

4-24-2019

Exploring Perceptions of Personhood of a Spouse in the Early Stage of Dementia

Marina Vravecic

University of Connecticut - Storrs, marina.vravecic@uconn.edu

Follow this and additional works at: <https://opencommons.uconn.edu/dissertations>

Recommended Citation

Vravecic, Marina, "Exploring Perceptions of Personhood of a Spouse in the Early Stage of Dementia" (2019). *Doctoral Dissertations*. 2157.

<https://opencommons.uconn.edu/dissertations/2157>

Exploring Perceptions of Personhood of a Spouse in the Early Stage of Dementia

Marina Vracevic, Ph.D.

University of Connecticut, 2019

It is estimated that by the year 2050, one in three Americans 65 years and older will be living with some form of dementia, a group of symptoms that includes over 50 known types of diseases and conditions that currently affect over 6.7 million people in the United States. Because the psychological and physical decline associated with dementia impairs memory, judgment, communication, and other abilities that make independent daily functioning possible, it is important to care for the afflicted individuals in a way that takes care of their basic needs and preserves their sense of self, or their personhood. Many individuals in the early stage of dementia (ESD) live at home and are cared for by their spouses. How caregiving spouses perceive their partner with dementia and what meaning they give to the psychological and cognitive decline may be extremely important to knowing how they provide care for their partners. This knowledge also can improve targeted support for couples living with dementia.

This study explored how eight caregiving wives perceived the personhood of their husbands in ESD. The three research questions were: (1) What meaning do caregiving wives give to the cognitive, behavioral, social, and physical changes in their husbands in the early stage of dementia? (2) What are caregiving wives' perceptions of personhood of their husband in the early stage of dementia? And, (3) What influences caregiving wives' perception of the personhood of their partner in the early stage of dementia?

The participants were recruited through the Alzheimer's Association of Connecticut. A 3-phase interview process was employed in this qualitative, interpretative phenomenological analysis study, so that caregivers could narrate their experiences in their own words. This interview process afforded the exploration of the participant's experiences in the broader context of her life (1st and 2nd interviews) and invited the participant to reflect more deeply on the meaning of these experiences (3rd interview).

Most wives felt that their husbands did not change in terms of personhood, despite the effects that dementia had on them by the early stages of the disease. The wives noticed the changes in their husbands' behavior prior to the husbands being diagnosed with dementia but did not seek support until these issues started affecting the husbands' daily functioning. Following the diagnosis, the wives worked to make adjustments to their daily lives and utilized social and medical support to provide the necessary care for their husbands. The findings suggest that the wives relied on their prior knowledge and exposure to dementia, as well as religion, friends, family, and supportive professionals to help them navigate and make meaning of their experiences of having a husband experiencing the early stages of dementia.

Exploring Perceptions of Personhood of a Spouse in the Early Stage of Dementia

Marina Vracevic

B. A., University of Connecticut, 2006

M. A., University of Connecticut, 2008

A Dissertation

Submitted in Partial Fulfillment of the

Requirements for the Degree of

Doctor of Philosophy

at the

University of Connecticut

2019

© Copyright by

Marina Vracevic

2019

APPROVAL PAGE

Doctor of Philosophy Dissertation

Exploring Perceptions of Personhood of a Spouse in the Early Stage of Dementia

Presented by

Marina Vracevic, M.A.

Major Adviser _____
Laura K.M. Donorfio, Ph. D.

Associate Adviser _____
Thomas O. Blank, Ph. D.

Associate Adviser _____
Keith Bellizzi, Ph. D.

University of Connecticut

2019

ACKNOWLEDGEMENTS

First, I would like to express my sincere gratitude to the members of my thesis committee, Laura K.M Donorfio, Ph. D., Thomas O. Blank, Ph. D., and Keith Bellizzi, Ph. D., for their guidance and support in the dissertation writing process. Special thanks to my major advisor, Laura Donorfio; thank you for your unconditional love and support along my unique path. Your humility inspires me.

Next, to all living with dementia: I wholeheartedly believe that one day you will be understood, and your unique purpose will be honored and applied. The world will recognize you as the great teachers of life, love, and God.

Special gratitude to the families who partook in this study. You have been my guides and my source of strength. For this, I will always be grateful to you.

Also, I thank all my family and friends. Your extraordinary lives have incited the writing of this dissertation. Your unconditional love and support are invaluable.

Lastly, to God: Thank you for giving me enthusiasm, strength, knowledge, and continuous opportunities to work with families living with dementia. Because of this, my work is an adventure, and my life is significant.

“By learning in great detail about the individual case, we are thus better positioned to consider how, at the deepest level, we share much with a person whose personal circumstances may initially seem entirely separate from our own (Smith, Flowers, & Larkin, 2009).”

TABLE OF CONTENTS

APPROVAL PAGE	iii
ACKNOWLEDGEMENTS	iv
LIST OF TABLES	ix
LIST OF FIGURES	x
CHAPTER 1: INTRODUCTION	1
Background to the Study	1
Statement of the Problem	2
Purpose of the Study	3
Conceptual Framework	4
Dementia and Meaning-Making	5
Research Questions	8
Significance of the Study	9
Definitions of Terms	10
Summary of the Chapter	10
CHAPTER 2: REVIEW OF THE LITERATURE	11
Research on Dementia and Personhood	11
Research on Persons Living with Dementia	19
Why Study Spouses' Perceptions About Personhood of Those Living with Dementia?	22
CHAPTER 3: RESEARCH DESIGN AND METHODS	24
Methodology	25
Role of the Researcher	27
Participants	28

Data Collection.....	30
Data Analysis	33
Validity.....	34
Summary of the Chapter	36
CHAPTER 4: FINDINGS	37
Introduction to the Participants	39
Participant One: “Rayleigh”	39
Participant Two: “Emilia”.....	39
Participant Three: “Magdalena”	40
Participant Four: “Eugenia”	40
Participant Five: “Marianna”	40
Participant Six: “Betty”.....	41
Participant Seven: “Estelle”.....	41
Participant Eight: “Raisa”.....	42
Overview of Themes	42
Research Question One (RQ1) Themes	42
RQ1, Theme One: Noticing Changes in Husband’s Functioning.....	43
RQ1, Theme Two: Responses to Diagnosis	49
RQ1, Theme Three: Making Adjustments, Managing Changes.....	52
Research Question Two (RQ2) Themes	57
RQ2, Theme One: Perceptions of Husband’s Emotional Capacity	58
RQ2, Theme Two: Assessment of Husband's Personhood - Same or Changed?	60
Research Question Three (RQ3) Themes	63

RQ3, Theme One: Prior Knowledge of Dementia.....	64
RQ3, Theme Two: Prior Exposure to Dementia Caregiving.....	65
RQ3, Theme Three: Role of Religion.....	66
RQ3, Theme Four: Wives’ Perceptions About the Influence of the Resources	67
Summary of the Chapter	70
CHAPTER 5: DISCUSSION.....	72
Introduction	72
Discussion of Themes	73
Themes related to RQ1: What meaning do caregiving wives give to the cognitive, behavioral, social and physical changes in their husbands in ESD?.....	73
Themes related to RQ2: What are caregiving wives’ perceptions of personhood of their husband in ESD?	76
Themes related to RQ3: What influences caregiving wives’ perception of the personhood of their partners in the early stage of dementia?.....	78
Overall Summary	79
Limitations	82
Future Research.....	82
Implications for Practice	84
Conclusion	85
REFERENCES	86
Appendix A Interview Protocol	98
Appendix B Initial Contact Script to Potential Participants	102
Appendix C Functional Assessment Staging Test (FAST).....	104

Appendix D Demographic Questionnaire.....	107
Appendix E Alzheimer's Association Letter of Support.....	108
Appendix F Institutional Review Board Approval Letter.....	109

LIST OF TABLES

Table 1. Demographics	38
Table 2. Research Question 1 Themes.....	43
Table 3. Research Question 2 Themes.....	57
Table 4. Research Question 3 Theme	63

LIST OF FIGURES

Figure 1. Conceptual framework for understanding what influences caregiving spouses’ views of personhood of their partner in the early stage of dementia.	4
---	---

CHAPTER 1: INTRODUCTION

Background to the Study

Today, more than 6.7 million Americans suffer from dementia, a condition associated with a progressive decline in memory, attention, critical thinking, visual perception, body movement, communication, and language abilities severe enough to interfere with normal daily functioning (2018 Alzheimer's Disease Facts and Figures, 2018). Alzheimer's disease is a leading cause of dementia. It accounts for 60% to 80% of all dementia. It is estimated that the incidence of dementia will more than triple by the year 2050 in correlation to the increase in the aging population in the United States (2018 Alzheimer's Disease Facts and Figures, 2018).

To address this imminent health crisis, multidisciplinary research efforts are underway to find ways to prevent and cure dementia and to develop proficient care and support for affected individuals and their caregivers (2018 Alzheimer's Disease Facts, 2018). Although significant progress has been made (e.g., it is now possible to diagnose dementia before it significantly impacts one's functioning abilities, and a medication that helps slow down a progression of dementia is available for use in treatment), at this time, there is no way to cure, prevent, or stop the progression of dementia. Consequently, many individuals and families continue to struggle with this disease, in terms of providing the most adequate care to their loved one with dementia.

About one quarter of all individuals living with dementia are cared for by their spouses (Fisher et al., 2011). In 2017, more than 16 million family caregivers provided over 18.4 billion hours of unpaid care valued at \$232 billion (2018 Alzheimer's Disease Facts, 2018). By the year 2050, the incidence of dementia is projected to increase threefold, and the value of care provided by families and friends will reach \$1.2 trillion (2018 Alzheimer's Disease Facts, 2018).

Persons with dementia (PWD) require ever-increasing assistance with the activities of daily living (ADL), such as, management of neurodegenerative symptoms (e. g., forgetfulness, lack of sufficient judgment about people and situations, difficulties with understanding and using language, etc.), and management of challenging behaviors (e. g., agitation, anxiety, inappropriate social conduct, etc.) caused by progressive deterioration in their cognitive functioning (2018 Alzheimer's Disease Facts, 2018). In addition to providing assistance with daily functioning for their partners with dementia, caregiving spouses play a very significant role in helping them make emotional adjustments as the disease unfolds (Robinson et al., 2011; Sorensen, Waldorff & Waldemar, 2008). The afflicted spouse experiences many losses in the course of dementia, including personality changes and forgetfulness. Their caregiving spouse, in many cases a lifelong partner, becomes a vital social relationship and works hard to preserve the husband's or wife's identity, sense of self, and the marital relationship (Calasanti & Bowen, 2006; Davies, 2011; Gilies, 2012; Hellstrom, Nolan & Lundh, 2005).

Statement of the Problem

In a society that values people based on their independence, functionality, and rationality, a progressive cognitive decline like dementia can cause the very personhood of the afflicted individual to be questioned (Buron, 2008; Kitwood, 1997; Palmer, 2013; Swinton, 2007). Kitwood (1997), a proponent of a person-centered approach in the field of dementia care, defined personhood as “a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust” (p. 8). Starting in the late 1980's, Kitwood spent time working in long-term dementia care settings in the United Kingdom, where he witnessed a lack of regard for the personhood, preferences, and routines of the residents with dementia (Kitwood, 1997). He came to realize that the diminishing quality of

life for people with dementia resulted not only from the symptoms of this disease, but also from the way that these individuals were treated by their formal caregivers. He named this phenomenon of diminishing personhood through poor care practices a “malignant social psychology.” Kitwood’s assessment of the state of dementia care at the time, and his efforts to improve it, stimulated interest in understanding the lived experience of people with dementia in the United Kingdom and United States.

To this day, however, a dominant model in the treatment and care of people with dementia is the biomedical model that focuses on the symptoms and pathology of the body and mind (Doyle & Rubinstein, 2014; Wellin & Jaffe, 2004). Consequently, a regard for personhood in dementia care practice continues to be understated and misunderstood, regardless of Kitwood’s sharp criticism and the ensuing evidence about positive outcomes of person-centered care with residents with dementia living in long-term care settings (Burack, Weiner, & Reinhardt, 2012; Chenoweth et al., 2009; Sloane et al., 2004).

Purpose of the Study

Although the biomedical perspective dominates the treatment and care of people with dementia, as the family caregiving research indicates, spouses invest tremendous effort in preserving the personhood of their loved ones (Calasanti & Bowen, 2006; Hellström et al., 2007; Hellström et al., 2005; Molyneaux et al., 2012; Perry & O’Connor, 2002). However, no studies to date have explored caregivers’ perceptions of the personhood of their afflicted spouses. Of particular interest to this study are the caregiving wives’ perceptions of their husbands’ personhood in the early stage of dementia (ESD), as over two-thirds of dementia caregivers are women (2018 Alzheimer’s Disease Facts and Figures, 2018). Research suggests that couples often lack pertinent information and continued support following a diagnosis of dementia, which

leads to difficulty in adjusting to a dementia-related decline, changes in the lifestyle, marriage, and long-held roles within the relationship (Pesonen, Remes, & Isola, 2013; Robinson, Clare, & Evans, 2005; Stokes, Combes, & Stokes, 2012). This study explored how caregiving wives perceived their husbands' personhood during the early dementia journey, and what influenced these perceptions.

Conceptual Framework

The conceptual framework proposed for this study places Parks meaning-making process in a context of an interactionist perspective on identity during chronic illness (Kelly & Field, 1996; 1998).

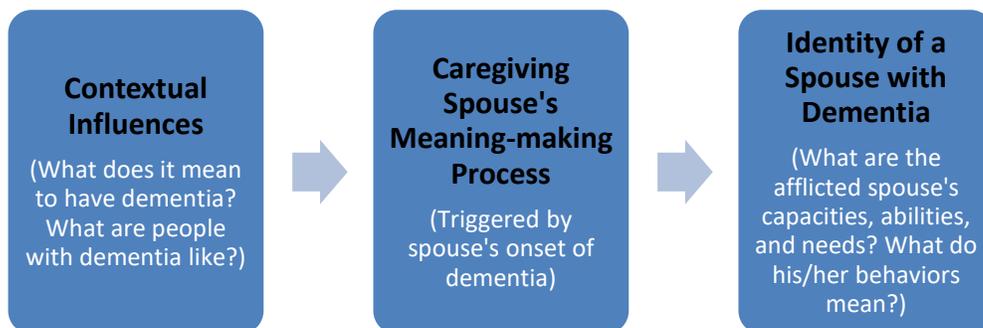


Figure 1. Conceptual framework for understanding what influences caregiving spouses' views of personhood of their partner in the early stage of dementia.

Drawing on the work of Kelly and Field (1996; 1998), the proposed conceptual framework posits that a person's chronic illness has the potential to influence his/her identity, or how he/she is perceived by others, to such an extent that it impacts his/her participation in social environments. Further, this conceptual model proposes that caring for a spouse with dementia triggers a meaning-making process; research has demonstrated that caring for a loved one with dementia can be very stressful, which elicits reflection (Arai, Zarit, Sugiura, & Washio, 2002;

Bauer, Maddox, Kirk, Burns, & Kuskowski, 2001; Kim, Chang, Rose, & Kim, 2012; Park, 2010). Caregiving spouses will engage in the meaning-making processes to deal with the progressive cognitive, behavioral, social, and physical changes in their partners with dementia. Lastly, in line with the interactionist approach, this conceptual model suggests that caregiving spouses draw upon the dominating social views about people with dementia while making meaning of their spouse's new condition. It is probable that the caregivers, who find themselves in stressful circumstances when their spouse first exhibits symptoms of dementia, use the information from their social context about "what people with dementia are like" to construct a new understanding of the afflicted spouse's capacities, abilities, behaviors, and needs.

In summary, the conceptual model proposes that the dominant social views about people with dementia influence the meaning that caregiving spouses give to the progressive cognitive, behavioral, social, and physical changes in their partners, and how they perceive the personhood of their spouse with dementia. The following two sections illustrate how the main concepts in this integrative conceptual framework are supported by the research literature.

Dementia and Meaning-Making

Meaning-making is a dynamic mental process of thinking about and constructing associations between concepts, events, objects, and relationships (Park, 2010). The meaning-making process is said to be triggered by highly stressful life events—in this case, becoming a caregiver for a spouse with dementia. Park (2010) posits that there are two aspects of meaning in the general meaning-making model: global and situational. Global meaning consists of general beliefs about how the world works, long-term goals, and a subjective sense of order and purpose. Situational meaning is assigned to a particular situation. When a stressful situation occurs, initial meaning (or appraised meaning) is assigned to the event. If a discrepancy between global and

appraised meaning is detected, a meaning-making process is activated to reduce the stress caused by this discrepancy. Successful meaning-making efforts lead to meaning made, that is, to an outcome or a resolution that eliminates a discrepancy between global and appraised meaning (generally, by making adjustments to global meaning or by re-appraising the stressful event).

The literature on meaning-making of spouses of people with dementia is very scarce (Williams, Morison, & Robinson, 2014). Given that dementia caregiving research has, until recently, focused mainly on challenges and losses associated with providing care to someone with dementia, this is not entirely surprising (Ducharme, Lévesque, Lachance, Kergoat, & Coulombe, 2011; Svanstrom & Dahlberg, 2004). No studies to date have been identified that explored the meaning-making of family caregivers in the context of their spouse's personhood with dementia. Since personhood is threatened due to the disease-related physical and psychological decline, it is also important to note that no studies were identified that explored the meaning-making of caregiving spouses in a context of cognitive, behavioral, social and physical changes in their partner.

A few quantitative studies suggest that finding meaning in caregiving has an overall positive effect on caregiver burden and mental health in spousal caregivers of PWD (McLennon, Habermann, & Rice, 2011; Quinn, Clare, & Woods, 2012; Sheehan & Donorfio, 1999). According to Farran (1997), family caregivers can find meaning and see the positive aspects of their caregiving experience and their spouse. McGovern (2011) proposed a model founded on relationship-based and strength-based approaches that challenged the predominantly negative perspective of a lived dementia experience. The main contribution of this model to future research on meaning-making of spousal caregivers of PWD is that it can provide a basis for viewing the dementia caregiving experience through a strength-based perspective. McGovern

argued that verbal and non-verbal communication, including conflict-resolution and decision making, can serve as the basis of meaning-making processes for the couple when one spouse is living with dementia.

While dealing with changes in their loved one with dementia, lifestyle, future plans, and feelings of fear, loss and anger, family caregivers search for meaning in these new circumstances (Sheehan & Donorfio, 1999). This can result in a new understanding of themselves, their relationships to others, and in an overall new perspective on the world around them. The goal of this study is to explore what meaning caregiving spouses give to the cognitive, behavioral, social, and physical changes in their partner in the early stage of dementia, and how this relates to their perceptions of the partner's personhood.

The concept of "personhood" is not well discerned from the concept of "identity" in the existing family caregiving literature, and the two are often used interchangeably. Kitwood defined "personhood" as a status given to an individual by others which "implies recognition, respect and trust" (1997, p. 8). In the social constructionist perspective, "identity" implies who one is, and what it means to be a person that holds particular roles and belongs to particular groups in a given society. Identity is constructed in a broader social, historical, political, and cultural context. To explore how caregiving wives perceive the personhood of their partners in ESD, this study draws on the interactionist perspective of identity in chronic illness from the work of Kelly and Field (1996; 1998).

When an illness impacts a person, it disrupts the continuity of daily life. Depending on how severe, long-lasting, and apparent the manifestations of the illness are to others, it has the potential to impact the individual's concept of self and identity (Kelly & Field, 1996; 1998). Kelly and Field theorized that although self and identity have enduring qualities across the

lifespan (i.e., an afflicted individual is known by others before he became ill), they can be changed by the illness. “Self,” a cognitive construct of who one believes he is, is considered inseparable from one’s physical body. When illness alters bodily functioning, it impacts how one views himself/herself. Because self and body are central to participation in daily life and interaction with others, how illness impacts one’s participation in a social environment can affect how others perceive the individual.

