Fall 12-18-2020

The Lived Experiences of Males within a Committed Relationship Who Are the Primary Caregivers for a Partner Diagnosed with Frontotemporal Dementia

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Recommended Citation

Scanlon, A. (2020). The Lived Experiences of Males within a Committed Relationship Who Are the Primary Caregivers for a Partner Diagnosed with Frontotemporal Dementia (Doctoral dissertation, Duquesne University). Retrieved from https://dsc.duq.edu/etd/1949

THE LIVED EXPERIENCES OF MALES WITHIN A COMMITTED RELATIONSHIP WHO ARE THE PRIMARY CAREGIVERS FOR A PARTNER DIAGNOSED WITH FRONTOTEMPORAL DEMENTIA

A Dissertation

Submitted to the School of Education

Duquesne University

In partial fulfillment of the requirements for

the degree of Doctor of Philosophy

By

Aniela Kathryn Scanlon

December 2020

DUQUESNE UNIVERSITY
SCHOOL OF EDUCATION
Department of Counseling, Psychology and Special Education

Dissertation

Submitted in Partial Fulfillment of the Requirements
For the Degree of Doctor of Philosophy (Ph.D.)

Executive Counselor Education and Supervision Program

Presented by:

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August 28, 2020

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ABSTRACT

THE LIVED EXPERIENCES OF MALES WITHIN A COMMITTED RELATIONSHIP WHO ARE THE PRIMARY CAREGIVERS FOR A PARTNER DIAGNOSED WITH FRONTOTEMPORAL DEMENTIA

By

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December 2020

Dissertation supervised by Dr. David Delmonico

Spouses who are caregivers for their partner with dementia experience significant changes within the relationship and in their daily lives. There is a focus in the extant literature on female caregivers and types of dementia that are more mainstream, like Alzheimer's disease. However, little is known about the lived experiences of male primary caregivers for a spouse or partner diagnosed with dementia such as frontotemporal dementia. This qualitative phenomenological study explored the lived experiences of male primary caregivers in a committed relationship who are the primary caregiver for a partner diagnosed with frontotemporal dementia (FTD) to understand how the male primary caregivers are personally impacted and how they experience interdependence and intimacy and ambiguous loss within the relationship. This study found male primary caregivers for a partner with FTD are deeply emotionally impacted by the changes in interdependency and intimacy within the relationship. This study also found that male primary caregivers retain their sense of independence even though their time to participate in individual activities is limited due to the caregiving role tasks.

DEDICATION

This dissertation is dedicated to George and Honey. You are my bright stars shining down.

ACKNOWLEDGMENT

There are so many people that went on this long and exhaustive journey with me. Their unconditional love, encouragement, and understanding is what kept me going.

Thank you to my committee members for their time, patience, and caring throughout this process: Dr. Laura Marshak, your feedback pushed me to be a better researcher and writer. I am so thankful for our initial conversation about ambiguous loss several years ago that inspired this study. You have been an extraordinary mentor over the last six years, and I will forever be grateful. Dr. William Casile, thank you for your eagle eye and attention to detail. Your humor and support eased the pain of editing. And a special thanks to my committee Chair, Dr. David Delmonico you were always supportive and respectful of my personal time and other life commitments throughout this three-year project. Thank you for your guidance, kindness, and the laughter.

A heartfelt thank you to my friends Kristen, Erin, Michelle and Jason, Deb and Marc, Suzi and Rich, and Megan and Harry for the hours of listening to me complain and stress out over this work. For knowing when I needed a drink, a good cry, or a smash box to burn at camp. I made it through because of you all.

To my sister, Bridgette, who took care of my Sophie while I traveled to Duquesne three times a week, ran two practices, taught classes, and finished this academic journey. I could not have done my life without you taking care of me. Thank you.

To my brothers, Mike, Tony, and Pat, thank you for being proud of me and reminding me how proud mom and dad would be of me too. You always have my back.

And finally, to Mark and Sophie the two loves of my life. Mark, thank you for being my best friend and biggest supporter. You are always on my side and had total faith that I would finish and never look back. You are secure in a way that allows me the freedom and independence to be me. Looking forward to more downtime together. I love you.

Sophie, you are the light of my life. Thank you for all the cards, paintings, voicemail messages, and little gifts you would leave for me. I am so proud of you for being you. I could not have finished this “book” without all your love and support. I love you so much.

