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Perspectives of the Female Spouse in Dementia Caregiving Formal Resource Use

By

ANNA SATAKE PhDc, RN, MSN, GCNS

DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

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in

Nursing Science and Health-Care Leadership

in the

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of the

UNIVERSITY OF CALIFORNIA

DAVIS

Approved:

Janice Bell, Chair

Elena Siegel

Helen Kales

Committee in Charge

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Dedication

I dedicate this study to all the family caregivers and the persons with dementia they care for 24/7. As a healthcare provider in geriatrics, I am reminded regularly how our society and system often fail to provide the acknowledgment and needed support for caregivers, not just at the time of a diagnosis but along the difficult and life-changing journey. We need to continue to find ways to wrap our resources and care around people with dementia and their entire caregiving network in a way that supports them mentally, physically, financially, and spiritually. May this study bring a small piece of knowledge to help improve how we support wife caregivers of persons with dementia.

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Chapter 1: Introduction

Statement of the Problem

Providing care for our increasingly aged population, especially those with dementia, is a daunting challenge. Approximately 47 million people worldwide are diagnosed with dementia (Prince et al., 2016), with nearly 6.5 million in the United States (Alzheimer's Association, 2022). Due to the rapid growth of the aging population, the number of people with dementia (PWD) in the United States is expected to double by the year 2050 (Alzheimer's Association, 2022). A person with dementia initially has impairments related to short-term memory loss. However, as memory continues to decline, it impacts executive functioning and causes a loss of ability to provide self-care (Braun, 2009). Currently, there is no cure for dementia, and the disease's progression can be arduous. Additionally, most of the caregiving responsibility lands on the family. While some family caregivers can manage the challenges of dementia care, many struggle and experience decrements in both physical and mental health (Kuzuya et al., 2011; Papastavrou et al., 2007; Schulz & Martire, 2004). Several studies have shown that the family caregivers who have reported the most significant strain are females (Ehrlich et al., 2014; Friedemann & Buckwalter, 2014; Friedman et al., 2015), spousal caregivers (Braun, 2009; Rigby et al., 2019), and those who reside with the person with dementia (Braun, 2009).

Resources for support and education can minimize family caregiver stress and burden (Bass et al., 2013; Cox, 1997; Luchsinger et al., 2018). Within the dementia caregiving literature, two types of support or resources are studied: formal and informal. Informal resources refer to caregiving assistance provided by family, friends, neighbors, or community members (Bakker et al., 2013). Formal support services generally fit into categories that provide professional or paid services such as home-based, community-based, and residential care such as nursing homes (Bakker et al., 2013; Li & Song, 2019). Formal home-based resources include assistance with

ADLs, respite and paid care leave, support groups, and integrated services (i.e., healthcare, case management, and social work) (Bakker et al., 2013; Li & Song, 2019). This research focuses on formal support services that are home or community-based, not including those that are solely diagnostic or medical management services.

The availability of formal caregiving resources varies depending on the area of residence (i.e., town, rural/urban, state, country) due to local or federal funding or the ability for financial assistance through insurance coverage. The variation in caregiving or dementia formal services is also partially influenced by a country's policies to help older adults age in place and to help decrease the need for institutionalization (Knapp et al., 2007). In the United States, access to formal caregiving resources is found within Senior Centers, non-profit organizations, private companies, or government agencies such as the Department of Veterans Affairs (Newkirk et al., 2020). Starting in the year 2000, the federal U.S. government passed the National Family Caregiver Support Program (NFCSP) (Title III-E of the Older Americans Act 2000 Reauthorization), which was created for states to implement in collaboration with the Area Agencies on Aging. However, with each state implementing the NFCSP differently, there has been inconsistency regarding the implementation and availability of formal support services across the U.S.

Although there is some evidence that family caregivers who use formal support services early can delay institutionalization (Gaugler et al., 2005), only 53% of dementia caregivers report being offered any such caregiver services (AARP and National Alliance for Caregiving, 2015). Interestingly, even when offered support services, only 25% of dementia caregivers report using them (Wolff et al., 2016). Not only are the use of formal resources already underutilized, but some research also shows that among family caregivers, those using the least are spouses (Cox,

1997; Robinson et al., 2013; Winslow, 1997) and women (Friedemann & Buckwalter, 2014; Sutcliffe et al., 2017). The purpose of this study was to explore female spousal caregivers' decisions regarding the use of formal caregiving resources in caring for a partner with dementia.

More recently, family caregiving and resource utilization has also been impacted by the COVID-19 pandemic that emerged in the United States in March 2020. This created a disproportionate, negative impact on older persons and those with comorbidities (World Health Organization, 2020). Persons with dementia are among the most vulnerable groups to contract and have complications from COVID-19 due to advanced age and comorbidities (Brown et al., 2020). Thus, it is crucial that those at high risk (i.e., family caregivers and persons with dementia) maintain social distance and, if needed, isolation (World Health Organization, 2020). These precautions may exacerbate an already identified issue regarding family caregivers' low utilization of resources and support services. Additionally, family caregivers using formal resources may have had an unplanned reduction or discontinuation of use due to less availability of services. These increased barriers and challenges may limit the family's ability to start using services as they newly identify the need. The pandemic's unique challenges were considered in this study regarding how family caregivers, particularly female spouses, decide on formal resource use.

Background and Significance

The large number of baby boomers turning 65 every day in the United States has set the stage for the multiple challenges that family caregivers encounter as they try to provide care to a relative with dementia. The growth in the aged population, the prevalence of dementia, and several chronic conditions lead to increased healthcare needs and care costs; thus, compounding

the necessity for family caregiving and formal support services. This next section explores these factors in more depth to frame the significance of the study.

Dementia

Dementia is a term used when describing a group of symptoms related to memory loss. According to the *Diagnostic and Statistical Manual of Mental Disorders*, dementia is the presence of cognitive decline impacting previous levels of function on one or more cognitive domains (complex attention, executive function, learning, and memory, language, perceptual-motor, or social cognition) and interfere with the ability to be independent in instrumental activities of daily living (IADL) (American Psychiatric Association, 2013). Currently, there is no cure for dementia, and the full progression of the disease can be variable and occur over several years with some PWD living up to 20 years after diagnosis. Because of this varying trajectory of progression, levels of caregiving assistance differ for different caregiver-PWD dyads.

With disease progression, the need for increasing assistance with activities of daily living (ADL) and managing behavioral symptoms that can interfere with their care occurs (Alzheimer's Association, 2018). The common behavioral changes seen in dementia include but are not limited to; wandering, paranoia, personality changes, and agitation (Alzheimer's Association, 2022). In addition to the challenging behavioral symptoms accompanying dementia, more than 95% of people with dementia have at least one chronic condition, adding to the cost, care complexity, and burden of caregiving (Alzheimer's Association, 2018). This results in family caregivers' higher care needs when compared to older adults without dementia.

Dementia Cost

Dementia being progressively debilitating, both mentally and physically, often requires significant resources. About 20% of Medicare expenses go to caring for persons with dementia,

costing three times more than caring for an older adult without dementia (Alzheimer's Association, 2020). It is estimated that by 2040, the cost of care for a person with dementia is expected to increase by 79% (Hurd, 2013). However, it is not just the healthcare system that is impacted by the growing dementia population; it also affects families. The annual cost of care per person with dementia is estimated to be \$33,329 (Hurd, 2013). Unpaid caregivers, often family, friends, or neighbors, account for 31% of that cost (Hurd, 2013). In 2021, the estimated 16 billion hours of family caregiving time spent in the US was worth \$271.6 billion (Alzheimer's Association, 2022). Understanding the amount of time and money needed to care for a person with dementia helps emphasize the societal impact of the condition. Thus, it is essential to provide support systems that families will utilize to assist in caregiving, helping to reduce the need for more expensive interventions such as early nursing home placement or hospitalizations. Furthermore, it is equally important to understand when and how family caregivers decide to utilize current support services so they can be fully leveraged to address caregiver and care recipient needs.

In addition to the unpaid care that families provide to persons with dementia (PWD), a growing body of research suggests families incur other costs of providing care. For example, some studies have documented how family caregivers experience repeated interruptions in their work to provide care (Collin et al., 2010; Schulz & Martire, 2004). Additionally, many family caregivers leave the workforce prematurely to provide the care and supervision that a PWD requires (Ory et al., 1999). This reduces the family caregiver's income and can significantly reduce accumulated retirement and pension funds (Alzheimer's Association, 2018).

Family Caregiving for Someone with Dementia

For many Americans, families are the first to assist in caregiving when the need arises. About 83% of the caregiving hours for persons with dementia are provided by family members or friends (Friedman et al., 2015). In the United States, about 11 million families or friends provide 16 billion hours of care to a person with dementia (Alzheimer's Association, 2022). Family caregiving is the act of meeting a person's needs regarding their health and well-being (Gaugler et al., 2005). This includes but is not limited to ADL fundamental activities such as bathing, dressing, eating, toileting, mobility, and continence care (Gaugler et al., 2005). Family caregivers also support managing finances, shopping, or using transportation, called instrumental activities of daily living (IADLs) (Lawton & Brody, 1969). They also assist with coordinating care and emotional support for the PWD (Alzheimer's Association, 2020). In addition to the need for assistance with ADLs and IADLs, caring for a PWD may also include assisting with behavioral disturbances such as agitation, psychotic symptoms, depression, sleep problems, wandering, and aggression (Ornstein & Gaugler, 2012).

Due to the impact of caregiving, family caregivers are sometimes called the *invisible* second patient (Brodaty & Donkin, 2009). Even though caregiving can be a rewarding experience for families, many have negative health impacts. About 34% of family caregivers of PWD suffer from depression and 43.6% from anxiety (Sallim et al., 2015). When multiple behavioral problems are present with a PWD, family caregivers are even more likely to have reports of burden and depression (Arthur et al., 2018). In a review of 37 studies, family caregivers for a PWD had more stress impacting their health and cognition compared to caregivers of a recipient without dementia (Fonareva & Oken, 2014). Families caring for a PWD are twice as likely to report emotional, physical, and financial strains compared to families providing care to someone without dementia (Brodaty & Donkin, 2009; Kasper et al., 2015).

Causes of stress among dementia family caregivers include a lack of support network, poor coping skills, low use of services, and care recipient behavioral problems (Alzheimer's Association, 2018; James et al., 2014). Additionally, compared to paid caregivers, family caregivers report an increased burden connected to cognitive impairment and disruptive behaviors (Seidel & Thyrian, 2019) and are more likely to have to assist with emotional and behavioral issues (National Alliance for Caregiving in Partnership with the Alzheimer's Association, 2017).

The adverse effects of being a family caregiver of a PWD are influenced not only by the numerous tasks required but also by feeling supported and competent in the role (Joling, O'Dwyer, Hertogh, & van Hout, 2017). Decreased competence and mastery in caregiving for a PWD have been associated with depression, burden, and anxiety for family caregivers (Chan et al., 2018; Joling, 2017; van der Lee et al., 2019). Increasing knowledge, services, and support for family caregivers improves confidence, reduces depression, and delays nursing home placement (Gitlin et al., 2015 & Black et al., 2013; Abrahams et al., 2018; James et al., 2014). Notably, the availability of and access to formal support services is positively associated with family caregivers of PWD continuing to provide care in the home setting (Benefield & Holtzclaw, 2014; Link, 2015; Martinez, 2015).

Caregiver Gender and Kinship

Adult children and spouses provide most of the care for PWD (Friedman, 2015; Rabarison et al., 2018). However, they have different experiences and outcomes. Multiple studies have shown higher reports of burden and poor health outcomes among spousal caregivers compared to adult children (Friedemann & Buckwalter, 2014; Pinguart & Sörensen, 2011; Roth et al., 2015; Roth et al., 2019). Some studies have identified that family caregivers who are

females (Ehrlich, 2014; Sallim et al., 2015), spouses (Sallim et al., 2015), and those who live with the person with dementia (Braun, 2009) have the most significant strain.

About two-thirds of family caregivers of PWD are women (Rabarison et al., 2018), and compared to men; they are 1.5 times as likely to experience depression (Sallim et al., 2015). Different mediating factors such as adaptability (Braun, 2009), mastery, and social support (McAuliffe et al., 2018) may explain increased reports of the burden by female caregivers. Kinship and gender are essential differences in dementia family caregivers regarding their experience and outcomes. Thus, it is important to learn more about the unique differences of those who are female spousal caregivers (FSCGs) to a PWD navigate in their role regarding their decision-making processes. This is particularly important because the use of caregiving resources has been shown to impact caregiving outcomes. This study provides insight for the gap in knowledge specific to this population of caregivers.

Aims of the Study

The purpose of this study was to explore female spousal¹ caregivers' (FSCG) decisions regarding the use of formal caregiving resources in caring for a partner with dementia. The study aims were:

1. To explore FSCG's willingness and/or reluctance to use formal caregiving resources.
2. To describe the factors influencing FSCGs' decision to use formal caregiving resources.

¹ In this proposal the term "spouse" or "spousal" will be used, however this term is inclusive of the terminology wife, domestic partner, civil union, significant other, or common law partner.

The findings from this study will inform future research on how decisions regarding resource use are made by female spouses – a group disproportionately affected by, and at high risk for poor outcomes related to, caregiving.

Chapter 2: Review of the Literature

This chapter will review the literature on dementia family caregivers' use of formal resources. A specific focus will be on how gender and kinship influence the use of formal resources that have been identified. To be included in this review, the studies needed to:

- Focus on family caregivers to persons with dementia who were home-dwelling; and,
- Analyze the use of formal caregiving resources by either gender or kinship.

A computerized literature search was done in SCOPUS and then PubMed using the following terms: caregiver, caregiving AND spouse, spousal, wife, husband AND dementia, Alzheimer's disease, AND community resources, formal support, AND utilization, use, AND gender OR gender differences. Using the listed terms, the computerized search identified 667 articles. Articles were excluded for the following reasons: if it was not a research article or review (n=182), not available in English (n=18) if the primary diagnosis of the care recipient was not dementia (n=192), it did not include the family caregiver as a focus of the research (n=200), if the study was focused on the effectiveness of one specific resource rather than caregiver decision-making about resource use (n=11), and if there was not an analysis of resource use by gender or kinship (n=44). One article was added after reviewing references of articles reviewed due to relevancy to the topic.

A total of 21 articles were included, ranging in publication date from 1995-2020. See Appendix A for a summary of the quantitative literature regarding family caregiver gender and formal resource use. Appendix B summarizes the quantitative literature regarding family caregiver kinship and formal resource use. In Appendix C, the qualitative literature is included regarding family caregivers of PWD and resource use or help-seeking. The research methods

included were 12 quantitative, one mixed-methods, and eight qualitative studies. Much of the research was done in the United States (n=12), with the others done in Australia (n=3), Canada (n=1), and Europe (n=5), showing some variety in location, with no representation from South America, Asian, or African countries. Among the 21 articles reviewed, there are several formal resources examined among the different studies (See Appendix A and B), including respite care (n=12), housework/meals (n=6), support groups (n=6), home care (n=5), transportation (n=4) and adult day care (n=3).