While individuals with dementia are viewed by their loved ones in the context of their life-long roles and relationships, a biomedical problem adds a new layer of identity to an individual with dementia. Although the biomedical perspective is not the only information that caregiving spouses use to make sense of their loved ones’ identities, it is powerful. It determines not only how the caregivers see their loved ones being treated and cared for by professionals, but also the type of information and support that caregivers receive to cope with dementia.

Given that people with dementia typically live ten or more years after receiving their diagnosis, and since, at this time, there is no cure or a way to prevent this disease, it is necessary to find alternative ways to improve the quality of life for affected individuals and their families (2014 Alzheimer’s Disease Facts and Figures, 2014). One way to move toward this goal is to change social perceptions and the treatment of people with dementia in ways that support their personhood.

Research Questions

The following research questions were used to conduct this study:

1. What meaning do caregiving wives give to the cognitive, behavioral, social, and physical changes in their husbands in the early stage of dementia?

2. What are caregiving wives' perceptions of the personhood of their husbands in the early stage of dementia?
3. What influences the caregiving wives' perception of the personhood of their partners in the early stage of dementia?

Significance of the Study

At this time there is no cure, prevention, or way to stop the progression of dementia. Therefore, preserving the personhood of afflicted individuals can help sustain their quality of life throughout the course of the disease (Coleman, 2009; Kitwood & Sabat, 2002; 2005). The limited family caregiving research on personhood with dementia suggests that spouses employ various preservation strategies or “adjustments” in activities, daily routines, roles, and relationships to preserve a sense of self for their spouses (Calasanti & Bowen, 2009; Hellström et al., 2007; Molyneaux, Butchard, Simpson, & Murray, 2012). However, it is the biomedical discourse that dominates dementia care practices, which in turn can influence the type of information and support family caregivers receive regarding the nature of the disease and how to best care for those affected by it.

Marriage partnerships are commonly characterized by a high degree of intimacy, familiarity, and well-established interdependent patterns of interactions between the spouses. Cognitive and physical declines in people with dementia affect how they function in their marriage and as a marriage partner (Hayes, Boylstein, & Zimmerman, 2009; O’Shaughnessy et al., 2010). The outcome of this study will provide professionals in the field of dementia care with insight about the resources (e.g., empowerment, education, etc.) that will support couples impacted by dementia.

Definitions of Terms

For purpose of this study, the following terms are defined:

Personhood: “A standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust” (Kitwood, 1997).

Meaning-making: A dynamic mental process of thinking about and constructing associations between concepts, events, object, and relationships (Park, 2010).

Summary of the Chapter

The purpose of this phenomenological study was to explore how wives perceived their husbands in the early stage of dementia. Personhood can be defined as “a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust” (Kitwood, 1997). The organization of the remaining chapters is as follows: Chapter 2: Review of the Literature, Chapter 3: Methodology, Chapter 4: Findings, and Chapter 5: Discussion.

CHAPTER 2: REVIEW OF THE LITERATURE

Research on Dementia and Personhood

Until the early 1900s, dementia was viewed mainly as a natural sign of aging, and little attention was paid to its consequences to the affected person (Papavramidou, 2018). The first significant record of dementia research was a case study published in 1906 by a German physician, Alois Alzheimer, who studied Augusta D., a 50-year-old woman with dementia symptoms. Dr. Alzheimer's research was valuable to the subject of personhood because he studied Augusta D. before and after her death and was the first known physician to recommend and practice a more humane treatment of people with mental health illnesses (Page & Fletcher, 2006).

With advancements in studies of brain biochemistry starting in the 1960s, dementia came to be recognized as a progressive, degenerative disease with biological causes. Since that time, emphasis has been placed on studying the physiological origins and symptoms of dementia, as well as the burden and cost of caring for the persons affected by this disease (Bauer et al., 2001; Harding et al., 2015; Katzman, 1976; Kim et al., 2012; Loy, Schofield, Turner, & Kwok, 2014; Schneider, Arvanitakis, Leurgans, & Bennett, 2009).

With the emergence of Kitwood's theory of personhood in 1980s, and the subsequent advocacy for person-centered care (PCC), researchers and professionals in the field of dementia began challenging the notion that progress and outcome of this disease are solely caused by the neuropathology of the brain (Doyle & Rubinstein, 2014; Kitwood, 1997; McNess, 2017; Swinton, 2007; Wellin & Jaffe, 2004). The research exposed poor treatment of PWD in long-term care facilities, which incited a recognition that detrimental attitudes and inept care can worsen the experience of the disease and deteriorate the PWD's quality of life (Hughes, Louw, &

Sabat, 2006; O'Connor et al., 2007). A handful of philosophical and religious essays have recently contributed to the "case for personhood" on the basis of historical and spiritual principles of their respective disciplines (Coleman, 2009; Hughes et al., 2006; Swinton, 2007). The authors of these essays advocate for a collective responsibility for treating PWD with respect and love and to uphold their personhood in spite of the functional and cognitive losses caused by dementia.

This recognition of the need to improve existing dementia care practices, coupled with the stark, gloomy projections about the future cost and burden to our society, has impelled greater public awareness of dementia in the last decade. A grand recognition that our country is taking a serious approach to addressing the impact of this disease came at the end of 2018, when the Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act was signed into a law. As a result, a stream of new federal funding will be directed to states for the purpose of improving early detection and diagnosis programs, strengthening support for caregiving families, reducing risk of premature hospitalizations, and public awareness campaigns (U.S. House Passes Bipartisan Alzheimer's Public Health Legislation, 2018).

Now work needs to be done to improve the support of PWD and their caregiving families (Burack et al., 2012; Chenoweth et al., 2009; Sloane et al., 2004; Swaffer, 2014). Research has shown that PWD are aware of their situations and can inform others about their needs and experiences (Clare, 2003; Harris, 2002; Kaufmann & Engel, 2014; McFadden, Ingram, & Baldauf, 2001; Sabat, 2002). Correspondingly, strength-based approaches are increasingly used to support families living with dementia, but personhood is rarely addressed in these interventions (Bryden, 2002; Scherrer, Ingersoll-Dayton, & Spencer, 2014). To advance these types of services and interventions, and to provide substantive directions to health policy with

respect with care of personhood, it is necessary to recognize that together with PWD, family caregivers are the most valuable, credible, and persuasive agents in igniting this desirable change.

No studies to date were identified that explored specifically spouses' perceptions of the personhood of their partners with dementia. In the course of the last two decades, however, a handful of qualitative studies examined families' support of their loved ones with dementia (Calasanti & Bowen, 2006; Hellström, Nolan, & Lundh, 2007; Hellström, Nolan, & Lundh, 2005; Kaldjian, Shinkunas, Bern-Klug, & Schultz, 2010; Molyneaux et al., 2012; Perry & O'Connor, 2002; Phinney, 2006; Purves, 2011, Svanstrom & Dahlberg, 2004). Of these caregiving studies, a few have focused on the lived experience of couples where one spouse has dementia (Calasanti & Bowen, 2006; Hellström et al., 2007; Hellström et al., 2005; Molyneaux et al., 2012; Perry and O'Connor, 2002). Three of the studies comprised mixed samples of family members (i.e., spouses, children, other relatives), one of which examined views of PWD's personhood in a context of palliative care (Kaldjian et al., 2010; Phinney, 2006; Purves, 2011). A small group of studies with PWD on the subjective experience of dementia is also included in the present review of the literature, because these studies reveal that aspects of the self traditionally thought to be destroyed by dementia can persist, even late in the disease process (Clare, 2003; Dalby, Sperlinger, & Boddington, 2012; Doyle, Rubinstein, & Medeiros, 2015; Fazio & Mitchell, 2009; McFadden et al., 2001; Menne, Kinney, & Morhardt, 2002; Nowell, Thornton, & Simpson, 2011; Phinney, Chaudhury, & O'Connor, 2007; Robertson, 2014).

It is important to note that the studies reviewed in this section utilized different qualitative methods of inquiry, had small samples of participants, and varied in terms of the specific research goals. Given their design uniqueness and exploratory nature, it is not possible

to make viable comparisons across these studies or to draw generalizable conclusions for the rest of the population of individuals and their caregiving families living with dementia. However, since the exploration of personhood is in the very early stages of development, it makes exploratory, qualitative studies appropriate. They are valuable because they reveal that dementia impacts the family as well as PWD; that the care of personhood is done by PWD and those closest to him or her; and lastly, that the person with dementia continues to play a significant role in the family. Consequently, it can be said that the impacts of considering the personhood of someone with dementia extend well beyond the afflicted individual.

A small group of family caregiving studies have explored the lived experience of couples where one partner had dementia. These studies found that couples made adjustments in their lifestyle, roles, and long-held routines to sustain the personhood of the PWD and their identity as a couple (Calasanti & Bowen, 2006; Hellström et al., 2007; Hellstrom et al., 2005a; Molyneaux et al., 2012; Perry & O'Connor, 2002). Three qualitative studies explored how marriage partners worked together to sustain personhood of the PWD and maintained an integrity of their relationship in midst of the changes brought on by the disease (Hellström et al., 2007; Hellstrom et al., 2005a; Molyneaux et al., 2012). The studies were conducted with both members of the couple. Recognition of PWD's perspective is an important step in maintaining their personhood. It is important to note, that the studies revealed that sustaining the personhood of the PWD is inseparable from work of maintaining the marriage.

Specifically, Hellström et al. (2007) interviewed twenty couples (N=20) living with dementia in a five-year-long longitudinal study to explore the strategies that couples use over time to live positively. Using a constructivist-grounded theory and methodology, the study reported three strategies that couples used to maintain quality of their life and relationship in

midst of the disease progression: “sustaining couplehood,” “maintaining involvement,” and “moving on.” Through these three themes or phases, the study highlighted the active cooperation of the partners who were working almost equally on tasks earlier in the disease process. Eventually, the caregiving partner did more, while the partner with dementia did less and ultimately withdrew from work on their personhood and the relationship. This study revealed that both spouses strove to maintain their marriage and lifestyle, and that taking care of personhood of the PWD was a part of work that couples did to maintain the relationship.

At an earlier phase of the same longitudinal study, Hellström et al. (2005a) explored how these twenty couples jointly constructed awareness of dementia to maintain a sense of self for the spouse with dementia and the integrity of the marriage relationship. The study found that “constructing awareness” for the couples was a process of managing how much information about the spouse’s dementia was shared with others, and purposely deciding how much impact the disease had on the daily life and the relationship. This study pointed to specific processes that married couples used to maintain their relationship and the personhood of the spouse.

Similarly, Molyneaux et al. (2012) interviewed five couples (N=5) to explore how they strived to maintain their identity as a couple, or “couplehood,” as one of the spouses developed dementia. Through the constructivist grounded theory methodology analysis, the study exposed five themes, or strategies (i.e., “shifting identities within couplehood;” “maintaining relationship despite dementia;” “good old days;” “technically being a caregiver;” and, “sharing experience of dementia”) that couples used to sustain the relationship identity. Notably, the couples reported making adjustments in their daily lives and “normalizing” their experience (i.e., viewing dementia as part of the aging process) to sustain a sense of normalcy and continuity in their relationship. They also reflected on their shared life together, especially the good times they had,

and finally, they expressed their frustrations with the disease, which made their current experience more tolerable.

In summary, these three studies were valuable to the study of personhood because they showed how marriage partners worked together to maintain their relationship, and consequently, they attested to the importance of the PWD to the sustenance of the couple's relationship and identity. These studies also were significant because they showed that dementia was not only experienced by the person suffering from the disease, but also by their partner, which made the caregiving spouses valuable informants about the disease experience.

Two studies examined the strategies that caregiving spouses employed to preserve the identity or personhood of the PWD (Calasanti & Bowen, 2006; Perry & O'Connor, 2002). Calasanti and Bowen (2006) found that caregiving spouses implemented care practices that helped preserve the gender identity of their spouse. Using a constructivist approach, the researchers interviewed twenty-two caregiving spouses (N=22) and found that spouses crossed gender boundaries and learned new skills to help the PWD maintain their identity. For example, to help their wives get ready for the day, caregiving husbands learned new skills, such as applying makeup, fixing hair, and ironing clothes. Notably, this study highlighted the importance of masculinity and femininity to the personal identity of PWD.

Through open-ended interviews with thirty-eight caregiving husbands and wives (N=38), Perry and O'Connor (2002) found that caregiving spouses supported the existing competencies of their spouse with dementia by setting up tasks and situations where they could perform successfully and by avoiding experiences of failure. These last two studies revealed that sustaining personhood of the PWD meant preserving their functioning abilities and an appropriate physical appearance.

Three studies, using mixed samples of participants (i.e., spouses, children, other relatives), explored how family members viewed or supported the personhood of their relatives with dementia (Kaldjian et al., 2010; Phinney, 2006; Purves, 2011). Like the previously described set of studies that focused on the couples with dementia, these three studies varied in terms of research goals and methods employed. They were, however, significant, because they revealed that family members have overall positive views of the personhood of their relatives with dementia.

For example, Kaldjian et al. (2010) studied beliefs of twenty family members (N=20) (only four spouses), about the impact of dementia on factors related to the personhood of their loved ones in a palliative care program. These family members, in the role of surrogates (i.e., decision makers on behalf of persons unable to make their own decisions due to impact of dementia), were interviewed about the goals of the care of their relative with dementia and were asked a few questions about the loved one's personhood. The study reported that while many of the surrogates acknowledged significant dementia-related changes in the relative's ability to reason, communicate, and relate to others, more than two thirds of respondents felt that dementia had not reduced their loved ones' value as a human being, their dignity, or the respect that they deserved from others. It is particularly significant that seventy-five percent of the surrogates felt that their relative's life still had a purpose, and sixty-five percent reported that the relative's life was worth living. This study demonstrated that family members believe that their loved ones with dementia had value and purpose despite their very advanced levels of cognitive deterioration.

In a case study guided by Harre and Langenhove (1991) with the interpretive framework of positioning, Purves (2011) explored how members of one woman's family described the

changes to their own and other family members' roles, as prompted by her dementia. The data was collected via interviews with individual family members and through recordings of family group discussions (e. g., family dinners). The most significant finding was that the family members spoke about the PWD in terms of her long-standing roles (e.g., wife, mother) and in terms of her new role as a person with dementia. This study illustrated that dementia leads to changes that require the renegotiation of roles and responsibilities of PWD. It pointed to the fact that families play an important role in setting a tone for how a PWD is viewed in terms of personhood throughout the disease process.

Lastly, in an interpretative phenomenological study with eight cohabitating family caregiving dyads (N=8) (i.e., seven married couples and one mother-daughter pair), Phinney (2006) interviewed the caregivers and PWD with early to moderate stage of dementia about the involvement and support of the PWD in daily activities. Through a 3-phase interview process, the study found that families used the following three strategies to support the PWD's involvement: "reducing demands;" "guiding;" and, "accompanying." Similar to Perry and O'Connor's (2002) findings in the study that focused on spousal caregivers, this study reported that family caregivers simplified tasks and provided instructions to help the PWD work through the activities. Additionally, family caregivers found new ways to spend time with PWD, either by taking them along (e. g., when doing errands), or engaging in new activities that they can do together. This study demonstrated that family members sustain their loved ones' personhood through support with daily functioning and, that together with PWD, they find new, meaningful family activities.

These three studies revealed that family members held positive views of the personhood of their relatives with dementia, despite the cognitive and functional losses brought on by the

disease. Given that family caregivers are major advocates for the PWD, they are a resource in strengthening person-centered care practices in formal dementia care settings, such as long-term care facilities and hospitals.

Research on Persons Living with Dementia

A subset of qualitative studies explored the subjective experience of people with dementia (Clare, 2003; Dalby et al., 2012; Doyle et al., 2015; Fazio & Mitchell, 2009; McFadden et al., 2001; Nowell et al., 2011; Phinney et al., 2007). These studies varied greatly in terms of their specific research inquiries as related to the subjective experience of dementia, but they were valuable to the current discussion on personhood because they challenged the popular notion that the dementia-associated cognitive decline destroys capacities and aspects of the self, such as emotional responsiveness, that enable one to experience his or her life in a meaningful way. Also, since most of these studies employed interviews as a means of data collection on the subjective experience of dementia, they promoted the value of PWD's perspective and gave recognition to their personhood.

Doyle et al. (2015) interviewed twenty (N=20) residents in a dementia-care facility and found that PWD's had a desire and an ability to be generative in their daily activities and that they were nurturing towards others in their social environments. This study challenged the popular notion that PWDs are passive recipients of care and showed that they had much to offer in social interactions with others. Similarly, in a community-based residential facility study, McFadden et al., (2001) observed twenty (N=20) elderly residents in moderate and advanced stages of dementia. They found that the residents engaged with their environment, displayed a range of feelings, such as sensitivity and caring, and used humor in their interactions with others (McFadden et al., 2001). The findings of this ethnomethodological observational study

demonstrated that even late in the disease process, people with dementia lead lives with meaning. Similarly, in an interpretative phenomenological study on the lived experience of spirituality and dementia, Dalby et al. (2012) interviewed six (N=6) older people living with mild to moderate dementia. The study found that faith played an important role in the participants' current lives, and most reported engaging in religious practices, spiritual community, and that they maintained spiritual values and attitudes.

Next, with a goal to explore persistence of self in dementia, Fazio and Mitchell (2009) examined self-recognition in a sample of seventy-eight adults with mild, moderate dementia, and those without impairment (N=78). Specifically, they asked the participants to recognize themselves in the photos taken a few minutes earlier and found that even the participants with cognitive impairment exhibited unimpaired self-recognition. The authors interpreted this finding as an evidence of persistence of self in dementia (Fazio & Mitchell, 2009).

In an exploratory study, Menne et al. (2002) interviewed six individuals in ESD (N=6) and learned that PWD have a desire to maintain continuity with their previous lives and strive to make meaning of their current experiences. Similarly, in a narrative case study of quality of life with dementia, Robertson (2014) found that one elderly woman strived to maintain continuity in her identity by looking at her past roles and by looking forward for momentum to maintain her ongoing, socially valuable sense of self.

In an interpretative phenomenological study, Phinney et al. (2007) interviewed and observed eight community-dwelling persons with mild to moderate dementia (N=8) to learn what constituted a meaningful activity in their lives. The study found that participants strived to stay active and engaged in activities that were personally meaningful. Through their involvement, participants experienced pleasure and enjoyment, felt a sense of connection and belonging, and

retained a sense of autonomy and personal identity. The findings are significant because they demonstrated that PWD strived to maintain activities which provided a sense of continuity and personhood and which benefitted their quality of life.

Clare (2003) interviewed twelve individuals in ESD (N=12) to explore how they responded to dementia-related changes in memory. She found that the participants dealt with their dementia by acknowledging, reacting, explaining, experiencing the emotional impact, and adjusting (Clare, 2003). Specifically, the participants engaged in “self-maintaining,” or normalizing the situation and minimizing the difficulties, thus maintaining continuity with their prior sense of self. They also learned to “self-adjust” as they confronted difficulties and adapted their sense of self. This study demonstrated that PWD were engaged with their disease processes. In a long-term care setting, Nowell et al. (2011) found that PWD demonstrated the ability to maintain their own personhood by adapting to their environment. They interviewed seven (N=7) residents with dementia in this interpretative phenomenological study and learned that they employed specific strategies to support their own personhood in a long-term care group setting, such as working out the system, adapting in order to survive it, using past and future roles to manage the present, and being both an individual and a valued member of the group.

In summary, although these studies differed in terms of their specific research inquiries as they related to the subjective experience of dementia, they were significant because they showed that many aspects of self previously thought to be destroyed by dementia, such as productivity, social and emotional capacities, spirituality, need for identity, and the desire to lead a meaningful life, remained in spite of the presence of the disease.

