., 2016). Adding to the differences found in studies, Giesbrecht et al. (2016) concluded that gender was merely a single factor in the multitude of more determinate factors for caregivers. The other factors, all of which play a role in well-being, included psychological capacity, culture, socioeconomic status, housing status, social connectedness, and relationship to the care recipient, the care recipient's health, and mental capacity. Hicks et al. (2018) found further data to illuminate the complexity of the issue and the abundant disharmony of conclusions on the topic. Hicks et al. noted that rather than in accordance with prior data where female caregivers were the ones to be more apt to report stressors or issue, they found that male caregivers were more willing to report a lack of social support stemming from a perceived but statistically valid lack of social support. Based on the statistics of prior data, Sharma et al. (2016) cited Yee and Schulz (2000) who conducted a seminal narrative-review on gender differences among caregivers. Yee and Schulz analyzed data from the 17 of the 30 studies in their review for the influences of gender on the caregiver burden. Although most studies indicated that women experienced higher levels of stressors and burden, the results of the meta-analyses showed otherwise, with suggestions to conduct further research.

The meta-analysis researchers examined 14 studies observing male and female caregivers who treated older individuals, some of whom had mental and psychological conditions. The finding, while again observing females as the ones more willing to report stressors, concluded that there were only insignificant differences of caregiver burden pertaining to genders (Sharma et al., 2016; Yee & Schulz, 2000). In a further meta-analysis of four studies, dementia patients treated by female caregivers reported poorer self-health, well-being, and coping skills; male caregivers treating dementia patients reported the same low well-being, self-help, and coping skills. These results concurred with the findings of Wang et al. (2019), who found a strong correlation between self-care for family caregivers treating relatives with dementia, and Riffin et al. (2017), who found family caregivers treating relatives with dementia to experience heightened levels of social isolation which may be the result of poor self-care and coping abilities. Furthermore, Sharma et al. (2016) recalled a meta-analysis of 176 studies on caregivers treating older adults with dementia where the researchers found a strong association between caregiver burden measured via stressors and older male caregivers treating seniors with dementia. Sharma et al. concluded that although studies had various findings, some conflicting between male and female caregivers caring for older adults, specifically those with dementia, there were far more similarities than differences. However, researchers must still acknowledge that less is known about male caregivers' needs.

Spendelov et al. (2017) studied the coping strategies of older adult male caregivers using four meta-thematic categories: finding meaning and purpose; creating new behaviors, roles, and identities; maintaining status quo and using existing resources; and promoting masculinities and taking charge. Spendelov et al.

established that despite the use of a thorough meta-thematic system of analysis, gender was the prevalent element that affected the social role that male caregivers thought they belonged to, resulting in a split outcome. Coping strategies varied based on traditional masculinity and more modern, flexible concepts of masculinity.

More support services for male caregivers need to be put in place to accommodate the increase of male caregivers around the world (Nance et al., 2018; Wallroth, 2016). Schwartz and McInnis-Dittrich (2015) found that one reason for the lack of social services for men was the lack of consistency in male caregiver data. Data on male caregivers are so dissimilar, one may find it challenging to incorporate their needs into social services. Schwartz and McInnis-Dittrich noted the impact of gender on role formation in society and posited that more traditional views of what it meant to be male might indicate an age cohort where generalized differences in male caregiver perception of masculinity could occur. This finding may explain why some male caregivers appear open to support while others appear guarded about social support programs. And even when support was available, it was not ensured to meet the needs of male caregivers, especially in a time when culture changed. Schwartz and McInnis-Dittrich presented four steps for dealing with male caregivers and making positive steps toward progress.

The first step in Schwartz and McInnis-Dittrich's (2015) action plan included making modifications to the Centers for Medicare and Medicaid Services (CMS) quality measure assessments. Schwartz and McInnis-Dittrich argued that accountable care organizations (ACO) must be reevaluated by those who they serve, which in this case are male caregivers and their patients. Although ACOs are analyzed by the CMS for quality assurance by caregivers and patients using questionnaires, more must be

known about the caregiver experience so that ACOs can be optimized to fit the variety of male caregiver needs.

Schwartz and McInnis-Dittrich (2015) presented the second step as implementing a caregiver care plan and assessments, including a mandatory care management structure to help better identify the various needs of male caregivers. The caregiver assessment plan would use detailed questionnaires to help gain insight into the complex situational factors to better predict the needs of caregivers. Additionally, the patients' experience would be documented and correlated with the potential needs of the caregiver.

Schwartz and McInnis-Dittrich (2015) also suggested that there should be mandatory inclusion of social workers at ACOs. The authors argued this would be beneficial given their macro- and micro-specializations pertaining to the fluid cultural climate and natural variability within it. Also, age might impact social gender perceptions and social workers could operate from a vantage point to anticipate how the aging process might change the sense of self a male caregiver may feel. For individual caregivers, the most fitting social workers with the most expertise could be assigned to a particular case.

Finally, Schwartz and McInnis-Dittrich (2015) argued for increased understanding that many male caregivers approach caregiving as a formal task and thus take a task-oriented approach. This aspect must be transmitted to the other healthcare professionals who work with the patient. Given that professionals' bias has been negative toward helping men get support, social workers can work as the mediator since most social workers are situated to be made aware of their own biases.

Of all the conclusions made, there was uncertainty emanating from the conflicting evidence and the lack of studies examining the relationship of caregiver gender relative to treating family members with dementia. The only thing that could be verified was the lack of unanimity regarding this issue. The gap of knowledge also indicated how little was known about the perceptions and lived experiences of male caregivers, especially those treating older family member with dementia. All that could be taken was relevant bits from various studies. The abundance of conflicting data illuminated the gap this study was designed to fill.

Methodology Used in Relevant Literature

The theoretical framework of a study played into the means of data collection. Authors of related studies took one of two primary approaches to data collection and analysis. Several studies used semi-structured interviews for data collection, while others used surveys or mixed-method instruments for data collection. The former was more closely aligned with the current study. For example, Eagly and Wood's (2012) study was premised on a gendered construction of social roles and utilized semi-structured interviews. Many similar studies were theoretically premised on the entanglement of gender and social roles, especially those expected social roles projected onto a person based on their genders. For example, Sharma et al. (2016) noted the prevalence of gendered social roles, who also employed such roles in their study. The work of these authors was of extreme relevance to this study, given that Sharma et al. examined the gendered differences of family caregiving, particularly for those relatives with mental illnesses.

Kirsi et al. (2004) also used a semi-structured interview approach to data collection. The study was performed in Finland on 13 male caregivers, albeit in

relation to wives with dementia, concluding those men's experiences as caregivers were vastly diverse and should thus be explored further. Differences in gender may also be from methodological variations of the studies. Both Eagly and Wood (2012) and Kirsi et al. (2004) provided examples of what could be accomplished in this area of interest utilizing semi-structured interviews and qualitative data analysis techniques. These studies were used to guide the methods of the current study.

Although the findings of Kahn et al.'s (2016) study was of significance to this study because of the focus on stigma and caregiver burden for caregivers working with dementia, the methods were divergent. This study fell into the survey design category of related studies. The methodology of data collection the researchers used for analyzing their 82-caregiver sample were the ZBI and the caregiver section of the *Family Stigma in the Alzheimer's Disease Scale* (FS-ADS-C). Score in the FS-ADS-C and ZBI were positively correlated with $r = .51$ and $p < .001$. This finding translates in a higher report FS-ADS-C; $t(80) = -4.37, p < .001$; of stigma for female caregivers and a higher burden on the ZBI; $t(80) = -2.68, p = .009$; compared to male caregivers. Further on the FS-ADS-C adult child caregiver reported undergoing greater stigma; $t(30.8) = -2.22, p = .034$; as well as burden for the ZBI; $t(80) = -2.65, p = .010$; than spousal caregivers (Kahn et al., 2016).

Kahn et al. (2016) also did not move from investigating male caregivers in a spousal context, unlike the intent of the current study. Additionally, the researchers did not account for the notion of gendered social roles, such as the SRT. Males have reported lower caregiver burden levels than females because they have been socially conditioned to do so. If anything, the methodology used by Kahn et al. only showed the need for further research to be conducted on male caregivers by using a

methodology that could adapt to the complexity and diversity of the male caregiver experience. On the other hand, Kahn et al. showed the need of more support for caregivers regardless of gender. Even by creating a study that compartmentalizes gender upon the presupposition that gender is a shared universal experience, such as if one is male, then they will share commonalities with other males as a hindrance of the potential depth of the study's findings.

Bartlett et al. (2016) cited Broughton et al. (2011) also used a survey methodology to explore gender identities using questionnaires. Broughton et al. who found that social roles were premised on gender roles. The traditional masculinity of males led male caregivers to not report when they felt burdened and uncertainty about caring.

These studies provided examples of how the variable designs, samples, data collection and analysis, assessment-procedures, and theoretical frameworks had given rise to the many variations that existed in the findings. Such findings may postulate gender differences amongst caregivers in areas where it may persist (Bartlett et al., 2016). All these findings highlight the emphasis that must be placed on the need for a multidimensional and intersectional methodology that a researcher must use to capture the depth and complex nature of the lived, dynamic experience of the caregiver. Using a one-dimensional methodology entails committing confirmation bias in relation to the findings.

In other words, the only potential outcome can be singular results if simply using a basic methodology to investigate a complex event. From examining the methodology of past studies, one should follow Eagly and Wood's (2012) SRT, a methodology should remain integral to the complex nature of what is at stake, the

ontological experience of the caregiver, further implicated in not only treating a family member but also one with dementia. There was no single study that examined all these three key elements synchronically that I investigated. Finally, to grasp how precise the rigor of the study must be, the methodology employed must not only be appropriate to analyze these three elements—social gender roles, family ties, and dementia caregiving—but also must reconcile the relationship between all these elements within the total caregiver experience.

Summary and Conclusions

As many researchers have found, taking up an approach of intersectionality is effective for gaining insight and into the experience of caregivers for males and females (Kahn et al., 2016; Pinquart & Sörensen, 2006; Sharma et al., 2016). Similarly, Bartlett et al. (2016) highlighted the conflicting data being not only the result of a multitude methodologies but also employed in different studies. Additionally, researchers believed that the occurrence of conflicting results was a sign that gender was either still not studied enough or, in contrast, was treated as an over-determinate factor of the caregiver experience. Further trends in data have indicated women experience more burden as caregivers and as such have lower levels of well-being. However, Bartlett et al. (2016) pointed out that this conclusion had been reached based on a surplus of studies examining female caregivers.