Resource Use: Gender & Kinship Differences

Out of the 13 quantitative or mixed-method articles, four quantitative articles analyzed formal resource use only by gender, three evaluated only by kinship and formal resource use, and 6 had both gender and kinship (See Appendix A and Appendix B). Eight qualitative studies provide further insight regarding kinship and/or gender and decisions regarding formal resource use. The following section will discuss the extent to which gender and/or kinship of the family caregiver is a factor in formal resource utilization.

Resource Use and Gender

Men and women often navigate decisions and experiences differently. There have been studies that have looked at how a family caregiver's gender influences or is associated with the use of resources in caring for a PWD (Brodaty et al., 2005; Collins & Jones, 1997; Cossette et al., 1995; Cox, 1997; Feldman et al., 2020; Martindale-Adams et al., 2016; Monahan & Hooker, 1995; Newkirk et al., 2020; Robinson et al., 2005; Sun et al., 2008). While ten studies explored gender and formal resource use, four of them found the gender of the caregiver to be a significant factor in family caregivers' formal resource use (Cossette et al., 1995; Newkirk et al., 2020;

Robinson et al., 2005; Sun et al., 2008). Being female was significantly correlated with initiating service use in only one study (Robinson et al., 2005). Although Newkirk et al. (2020) found gender was not significant in initiating resource use, among those who used services, women significantly used them more frequently than men. Similarly, Cossette et al. (1995) found a significant correlation between women and the frequency of formal resource use.

Sun et al. (2008) was the only study that evaluated the significance of gender and the relationship to specific types of formal resource use. The use of transportation and in-home services was dependent on gender; female caregivers were less likely to use in-home services and more likely to use transportation services than males. Still, daycare and support groups were not found to have a significant relationship to gender (Sun et al., 2008). This highlights that not all formal services are viewed or used the same by each gender, thus leading to different utilization practices.

These studies results may have varied due to differences regarding the care recipients' level of assistance needed or the stage of the disease. Some studies found that the severity of cognition or ADL assistance significantly impacted use of formal support (Newkirk et al., 2020; Robinson et al., 2005). According to Newkirk et al. (2020), increased level of cognitive impairment, assistance with ADLs, comorbid conditions and the Blessed-Roth *Dementia* Rating Scale (*BRDRS*) rating were each significantly associated with the likelihood of formal service use by a family caregiver ($p < 0.05$ for first three factors and $p < 0.001$ for the *BRDRS*). Robinson et al. (2005) similarly found increased odds of a family caregiver using formal community resources as the care recipient required more need for assistance with ADLs ($p < .05$), worsening memory, and behavioral problems ($p < .01$). However, in these studies, there was no analysis of caregiver gender or kinship, and if the impairment of the care receiver had any correlation to

formal resource use specifically. Thus, the studies' results are difficult to compare given that among studies, the level of impairment of the PWD was not included or was measured differently and that there was a diverse range of physical or cognitive impairment.

Overall, the studies are inconsistent in identifying how or if gender is associated with a family caregiver's decision to use formal resources. However, it has been shown that the type of resource use is influenced by gender (Sun et al., 2008), and once the formal resource is initiated, females use it more frequently (Cossette et al., 1995; Newkirk et al., 2020). Understanding gender differences of family caregivers for PWD regarding resource utilization helps identify lower utilizers and where more outreach or education should be focused.

Resource Use and Kinship

The relation type (in other words, “kinship”) a family caregiver has with the care recipient or PWD can contribute to how or what decisions are made regarding using formal resources. There have been some studies that have looked at how kinship of the family caregiver influences or is associated with the use of resources in caring for a PWD (Brodaty et al., 2005; Cossette et al., 1995; Cox, 1997; Martindale-Adams et al., 2016; Newkirk et al., 2020; Robinson et al., 2013; Robinson et al., 2005; von Kutzleben et al., 2016; Winslow, 1997). All of the studies used a survey, with three being longitudinal (Cossette et al., 1995; Cox, 1997; Winslow, 1997) and five cross-sectional (Brodaty et al., 2005; Martindale-Adams et al., 2016; Newkirk et al., 2020; Robinson et al., 2013; Robinson et al., 2005) and one mixed-methods study using cross-sectional surveys and interviews (von Kutzleben et al., 2016).

While nine studies explored kinship and formal resource use, five found kinship of the caregiver to be a significant factor in family caregivers' formal resource use; however, results

were mixed. In four studies, spousal caregivers were significantly less likely to use formal resources compared to other family relation caregivers (Robinson et al., 2013; Robinson et al., 2005; von Kutzleben et al., 2016; Winslow, 1997); conversely, one study found spouses to be more likely to use formal resources (Martindale-Adams et al., 2016). Other studies showed no significant differences between kinship and formal resource use (Brodaty et al., 2005; Cossette et al., 1995; Cox, 1997; Newkirk et al., 2020).

Several differences among the studies may account for some of the diverse results. The varying definitions of the term formal support is one example. Martindale-Adams et al., (2016) included the broadest range of services, including treatment and diagnosis such as inpatient, emergency room, nursing home, and clinic services among the formal support services (i.e., Daycare, transportation, home assistance). The other studies included a range in the amount and types of formal resources (see Appendix B). Another difference was the categories of the kinship of the caregiver to the PWD. While all the articles had the category “spouse”, most had “adult child”, and some had “other” or “other family” (see Appendix B). Another difference among studies was in the approach toward recruitment. While some of the studies required the caregiver to be family, others used the term, informal caregiver (i.e., partner, friend, neighbor). Finally, between studies, not only were there differences in categories of caregivers, there was a wide range of various kinship types. For example, spouse representation ranged between 26% and 74% between studies. Therefore, the studies’ conclusions and comparability may have been impacted by these differential methods.

Among the kinship studies, there also is variation in including of dementia progression and assistance needed by the care recipients (See Appendix B). While some studies did not report the stage of dementia or the level of assistance needed, those who reported the level of

impairment had a wide range of deficits. However, these studies did not analyze the potential interactions between caregiver kinship and the impairment level of the PWD which may impact the decisions to use formal resources.

Spousal Caregivers

While some studies explored gender and kinship differences regarding formal resource use, only three quantitative studies (Collins & Jones, 1997; Cossette et al., 1995; Monahan & Hooker, 1995; Sun et al., 2008) and four qualitative studies (Brown & Chen, 2008; Brown & Allgood, 2004; Donnellan et al., 2015; Meyer et al., 2016; Morrisby et al., 2019; Sinclair et al., 2018a) looked at the differences between husbands and wives or in how spouses made decisions in formal resource use. All these studies evaluated different aspects of caregiving and formal resource decision-making to help better understand the spousal experience.

Collins and Jones (1997) only included spouses in their study and analyzed the differences regarding formal resource use between men and women (i.e., husbands and wives). Although there was no significance found between spouse gender and formal resource use, there were differences in general caregiver attitudes that impacted resource use. Results showed a significant association with wives reporting more guilt regarding relinquishing care, more difficulties with having their spouse with dementia depend on them, and less satisfaction in caregiving (Collins & Jones, 1997). In another study done by Sun et al. (2008) they did not analyze formal resource use by kinship, however, they added variables including religiosity when comparing husbands and wives and formal resource use. Through mediation tests, they found that religiosity may explain the relationship of formal support use differences between wives and husbands (Sun et al., 2008).

Donnellan et al., (2015) did a qualitative study, interviewing spouses caring for a PWD looking at resilience characteristics and suggesting that husbands' resilience was associated with the use of formal services. Additionally, resilient caregivers reported feeling knowledgeable about caregiving and felt well supported by friends and family (Donnellan et al., 2015). In another study done with focus groups, they sought to identify the perceived need for support services (Granbo et al., 2019). These perceived needs differed depending on if the caregiver lived with the PWD; in such cases which were most often spouses co-residence led to the "caregiver's role being all-consuming" and losing social networks and support (Granbo et al., 2019).

Reluctance or Willingness to Use Resources

The literature uses different terms to describe factors that might influence a caregiver's use of resources in caring for a PWD: facilitators/barriers, enabling or impeding factors, or help-seeking behaviors. For example, among the studies reviewed, the most common model to identify variables that impact resource use (Cox, 1997; Martindale-Adams et al., 2016; Robinson et al., 2005) was the Behavioral Model of Health Service Utilization (BMHSU) (Andersen, 1995). The BMHSU model has been used throughout literature for health service utilization, for different types of populations besides PWD. The BMHSU posits three main elements contributing to a person's use of health services, including predisposing characteristics (e.g., demographic, social structure, and health beliefs); enabling or impeding factors (e.g., community and personal resources, including socioeconomic factors); and evaluated and perceived need factors (Andersen, 1995). These "enabling" or "impeding" factors provide a general understanding of the common terms and domains studied in healthcare resource utilization. However, a deeper understanding of what contributes to the willingness and reluctance to use

resources may be a gap, since they are not explicitly integrated into this model. While the concepts of willingness and reluctance could influence or stem from these domains and ultimately drive decision-making, they are not specifically discussed. For the purposes of this research, all these terms will be reviewed under what may influence reluctance or willingness to use formal resources.

Several of the articles examined willingness or reluctance factors associated with using formal resources (Brodaty et al., 2005; Brown & Chen, 2008; Morrisby et al., 2019; Newkirk et al., 2020; Richardson et al., 2019; Winslow, 1997). Brodaty et al. (2005) found that contact or recommendations from a provider or social worker increased the willingness to use formal resources. In a study of spousal caregivers, Morrisby et al., (2019) concluded that caregivers were more willing to use resources to help keep the PWD at home as long as possible.

Brown and Chen (2008) examined different aspects of willingness and reluctance in a small qualitative study, specifically the differences between husbands and wives. They found both husbands and wives had apparent differences in how they sought help (Brown & Chen, 2008). Husbands were more likely to “reach out” to others for help early on, while wives would first “reach within” and provide much of the care themselves before eventually utilizing formal resources (Brown & Chen, 2008). Wives also reported that protecting their husband’s image was essential and delayed their willingness to seek support or resources. Brown and Chen (2008) were the only study that identified that there were internal (i.e., attitudes, beliefs, values, and relational situations) versus external factors (i.e., cost availability, time, knowledge, and past experience) expressed by caregivers which influenced seeking resources. However, these were not analyzed by how the spouses by gender may have experienced these differently.

In three studies, caregivers' reluctance to use resources was associated with the care recipient's resistance to using those resources (Brodaty et al., 2005; Newkirk et al., 2020; Winslow, 1997). In addition, Brodaty et al. (2005) found that a caregiver's lack of perceived need for help was associated with greater reluctance to use services. In contrast, Winslow (1997) found that caregivers who believed that caregiving was the family's responsibility were more reluctant to use formal resources. Richardson et al., (2019) specifically evaluated the family caregiver variation in experiences across different cultures in the U.S. and found that not having culturally sensitive food options and language barriers contributed to a reluctance to use some formal resources.

When looking at the resources themselves, several barriers have been identified. For some, poor quality or mistrust of the resource(s) and accessibility were barriers to use (Brown & Chen, 2008; Morrisby et al., 2019; Newkirk et al., 2020; Richardson et al., 2019; Winslow, 1997). While some studies found finances a barrier to formal resource use (Brown & Chen, 2008; Winslow, 1997), other studies did not find resource affordability or availability a barrier (Brodaty et al., 2005; Morrisby et al., 2019). Understanding where to seek help was also identified as a barrier (Brown & Chen, 2008; Richardson et al., 2019).

It is important to note that when identifying facilitators and barriers to formal caregiving resources, location of the study is also important due to the societal and government structures. Communities, government policies and healthcare systems contribute to what resources are provided, to whom they are available, and the extent of accessibility regarding cost and location. Thus, factors (i.e., quality, mistrust, accessibility, cost) that may contribute to a willingness or reluctance to use resources might vary based on the study location.

Summary

Based on this literature review, the extent of significance in formal resource use and gender and kinship differences are complex and have mixed results. Regarding what motivates a family to use formal resources, there are internal and external factors to consider that influence the caregivers' willingness or reluctance. However, the research is limited when evaluating the nuances of gender or kinship and the influencing decision factors to use formal resources in caring for a PWD.

There were several limitations and gaps in the literature regarding gender, kinship, and formal resource use of family caregivers caring for a PWD. Overall, the studies used convenience sampling, therefore those who volunteer to participate may differ from the larger population in characteristics making generalizability difficult. Additionally, the family caregiver participants provided varying levels of caregiving, which may have also impacted the results of the studies. Most importantly, few studies are focusing on differences in the decision to use formal resources between male or female spousal caregivers, particularly in dementia care.

To better understand what contributes to family caregivers' decisions to use resources, it is important for further research to closely evaluate the factors that impact willingness or reluctance. However, family caregiver dementia research is not consistent in capturing this information or analyzing the impact. One example is how studies do not always separate the type of relationship of the family caregiver (i.e., spouse, sibling, adult child). There are distinct differences between spouses and adult children as individuals and in a relationship with the care recipient. Additionally, some studies recruited participants who were already using a resource for caregiving. Thus, more information is needed regarding the population of family caregivers who are not connected to services. Most of the studies were cross-sectional designs, limiting the

ability to understand causality, or how the caregiving experience and decision to use resources changes over time.

Furthering research in dementia family caregiving to ensure utilization of formal resources is important, especially among those providing substantial caregiving but who have low use. Researchers have recommended evaluating more diverse groups of dementia caregivers' service use and non-users (Feldman et al., 2020) along with expanding the knowledge regarding specific help-seeking processes (Brodaty & Donkin, 2009). A study that explores why female spousal caregivers decide to use resources would fill important gaps in our understanding of how to better support family caregivers with PWD. A better understanding of what influences female spouses to use formal resources can help researchers, clinicians, and policymakers create resources that are more frequently used. Providing more support would benefit the caregiver and care recipient to assist in delaying institutionalization and contributing to a more positive caregiving experience.

Chapter 3: Methodology

Study Design

This study explored female spousal caregivers' decisions regarding using formal resources in caregiving for an older adult with dementia using a qualitative descriptive design (Sandelowski, 2000) . A qualitative descriptive approach was chosen to help provide a comprehensive range of experiences across FSCGs to describe the factors influencing when and why they decide to use formal caregiving resources.

Ethical Considerations

This study was approved by the University of California, Davis (UCD) Institutional Review Board (IRB) (IRB ID: 806357-1) as an exempt study. According to the UCD IRB, an exempt study allowed for an abbreviated consent process, including verbal consent. Once participants were screened and met the inclusion criteria for the study, information in the study consent document was verbally reviewed with prospective participants, and a copy was emailed to them (See Appendix D). The consent document included the following information about the research and participation: the purpose of the study, possible risks and benefits to the participant, compensation for the study, confidentiality protection, rights to voluntarily join the study and decline participation at any point throughout the process without judgment. Consent was verbally obtained before planning the interview date and discussed again before the interview recording started to confirm agreement to proceed and to answer any questions the participant may have had about the study and/or participation. After the interview, compensation of a \$15 gift card as a small token of appreciation was offered for Amazon or Target via mail or digitally per the participant's preference. Additionally, participants were emailed a list of dementia caregiving resources unless they declined (See Appendix H).