Why Study Spouses' Perceptions About Personhood of Those Living with Dementia?

There is no known cure for dementia (What is dementia, 2019). Thus, it is necessary to provide high-quality care and support to the persons and families living with this disease. The family caregiving research studies summarized in this chapter attest to the importance of the family members in sustaining the personhood of individuals with dementia. What is more, approximately one quarter of those living with dementia are cared for by their spouses, and the research reveals that spouses play a major role in helping PWD make functional and emotional adjustments as the disease unfolds (Calasanti & Bowen, 2006; Davies, 2011; Fisher et al., 2011; Gilies, 2012; Hellström et al., 2007; Hellstrom et al., 2005; Molyneaux et al., 2012; Perry & O'Connor, 2002; Robinson et al., 2011; Sorensen et al., 2008).

A myriad of dementia caregiving resources is available to the public on topics including communication strategies, solutions to challenging behaviors, intimacy, coping, legal matters, caregiver self-care, nutrition, and driving (e.g., through Alzheimer's Association, Family Caregiver Alliance, National Institute on Aging, etc.) None of these resources, however, specifically address the care of personhood of those living with dementia. Likewise, a review of caregiving research literature brought up only two interventions for families of PWD that gave attention to issues of personhood (Bryden, 2002; Scherrer et al., 2014). Bryden (2002) described a counseling approach for people in early stages of dementia based on Kitwood's concept of person-centered care. Notably, the counseling approach identified the family environment as a critical social context where PWD expressed their experience of cognitive and physical decline and recognized that it could significantly impact the PWD's experience of the disease. Alternatively, Ingersoll-Dayton and Spencer (2014) described a dyadic intervention known as the Couples' Life Story Approach, designed to help the marriage partners reflect on their shared life.

At this time, however, without further evidence in the literature about the use of these interventions, it is hard to estimate their benefit to the general population of families impacted by dementia.

Research has found that following a diagnosis of dementia, couples often lack proper support, which can lead to difficulty in adjusting to the psychological and physical decline in the PWD and changes in the couple's lifestyle and relationship (Pesonen et al., 2013; Robinson et al., 2005; Stokes et al., 2012). The current study explored caregiving wives' perceptions of the husbands' personhood in the early stage of dementia (ESD). Given the apparent lack of available resources for supporting the personhood of those living with dementia, the current study also explored what factors influenced the wives' perceptions of their husbands' personhood early in the disease process. The next chapter describes the research approach in this study.

CHAPTER 3: RESEARCH DESIGN AND METHODS

The goal of this study was to understand the experience of wives as they cared for their husbands in ESD. The study used an interpretative phenomenological analysis (IPA) as its methodology because of its aim to understand participants' personal perceptions of a situation or an event, as opposed to attempting to produce an objective understanding of the phenomenon (Smith & Osborn, 2008). IPA allows the researcher to consider the perspective of the participant with the goals of understanding the lived experience of interest and how the participant is making sense of their personal and social world. While one goal of IPA is to gain a close understanding of the respondent's personal world, it is acknowledged that this cannot be completely accomplished. Instead, the access is dependent on the researcher's own conceptions which are required to make sense of the respondent's personal world through a process of interpretative activity. The setting for this study was not limited to a specific place, as the primary goal was to recruit participants who have experienced the phenomenon under study.

The researcher's hope is that this study will provide professionals in the field of dementia care with needed insights regarding resources that will best support couples impacted by dementia. While the limited research suggests that couples living with dementia make adjustments in their lifestyles and daily routines in order to preserve their identity as a couple and the identity of the spouse with dementia (Calasanti & Bowen, 2009; Hellström et al., 2007; Molyneaux et al., 2012), the biomedical model of care, which portrays the person with dementia as a victim of a progressive decline becoming more dependent on others for subsistence, is overwhelmingly present in educational and support resources available to families.

As stated above, the conceptual framework proposed for this research positioned the meaning-making process (Park, 2010) in a context of the interactionist perspective of identity in

chronic illness (Kelly & Field, 1996; 1998). Specifically, the study theorized that caregiving wives would reach for predominant social views of people with dementia to make sense of the changes that their husbands were experiencing as a result of having dementia.

The remainder of this chapter presents the study design. It describes the role of the researcher, characteristics of the sample population and participants, and the selection of the research design for the study. Next, it discusses data collection procedures, data analysis techniques, validity and limitations. Finally, the chapter concludes with a brief description of findings and a summary.

Methodology

The chosen methodology for this study was interpretative phenomenological analysis. IPA allowed for an exploration of caregiving wives' perceptions of the personhood of their husband in ESD, and the meanings they gave to the dementia-related cognitive, behavioral, social and physical changes in their spouses. Smith and Osborne (2008) described IPA as a two-stage process in which the participants are trying to make sense of their lived experience, while the researcher tries to make sense of the participants' trying to make sense of this experience. A few predominantly qualitative studies have explored how families preserved the personhood of their loved ones with dementia (Kaldjian et al., 2010; O'Sullivan, Hocking, & Spence, 2014; Phinney, 2006; Purves, 2011, Svansson & Dahlberg, 2004). However, to date, no studies were identified which explored caregivers' perceptions of the personhood of their afflicted spouses. The existing research suggests that couples often lack pertinent information and continued support following a diagnosis of dementia, which can lead to difficulty in adjusting to a dementia-related decline, changes in the lifestyle, marriage and long-held roles within the relationship (Pesonen et al., 2013; Robinson et al., 2005; Stokes et al., 2012). This study adds to

the literature by offering valuable insights about caregiving wives' perceptions of their husbands' personhood in the early stage of dementia; it can be used to inform professionals in the field of dementia care regarding resources that support couples living with dementia.

In addition to using IPA, based on the researcher's past work with couples with dementia, it was felt that participants need to process their experience with a past point of reference in order to make meaning. Following the recommendations of Seidman (2005), in order to gain an understanding of the lived experience of caregiving spouses and the meaning they give to their experience as it relates to phenomenon of personhood in dementia, this study employed a series of three in-depth interviews. The interviews were semi-structured and consisted of open-ended questions to allow the participants to tell their stories in their own words. The three-series interview began with exploring a context of the participant's experience as it relates to the phenomenon under study (1st interview), followed by the deeper exploration of the participant's present experience of the phenomenon (2nd interview), and ended with inviting the participant to reflect more deeply on the meaning of the experience (3rd interview). Seidman (2005) argued that the three-interview series allows the investigator and the correspondent to adequately set the participants' experience under study in the broader context of their life. Seidman (2005) wrote: "People's behavior becomes meaningful and understandable when placed in the context of their lives and the lives of those around them. Without context, there is little possibility of exploring the meaning of an experience" (p. 16-17). For the purpose of attaining a more complete contextual understanding of the participant's experience as it relates to the phenomenon under study, the first interview protocol encompassed a set of questions about the participant's prior knowledge of dementia. This was done to capture participants' diverse caregiving experiences, knowledge of the disease process and level of familiarity with other individuals suffering from

dementia, all of which may have impacted wives' perceptions of the personhood of their afflicted husbands. Each of the three interviews lasted approximately 60 minutes (a total of 3 hours for each participant), and each interview occurred 3 days to one week apart (Seidman, 2005). See Appendix A for the interview protocols.

Role of the Researcher

The researcher's role in this IPA study was to encourage the caregiving wives to deeply reflect on their lived experience of having a husband in ESD. The ultimate goal of this study was to identify themes in the reflections and feelings surrounding the caregiving wives' experiences of living with, and caring for, a husband in ESD.

The researcher works as the Senior Center Coordinator (SCC) in Connecticut and has previous experience as the family support group facilitator at the Alzheimer's Association in Virginia. As a volunteer, the researcher has facilitated support groups for families of individuals living with dementia. The participants for this study were selected from the sample population of Alzheimer's Association support group members in Connecticut.

The researcher's inspiration to conduct this study came from her work with families affected by dementia. She observed situations when personhood of those with dementia was undermined or ignored, predominantly in professional caregiving settings, such as nursing homes and assisted living centers. At the same time, she perceived that families, in their interactions and care of loved ones with dementia, spent much time talking with them about the significant people, relationships and events from their earlier life. The researcher noticed that PWD were frequently responsive and engaged in these types of interactions, and she thought that perhaps, this was the caregivers' strategy of honoring and preserving the care-receivers' personhood.

It is important for a researcher to reflect on his or her biases that they bring to the subject area. Potential researcher bias here includes the researcher's passion to contribute to family caregiving literature which comes from a cultural background that emphasizes strong obligations to care for "one's own." Her Christian background motivated the researcher to pursue the subject of personhood. Christianity teaches oneness and interdependence of all living beings. Like the Father, the Son and the Holy Spirit who make up the Holy Trinity, we are inseparable, interdependent, and are a part of a greater whole.

Participants

The participants for this study were wives who were caring, at home, for a husband in ESD. For the purpose of clarity, the decision was made to focus on female spouses because two-thirds of dementia caregivers are women, and also because of the known differences in how men and women approach caregiving (i. e., women provide the majority of hands on care, while men provide more logistical coordination of care) (2018 Alzheimer's Disease Facts and Figures, 2018; Bédard et al., 2005; Calasanti, 2010). In line with IPA recommendations, this study employed a purposive sampling procedure (Smith & Osborn, 2008). Purposive sampling targets specific population of interest. Dementia studies have shown that the more advanced the people are in the disease process, the more their personhood becomes "at risk" of being diminished. Therefore, it is important to examine perceptions of personhood throughout the course of dementia (Kitwood, 1997; Sabat, Napolitano, & Fath, 2004). However, this study was concerned with wives' perceptions of personhood of their husbands only in the early stage of dementia because of the dramatic transitions the couples were facing in their daily lives during this stage, including the initial emotional impact of the disease, challenges in daily functioning, and changes in roles and relationships (Pesonen et al., 2013; Robinson et al., 2005; Yale, 2013).

Caregiving wives whose husbands with dementia had HIV/AIDS, leprosy, diabetes, cancer, obesity, skin disorders, venereal diseases and mental illnesses other than dementia were excluded from this study, because the research literature shows that these are among the highest stigmatized health conditions (Engebretson, 2013; Hillson, 2014; Puhl & Heuer, 2010; Sartorius, 2007). By excluding participants with these health conditions, the goal was to eliminate an impact that the conditions may have had on wives' perceptions of their husband's personhood.

Initially, the intention was to limit the study's sample to the couples in which the care-receiver husband was at least 70 years old to avoid the following two issues. First, individuals who were diagnosed with dementia before the age of 65 years are generally considered to be living with the "early onset" dementia. They tend to face different challenges in terms of the nature and progression of the disease than those who are diagnosed with dementia after the age of 65 (Armari, Jarmolowicz, & Panegyres, 2013; Vugt, Koopmans, Bakker, Verhey, & Vliet, 2010). Second, by limiting the sample to participants whose husbands were at least 70 years old, the goal was to avoid recruiting wives whose husbands were still employed; individuals diagnosed with dementia while working experience a different set of lifestyle challenges than those who are diagnosed post-retirement. However, with the exclusion of men with dementia who have highly stigmatized health conditions, it was extremely difficult to recruit participants; ultimately, the decision was made to include one couple in which the husband was 67 years old, but who was retired before receiving the diagnosis of dementia. The last criterion for inclusion in this study is that caregiving wives were able to understand, speak, read and write in the English language at an advanced or native proficiency level. The number of participants interviewed in this IPA study depended on when the saturation in data, or thematic saturation, would be reached, as the goal of qualitative research is to explore the range of views and collect

“rich” data (Bowen, 2008; O’Reilly & Parker, 2012). However, it is important to note that the concept of saturation has an inherent weakness, in a sense that there is always new data to be discovered and data can never be truly saturated (Wray, Markovic & Manderson, 2007).

Smith and Osborn (2008) stated that sample size in interpretative phenomenological analysis (IPA) studies depend on “the degree of commitment to the case study level of analysis and reporting, the richness of the individual cases, and the constraints one is operating under” (p. 56). While they did not make specific recommendations about a sample size, Smith and Osborn (2008) recommended a sample size of 3 to 6 participants. No studies were identified that employed IPA in exploring personhood in dementia with a population of spousal caregivers. Of the two family caregiving studies that explored general caregiving experiences of spouses of PWD and that utilized IPA as a method of inquiry, the first had a sample sizes of 7 participants, and the second study had 6 participants (O’Shaughnessy, Lee, & Lintern, 2010; Walters, Oyeboode, & Riley, 2010). It was estimated that approximately 6 participants will be needed to reach saturation in the current study.

Data Collection

To ensure that this study posed a minimal risk or potential physical, psychological, social, economic, or legal harm to the participants, it was reviewed and approved by the Institutional Review Board (IRB) at the University of Connecticut before any data was collected (Creswell, 2009) (See Appendix F). The leadership of the Alzheimer’s Association was approached prior to the beginning of the study and the researcher was granted permission to solicit potential participants in their support groups upon the approval of the study by the IRB (See Appendix E). A purposive sampling procedure was employed in selection of the potential participants for this study (Smith & Osborn, 2008). The support groups for caregiving spouses of the Alzheimer’s

Association in Southington, CT were visited, and participants were given a short description of this study's purpose. Next, support group participants were asked if they would like to participate in this study, if they meet the initial screening criteria: 1) lived at home with husband; 2) husband was at least 70 years old; 3) husband had early stage dementia; 4) husband did not suffer from highly stigmatized conditions: HIV/AIDS, leprosy, diabetes, cancer, obesity, skin disorders, venereal diseases, and mental illnesses other than dementia, and 5) wives spoke English language at advanced or native proficiency level (See appendix B).

The purpose of the initial contact with the potential participants was for the researcher to introduce herself, to explain the purpose of the study, and to ensure that the participants met the basic eligibility requirements of the study. The initial contact recruiting script and the basic eligibility questions are listed in Appendix B. If the participants met this basic criterion for the study, the researcher reviewed the Informed Consent form with them, and answered any questions they had. The participants were given the consent form and asked to sign and return the form to the researcher when they were ready to begin participating in the study. The researcher collected the form in person within a few days of the initial contact if the participants chose to keep the form for review beyond the initial meeting.

Following this first meeting with the participants, the final eligibility screening instrument, the Functional Assessment Staging Test (FAST), a common test used by the researcher in her work on memory care unit, was administered over the phone to the participants who enrolled in the study (Reisberg, 1988; Reisberg, 2007). This interview-based assessment instrument is used to evaluate functional abilities of a person with dementia and is founded on the observations of the person's family or professional caregiver. The seven functional stages of the scale range from "normal older adult" (Stage 1) to "severe dementia" (Stage 7). The current

study recruited wives whose husbands were living in ESD, represented on the FAST scale by Stages 3 and 4. ESD is characterized by increasing memory loss which becomes apparent to family, close friends and co-workers. The affected individual becomes less able to remember names of persons just introduced to him or her. He or she may have difficulty managing finances, counting money and travelling to new locations. Finally, the person's knowledge of current and recent events decreases. A more detailed description of FAST and the seven stages of dementia can be found in Appendix C. Also, for the demographic questionnaire see Appendix D.

Next, the interviews for data collection were arranged. All interviews were conducted via phone and lasted up to one hour. The decision was made to conduct interviews over the phone only in order to reduce non-verbal communication cues. The researcher called each participant from a private room that was free from interruptions (Smith & Osborn, 2008). Each participant was interviewed three times, and each interview was scheduled 3 to 7 days apart. Upon completion of the interviews, the researcher reviewed the interviews with the participants to ensure that the researcher's interpretation of the participants' narrations was accurate.

The interviews were audio-recorded. This allowed the researcher to give full attention to the participant and to fully engage in the conversation instead of taking notes while the participant was speaking (Smith & Osborn, 2008). During the interviews, the researcher used two recording devices in order to prevent interruptions in the interview process due to possible mechanical malfunctions of the recording devices (Groenewald, 2004). The recordings were coded with numbers unique to each participant in order to maintain confidentiality. The recordings and the transcripts, associated by the numerical codes, were stored on the separate password protected flash drives, and are kept in the locked cabinets at undisclosed locations. At

the completion of the interviews, the recordings were transcribed, and generous margins were left on the sides of the transcript for notes to be made during the analysis. The goal of IPA transcription is to capture the meaning rather than the grammatical correctness and structure of the participants' accounts of their experience (Smith & Osborn, 2008).

Data Analysis

Smith and Osborn (2008) asserted that IPA is an analytical framework in which “meaning is central, and the aim is to try to understand the content and complexity of those meanings rather than to measure their frequency” (p. 66). After all interviews were completed and transcribed, following the recommendation of Smith and Osborn (2008), the transcripts were read and re-read in order to become familiar with the material.

The qualitative data analysis software NVIVO 12 was utilized to organize the data. Analysis was done one case at a time. First, the researcher made initial comments “on similarities and differences, echoes, amplifications and contradictions in what a person is saying” (Smith & Osborn, 2008, p. 67). Second, the researcher went back to the beginning of the transcript and documented emerging themes. Initial notes were transformed into phrases that captured the overall meaning of what was found in the first transcript. Smith and Osborn wrote that these theme phrases should “allow theoretical connections within and across cases but...still [be] grounded in particularity of a specific thing said” (2008, p. 68). Third, the researcher sought connections between the emerging themes, and the ones that appeared to belong together were clustered together with the help of NVIVO 12 software. At this point, as Smith and Osborn (2008) suggest, some themes began to emerge as superordinate concepts with lower-order (subordinate) themes clustered around them. The themes that did not fit well with the emerging structure were set aside for further analysis after all case studies had been analyzed. This

concluded the initial analysis of the first transcript. This analysis sequence was followed with all succeeding interviews. The interviews were analyzed as each interview was completed.

Saturation was reached at interview with the sixth participant, but since two additional interviews were in process, the decision was made to complete them. No additional themes were identified via interviews of these additional two participants.

The next step was to analyze the remaining transcripts. Smith and Osborn (2008) stated that the themes from the first case could be used to orient the subsequent analysis, or start fresh, all the while discerning between repeating and newly-emerging themes. Once all the cases were analyzed, the researcher constructed a final table of superordinate themes. Following Smith and Osborn's (2008) recommendation, focus was placed on the themes that were most prevalent in the data, as well as the ones that best represented the "richness" of the data.

Validity

Smith, Flowers, and Larkin (2009) suggest that validity in IPA studies should be assessed using four principles: sensitivity to context, commitment and rigor, transparency and coherence, and impact and importance (Yardley, 2000). The first principle, sensitivity to context, began with the early phases of this research process by selecting IPA as a methodological approach. There was a great need for close engagement and specificity in the exploration of how spouses perceived the personhood of their partners in the early stage of dementia, and what meaning they gave to dementia-related psychological and physical changes in their partners. Further, Smith et al. (2009) argued that IPA requires purposive samples of participants who share a lived experience under investigation. As such, they can be difficult to access, to establish rapport with, and to sustain engagement with throughout the research process. Throughout the data collection process, a recognition of "interactional difficulties" was demonstrated by showing empathy and

sensitivity (i.e., the researcher shared her own family caregiving experience with the participants, as well as her professional caregiving experience with PWD), and a great effort was made to put the participants at ease during interviews (Smith et al., 2009).

At the analysis phase of the study, where IPA dictates it is necessary to “make sense of how the participant is making sense,” the researcher reviewed the transcripts and notes with the participants following each interview to ensure that information recorded in the transcripts and the researcher’s interpretation of the text was accurate. Finally, the final written report included a number of verbatim quotes from interview transcripts, in addition to the researcher’s interpretations, so that readers could compare the researcher’s interpretations with what was said by the participant. The claims made in this report were specific to the sample of participants in this study and were grounded in the relevant literature in the discussion of the study’s findings.