Given that male caregivers have steadily risen in the United States and many other developed countries in Europe, Scandinavia, and Mexico, the need to gain a deeper understanding of male caregiver experience is integral in implementing a more viable system of support and resources (Nance et al., 2018). Support for caregivers in general, specifically males support, is needed because Schwartz and McInnis-Dittrich

(2015) declared that male-specific support systems remained deficient in countries where men in the role of caregivers had increased. A further inference aligning amongst researchers who studied caregivers dealing with relatives with dementia is that there were not enough studies to know anything of the issue in minute detail (Cheng, 2017; Kahn et al., 2016; Livingston et al., 2017). Caregivers treating those with dementia have an intensified risk of social isolation, decreased levels of well-being, and perhaps even poorer coping abilities (Riffin et al., 2017).

Regarding coping strategies, Schwartz and McInnis-Dittrich (2015) conducted a meta-thematic analysis and found that gender was a prevalent constituent of the variability of their findings on male caregivers. Schwartz and McInnis-Dittrich believed this finding to be from how male caregivers sensed their roles in relation to their genders; orthodox roles of masculinity had suppressed coping methods, while a less masculine, more feminine, and flexible approach allowed for more open coping strategies. Schwartz and McInnis-Dittrich concluded that studies on male caregivers within the domain of coping and well-being, among other things, still warranted future research to gain deeper knowledge on the subject.

An outstanding reason that more research is needed for male caregivers is the prevalence of the issue surrounding the occurrence of caregiver burden. Caregivers who treat those with dementia reported experiencing a higher rate of caregiver burden (Kahn et al., 2016; Peipert et al., 2018); although advancements have been made, the healthcare system must adapt further whilst in such a precarious social position. As Schwartz and McInnis-Dittrich (2015) stated, changes must be made to improve the future of both the caregiver and the patient. Establishing a more diverse system of

support and a network of communication amongst all medical professionals involved is the most effective method for success (Peipert et al., 2018).

As ACOs have developed further throughout the United States, Schwartz and McInnis-Dittrich (2015) suggested that they should attempt to integrate data reported by caregivers and patients alike better. These organization leaders must work in synchronic collaboration with the various facets of state appointed medical systems, such as community social workers, mental health professionals, Medicaid programs, and caregivers. A system of communication must be established among all individuals who play vital roles linked to the experience of the patient. Future researchers of caregivers should consider this network of individuals commonly linked to experience of the patient. Accountable care organization leaders must come to a position of being better equipped to handle the diverse range of needs for caregivers of all backgrounds based on shifting gender and social roles.

Knowledge gained at the conclusion of this study can serve as means to getting male caregivers the resources and support they need, as self-care is what sustains both caregiver and patient. Wang et al. (2019) advocated that the awareness, motivation, and knowledge of self-care, in addition to knowledge of healthcare resources, were vital prerequisites for caregivers. Caregivers could then achieve a stable, healthy level of self-care management, benefitting both patient and caregiver. In developed countries around the world women have started to take up white-collar positions, while the volume of men has increased as caregivers and homemakers (Wallroth, 2016). From a feminist perspective, male caregivers should obtain more support, and their experiences should be heard in solidarity with deconstructing gender stereotypes and allowing people to follow their dreams.

Chapter 3: Research Method

Introduction

The purpose of this qualitative interpretative phenomenological study was to contribute to the empirical literature on the phenomenon of the social support of caregiver sons of parents with dementia. In this chapter, I provide information on (a) the research design and rationale for the study, (b) the role of the researcher in this study, (c) the methodology used in the study, and (d) issues regarding trustworthiness. I finish with a summary of the chapter.

Research Design and Rationale

I sought to answer the following research question: What is the lived experience of the social support of caregiver sons of parents with dementia? The central phenomenon that I examined in this study was the lived experience of the social support of caregiver sons of parents with dementia. The study was a phenomenological qualitative study where semi structured interviews were used to collect data related to the phenomenon. Qualitative examination was appropriate in this study as I sought to explain a phenomenon (social supports for male children caring for their parents with dementia) using the lived experiences of participants (Flick, 2019; Sundler et al., 2019). Unlike many examples of quantitative research, the goals of this study were not to isolate cause and effect or measure and quantify phenomena (Sundler et al., 2019). Conversely, qualitative researchers can explore the perspectives of participants, their similarities, and their diversities to explain a phenomenon in the context in which it exists (Sundler et al., 2019).

The study was phenomenological. This research tradition relies on the careful description and analyses of subjects' experiences or "life worlds" and the meaning

and understanding subjects apply to their experiences (Sundler et al., 2019). Phenomenology was appropriate for the study because I sought to understand how the participants experienced a particular phenomenon through an exploration of their lived experiences (see Sundler et al., 2019). Ethnography was inappropriate for this study because an ethnographer would immerse themselves in a community and explore emerging themes (see Flick, 2019). Thus, the ethnographer does not seek to explain a particular phenomenon, rather being guided by what arises naturally from their observations (Flick, 2019). A narrative approach was also inappropriate for the study as a narrative researcher would focus on weaving together a sequence of events, rather than studying a specific phenomenon (see Flick, 2019). A case study researcher seeks to combine multiple data sources to explain an event or organization. Therefore, a case study was inappropriate as I sought to explore a phenomenon as described by participants, rather than combining multiple data sources to derive meaning (see Sundler et al., 2019). Grounded theory was also inappropriate for the study as grounded theory involved exploring process, action, and interaction to develop a theory based on observations (see Sundler et al., 2019). A grounded theory approach would have been at odds with the goal of the study, which was to understand and explain the lived experiences of participants to describe a phenomenon. Therefore, I selected a phenomenological design for the study.

Role of the Researcher

My role as the researcher in this study was to access the thoughts, feelings, and experiences as described by the participants (see Flick, 2019). I found this process a challenge as I asked participants to talk about things that are personal and difficult to share with a stranger. Thus, I practiced active informed consent and approached all

topics with understanding, compassion, and a lack of judgment (see Rubin & Rubin, 2012).

I had no personal relationships with any participants that influenced the outcome of the interviews or the power dynamic between me, the researcher, and the participants. As the participants were previously unknown to me, it was important for me to garner their trust so I could extract deep and meaningful data (see Flick, 2019). However, the previously unknown relationship also helped participants speak about their experiences candidly without fear of retribution from me or judgment (see Rubin & Rubin, 2012).

During and after research collection, one of my most important roles as researcher was to safeguard the data and the participants' privacy (see Rubin & Rubin, 2012). I did so by removing identifiable information from transcripts of the interviews (name, birth date, location, etc.) and communicating with the participants in a way that was secure and not shared with other people. This process was done through a private email account secured with a unique password.

I have experience working with the target population through the University of Southern California's Family Caregiver Support Center, which provided support, resources, and advocacy for family caregivers of older adults. This previous experience with the population being studied meant I needed to lay aside preconceived notions or biases about the experiences described by participants. I accomplished this task by considering each participant as an individual, by not asking leading questions, and by not assuming understanding related to the participants' experiences before they completed their interviews. Appendix A contains the interview questions used in the study.

Methodology

The target population for this study included caregiver sons of parents with dementia. The population was in the United States.

Participant Selection Logic

Mason (2010) indicated that five to 25 participants are usually enough to reach data saturation in a phenomenological study. According to Patton (2015), the focus of qualitative research is to explore an issue and that it should therefore involve a relatively, small sample (pp. 310–311). I selected participants based on the following criteria: (a) they were male, and (b) they were involved caregivers for their aging parents with dementia. Individuals were excluded if they were female or a male caregiver caring for another relative, such as a wife, child, or other family member. These exclusions were identified as necessary to support the purpose of the study, which was to study the social supports of sons caring for their aging parents with dementia.

Because I conducted the study during the COVID-19 pandemic (CDC, 2019), I used the social media platform Facebook as a recruitment tool. I posted the flyer on a Facebook page devoted to the study. The flyer (see Appendix B) gave potential participants a contact phone number and email address that they could use to express interest in the study. I then contacted potential participants to confirm that they identified as male and that they were involved caregivers for at least one aging parent with dementia. As the research was conducted in English, participants needed to be English-speaking. As those were the only criteria for entry into the study, I scheduled the interviews with all the individuals who met the criteria and were willing and able to participate in the study.

Instrumentation

I acted as the research instrument (Pietilä et al., 2016) for the study. I used a semistructured research instrument that I developed for the purposes of this study and revised after each subsequent interview to integrate the information received from each interview (see Pietilä et al., 2016). This instrument was semi structured to allow for possible deviation from the research instrument as necessary to follow a participant's line of thought. This method of interviewing allows a researcher to fully flesh out the experience of each participant and not constrain the interview based on predetermined questions (McIntosh & Morse, 2015).

Before data collection, the research instrument was validated by a small field study. I used sequential interviewing, in which one participant was interviewed and the data from that interview were analyzed before the next interview was completed (Englander, 2012). This process is common in phenomenological interviewing, allowing a researcher to adapt the research protocol based on the findings of the previous interview, creating a protocol informed by the participants and leading to richer descriptions (Englander, 2012).

Procedures for Recruitment, Participation, and Data Collection

This field study consisted of three participants. I interviewed these participants using the interview protocol to determine what questions, if any, might be confusing and to determine if the protocol elicited the intended data sought in the study. I then adjusted the protocol accordingly before beginning data collection with study participants. The selection of the individuals to participate in the field study was strategic and included one person who was a caregiver of a parent but was not included in the main study, a service provider, and finally a subject matter expert in

qualitative research. These three individuals provided the range of experience necessary to ensure that the initial protocol was thoughtfully designed and would capture the necessary information.

Data collection was sequential. I gathered data from eight participants using an interview protocol validated in the field study and revised after each subsequent interview to integrate what was learned in each interview (see Pietilä et al., 2016). Data were collected virtually or by phone or email. In this time of social distancing and social isolation due to COVID-19, virtual, phone, and email interviews were practical alternatives for conducting interviews. Each interview lasted no more than 60 minutes to respect the participant's time and energy. Each interview was recorded using an audio recorder and translated into a text transcript for data analysis.

I took notes during the virtual interviews that included observations related to the participants' affect and other things of note that were sufficiently captured in transcripts, such as voice inflection, and implied meaning, such as a participant stressing a certain word or being sarcastic. Continuous recruitment was used to ensure enough participants were recruited. Participant confidentiality was ensured by giving each participant a number (e.g., P1, P2, P3, etc.) instead of using their real names. Once data saturation was reached, I took recruitment flyers down, and I interviewed any remaining qualified individuals who wished to participate.

Upon completion of interviews, I emailed each participant a copy of his interview transcript. This process allowed the participants to make comments about the accuracy of the transcript to clarify or correct their responses. I also followed up with another email to the participants, thanking them for their participation and contribution.

Data Analysis Plan

Data analysis was sequential, meaning that data from each interview were analyzed after the interview was completed and before moving on to the next interview (see Pietilä et al., 2016). I completed data analysis by coding for meaning units. This type of coding involves coding words and sentences that convey similar meanings with the same code (Belotto, 2018). This type of coding allowed me to interpret texts and transcripts in new ways based on meaning, rather than on explicit statement (Belotto, 2018). Upon completion of initial coding, I reviewed each transcript and the codes to look for overarching themes and patterns within the data. This type of coding proved challenging as it produced many codes. However, it produced insights into how participants make sense of caring for the aging parents (Belotto, 2018). Coding was supported with the use of NVivo 11, a qualitative analysis software that assisted in data organization.