All research-related files, transcripts, and recordings were kept in a password-protected drive or application to protect the participants' confidentiality. To protect the identity of participants, transcripts were labeled with numbers and the interview date. No links were maintained between the transcripts, participant names, or other identifiers. Within the transcripts, FSCG participants and their husbands with dementia were given pseudonyms. Additionally, when the names of providers or other family members were stated in the interview, they were removed. Participant names and contact information will be destroyed six months after publication of the results. Data will not be retained for any future use beyond this study.

Recruitment & Sampling

Once IRB approval was obtained, a recruitment flier and StudyPages account were developed (See Appendix E). StudyPages is a website where UC Davis Health clinical studies are posted to help recruit through sharing a brief description of the study, inclusion and exclusion criteria, and the benefits and risks of participating. StudyPages is a platform that allows for confidential communications for texting, calling, and emailing potential participants. StudyPages was used to track the process of screening, in-process, and completion of an interview. It was used to schedule interviews and to send participants reminders. The study overview and contact information for the investigator were made available on StudyPages, for potential participants to view.

Purposive sampling was used to recruit female spousal family caregivers through the UC Davis Healthy Aging Clinic, Family Caregiver Institute, and the UC Davis StudyPages account. UC Davis Health serves 33 different counties in Northern California, representing a diverse population related to race, ethnicity, and socioeconomics. Subsequently, recruitment expanded to local organizations focusing on working with older adults.

The recruitment of the participants initially occurred on-site at the UC Davis Healthy Aging Clinic, Family Caregiver Institute (FCI), with an expectation that in-person recruitment would contribute to building trust. I initially spent one day a week on-site, in a separate room from the patients and their families. The clinicians who provided weekly family caregiver consultations were trained to identify potential participants that were female spouses caring for a PWD who might meet the criteria for the study. The FCI Director or designated FCI clinician waited until after their consultation visit to ask if the female spousal caregiver would be interested in learning more about the study. If an interest to learn more or to participate was indicated, I was introduced, and further screening was done. If there was interest in learning more but they were unable to meet with me at that time, they were provided a flier with information about the study, the StudyPages.com site, and the researcher's contact information. After eight weeks of recruiting through the Healthy Aging Clinic seven referrals and six interviews resulted. Recruitment was then expanded outside the clinic through other IRB-approved strategies, including flyers professional and community contacts. Recruitment extended over four months, and in that time sixteen were screened, eleven interviewed through data saturation and five excluded. The reasons for exclusion were: loss to follow up (1), declining the interview due to change in the condition of the PWD (1) and not meeting inclusion criteria due to not having a formal dementia diagnosis for their husbands (3).

The screening process was conducted by phone or in person (depending on the recruitment strategy utilized) to review inclusion/exclusion criteria and determine participant eligibility (See Appendix F). Once a potential participant was screened and met the inclusion criteria, the verbal consent processes was completed and the interview via ZOOM meeting application (www.zoom.us) was scheduled. All the participants were caregivers; thus, it was

necessary to schedule the discussion at a time that would work best for their schedule. Before scheduling the interview, I discussed possible considerations to optimize a successful virtual interview, including ensuring a quiet environment with limited interruptions. I also offered to test or provide instruction to use the technology (ZOOM) in an effort to identify and work through potential issues before the interview (See Figure 1). All participants had used ZOOM before and none requested a tutorial.

The participant inclusion criteria were FSCGs of a husband with dementia in the home setting. The dementia diagnosis by a physician was self-reported by the FSCG participant since this study did not access medical records or provide a clinical assessment to confirm a diagnosis. The PWD needed to require assistance with at least one Instrumental Activity of Daily Living (IADL) (using the telephone, shopping, preparing food, housekeeping, doing laundry, using transportation, handling medications, handling finances) (Lawton & Brody, 1969). Additionally, the prospective participant (i.e., partner, wife, or spouse) was required to live with their partner when caregiving to be able to capture the experience of how they decided to use or not use formal resources in the community setting. Participants were also required to be English-speaking due to the inability for translation resources in this study. They had to have access to a computer, tablet, or smartphone with a camera and microphone features that can connect to the internet for web-based video conferencing using Zoom for the interview. An exclusion criterion was if the PWD was less than 65-years-old. This eliminated persons with possible Early Onset Dementia (defined as onset of dementia before age 65), to exclude other challenges not studied in this research project, such as balancing the commitments of a young family and work.

While the initial goal was to interview at least 20 wives, regarding sample size, Sandelowski (1995) states that it cannot solely be a specific number, but a collection of events or

experiences. Data saturation was identified once no new information or data was obtained in interviews (Bradshaw et al., 2017). After the 9th interview, no further codes were created; after the 11th interview, data saturation was achieved, resulting in a sample n =11.

Data Collection Procedures

Instruments

Data were collected using three instruments. The Lawton Instrumental Activities of Daily Living Scale (IADL) (Lawton & Brody, 1969) (See Appendix F) was used during the screening process and included a question about the PWD's age. The Functional Assessment Staging Tool (FAST) (Sclan & Reisberg, 1992) and a semi-structured interview guide, including demographics (Appendix G), were used to collect data during Zoom interview sessions.

The IADL tool includes eight areas of activities in which a score for the level of ability is chosen. The eight areas are the ability to use the phone, shopping, food preparation, housekeeping, laundry, mode of transportation, responsibility for own medications, and ability to handle finances. In each category a 0 or 1 is chosen which describes the highest level of function ability. The higher the number means higher functional ability. The FAST tool was used to measure the stage of dementia based on the caregiver's report of the PWD's cognition and function. The FAST tool includes a list of 7 stages with each having a description of a functional level. The higher stage number corresponds to increased functional loss, thus a more progressive stage of dementia (see Appendix G). The tool was visually shared through ZOOM and read aloud if needed to help the participants answer the questions. Both the FAST and IADL tools assisted in identifying stage of dementia and functional ability of the PWD. On an individual level, the tools were helpful to understand the stage of dementia the participant was talking about

and when they needed help with prompts in questions regarding caregiving needs and possible resources used. The tools were also used to evaluate characteristics of the sample to show the range of dementia and care needs of the care recipients of the participants (a gap in the prior literature).

A semi-structured interview guide with prompts was developed for this study. The interview guide was designed to gather information to achieve the aims of the study. Questions were open-ended to allow exploration of each topic to be elicited from the participant. (Sandelowski, 2000). The interview guide was structured to illicit responses to understand what resources were or were not used and the caregiver's decision-making process (See Appendix G). Questions were strategically ordered in the interview guide so that more sensitive or difficult topics were at the end to help with developing a level of trust and comfort between the participant and researcher (Britten, 1995). To help aid the discussion, a slide was shown via ZOOM with a list of common formal caregiving resources/services. Participants were also asked to speak about resources or support services which were not listed if they wished. Probes were used to better understand why that resource was specifically chosen and why it was chosen at that time. The interview guide also had one question that asked how the COVID-19 pandemic impacted their use of resources. Given the current environment of the pandemic, this question provided opportunity to better understand the experience of caregiving and resource use, and needs or barriers to use which may have been impacted due to this unique situation. During the interview, clarifying questions were used to confirm an understanding of what had been stated, as well as to help engage the participant in elaborating on their story when needed (Charmaz, 2006). The interview guide was piloted with three persons who had been caregivers to family members. In the pilot, feedback

was provided to focus on flow and understandability of the interview guide. This led to rewording and the changing the order of questions.

Description of Participants

Participants for this study included eleven FSCG who all lived in or near Sacramento County in California. See Table 1 for individual and group characteristics. All participants were white and had a mean age of 69.7 (63-77 range). The PWD to whom they provided caregiving were, on average, older than them with a mean age of 78.2 (73-87 range). The mean years married or partnered was 39.5, with a range of 23 – 54 years. The number of years the participants had provided caregiving to their partner with dementia ranged from 1.5 to 10 years, with a mean of 4.4 years. The stage of dementia ranged from 4 – 6 and had a mean of 5. Stage 5 FAST is considered Moderate Dementia. The IADL score ranged from 1-5 with a mean of 2. All the participants had experienced at least one formal caregiving service, with a range of 1 – 6 services used and a mean of 3.4.

Table 1*Participant and PWD Characteristics*

Participant pseudonym	Wife-Caregiver				PWD Care recipient		
	Age	Married years	Caregiving years	# Formal Caregiving services	Age	FAST score	IADL score
Mean (range)	69.7 (63 – 77)	39.5 (23 – 54)	4.4 (1.5 – 10)	3.4 (1 – 6)	78.2 (73 – 87)	5 (4 – 6)	2 (1 – 5)
Anne	63	33	4	3	74	6	1
Bernice	66	25	3	2	76	5	2
Cynthia	71	44	1.5	2	81	4	2
Doris	71	54	2	1	75	4	1
Ellen	69	45	10	4	73	6	1
Fiona	75	48	2	4	78	5	3
Gina	63	35	2	2	73	4	5
Hannah	72	44	6	6	87	6	2
Irene	65	28	3	3	76	4	1
Jane	75	56	7	4	81	5	3
Karen	77	23	8	6	86	6	1

Interview Process

Once participants provided consent, a date and time for the interview was arranged. Interview length ranged from 33 to 67 minutes with a mean of 52 minutes. The interview took place using ZOOM, an internet-based video conferencing system, due to the ongoing pandemic and health risks of an in-person interview. The participant did not need to have a ZOOM account but had to have a device to receive an email, text message, or access the ZOOM mobile application. The semi-structured interview guide was used to collect data. Only the audio component of the ZOOM interview was recorded to protect the participant’s identity.

Field Notes and Memos

As the data collection instrument, I wrote field notes, observations, and crucial impressions. Memos were kept throughout the data collection and analysis process to record

initial thoughts about the data, reflections about positionality, and potential interpretations.

Keeping analytic memos assisted in tracking and reflecting on the rationale for why choices were made regarding codes or theme identification and emerging patterns (Rogers, 2018). Field notes were written during and after the interview to provide context and meaning to what was stated in the interview. Observations of nonverbal cues and crucial impressions were noted using memos. For example, memos would be included if the statement made was done in a sarcastic tone, or there was laughter or tearfulness. Sometimes there were hand gestures that weren't captured in the audio which added context to a story being told. I wrote memos that were in three different categories; reflection, analytic, and interview process. The reflection category included my thoughts, impressions and possible biases. The analytic category was related to the identifying themes, codes and the decisions to categorize information. The interview process category included memos about what went well or what could be improved on regarding the process of setting up or doing the interview. These memos helped me to organize thoughts that were my immediate reflections to the interview and what I was feeling or thinking, ideas around analysis that were emerging and reminders to myself about the interview regarding what went well and how I could improve for the next one. I continued to write memos while reviewing the transcripts and during the coding process.

Data Analysis

The researcher alone collected data, coded, and analyzed with the supervision and guidance of research mentors. A transcription software program, Otter ai [Version 3.8.0™](#) was used for digital transcription from the ZOOM audio recordings. All digital transcriptions were verified verbatim by the researcher. The process of coding and analysis started with the first interview. While verifying the transcripts, key phrases and words were highlighted and revisited

later when the more formal coding process began. Memos were also added on the transcript in regards to nuances heard in the audio that provided meaning to the verbiage. Memos were written within the data management tool which allowed for them to be connected to specific interviews or clusters of interviews. Examples of memos which assisted in understanding the meaning behind the transcript included emotions exhibited, tone or emphasis in language that colored the interpretation of what was said. A qualitative data management tool, Dedoose-9.0.54™, was used for organizing codes and categories by the researcher.

A thematic analysis was used for this study to assist in identifying the commonly shared themes within and across interviews (DeSantis & Ugarriza, 2000). The initial round of coding was descriptive, allowing for larger groups of content to be captured, and organized into categories of similar themes (Colorafi & Evans, 2016). Codes were created or changed to ensure the best fit (Sandelowski, 2000). When codes were changed throughout the analysis process, the previously coded data were recoded to ensure accuracy and consistency (Colorafi & Evans, 2016). In other words, if the name or definition of a code was changed through the process, the previous material coded would be reviewed to ensure that the changed code still applied or if a new or different code would be needed. In the first interviews analyzed, codes captured broad concepts such as *factors influencing reluctance to use a resource*. Next, the broader concepts were analyzed and organized into sub-codes such as *caregiver readiness* and *PWD readiness*. Another layer of sub-codes was created when needed. For example, for the code *caregiver resistance*, sub-codes were added to differentiate various aspects of caregiver readiness factors of reluctance such as *not ready to know*, *denial*, *lack of trust*, *can handle it*, *not there yet*, and *physically able*. Codes were organized into categories that were evaluated for relevance and limited to the purpose of the study (Bradshaw et al., 2017). Tables and color coding were used to

identify patterns to assist in analysis and interpretation (Bradshaw et al., 2017). Tables from Dedoose-9.0.54™ were used to help identify patterns of codes across interviews and in relation to formal caregiving services.

Trustworthiness

To ensure trustworthiness in data collection and analysis, Lincoln and Guba (1986) recommend four main elements; credibility, transferability, dependability, and confirmability (which will be defined below). Credibility was established through peer debriefing. To ensure researcher authenticity or fairness in data collection and analysis, debriefing occurred with the research mentor through frequent sharing and discussion of the process of analysis, and memos.

Transferability illustrates the degree to which results can be transferred to other settings (Lincoln & Guba, 1986). To ensure transferability, thick descriptive data was used to clarify the context and allow others to be able to identify the appropriateness of how the data was relevant to the setting (Lincoln & Guba, 1986). The descriptions were collected in context of this study in regards to the participants recruited, their caregiving situations and how I analyzed their data on formal caregiving use decisions, in order to assist with knowing the level of transferability for other settings.

The dependability of the results is important to be able to demonstrate the extent to which the study findings can be replicated among similar participants by other researchers (Lincoln & Guba, 1986). In addition, dependability of the study allows for an audit or critique of the entire research process (Sandelowski, 1986). To ensure dependability, an audit trail was established, detailing how the data was collected, transcribed, de-identified, and analyzed (Forero et al., 2018). The audit trail includes information regarding approaches and decisions regarding coding

definitions and the creation of categories to get to the results. The audit trail was reviewed with faculty advisors to ensure it captured the data analysis process accurately.

Confirmability ensures the ability for other researchers to have confidence in the ability to validate the findings (Lincoln & Guba, 1986). This was accomplished through detailed notes and having an audit trail. Reflexive journaling or memos was done to identify personal biases and assumptions throughout the entire process of collecting and analysis of data (Bradshaw et al., 2017). In regular meetings with an experienced research mentor, the reflections were reviewed and discussed to ensure the limited impact of biases on the data collection and analysis. A peer-reviewer independently coded a de-identified sample of raw data. They were provided the coding list with definitions to use. Then, the peer-reviewer and I as the researcher met to reconcile differences and revise coding scheme/coding definitions as needed. The coding of three interviews was confirmed with at least 85% agreement between the peer-reviewer and researcher. Additionally, feedback was received from the research mentors regarding the accuracy and the process of coding by reviewing deidentified samples of coding and coding definitions throughout the data analysis process. The researcher and mentor met to review the data excerpts and reconcile differences in the way each person coded. Differences may be in the code chosen, or whether a section was coded at all given the list of codes and definitions provide at the time. Revisions to coding definitions were made as needed. Coding decisions regarding changes to definitions or to merge codes were documented within Dedoose-9.0.54™.