The second principle, commitment and rigor, referred to the degree of attentiveness and thoroughness throughout the research process. This principle was addressed during the data collection process by paying attention to a participant’s tone of voice, listening intently to what he or she was saying, and generally ensuring that the participant was comfortable. Also, close attention was given to each individual case throughout the data analysis process. The rigor principle was addressed by selecting participants that met the inclusion criteria. An effort was made to assure that the interviews were carried out to the highest degree of quality, in a private environment with a minimum of interruptions. The data analysis was systematically carried out, and great effort was made to move beyond simple description of the text towards a deeper examination of the meaning of participants’ accounts of their experience.

The third principle, transparency and coherence, referred to how clearly the research process was described in the report of the study, and how clear and coherent the analysis of the

data is. The transparency principle was addressed by clearly describing each step of the research process, including the selection of participants, construction of the interview, and steps in the analysis process. The coherence principle was addressed by providing rich descriptions of the participants' experiences from the researcher's perspective, and by clearly stating that the analysis was the researcher's own interpretation of the participants' interpretations of their experience.

The last principle, impact and importance, implies that the research must state something interesting, important and useful. Exploring how the personhood of people with dementia is supported through family caregiving is extremely significant to preserving quality of life of those living with this disease. A great deal of effort was made to provide clear and thorough descriptions of the meaning that the participants give to their lived experience.

Summary of the Chapter

This chapter described interpretative phenomenological analysis, the analytical model used in this study. It outlined the research design and the role of the researcher, described the sample population, the methods for data collection and data analysis, validity of IPA. The following chapter presents the findings of this study.

CHAPTER 4: FINDINGS

The findings of this study were written in narrative form with the goal of bringing the participants' stories to life. The last phase of interpretative phenomenological analysis is "concerned with moving from the final themes to a wrap-up and final statement outlining the meanings inherent in the participants' experience" (Smith, 2008, p. 76). The findings of the study were written following Willing's (2001) set of recommendations for presenting qualitative research findings. The method designed by Willing (2001) allows for the presentation of findings with a clear distinction between participants' interpretations of the phenomenon and the researcher's reactions to it. First, each theme was presented and described. Second, participants' quotes were included to support and enrich description of the themes. Third, a table was created that outlined the superordinate and subordinate themes that emerged from the interviews. Finally, a discussion section analyzed the implications of the findings, connected the study's results to related literature and the conceptual framework, and offered recommendations for practice and future research (Willing, 2001).

This chapter presents the experiences of eight (n=8) wives who lived with and cared for husbands in ESD at the time when this study was conducted. The chapter is divided into two main sections: introduction of the participants and findings. The first section describes each participant's demographics and provides a brief background, focusing on her married life and knowledge of dementia prior to her husband's diagnosis. The second section of the chapter discusses the findings of the study through a presentation of nine superordinate themes and several subordinate themes that emerged during analysis. These themes were organized in three major groups, each corresponding to one of the three research questions of this study.

Upon soliciting the local Alzheimer’s Association family support groups and screening potential participants, eight caregiving wives qualified and committed to participate in this study. All wives identified as Caucasian and ranged from 61 to 77 years of age. The highest level of education amongst the wives was a professional degree (e.g., MD, DDS), and the lowest was high school. The household income for the sample extended from \$20,000 to over \$100,000. The care-receiving husbands were between the ages of 67 and 86 years, with the Functional Assessment Staging Test (FAST) score values ranging between 3 and 4, which is indicative of ESD. All husbands were retired prior to being diagnosed with dementia, and all couples lived together, in their own homes. The length of time of husbands having dementia was not a factor in the current study, as dementia progresses at various rates, for various individuals (What is dementia, 2019). See Table 1 below for a summary of the participants’ demographics.

The caregiving wives answered questions about their experiences of living with a husband in ESD. Pseudonyms were given to the participants (instead of the numerical codes assigned in place of their names at the beginning of the study) to make their reflections and words sound more personal and authentic.

Table 1

Demographics

Participant	Race	Age	Education	Employment	Income	Husband’s Age	Husband’s FAST Score
“Rayleigh”	Caucasian	77	High Schl.	Retired	\$50,000- \$74,999	79	4
“Emilia”	Caucasian	63	Bachelor’s	Full Time	\$75,000- \$99,999	67	3
“Magdalena”	Caucasian	61	Associate	Full Time	\$50,000- \$74,999	71	4
“Eugenia”	Caucasian	77	High Schl.	Part Time	\$20,000- \$34,999	86	3-4
“Marianna”	Caucasian	75	Master’s	Retired	\$75,000- \$99,999	77	3
“Betty”	Caucasian	74	Professional	Retired	\$50,000- \$74,999	80	3

“Estelle”	Caucasian	70	Master’s	Retired	Over \$100,000	71	3
“Raisa”	Caucasian	76	Master’s	Retired	Over \$100,000	79	3-4

Introduction of the Participants

Participant One: “Rayleigh”

Rayleigh was a 77 year old, retired, caregiving wife living with a 79 year old husband in ESD (FAST Score = 4). Rayleigh stated that she and her husband had an “easy life,” overall. She spoke about raising children, attending children’s sports games, traveling, and participating in the church activities as the highlights of their life together. “Balancing the budget,” Rayleigh said, was the most challenging aspect of the early years of their marriage: her husband was the only one working while she stayed at home and took care of their young children.

Participant Two: “Emilia”

Emilia was a 63-year-old wife who worked full-time and cared for her 67-year-old husband in ESD (FAST Score = 3). She described the early years of their marriage as “a really happy time” when she and her husband both worked and traveled a lot. They waited a few years to start a family, and once they had children, Emilia stayed home for a number of years before returning to full-time work. One of the challenges they experienced early on was finding “the right” faith community that would accommodate her and her husband’s differing religious beliefs. Ultimately, Emilia said, they picked a church that was “well-liked” in their neighborhood. Furthermore, she acknowledged that frequent moves for her husband’s job while the children were young was difficult, but overall, she said she feels they “had far more good times than bad.” The “good times” included their first trip to Europe, activities with their children, and finally, the renewal of their marriage vows late in life.

Participant Three: “Magdalena”

Magdalena was a 61 year old wife who was working full-time and living with a 71 year old husband in ESD (FAST Score = 4). She spoke about the early years of her marriage as particularly enjoyable. She and her husband played sports, went to sports tournaments, and attended community events with friends. Magdalena said that she and her husband both came from big families, so most of their shared memories were of the family gatherings and holiday celebrations. She recalled the birth of their children as a particularly happy time in her life. Their most difficult moments involved moving to the United States and starting a new life. Magdalena said with much sadness: “We had to leave our own families and live far away from home.”

Participant Four: “Eugenia”

Eugenia was 77 years old, working part-time and caring for her 86 year old husband in ESD (FAST Score = 3-4). She described her husband as a “very attentive and romantic” man who, like her, was highly religious. Eugenia said that the early years of their marriage were most challenging because she and her husband were raised with different family values. When asked about the highlights of their married life together, Eugenia answered: “That's hard to say. We never took that many vacations.”

Participant Five: “Marianna”

Marianna was 75 years old. She was a retired, caregiving wife living with a 77 year old husband in ESD (FAST Score = 3). She described her married life as a very busy and exciting time. Her husband was in the army, so they moved several times, and Marianna described this period as a highlight in their life together. The careers were very important to both of them, she said, and they enjoyed working. The most challenging event in their lives was when her

husband's mother had a stroke and died before he was able to see her one last time. Marianna said that religion never played a big role in her and her husband's lives.

Participant Six: "Betty"

Betty was 74 years old, retired, and caring for an 80 year old husband in ESD (FAST Score = 3). Their marriage was the second for both Betty and her husband. She described moving out of state, building a successful business together, and welcoming grandchildren as the highlights of their life. The biggest challenge they had, Betty explained, was spending all their time together. In terms of religiousness, Betty briefly mentioned that she and her husband were "spiritual," and "believed in higher power," but did not belong to a faith community.

Participant Seven: "Estelle"

Estelle was 70 years old. She was a retired, caregiving wife living with a 71 year old husband in the Early Stage of Dementia (FAST Score = 3). She described the early years of her marriage as a time of balancing work, education, and raising children on a small financial budget. "We were pretty poor, but we managed," she said. "Neither one of us came from families that had a lot of money, so it wasn't hard to skimp." Life-long teaching careers, raising children, accompanying them to sports games, and traveling around the world were the happiest aspects of their marriage. When asked about any notable challenges in their life together, Betty said that "nothing really stands out as a difficult time." Betty spoke of being highly involved in their church, and how she and her husband started teaching the Bible school after they retired.

She noted:

My husband's still teaching the men's class. But the guys in the class help him by helping him remember where he was at. Because his long-term memory is pretty good, because he's been a Christian for a long time, he has a solid understanding of the Bible. But he might forget what question somebody asked. So, the other guys help him. Funny how it works, isn't it?

Participant Eight: “Raisa”

Raisa was a 76 years old, retired, caregiving wife living with a 79 year old husband in ESD (FAST Score = 3-4). She described the early years of her marriage as the most challenging for her and her husband. She got pregnant as soon as they were married and developed health issues right after the baby was born. After her health improved, they enjoyed prestigious careers in education, travelled, attended music concerts and plays, and enjoyed family activities together. These, she said, were the highlights of their lives together. She also noted that she enjoyed serving in the community organizations while her husband enjoyed gardening and spending time outdoors.

Overview of Themes

The findings presented in the remainder of this chapter are organized into three sections according to the study’s three core research questions. In each section, a table summarizes the superordinate and subordinate themes that emerged during analysis of all transcripts. Following each table is a detailed description of the themes. In line with Smith and Osborn’s (2008) recommendation, the analysis focused on the themes that were most prevalent in the data, as well as the ones that best represented the “richness” of the data.

Research Question One (RQ1) Themes

The first research question was: “What meaning do caregiving wives give to the cognitive, behavioral, social and physical changes in their husbands in ESD?” Through careful questioning during interviews and methodic analysis of interview recordings, three major themes surfaced that exposed the meanings that wives gave to the changes in their husbands in ESD: 1) Noticing Changes in Functioning; 2) Responses to Diagnosis; and 3) Making Adjustments,

Managing Changes. Table 2 indicates the superordinate and sub-themes that are relevant to this research question.

Table 2

Research Question 1 Themes: What meaning do caregiving wives give to the cognitive, behavioral, social and physical changes in their husbands in ESD?

Superordinate Theme
Sub-theme
Noticing changes in husband's functioning
Before diagnosis
After diagnosis
Relational and social changes
Responses to diagnosis
Wives' responses to husband's diagnosis
Husbands' responses to diagnosis
Family and friends' responses to husband's diagnosis
Making adjustments, managing changes
Areas of struggle
Getting medical support
Getting social support
Navigating the journey

RQ1, Theme One: Noticing Changes in Husband's Functioning

In order to uncover the meaning that wives gave to the cognitive, behavioral, social and physical changes in their husbands in ESD, wives were asked to describe the changes they noticed in their husbands after the onset of dementia. All wives spoke about the changes they noticed in their husbands before and after the husband was diagnosed with dementia, and some wives described what they thought these changes meant at the time. The wives also described

relational and social changes that they and their husbands, as a couple, experienced as a result of the husband getting dementia.

Before Diagnosis

Prior to diagnosis, the wives reported noticing the following changes in their husbands: memory loss and confusion, difficulties with taking initiative and making decisions, and challenges with processing new information. Overall, the wives reported not taking these changes seriously until they became more frequent and began interfering with the husband's daily functioning. Six of the wives spoke about noticing memory loss and confusion in their husbands prior to being diagnosed with dementia. Magdalena, Emilia and Estelle reported that their husbands began getting lost while driving in familiar streets. Rayleigh reported: "We began losing things a lot...Specifically his keys and his glasses." Betty recalled a conversation with her husband's volunteer friends about him "getting mixed up on things" while working on a group project, but not thinking much of it at the time because many of their friends were having some memory issues.

Three of the wives described the changes they noticed in regard to their spouse's initiative and decision-making abilities. Betty and Raisa reported that their husbands withdrew from long-term hobbies. Betty remembers: "There was something a little bit different about him, but it was very vague." She reported that her husband withdrew from a long-term volunteering project without a clear explanation for doing so. Similarly, Raisa said that her husband was doing less gardening and that his actions were becoming disorganized: "He seemed like he'd get focused on one thing and do that and forget about turning the garden over. Instead, he'd be playing around in the rock garden, you know?" Betty and Raisa remembered attributing these changes in their husband's behavior as a loss of interest in the activities. "And it's a while

before you, as a spouse, recognize that it's just not his old ordinary self," Raisa noted, as she reflected on her experience. In the similar way, Emilia recalled the early changes in her husband's communication. "He would tend to not be definitive," when a decision needed to be made, she said. "I would say, I was probably not very patient with that because I felt more like either he wasn't paying attention, or he just didn't want to be involved or whatever." Emilia also reported having to initiate projects around the house and provide daily reminders and follow ups to get projects completed: "It was that constant kind of prodding to get him to do it," she recalled.

Four of the wives described noticing that their husbands were struggling with processing new information. Emilia remembered her husband complaining about the reports he had to write at his new job. At the time, she said, she attributed it to her spouse not liking to write reports, or not being open to learning a new computer software that he had to use to complete the report. Marianna and Estelle also spoke about their husbands struggling with new technology, such as a new telephone answering machine or a new car. Magdalena said that her husband started to struggle when choosing food items during grocery shopping trips.

After Diagnosis

After their husbands were diagnosed with dementia, six wives reported noticing cognitive decline and a need for medication to manage dementia symptoms. Overall, the wives reported noticing more cognitive and functional decline in their husbands after receiving the diagnosis of dementia. A couple of wives described the strategies they began using to help their husbands manage daily life, such as calendar reminders and participation in the memory program. Five of the wives reported an increase in cognitive decline after the husband was diagnosed with dementia. For example, Betty noted growing memory loss and a decrease in her husband's

activity level. With the goal of keeping her husband active, Betty enrolled him in the memory program at the local senior center: “When he’s home, he would just sit in a chair with his eyes closed or go back to bed.” Likewise, Raisa said that, since the diagnosis, she started writing calendar notes to remind her husband of the daily activities and upcoming appointments.

Eugenia and Raisa reported that, due to growing confusion and memory loss, their husbands could no longer perform errands that they had previously done alone. On the same note, Marianna described her husband’s growing confusion with the following example: “...he’ll take part of one story and part of another story and put them together as a new story that to him is very true.” Estelle reported that planning and organizing (e.g., organizing house tasks, garage cleaning, etc.) had become increasingly difficult for her husband since the diagnosis. A couple of the wives said that after being diagnosed with dementia, their husbands were prescribed medication, which they felt had helped with some of the dementia symptoms, such as memory loss, restlessness, anxiety, and depression.

Relational and Social Changes

All of the wives reported experiencing changes in their marriage and social life due to their husbands’ dementia. Overall, the wives reported taking on more responsibility in order to meet the demands of daily life and to preserve their husbands’ safety and well-being. A couple of the wives reported changes in long-held marriage roles due to the husband’s functional decline and growing dependence. Most of the wives said that they started spending less time with friends and other couples and more quiet time at home. Lastly, the majority of the wives informed their friends and family of the husband’s dementia. Only a couple of them chose not to share the diagnosis.

Five of the wives reported experiencing a greater personal responsibility in their marriage. Specifically, they had to take on additional tasks that previously belonged to their husbands in order to meet the demands of daily life (i.e., financial decision-making, home repairs, vehicle maintenance, etc.) Rayleigh, for example, noted: “Every day is on my shoulders... because a lot of things he did, he’s not sure of doing anymore.” She admitted that she no longer left her husband alone at home because she worried that he wouldn’t eat healthy meals, properly take medications, and keep the house safe. Raisa described dealing with similar increasing personal obligations by telling herself: “I’m going to sort of pretend that I am living alone, and just do the things alone I need to do...the stuff that he used to do.” Additionally, two of the wives reported experiencing “role-switching” in their marriage as a consequent of the husband’s dementia. While their husbands had previously been their “protectors,” after the onset of dementia the wives found themselves protecting their husbands due to the men’s growing dependence and vulnerability.

The wives were asked if their marriage had changed as a result of their spouse getting dementia. Two wives, Betty and Eugenia, felt that their marriage was no longer the same because their husbands were no longer able to communicate in a meaningful way. Eugenia added that she no longer had a “partner in life” because her husband was not able to do many of the things he used to do. In comparison, despite the changes they noticed in their spouses, Emilia, Magdalena and Estelle felt that their marriage had not changed.

In terms of social relationships, five of the wives reported spending more time at home since their husbands started experiencing dementia. All reported that the frequency of visits with friends had decreased over time, and that their husbands were less engaged in the company of others. In particular, Rayleigh spoke about being left out of the traditional card game nights with

friends: "... sometimes I'll hear they'll say they get together, and they played cards. But they hadn't called... I don't know if it's because of him or what."

Finally, all wives were asked whether or not they told family and friends that their husband had dementia. Six wives reported being open with their husband's condition; some, because honesty and openness was a part of their character, and others, in the hope of gaining support and understanding from others. On the other hand, two wives said that they did not share their husband's diagnosis. Aside from her immediate family, Emilia chose not to share her husband's diagnosis with others because she did not want her husband to be treated "differently." Magdalena spoke about not sharing the diagnosis with some friends who were not understanding of her husband's condition. She explained: "That's how I am keeping away some people who really don't understand this situation."

RQ 1, Theme 1 Summary

In summary, the wives were asked to describe the changes they perceived in their husbands before and after the men were diagnosed with dementia in an effort to explore the meaning they give to the cognitive, behavioral, social and physical changes that occurred as a result of their husbands' dementia. Prior to the diagnoses, the wives reported noticing memory loss and confusion, difficulties with taking initiative and making decisions, and challenges with processing new information. Once these changes started affecting the husbands' independent daily functioning, each of the couples decided to turn to medical providers for help.

After the diagnoses, most wives reported noticing further increase in their husbands' cognitive decline. A couple of wives reported using calendar reminders and engaging their husbands in memory programs to support their husband's functioning. Some wives reported that their husbands were prescribed medication which was helpful with managing dementia-related

memory loss, restlessness, anxiety, and depression. The wives also reported changes in their marriage and social life, such as taking on more personal responsibility and experiencing role-switching in their married relationship and spending less time with friends.

Lastly, most wives informed their friends and family of their husbands' dementia, and only couple of them chose not to share the diagnosis.

RQ1, Theme Two: Responses to Diagnosis

In order to explore the meaning that wives gave to cognitive, behavioral, social and physical changes in their husbands living with ESD, they were asked to describe their reactions to their husbands' diagnoses and to reflect on their husband's, family members, and friends' responses to learning that the husband had dementia. The wives reported a range of responses to learning that their husband had dementia. Their reactions varied in terms of how surprised they felt when the medical provider revealed the husband's diagnosis. Some wives described feeling a multitude of emotions, and a few reflected on how their reactions have changed over time. Only one wife said that she has become more accepting of her husband's diagnosis over time.

Wives' Responses to Husband's Diagnosis

Five of the wives interviewed recalled how difficult it was to hear the doctor say that their husbands had dementia. Rayleigh and Marianna remembered feeling "scared," and Emilia and Eugenia said they felt "devastated." Raisa described "a sinking feeling" after receiving confirmation from the doctor. Magdalena said she felt surprised, sad, and worried. She remembered thinking: "I know what's going to happen." At the same time, three other wives said they were not surprised to learn that their spouses had dementia. Notably, Betty said that finding out was, in some ways, "reassurance that there was an issue, and we would just have to learn how to deal with it." Rayleigh, Raisa, and Marianna recalled that, at some point after

receiving the diagnosis, they decided to take “one day at a time” and not think too much about the future. Lastly, one wife, Eugenia, reported that she became more accepting of the husband’s diagnosis over time, and added, “I have more patience with him now, too.” In contrast, Betty, Emilia, and Marianna said that so far, there were no changes from their initial reactions.