Issues of Trustworthiness

I ensured credibility of the study by interviewing at least eight participants and by reaching data saturation. Data saturation refers to the point at which no new or novel information is being collected from participants (Rubin & Rubin, 2012). By reaching data saturation, I prevented the data from being skewed by unique experiences that were not generally experienced by others in the population. Although each participant's experiences were unique to them, reaching data saturation ensured that the experiences described by participants were at least relatable to others within the population. Reaching data saturation also helped ensure transferability of the data.

I ensured dependability by transcribing participant interviews verbatim and by asking each participant to review their transcripts upon completion. This process

ensured that the data were not accidentally misrepresented by the participant or me, the researcher. The participants clarified their remarks after. This process helped ensure that the participants' statements accurately represented their experiences. Data were then coded by identifying meaning units.

After initial coding, I reviewed the codes and transcripts, refining codes as the data required and ensuring that coding drift did not occur. As my understanding of the themes and codes emerged from the data, coding drift could have occurred. Coding drift refers to the phenomenon where a code may mean something different at the beginning of coding than at the end of coding (Ratajczyk et al., 2016). By adjusting the codes as necessary, I ensured the codes remained consistent throughout coding and that another researcher could replicate the coding process, thus establishing confirmability.

Ethical Procedures

Before data collection commenced, I gained IRB approval from the IRB organization. During data collection, I practiced active informed consent by informing participants that they could discontinue the interview at any time or could not answer a question and move on to the next if they wished to skip a question but wanted to continue the interview. I explained the purpose of the study to the participants before the interview started, informing them that some questions might be considered personal or hard to answer by some people. I encouraged the participant to let me know if they felt uncomfortable during the interview. I also watched and listened for signs of discomfort during both the virtual and phone interview to ensure participants were not unduly stressed, embarrassed, or upset by any questions. Appendix C contains a list of mental health resources offered to participants, if needed.

I safeguarded audio recordings until after data analysis was complete. Once participants approved their interview transcripts, all identifying information was removed from the transcripts to ensure that participants could not be identified in the final presentation of the data. Once data analysis was complete, all interview transcripts and recordings remained in a secure location, specifically on a password-protected computer. All the transcripts and recording will be kept for five years before being destroyed.

Summary

The purpose of this qualitative interpretative phenomenological study was to contribute to the empirical literature on the phenomenon of the social support of caregiver sons of aging parents with dementia. The study was guided by the following research question: What is the lived experience of the social support of caregiver sons of aging parents with dementia? The study was a phenomenological qualitative study that used semi-structured interviews to collect data related to the phenomenon. Qualitative examination was appropriate because I sought to explain a phenomenon (male children caring for their parents) using participants' lived experiences. Unlike many examples of quantitative research, the goals of this study were not to isolate cause and effect or to measure and quantify phenomena as is appropriate in quantitative research (see Flick, 2019). Phenomenology was appropriate for the study as I sought to understand how the participants experienced a particular phenomenon by exploring their lived experiences (see Flick, 2019).

The target population for this study included sons who cared for their parents with dementia in the United States. Participants were recruited for this study via a Facebook page. I obtained IRB approval before data collection commenced. Each

semistructured interview lasted no longer than 60 minutes. Each interview was recorded, transcribed, and then reviewed by the participant to ensure accuracy. Data analysis was completed by coding the interview transcripts.

Chapter 4: Results

Introduction

I addressed the problem of the lack of a model about the lived experiences of caregiving sons of parents with dementia. In Chapter 3, I discussed the appropriateness of a phenomenological design to understand how caregiving sons described the meanings ascribed to their experiences. The goal of this qualitative interpretative phenomenological study was to contribute to the empirical literature on the phenomenon of the social support of caregiver sons of aging parents with dementia. The research question that I sought to answer in this study was the following: What is the lived experience of the social support of son caregivers of parents with dementia?

This chapter includes a presentation of the data analysis and results. I describe the setting and provide demographics of the eight male caregivers whom recruited through Facebook. The chapter also contains descriptions of the data collection and data analysis procedures, including the procedures for the semistructured individual interviews and the sequential coding for meaning units. The evidence of trustworthiness is then presented. The results of the data analysis follow. I describe common themes that represent the participants' lived experiences as caregiving sons to parents with dementia. Lastly, a summary concludes the chapter.

Field Study

I tested the questionnaire by interviewing three participants who were not part of the actual study. The critical factor in the field study was to ensure that the instrumentation or the questionnaire items accurately addressed the research question. During the field study, I tested whether the questionnaire items were comprehensible

and appropriate. I tested if the questions were well defined, clearly understood, and presented consistently. Additionally, I tested the length of time it took participants to respond to the questions. The field study also encompassed testing the participant information statements and consent forms for clarity. The final versions of the questionnaire and consent form considered the field study participants' comments.

Setting

I conducted this phenomenological study during the COVID-19 pandemic. During this crisis, the CDC (2019) implemented health and safety protocols, including the stay-at-home order and social, or physical, distancing. Thus, recruitment was conducted online via the platform Facebook. The interviews were held either via Zoom, FaceTime, or telephone call.

Demographics

The sample of the study consisted of eight caregiving sons of parents with dementia. I selected the participants using the social media platform Facebook. All participants were English-speaking primary caregivers to at least one of their parents with dementia. The participants were from different ethnic backgrounds and ages, as shown in Table 1.

Table 1

Demographic Information

Participant	Age	Ethnicity	Parent with dementia
Son 1	68	Hispanic	Both parents
Son 2	69	Black	Mother
Son 3	30	Black	Father
Son 4	55	Asia Pacific Islander	Mother
Son 5	59	Black	Mother
Son 6	50+	White	Father
Son 7	54	White	Mother
Son 8	55	Asia Pacific Islander	Mother

Son 1

Son 1's parents were immigrants from a South American country. He was an only child who thought that being his parents' caregiver was "priceless." Son 1 shared that his father worked until the age of 80 when his dementia got severe. At that time, his mother also suffered from dementia. When both parents got worse, Son 1 noted that he "could not do everything" by himself anymore. During that time, he took his parents to live in a "group home," which he considered "very bad." He stated that "there was abuse."

Son 2

Son 2 was the youngest of three brothers. His older brother passed away, and his second brother was an amputee, diabetic, and unemployed when their mother was diagnosed with dementia. His second brother passed away a year after their mother got sick. Son 2 moved back to a neighborhood close to his mother's home in 1996. In 2006, his mother "had an episode" where she fainted in a public place. Since then, Son 2 let his lease expire and then moved back in with his mother to take care of her. His mother also developed dementia when she suffered a stroke. The participant took care of his mother for four more years before she passed away at the age of 91.

Son 3

Son 3 has a close relationship with his father. He described his father by saying, "He's my hero. He was always there for me, a career military man. He kept pushing me to go to college. He instilled in me the value of hard work." Son 3's father suffered from a medical condition that led to his physical disability and bounded him to a wheelchair. The participant moved back in with his father to take care of him. His father later suffered from dementia and became dependent on the participant.

Son 4

Son 4 said he “sacrificed” his career for his siblings to continue their jobs while he took full-time care of their mother. He started his role as a temporary caregiver when he took an extended leave of absence from work, only to come back to unsupportive colleagues. The participant thought that because his children had already graduated from school and he had his pension, his wife’s income could sustain their needs; therefore, he decided to leave his job and take care of his mother while conducting deliveries as a job.

Son 5

Son 5 was the primary caregiver of his nonbiological mother who was also his biological aunt. The participant’s biological father passed away when he was 9, and his biological mother passed away when he was 10. His aunt raised him like her own son. Son 5 stated, “She is my mom and she treated me as her own son. She was the one who gave me all the opportunities to be where I am at now.” Son 5 took care of his mom when she was 92 until she was 98, when she had to be transferred to a nursing home.

Son 6

Son 6 identified as a gay, White man. They “just sort of fell into” the role of their father’s primary caregiver due to being the family member with the most available time. Furthermore, Son 6 insisted, “I ... was already familiar with my parent's health history as well as with his doctors, health insurance, finances etc. ... Besides, I also don't really trust anyone else with his care.”

Son 7

Son 7 said he became his mother's primary caregiver after she suffered a stroke, "became demented," and could not "live alone safely" in her Los Angeles home. The participant had an older brother living in Florida. The brothers agreed that they did not want their mother to be placed in "a long-term care facility just yet." Son 7 lived in Los Angeles and "jumped in" to the role "without a thought" despite also supporting his wife and his young daughter. The participant stated that he was divorced from his wife because of three years of being his mother's primary caregiver.

Son 8

Son 8's mother suffered from a brain injury. His mother had lived with him since 2002, when his father passed away. He was a widower with no children. Son 8 described his relationship with his mother in a way that showed they were close. They were "a team of two." Son 8 had a sister who lived in a different state and had a family of her own.

Data Collection

The data collection method used in this study was semi structured interviews. I interviewed half of the participants individually via the online video conferencing software Zoom. The other half were interviewed by FaceTime or telephone. All the participants expressed their preferences for having the interviews conducted online or by phone rather than face-to-face. The interviews were conducted during the time when COVID-19 restrictions were in place (CDC, 2019).

All the participants understood that they needed to be English speakers to participate. They also knew and understood the terms and conditions of their

participation, as indicated by the signed informed consent forms they submitted prior to the interview. Only participants who submitted a signed informed consent form were interviewed. The interviews were audio and video recorded with the participants' consent.

I used a semi structured interview protocol to guide the discussion during the interviews. I asked probing and follow-up questions as necessary to collect a comprehensive description of the participants' lived experiences. I used the interview protocol to allow for a standard in the duration of the interviews, which lasted for 30 to 45 minutes each.

Data Analysis

Data analysis revolved around coding units of meaning and then developing patterns from the codes to generate themes. I began the coding process by reading and rereading each line of the transcripts in search of meaning units that depict the experiences of the participants as caregiving sons to parents with dementia. I coded the text by highlighting phrases or sentences that contain descriptions of the lived experiences of the participants in relation to social support when taking care of their parents with dementia. I compared the small units of meanings or codes with one another such that codes with similar patterns of meaning were clustered together to form the initial themes. I reviewed the themes in terms of their relationship with one another and the research question, as well as how well these themes represented the data. At this point, some themes emerged as small subunits of meaning patterns. These themes were considered as subthemes. Table 2 shows the themes, subthemes, and codes derived from data analysis.