Confirmation bias occurs when beliefs or partiality of the researcher impact the collecting or interpretive analysis of the data (Nickerson, 1998). Efforts were made to limit confirmation bias through a frequent reevaluation of impressions and assumptions shared in the interview and throughout the analysis process.

Positionality and Bracketing

The potential for bias and my positionality was taken into consideration throughout the steps of the research from developing to interviewing and to analyzing the data. As a Geriatric Clinical Nurse Specialist with a background in cognitive impairment and with work experience in a large healthcare system, I was aware of the possible bias towards assumptions that families are informed of what dementia is and what is available in caring for someone with dementia. Most importantly, I realized a bias towards how a caregiver “should” be caring for someone with dementia. It was important for me to attempt to remain as neutral as possible during the interview by ensuring my opinions were not stated along with being aware of body language and not allowing for confirmation bias through strategies discussed earlier. Also, reflection was done after each interview on these possible biases. This activity was important to make sure they were not affecting the analysis of the data. As a middle-class Caucasian female, without family caregiving experience, assumptions or limited cultural understandings may cause bias requiring further reflection throughout the process. This process of bracketing and reflexivity assisted in ensuring awareness of my preconceptions or assumptions of the data collected or in the process of analysis (Charmaz, 2006).

Chapter 4: Results

The participants in this study described a number of factors that influenced their decisions to use formal caregiving resources and supports to help them in caring for their husbands with dementia. They were able to describe why they had refrained from starting or stopping caregiving support services through the concerns they had about using them in general, or specific resources or services. Additionally, they articulated what motivated them from being reluctant to use a caregiving resource to becoming willing or interested in starting to use it.

While there were two different aims of this study, one to explore willingness and reluctance, and the second to describe factors influencing the decision to use formal caregiving resources, the factors influencing decisions to use formal caregiving resources were also described as what contributed to willingness or reluctance, or influenced the context in which the decisions were made. In the following paragraphs, the results are organized according to factors contributing to decisions using formal caregiving resources in regard to reluctance or willingness. Subsequently, I will discuss results which were shared about the broader circumstances the participants stated, providing a contextual background for beginning to understand their caregiving decisions. All the participants quotes and the PWD they discuss are labeled with pseudonyms to protect their privacy.

Reluctance and Willingness Factors

The participants reported several factors that impacted their willingness or reluctance to use formal caregiving resources, organized in three categories: caregiver readiness, PWD readiness and resource qualities (see Table 2). Caregiver readiness reflects participants' references to their own emotional, mental or physical state or needs in regard to using a resource. PWD readiness reflects what the caregiver perceived as factors specific to the PWD's physical

needs or emotional or mental receptiveness to the participant's use of resources. Resource qualities include any participant reference to the characteristic or understanding of a resource or the value of that resource contributed to willingness or reluctance to use it. All of the participants were asked if or how the COVID pandemic impacted their need for caregiving resources. In some situations, the pandemic limited the access to community-based resources (e.g., day care centers closed). Interestingly, some participants noted that their partner with dementia was diagnosed or had the most cognitive or physical decline within the pandemic time frame (2020 – 2022). While they didn't all attribute their husbands' decline to the pandemic per se, they spoke about the impact it had.

Table 2 outlines key factors in each of the three categories of willingness and reluctance. Some participants spoke about more than one factor contributing to their decisions to use or not use a formal caregiving service, and in some situations, they described competing factors (i.e., a factor that supported willingness and a factor that supported reluctance). The results were organized by the factors which were stated as the primary reason for the decision. First, I will discuss the factors which contributed to reluctance to use formal caregiving resources, then will discuss the willingness factors.

Table 2*Reluctance and Willingness Factors*

	Caregiver Readiness	PWD Readiness	Resource Qualities
Reluctance	Not there yet	Intolerant	Limitations
	Can handle it	Physical ability	Fit
	Wife role	Buy-in	Time commitment
	Responsibility		Preconceived notions
	Being a doer		
	Caring instinct		
	Protect dignity		
	Lack of trust		
Willingness	Knowledge	Increased need	Trusted
	Learning about caregiving	Physical ability loss	recommendation
	Peer support	Safety or behavior need	Friend/family
	Physical limits	Interest	Clinician
	Timing of readiness		Ease of use/Accessibility
	Other obligations		
	Work		
	Self-care		
	Family		

Reluctance

Participants spoke about factors that contributed to reluctance to use a formal caregiving resource in a number of ways. Reluctance reflects participants' references to hesitation to start, consider or stop using a resource or support service. Factors of reluctance are organized in three categories: caregiver readiness, PWD readiness and resources qualities.

Caregiver Readiness and Reluctance. Participants spoke about their own readiness as a wife caregiver and factors contributing to reluctance to use resources for caregiving. Reluctance to use a resource was due to "*not being there yet*", as it related to acknowledging the stage of disease or not being mentally or emotionally ready. Others mentioned that the lack of trust of formal caregivers contributed to their resistance to a caregiving service. Others thought they could "*handle*" everything the PWD needed or were "*not there yet*" suggesting it may be necessary for the future. The wives' views of caregiving focused on what the participant reported

as traits (i.e., being a doer) or wife role (i.e., motherly instinct, wife responsibility) or the responsibility of protecting the dignity of the PWD that drove them to provide caregiving themselves and not use other formal caregiving resources. Findings related to each of these subcategories are detailed below.

Not There Yet. Many participants reported a sense of being *not there yet* or not being ready, where they referred to a possibility of use in the future. References to not being there yet were usually mentioned with paid caregiving types of resources. Participants spoke about considering using resources such as a nursing home or respite care in the future, but not yet. Some elaborated on what “*there*” would be in a moment in the dementia stage or physical changes of the PWD that they have not reached.

...I realized that there's going to be a point when that's [going to be] be probably very necessary [referring to a nursing home], simply because in the late stages of Alzheimer's disease, ...they can't feed themselves. Sometimes they can't swallow. Sometimes they have breathing problems. And that's not going to be something I can manage on my own. So, I know that that's probably going to have to happen, but at this point, not yet. (Ellen)

While some participants were able to clearly articulate the point in the disease process in which they may face in the future; others appear to mean that they just did not feel that they needed a specific caregiving resource at the time.

Can Handle It. Several participants also spoke about being able to *handle* caregiving or being able to meet the needs of the PWD as a reason for not using a caregiving resource at a specific time. They spoke about being able to handle caregiving needs in a variety of ways. The ability to *handle it* was described as their comfort or confidence in being able to do specific

caregiving tasks. For example, one participant talked about being able to handle it due to her confidence in managing her husband's current stage of dementia.

Yeah, ... I was reluctant. Because ... I felt pretty confident that I could handle this beginning stage. And these beginning problems, that I really didn't need any help, that I could, I could do it. And I could be successful at it. (Fiona)

Another participant who had assistance with housework and no other formal caregiving resource or support service at the time of this interview spoke more generally about being able to handle it. "But no, I haven't used any of these things. I just pretty much handle it" (Doris).

One participant, spoke about the concept of being able to "*handle it*" slightly differently and noted that denial of the severity of the dementia was a contributor to why she hadn't used a home health aide earlier and thought she could "*manage it*" on her own. The denial was not just about the PWD's stage of dementia but about her abilities to manage his care. "...it was probably more of a denial of how serious things were getting. And me just wanting to be able to manage it and then ultimately having to, to just face facts, not manageable, can't do it" (Ellen).

Wife Role or Trait. Some participants also spoke about their wife role contributing to not using a formal caregiving resource. Participants spoke about the wife role as specific traits that drew them to reasons for caring for their husband themselves instead of using other resources in terms of "*instinct to care*" need to "*protect dignity*", being a "*doer*", or "*responsibility*".

Many spoke about the responsibility as a wife and needing to protect the PWD dignity or privacy. In one example, a participant stated that her trait as a doer served her in assisting her husband through past health issues and now, that trait possibly stood in the way of her using resources earlier.

I think the one thing that I did, that if I could have, have helped myself differently would be, ... is I shouldn't have allowed myself, my personality is a doer. My personality is because of the history, not only of the relationship but all his medical things. I didn't allow myself to look at this as different. ...I got caught up in always be able to do. (Amy)

Another participant spoke about why she thought wives might delay using caregiving resources due to the “responsibility” as a wife. The responsibility of being a wife, was described by another participant, included the need to provide caregiving. “I do feel responsible to take care of him...And I feel guilty, so I mean, to me, I am responsible for him. He’s, my husband” (Cynthia). Her sense of duty and responsibility as a wife seem to drive the decisions to provide the caregiving herself instead of using caregiving resources.

Some wives also spoke about the importance of protecting their husband’s dignity or privacy by not using a formal caregiving resource as part of their role. When one participant was asked in the interview why she hadn’t used respite services (e.g., someone coming to the home or the PWD going to a facility), she spoke about the concern of him not being comfortable due to privacy. A couple of participants spoke specifically about how having a paid caregiver assist with personal activities such as showering or toileting would be a breach of dignity or privacy, and they felt the need to protect their husband.

...I can't imagine that he would be comfortable with someone else that close.... I'm still reluctant to do things... like, having given him a shower. It's those privacy things that I identify as privacy, that I've made a hurdle that didn't have to be a hurdle. (Irene)

Lack of Trust. Another participant, spoke about how their lack of trust in having a caregiver in the home where her property could be broken or stolen contributed to them not wanting to use

that resource. In addition to the concern over property, she worried about the safety of her husband and the potential for financial abuse.

PWD Readiness and Reluctance. Almost all the participants stated that a contributing factor to not using or having resistance to using a formal caregiving resource (e.g., housekeeping, nursing home, support group, paid caregiving and adult day care) related to the PWD's lack of readiness, and the PWD's "buy-in", physical ability, or intolerance.

Intolerance. Intolerance was described by participants as the PWD not wanting to participate in formal caregiving resources due to: not being around people, how they view themselves, not wanting to engage in a group, or not wanting to receive a caregiving service or resource that involved other people. One participant spoke about a PWD's intolerance due to past experience with staff that were part of a caregiving resource.

Physical ability. A few participants spoke about the physical ability of the PWD influencing the choice not to use a resource in different ways. It was discussed in terms of the PWD or caregiver's perspective of the PWD's abilities as still capable (i.e., physically or cognitively) or being too advanced to benefit from a specific service such as paid caregivers or adult day care. For example, one participant described their spouse's frailty as a reason not to use adult day care: "I don't know that [Hank] would be interested at this point. Because, at this point, physically, he is much more frail than he was." (Hannah).

Another participant spoke about the PWD's abilities not yet at point of needing adult day care:

I don't think I have objections to using them; I don't think we need them right now. I mean, he's able to get his own breakfast, he gets dressed just fine, he showers, he shaves

all those things that you know he's supposed to do he, he does. ...so, he can still do quite a few things. (Doris)

Buy-in. A few participants spoke about having the PWD's buy-in as a factor in the decision to use a caregiver resource, specifically paid caregiving services.

I am reluctant to consistently make decisions without [Frank's] input. ... So, though, I know that there will probably come a stage where I will just need to make the decisions. But ... the consequences of those decisions can be... long reaching. ... And so, as long as I can get some buy-in, things go a lot smoother. And he's, you know, he's not as reluctant to do things when he's part of the decision. Because I know, someday he probably won't be part of the decision, and then I'll really have to take over. (Fiona)

The participants spoke about *buy-in* in terms of shared decision-making or the acceptance of assistance and the PWD's comfort. The importance of having buy-in when making a decision to consider a caregiving resource was stated as having transient importance, referring to the participant understanding that due to the progression of dementia including the PWD in decision making will not be a central factor.

Resource Qualities and Reluctance. All of the participants referred to the quality of resources when mentioning reluctance to using formal caregiving resources, with a focus on resource limitations or fit based on their needs. Others couldn't *justify the need* of the specific resource or commit the time for it. Also preconceived notions of a specific resource due to an experience or through word of mouth impacted their reluctance to use it.

Limitations. Most of the caregivers discussed the limitations of a resource as contributing to their reluctance. For some it was the commute, format or timing of a support group or it was

the cost or availability of paid caregiving. Caregivers discussed these limitations as they intertwined with their personal responsibilities and priorities as a caregiver. These decisions were made as they balanced and evaluated what they identified as most important.

The closest one is [name of a town]. And that's quite a drive for me. So, I mean, I've looked, and it's not easy to find one. ... I know there is something in [name of town] that I saw they meet every Tuesday night, whatever, from 5:30 to 7:30. Well, that's not good for me. Because I'm the dinner person, you know, I have to have dinner. I don't want night meetings. By nighttime, I'm ready to shut down. ...I need a daytime support group.
(Cynthia)

Several participants spoke about the limitation of the resource in regards to being available at a more desirable time of day.

Some participants spoke about formal caregiving services they were using, but that were no longer available due to COVID restrictions or changes in how they were provided, as in the example below. In one example, the service being used was changed to a video platform due to COVID, and the participant decided not to engage in it.

One of my main goals is that I want to find an in-person support group for both Frank and I that meets at the same time. And that just is not going to happen during this COVID time. They're all either on Zoom or telephone calls or something else. (Fiona)

Fit. Some participants spoke more about the resource not being a “fit” for them as the caregiver or PWD. The concept of fit included anything discussed in reference to a specific resource not adequately meeting their needs or priorities as a caregiver or a couple. In one

example, the participant talks about nursing homes not being home-like enough, impacting her lack of interest.

I think probably the nursing home ... is something that I'm resistant to. Just because, ... at some point, it may become necessary. But I, I think the longer I can keep [Ernest] in an environment that is that is either home or like home, the better. And a nursing home is not it, typically. (Ellen)

Another participant spoke about using a formal caregiver in the home but stopping the use for multiple reasons, such as the lack of fit between what the PWD needed or was capable of and what the paid caregiver provided. Thus, although there was interest or willingness of the caregiver, the resource needed to fit what was needed.

A few caregivers spoke about “*fit*” as not being able to justify the need for a specific caregiving resource in terms of not matching their needs at the time, “I can't justify somebody coming in here and not helping with laundry or doing something other than sitting around. ... See, I just I can't justify that” (Cynthia). Some participants spoke about reasons they decided to stop or not continue a resource due to the cost not justifying what was needed. An example was participant Hannah who spoke about the PWD sleeping most of the day and not requiring much interaction from a paid caregiver which was seen as spending money unnecessarily. Within the COVID pandemic a few stated that their ability to work from home due to the stay-at-home orders allowed for them to provide more caregiving recreating the need for outside help. “Actually, I think COVID, as far as Ernest is concerned, helped the delay ... getting a (formal) caregiver because I was home” (Ellen).