Husbands’ Responses to Diagnosis

The wives also reflected on their husbands’ reactions to receiving a diagnosis of dementia. The interviews revealed that, just like the wives’ reactions to the diagnosis, the husbands’ responses varied significantly. Some of the wives observed that their husbands were not surprised by the diagnosis. Others reported that the husbands did not believe they had dementia. A few wives stated that their husbands had not discussed their reactions to the diagnoses. Lastly, some thought that their husbands did not grasp the implications of being diagnosed with dementia.

A couple of the wives felt that their husbands were not surprised when told that they had dementia. Marianna said, “He just knew that there was something,” and Betty remembered perceiving that her husband was “relieved” to hear his diagnosis. To explain what his condition felt like, Betty’s husband told her, “Trying to do anything in my mind is like stirring cold molasses.” Three wives, Emilia, Estelle and Eugenia, expressed that their spouses didn’t believe they had dementia. For example, Emilia said her husband believed that he is “...just being forgetful;” Estelle’s husband attributed his condition to a concussion injury from his youth; and Eugenia’s husband “blames it on getting older.” Rayleigh, Eugenia, and Raisa reported that their husbands never expressed how they felt about being diagnosed with dementia. Finally, two wives felt that their spouses did not comprehend the implications of having dementia. Rayleigh,

for example, reported that after the diagnosis, her husband often asked her, “Do you think I’ll ever get better?”

Family and Friends’ Responses to Husband’s Diagnosis

The wives also reflected on the responses of friends and family members to hearing the news of their husbands’ diagnoses. They reported the following responses: shock and disbelief (i.e., “never would have thought”), lack of understanding about seriousness of the disease, sympathy due to personal experience with dementia, and an outpouring of unsolicited advice.

A couple of wives said that their family members and friends were “shocked” and completely surprised to hear the news. Raisa explained: “They didn’t believe me, because he compensates very well.” Similarly, Marianna said: “... you can have a conversation with him and not know. I mean, he’s perfectly lucid.” Two wives reported that their friends and family were very sympathetic when they heard the news of the diagnosis. Eugenia explained: “Because most people know, have known someone, either a friend or a relative who’s had dementia.” Raisa said after learning he had dementia, her neighbors started keeping a closer watch on her husband when they saw him alone outside the house.

Two wives spoke of family members and friends who did not understand the implications of the husband’s dementia diagnosis. Rayleigh reflected on a conversation with relatives who did not believe her husband was “as bad” as she was telling them: “But I am here with him all day. I know what’s going on.” On the same note, Magdalena conveyed: “... our social life is almost sad. Because we have a lot of friends who don’t understand.” On the other hand, three wives—Rayleigh, Emilia and Marianna—reported getting a lot of unsolicited advice when they shared the news of the husband’s diagnosis with friends and family members. Rayleigh said:

“The kids were... jumping on me to do this, do that, and all this other stuff.... I didn’t know what way to turn.” Similarly, Emilia complained: “I get everybody giving me advice on what he should be doing, how he should be treated... all of these things, when I’ve been living it every day.” Marianna recalled a conversation with a family member who suggested that she and her husband should move into an assisted living facility, for which, Marianna said, she was not ready.

RQ 1, Theme 2 Summary

In summary, while some wives and husbands were not surprised by the diagnoses, friends and family reportedly experienced a multitude of strong negative emotions such as shock, fear and disbelief. A few wives reported that their husbands had not shared their reactions to their own diagnoses, and some said that their husbands had not grasped the implications of being diagnosed with dementia. The wives reported receiving a similar range of responses from family members and friends: some expressed sympathy due to personal experience with dementia, while others offered unsolicited advice concerning how to best care for the husband.

RQ1, Theme Three: Making Adjustments, Managing Changes

Finally, to explore the meaning that wives gave to cognitive, behavioral, social and physical changes in their husbands living in ESD, the wives were asked to describe how their daily lives had changed since their husbands started experiencing dementia. The wives spoke about common daily struggles and how they utilized medical and social support in dealing with these challenges. They also described a few strategies they found to be helpful in navigating through everyday challenges of living with a husband in ESD. The most commonly reported challenges were meeting their own and husband’s needs, lack of personal stress outlets, and struggling with medical care providers.

Areas of Struggle

Four wives described their concerns about being able to meet their own and their husband's needs. They shared their fears surrounding lack of sufficient care and supervision for the husband in a context of competing demands of daily life. Two wives, for example, spoke about feeling uneasy when leaving their husband at home alone to run errands, and one of them said she recently employed a professional caregiver to stay with her husband when she was out of the house. Similarly, two others expressed a concern over a lack of adequate care for themselves and their husbands in case of their own illness. For example, Raisa said that her spouse got very confused anytime she was sick and "doesn't know what to do." Similarly, Rayleigh expressed: "I get scared that something will happen to me, and then I won't be able to take care of him."

Two wives reported giving up leisure and stress-relieving activities in order to provide more care and supervision for their spouses with dementia. For example, Emilia reportedly made "drastic" change in her lifestyle when her husband started experiencing dementia. While she previously engaged in recreational activities with friends a few nights per week, she had begun going straight home from work every day to be with her husband, who otherwise spent the whole day alone. Likewise, Estelle said that she was no longer able to go on annual vacation trips with her girlfriends because she did not feel it was safe to leave her husband alone for several days.

Another type of struggle, reported by four of the wives, was witnessing incidences when their spouses with dementia were treated poorly by medical care providers. For example, Emilia described an incident when her husband was hospitalized for a blood clot treatment. The medical staff ignored the note on the husband's file about his memory loss, and repeatedly asked

him to compare his past and current pain levels, which he was not able to do accurately. As a result, he kept receiving frequent, large doses of morphine. Emilia said that she “had to make a scene” in order for the medical staff to change their approach. She concluded her story by saying: “Our doctors knew us, but when we were in new medical care settings, we had issues, and I learned to be on high alert and ready to protect him.” Three other wives described similar instances when they perceived that medical providers failed to take their spouses seriously, and one wife, Betty, said that she changed her husband’s doctor as a result of an incident.

Getting Medical Support

Six of the wives in this study reported that, prior to being diagnosed with dementia, they turned to medical care providers for help understanding the changes they were noticing in their husbands. Two wives said that their husbands went for regular physical exams and told their doctor about the changes they were experiencing. Subsequently, the doctors administered or recommended cognitive evaluation. The other four of the wives reported specifically seeking memory testing, either from their primary care physician or a specialist.

Getting Social Support

The wives reported relying on family members, friends, and professionals for support in dealing with their husband’s condition. They spoke about turning primarily to families for advice and emotional support, but also to friends and professionals in the field of dementia care. Four of the wives in this study reported relying on their family members, primarily their children, for comfort, validation, assistance with finding helpful resources, and other types of support (e.g., instrumental, financial, etc.) For example, Rayleigh and Eugenia said that their daughters were highly involved and supportive, and Betty reported that her son and daughter

helped “when asked.” Similarly, Magdalena primarily relied on her children, but said that other family members and friends occasionally provided advice and physical assistance.

Three wives described how they use their friendships as a source of support for dealing with their husbands’ dementia. Two wives stated that they used time with their friends to distract themselves from thinking about their spouses’ dementia. Although they regularly informed their friends about the husband’s condition, they preferred to use time with friends for fun and relaxing conversations and activities. Betty explained: “...we do talk about it, but not in a dependent way.” She said that she sought formal care advice from dementia care providers. Only one wife, Eugenia, said she sought advice on how to best care for her husband equally from friends and professionals. Finally, four of the wives interviewed reported utilizing support groups for advice and validation. It was important to them to share their experiences with others caring for a loved one with dementia.

Navigating the Journey

The wives reported a handful of strategies they found useful in enhancing their own and their husbands’ confidence in living with dementia. They spoke about seeking knowledge, protecting the spouse from others’ judgement, and comparing dementia to other illnesses. They also described their husbands’ efforts to remain independent and helpful throughout a typical day. Five wives emphasized the importance of seeking knowledge to help them understand and deal with the impacts of dementia. They searched for answers on a variety of subjects (basic information about dementia, medical interventions, dietary supplements, emotional coping, home safety, and recreational activities) in books and articles. They sought advice from dementia professionals and others who had similar experiences. One wife said that reading dementia resources helped her understand how her husband’s dementia would progress: “This was just

beginning, and I know as time goes on, it's going to be worse and worse... and what was going to happen in one year or a couple of months. Depends how quickly the sickness is going."

Three wives explained the strategies they have used to protect their husbands from judgement by others. Emilia said that she initially did not tell anybody about the changes that her husband was experiencing. "I didn't want anybody to treat him differently," she recalled. Magdalena said that she purposefully avoided friends who were not understanding of the changes in her husband: "I can't blame these friends, because I think they don't know enough about this sickness." She says she tried to spend more time with friends who were more understanding, "... who are not going to laugh when he starts... saying stuff over and over..." Rayleigh recalled scolding a store clerk who was being rude after her husband asked him a confusing question: "Can you just be a little bit more patient or be a little bit nicer?" Finally, one wife, Marianna said that the best way she had found to relieve some of her husband's fears was to compare his "damaged brain" to other illnesses that some of their friends had: "You know you didn't cause it," she said. "Would you be beating yourself up if you had lost one of your kidneys?"

Finally, five of the wives in this study spoke of their husbands' efforts to remain active and helpful with the responsibilities of daily living. Some of the husbands tried to do the things they had been doing throughout their marriages, while others had taken over tasks that the wives had traditionally done. For example, Betty said: "...now he's doing some of the women's work, because he is trying to take some of the burden off of me."

RQ 1, Theme 3 Summary

In summary, the wives described the day-to-day struggles of living with a husband in ESD. The most commonly reported challenges were concerns over sufficiently meeting their

and their husbands’ needs, a lack of personal stress outlets, and dealing with unsympathetic medical care providers. Most wives reported initially turning to medical providers for help understanding the cognitive changes in their husbands. The wives relied primarily on family members, but also on friends and dementia care professionals for social support. Lastly, they described a few strategies they used to build theirs and their husbands’ confidence and relieve fears of daily living with dementia.

Research Question Two (RQ2) Themes

The second research question was: What are caregiving wives’ perceptions of personhood of their husband in ESD? Two major themes emerged in the analysis: 1) Perceptions of Husband’s Emotional Capacity, and 2) Assessment of Husband’s Personhood – Same or Changed? Table 3 indicates the themes and sub-themes relevant to this research question.

Table 3

Research Question 2 Themes: What are caregiving wives’ perceptions of personhood of their husband in ESD?

Superordinate Theme
Sub-theme
Perceptions of husband’s emotional capacity
Ability to express respect, love and attention towards others
Ability to perceive respect, love and attention from others
Determining emotional capacity is not simple
Assessment of Husband’s Personhood—Same or Changed?
Wife’s assessment of the husband
Husband’s assessment of himself
Family and friends’ assessment of the husband

RQ2, Theme One: Perceptions of husband's emotional capacity

In order to explore caregiving wives' perceptions of their husbands' personhood in ESD, the wives were asked questions about their husbands' emotional capacities. Specifically, they reflected on their spouses' capacity to express and perceive respect, love, and attention when interacting with others. While speaking about their husbands, many wives also described and referred to their observations of others with dementia in respect to these capacities. Most of the wives in this study shared the belief that their husbands and others who have dementia were capable of expressing love, respect, and attention towards others. However, based on their familiarity with multiple people who had dementia, the wives noted that there may be a variability in PWD's individual capacities to express emotions depending on the type of dementia they have and how far along they are in the disease process.

Ability to Express Respect, Love and Attention Towards Others

Five of the wives interviewed felt that their husbands and others with dementia were capable of expressing respect, love, and attention towards others. The particularity in some of the wives' accounts was noteworthy. Rayleigh, for example, reported that her husband had become more affectionate to her since he got dementia. Magdalena noted that her husband's expressions of respect, love and attention were subtle and unique once he had dementia. She said that it was important for caregivers to know the person and be present with the person in order to perceive these expressions. Finally, through her work at a nursing home, Estelle observed that PWD were particularly appreciative and affectionate toward those who treat them well. She said that PWD grew to prefer certain caretakers, although they may have been unable to remember specific details about them (e.g., their name or how they knew them).

Ability to Perceive Respect, Love and Attention from Others

The same five wives believed that PWD were capable of perceiving others' gestures of respect, love and attention. Based on personal observations, Magdalena and Estelle pointed out that PWD were more responsive and affectionate towards caregivers who treat them with kindness and love, even in later stages of the disease. On this note, Emilia described her mother's reactions to family members' affection late in the dementia: "... her eyes would be different, just for a minute or thirty seconds, but you could see in her eyes, she maybe didn't know who you were, but she knew it was different." In essence, the wives expressed that PWD were capable of perceiving how others treated them because they had observed PWD reacting positively to those who treated them well, and negatively to those who mistreated them.

Determining Emotional Capacity is Not Simple

When asked about the emotional capacities of PWD, two other wives interviewed expressed uncertainty. To elaborate, they recalled observing PWD with different functional abilities at various stages of the disease, as well as fluctuations in their abilities from one moment to another. Marianna recalled her mother's battle with dementia toward the end of her life: "... when she couldn't make that connection, the confusion would set in, and it would be hard for her to express the appropriate emotion, I would say." Similarly, Raisa compared her sister-in-law who was more functional, but less emotionally responsive, than her mother who, as a result of a severe stroke, lost her ability to move or speak. Raisa remembered visiting her mother in the last few weeks of life: "It was like death watch almost...but she always knew us."

RQ 2, Theme 1 Summary

While most of the wives stated that they believed their husbands and others with dementia were capable of perceiving and expressing love, respect, and attention, even late in the

disease process, two wives reported feeling uncertain about the presence of these capacities in PWD.

RQ2, Theme Two: Assessment of Husband's Personhood – Same or Changed?

The wives were asked if their husbands had changed since they got dementia, and if so, in what ways. Most wives felt that their husbands had stayed the same person despite the changes brought on by the disease. Simultaneously, most wives felt that others perceived their husbands as changed by dementia, and three of the wives reported that their husbands talked about feeling changed by the disease.

Wife's Assessment of the Husband

Six of the wives felt that the husband had stayed the same person, even though his abilities had changed. When asked what had stayed the same about their husbands, the wives spoke specifically of values, attitudes, personality quirks, and a sense of humor. For example, Emilia said that her husband was equally considerate, showed love for his family, and had the same strong passion for politics. Estelle said that although her husband was less capable of doing things he used to do well, "... he's still the same crazy person he was before... He likes to tease, and all that kind of stuff is the same." Finally, Marianna thought her husband was still the same person: "Because his heart and his thinking about the importance of family, the situation the world is in politically, his attitudes, all of those are the same." Other wives noted the specific abilities, interests and personality traits that had changed since their husbands got dementia. For example, Betty expressed that her husband had become less patient, and Raisa felt that her husband's negative personality traits had been intensified by dementia. Magdalena believed that dementia had affected her husband's personality because he once in a while acted like a

“different” person. Despite these changes, all of these wives felt that their husbands essentially remained the same person.

In contrast, two of the wives felt that their husbands were no longer the same person they were before they got dementia. Eugenia simply explained, “We don’t relate to each other the way we used to anymore.” Rayleigh said that her husband is a different person because “a lot is changing about him, like the things he used to do, and his personality.”

Husband’s Assessment of Himself

Three of the wives revealed that their husbands talked about feeling changed by the disease, and two reported perceiving that their husbands felt diminished due to their condition. Of the three wives who reported that their husbands talked about feeling changed by the disease, two provided specific examples from their husbands’ accounts of how the disease had impacted their functioning. Raisa said that her husband often spoke about his memory loss, confusion getting in the way of doing tasks around the house, and why he could no longer drive a car. Marianna says that her husband talked about increasing difficulties with starting his day, planning activities, and reasoning through problems.

Two wives reported perceiving that their husbands felt diminished as a result of having dementia. Emilia noted a loss of self-confidence in her husband. She said that he looked for her confirmation when he answers questions and was growing more reluctant to engage in conversations in a group setting. Marianna also thought that her husband felt a sense of inadequacy because he was no longer able to remember and do things as well as he used to. She added: “He uses his sense of humor to deal with not being able to remember.”

Family and Friends’ Assessment of the Husband

Most wives reported feeling that others perceived the husband as different, and a few said it depended on how well they know him and what they know about dementia in general. Six wives provided examples of situations when they noticed that others were perceiving their spouse as different or changed by dementia. Rayleigh, for example, observed family members “not being themselves” around her husband: they were more serious and no longer joked around with him. Similarly, Raisa noticed that the cousins were excluding her husband from the conversations at family gatherings. Finally, Emilia said that her children insisted on taking on her husband’s power-of-attorney rights over her.

Two wives reported feeling that others saw the husband as the same person he always was. Betty thought that others viewed him as the same person because he was lucid and able to converse as well as he always did. Marianna also thought that others viewed him in the same way, “because they always talk about the same things that they’ve been talking about for years.” Three wives pointed out that others’ perceptions of their husband depended on how well they knew him throughout his life. Because the changes were subtle, these wives felt that those who did not know their husbands before dementia could not tell if he had changed. Two wives, Magdalena and Marianna, felt that others’ personal knowledge of dementia influenced how they perceived their husbands.

RQ 2, Theme 2 Summary

In summary, most wives felt that their husbands had not changed as a person despite the dementia-related changes they were exhibiting. Interestingly, at the same time, most wives reported feeling that their family members and friends thought of their husbands as different people, mainly because they had observed family members and friends acting differently around the husbands since learning that they had dementia. Finally, three of the wives reported that their

husbands talked about feeling changed by the disease, mostly in terms of not being able to do things as well as they used to.

Research Question Three (RQ3) Themes

The third research question was: What influences caregiving wives' perception of the personhood of their husband in ESD? The analysis related to this question revealed four major themes that point to major influences on the wives' perceptions of their husbands' personhood during ESD: 1) Prior Knowledge of Dementia, 2) Prior Exposure to Dementia Caregiving, 3) Role of Religion, and 4) Wives' Perceptions About the Influence of Resources. Table 4 indicates the themes and sub-themes that are relevant to this research question.

Table 4

Research Question 3 Theme: What influences caregiving wives' perception of the personhood of their husband in ESD?

Superordinate Theme
Sub-theme
Prior knowledge of dementia
What someone with dementia is like
What a person with dementia can and cannot do
Dementia education through work
Prior exposure to dementia caregiving
Knowing other dementia caregivers
Personal prior dementia caregiving experience
Exposure through work or volunteering
Role of religion
Significant to dealing with dementia
Not significant to dealing with dementia
Wives' perceptions about the influence of the resources
What resources taught me
Resources help come to terms with husband's dementia

RQ3, Theme One: Prior Knowledge of Dementia

In order to explore the factors that influenced caregiving wives' perceptions of their husbands' personhood, the wives were asked to think back and describe their knowledge of dementia before their husband had dementia. The wives reflected on what they had thought a person with dementia was like, and what he or she could and could not do. Two wives had previously learned about dementia as part of required work trainings. Specifically, in line with her work at a hospice organization, Marianna took gerontology classes, attended educational seminars and read research articles and books about dementia. Similarly, Raisa learned about dementia in the nursing home where she worked through required trainings and educational seminars.

What Someone with Dementia is Like

All wives in the study, with the exception of one who reported having no previous knowledge of dementia, shared what they knew about PWD before their husbands were diagnosed. All stated they thought that PWD tended to be "forgetful," and two wives also cited confusion as a trait of dementia. Rayleigh recalled observing her mom getting lost and parking her car in unusual locations. On a similar note, Betty observed that PWD could not recognize family members and friends in the later stages of the disease. Emilia, however, indicated that she observed great variations between individuals depending on the stage and type of dementia they had. For example, she pointed out that her mother's "clarity came and went" at various points in the disease process. Finally, Magdalena recalled that her friend's mom needed to be supervised for safety when doing some tasks around the house, such as cooking, washing and ironing clothes.