Table 2*Codes, Subthemes, and Themes*

Code	Subtheme	Theme
Severe dementia Comorbid disease Good and bad days Bathing and maintaining Mom's hygiene Knew nothing about dementia	Dealing with parents' dementia and other health problems	Theme 1: Unprepared for caregiving
Jeopardized marriage Sacrificed social life Worry about own health and future Has own family to support Busy with everyday tasks Sacrificed job Physically and mentally tired	Juggling caregiving and personal life	
Accomplishing daily routine Taking parents to the doctor Managing finances Making parents comfortable	Tasks of son caregivers	Theme 2: Family and friends are the main social supports
Siblings could not help Parents' sickness was sudden Managing expenses No other responsibility Change role from Breadwinner to caregiver	Suddenly becoming the primary caregiver	
Difficulties specific to being a male Dealing with other people	No subtheme	
Friends and family No other caregiver Social security benefits Parents' doctor Caregiver support group Patients with dementia Support group	No subtheme	

(table continues)

Code	Subtheme	Theme
Caregiver Assisted living facility Group home Parent's savings paid for the services	Hiring professional help	Theme 3: The sons cannot do it by themselves
Kept busy at work Exercised Took parent out Talked to other people Listened to podcasts Watched movies and TV Took a walk	Taking a break from caregiving	
Thinking positively Seeking information Acceptance	No subtheme No subtheme No subtheme	
Felt rewarded for taking care of parents Close, loving relationship with parent Moral choice to give back to parent Made sure that parent is cared for	No subtheme	Theme 4: The sons do it for love
Need for formal training on how to care for dementia patient and for their own mental health Need easier access to information Need to hire professional help Need to reach out other to family and friends Need to be prepared Need for support groups	No subtheme	Theme 5: Lessons learned from being a son caregiver

Evidence of Trustworthiness

Techniques to increase the trustworthiness of the study were employed. Trustworthiness has four components: credibility, transferability, dependability, and confirmability. The techniques to address each component are described in this section.

I employed techniques to increase credibility beginning from the extended exposure to the setting of the study. I conducted the data collection process over the online video conferencing platforms Zoom and FaceTime and telephone calls during the COVID-19 pandemic (see CDC, 2019). Thus, my prolonged engagement with the

setting involved my familiarity with the platforms I used such that I resolved any issues, especially with technical and connectivity issues, before contacting the participants. I also adhered to COVID-19 health and safety protocols during that time, noting my predispositions about the pandemic that would have influenced my perceptions of the roles of son caregivers. Before data collection, I ensured I had the characteristics of “human instruments” in qualitative research, including my knowledge of the context, my qualitative researcher skills, my theoretical knowledge about the phenomenon, and my execution of the appropriate research methodology (see Miles & Huberman, 1994). I self-developed the interview protocol used for data collection; therefore, I had a high level of awareness of the items in the protocol and could ask relevant probing questions. This process increased the accuracy of how I elicited the “true” perceptions of the participants (Forero et al., 2018). I practiced member checking, where I allowed participants to review the accuracy of the transcription. Once participants approved their interview transcripts, all identifying information were removed from the transcripts to ensure that they could not be identified in the final presentation of the data.

Transferability involved techniques to reach data saturation (see Forero et al., 2018). Data saturation, the point where no new information emerged from the data, was reached during the analysis of Son 5’s interview data. The interviews with Son 6, Son 7, and Son 8 were conducted and analyzed to confirm that saturation had been reached.

Dependability involved techniques that increased the reliability of the findings (see Forero et al., 2018). Repeated immersion in the data ensured that the meanings of each code and theme were clear and distinct such that code drift did not occur. I also

kept records and rich descriptions of the research methodology that allowed for a trackable documentation for the sake of consistency. All the materials and protocols I used in the study are attached in the appendices, and Chapter 3 provides a concise description of the research procedures.

I increased the confirmability of the study through reflexivity (see Forero et al., 2018). I kept notes about my thoughts regarding decisions during the research process. I reported this transparency in the setting, data collection, and data analysis sections. I also reported my interest in the study and my personal background (see Dodgson, 2019).

I ensured the protection of the data starting from the interview process. I kept the participants' identities private and confidential. All the digital data I collected from each participant were kept in a password-protected computer and backed up in an encrypted flash drive. I will permanently delete all the data five years after the conclusion of this study.

Results

The results of this phenomenological study were generated from the coding and thematizing processes. The results were developed to answer the following research question: What is the lived experience of the social support of son caregivers of parents with dementia? The commonalities in the lived experiences of the eight caregiving sons to parents with dementia interviewed in this study involved five themes. The themes included (a) unprepared for caregiving, (b) family and friends are the main social supports, (c) the sons cannot do it by themselves, (d) the sons do it for love, and (e) lessons learned from being a son caregiver. The theme unprepared for caregiving revealed four subthemes: (a) dealing with parents' dementia and other

health problems, (b) juggling caregiving and personal life, (c) tasks of son caregivers, and (d) suddenly becoming the primary caregiver. The theme the sons cannot do it by themselves also revealed two subthemes: (a) hiring professional help and (b) taking a break from caregiving. Table 3 shows an overview of the themes and subthemes with the number of supporting participants and references in the data. Each theme and subtheme are further detailed in the following subsections.

Table 3

Overview of Themes and Subthemes

Theme	Subtheme	Number of supporting participants	Number of supporting references in the data
Theme 1: Unprepared for caregiving		8	71
	Dealing with parents' dementia and other health problems	7	19
	Juggling caregiving and personal life	6	15
	Tasks of son caregivers	8	14
	Suddenly becoming the primary caregiver	6	13
Theme 2: Family and friends are the main social supports		7	32
Theme 3: The sons cannot do it by themselves	Hiring professional help	8	29
	Taking a break from caregiving	5	12
Theme 4: The sons do it for love		6	12
Theme 5: Lessons learned from being a son caregiver		8	27
		8	16

Theme 1: Unprepared for Caregiving

The lived experiences of caregiving sons to parents with dementia generally involved difficulties impacting their social support. The difficulties centered on their parents' illnesses, their personal lives, their daily tasks, and the suddenness of taking

on the caregiving role. These findings emerged as subthemes further elaborated in the following subsections.

Nonetheless, two findings also emerged from the data but were not sufficiently evidenced. Three participants made six references about the difficulties encountered in caregiving that they perceived as gender specific. Son 7 and Son 8 reported that the available information and intervention for developing coping strategies in caregiving were generally geared towards women. Son 7 perceived that these supports improved since he became a son caregiver; however, during his time to take care of his mother, support was scarce. Son 4 and Son 8 additionally noted that men who manifested stress and emotions were perceived as “weak,” which negatively influenced their attempt to access social support. The other finding was reported by two participants with four references. The finding revealed that caregiving sons tended to have difficulties in hearing criticisms and judgment of relatives and other people. Son 6 shared the following about his brother and sister-in-law: “They ... are not afraid to ... criticize me when they come to visit once in a blue moon ... it would be nice to get some help from them, but I don't want them involved in dad's care for that very reason.”

Dealing With Parents' Dementia and Other Health Problems

Seven participants expressed the difficulties experienced as caregiving sons involved taking care of their parents' health. Such difficulties were encountered when the symptoms of dementia became severe. Five participants defined severe dementia as being forgetful to the point of their parents not recognizing them. Son 1, whose father and mother suffered from dementia simultaneously, revealed, “It was also painful for me that they didn't recognize me.” Sons 7 and 8 shared that their mothers

did not recognize them “towards the end” and articulated that their mothers thought they were hired help. Son 8 added the following:

She was actually able to do things on her own until the last two years of her life when the dementia got bad. It got bad because sometimes she thought I was someone else and had called the police on me twice. She thought I was an intruder ... She had her screaming episodes. Those were tough because I was afraid the neighbors thought I was abusing my mom.

Son 1 added that the symptoms of his parents’ dementia “went downhill fast.”

Three participants shared that their parents’ dementia was comorbid of another illness.

Son 2 shared, “After her stroke, her mind declined. She developed dementia.” Son 7 had the same experience with his mother. Son 8’s mother had “atrial fibrillation or AFib” comorbid with dementia. For Son 8, his mother’s comorbid illnesses were difficulties in that his mother did not inform him when she felt any discomfort.

Sons 7 and 8 reiterated that their experiences with their mothers’ dementia involved “good days” and “bad days.” Son 8 stated, “On good days, mom was fine, cheerful, and easy to work with. On bad days, she would not recognize me.” The experiences of “bad days” referred to failure to recognize close family members. Son 7 cited the following:

On her bad days, my mom thought I was her only son maybe because she didn’t see him as often as she needed to. Twice, my brother flew to LA from Florida to see mom. He stayed with her while he was here. Moving mom to Florida to live with my brother was not an option. Mom has her home here, and this is where she should be.

In relation to his mother's dementia, Son 2 shared that a point came when his mother could not perform daily tasks anymore, such as bathing. The participant experienced difficulties with feeling uncomfortable having to bathe his mother. Son 2 reported, "I wasn't comfortable bathing my mom and doing any hygienic care for her. That's why I hired my female neighbor to help with the bathing and hygienic care." Lastly, Son 3 was the only participant who shared, "I didn't know anything about dementia, and that caused me a lot of stress."

Juggling Caregiving and Personal Life

Six participants shared their experiences of difficulties juggling their caregiving roles along with their personal lives. Generally, the participants sacrificed one aspect of their life to fulfill their caregiver role and other priority obligations. Other obligations included taking care of their families and jobs. The aspect often sacrificed was their social life. Son 4 shared, "I basically gave up my social life, because aside from looking after my mom we also do foster care. We have four foster kids right now." Son 3 expressed the following:

I had my work life and home life. Yes, I had a social life at work. But, after work, my co-workers would ask if I wanted to hang with them, I would say no, I have a sick parent at home. I have to get some sleep before he wakes up. I couldn't do anything else outside of work and home. I had an online social life but I don't really count that.

Son 8 also "sacrificed" a social life and stated, "I sacrificed my social life when I took on caring for my mom. I didn't reach out to friends because I was just too busy. My friends would occasionally reach out to me just to ask how I was."

Among all the participants, only Son 7 experienced having to jeopardize his marriage and worried over supporting his own family while fulfilling his role as a caregiving son. Son 7 shared, "I have a wife and a young daughter to support on top of everything." Son 7 further elaborated with the following:

One difficulty I had was juggling my time between caring for my mom and spending quality time with my own family. My wife was not involved in the care of my mom. I couldn't blame my wife and I would not force her to... For some reason, my wife was jealous of me spending all that time with my mom. I never understood my wife's lack of support. All I asked was for her to be more understanding of my situation. I guess she could not understand my situation because she was never close to her parents.

Son 7 added that he was "fatigued" from taking care of his mother: "Taking care of mom and her needs caused a change in the chemistry between me and my wife. I was tired all the time. I think my fatigue negatively affected my relationship with my wife." Son 4 also referenced feeling "physically and mentally tired." Son 4 articulated the following:

Physically, most at night I lack sleep as I have to change her diapers once or twice a night. That's why it's a great relief when mom stays with my siblings on the weekends. Emotionally, the mere thought that she doesn't remember anyone of her children, no, as in zero, recollection of her raising us is devastating. And she is just in stage three of Alzheimer's, we have been told that her condition will worsen. I am preparing myself for that.