Time Commitment. Some participants spoke about the amount of time needed to participate in the caregiving resource, specifically a support group or educational service, contributing to their reluctance to use it.

I thought I would take ... a certification course online on the Alzheimer's website. And I thought I would take that just because I knew it would educate me more in terms of, you know, ideas and information and what to expect and how to redirect things. ... but I haven't had the time to really invest in it. (Ellen)

Thus, while this participant had an interest in an educational resource and the desire to learn more to help in her caregiving, it was the time commitment needed that was holding her back from taking the next step to use the resource. Another participant spoke the value of her time and not committing to a support group, especially during COVID pandemic.

...Oh, it was like an eight-week, once-a-week support group ... And when COVID came around, we just dropped it off the horizon. Well, we couldn't meet in person. And there were just other things that felt that at the time were more valuable to do in that time slot. (Irene)

Preconceived Notions. Some participants described preconceived notions of the resource and how that impacted their reluctance to try it. Preconceived notions reflect participant reports of past experiences or judgements of a resource which contributed to their reluctance. One participant spoke about knowing people who moved to nursing homes and experienced a decline in their health afterward which contributed to their disinterest in this option.

And a nursing home ... I think I wouldn't be able to do that. I've had good friends and some relatives in the nursing home, which was never very appealing to me. And what

happened was that 100% the people who went there declined quite rapidly. ... I don't want that to happen. So ... particularly the adult daycare and the nursing home, would be my last choice in caregiving. (Fiona)

Another participant, spoke about not using a caregiver in the home in the past because of a preconceived notion that she had, thinking she would not have oversight in the care, but realized once she tried the caregiving service her past beliefs were incorrect.

I didn't know that I was basically their employer. I didn't; that piece was missing from me. ... I should have been more aware of that. ... I didn't think I was their employer. You know, the agency is their employer. They're giving the direction. And that was nowhere near the case. (Amy)

While some participants didn't relate a specific decision to a preconceived notion, they spoke about how prior experience with someone with dementia, caregiving or a resource impacted how they would make decisions in the future. In one example, the participant's father-in-law had dementia, and she spoke about having "*waited too long*" to have him placed in a nursing home and how she wouldn't let that happen to her husband. Both her experience with nursing home placement and also with dementia influenced her readiness or interest for using caregiving resources in the future.

And we waited ... too long to have him [father-in-law] put in a home. Because by the time he did it, he ... had a 5150 filed. And ... they took him into a hospital for three days stay and he could never live on his own again. So the whole family had been trying to tell him [participant's husband] that his father was in trouble. ... I will not allow my husband

to get to the point where he could harm himself or someone else or something like that. I will not let it get that far before I would think about doing home nursing.... (Doris)

For these participants, past experiences with caregiving and dementia helped them to be more aware of what is to come and brought a feeling of being prepared for future decisions.

Willingness

In all of the interviews, participants discussed points in their caregiving where they pivoted from reluctance to willingness to use a specific caregiving resource. Although a few reported willingness to use a particular resource right away, the same participants reported reluctance changing to interest/willingness to use another resource. The caregivers in this study described different sets of factors that influenced their willingness to use resources to help them in caring for their husbands: (1) their own readiness to accept help; (2) the PWD's readiness to use outside resources; and, (3) the quality of the specific resource under consideration.

Caregiver Readiness and Willingness. Contributing factors for the participant, as the caregiver, to be ready and willing to access formal caregiving resources were reported in various ways. The factors reported as impacting the readiness of the caregiver to be willing to use a formal caregiving resource included; to seek knowledge, own physical limitations, timing of their readiness, and other obligations to work or family.

Knowledge. Several caregivers described their willingness to consider support groups or other educational programs in order to enhance their knowledge about dementia and to get advice and support from peers.

... we both are yearning for a group that is like-minded, that we can actually talk with and share common concerns.... I would like the support group to discuss ways ...that I could help ..., I think, would give us a little independence. (Fiona)

Participants referred to not only the support group providing peer support but also helping to maintain their ability to care for their partner with dementia and allow them to stay independent as a couple in their home. Hearing others' stories about more advanced stages of dementia helps them plan for the future. "I just thought the more we knew, the better that we could face the future" (Jane). One caregiver pointed out the importance of the support group being "*other women that are going through the same thing.*" Another participant joined a support group because of her need to "*get some ideas*" from other spouses or peers in different stages of the caregiving journey. The interest in joining the support group was not only about the knowledge of how to support the PWD but for some it was also was an avenue to get information about other caregiving resources to consider in the moment or in the future as the disease progresses. "But it was really good to learn things like that, for instance, that either adult daycare or in-home care, like assisted living, was better done sooner than later, because of the impact on the patient was... an easier adjustment" (Karen). Overall, some spoke about the purpose of wanting to learn as a way to help "*face the future*" or help with "*adjustment*" in regards to their partnership with their husband with dementia.

Physical limitations. A few caregivers spoke about their own physical limitations impacting their ability to care for their husband with dementia and wanting to use a caregiving resource. The types of physical changes discussed were related to injuries, recent illness or natural changes in aging contributing to limitations in some physical activity. Some participants chose to get extra help in the home, while others decided to place their husband with dementia in

a nursing home due to changes in their physical abilities to do caregiving tasks. "...it was the right thing to do, ... And I'm concerned because I just physically, was not able to manage, you know, and help each other" (Karen).

Timing of Readiness. For some participants, their readiness and willingness to use a formal caregiving resource had to do with timing. The category of timing and readiness was not discussed in relation to a specific resource but several resources. When talking about being ready to join a support group, some participants emphasized the importance of timing as being prepared to hear other people's stories or learn about what the future may look like in regards to dementia stages or care needs.

I am interested now, to understand other person's roles in moving their husband to different locations for care. I think I would feel now I'm ready. I wasn't before. And I think now I'm ready to hear other people's stories. ...I wasn't ready to even think about having my husband somewhere else. (Amy)

Another participant also spoke about being ready to join a support group as it aligned with coming to the point of awareness of needing help. Just as the PWD has stages of the disease occurring, participants described the fluid process of their caregiving experience where timing of their readiness influenced their willingness to start or consider using a caregiving resource. The importance of timing for the caregiver was discussed in terms of an emotional and/or mental moment of acceptance of needing or wanting help.

Other Obligations. The motivations for starting a formal caregiving resource sometimes centered around the participant's other obligations, which required them to need more outside support in caring for their partner with dementia. Participants spoke about having obligations to

their work, self-care and family as impacting their willingness to use a resource. Out of the eleven participants, only one reported still working while being a caregiver for their partner with dementia. She spoke about the need to have time to continue to work as his disease progressed and the reasons for starting to use an in-home caregiver.

And so having her there allows me to be able to focus on my work. Because I know he's being taken care of, I know he is safe.... And that's what drove me to getting a caregiver, to begin with; I mean, it was just, it was becoming impossible for me to have any kind of ... work schedule to maintain any kind of consistent pattern of living. (Ellen)

A couple of other participants spoke about needing to support other family members either as a caregiver or to meet other family member obligations requiring their time; in such situations, they spoke about using respite care. A few participants spoke about the need for self-care such as exercise, spending time with friends or having time alone and how this need contributed to their willingness to join a support group, and/or use in-home caregiving or respite. In one case, the desire to use respite included the need for self-care and to support other family members.

And at that particular time, I needed more time to leave the house...I felt the need to have more hours to be away from it to get a 'mind fresher'. I also thought the additional hours would help me support my family.... (Amy)

It's only been recently that I've considered getting somebody in, and the reason is that I need a break. ...I want to be able to go for my daily walk and not keep thinking about what's he doing? ... So that's it's just been recently because I've been so burned out. (Cynthia)

Although the reason for self-care varied across the caregivers, the importance of taking time for themselves as a motivation for using formal caregiving resources was a common thread.

PWD Readiness and Willingness. All of the caregivers who participated in this study spoke about factors related to the readiness of their husband with dementia which influenced their willingness to choose using a formal caregiving resource. The factors the caregivers reported that were related to use a caregiving resource were discussed in terms related to the increased needs of the PWD and their interest in participating or using the resource.

Increased Need. The participants spoke about the increased need of the PWD in terms specific to their physical ability loss or safety concerns as contributing to their interest in using a formal caregiving resource. Caregivers stated wanting to start a caregiving resource because of a change in the PWD's physical or cognitive ability, including their ability to carry out ADLs. Many caregivers referred to the changes in the PWD's ability as one of the factors contributing to their willingness to use a caregiving resource now or what they may consider in the future. The types of resources of interest due to the PWD increased needs were caregiving resource centers and paid caregiving services. In some examples below, caregivers talked about getting in-home caregiving due to husbands with dementia needing more "*hands-on time*." "More hands-on time; for [Adam], his needs had increased" (Amy). Another caregiver spoke about the increased physical needs over time – in general - leading her to reach out to formal caregiving services. While others spoke about specific physical changes that led them to use a particular caregiving resource, such as losing the ability to toilet or shower, or might lead them to use the resource in the future. "Well, for me, if he can't toilet himself or shower himself to me, he will be ready, and I will be ready to" (Jane).

... I guess I was becoming more aware each month of things he either couldn't do or had struggles doing that I had not seen before. ... And I knew that we needed [and] I needed to connect with something that was outside just our family group.” (Fiona)

As previously mentioned, for some FSCGs it was the hands-on caregiving tasks, which can be very private, that were described as precipitating factor for using a paid caregiver, such as a nursing aide. This contrasts with other participants who were reluctant to use a paid caregiver due to the need to protect their partner’s dignity.

The increased needs of the PWD regarding safety were frequently mentioned as reasons for using a caregiving resource, such as respite, adult day care services, or other paid caregiving services. The extent of the concern for safety or the types of behaviors associated with safety varied among the participants.: “I’m trying to get ahead of the curve a little bit because I know there's going to be a point where I simply cannot keep him at home and keep them safe. For one thing, he wanders” (Ellen). In contrast to “*getting ahead of the curve*”, one participant indicated she was ok with her husband wandering until he did something unsafe such as walking on the highway and that triggered her to search for other caregiving resources. Another participant spoke about a threshold of comfort regarding safety and “*leaving him alone*” for a specific amount of time; then, when that time got longer, she was no longer comfortable.

And at the very big beginning, I had somebody coming in. I kind of overreacted when he was first diagnosed and felt like oh my gosh, I can't leave him alone. And at the time, I had two different volunteer jobs that I was doing. One was just a two-hour commitment once a week. And so, I felt comfortable leaving him alone for that period of time. But the other one was usually four to six hours, sometimes once a week, sometimes twice a week,

and I felt uncomfortable leaving him alone. So, I hired through an agency someone to come in. (Hannah)

The participants' remarks about safety suggest that it is not just the specific change in the PWDs safety or physical changes, but the caregiver's perceptions of those changes and their ability to meet those needs which were intertwined in how they made decisions about using a specific caregiving resource at a specific time.

Interest. Whether or not there was a specific physical need requiring more caregiving resources identified by the participants, several FSCGs spoke about the PWD's interest or willingness to use a caregiving resource was pivotal in their decision. Ensuring the PWD was interested or willing to participate in the resource was stated as important in the use of several different resources: education, support group, caregiver, housekeeper, and adult day care or respite. The participants spoke about education and support groups which also included activities in which the PWD could also participate. One participant utilized the adult day program, relaying it was her husband's idea as he was interested in ensuring she had a break from caring for him.

You know, that was actually [Hank's] idea. He and I forget how we heard about it. It must have been at one of the seminars that we went to, and he said, you know, maybe I could do this. ... he just said, maybe I could go one day a week, and that would give you a break. (Hannah)

Another FSCG discussed her decision for her husband to move to an assisted living occurred once her husband stated he was ready, although she was interested before that. It was his realization of his limitations to be there for her as her partner and her being able to care for him physically. Another caregiver referred to her husband's ability to tolerate or being willing to the

use of a housekeeper as important. When her husband is not able to take it, she decides to stop using the resource even when she could use the help, which she mentions later in the interview.

... we have a housekeeper who comes once a month. That was what I've been able to talk him into right now. ... And then he used to be willing to tolerate it if I made a space for him to lay down, and then they would clean it around him. (Bernice)

In contrast, some participants had difficulty even considering using a caregiver for their husbands due to them believing they had no challenges and their lack of understanding of their own condition. For these wives, this contributed to their role as caregivers and supporting their husbands' difficulty. Other participants described similar experiences of their husbands having poor self-awareness of their condition and abilities. This, however; didn't impact their willingness to use a resource; rather, they described this as a challenge contributing to the context of the caregiving experience. Sometimes the PWD still sees themselves as capable, even in complex tasks such as driving.

Resource Qualities and Willingness. Many caregivers spoke about the resource itself or perceptions of the resource which contributed to their willingness to use it, including trusted recommendations and ease of use.

Trusted recommendations. Several participants spoke about the value of receiving a trusted recommendation – from a trusted friend, family, or clinician - for various resources, including: education, caregiver or dementia resource centers, paid caregivers, adult daycare, respite, and support groups. Some participants spoke about people they knew who were caregivers for someone with dementia making specific resource recommendations that influenced their decision. "... And one of the Bible study women has a husband who had early onset dementia.

And she really said that the [Dementia resource center] was just so helpful throughout her journey, that she really recommended it.” (Fiona). Other participants spoke about the importance of a clinician or healthcare worker they knew who suggested a specific resource. In one example is the importance of a trusted recommendation from a caregiver resource center helping her to decide to use an adult day care because “*they vet them.*” Yeah, they have great resources. And I feel like they vet ...you wouldn't want to just drop somebody off and or at least I wouldn't, ... I think it's a good place to get good insight. (Jane) Additionally, some spoke about recommendations from doctors, social workers, or nurses. Thus, not a specific provider type was consistently mentioned in these interviews.

Ease of Use/Accessibility. Some participants reported ease-of-use and/or accessibility as factors contributing to their willingness to use a specific caregiving resource. References to ease of use or accessibility focused on price, availability, location, flexibility, or quality of the program/service. References to ease-of-use were associated with using a resource center, support group, or educational services. In contrast, participant perspectives about accessibility and cost of professional caregiving services in or outside the home were not consistent. For example, a participant spoke about choosing to use an adult daycare because the service’s high quality is more important than the cost or the long commute in her decision.

I made an appointment at the [adult day care]. And the Auburn program was much smaller. And it was more expensive. And it was there were only like, it wasn't as flexible. So, I knew it was going to be a drive. But I felt like they really had some people that really kind of knew what they were doing. And it was very focused and towards people like Jack and he thoroughly enjoyed it. (Jane)

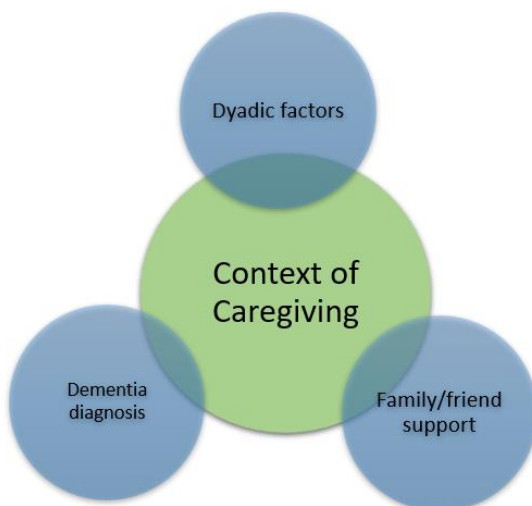
A few participants spoke favorably about the flexibility of the service resource moving to ZOOM during the pandemic and as necessary to starting or continuing a resource. Having educational classes online and shorter in length were important aspects to another participant who had a busy schedule and was still working.