What a Person with Dementia Can and Cannot Do

Seven wives also reflected on what they previously thought PWD could and could not do as a consequence of the disease. In general, the wives felt that PWD's abilities deteriorated as the disease progressed. Betty noted that in later stages, she observed that PWD could not dress themselves. In comparison, Raisa expressed: "I thought they were suddenly very incoherent and unable to do things for themselves, highly dependent and wandering." Finally, three of the wives had believed that PWD could not properly do some more complex daily tasks such as manage finances, take medications, drive, and cook.

Dementia Education Through Work

Two wives reported having prior dementia education. Specifically, in line with her work at the hospice organization, Marianna took gerontology classes, attended educational seminars and read research articles and books about dementia. Similarly, Raisa learned about dementia in the nursing home where she worked, through required trainings and educational seminars.

RQ 3, Theme 1 Summary

The wives reflected on their knowledge about PWD and their abilities prior to the onset of the disease in their husbands. The wives reported thinking that PWD had memory issues, confusion, and that they lost functional abilities as their disease progresses. Lastly, two wives reported having previous dementia education and knowledge from their work at aging care organizations.

RQ3, Theme Two: Prior Exposure to Dementia Caregiving

The wives were asked to describe what they had known about caring for someone with dementia before their husband had the disease. Half of the wives interviewed had previously known people who provided care to PWD. Two of the wives also personally cared for another

family member with dementia before their husbands developed dementia. Finally, a couple of wives reported caring for PWD as part of their professions.

Knowing Other Dementia Caregivers

Four wives in this study reported initially learning about dementia through the experiences of other caregivers. Two wives, Betty and Magdalena, had girlfriends who shared their experiences of caring for mothers with dementia. One wife, Raisa, had two relatives who were dementia caregivers for someone in their family. Emilia said that a few of her friends at work talked about their dementia caregiving experiences.

Personal Prior Dementia Caregiving Experience

Two of the wives who knew other dementia caregivers also reported prior personal caregiving experience; both women had cared for their mothers who had dementia.

Exposure Through Work or Volunteering

Two wives reported caring for PWD through work at the aging care organizations, and one of the wives volunteered at a nursing home where she interacted with individuals living with dementia.

RQ 3, Theme 2 Summary

Half of the wives who participated in this study knew someone who provided care to a person with dementia, usually a family member. Two of the four wives also cared for their mothers with dementia. A couple of wives reported caring for individuals with dementia as part of their work roles, and one of these wives interacted with PWD through a volunteer position at a nursing home facility.

RQ3, Theme Three: Role of Religion

The wives were asked to speak about the role that religion played in their current daily lives. All but one wife reported that religion was important and helpful to them.

Significant to Dealing with Dementia

Four of the wives said that attending church events was an important part of their lifestyle as a couple because it was an opportunity to interact with friends and family. For example, Estelle said that she and her husband still taught Sunday School as they had done for many years prior to husband's onset of dementia. Another wife, Betty, said that she and her husband did not belong to a particular church, but did believe in God and relied on their spirituality to cope with dementia. Two wives, Eugenia and Estelle, said that their faith helped them get through their daily life after the onset of their husbands' dementia. Eugenia said that religion helped her and her husband to cope by helping them be more patient and understanding. Estelle said that she relied on God to help her through this experience with her husband: "God uses rough situations in your life to draw you close to him because you can't go through them without him." Finally, two wives, Emilia and Estelle, stated that church was a major support resource for them at this time. Emilia said that attending church services was a way for her and her husband to gain psychological and emotional strength needed to carry on. Eugenia said that she had a personal relationship with the priest whose mother died of dementia, and that she regularly shared her experience with, and sought advice from, him.

Not Significant to Dealing with Dementia

Only one wife, Marianna, said that religion did not play a part in her and her husband's life. She said that she relied on her social network and professionals for support in dealing with her husband's condition.

RQ 3, Theme 3 Summary

Aside from one participant, all the wives in this study reported that religion played a significant positive role in their current daily lives, either as component of their lifestyles as a couple, or as a coping and supportive resource for dealing with dementia.

RQ3, Theme Four: Wives' Perceptions About the Influence of the Resources

Finally, in order to explore what influences caregiving wives' perception of the personhood of their husband in the early stage of dementia, the wives were asked to speak about how the resources that they have been using help them in dealing with the husband's condition.

What Resources Taught Me

Four wives discussed what they learned about dementia through the support groups, by reading educational resources and by knowing multiple people with dementia. Rayleigh pointed out that reading about dementia helped her recognize what her husband was going through in terms of the impact of the disease on his brain. Emilia said that online resources helped her understand and proactively address challenging behaviors, rather than being frightened about them. Similarly, Marianna learned how to deal with her husband's bad moments, how to talk to his doctors, and how to care for herself.

Magdalena said that previously knowing others with dementia helped her recognize that her husband had dementia and helped her know what to expect as the disease progressed.

Finally, Emilia said that the most important thing she learned from observing multiple people with dementia is that dementia did not have to progress in a fixed way. She ended the interview by saying:

I know that there will be changes in his personality as we go along. I expect there will be changes in what he can do and how much independence I can let him have. I know that it is very likely that there will come a time when it may be very difficult for me to physically be able to care for him even though that's what I

really got my heart committed to... There's no one thing that I know for sure about what will happen to him. I know it won't get better.

Resources Help Come to Terms with Husband's Dementia

Two wives reported that learning from other family caregivers, dementia professionals, and reading resources had helped them come to terms with their husbands' condition. Emilia, for example, recalled: "I think it's helped me not to panic about things or not to be, kind of, exaggerating things, learning that everybody has a bad day. I just think it's helped me to be calmer and to help him feel comfortable... [To make sure] That he's not being judged, that he's not being criticized or whatever. That we just make adaptations as we need to." Similarly, Eugenia said that studying dementia resources helped her feel less overwhelmed: "... Reading about the symptoms of dementia and the stages of it helps a lot for me to understand what he's going through and how I need to deal with it."

Impact of Supportive Professionals

Three wives described the important roles that supportive professionals played in their experience of living with a husband who has dementia. Emilia said that her husband's primary care physician and dentist wrote her notes if she was not able to attend his appointments, which helped her stay in control of her husband's care. Moreover, her work colleagues advised her about relevant resources in the community. Similarly, Magdalena said that her husband's caseworker facilitated communication with the medical providers, answered questions, and suggested resources. Lastly, Marianna said that her husband's dementia specialist's extensive knowledge, understanding of the disease, and compassionate attitude supported her and boosted her husband's confidence in living with dementia. Marianna described visits to her husband's dementia specialist:

Oh, it was the way she responded to him. And the questions that she asked him, and it was just the way she saw him as the person that he was without even knowing who he was. She knew that, she sensed that, and I think she sensed it. She had some history of his work in the past and his life. It was almost-- I don't know that there are actually words to describe it, it was the way she-- her quietness, the way she looked at him. The information that she had, and she knew where that information was. Do you know how you go to the doctor and you fill out all this paperwork and you get the feeling that nobody ever looked at it?

Interviewer: Yeah.

Marianna: Well, she had looked at it. And not only has she looked at it, but she had it in a binder folder marked and had access to it immediately without sounding like a statistician or whatever. But it was her personal connection, it wasn't just the eye contact, it wasn't that we were seated all on the same level. It was almost a non-verbal connection...by her having factual information to support where she was going with what she was saying. I know I'm being vague.

Interviewer: No, I understand.

Marianna: But it was such an incredible relief to go to see her, to spend 45 minutes with her and to leave and feel somebody really understands us.

RQ 3, Theme 4 Summary

The wives described what they learned from educational resources, support groups, and other cases of dementia, and how these resources helped them in dealing with their husbands' dementia. Finally, the wives acknowledged the caring and sympathetic professionals who go above and beyond to support them and their spouses on the journey through dementia.

Summary of the Chapter

This chapter presented the data discovered using interpretive phenomenological analysis in order to understand eight wives' perceptions of personhood in their husbands, all of whom were in ESD. These wives were interviewed in order to better understand the experience of having a husband recently diagnosed with dementia. A 3-phase interview process encouraged an exploration of the wives' experiences in the broader context of their lives, along with deeper

reflections on the meaning of their experiences. During the analysis of these interviews, nine major themes emerged under the three research questions of this study:

1. Research Question 1: What meaning do caregiving wives give to the cognitive, behavioral, social and physical changes in their husbands in ESD?
 - Noticing Changes in Functioning
 - Responses to Diagnosis
 - Making Adjustments, Managing Changes
2. Research Question 2: What are caregiving wives' perceptions of personhood of their husband in ESD?
 - Perceptions of Husband's Emotional Capacity
 - Assessment of Husband's Personhood – Same or Changed?
3. Research Question 3: What factors influence caregiving wives' perceptions of their husbands' personhood in ESD?
 - Prior Knowledge of Dementia
 - Prior Exposure to Dementia Caregiving
 - Role of Religion
 - Wives' Perceptions About the Influence of the Resources

CHAPTER 5: DISCUSSION

Introduction

This chapter presents a discussion of the major themes drawn from the data presented in Chapter 4. It also offers recommendations for future research, discusses implications of this study's findings for practice, and finally, outlines the conclusions reached by the researcher.

This section of the chapter connects this study's results to its conceptual framework and related literature. This section discusses the major themes that emerged from analyzing the interviews with this study's eight wives, and then discusses the core research questions. The themes are discussed in the order in which they were presented in Chapter 4 and are grouped beneath their corresponding research questions.

To maximize support for couples living with dementia, it is necessary to understand how caregiving spouses perceive the personhood of their significant others who have this disease. This study is based on a framework which draws on Park's (2010) theory of meaning-making processes, and on Kelly and Field's (1996; 1998) work on identity in chronic illness and social interactionism theory. The conceptual model proposes that the dominating social views of people with dementia influence meaning that caregiving spouses ascribe to the progressive cognitive, behavioral, social and physical changes in their partners, and consequently, how they perceive the personhood of their spouses with dementia. The purpose of this phenomenological study was to understand how caregiving wives perceive the personhood of their husbands in the early stage of dementia, and what factors influence these perceptions. Personhood is defined as "a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust" (Kitwood, 1997).

Discussion of Themes

Themes related to RQ1: What meaning do caregiving wives give to the cognitive, behavioral, social and physical changes in their husbands in ESD?

As previous studies have also demonstrated, the wives in this study noticed changes in their husbands' behavior and daily functioning prior to dementia diagnoses (Adams, 2006; Brown & Alligood, 2004; Leung et al., 2011). Initially, the wives attributed these changes to the aging process. This is similar to what Molyneaux et al. (2012) found in their study on how spouses work to maintain identity as a couple when one of them gets dementia. Furthermore, in agreement with studies by Brown and Alligood (2004) and Krull (2005), this study found that couples started to seek medical help once memory loss, confusion and other dementia-related symptoms became more frequent and began interfering with the affected person's normal daily functioning.

With the worsening of the symptoms following dementia diagnoses, some wives reported using strategies to support their husband's daily functioning. This trend was consistent with previous research that showed how caregiving partners supporting existing competencies of their spouses with dementia (Perry & O' Connor, 2018). Moreover, following the diagnosis of dementia, some wives in this study reported that their husbands were prescribed medication which helped manage dementia-related memory loss, restlessness, anxiety and depression. This finding was not surprising, as a variety of medications are frequently prescribed to treat dementia symptoms (Medications for Memory Loss, 2019; Wang, Brookhart, Setoguchi, Patrick, & Schneeweiss, 2006). Like the caregiving spouses in other dementia caregiving studies, the wives in this study also reported changes in their marriages and social lives. These changes included

taking on more personal responsibility and experiencing role-switching in the relationship (Calasanti & Bowen, 2006; Hellstrom et al., 2007; Molyneaux et al., 2011).

Most wives in this study said that they informed their friends and family of their husbands' dementia; only a couple of them chose not to share the diagnoses in order to "keep things the same" for them and their partners. A study by Hellstrom et al. (2005a) found that couples living with dementia purposely controlled how much information about the spouse's condition they shared with others in order to protect the spouse with dementia and the integrity of the relationship.

Most wives in this study reported that it was very difficult to hear that their husband had dementia, and a few reported that they were not surprised. Vernooij-Dassen, Derksen, Scheltens, and Moniz-Cook (2006) found similar responses in their sample of eighteen couples interviewed within weeks after one of the spouses was diagnosed with dementia. Vernooij-Dassen et al. (2006) also found that those who did not expect the dementia diagnosis felt shocked and threatened, while most experienced the diagnosis as a confirmation of their suspicions.

The current study is novel because it explores spousal caregivers' perceptions of PWD's reactions to diagnoses. While some husbands in this study were surprised by their diagnoses, and others were not, it is significant that a few did not discuss their reactions with the wives. A couple of wives felt that their husbands did not grasp the implications of being diagnosed with dementia. It is imperative that future research examines PWD's reactions to their diagnoses in light of previous findings that couples often lack appropriate support following a diagnosis of dementia. Insufficient support can lead to difficulty in dealing with the diagnosis (Pesonen et al., 2013; Robinson et al., 2005; Stokes et al., 2012), and the emotional reactions to the dementia diagnosis are insufficiently explored in the dementia literature (Halpin, Dillard & Puentes, 2017).

The current study is also novel because it examines caregiving wives' perceptions of others' reactions to their spouses' diagnoses. Wives perceived mostly disbelief and lack of understanding in family members and friends' reactions to their husbands' diagnoses. This finding warrants further research examination of the perceptions of personhood in dementia.

Research on family caregivers' adjustments to the onset of dementia is limited. The wives in this study described the day-to-day struggles of living with a husband in ESD. Commonly cited struggles included concerns over sufficiently meeting their and their husband's daily needs, a lack of personal stress outlets, and dealing with unsympathetic medical care providers. In a qualitative phenomenological study with twenty family caregivers, the majority of whom were spouses, Adams (2006) found that caregivers experienced negative feelings after the loved ones' onset of dementia, specifically frustration, resentment towards the care-receiver, grief, and relational deprivation, along with increased protectiveness towards PWD. Most wives reported initially turning to medical providers for help with understanding the cognitive changes in their husbands, analogous to what family caregivers in Adams' study reported (2006).

Consistent with the findings in Adams' (2006) work on transitions to dementia caregiving, the wives in this study reported relying primarily on family members, but also on friends and dementia care professionals for social support. Unlike the caregivers in the current study, participants in Adams's (2006) study reported some reluctance to utilize social support because they did not want to burden to others. Adams (2006) also reported that caregivers in her study reported getting "unhelpful" advice from others; similarly, some participants in the current study also received "unsolicited advice" from family members and friends.

Some of the wives in the current study were concerned with protecting their spouses from others' judgement. This was also noted by Perry and O'Connor (2002) in their study on how

spouses work to protect their loved ones' personhood when they get dementia. A novel strategy described by one of the wives in the current study was that of comparing her husband's dementia to other illnesses in order to relieve his and her negative feelings about dementia.

Themes related to RQ2: What are caregiving wives' perceptions of personhood of their husband in ESD?

No previous studies have explored caregivers' perceptions of PWD's emotional capacities. Drawing on their previous knowledge and experience with people with dementia, most of the wives in this study believed that their husbands and others with dementia were capable of perceiving and expressing love, respect, and attention, even late in the disease process. Given the pervasiveness of dementia, it is not surprising that many wives formed these views from previous knowledge or even personal dementia caregiving experience (2018 Alzheimer's Disease Facts and Figures, 2018). In an earlier study that explored how family members and formal caregivers understand awareness abilities of PWD in the late stages of dementia, Quinn, Clare, Jelley, Bruce, and Woods (2013), found that family members believed that a PWD's awareness depended on whether the PWD could respond to his/her name being called (i.e., recognize self), and whether the PWD could recognizing familiar people. This finding is consistent with what a couple of wives said in the current study: they based their beliefs about their loved ones' emotional capacities on whether they recognized familiar people or how they responded to family members. Moreover, consistent with the findings of Quinn et al. (2013), one of the wives in this study believed that the ability to perceive a PWD's emotional capacity is dependent on how well the caregiver can read the person's subtle gestures.

Two wives in this study reported feeling uncertain about the presence of the emotional capacities in PWD. This is not surprising, as dementia can exhibit differently depending on the

type and stage of disease process, and its symptoms can fluctuate within and between cases (2018 Alzheimer's Disease Facts and Figures, 2018). Quinn et al. (2013) also reported that some family members felt that PWD's awareness fluctuated over time.

Most wives felt that their husbands had not changed as a person despite the dementia symptoms they were exhibiting. Although no previous research has specifically examined whether spouses perceived that a PWD had changed as a person due to dementia, the small number of related studies reported that spouses made adjustments to support their partners' deteriorating abilities as the disease progressed in order to help maintain their identity or personhood (Calasanti & Bowen, 2006; Hellström et al., 2007; Hellström et al., 2005a; Molyneaux et al., 2012; Perry & O'Connor, 2002).

Three of the wives reported that their husbands talked about feeling changed by the disease, mostly in terms of not being able to do things as well as they used to. In Adams's (2006) study of family members of PWD (most of whom were spouses), the caregivers reported that PWD in the early stages of the disease were aware of their dementia-related changes. Like the husbands in the current study, PWD in Adams's (2006) study also made efforts to stay involved in daily activities.

Interestingly, while most wives reported believing that their husband had not changed, they also reported perceiving that family members and friends thought of the husband as a different person. No previous, relevant research exists that may help to understand this finding. However, based on the current study's conceptual framework, it can be speculated that others may be relying on the dominant social perceptions of "what PWD are like" and perceiving the husbands with dementia in this study as strongly and negatively impacted by the disease.

Themes related to RQ3: What influences caregiving wives' perception of the personhood of their partners in the early stage of dementia?

The wives in this study reported knowing others with dementia before their husbands were diagnosed with the disease, and some of them reported previously learning about the disease as part of their mandatory work education. Given that 6.7 million Americans are currently living with this disease, it comes as no surprise that most of the wives in this study knew someone who had dementia before their husbands were diagnosed. A couple of wives in the current study reported that prior to caring for their husbands in ESD, they had cared for someone with dementia (e. g., in the family, through work, volunteering). Half of the wives reported knowing others who cared for someone with dementia. There are no studies in the literature on dementia and family caregiving that address multiple dementia caregiving experiences. Consequently, further exploration of this topic might be worthwhile.

All but one wife in this study reported that religion played a significant positive role in their current daily lives as a component of the couple's lifestyle or as a supportive resource. Research has demonstrated that religion plays an important role in helping families cope with dementia (Snyder, 1999; Stolley, Buckwalter, & Koenig, 1999; Stuckey, 2001). Stuckey (2001) found that family caregivers of PWD used religion to make sense of their stressful situations. Likewise, in a small IPA study of six persons living with mild to moderate dementia, Dalby et al. (2012) found that faith played an important role in lives of the participants. Most PWD in their study reported engaging in religious practices, spiritual community, and maintained spiritual values and attitudes.

The wives in the study reported that educational resources helped them understand the disease process, the impact on their husbands, how to proactively address the "challenging

behaviors” that can occur in dementia, how to talk to medical professionals about dementia, and how to care for themselves. Given that personhood in dementia is relatively unexplored, it is not surprising that resources for supporting the personhood of PWD are lacking. A simple online search for resources geared toward family members of PWD revealed that most educational materials were based on biomedical perspectives of dementia and care strategies that targeted symptom management. Indeed, the wives in this study reported finding resources that described the effects of dementia on the brain, why symptoms occur, and how to manage symptoms. Given the lack of readily available resources on supporting the personhood of PWD, it is not surprising that the wives reported only learning about the biological origins of the disease symptoms but had not learned about care of personhood for PWD.