Some participants expressed their worries over their own health and their future. Son 6 cited, "Sometimes it just gets overwhelming. You have your own life to

worry about too, and certain things take a backseat, like your own health. I also constantly worry about the future.” Son 4 experienced difficulties in having to decide to give up his job:

It's quite complicated. I initially took a leave of absence from work for three months to look after mom. I have more than 8 months of sick leave and a year of annual or recreation leave. When I returned to work, it seemed that majority of my staff had turned against me. To make the long story short, I just sacrificed my career so my siblings can continue with their jobs. My children are done with their studies anyway and my wife's income can sustain our living anyway. I know I can still survive with my pension. I accessed it when I retired and do Uber driving although I'm only earning a quarter of my salary.

Tasks of Son Caregivers

All eight participants experienced difficulties in fulfilling tasks associated with being a son caregiver. Seven participants described the difficulties in accomplishing daily routines and chores. Son 3 described his father as a patient of dementia: “My dad had to re-learn to do everything.” Son 3 specified the following:

He had to relearn getting up, getting dressed, putting on a shoe, all the basic stuff we take for granted. I was responsible for making sure he is doing okay. I did a lot of things around the house, maintaining the house. I also maintained the yard, cooked, and went to the grocery.

The participants generally shared similar experiences in doing the cooking, cleaning, and grocery shopping for their parents. Son 7 added, “I also had to watch her to make sure she didn't wander out of the house. She didn't really do that, though.” Son 4 highlighted the following:

It has changed over the past three years but basically nowadays I drive her around, including bring and fetch her to my brother on from Mondays to Wednesdays, and to her social group on Fridays, and to her doctor's appointment, prepare breakfast and medicines, wash soiled bed linen and clothes, change her diapers at night, which is the most difficult part nowadays as it disrupts my sleep, bring her to daddy's cemetery, malls, parks, and other places, act as companion, give her a shower until two years ago.

The participants' parents needed to be monitored regarding their food and medicine intake. Son 8 reported, "I called her throughout the day to remind her to take her medications and eat her meals. I installed a camera to monitor how she was doing." Four participants shared that their tasks included monitoring doctor's appointments and taking their parents to see their doctors. Son 1 noted, "I did the best I could to help them like taking them to their doctor's appointments." Two participants described their tasks to include managing and paying the bills. Son 6 stated, "[I] take care of his insurance, prescriptions, pay bills, deal with all financial stuff, grocery shop for him." Son 5 reiterated that the important task was to make sure his mother was "comfortable." The participant described the following:

I did things to remind her that she's home and make her feel comfortable and at home. I played old music from the 20s, old jazz music that she loved and stuff like that. I would take her to the senior center where she liked participating in arts and crafts. She enjoyed those arts and crafts classes. I helped to keep her active, took her to church, too.

Suddenly Becoming the Primary Caregiver

For six participants, the difficulties in being a caregiving son included the suddenness of taking on the role due to various reasons. The difficulties in the abruptness of being a son caregiver included reasons that their siblings could not help or that they had no siblings, their parents' sickness was sudden, and their added expenses.

Three participants shared that their siblings could not help caring for their parents due to living far away or that they were also sick themselves. Son 8 expressed, "My older sister lives out in Vegas, with her husband and my nephew. She tried to be more involved, but she's also busy with her family." Son 7, whose brother lived in Florida, could not physically help support him taking care of their mother. However, Son 7 added, "My brother and I were constantly communicating with each other, just giving updates about how mom was doing." Son 2 narrated the following:

I had two brothers who had passed away. My oldest brother had already passed away when mom got sick. My middle brother by that time was already ill, diabetic and was a World Trade Center survivor. He was out of a job when the building blew up. His leg had to be amputated in 2008. He couldn't help. He died in 2013, a year before my mom did. I am the youngest of us, three brothers.

Apart from having no siblings/no other siblings available to take care of their parents, the participants believed that their parents' illnesses were sudden. Son 7 specified, "I was suddenly thrust into caregiving when my mom experienced a stroke." Son 3's father suddenly became immobile due to a comorbid illness. The participant took on the role of assisting and caring for his father.

Sons 3 and 5 experienced difficulties in suddenly managing their expenses and finances in connection to their parents' dementia. Son 5 shared, "Between the two of us, when I quit my job to care for her full-time, we were splitting two chicken wings and a can of string beans. That was enough for her, but it wasn't enough for me." Son 3, who took care of his father after graduating from college, could not secure a stable job. Son 3 stated the following:

I just graduated from college. I was expected to go into the workforce, but it didn't happen that way. I graduated from college in 2014. And I immediately moved back home. My dad passed away in late 2019. I became a full-time caregiver. I didn't know that the government had a program where they pay you if you became your parent's caregiver. I didn't have any income. I had a car payment. I had to take a job on the side where I had to work at night when my dad was asleep so I can make money and make my car payments.

Theme 2: Family and Friends are the Main Social Supports

Most participants shared that their social support as caregiving sons to parents with dementia came from their families and friends. Social support came in the form of encouragement, physical help, or in "always being there" (Son 6).

Three participants reported that their spouses offered them social support. Son 1 noted, "I'm an only child like I said. But, yes, I have my own family. I have my wife and three adult children. My wife helped when she could." Son 4 expressed the following about his wife: "I can't do this without the support of my wife. I feel like she does more than I do. She washes my mom's clothes, cooks the food and other chores." Son 6 reiterated, "My husband is always there for me."

Son 1 added that his adult children “helped when they could.” Son 6 supplemented that having a cousin who had similar experiences also provided social support. The participant stated, “I have a cousin going through a similar situation as mine, so I can contact her if I have a question, or just need to vent.” Son 2 expressed that several extended family members worked in the medical field and offered social support. Son 2 stressed, “I had a lot of help. There were a lot of medical people in the family. My mother was a dietician for 35 years. We have nurses in the family.”

However, some participants chose to not rely on friends and family to take care of their parents. Son 3 elucidated the following:

My siblings were fine. I am the only boy. I was fresh out of college; my sisters didn't attend college. My sisters are all married, and they already have families and children of their own. I didn't really expect for them to drop everything to help dad. I moved back in with dad to take care of him. I was in a position to help him. I mean they could have, but they had kids themselves. They have their husbands and they just got married, that's just too much for them. So I'm fresh out of college, and I could help dad. I didn't mind doing most of the caregiving.

Son 6 happened to be the close family member who was the most available when their father was diagnosed with dementia. Additionally, Son 6 stated, “Out of almost everyone, I had more time to give, was already familiar with my parent's health history as well as with his doctors, health insurance, finances etc.”

Some participants had no family and friends to offer support. Son 5's biological parents passed away when he was young, and he had no siblings. He took

care of his aunt who was his nonbiological mother, as no other family members wanted to take on the caregiving role. However, Son 5 emphasized the following:

The other family members were just not involved. They didn't want to be involved. I was the one who spent the most time with my aunt, so in the end, I had to take on the responsibility of caring for her when she became ill. Like I said, I took on the responsibility willingly and with much love. I don't blame the other family members. People are who they are. I cannot make them do things they don't want to do.

Some participants perceived that social support included aid from the doctors, government, and support groups. Son 6 responded, "My dad's doctor is also very helpful. He is really invested in my dad's well-being and is always a phone call or email away." Sons 1 and 2 shared the benefits of social security. Son 2 reported the following:

I got a stipend from the State for taking care of my mom, and I paid some of it to the hired caregiver to help with mom's hygiene... my mother had Social Security income, Medicare, and Medicaid, and that helped. My mom also received \$200 of food stamps.

Son 4 took his mother to a "social group" once a week: "Her Friday social group participation has been delaying the deterioration of her illness." Son 5 once attended a support group for caregivers; however, the participant perceived that the group did not help him address his problems. Son 5's difficulties in taking care of his mother were generally because of the legal issues involved:

I went to one caregiver support meeting at the clinic at the senior center. It was nice and all but...Dealing with my aunt was easy, and that was not a problem

to me. I've known my aunt all my life, and I consider it as a privilege to take care of her. The problem for me was all the legal junk that was being thrown at me to try to make me fail.

Theme 3: The Sons Cannot Do It by Themselves

The experiences of the participants that they referred to as coping strategies to address their problems as son caregivers to parents with dementia generally involved paying for a service or taking a break from their role as caregivers. When the participants' parents' dementia worsened, participants believed that they became unqualified to take care of them. They resorted to hiring professional caregiving services. Additionally, when the participants were overwhelmed with the duties of being a son caregiver, they generally chose to take a break. These two subthemes under coping strategies are described in this section.

Additional findings emerged from the data but were not considered subthemes due to lack of evidence. Three participants reported three references to describe their coping strategies involving positive thinking and expressing gratitude. Son 1 shared, "I kept my thoughts positive. And I thank God for keeping me well. I am good." Another finding from Son 3 involved an information-seeking approach to cope with his father's dementia: "I would read up about the disease, educate myself ... So, learning about the condition, learning about the medications and learning about how the medications affected him."

The third finding entailed accepting that the parent had the illness. Son 5 elaborated with the following:

Most people don't understand how to care for someone who has Alzheimer's.

When dealing with people with dementia or Alzheimer's, it's better to be kind

than right. It's better to be kind than right. So, when the person with Alzheimer's tells you that she can get eggs and peanut butter from the moon, then just say exactly! You can get eggs, peanut butter, and rocket ships from the moon. Exactly. It doesn't make sense to question her ... you're being confrontational and that can only escalate. So, whatever she is saying, just say you're right. Just smile and nod your head. Just like when you're in a foreign country, and they tell you things you don't understand, just smile, and nod your head in agreement. Same thing.

Hiring Professional Help

When the tasks involved in caregiving was beyond the son caregivers' capabilities, five participants hired professional help. The professional help discussed by the participants included a private caregiver, an assisted living facility, and a group home. Sons 2 and 7 employed private caregivers to help their mothers with bathing. Son 7 added that a private caregiver served as his mother's companion while he worked:

I hired a caregiver to do the cooking and to bathe her. I lived nearby, and I worked during the day. I have a wife and a young daughter to support on top of everything. While I was away, the caregiver would stay with mom. I would spend the night with mom most of the time. When I could not be there, a caregiver was there.

Son 8 perceived that his mother could not be left alone for safety reasons, and one way to lessen his worry about her was to hire a private caregiver. Son 8 reported, "I hired a caregiver to come in the middle of the day to check on her." However,

when Son 8's mother developed severe symptoms of dementia and atrial fibrillation, he opted to transfer her to an assisted living facility:

I also used caregiver services. And when mom grew worse, I had no choice but to take her to an assisted living facility... I had to take her to the facility because she could not be left alone safely anymore. She would fall because of dizzy spells because of her AFib.