Context of Caregiving

While not specifically the focus of interview questions, participants identified a number of contextual factors that influenced their overall caregiving experience. These were not specifically the factors contributing to willingness or reluctance to use a resource, but reflected the context of caregiving and the impacted difficulty of the decision. The factors that were mentioned as part of the context of caregiving included: getting a dementia diagnosis, dyadic factors, and family/friend support. Each of these subcategories will be discussed further in the next section along with their contributions to the context of the caregiving experience.

Figure 1

Context of Caregiving



Dementia Diagnosis. Several participants spoke about the challenge of getting a dementia diagnosis. A formal diagnosis not only provided knowledge of what was contributing to the symptoms being observed, but also contributed to the ability to reach out or even consider dementia caregiving resources or services. Thus, getting a dementia diagnosis contributed to the context of the experience as a caregiver, impacting the ability to take next steps in resource utilization. One caregiver spoke about an experience of getting a diagnosis that took about four years. In finally getting a dementia diagnosis, she felt comfortable seeking out a support group.

...Alzheimer's diagnosis was finally confirmed, maybe April of this year.... And before that, they were not listening to me very well... And the neurologist looked at things and said, you know, so far, it doesn't look like Parkinson's, and it doesn't look like Alzheimer's, and it doesn't like this or that. ...So, stop, stop making noise at me about this and take me seriously, because this is you know he's not doing well. And so, I think it was sometime after that actual Alzheimer's diagnosis. (Bernice)

Thus, the timeliness of getting a dementia diagnosis provides context to the situation and influences how the caregiver and PWD are able to plan their approach in managing the condition and everyday life.

Dyad Relationship Dynamic. The challenges of being a caregiver and making decisions regarding the use of caregiving resources were also discussed in the context of the relationship dynamic. When some participants spoke about their husbands with dementia and their caregiving journey, they discussed their dynamic as a couple before the diagnosis, which influenced how they functioned as caregivers and care recipients. One participant expressed how the complex personalities and relationship dynamics as a couple, made it more difficult for her to make caregiver choices.

Well, it's an old relationship issue we've had... But it's either my way or your [referring to her husband] way. ... And, and my way was never the way. ... And so, for me, it felt like an arm wrestling the whole time... To then just stand my ground, smile, try not to be reactive. (Amy)

Another participant referenced how each of them is “stubborn” and the change within the roles as a couple (i.e., partner to caregiver) contributes to her feeling angry about the situation.

But he's very stubborn. So am I. So just our relationship as you... honestly, I don't know, a different way to say it. As you're losing your partner, you're becoming more of a caregiver. There are emotional changes that you as an individual have because you have to deal with that loss at the same time, you're dealing with a new role, and get all the emotions that can come up, come up. So that was why I knew I needed help. Because I think there were times when I was really angry, but I knew I wasn't angry at him I was really angry with the situation. (Karen)

Another participant, mentioned the change in roles in the relationship related to decision-making as challenging as a caregiver. Some spoke about the complexity of individual personalities and characteristics of themselves as a couple, which contributed to the context of caregiving.

Participants discussed how their roles, communication, individual traits and dynamics as a couple impacted their decision making but not always specific willingness or reluctance to use a resource. Specifically, these factors were viewed as adding more or less friction in the process.

Family/Friend Support. In addition to the nature of the dyadic relationship, several participants spoke about how having or not having the support or understanding of families or friends influenced their caregiving experience, making it easier or more challenging. For

example, one participant described how a complex family dynamic made it challenging to decide about nursing home placement.

... And she [PWD's daughter] just was so disrespectful, for her dad's wishes at that point.
... She tried to meddle in his ... medical stuff.... And you know, and it was just where there hadn't been much input from after [the dementia diagnosis] ... And he sent her a couple of emails that kind of layout, you know, my decision, leave me alone. And that was...an unfortunate time. On the other hand, for his boys and his ex-wife [they] really helped out. (Karen)

The timeliness of the dementia diagnosis, available family/friend support or the nuances of the dyad dynamic, were all factors contributing to the landscape of their life, relationship and the experience of caregiving.

Chapter 5: Discussion

Summary of Findings

Findings from this qualitative inquiry suggest that FSCGs willingness or reluctance to use any resources was influenced by factors that related to themselves (e.g., caregiver readiness such as assessment of their skills/abilities), their husband (e.g., PWD readiness such as his belief he didn't need help) and, to a lesser degree, the resource qualities (e.g., cost, availability). The participants frequently seemed to make the decision to use resources when there was readiness from their husband including his understanding of what he needed, how well the resource would fit for him and whether he would accept the help. Interestingly, factors like cost and access were mentioned less frequently as reasons influencing a caregiver's use of a resource. However, factors specific to the resource were mentioned more frequently as reasons for being resistant to using versus contributing to the willingness to use. Overall, the findings from this study suggest the decision-making process for a wife caregiver regarding the care for a partner with dementia is multifactorial and involves their readiness and needs as the caregiver, the needs and readiness of the persons with dementia, and the qualities of the resources. These multiple factors were discussed over the time period of caregiving impacting decisions about different types of caregiving resources. Given that multiple factors impact readiness to use a resource it is important that clinicians and providers of formal caregiving services engage in ongoing conversations with caregivers and conduct assessments to assess both willingness and reluctance to start a specific service at different time points throughout the caregiving journey

This study reinforced some of the findings in other work. For instance, Brown and Chen (2008) examined help-seeking factors of spouses using community resources where wife caregivers realized the "need for help" after a significant event. Participants in this study also spoke about changes in their own physical abilities or the abilities of the PWD as being catalysts

for deciding to use a resource. Reasons to not use a resource related to “lack of perceived need” were also identified by Brodaty et al. (2005) and Granbo et al. (2019) among a variety of family relations studied. von Kutzleben et al. (2016) identified care burden and relief as reasons for using resources, which was consistent with findings in this study related to participant discussion about the need for time for self-care.

The need for the wife to “protect dignity” of the PWD was a finding similar to that in in the study by Morrisby et al., (2019), where the need to protect husbands’ image” was cause for delaying caregiving resource use. The need for wife caregivers to have buy-in from their husband with dementia was also found by Sinclair et al. (2018b) as “relational decision-making” impacting the decision to use a caregiving resource. Similar to a few other studies, the PWD’s resistance to use resources contributed to the caregivers’ reluctance (Brodaty et al., 2005; Newkirk et al., 2020; Winslow, 1997). This further supports the complexity of decisions of a spousal couple, even when one has dementia their input and willingness is seen as being of value to their partner.

There were several unique results of this study to add to the current literature. Unlike Newkirk et al. (2020) specifics regarding the resource qualities were not mentioned by many participants as factors associated with willingness to a resource, but more frequently stated as a reason for not using them. When looking at resource qualities in relation to contributing to willingness or reluctance to use a formal caregiving resource, participants stated that the recommendations of others (i.e., friends, family, clinician) was an important driver of resource use. For others, it was not the opinions of others which impacted their reason to not use a resource, but the caregivers’ preconceived notions of it were influential. Some stated that once they tried the resource, they realized their perception was incorrect.

This study contributed to the literature gap related to knowledge specific to the decision-making process of wives caring for husbands with dementia. This is the only study that has focused on wife caregivers of persons with dementia specifically in relation to what they perceive as factors which influence their willingness or reluctance to use of any formal caregiving resources. The distinctive results of this study are that the wife caregivers expressed their decision-making experience for using formal caregiving resources as a process where they balance their own need and readiness with the PWD's readiness to accept or need a specific resource and to a lesser extent the resource qualities themselves. The aspects to decision making were multifactorial. Some spoke about this process as they had a need or interest in the resource, but were waiting for the PWD to be open or willing to accept the resource. For others, there was a need and interest, but the resource they were interested in was not available in a way that fit their needs. The process included their reassessment of their own readiness, PWD readiness and the resource as the disease progressed and needs changed. Most importantly the need to protect the PWD's dignity as an important factor for several wives as a reason for reluctance to use a caregiving resource was a distinctive finding from this study. This finding was specific to hands-on caregiving resources where help was providing hygiene or ADL care. Further studies need to explore if the protection of dignity is specific to wife or female caregivers compared to other relations and gender.

This study identified factors that did not specifically impact the decision to use a resource but factors explained by participants as influencing their experience as a caregiver of PWD and contributing to making decisions easier or harder. These factors were discussed as part of the context of caregiving: dyadic factors, family/friend support, and getting a dementia diagnosis. Further research is needed to identify other possible contextual factors which may be present and

to what extent they influence the caregiver's decision making. These findings highlight the potential role of the relationship dynamic in understanding the caregiver and their experience. It may benefit healthcare providers and caregiving resource organizations to acknowledge and provide assistance to caregivers in helping to navigate their relationship and decisions as a couple with the changes in roles and decision making. Family and friend support was discussed as a mixture of useful and challenging depending on the individuals, which was not found in the literature. Considering a caregiver's support system as not just the people in their life but how they contribute to easing caregiving or adding friction may be beneficial when assessing a given caregiver's situation and what support they may need in navigating or mobilizing their family/friends. Also, getting a timely dementia diagnosis was mentioned by several participants as adding to their frustration as a caregiver. Dementia is difficult to diagnose since there is not a simple test, but a diagnostic process where alternative diagnoses need to be ruled out before ruling in dementia. The results help to identify that having the dementia diagnosis contributed to caregivers and the PWD being able to name the condition and take further steps if needed. While the diagnosis was not the key in decisions to use a resource, it did create the context of understanding what was occurring and provided more clarity about what the PWD and caregiver should expect in the future.

Limitations

There were several limitations of the study. The small sample of participants (n=11) were not diverse in ethnic/racial backgrounds; all of the participants were white, non-Hispanic and spoke English. This study did not collect information regarding level of education, affluence or socioeconomic status of the participants. Furthermore, due to all participants having access to caregiving resources and being recruited through a specialty clinic, they may not represent the

experience of caregivers with limited financial or health resources. The results of this research study are therefore have limited transferability; however, the findings provide an important foundation for future research with larger, more diverse samples of wife caregivers of PWD. In addition, all of the participants reported utilizing at least one formal caregiving resource. This may have been due to their spouses' stage of dementia, the fact that they were enrolled in ongoing clinical services with likelihood of receiving referrals. Participants who volunteered to participate may have been more driven to learn about dementia and/or caregiving formal resources than a non-participant. Thus, this may have affected results about willingness and reluctance to use formal resources.

On average, the wives were about 9 years (69.74 years vs. 78.2 years) younger than their partners with dementia. This may have contributed to only a few of the participants speaking about their physical limitations as contributing to their desire to use a formal caregiving resource. These findings may have been different if the caregivers were older and this needs further study. The cognitive and functional level of the PWD cared for by the participants should also be considered. All of the PWD had at least a FAST score of 4 suggesting mild dementia with seven of them having moderate dementia (FAST score 5 or 6). There were no participants who cared for a PWD with a FAST score of 7 suggesting severe dementia. Of note, the study inclusion criteria purposefully excluded those caring for a PWD who didn't have at least one IADL need, which would most likely also exclude FAST scores less than 4. This helped to ensure the dementia was at a stage where resources would be more likely to be either considered or needed. Since there were no participants with care recipients in the severe stage of dementia, however, the results are not transferable to wife caregivers managing a PWD at the late stage.

Recall bias may have been a factor especially when caregivers attempted to recall information over years. The social desirability of the responses may also play a role if participants feel that the interviewer is seeking a preferred answer or what they perceive as a more socially acceptable answer. To limit social desirability in responses, I attempted to destigmatize the topic by starting the interview with statements about the wide range of help needed or resources used by caregivers and assured participants that there is no right or wrong amount of resource use.

Given the qualitative descriptive study design, there was limited amount of interpretation of the data. While the willingness and reluctance factors were identified, there was no deeper interpretation of how the factors were interrelated, overlapped or differed in importance for decision making. Additionally, analysis of the factors across participants and their unique demographics and qualities were not explored.

Implications

Research Importance

A limited amount of research has focused on the specific experience of FSCG of a partner with dementia to understand what influences their willingness or reluctance in deciding to use or not use formal support resources. Studies have shown more strain in family caregivers of PWD who are women (Ehrilch et al., 2014; Friedemann & Buckwalter, 2014; Friedman et al., 2015), spouses or living with the PWD (Braun, 2009; Rigby et al., 2019). Therefore, it was important to examine the uniqueness of the wife caregiving experience and what impacts their decisions to use formal services. As the PWD has physical and cognitive changes through the progression of dementia, the caregiver is continually adjusting in their role and reevaluating what is needed to meet their needs. This study showed that the factors impacting the decisions of wife

caregivers were multifaceted. Through their interviews, healthcare providers and formal caregiving resource services can better understand the caregiving needs and readiness to use a resource by assessing the readiness of the wife in perceiving their need for help, the interest of the PWD, and the fit of the resource. Most importantly, the caregiver's readiness needs to be frequently assessed to identify when they are shifting from reluctance to willingness to use a resource. An enhanced understanding of these processes can help to inform the creation of effective formal dementia support services and how there are publicized within the community to ensure improved engagement of wives caring for a PWD.

Future Research

In order to further understand how FSCG of PWD make decisions for using formal caregiving support, future studies are to understand how more diverse groups of caregivers make these decisions. Diversity is needed related to culture, race/ethnicity, education and language spoken to identify the similarities and differences across groups in their willingness and reluctance to use caregiving resources. Further research is needed to include participants who have varying access to formal caregiving resources such as those with economic limitations or residing in rural settings. Additionally, a longitudinal qualitative study with FSCGs could illuminate how decision making unfolds throughout the caregiving process and the progression of disease. A grounded theory approach in a similar study would help to identify possible interrelationships between the factors in willingness and reluctance and may, in turn, be used to develop a working theory. Lastly, this study should be replicated with other family relations caregivers (i.e., husband, daughter, son, sibling) to emphasize the similarities and uniqueness in factors influencing their decisions to use formal caregiving resources by relationship status.