A few wives in this study reported that they received a great deal of support from dementia care professionals, social workers and medical providers. This finding is (pleasantly) surprising, considering the fact that existing research suggests that couples often lack pertinent information and continued support following a diagnosis of dementia (Pesonen et al., 2013; Robinson et al., 2005; Stokes et al., 2012).

Overall Summary

This study’s findings support the notion suggested by the conceptual framework that caregiving wives will attempt to make meaning of their husbands’ dementia symptoms. The wives spoke about initially attributing their husbands’ cognitive changes to normal changes due to aging. However, once the changes began interfering with their husbands’ daily functioning, the wives went in the search of answers by turning to medical providers and educational resources. They also reported drawing on previous knowledge and experiences with people who had dementia. No other studies have explored caregiving spouses’ (or any other caregivers’)

meaning-making processes in response to the onset of dementia in a loved one. Also, no other studies have explored meaning-making among family caregivers within the context of personhood. Because research on personhood in dementia is in its early stages, the lack of pertinent studies is not entirely surprising.

No previous studies have explored how caregiving spouses perceive the personhood of a loved one in the early stages of dementia. A subset of family caregiving studies explored the lived experience of couples with dementia, and found that couples made adjustments in their lifestyle, roles and long-held routines to sustain identities or the personhood of the spouse with dementia, as well as their identity as a couple (Calasanti & Bowen, 2006; Hellström et al., 2007; Hellstrom et al., 2005a; Molyneaux et al., 2012; Perry & O'Connor, 2002). However, none of these studies asked about the spouses' perceptions of the personhood of their partners with dementia.

The current study found that most wives felt that their husbands did not change in terms of personhood despite the effects of early stage dementia. Also, most of the wives believed that their husbands and others with dementia (even in the late stages of the disease) had emotional capacities and were capable of perceiving and expressing emotions such as love, respect and attention. It is important to note that a couple of wives believed that there may be variability in PWD's individual capacities to express these emotions depending on the type of dementia they have and how far along they are in the disease process. Furthermore, most wives perceived that their family members and friends thought of their husbands as different people, mainly because they had observed family members and friends acting differently around their husbands after learning he had dementia. Last, three of the wives reported that their husbands talked about

feeling changed by the disease, mostly in terms of not being able to do things as well as they used to.

Two earlier studies explored how family caregivers (some of whom were spouses) viewed their loved ones' personhood or identity when they had dementia. In a palliative care study with family members of persons with advanced dementia, Kaldjian et al. (2010) found that more than two thirds of responders felt that dementia had not reduced their loved ones' dignity, value as human beings, or the respect they received from others. The majority of these family members expressed believing that their loved ones with dementia had value and purpose despite their very advanced dementia-related decline. Additionally, Purves (2011) found that family members spoke about their elderly relative with dementia in terms of her long-standing roles (e.g., wife, mother), and in terms of her new role as PWDs. These two studies demonstrated that family members contemplated the impact of dementia on their loved ones' identity or personhood; they can therefore serve as a resource for how personhood is viewed in dementia.

The findings of the current study suggest that caregiving wives will use the information from their social environment about "what people with dementia are like" to construct understandings of their husbands' capacities, abilities, behaviors and needs. The wives in the current study reported relying on previous knowledge of dementia (i.e., knowing others who had dementia before their husband was diagnosed), theirs and others' dementia caregiving experience, religion, and educational family caregiving resources to help them understand their experience of having a husband with dementia. No other research studies have explored what information family caregivers rely on in order to make sense of the cognitive, behavioral, social and physical changes in their loved ones. Also, no other studies have explored what influences caregivers' perceptions of personhood of the individuals living with dementia.

Limitations

This study had two major limitations: a small sample size, and selection of participants from a support group in a small geographic region. Instead of attempting to produce an objective understanding of the phenomenon, the goal of the study was to explore and describe perceptions of a group of wives about the personhood of their husbands with dementia, and the meanings they assigned to the dementia-related cognitive, behavioral, social and physical changes in their spouses. In order to successfully capture and communicate the meanings that individual caregivers ascribed to their experience, IPA demands a small sample size (Smith et al., 2009).

Also, as stated earlier, the participants for this study were recruited from the family support group at the local chapter of the Alzheimer's Association in Southington, Connecticut. The support group attendants are a small minority of those caring for PWD, and therefore could not be considered representative of the larger population, as they chose to seek and engage in formal social support programs. However, the decision was made to focus on support group attendants only, as the goal of the study was to recruit participants who acknowledged that they are caregivers. Also it would have been difficult to account for too many differences among participants at the analysis phase of the study. Finally, as an additional measure of caution, the claims made by this study were limited to this particular sample of participants without attempting to overgeneralize to other populations of dementia caregivers.

Future Research

Because there is presently no cure for dementia, further research is needed in order to create better support for caregiving families and persons living with dementia. It is necessary to advance understanding of how families perceive and support the personhood of their loved ones at various stages of the disease, and what factors influence their perceptions. Because of the

known differences in how men and women approach caregiving, the researcher recommends comparative qualitative studies that examine perceptions of personhood among caregiving husbands and wives (Bédard et al., 2005; Calasanti, 2010). Moreover, as described in the earlier chapters, only wives were interviewed in the current study, as a majority of the dementia caregivers are women. As a note of caution, it might be important to consider that there may be differences in how caregiving husbands and wives perceive personhood of their spouse living with dementia. Future research may provide valuable insight into gender differences in perceptions of personhood of men and women living with dementia.

Similarly, to further the understanding of personhood in dementia, exploring and comparing perceptions of caregiving spouses and children could be beneficial, as these two types of family members are the most frequent caregivers for PWD. Using many of the current study's questions in future research endeavors could be intriguing and helpful. Likewise, a deeper exploration of the study's questions could provide richer, more holistic insights into the concepts examined in this study.

The nine themes that emerged in the current study offer prospects for future research by offering a greater understanding about the persistence of personhood in dementia. For example, exploring why caregiving wives perceive that others see their husbands as changed by the disease, while they saw their husbands as still the same, may offer valuable insights about various threats and opportunities for the sustenance of personhood in dementia.

Lastly, conducting dyadic analysis, expanding the current study to include both members of the couple while asking many of the same questions would add PWD's precious perspectives on their own personhood and lived experience of ESD. Both spouses are involved in processes of maintaining the marriage relationship and the personhood of a spouse with dementia

(Hellström et al., 2007; Hellstrom et al., 2005a; Molyneaux et al., 2012). A longitudinal design might be appropriate if such research opportunities are pursued over time to allow for a deep and rich exploration of couples' lived experiences. A longitudinal research study could explore more specifically how perceptions of personhood change as the disease progresses beyond ESD.

Implications for Practice

A major goal of conducting research is to provide sound recommendations for practice. This phenomenological study examined the lived experience of couples dealing with ESD. It highlighted the need for resources (e.g., education, empowerment, etc.) of couples impacted by early stage dementia. Specifically, there is an urgent need to develop resources that help families support the personhood of PWD. A few religious and philosophical essays describe the value of PWD despite their cognitive losses and argue for collective responsibility to improve the treatment of PWD (Coleman, 2009; Hughes et al., 2006; Swinton, 2007). These perspectives should be developed into support interventions for families living with dementia, and perhaps could be carried out by professionals in the roles of chaplains.

Finally, as the prevalence of dementia rises in the United States and worldwide, this study provides insights regarding the challenges that some caregiving spouses face early in the disease process. Some of the wives in the study reported that they felt devastated by the news of the husband's diagnosis, and their reaction had not changed over time. These women, and many others like them, could benefit from formal support services, such as counseling, to help them cope with their loved ones' diagnoses and to deal with other challenges surrounding their loved ones' diseases. Reflecting on the findings of this study and their implications for dementia care will hopefully result in greater support of couples coping with dementia, especially with respect to creating resources that help support the personhood of PWD. In a recently published article,

Faux advocates for stronger involvement of medical providers in preserving personal autonomy and rights to make decisions amongst the population of patients with cognitive decline, such as dementia (2019).

Conclusion

Supporting personhood can lead to a better quality of life for those affected by dementia. The notion that poor care practices worsen the outcome of the disease has been echoing through the field of dementia caregiving research for some time now (Doyle & Rubinstein, 2014; Hughes et al., 2006; Kitwood, 1997; McNess, 2017; O'Connor et al., 2007; Swinton, 2007; Wellin & Jaffe, 2004). Integrating the findings of the current study about wives' perceptions of the personhood of their husbands in ESD might enrich understanding of how PWD's personhood is threatened in the early phase of the disease. This study, as well as future research like it, can help the development of much needed family education and resources geared toward supporting the personhood of those living with dementia.

REFERENCES

- “2018 Alzheimer’s Disease Facts and Figures” (2018). Retrieved December 5, 2018, from http://www.alz.org/downloads/facts_figures_2018.pdf
- Adams, K. (2006). The transition to caregiving: The experience of family members embarking on the dementia caregiving career. *Journal of Gerontological Social Work*, 47(3-4), 3-29.
- Arai, Y., Zarit, S. H., Sugiura, M., & Washio, M. (2002). Patterns of outcome of caregiving for the impaired elderly: A longitudinal study in rural Japan. *Aging & Mental Health*, 6(1), 39-46.
- Armari, E., Jarmolowicz, A., & Panegyres, P. K. (2013). The needs of patients with early onset dementia. *American Journal of Alzheimer's Disease and Other Dementias*, 28(1), 42-46.
- Bauer, M. J., Maddox, M. K., Kirk, L. N., Burns, T., & Kuskowski, M. A. (2001). Progressive dementia: Personal and relational impact on caregiving wives. *American Journal of Alzheimer's Disease and Other Dementias*, 16(6), 329-334.
- Bédard, M., Kuzik, R., Chambers, L., Molloy, D. W., Dubois, S., & Lever, J. A. (2005). Understanding burden differences between men and women caregivers: The contribution of care-recipient problem behaviors. *International Psychogeriatrics*, 17(1), 99-118.
- Bowen, G. (2008). Naturalistic inquiry and the saturation concept: a research note. *Qualitative Research*, 8(1), pp.137–152.
- Brown, J., & Alligood, M. (2004). Realizing wrongness: Stories of older wife caregivers. *Journal of Applied Gerontology*, 23(2), 104-119.
- Bryden, C. (2002). A person-centered approach to counselling, psychotherapy and rehabilitation of people diagnosed with dementia in the early stages. *Dementia*, 1(2), 141-156.

- Burack, O. R., Weiner, A. S., & Reinhardt, J. P. (2012). The impact of culture change on elders' behavioral symptoms: A longitudinal study. *Journal of the American Medical Directors Association*, 13(6), 522.
- Buron, B. (2008). Levels of personhood: A model for dementia care. *Geriatric Nursing*, 29(5), 324-332.
- Calasanti, T., & Bowen, M. E. (2006). Spousal caregiving and crossing gender boundaries: Maintaining gendered identities. *Journal of Aging Studies*, 20(3), 253-263.
- Calasanti, T. (2010). Gender relations and applied research on aging. *The Gerontologist*, 50(6), 720-734.
- Chenoweth, L., King, M., Jeon, Y., Brodaty, H., Stein-Parbury, J., Norman, R. , ... Luscombe, G. (2009). Caring for aged Dementia Care Resident Study (CADRES) of person-centered care, dementia-care mapping, and usual care in dementia: A cluster-randomized trial. *Lancet Neurology*, 8, 317–325.
- Clare, L. (2003). Managing threats to self: Awareness in early stage Alzheimer's disease. *Social Science and Medicine*, 57, 1017 – 1029.
- Coleman, P. G. (2009). Ageing and personhood in twenty-first century Europe: A challenge to religion. *International Journal of Public Theology*, 3(1), 63-77.
- Creswell, J. W. (2009). *Research design: Qualitative, quantitative, and mixed methods approaches* (3rd ed.). Thousand Oaks, CA: Sage Publications, Inc.
- Dalby, P., Sperlinger, D., & Boddington, S. (2012). The lived experience of spirituality and dementia in older people living with mild to moderate dementia. *Dementia*, 11(1), 75-94.
- Davies, J. C. (2011). Preserving the “us identity” through marriage commitment while living with early-stage dementia. *Dementia*, 10(2), 217-234.

- Doyle, P. J., & Rubinstein, R. L. (2014). Person-centered dementia care and the cultural matrix of othering. *The Gerontologist*, 54(6), 952.
- Doyle, P., Rubinstein, R., & Medeiros, K. (2015). Generative acts of people with dementia in a long-term care setting. *Dementia*, 14(4), 409-417.
- Ducharme, F., Lévesque, L., Lachance, L., Kergoat, M., & Coulombe, R. (2011). Challenges associated with transition to caregiver role following diagnostic disclosure of Alzheimer disease: A descriptive study. *International Journal of Nursing Studies*, 48(9), 1109-1119.
- Engebretson, J. (2013). Understanding stigma in chronic health conditions: Implications for nursing. *Journal of the American Association of Nurse Practitioners*, 25(10), 545-550.
- Farran, C. J. (1997). Theoretical perspectives concerning positive aspects of caring for elderly PWD: Stress/adaptation and existentialism. *The Gerontologist*, 37(2), 250-256.
- Faux, B. (2019). Innovative methods to preserve autonomy in patients with cognitive decline. *Today's Geriatric Medicine*, 10(2), 16.
- Fazio, S., & Mitchell, D. (2009). Persistence of self in individuals with Alzheimer's disease: Evidence from language and visual recognition. *Dementia*, 8(1), 39-59.
- Fisher, G. G., Franks, M. M., Plassman, B. L., Brown, S. L., Potter, G. G., Llewellyn, D., ... Langa, K. M. (2011). Caring for individuals with dementia and cognitive impairment, not dementia: Findings from the aging, demographics, and memory study. *Journal of the American Geriatrics Society*, 59(3), 488-494.
- Gillies, B. (2011). Continuity and loss: The career's journey through dementia. *Dementia*, 11(5), 657-676.
- Groenewald, T. (2004). A phenomenological research design illustrated. *International Journal of Qualitative Methods*, 3(1), 42-55.

- Halpin, S. N., Dillard, R. L. & Puentes, W. J. (2017). Socio – Emotional Adaptation Theory: Charting the Emotional Process of Alzheimer’s Disease. *The Gerontologist*, 57(4), 696-706.
- Harding, R., Gao, W., Jackson, D., Pearson, C., Murray, J. & Higginson, I. J. (2015). Comparative analysis of informal caregiver burden in advanced cancer, dementia, and acquired brain injury. *Journal of Pain and Symptom Management*, 50(4), 445-452.
- Harre, R., & Van Langenhove, L. (1991). Varieties of positioning. *Journal of the Theory of Social Behavior*, 21(4), 393-407.
- Harris, P. B. (2002). *The person with Alzheimer’s disease: Pathways to understanding the experience*. Baltimore, MD: The John Hopkins University Press.
- Hayes, J., Boylstein, C., & Zimmerman, M. K. (2009). Living and loving with dementia: Negotiating spousal and caregiver identity through narrative. *Journal of Aging Studies*, 23(1), 48-59.
- Hellström, I., Nolan, M., & Lundh, U. (2007). Sustaining ‘couplehood:’ Spouses' strategies for living positively with dementia. *Dementia*, 6(3), 383-409.
- Hellstrom, I., Nolan, M., & Lundh, U. (2005a). Awareness context theory and the dynamics of dementia: Improving understanding using emergent fit. *Dementia*, 4(2), 269-295.
- Hellström, I., Nolan, M., & Lundh, U. (2005b). We do things together: A case study of 'couplehood' in dementia. *Dementia*, 4(1), 7-22.
- Hillson, R. (2014). Embarrassing diabetes. *Practical Diabetes*, 31(8), 313-314.
- Hughes, J. C., Louw, S. J., & Sabat, S. R. (Eds.) (2006). *Dementia: Mind, meaning and the person*. Oxford, UK: Oxford University Press.

- Johnston, B., Lawton, S., & Pringle, J. (2017). 'This is my story, how I remember it': In-depth analysis of Dignity Therapy documents from a study of Dignity Therapy for people with early stage dementia. *Dementia, 16*(5), 543-555.
- Kaldjian, L. C., Shinkunas, L. A., Bern-Klug, M., & Schultz, S. K. (2010). Dementia, goals of care, and personhood: A study of surrogate decision makers' beliefs and values. *The American Journal of Hospice & Palliative Care, 27*(6), 387-397.
- Katzman, R. (1976). A prevalence and malignancy of Alzheimer's disease: A major killer. *Archives of Neurology, 33*(4), 217-218.
- Kaufmann, E., & Engel, S. (2016). Dementia and well-being: A conceptual framework based on Tom Kitwood's model of needs. *Dementia, 15*(4), 774-788.
- Kelly, M. P. & Field, D. (1998). Conceptualizing chronic illness. In D. Field and S. Taylor (Eds.), *Sociological perspectives on health, illness and healthcare*. Oxford, UK: Blackwell.
- Kelly, M. P., & Field, D. (1996). Medical sociology, chronic illness, and the body. *Sociology of Health and Illness, 18*(2), 241-257.
- Kim, H., Chang, M., Rose, K., & Kim, S. (2012). Predictors of caregiver burden in caregivers of individuals with dementia. *Journal of Advanced Nursing, 68*(4), 846-855.
- Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Philadelphia, PA: Open University Press.
- Krull, A. (2005). First signs and normalizations: Caregiver routes to the diagnosis of Alzheimer's disease. *Journal of Aging Studies, 19*(4), 407-417.
- Leung, K., Finlay, J., Silvius, J., Koehn, S., McCleary, L., Cohen, C., ... Drummond, N. (2011). Pathways to diagnosis: Exploring the experiences of problem recognition and obtaining a

- dementia diagnosis among Anglo-Canadians. *Health & Social Care in the Community*, 19(4), 372-81.
- Loy, Schofield, Turner, & Kwok. (2014). Genetics of dementia. *The Lancet*, 383(9919), 828-840.
- McFadden, S. H., Ingram, M., & Baldauf, C. (2001). Actions, feelings, and values: Foundations of meaning and personhood in dementia. *Journal of Religious Gerontology*, 11(3), 67-86.
- McGovern, J. (2011). Couple meaning-making and dementia: Challenges to the deficit model. *Journal of Gerontological Social Work*, 54(7), 678-690.
- McLennon, S. M., Habermann, B., & Rice, M. (2011). Finding meaning as a mediator of burden on the health of caregivers of spouses with dementia. *Aging & Mental Health*, 15(4), 522-530.
- McNess, A. M. (2017). Personhood and vulnerability: Understanding social attitudes towards dementia. *Ethics and Social Welfare*, 11(4), 396-403.
- Medications for Memory Loss (2019). Retrieved February 24, 2019, from:
<https://alz.org/alzheimers-dementia/treatments/medications-for-memory>
- Menne, H., Kinney, J., & Morhardt, D. (2002). 'Trying to continue to do as much as they can do:' Theoretical insights regarding continuity and meaning-making in the face of dementia. *Dementia*, 1(3), 367-382.
- Molyneaux, V. J., Butchard, S., Simpson, J., & Murray, C. (2012). The co-construction of couplehood in dementia. *Dementia*, 11(4), 483-502.
- O'Connor, D., Phinney, A., Smith, A., Small, J., Purves, B., Perry, J., ... Beattie, L. (2007). Personhood in dementia care. *Dementia*, 6(1), 121-142.