Son 5 specified, "That's when her memory started to fail her. I was with her until she was 98, that's when I had to move her to a nursing home." Son 1 revealed that he took both his parents to a group home when their dementia worsened. However, instead of helping him cope with his problems, Son 1 shared that the decision to move his parents was "a mistake." Son 1 stated the following:

Boy, that was a mistake because there was abuse. It was very bad. That was very painful for me ... I hear these places are better now. But, when my parents needed to be placed, I didn't have many choices. They all seemed bad, with unqualified staff.

Taking a Break From Caregiving

Six participants took breaks to cope with their caregiving challenges. Three took breaks to talk to their spouses and/or children. Sons 4 and 6 also perceived that talking to their loved ones added to the quality time spent together. Son 6 shared, "Talking with or doing something with my husband always calms me down. He's good for a laugh." Apart from loved ones, Son 4 also used "social media ... as an escape tool," and he usually talked to people at work about his situation. Son 4 stated, "Nowadays, [omitted company name] driving has been helping me a lot, especially when I tell my riders about my situation."

Some participants shared that they engaged in other activities to take a break from caregiving. Other activities included working, exercising, taking a walk, listening to podcasts, and watching television or movies. Like Son 4, Sons 1 and 7 used their work to take their minds off their caregiving roles. Son 7 detailed, “To cope with the stress, I would spend time alone in my office at work. Just did a lot of thinking and hoping.” Apart from spending time in the office, Son 1 added, “I went back to the gym, swam in the pool all the time.” Son 6 described television and movies as “a good escape” from the caregiving role.

Sons 5 and 8 took walks to “clear the mind.” Son 5 took leisurely walks, stating, “Mostly afternoon walks. Those walks helped me clear my mind. I listened to music a lot. I would go to the mall to walk around, just to get away, eat ice cream.” Son 8 shared that going to the gym or for a walk helped him clear his head: “I would take a walk around the block. I would go to the gym to de-stress. I’d jump into the Jacuzzi. And then I’d go back to realizing that it’s not mom, it’s the disease.” Son 8 added the following:

I like listening to podcasts. They are one of my favorite ways to get information. I can listen to a podcast almost anywhere while doing anything. I usually will listen as I drive or in the gym. I listened to a lot of podcasts on dementia, caregiving for the parent with dementia.

Theme 4: The Sons Do It for Love

All the participants were enthusiastic and willing to serve as their parents’ caregivers. All the participants shared that they were “glad” and “felt good.” They felt rewarded concerning taking care of their parents. Son 3 explained the following:

I mean I [got] to spend a lot of time with my dad. My dad is my hero anyway. I was very happy, even though he felt he was being a burden. But, that wasn't the case, though. I was happy making sure he was being taken good care of. I was there for him, man. So, I was the one who decided to move in and live in with him.

Five participants shared that their motivations for being a caregiving son were that they loved their parents. Son 7 emphasized, "I had no other motivation but love ... I did it out of love. My help was needed, so I jumped in without a thought." Son 1 reiterated the following:

I did it for love. What they've done for me is priceless ... there's a lot of pressure, confusion in being a caregiver but it is worth it for me. It's part of the deal, part of life. I am happy and proud of what I have accomplished in caring for my parents. I loved both of my parents, and I am glad to have been there for them in their time of need. My daddy is a good father, a good husband. My mommy, too, she was a good woman.

Son 8 also contended that his motivation was his love for his mother with whom he had a close relationship. Son 8 shared, "Well, I love mom. I was a mama's boy. We've been through a lot together. We consoled each other when dad passed away. We were there for each other in good and bad times."

Three participants reported that being their parents' caregiver was a choice they made to be able to give back. Son 1 stated, "It was a moral choice, the right thing to do." Son 5 stated, "I felt the need to repay my aunt, whom I considered as my mom ... I wish I could have done more to care for her and protect her, but God knows I tried my best." Son 3 reiterated the following:

Oh, my father has always been there for me. He's my hero. He was always there for me, a career military man. He kept pushing me to go to college. He instilled in me the value of hard work. So, it was a no-brainer for me when he told me. He said he hated it when I did it but was happy that I put my life on hold for him. But I never felt that way. He was there for me and I needed to be there for him.

Theme 5: Lessons Learned From Being a Son Caregiver

All the participants perceived that the lessons they learned from being son caregivers were the needs that would improve the social support for other son caregivers. Most participants learned of the need to have formal training on caregiving, as well as on handling psychological issues, to help son caregivers better aid their parents with dementia. Son 8 reiterated, "So, I got to be familiar with her condition. I guess that's a training, right? But, for sure, a training in caring for someone who has a cognitive impairment would help." Son 3 shared the following:

But it was really tough for me. If it was up to me, I could use some psychological training. I could have gone through a psychological training, a support group that could have told me, hey, these are the things that you may face when you're dealing with a parent, take care of a parent who has become ill or is now dependent on you.

Two participants learned that access to information about dementia and forms of support for son caregivers would have helped them in their roles. Son 6 stated, "Informative, easy to navigate, comprehensive websites would also be useful. Sometimes you just have a quick question about insurance or a power of attorney or a

recommendation of some sort. You can spend hours researching online.” Son 6 also learned a need for support groups for son caregivers.

In relation to the coping strategies described by most participants, two son caregivers stated that they learned of the need to reach out to their friends and family members for help. Son 8 contended, “You cannot go at it alone. Reach out to your siblings or other family members for support. It is a better option than trying to take on the situation entirely on your own.” Additionally, Son 7 reported the need to hire professional help if the budget allowed. Son 7 expressed, “Lesson learned is get help for yourself. If you can afford it, hire a caregiver to help you. You can’t do it on your own.”

Summary

The purpose of this qualitative interpretative phenomenological study was to contribute to the empirical literature on the phenomenon of the social support of caregiver sons of parents with dementia. The results of this study answered the research question: What is the lived experience of the social support of son caregivers of parents with dementia? The lived experiences of the eight caregiving sons to parents with dementia interviewed in this study involved five themes. The themes included (a) unprepared for caregiving, (b) family and friends are the main social supports, (c) the sons cannot do it by themselves, (d) the sons do it for love, and (e) lessons learned from being a son caregiver. The theme unprepared for caregiving revealed four subthemes: (a) dealing with parents' dementia and other health problems, (b) juggling caregiving and personal life, (c) tasks of son caregivers, and (d) suddenly becoming the primary caregiver. The theme of the sons cannot do it by

themselves also revealed two subthemes: (a) hiring professional help and (b) taking a break from caregiving.

The participants' lived experiences uncovered a need to improve the social support of son caregivers. These adult sons faced a myriad of difficulties as caregivers that were not necessarily because of gender roles, but because of their parents' health problems, their careers and families, their daily tasks, and the suddenness of taking on the primary caregiver role. The current social support of son caregivers was limited to whichever friend or family was available. Professional caregiving services were only sought when the sons perceived that they could no longer take care of their parents by themselves. Thus, hiring professional help was identified as a common coping strategy among the participants. Another coping strategy was to take breaks from their caregiver role and to do activities that helped them relax or at least keep their minds off the pressures of caregiving. However, all the participants willingly, and enthusiastically took on the role as their parents' caregivers, mostly due to love and to give back to their parents. A need to improve social support was further fortified in the findings regarding the lessons learned by the participants while playing the role of their parents' primary caregiver. The lessons entailed the need for formal training on caregiving, as well as the need to access of information, to access professional caregivers, reach out to family and friends, and have support groups for son caregivers.

The findings of this study appeared to break gender role stereotypes as son caregivers did not display assertiveness, leadership, and independence but showed caregiving behaviors of nurturance. These findings are further discussed and interpreted in the next chapter through the lens of the SRT (see Eagly & Wood, 2012).

Chapter 5 also contains the implications, limitations, recommendations, and conclusions of the study.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

Changing cultural and societal dynamics with more women entering the workforce have decreased the availability of daughters to care for their older adult parents, and sons have increasingly filled the role of primary caregiver instead (Wallroth, 2016). Male caregivers experience the caregiving role differently and need social support and resources that are male-specific (Edwards et al., 2017; Giesbrecht et al., 2016). However, these resources are lacking, and knowledge about the needs and social support of male caregivers, particularly those who care for parents with dementia, is very limited (Schwartz & McInnis-Dittrich, 2015). Therefore, there is a need for more research in this area to understand better the experiences of sons caring for parents with dementia to provide them with supportive resources needed to be more successful in this caregiver role.

The purpose of this study was to contribute to the empirical literature on what facilitates or hinders a son in his ability to successfully care for a parent with dementia. I conducted the study from a qualitative interpretive phenomenological perspective that focused on a son's health while in the caregiver role and experiences with obtaining assistance and support. I interviewed the participants with the aim of answering the following research question: What is the lived experience of the social support of son caregivers of parents with dementia?

Key findings from this study indicated a need to improve the social support of son caregivers that included formal training on caregiving, access to information on professional caregivers, contact with family and friends, and support groups for son caregivers. The findings of this study also countered gender role stereotypes (Cheng,

2017; Kahn et al., 2016; Livingston et al., 2017) in that son caregivers in this study did not display assertiveness, leadership, and independence, but showed caregiving behaviors of nurturance.

Interpretation of the Findings

Theoretical Framework

The theoretical framework for the study was Eagly and Wood's (2012) SRT. Eagly and Wood posited that gender stereotypes perpetuate through individuals being exposed to them and perceiving them in others. The basis of the SRT is the proposition that gender is witnessed in others and serves as a template for the norms of how one should act and be (Eagly & Wood, 2012). When followed through, Eagly and Wood's (2012) SRT infers the belief that the root of all societal roles for men and women are due to psychological differences between the sexes as the result of thousands of years of evolutionary biology.

These main differences between sexes are the notable size and strength of men, in contrast to women's heightened ability to nurse children or those in need of care (Eagly & Wood, 2012). These differences have led to an increased ability of women to be more efficient at caregiving while men seem to be better suited for other work (Eagly & Wood, 2012). Culture promotes gender stereotyping where women are assigned attributes of nurturing and domestic tasks, while men are given archetypes of assertiveness, leadership, and independence (Eagly & Wood, 2012). Although people enact a specific social role, they carry out the gender role on which it was modeled. Eagly and Wood (2012) also noted how gender roles were biosocial, reverberating in hormonal fluctuations, social self-regulation, and social self-regulation in relation to

the expectation of others' gender norms. Eagly and Wood postulated that gender roles were not only biosocial but also psychosocial.

Gendered expectations may lead to self-fulfilling prophecies and the societal idea that male caregivers are unrealistic. However, findings suggest that the sons in this study perceived that being a male caregiver was realistic and necessary to ensure that their parents with dementia would be properly cared for. Due to dementia's progressive nature, caregivers of a family member with dementia are at an increased risk of stress, depression, and other chronic illnesses (Cheng, 2017; Kahn et al., 2016; Livingston et al., 2017). The self-care management of these caregivers is what helps to sustain their ability to care for their loved one. Self-care means knowing how to take care of oneself and the aging parent (Cheng, 2017; Kahn et al., 2016; Livingston et al., 2017). Self-care also involves knowing how and where to obtain help from the community and from relatives and friends when needed. To sustain oneself while committing to caring for another person calls for self-care activities on an ongoing basis (Cheng, 2017; Kahn et al., 2016; Livingston et al., 2017). Using Eagly and Wood's (2012) SRT showed a totalized view of how gender and social roles were interlaced.