Practice or Policy

This study reinforces the importance of ensuring that formal caregiving resources are not only available, but that they meet the needs of the different types of caregivers and are offered at the time they are needed. Most importantly, a caregiver's gender and relationship role with the PWD may point out the need for different approaches when assessing the need for resources. While more research needs to be done to make any generalizations about the population of wife caregivers of PWD, it may benefit healthcare and caregiving services to incorporate a few changes to improve resource utilization among this group. Firstly, given that several participants became more willing to use a resource when a trusted clinician suggested it, healthcare professionals should be knowledgeable about formal caregiving resources. This means that conversations with the caregiver are important during routine visits to evaluate their need and readiness for a specific resource. Secondly, wife caregivers in this study frequently reported the importance of the PWD being willing to accept or participate in the resource. Thus, it is important for providers to help the wife navigate these conversations with their husband with dementia so they are comfortable taking the next steps in utilizing a formal caregiving resource. To ensure these practices of assessing needs and offering specific resources to caregivers of PWD, future policy changes including (provider incentives) should be considered to increase the likelihood of practice change that includes these recommendations among healthcare professionals who manage persons with dementia in the community setting.

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Appendix A

Summary of Quantitative Literature: Gender of Caregiver and Formal Resource Use

Reference	Study Design	Setting	Sample	Caregiver gender	Caregiver Kinship type	PWD	Formal Support service	Gender & Resource use findings
Sun et al, 2008	Cross-sectional, Survey	US	n=720	77% F, 23% M	60% males = spouse, 42% females = spouse	Mean MMSE = 11-12, mean ADL/IADL = 12.4-12.9	In-home service, transportation, daycare, support group.	Significance: In-home services: F < M caregivers to use (M = 0.83 vs. M = 1.06, p < .01). Transportation services: F > M to use (p < .01) No significance: M vs. F Day care: (p = .06) or support groups (p= .58).
Cossette et al., 1995	Longitudinal, survey	Canada	n=192	66% F, 44% M	26% dtr, 40% wives, 34% husband	75% AD, 6% multi-infarct, 19% nonspecific	Transportation, respite, housework, IADL/ADL assist, informational support, emotional support	Significance: Women showed significant correlation coefficients and the men nonsignificant correlation coefficients for the relationship of the frequency of resource use and satisfaction.
Monahan & Hooker., 1995	Cross-sectional, survey	US	n=51	51% F, 49% M	100% spouse	100% formal dementia diagnosis	Paid caregiving	No significance: F vs. M no significant difference in the use of paid hours of help/week
Newkirk et al., 2020	Descriptive, cross-sectional, survey, study from 2006–2009	US	n = 220	68% F, 32%F	54% spouse, 42% other family, 4% other	100% formal dementia diagnosis, mean MMSE score = 19.99	Support groups, adult day services, respite	No significance Gender of caregiver not significant in initiating resource use. Significance Among those who used services (i.e., the exponential regression

Reference	Study Design	Setting	Sample	Caregiver gender	Caregiver Kinship type	PWD	Formal Support service	Gender & Resource use findings
								within the hurdle model). F > M used resources more frequently (IRR=1.39, p<0.05).
Feldman et al., 2020	Cross-sectional, National Poll on Healthy Aging (NPHA)-	US	n = 148	60.8% F, 39.2% M	19% spouse, 59.7% adult child, 21.3% other	36.6% moderate memory loss, 16.2% severe memory loss. 30.4% require ADL assist.	Support groups, family therapy, classes/training, respite, family leave	Not significant: Gender of caregiver was not significant on use of formal service (p>.05).
Martindale-Adams et al., 2016	Cross-sectional surveys,	US	n= 642	83% F, 17% M	42% spouse, 47.8% adult child, 10% other	At least 1 ADL limitation or 2 limitations in IADLs and MMSE < 24.	Homemaker, home health aide, meals, transportation, visiting RN, daycare support group, physician visit, mental health visit, emergency room, inpatient care, nursing home	Not significant Gender of caregiver was not significant in-service use (p= .41)
Robinson et al., 2005	Cross-sectional, National Caregiver Training Project survey	US	n=241	74% F, 26% M	64% spouse, 23% adult child, 13 % other	85% moderate to severe dementia	Respite services, caregiving assistance	Significant Caregiver gender had modest correlations with service use (p<.05 2-tailed). Being a female caregiver positively correlated with service use.
Cox, 1997	Longitudinal. 1992-93, survey.	US	n=-228	85% F, 15% M	26 % spouses, 50 % adult child, 24 % other	Mean ADL score = 18.3	Respite	Not significant Caregiver gender not significant in users, stoppers, or nonusers of resources (p >.05).

Reference	Study Design	Setting	Sample	Caregiver gender	Caregiver Kinship type	PWD	Formal Support service	Gender & Resource use findings
Brodsky et al., 2005	Cross-sectional. Computer Assisted Telephone Interviewing	Australia	n=162	73% F, 27% M	33% spouse, 55% adult child, 12% other	Some ADL assist needed 61%, most ADL assist needed 4.7%. Moderate cognitive impairment = 33.9%, severe cognitive impairment = 33.9%.	Home help, community nursing, meal, home maintenance, transport services respite	Not significant: Gender and service use were not significant (p=0.82).
Collins & Jones., 1997	Cross sectional, surveys	United Kingdom	n= 48	50% F, 50% M	100% spouses	Required assistance with at least 1 ADL, 67% scored moderate on CDR for dementia severity.	House chore assistance, respite	Not significant: Gender and service use were not significant. (p<0.05)

Note: ADL = Activities of daily living, IADL = Instrumental activities of daily living, MMSE = Mini-Mental Status Exam, M = Male, F = Female, dtr = daughter

Appendix B

Summary of Quantitative Literature: Kinship of Caregiver and Formal Resource Use

Reference	Quantitative Study Design	Setting	Sample	Caregiver gender	Caregiver Kinship type	PWD	Support service	Kinship & Resource use findings
Cossette et al., 1995	Longitudinal, survey	Canada	n=192	66% F, 44% M	74% spouse 26% dtr,	75% AD, 6% multi-infarct, 19% nonspecific dementia	Transportation, respite, housework/meals, IADL/ADL assist, informational support, emotional support	No significance: No significant differences between spouses and daughters in frequency of formal support use.
Newkirk et al., 2020	Descriptive, cross-sectional, survey, study from 2006–2009	US	n = 220	68% F, 32%F	54% spouse, 42% other family, 4% other	100% Had formal dementia diagnosis, mean MMSE score = 19.99	Support groups, adult day services, overnight residential respite, and family respite	Not significant: Kinship and service use or frequency of use
Robinson et al., 2013	Cross-sectional, retrospective. National survey between 1995-1997	US	n= 241	74% F, 26% M	65% Spouse, 23% % adult child. 12% other	66% ALZ, 5% multi-infarct dementia, 7% mixed, 10% other, 13% unknown	Respite or caregiving assistance	Significant: Relationship type with the caregiver was significantly associated with the use of services (p = .001). Non-spouse > spouse to use resources.

Reference	Quantitative Study Design	Setting	Sample	Caregiver gender	Caregiver Kinship type	PWD	Support service	Kinship & Resource use findings
Martindale-Adams et al., 2016	Surveys, cross-sectional	US	n= 642	83% F, 17% M	42% spouse, 47.8% adult child, 10% other	PWD with at least 1 ADL limitation or 2 limitations in IADLs and MMSE < 24.	Homemaker, home health aide, meals, transportation, visiting RN, daycare support group, physician visit, mental health visit, emergency room, inpatient care, nursing home	Significant: Relationship to care recipient was significant for service use (p<.001). Spouses more likely to use resources.
Robinson et al., 2005	Cross-sectional multisite experiment, National Caregiver Training Project survey	US	n=241	74% F, 26% M	64% spouse, 23% adult child, 13 % other	85% moderate to severe dementia	Respite services, caregiving assistance	Significant Being a spouse was the largest unique contribution (.060) to the Nagelkerke R2, indicating the best predictor of lack of use of services Spouse less likely to use resources (p < .001).
Cox, 1997	Longitudinal. 1992-93, survey.	US	n=-228	85% F, 15% M	26 % spouses, 50 % adult child, 24 % other	Mean ADL score = 18.3	Respite	Not significant. More spouses were nonusers, but not significant (p > .05).

Reference	Quantitative Study Design	Setting	Sample	Caregiver gender	Caregiver Kinship type	PWD	Support service	Kinship & Resource use findings
Brodaty et al., 2005	Cross-sectional. Computer Assisted Telephone Interviewing	Australia	n=162	73% F, 27% M	33% spouse, 55% adult child, 12% other	Some ADL assist needed 61%, most ADL assist needed 4.7%. Moderate cognitive impairment = 33.9%, severe cognitive impairment = 33.9%.	Home help, specific home help, community nursing, meal service, home maintenance, transport services respite	Not significant Kinship and service use were not significant (p=0.63).
Winslow, 1997	Secondary analysis of longitudinal study: 4 surveys over 1yr	US	n=452	68.5% F, 31.5% M	57.5 % spouse, 42.2% adult child,	100% with Alzheimer's disease	11 different services counted as formal support. Types not provided.	Significant: Inverse relationship between spouse relationship and formal support use ($\beta = -.184$, $p < 0.01$), Spouse less likely to use resources
von Kutzleben et al., 2016	Mixed method-cross-sectional, survey and interviews-thematic analysis	Germany	n= 168, (n= 84 caregivers, n= 84 PWD)	79.5% F, 20.5% M	58.3% Adult children/child-in-law, 27.4% spouses, 7.2% other	92.9% medically diagnosed dementia. 39% require around the clock supervision.	Home care, daycare, respite, meals on wheels, companion home visits, social care groups	Significant: association with the caregiver relation to the person with dementia and perceived stability (i.e.no support needed) (P = 0.007). Men cared more for by spouses, and women by non-spouse caregivers. Non-

Reference	Quantitative Study Design	Setting	Sample	Caregiver gender	Caregiver Kinship type	PWD	Support service	Kinship & Resource use findings
								spouse caregivers of women greater report of stability and no support needed.

Note: ADL = Activities of daily living, IADL = Instrumental activities of daily living, MMSE = Mini-Mental Status Exam, M = Male, F = Female, dtr = daughter

Appendix C

Summary of Qualitative Literature: Gender & Kinship of Caregiver and Formal Resource Use

Reference	Study Design	Study Purpose	Setting/ Participants	Caregiver Gender/Kinship	PWD Characteristics	Support Service Types	Results
Brown & Alligood, 2004	Qualitative-Grounded Theory	To explore patterns of help-seeking by a select group of caregivers, older wife caregivers of husbands with dementia.	US n= 11	100%F 100% spouse	Mean years diagnosed w/dementia = 3.9.	Home health, companion services, housekeeping	<p>Created the Theory of Help-Seeking Choices: Taking One Day at a Time. Wives made choices through Realizing (wrongness, accepting direction, help needs lead to reaching out and within (informal/formal help or self-managing), Actions to make choices (avoiding, shouldering, facing), and then consequences to continuing care. Wives were not able to reach out for help needs until the realization of wrongness (accepting a problem exists).</p> <p>Depending on choices made and the effectiveness of the help obtained, care at home was continued with less or greater cost to the wife caregivers.</p>

Reference	Study Design	Study Purpose	Setting/ Participants	Caregiver Gender/Kinship	PWD Characteristics	Support Service Types	Results
Brown & Chen, 2008	Qualitative-Descriptive	What are the similarities and differences in help-seeking patterns between husband-and-wife spousal caregivers	US n=20	55% F, 45% M 100% spouse	All were diagnosed with some form of dementia including.	Home health, companion services, housekeeping	Help-seeking: Wives - "continuing care", "reaching within" do work themselves, if possible, "avoidance" to delay seeking help. Husbands-"continuing on" through "letting others" and doing my part". Realizing a need for help: husbands identified changes earlier and sought help earlier than wives. Wives, more than husbands, had difficulty recognizing problems in the spouse and therefore delayed seeking a diagnosis or help.
Meyer et al., 2016	Qualitative-descriptive phenomenological	To describe spouses' experiences of living with a partner affected with dementia.	Europe-Sweden n=7	3F, 4M 100% spouses	Range years of dementia dx = 2-16	Respite, day services	From togetherness to loneliness. Three descriptive categories describe the phenomenon: 1- Changes in the partner's behavior, (lack of understanding that behavior changes were signs of dementia and desire to have known more and to reacted differently), 2- Changes in everyday life. (Gradual changes in partner and care

Reference	Study Design	Study Purpose	Setting/ Participants	Caregiver Gender/Kinship	PWD Characteristics	Support Service Types	Results
							providing needs). Knowing that support (day center or respite) was available made the participants feel that they could continue to care for their partner at home. 3-A changed future. (Changing finances, living situation, hobbies/interests).
Donnellan et al., 2015	Qualitative-Grounded Theory	To assess whether spousal dementia carers can achieve resilience and to highlight which assets and resources they draw on to facilitate or hinder resilience, using an ecological framework	Europe-Northwest England n= 20	13 F, 7 M 100% spouse	No information	health and social care services (i.e., day or respite support group, home help)	A resilient carer: characterized as someone who stays positive and actively maintained their relationship and loved one's former self. Resilient carers were knowledgeable and well supported by family but especially friends, with whom they shared this knowledge. Men: More resilient caregivers and more actively engaged in services such as respite.

Reference	Study Design	Study Purpose	Setting/ Participants	Caregiver Gender/Kinship	PWD Characteristics	Support Service Types	Results
Granbo et al., 2019	Qualitative-Explorative phenomenological	To gain more knowledge about the caregivers' perspectives and perceived needs for health care services for older people with dementia	Europe-Norway n=8	(6F, 2M) 2 daughters, 2 husbands, 4 wives	Dementia reported by family.	day center, nursing home	Themes emerged from the analysis: 1) A gap between current health care services and perceived needs;(passive care, not individualized to needs and unpredictability of quality) 2) Caregivers' role is all-consuming; the sole caregiver, a loss of social networks, and feeling conflicting desires (reported more by spouses) 3) Involvement and participation are necessary for improving services.
Sinclair et al., 2018	Qualitative-Interpretative Phenomenological Analysis,	To understand the lived experiences of couples in which one partner is diagnosed with dementia, in healthcare, lifestyle, and everyday decision-making.	Australia n=28	(9F, 6M) 100% spouse (1 same sex spouse)	2-12 years with dementia dx	not specified	Three overarching themes to capture the experience of decision-making for these couples: "knowing and being known;" "maintaining and re-defining couple hood;" and "relational decision-making."

Reference	Study Design	Study Purpose	Setting/ Participants	Caregiver Gender/Kinship	PWD Characteristics	Support Service Types	Results
Morrisby et al., 2019	Qualitative interpretive description	To identify care and support needs, as reported by people with dementia and their spousal carers living in the community in metropolitan Western Australia.	Australia n=20 (10 dyads)	(6F, 4M) 100% spouse	FAST range score 5-6D. Confirmed dementia diagnosis.	Formal community services: respite, home care, assessment/diagnosis, financial support	3 themes: (a) environmental enablers to support care; (need for a social environment that is supportive and well educated, Institutional support that is timely, effective, and affordable, need for safe home and community) (b) strong caring relationships; and (c) adaptation of daily life roles. there was a greater focus on changes in spousal relationships and needing to continually adapt their roles as spouse and carer.