- O'Reilly, M. and Parker, N., (2012). 'Unsatisfactory Saturation': a critical exploration of the notion of saturated sample sizes in qualitative research. *Qualitative Research*, 13(2), pp.190–197.
- O'Shaughnessy, M., Lee, K., & Lintern, T. (2010). Changes in the couple relationship in dementia care: Spouse caregivers' experiences. *Dementia*, 9(2), 237-258.
- O'Sullivan, G., Hocking, C., & Spence, D. (2014). Dementia: The need for attitudinal change. *Dementia*, 13(4), 483-497.
- Page, S., & Fletcher, T. (2006). Auguste D. One hundred years on: "The person" not "the case." *Dementia* 5(4), 571-583.
- Palmer, J. L. (2013). Preserving personhood of individuals with advanced dementia: Lessons from family caregivers. *Geriatric Nursing (New York, N.Y.)*, 34(3), 224.
- Park, C. L. (2010). Making sense of the meaning literature: An integrative review of meaning-making and its effects on adjustment to stressful life events. *Psychological Bulletin*, 136(2), 257-301.
- Papavramidou, N. (2018). The ancient history of dementia. *Neurological Sciences*, 39(11), 2011-016.
- Perry, J., & O'Connor, D. (2002). Preserving personhood: (Re)membering the spouse with dementia. *Family Relations*, 51(1), 55-62.
- Pesonen, H., Remes, A. M., & Isola, A. (2013). Diagnosis of dementia as a turning point among Finnish families: A qualitative study. *Nursing & Health Sciences*, 15(4), 489-496.
- Phinney, A. (2006). Family strategies for supporting involvement in meaningful activity by PWD. *Journal of Family Nursing*, 12(1), 80-101.

- Phinney, A., Chaudhury, H. & O'Connor, D. L. (2007). Doing as much as I can do: The meaning of activity for people with dementia. *Aging & Mental Health, 11*(4), 384-393.
- Puhl, R. M., & Heuer, C. A. (2010). Obesity stigma: Important considerations for public health. *American Journal of Public Health, 100*(6), 1019-1028.
- Purves, B. A. (2010). Exploring positioning in Alzheimer disease through analyses of family talk. *Dementia, 10*(1), 35-58.
- Quinn, C., Clare, L., Jelley, H., Bruce, E., & Woods, B. (2013). 'It's in the eyes:' How family members and care staff understand awareness in people with severe dementia. *Aging & Mental Health, 1*-9.
- Quinn, C., Clare, L., & Woods, R. T. (2012). What predicts whether caregivers of people with dementia find meaning in their role? *International Journal of Geriatric Psychiatry, 27*(11), 1195-1202.
- Resiberg, B. (1988). Functional Assessment Staging (FAST). *Psychopharmacology Bulletin, 24*(4), 653-659.
- Reisberg, B. (2007). Global measures: Utility in defining and measuring treatment response in dementia. *International Psychogeriatrics, 19*(3), 421-456.
- Robertson, J. (2014). Finding meaning in everyday life with dementia: A case study. *Dementia, 13*(4), 525-543.
- Robinson, C., & Evans, (2005). Making sense of dementia and adjusting to loss: Psychological reactions to a diagnosis of dementia in couples. *Aging & Mental Health, 9*(4), 337-347.
- Robinson, L., Gemski, A., Abley, C., Bond, J., Keady, J., ... Manthorpe, J. (2011). The transition to dementia--individual and family experiences of receiving a diagnosis: A review. *International Psychogeriatrics / IPA, 23*(7), 1026-1043.

- Sabat, S. R. (2005). Capacity for decision-making in Alzheimer's disease: Selfhood, positioning and semiotic people. *Australian and New Zealand Journal of Psychiatry*, 39(11-12), 1030-1035.
- Sabat, S. R. (2002). Surviving manifestations of selfhood in Alzheimer's disease: A case study. *Dementia*, 1(1), 25-36.
- Sabat, S. R., Napolitano, L., & Fath, H. (2004). Barriers to the construction of a valued social identity: A case study of Alzheimer's disease. *American Journal of Alzheimer's Disease and Other Dementias*, 19(3), 177-185.
- Sartorius, N. (2007). Stigmatized illnesses and health care. *Croatian Medical Journal*, 48(3), 396-397.
- Scherrer, K., Ingersoll-Dayton, S., & Spencer, B. (2014). Constructing couples' stories: Narrative practice insights from a Dyadic Dementia Intervention. *Clinical Social Work Journal*, 42(1), 90-100.
- Schneider, J., Arvanitakis, Z., Leurgans, S., & Bennett, D. (2009). The neuropathology of probable Alzheimer disease and mild cognitive impairment. *Annals of Neurology*, 66(2), 200-208.
- Seidman, I. (2005). *Interviewing as qualitative research: A guide to researchers in education and social sciences*. New York, NY: Teacher's College Press.
- Sheehan, & Donorfio. (1999). Efforts to create meaning in the relationship between aging mothers and their caregiving daughters: A qualitative study of caregiving. *Journal of Aging Studies*, 13(2), 161-176.
- Sloane, P. D., Hoeffler, B., Mitchell, C. M., McKenzie, D. A., Barrick, A. L., Rader, J., ... Koch, G. G. (2004). Effect of person-centered showering and the towel bath on bathing-

- associated aggression, agitation, and discomfort in nursing home residents with dementia: A randomized, controlled trial. *Journal of the American Geriatrics Society*, 52(11), 1795-1804.
- Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research*. Los Angeles, CA: SAGE.
- Smith, J. A., & Osborn, M. (2008). Interpretive phenomenological analysis. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to methods*. (2nd ed). London, UK: Sage.
- Snyder, L. (1999). *Speaking our minds: personal reflections from individuals with Alzheimer's*. New York, NY: Freeman.
- Sorensen, L., Waldorff, F., & Waldemar, G. (2008). Coping with mild Alzheimer's disease. *Dementia*, 7(3), 287-299.
- Stokes, L. A., Combes, H., & Stokes, G. (2012). Understanding the dementia diagnosis: The impact on the caregiving experience. *Dementia*, 13(1), 59-78.
- Stolley, J. M., Buckwalter, K. C., & Koenig, H. G. (1999). Prayer and religious coping for caregivers of persons with Alzheimer's disease and related disorders. *American Journal of Alzheimer's Disease*, 14, 181-91.
- Stuckey, J. C. (2001). Blessed assurance: The role of religion and spirituality in Alzheimer's disease caregiving and other significant life events. *Journal of Aging Studies*, 15, 69-84.
- Svanstrom, R., & Dahlberg, K. (2004). Living with dementia yields a heteronomous and lost existence. *Western Journal of Nursing Research*, 26(6), 671-687.
- Swaffer, K. (2014). Dementia: Stigma, language, and dementia-friendly. *Dementia*, 13(6), 709-716.

- Swinton, J. (2007). Forgetting whose we are: Theological reflections on personhood, faith, and dementia. *Journal of Religion, Disability & Health*, 11(1), 37-63.
- U.S. House Passes Bipartisan Alzheimer's Public Health Legislation (2018). Retrieved December 19th, 2018, from: <https://www.alz.org/news/2018/u-s-house-passes-bipartisan-alzheimer-s-public-he>
- Vikström, S., Borell, L., Stigsdotter-Neely, A., & Josephsson, S. (2005). Caregivers' self-initiated support toward their partners with dementia when performing an everyday occupation together at home. *OTJR: Occupation, Participation and Health*, 25(4), 149-159.
- Vikström, S., Josephsson, S., Stigsdotter-Neely, A., & Nygård, L. (2008). Engagement in activities: Experiences of PWD and their caregiving spouses. *Dementia*, 7(2), 251-270.
- Vugt, M. E. D., Koopmans, R. T. C. M., Bakker, C., Verhey, F. R. J., & Vliet, D. v. (2010). Impact of early onset dementia on caregivers: A review. *International Journal of Geriatric Psychiatry*, 25(11), 1091.
- Walters, A. H., Oyeboode, J. R., & Riley, G. A. (2010). The dynamics of continuity and discontinuity for women caring for a spouse with dementia. *Dementia*, 9(2), 169-189.
- Wang, P., Brookhart, S., Setoguchi, M., Patrick, A., & Schneeweiss, S. (2006). Psychotropic medication uses for behavioral symptoms of dementia. *Current Neurology and Neuroscience Reports*, 6(6), 490-495.
- Ward, R., Howorth, M., Wilkinson, H., Campbell, S., & Keady, J. (2012). Supporting the friendships of people with dementia. *Dementia*, 11(3), 287-303.

- Wellin, C., & Jaffe, D. J. (2004). In search of “personal care:” Challenges to identity support in residential care for elders with cognitive illness. *Journal of Aging Studies, 18*(3), 275-295.
- “What is dementia?” (2019). Retrieved March 23, 2019, from: <https://www.alz.org/alzheimers-dementia/what-is-dementia>
- Williams, K. L., Morrison, V., & Robinson, C. A. (2014). Exploring caregiving experiences: Caregiver coping and making sense of illness. *Aging & Mental Health, 18*(5), 600-609.
- Willing, C. (2001). *Introducing qualitative research in psychology*. Philadelphia, PA: Open University Press.
- Wray, N., Markovic, M. and Manderson, L., 2007. ‘Researcher saturation’: the impact of data triangulation and intensive-research practices on the researcher and qualitative research process. *Qualitative health research, 17*(10), pp.1392–1402
- Yale, R. (2013). *Counseling people with early-stage Alzheimer's disease: A powerful process of transformation*. Baltimore: Health Professions Press.
- Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology & Health, 15*(2), 215-228.
- Yarry, S., Judge, K., & Orsulic-Jeras, S. (2010). Applying a strength-based intervention for dyads with mild to moderate memory loss: Two case examples. *Dementia, 9*(4), 549-557.
- Young, T. J., Manthorp, C., Howells, D. & Tullo, H. (2011). Developing a career communication intervention to support personhood and quality of life in dementia. *Aging and Society, 31*(6), 1003-1025.

Appendix A

Interview Protocol

Interview 1: Establishing the context for participant's experience of phenomenon

In this first interview, I would like to learn about your and your spouse's life before he had dementia, and also, what you knew about dementia in general before your spouse was diagnosed with this disease.

1. Please describe how you met your spouse.
2. How would you describe your courtship?
3. How would you describe early years of your marriage?
4. Do you have children?
5. What kind of work have you and your spouse done?
6. How important is religion to you and your spouse?
7. What are some talents, special skills and/or hobbies that you and your spouse have?
8. What are some highlights of your life together?
9. What are some difficult moments in your life together?

Previous knowledge about dementia:

10. What did you know about dementia before your spouse was diagnosed? (If applicable: Where did you learn this information?)
11. What did you know about people with dementia in general before your spouse was diagnosed? (If applicable: Where did you learn this information?)
12. Did you previously know anyone that had dementia? (If applicable: What was he/she like?)

13. Did you previously know anybody that cared for someone with dementia? (If applicable: What do you know from him/her about caring for someone with dementia?)
14. What are some things that you thought people with dementia can and cannot do?
15. Did you think that people with dementia are capable of recognizing our love respect and care for them?
16. Did you think that people with dementia are capable of expressing love respect and attention towards others?

Interview 2: Encouraging the participant towards deeper exploration of the present experience of the phenomenon

Last time we spoke about your life with your spouse before dementia. In this interview, I would like to learn specifically about your experience from the time when you started noticing changes in your spouse, through diagnosis, until the present time. I would like to know what your thoughts and reactions were to these events, and how, in your opinion, they affected your and your spouse's daily activities, marriage and lifestyle.

1. When did you first get a sense that something was "different" about your spouse?
2. Did your spouse mention anything or complain of any difficulties that made you think that something might be wrong?
3. Did something happen that alerted you to visit a doctor? (If applicable: Please share the details of the event. Please share the details of your visit to the doctor.)
4. Please share your experience of receiving the news of your spouse's diagnosis of dementia.

5. What was your initial reaction to finding out that your spouse has dementia? What were your thoughts? How did you feel?
6. What was your spouse's reaction? What were his thoughts? How do you think he felt?
7. Did your reactions change over time? How so?
8. Did things at home change as a result of your spouse having dementia? (If applicable: How so?)
9. Did anything change in your marriage as a result of your spouse having dementia? (If applicable: How so?)
10. Did anything change in your social interactions with family and friends as a result of your spouse having dementia? (If applicable: How so?)
11. Have you shared the diagnosis with any of your family members and/or friends? Why / why not? (If applicable: What was the reaction of your friends and family to

Interview 3: *Inviting participants to reflect on the meaning that the experience holds for them*

When we spoke the last time, I asked you about the details of your experience of learning that your spouse has dementia, and how your spouse's condition impacted on your daily life, relationship and lifestyle. In this last interview, I would like to learn if your spouse has changed as a result of having dementia, and in what ways he/she has changed.

1. Do you believe that your spouse has changed as a result of having dementia? (If applicable: In what ways? If not, why?)
2. Do you think that your spouse is the same person as he/she was before dementia?

3. Does your spouse talk about feeling changed by dementia? (If applicable: If so, in what ways? If not, why do you think that he/she does not feel changed by the disease?)
4. Do you think others think of him as a different or same person? (If applicable: If so, in what ways? Why do you think others think that he is changed or stayed the same?)
5. What, or who do you rely on to deal with your spouse's condition?
6. Do you think that these resources influence how you perceive your spouse?
7. In what ways do these resources influence how you perceive your spouse?

Appendix B

Initial Contact Script to Potential Participants

Hello,

My name is Marina Vracevic, and I am a Ph.D. candidate in Human Development and Family Studies, at the University of Connecticut (UConn). My reason for being here today is to tell you about my doctoral dissertation study, and to ask that you consider participating in this study. I am exploring how caregiving wives perceive their husbands in the early stage of dementia, and what meaning they give to dementia-related psychological and physical changes in their partners.

Please consider participating in this study if the following applies to you:

1. You and your husband live at home;
2. Your spouse is 70 years of age or older;
3. To your knowledge, your spouse does not have any of the following health conditions:
HIV/AIDS, leprosy, diabetes, cancer, obesity, skin disorders, venereal diseases, and mental illnesses other than dementia
4. You understand, speak, read and write the English language at advanced or native proficiency level.

If you agree to participate in this study, I would ask that we speak over the phone on three separate occasions, so I may interview you about your perceptions of your spouse who is living with dementia. Each interview will last about one hour, and with your permission, I will audiotape each of our conversations. The interviews will be scheduled 3-7 days apart, so your involvement in this study will take up to three weeks. We will schedule each interview at times most convenient for you. Your identity and the information that I collect from you will be treated confidentially.

If you are interested in participating in this study or if you have questions about this study, please feel free to speak to me after this meeting, or e-mail me at marina.vracevic@uconn.edu, or call me at 860-494-5938. We will review the study's Informed Consent form together in person, and you are welcome keep the form for further review, before signing and returning it to me. Your participation in this study will begin after you have reviewed and signed the Informed Consent Form. I will arrange to collect the form from you in person, at your convenience.

Thank you for your time.

Best,

Marina Vracevic, M.A.

Dept. of Human Development and Family Studies, University of Connecticut

Appendix C

Functional Assessment Staging Test (FAST)

FAST SCALE ADMINISTRATION

The FAST scale is a functional scale designed to evaluate patients at the more moderate-severe stages of dementia when the MMSE no longer can reflect changes in a meaningful clinical way. In the early stages the patient may be able to participate in the FAST administration but usually the information should be collected from a caregiver or, in the case of nursing home care, the nursing home staff. The FAST scale has seven stages: 1 which is normal adult; 2 which is normal older adult; 3 which is early dementia; 4 which is mild dementia; 5 which is moderate dementia; 6 which is moderately severe dementia, and 7 which is severe dementia.

FAST Functional Milestones

FAST stage 1 is the normal adult with no cognitive decline. FAST stage 2 is the normal older adult with very mild memory loss. Stage 3 is early dementia. Here memory loss becomes apparent to co-workers and family. The patient may be unable to remember names of persons just introduced to them. Stage 4 is mild dementia. Persons in this stage may have difficulty with finances, counting money, and travel to new locations. Memory loss increases. The person's knowledge of current and recent events decreases. Stage 5 is moderate dementia. In this stage, the person needs more help to survive. They do not need assistance with toileting or eating but do need help choosing clothing. The person displays increased difficulty with serial subtraction. The patient may not know the date and year or where they live. However, they do know who they are and the names of their family and friends. Stage 6 is moderately severe dementia. The person may begin to forget the names of family members or friends. The person requires more assistance with activities of daily living, such as bathing, toileting, and eating. Patients in this

stage may develop delusions, hallucinations, or obsessions. Patients show increased anxiety and may become violent. The person in this stage begins to sleep during the day and stay awake at night. Stage 6 is severe dementia. In this stage, all speech is lost. Patients lose urinary and bowel control. They lose the ability to walk. Most become bedridden and die of sepsis or pneumonia.

2/13/2008http://geriatrics.uthscsa.edu/educational/med_students/fast_scale_admin.htm

Functional Assessment Staging Test (FAST)©

STAGE	SKILL LEVEL
1.	No difficulties, either subjectively or objectively.
2.	Complains of forgetting location of objects. Subjective word finding difficulties.
3.	Decreased job function 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 (forgetting to pay bills), difficulty marketing, etc.
5.	Requires assistance in choosing proper clothing to wear for day, season, occasion.
6a.	Difficulty with putting clothing on properly without assistance.
b.	Unable to bathe properly (e.g., difficulty adjusting bath water temperature), occasionally or more frequently over the past weeks.*
c.	Inability to handle mechanics of toileting (e.g., forgets to flush the toilet, does not wipe properly or properly dispose of toilet tissue) occasionally more frequently over the past weeks.*
d.	Urinary incontinence, occasional or more frequent.
e.	Fecal incontinence (occasional or more frequent over the past week).

- 7a. Ability to speak limited to approximately a half dozen different words or fewer, in a course of an average day or in the course of an intensive interview.
- b. Speech ability limited to the use of a single intelligible word in an average day, or in a course of an interview (the person may repeat the word over and over).
- c. Ambulatory ability lost (cannot walk without personal assistance).
- d. Ability to sit up without assistance lost (e.g., the individual will fall over if there are no lateral rests [arms] on the chair).
- e. Loss of the ability to smile.

STAGE: _____

*Scored primarily on the basis of information obtained from a knowledgeable informant and/or caregiver.

©1984 by Barry Reisberg, M.D. All rights reserved. Reisberg, B. Functional Assessment Staging (FAST). *Psychopharmacology Bulletin*. 1988;24: 653-659.

Appendix D

Demographic Questionnaire

What is your age? _____

1. What is your husbands age? _____
2. Are you of Hispanic, Latino, or of Spanish origin?
 - a. Yes
 - b. No
3. How would you describe yourself?
 - a. American Indian or Alaskan Native
 - b. Asian
 - c. African American
 - d. Native Hawaiian or Other Pacific Islander
 - e. Caucasian
4. What is the highest degree or level of school you have completed? (If you're currently enrolled in school, please indicate the highest degree you have *received*.)
 - a. Less than a high school diploma
 - b. High school degree or equivalent (e.g. GED)
 - c. Some college, no degree
 - d. Associate degree (e.g. AA, AS)
 - e. Bachelor's degree (e.g. BA, BS)
 - f. Master's degree (e.g. MA, MS, MEd)
 - g. Professional degree (e.g. MD, DDS, DVM)
 - h. Doctorate (e.g. PhD, EdD)
5. What is your current employment status?
 - a. Employed full time (40 or more hours per week)
 - b. Employed part time (up to 39 hours per week)
 - c. Unemployed and currently looking for work
 - d. Unemployed and not currently looking for work
 - e. Student
 - f. Retired
 - g. Homemaker
6. What is your household income?
 - a. Less than \$20,000
 - b. \$20,000 to \$34,999
 - c. \$35,000 to \$49,999
 - d. \$50,000 to \$74,999
 - e. \$75,000 to \$99,999
 - f. Over \$100,000

Appendix E

Please see attached appendix E.

Appendix F

Please see attached appendix F.