Study Themes

The commonalities in the lived experiences of the eight caregiving sons interviewed in this study were reflected in the five themes that emerged from data analysis. These themes included (a) unprepared for caregiving, (b) family and friends are the main social supports, (c) the sons cannot do it by themselves, (d) the sons do it for love, and (e) lessons learned from being a son caregiver. The theme difficulties of being their parents' caregiver revealed four subthemes: (a) dealing with parents'

dementia and other health problems, (b) juggling caregiving and personal life, (c) tasks of son caregivers, and (d) suddenly becoming the primary caregiver. The theme of sons doing it by themselves also revealed two subthemes: (a) hiring professional help and (b) taking a break from caregiving.

Unprepared for Caregiving

The lived experiences of participants as caregiving sons of parents with dementia generally involved difficulties that affected their social support. These findings confirm previous findings in the literature that revealed that regardless of gender, family caregivers who provide care for family members with dementia are at a high risk of suffering from social isolation (Riffin et al., 2017). These findings may also confirm previous findings that masculine men can feel isolated when in the role of caregiver if others look down on them (Bartlett et al., 2016; Riffin et al., 2017). Participants shared their experiences of difficulties in juggling their caregiving role along with their personal lives. Generally, the participants sacrificed one aspect of their life to fulfill their caregiver role and other priority obligations, and the aspect that was often sacrificed was a social life.

Seven of the eight participants also expressed the difficulties they experienced in taking care of their parents' health, particularly when the symptoms of dementia became severe. Previous research conducted by the National Alliance of Caregivers (2015) also emphasized the high burden of care that dementia caregivers experience, with the additional distress that impacts their lives, and older male caregivers who care for those with dementia consistently experience a higher level of a multiple burdens, other research shows (Sharma et al., 2016). However, these findings appear to disconfirm previous findings in the literature that males who were caregivers for

those with dementia experienced lower levels of caregiver burden (Bartlett et al., 2016), and women experienced a greater burden while providing care to dementia patients (Pillemer et al., 2017). This apparent contradiction in the existing literature could be explained by the theoretical framework for this study of Eagly and Wood's (2012) SRT and what has previously been demonstrated in other research that because of the way gender constitutes social roles, males who perceive themselves as masculine may resist the temptation of reporting caregiver burden (Broughton et al., 2011).

Another difficulty in being a caregiving son that many participants shared was the suddenness of taking on the role due to various reasons. The sudden need for these sons to become caregivers aligns with the growing body of literature in this area that is shrinking. Geographically separated families require the need of immediate and extended family caregivers to care for older relatives and other family members with chronic illness (Wolff et al., 2016). These findings also support previous findings that in the last 10 years, a male family member, such as a son, available to take up the task has met the need for care of a growing number of older adults (Hicks et al., 2018).

Family and Friends are the Main Social Supports

Most participants in this study shared that their social support as caregiving sons to parents with dementia usually came from their family and friends, though some participants perceived that their social support came from doctors, the government, and support groups. The types of support offered generally came in the form of encouragement and physical help. These findings, for some participants, might disconfirm previous findings that men who were caregivers who identified as masculine had trouble maintaining contact with their male friends due to the

perceived role they took up as caregivers (Bartlett et al., 2016). However, two participants learned during their caregiving experience of the need to reach out more to family and friends, which could confirm these previous findings. Bartlett et al. (2016) further concluded that the reported experience for male caregivers is quite variable and diverse. These findings may also disconfirm the findings of Edwards et al. (2017), who used data from the 2009 BRFSS and found that in contrast to female caregivers, male caregivers were more ready to report a lack of social support.

The Sons Cannot Do It by Themselves

Coping strategies to address their problems as son caregivers to parents with dementia generally involved paying for a service or taking a break from their role as caregivers. Usually when the participants' parents' dementia worsened, they felt that they became unqualified to take care of them. They resorted to hiring professional caregiving services. These findings supported previous findings in the literature that 67% of those who care for those with dementia reported performing medical and nursing tasks with no training or preparation for such roles (National Alliance for Caregiving, 2015).

Additionally, when the participants in this study were overwhelmed with the duties of being a son caregiver, they generally chose to take a break. The willingness of the son caregivers in this study to take a break confirmed previous conclusions in the existing literature that a large part of self-care is understanding one's feelings about caregiving, which can help one cope with the role (Wang et al., 2019).

According to Orem et al. (1995), every person has the capacity to self-care and is responsible for their own health and the health of others they care for. These findings also aligned with previous literature. Researchers showed that depending on how male

caregivers sensed their roles based on their genders, traditional roles of masculinity led to suppressed coping methods (Eagly & Wood, 2012; Schwartz & McInnis-Dittrich, 2015). A less masculine, more feminine approach allowed for more open coping strategies (Eagly & Wood, 2012; Schwartz & McInnis-Dittrich, 2015). These finding showed the complexity of gender and the validity and applicability of the SRT for this study.

The Sons Do It for Love

All the participants expressed that they were enthusiastic and willing to serve as their parents' caregiver. All the participants also shared that they were "glad," "felt good," and felt rewarded for taking care of their parents. Five participants shared that their motivation for being a caregiving son was that they loved their parents, and three participants reported that being their parents' caregiver was a choice they made to be able to give back. Traditionally, societal expectations dictate that women fill the role of caregivers, and they tend to dominate such roles (Riffin et al., 2017). The motivations and reasons given by the son caregivers in this study for being willing to take care of their parents with dementia expanded on the knowledge provided in existing literature of the SRT. The SRT showed that men's roles defined by environmental, psychological, and biological factors affected their decisions to care for older adult parents (Gilbert et al., 2018).

Lessons Learned From Being a Son Caregiver

All the participants perceived that the lessons they learned from being a son caregiver were the needs that would improve the social support for other son caregivers. Most participants learned of the need to have formal training on caregiving, as well as on handling psychological issues, to help son caregivers better

aid their parents with dementia. Two participants learned that access to information about dementia and about forms of support for son caregivers would have helped them in their roles. Two son caregivers also stated that they learned of the need to reach out to their friends and family for help. The recognition of the need for improved social support for male caregivers aligns with existing literature that expressed this same need for the development of tools and resources that will meet the requirements of the male family caregiver, specifically male caregivers who are aiding family members with dementia (Riffin et al., 2017). As Schwartz and McInnis-Dittrich (2015) also stated, changes must be made to improve the future of the caregiver and patient by establishing a more diverse system of support and network of communication amongst all medical professionals (Peipert et al., 2018). These findings also extend the knowledge within the existing literature of how social support can be improved for male caregivers, particularly for those caring for parents with dementia. Participants cited the need for more formal training and support with coping with psychological issues. They also discussed the need to learn how to access information about dementia and more support and the need to understand the importance of reaching out to family and friends for support.

Breaking Gender Role Stereotypes

The findings of this study appeared to break gender role stereotypes as the son caregivers in this study did not display assertiveness, leadership, and independence but showed caregiving behaviors of nurturance. However, a variety of factors influence gendered behavior, including socialization and gender stereotyping (Lee & Tang, 2015). These researchers also did not deny the role of differentiated hormonal responses as a means of explaining behavior under different conditions (Lee & Tang,

2015). A second factor explaining behavior was self-standards or the internalized gender roles that people integrated and used to regulate their behavior in response to their environment. The last factor explained behavior as regulation in response to expectations (Eagly & Wood, 2012; Lee & Tang, 2015). Certain personality traits are promoted and encouraged, and specific types of behavior are supported among individuals of different genders (Swinkels et al., 2017). Therefore, although the findings in this study appeared to break gender role stereotypes, they also confirmed these previous findings in the literature of the conclusion that people regulate their behavior in response to their environment and expectations when certain personality traits are promoted and encouraged among individuals of different genders. The son caregivers in this study adapted to and regulated their behavior in response to their environment and the expectations of caring for their parents with dementia by becoming more nurturing to be more effective caregivers. The stereotypical male-gendered traits of assertiveness, leadership, and independence were not as needed in response to their environment and may have even interfered with or obstructed their ability to be more effective as caregivers.

However, retaining the more stereotypically male-gendered trait of assertiveness may have facilitated the ability of these son caregivers to obtain needed social supports in the areas of more formal training, more support with coping with psychological issues, the need to learn how to access information about dementia and other social supports, and the need to understand the importance of reaching out to family and friends for help. Being more assertive though to obtain these needed social supports could have created a masculine gender stereotype conflict with displaying the behaviors of independence and leadership of not appearing to need additional

social support and help. Bartlett et al. (2016) highlighted this type of conflict that male caregivers experienced was a gender role conflict deemed more significant than gender identity as they struggled to construct themselves in the role of caring. This gender role conflict also demonstrates why men may be so reluctant to reach out to support services and why men need services and resources made readily available.

It has also been demonstrated that because gender constitutes social roles, males who perceive themselves as masculine may resist the temptation of reporting caregiver burden (Broughton et al., 2011). Hicks et al. (2018) also noted that rather than following prior data where female caregivers were the ones to be more apt to report stressors or issues, they found that male caregivers were more willing to report a lack of social support stemming from a perceived but statistically valid lack of social support. These studies are all examples of the persistent masculine stereotype gender role conflict that exists for male caregivers among the behaviors of nurturing or assertive, leadership, and independence. Another study also demonstrated how the variable designs, samples, data collection and analysis, assessment-procedures, and theoretical frameworks have given rise to the many variations that exist in the findings and may postulate gender differences amongst caregivers in areas where it may or may not persist (Bartlett et al., 2016).

The findings from this study extend the knowledge within the existing literature by providing a specific scenario of the environment and expectations of the male caregiver role to understand better the fluidness and adaptability of gender that breaks stereotypes. The son caregivers who shared their experiences in this study of caring for their parents with dementia appeared to emphasize the stereotypically feminine trait of nurturing over the more stereotypically masculine traits of

assertiveness, leadership, and independence to be more effective caregivers. The resulting masculine stereotype gender role conflict that they experienced aligns with existing literature, particularly how it negatively impacted their ability to access needed social support (Bartlett et al., 2016).

Summary of Findings

Generally, the participants' lived experiences uncovered a need to improve the social support of son caregivers. Adult sons as caregivers faced many difficulties, not necessarily because of gender roles but because of their parents' health problems, careers and families, daily tasks, and the suddenness of taking on the primary caregiver role. These findings appear to disconfirm some of the basic tenets of the theoretical framework for this study of the SRT of Eagly and Wood (2012), which states that gender stereotypes are perpetuated through individuals being exposed to them and perceiving them in others. The basis of the SRT is that gender is witnessed in others and serves as a template for the norms on how one should act and whom they should be, with the main differences between sexes being the notable size and strength of men, in contrast to the women's heightened ability to nurse children or gestalt those in need of care, with these differences leading to an increased ability of women to be more efficient at caregiving while men seem to be better suited for other work.