Reference	Study Design	Study Purpose	Setting/ Participants	Caregiver Gender/Kinship	PWD Characteristics	Support Service Types	Results
Richardson et al., 2019	Qualitative-ethnocultural	What similarities in caregiving emerged across participants? What differences appeared and how did culture influence the use of services?	US-Ohio, California n=15	(11F, 4M) 6 dtr, 2 son, 5 spouse, 1 cousin, 1 friend	All with dementia, unclear how confirmed or stage or type.	nursing homes, PASSPORT program (Ohio Medicaid in-home service program), support group	Themes: 1-caregiver stress was pervasive across all subgroups. 2-view that mental decline is an expected part of the aging process, and a lack of information about Alzheimer's disease, were most prominent among the Korean and Hispanic dementia caregivers. 3-daughters were involved more often with hands-on caring and then sons contributed more economic support. 4-differences across ethnic groups operated through coping styles, such as spirituality and religious involvement, and resources, including language and cultural differences concerning gender roles, attitudes about care, and knowledge and understanding of dementia and where to seek help.

Note: ADL = Activities of daily living, IADL = Instrumental activities of daily living, MMSE = Mini-Mental Status Exam, M = Male, F = Female, dtr = daughter

Appendix D: Study Consent

University of California at Davis

Consent to Participate in Research

Title of study: Perspectives of the female spouse in dementia caregiving in formal resource use

Investigator: Anna Satake

Introduction and Purpose

You are being invited to join a research study.

The purpose of this study is to identify the factors which contribute to using or not using formal caregiving resources or support. Specifically, we want to know about women who are caregivers for a partner or husband with dementia, and the factors which influence their willingness or reluctance to use formal caregiving resources or support.

If you agree to participate in this research, you will be asked to complete a one-on-one interview using the video platform ZOOM. You will be asked questions about how you provide caregiving or assistance to your husband/partner with dementia and regarding your decisions to use formal resources or support for caregiving. It will take about 1 to 1.5 hours to complete the interview.

The interview will be audio recorded and transcribed, but your name will not be included in the transcription.

There is no direct benefit to you from taking part in this study. We hope that the research will help us better understand what influences a wife's decision regarding the use of dementia caregiving formal resources. This knowledge may help inform healthcare providers and those who provide formal caregiving resources on how to best educate and reach out to wives and other family caregivers more effectively. It may also inform policy, or the types of resources developed in the future.

The risks of this research are minimal. Some of the questions might make you feel uncomfortable or upset. You do not have to answer any of the questions you do not want to answer.

Confidentiality

As with all research, there is a chance that confidentiality could be compromised; however, we are taking precautions to minimize this risk. Your responses to the interview questions will not include information that identifies you. This identifiable information will be handled as confidentially as possible. However, individuals from UC Davis who oversee research may access your data during audits or other monitoring activities.

To minimize the risks of breach of confidentiality, we will password-protect all data and identifiable information. Recordings will be deleted after transcriptions have been completed. Any identifiable data such as your name or contact information will be deleted once the research is completed. Participants will be given pseudonyms when transcripts are made and when writing up the research. Only the researcher and two UC Davis faculty will have access to password-protected recordings stored on a local computer

Compensation

To thank you for participating in this study, you will receive a \$15 gift card from either Target or Amazon, per your preference. It can be emailed or mailed to you within 2 weeks after you complete the interview

Rights

Participation in research is completely voluntary. You are free to decline to take part in the project. You can decline to answer any questions and you can stop taking part in the project at any time. Whether or not you choose to participate, or answer any question, or stop participating in the project, there will be no penalty to you or loss of benefits to which you are otherwise entitled.

Questions

If you have any questions about this research, please feel free to contact the investigator Anna Satake by phone at 707-652-3959 or asatake@ucdavis.edu.

If you have any questions about your rights or treatment as a research participant in this study, please contact the University of California Davis, Institutional Review Board at 916-703-9158 or HS-IRBEducation@ucdavis.edu.

If you agree to take part in the research and allow the interview to be recorded, please give verbal consent.

You will be provided a copy of this page for future reference as well.

Appendix E: Study Flyer

UC DAVIS
HEALTH

BETTY IRENE MOORE
SCHOOL OF NURSING



Research Study:

Looking for women caring for their husband with dementia.

This research study aims to learn about how women decide to use or not use caregiving resources for their husband/partner with dementia.

You might qualify for participating in this study if you:

- Are a woman who lives with your husband/partner with dementia.
- Speak English.
- Can participate in an interview through a device with a camera and microphone (i.e., smartphone, iPad, computer).

If you are interested in participating in this research study, please contact the researcher, Anna Satake by phone **707-652-3959** or email asatake@ucdavis.edu.



Learn more about the study at

This study has been approved by the UC Davis IRB (IRB # 1908357-1)

Appendix F: Screening Script

Perspective of the Female Spouse in Dementia Caregiving in Formal Resource Use

Screening Script

1. Study Introduction

If a researcher is introduced at the recruitment site:

Thank you for being willing to meet with me today to learn more about our research study.

If the potential participant contacted the researcher:

Thank you for contacting me to learn more about our research.

If the participant left their contact information with the goal of the researcher to call them:

I am contacting you due to your interest in learning more about our research study.

My name is Anna Satake, and I am conducting research at the University of California Davis through the Betty Irene Moore School of Nursing as part of my Ph.D. program. The purpose of the study is to identify the factors which contribute to using or not using formal caregiving resources or support. Specifically, we want to know about women who are caregivers for a partner or husband with dementia, and the factors which influence their willingness or reluctance to use formal caregiving resources or support.

The study would involve one on one interviews with me for about an hour where a series of questions will be asked.

Do you have any questions or concerns?

Now that you have a basic understanding of the study, do you think you might be interested in participating?

2. If the person is interested

Before enrolling people in the study, I need to see if you may be eligible to participate. I would like to ask you a few questions which may take about 15 minutes.

I will be asking some personal questions and there is a possibility that some of the questions may be uncomfortable, if so please let me know. We can stop the screening process whenever you wish.

I will keep all the information you provide during this screening process confidential, including your name.

The purpose of the questions is to identify if you may be eligible to participate in this study. Additional screening at a later time may be needed beyond answering these questions.

Your participation is voluntary. You do not need to complete these screening questions, so feel free to stop me at any time and ask any questions.

Do I have your permission to ask you these questions?

If No- Skip to part 5 of the script.

3. Screening questions

Do you provide caregiving or assistance to a husband/male partner with dementia?
 When providing this caregiving/assistance did you live together?
 How old is your partner/husband with dementia? _____
 Can you tell me if you assist your husband/partner with any of the activities that I will list?

(Instrumental Activities of Daily Living)

Lawton, M. P., & Brody, E. M. (1969). Assessment of older people: self-maintaining and instrumental activities of daily living. *The Gerontologist*, 9(3_Part_1), 179-186.

<p>Ability to use the telephone <i>Help using the telephone would include:</i></p> <ul style="list-style-type: none"> ○ Dials a few well-known numbers. ○ Answers telephone but does not dial. ○ Does not use the telephone at all. 	<p>Ability to do laundry <i>Help doing laundry would include:</i></p> <ul style="list-style-type: none"> ○ If able to do some laundry, requires supervision or cueing. ○ All laundry must be done by other.
<p>Ability to shop <i>Help shopping would include:</i></p> <ul style="list-style-type: none"> ○ Shops independently for small purchases. ○ Needs to be accompanied on any shopping trip. ○ Completely unable to shop. 	<p>Ability to use transportation <i>Help using transportation would include:</i></p> <ul style="list-style-type: none"> ○ Travel limited to taxi or automobile with assistance from another. ○ Does not travel at all.
<p>Ability to prepare food <i>Help preparing food would include:</i></p> <ul style="list-style-type: none"> ○ Prepares adequate meals if supplied with ingredients. ○ Heats, serves, and prepares meals but does not maintain adequate diet. ○ Needs to have meals prepared and served. 	<p>Ability to manage own medications <i>Help with medication management includes:</i></p> <ul style="list-style-type: none"> ○ Takes responsibility if medication is prepared in advance in separate dosage. ○ Is not capable of dispensing own medication.
<p>Ability to housekeep <i>Help keeping the house would include:</i></p> <ul style="list-style-type: none"> ○ Participates in simple chores with supervision. ○ Does not participate in any housekeeping tasks. 	<p>Ability to handle finances <i>Help with finances would include:</i></p> <ul style="list-style-type: none"> ○ Incapable of handling money.

Do you have access to a smartphone, computer or tablet which has a camera and microphone capability?

4. Post Response Communication

If potentially eligible:

Based on your answers to the questions, it appears you may be eligible to participate in the research study. The information you shared today will be stored for the duration of the study, but there will be no personal identifiers attached to the information shared.

Would you like to schedule our interview at this time, or would you prefer me to contact you at another time to schedule the interview?

Obtain the potential participant's contact information.

Your contact information will be stored in a password-protected computer and destroyed after the research study has been completed.

If not eligible:

Unfortunately, based on your responses, you are not eligible to participate in the research study. The information collected during the screening process will not be stored and will be destroyed after this session to protect your confidentiality.

5. Closing and Study Team Contact Information

Thank you for taking the time to talk with me today. If you have any questions or concerns, please contact me. My name is Anna Satake, and I can be reached at 707-652-3959 and/or asatake@ucdavis.edu.

Appendix G: Interview Guide

Interview Introduction

- Introduce self and discuss study goal.
- Discuss how their participation is important in the research and learning about the topic of dementia caregiver formal resource use.
- Review confidentiality and recording of the interview process.
- Answer any questions about the interview or research before starting.

Interview Questions

Demographics

Participant age: _____ Age of person with dementia: _____ Caregiver Race/Ethnicity: _____

Years married or partnered: _____ Years helping your partner with dementia: _____

Functional Assessment Staging of Alzheimer’s Disease (FAST)

Functional Assessment Staging Test (FAST)	
Stage	Function Level
1	No functional decline. No difficulties, either subjectively or objectively.
2	Personal awareness of some functional decline. Complaints of forgetting the location of objects or word-finding difficulties.
3	Decreased job functioning evident to co-workers. Difficulty in traveling to new locations. Decreased organizational capacity.
4	Decreased ability to perform complex tasks, (e.g., planning dinner for guests, handling personal finances, such as paying bills, etc.)
5	Requires assistance in choosing proper clothing to wear for the day, season, or occasion, (e.g., may wear the same clothing repeatedly unless supervised)
6	Occasionally or more frequently over the past weeks, one of the following has occurred: <ul style="list-style-type: none"> • Improperly putting clothes without assistance or cueing. • Unable to bath properly (not able to choose proper water temp) • Inability to handle mechanics of toileting (e.g., forget to flush the toilet, does not wipe properly or properly dispose of toilet tissue) • Urinary incontinence • Fecal incontinence
7	A) Ability to speak limited to approximately ≤ 6 words in an average day. B) Speech ability is limited to the use of a single intelligible word in an average day. C) Ambulatory ability is lost (cannot walk without personal assistance.) D) Cannot sit up without assistance (e.g., the individual will fall over if there are no lateral rests on the chair.) E) Loss of ability to smile. F) Loss of ability to hold up head independently.

To better understand your family members’ cognitive impairment and need for assistance I will share with you some descriptions of the symptoms. In each section, please state the number that most closely applies to the participant. This is a general form, so no one description may be exactly right -- please choose the one that seems to apply most of the time.

1. What are the kinds of ways you help your husband due to his dementia?

Probe: Can you tell me about what a typical morning (afternoon, evening) looks like, and the types of care needed?

Probe: Does anyone else come in and support you or your husband with any of this care?

There are different kinds of caregiving resources out there. Some caregivers are interested in using resources and others are hesitant. There is no one right way to be a caregiver or to use resources.

Here is a list of common formal community resources or support services for caregiving.

2. Can you tell me if you have had any experience with any of these resources?

3. Take a few moments to remember the time in which you decided to use _____ resource. When you decided to use _____ resource(s), tell me about how you chose to use it.

Probe: Why did you choose to use that resource specifically?

Probe: Why were you willing to start using that resource at the time and not before?

Probe: During that time, can you reflect on what was happening to you at that time.

Probe: Accepting help can be very difficult for family caregivers, how did you come to the decision to accept help by using this resource?

We know a lot of caregivers don't use formal resources for a lot of different reasons.

4. Regarding the formal resources that you have not used (add from previous questions), are there ones you have thought about using them in the past? Why or why not?

Probe: Looking back, are there resources you wish you had tried to help you in caring for your husband?

Probe: What are the kinds of reasons for not using these resources you mentioned earlier?

Probe: What has kept you from wanting to use the resource?

5. Given the current COVID pandemic, tell me how it has impacted your use or need for services.

Is there anything else you would like to add that was not covered today?

Thank you for participating in this interview today and discussing your experience as a caregiver.

Appendix H: Dementia Resources

Family Caregiver Alliance

<https://www.caregiver.org/caregiver-resources/health-conditions/dementia/>

- Includes educational videos, articles, and resources

Alzheimer's Association

www.alz.org

- Provides education, support, and service for people diagnosed with Alzheimer's disease and related conditions.

Alzheimer's Disease Education and Referral Center

www.nia.nih.gov/alzheimers

- Provides information about Alzheimer's disease, current research, and clinical trials.

Alzheimer's Foundation of America

www.alzfdn.org

- Offers support, respite grants, and a toll-free phone line for family caregivers who wish to speak with a social worker, online articles, professional education, and training, and AFA Teens.

Eldercare Locator

www.eldercare.acl.gov

- Helps older adults and their caregivers find local services including health insurance counseling, free and low-cost legal services, and information for local Area Agencies on Aging.

California Caregiver Resource Centers (CRCs)

<https://www.caregiver.org/californias-caregiver-resource-centers>

- Offers information and support services to family caregivers in California including:
 - Specialized Information
 - In-home Assessment of Caregiver Needs
 - Family Consultations and Care Planning
 - Education
 - In-person and Online Support Groups
 - Counseling
 - Legal and Financial Consultation
 - Respite Care
- **Care Recipient Eligibility:** Anyone age 18 or older who has an adult-onset cognitive impairment (e.g., Alzheimer's Disease, Stroke, Parkinson's Disease, Traumatic Brain Injury).
- Contact Information: (800) 445-8106 Available weekdays 9am - 5pm (Pacific Time).

California Family Caregiver Support Program (FCSP)

https://www.aging.ca.gov/Programs_and_Services/Family_Caregiver_Services/

FCSP services for family caregivers are provided through local area agencies on aging (AAAs) and include:

- Information
 - Assistance
 - Individual counseling, support groups, and caregiver training
 - Respite care
 - Limited supplemental services, such as transportation and home modifications
- **Care Recipient Eligibility:** - Anyone age 60 or older Exception: - Adults with dementia can be any age
 - **Caregiver Eligibility:** - Anyone age 18 or older caring for someone who meets care receiver eligibility Special Populations: - Adults age 55 or older who are caring for anyone (that is not their child) over 18 years old with developmental disabilities - Grandparents or other relatives age 55 or older caring for children (age 18 and under)
 - **Contact Information:** To be connected to your local AAA within California, call: (800) 510-2020