All the son caregivers who shared their lived experiences of caring for their parents with dementia were able to break any gender stereotypes and norms that they had been exposed to of how they should act or who they should be and perceived that it was not a conflict with gender stereotypes that was a significant difficulty for them. Instead, it was the caregiving challenges of their parents' health problems, their

careers and families, their daily tasks, and the suddenness of taking on the primary caregiver role, all challenges that a female caregiver might also experience, even if she would be more 'suited' to being a caregiver because of gender stereotypes.

However, these findings confirm the psychosocial aspects of the SRT regarding enacting a specific social role of caregiver and social self-regulation concerning the expectation of others' about gender norms by displaying the caregiving behavior of nurturance instead of the behaviors of assertiveness, leadership, and independence.

The current social support of son caregivers was limited to whichever friend or family was available. Professional caregiving services were only sought when the sons perceived that they could no longer take care of their parents by themselves. Thus, hiring professional help was identified as a common coping strategy among the participants. Another coping strategy was to take breaks from their caregiver role and to do activities that helped them relax or at least keep their minds off the pressures of caregiving. However, all the participants willingly and enthusiastically took on the role of their parents' caregiver mostly due to love and to give back to their parents. A need to improve social support was further fortified in the findings regarding the lessons learned by the participants while playing the role of their parents' primary caregivers. The lessons entailed the need for formal training on caregiving and the need to access information, access professional caregivers, reach out to family and friends, and have support groups for son caregivers.

Limitations of the Study

A significant limitation of this study was the small sample size of eight participants. Another limitation of the study that might have contributed to this small sample size was that the United States was currently experiencing a pandemic related

to the novel coronavirus COVID-19 (CDC, 2019) when this study was conducted. This issue might have prevented some potential interviews from taking place. An additional limitation of the data was that participants might have been less likely to disclose personal information fully during an interview with a stranger or in a public place (see Seidman, 2012). This limitation may have been partially offset by participants being interviewed via Zoom, phone, or email rather than face-to-face in a public place.

Although every effort was made to ensure the study's credibility by interviewing at least ten participants and reaching data saturation, there were only eight participants, which therefore presented as another limitation to the trustworthiness of this study. Data saturation refers to the point at which no new or novel information is being collected from participants (Rubin & Rubin, 2012). Reaching data saturation prevents the data from being skewed by unique experiences that are not generally experienced by others in the population. Although each participant's experiences are unique, reaching data saturation ensures that the experiences described by participants are at least relatable to others within the population. Reaching data saturation also helps ensure the transferability of the data.

Recommendations

Most research to date has focused exclusively on female family caregivers in the United States, which has led to a limited understanding of the experiences of men who care for aging parents and the need to gain a deeper understanding of the male caregiver experience to implement a more viable system of support and resources (Nance et al., 2018). Furthermore, when noting the risks common to both genders, such as feelings of social isolation when caring for family members with dementia,

there is also the need to study the experiences of male caregivers to develop tools and resources that will meet the requirements of the male family caregiver (Riffin et al., 2017). This study has helped to fill the gap in the existing literature by providing more insight into the male caregiver role as sons and the struggles and difficulties they faced when caring for aging parents with dementia, as well as their presenting needs and the social supports that they perceived were necessary to be empowered to more successful as son caregivers. An important contribution was made as well for better understanding how the SRT, as posited by Eagly and Wood (2012), intertwines and interacts with the male caregiver role and specific reasons why the SRT shows that male roles as defined by environmental, psychological, and biological factors affect their decision to care for older adult parents (Gilbert et al., 2018). A deeper understanding of the fluidity and adaptability of gender roles was also provided to expand on the existing literature of sons who broke gender stereotypes and norms by displaying the behavior of nurturing rather than the behaviors of assertiveness, leadership, and independence.

The limitations of this study of small sample size and being conducted under the unusual conditions of a pandemic though invite and recommend further research of the lived experiences of son caregivers of parents with dementia to ensure even greater data saturation and trustworthiness. Further exploration into the themes of son caregivers who care for parents with dementia in the areas of the caregiving difficulties that they experience, social supports they currently access, coping strategies, and perceived social supports that are still needed will continue to expand on the existing literature, with important contributions that are needed to improve the tools, resources, and supports currently available to them. Further research into how

the SRT, gender role stereotypes, and resulting gender role conflicts all interact and influence son caregivers is also recommended to add a deeper understanding to the existing literature for improving existing tools, resources, and supports.

Implications

The implications of this study offer many opportunities to promote positive social change on the individual, family, and organizational levels. Individuals who are male caregivers, particularly those who are son caregivers that are caring for their parents with dementia, could benefit from the lived experiences that these other son caregivers have shared about their difficulties with caregiving, their coping strategies, and lessons that they have learned by comparing their experiences with caregiving and learning and growing through such a process. In turn, further empowering these son caregivers to be more successful in the caregiving role could also help build better relationships with their parents and strengthen the entire family unit. Particularly in terms of strengthening social supports on the family level and then to the organizational level, the implications from this study also offer valuable and deeper insights for ways to improve existing tools, resources, and supports for son caregivers by offering formal training on caregiving, training on how to access needed information, access to professional caregivers, training on how to reach out to family and friends for help, and support groups specifically offered for son caregivers.

The findings of this study also have implications for a deeper understanding of the theoretical framework of the SRT as posited by Eagly and Wood (2012) and how gender role stereotypes compare with the fluidity and adaptability of gender in response to social expectations and the need to be more effective in social roles. Although a gender role conflict was not explicitly shared by the son caregivers who

participated in this study when they were able to break the gender role stereotypes of the caregiver role by displaying the behavior of nurturance rather than the behaviors of assertiveness, leadership, and independence, a conflict was still implied when considering their need to also access more social supports by being more assertive and how this need for more help could also conflict with the need to be leaders and independent. These findings regarding the SRT have implications for male caregivers the need to continue to understand further the interaction of gender role stereotypes, the fluidity and adaptability of gender, and any resulting gender role conflict that they may experience to empower them to be more successful on every level in the caregiver role.

Conclusion

This study on the lived experiences of son caregivers who are caring for their parents with dementia shared important insights that contributed to the gap in the existing literature. I provided a better understanding of the difficulties they experienced in the caregiver role, the social supports they accessed, their coping strategies, their reasons for becoming a caregiver, and the lessons they learned as caregivers. Significant findings from this study included the recognition that gender role conflict as a male in the caregiver role was not reported by these participants as being a major difficulty for them, as they were able to adapt to the caregiver role and break gender stereotypes by displaying the behavior of nurturance rather than the behaviors of assertiveness, leadership, and independence. The perceived major difficulties that these son caregivers shared that they experienced instead were their parents' health problems, their careers and families, their daily tasks, and the suddenness of taking on the primary caregiver role. These son caregivers could access

some limited social supports such as family and friends, doctors, the government, support groups, and professional caregiving services as a part of their coping strategies, particularly when the symptoms of dementia became more severe.

However, all the participants perceived that the lessons they learned from being a son caregiver were the needs that would improve the social support for other son caregivers in formal training on caregiving. Participants also cited the need to access information and professional caregivers and reach out to family and friends. They discussed the need for support groups for son caregivers.

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Appendix A: Interview Questions

1. Tell me how you ended up becoming the caregiver for your parent.
2. Tell me about your motivations for the taking on the caregiver role for your parent?
3. Tell me about the tasks you perform as a caregiver for your parent?
4. Describe for me any tool or training that would be most helpful for you.
5. Tell me about the difficulties you have experienced in your caregiver role.
6. Tell me about the satisfaction you derive from your caregiver role.
7. Tell me about your experience with stress of being a caregiver and your coping strategies.
8. Tell me about the social supports you have and use?
9. Describe your interpersonal relationships with your siblings, spouse,
10. Describe your relationships with other family members and friends.
11. Describe for me any take away from the experience of providing care for your parent?

Appendix B: Flyer

**Research Volunteers Needed: Sons Who Care for a Parent with Dementia**

I am conducting a research study titled Social Support of Caregiver Sons of Parents with Dementia. The study will focus on the son's experiences in obtaining assistance and support, and the son's health. If you are a son caring for a parent with dementia who is interested in sharing your experience for the purpose of the study, please email or phone the researcher using the contact details at the end of this flyer.

You may qualify if you are:

- 18 years of age or older
- Involved son caregiver of an aging parent with dementia

Participation involves:

- Formally consenting to participate in the research study
- 60-minute audio recorded interview
- Interview conducted via Skype due to COVID-19
- Checking interview transcripts for accuracy

If you are interested in participating or receiving additional information, please contact Ralph Pascual at [telephone number and email address redacted].

Appendix C: Mental Health Services Support List

FREE OR LOW COST MENTAL HEALTH /COUNSELING SERVICES	
<input type="checkbox"/> 211.org Call 211 for the most comprehensive source of locally curated social services programs/information in of the U.S. and Canada.	<input type="checkbox"/> Los Angeles County Department of Mental Health 320 W. Temple Street Suite 9 Los Angeles, CA 90012 (213) 974-0515 https://www.dmh.lacounty.gov/ Contracts with close to 1,000 organizations and individual practitioners to provide a variety of mental health-related services.
<input type="checkbox"/> Los Angeles Caregiver Resource Center 3335 S. Figueroa Street Suite E Los Angeles, CA 90007 (800) 540-4442 https://www.fcsc.usc.edu/	<input type="checkbox"/> California Mental Health 14305 Morgan Street Baldwin Park, CA 91708 (626) 453-6233 https://www.californiamhc.org/
<input type="checkbox"/> Stars Behavioral Health 9040 Telstar Avenue Suite 101 El Monte, CA 91731 (626) 774-5809 https://starsinc.com/	<input type="checkbox"/> Arcadia Mental Health 330 E. Live Oak Avenue Arcadia, CA 91008 (626) 821-5858 https://locator.lacounty.gov/
<input type="checkbox"/> Didi Hirsch Mental Health Services 323 N. Prairie Avenue Inglewood, CA 90304 (310) 877-7808 https://didihirsch.org/	<input type="checkbox"/> SAMHSA Behavioral Treatment Services Locator Confidential and anonymous source of information for individuals seeking treatment facilities in the U.S. for mental health issues. (800) 862-4357 https://findtreatment.samhsa.gov
<input type="checkbox"/> Mental Health.gov Provides one-stop access to U.S. government mental health problems information. U.S. Department of Health and Human Services 200 Independence Avenue, S.W. Washington, D.C. 20201 https://mentalhealth.gov/	<input type="checkbox"/> Betterhelp.com Affordable, private online counseling https://betterhelp.com/