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CHAPTER I

INTRODUCTION

When a spouse or partner is diagnosed with dementia it can be overwhelming. And being the primary caregiver, the person providing most of the in-home physical and emotional care for someone diagnosed with dementia can be even more complex. Although several studies explore the role of caregivers for those diagnosed with dementia, there is little information about male primary caregivers for a spouse or partner diagnosed with dementia, and even fewer studies of male primary caregivers and a specific dementia such as frontotemporal dementia (FTD).

Caregiving is “the process of helping another person who is unable to do for themselves in a ‘holistic’ (physically, mentally, emotionally, and socially) manner” (Hermanns & Mastel-Smith, 2012, p. 15). It is “facilitated by certain character traits, emotions, skills, knowledge, time, and an emotional connection with the care recipient” (p. 15). The decision to become the caregiver for a loved one is often one of necessity (Friedemann & Buckwalter, 2014; Papastavrou et al., 2007). And moreover, being a caregiver for a loved one may cause severe changes within family roles, with work outside of the house, and with social interactions for all involved (Pinquart & Sorensen, 2006).

According to Papastavrou et al. (2007), most of the females in their study expressed not possessing the skill set needed to assume the caregiving role. However, women are expected to know how to be a caregiver just based on being female (Calasanti & King, 2007; Robinson et al., 2014). Extant literature suggests female caregivers feel societal pressure to “step up” and even more pressure when they decline being the caregiver (Robinson et al., 2014).

In contrast, other studies found males do not experience the same “squeeze” from society to be primary caregivers for loved ones. However, men are expected to maintain their masculinity (Calasanti & King, 2007; Friedemann & Buckwalter, 2014; Robinson et al., 2014). According to Phinney et al. (2013) and Friedemann and Buckwalter (2014), males feel “manly” in their work world. Therefore, if males were to transfer their work world confidence and sense of being “manly” to the role of caregiver, they could feel a possible sense of accomplishment and fair well (Friedemann & Buckwalter, 2014; Phinney et al., 2013). Primary caregivers, whether male or female, are pressured by societal expectations and role norms.

According to The Alzheimer’s Association, caregivers for those living at home with dementia are taken care of by family or friends 80% of the time. Out of those family and friends, 60% are female caregivers, mainly wives or daughters (alzfnd.org 2010 Women and Alzheimer Poll of AD; Ford et al., 2012). This suggests the other 20% of caregivers are male and husbands or sons. However, there is little information in current research about males’ experiences as primary caregivers for partners with dementia because female participants outnumber male participants in many existing studies regarding any type of illness and caregiving. As an example, a recent study by Friedemann and Buckwalter (2014) had a total sample of 613 caregivers of frail or older relatives and was conducted to research the family caregiver role and the burden related to gender and family relationships. Of the 613 caregiver participants, 524 were female and 109 were male.

In addition, a study conducted by Savundranayagam and Montgomery (2010) regarding caregiver burden stress when caring for a loved one diagnosed with dementia, females made up two thirds of the participants with only one third being male. Whether male or female, caregivers reported assisting spouses with activities of daily living (ADLs) was only a burden and stressful when they felt it as "going beyond the call of duty" (p. 192). However, caregivers experienced more caregiver burden when they dealt with more behavioral problems. Behavioral problems can be defined as a "relational stressor, one that undermines the human connection and interaction that is necessary to maintain one's identity as a spouse and one that threatens to create greater emotional distance within the familial relationship" (p. 193). The participants who overextended themselves to maintain the relationship experienced caregiver burden.

Spouses are more inclined than other types of caregivers to want to do all the caregiving themselves for a partner or spouse (Marks et al., 2002). According to Lloyd and Stirling (2011), "services for dementia carers can be understood as benevolent—but not necessarily benign—interventions into their private social worlds" (p. 910). In addition, according to Usita et al. (1998) it is hard to comprehend caring for a person with dementia and its impact on everydayness if one has never experienced it.

Some previous research findings suggest that female caregivers for those diagnosed with dementia are more aware of their partner's intimate needs, defined as "positive affective, cognitive, and physical closeness one experiences with a partner in a reciprocal relationship" (Moss & Schwebel, 1993, p. 33), and therefore are in danger of unfavorable outcomes of caretaking (Harris et al., 2011; Monin & Schulz, 2009). However, not included in extant literature is how male caregivers view and experience intimacy while being the primary caregiver for a partner diagnosed with dementia (Harris et al., 2011).

In addition, other challenges of being a primary caregiver for a spouse or partner diagnosed with dementia need to be addressed. According to Savundranayagam and Montgomery (2010), the role of a caregiver for a spouse or partner with dementia happens without “discreet demarcation” (p. 176). There is no transition into becoming a caregiver as there is in becoming a parent with the birth of a child. The role evolves out of the already existing relationship. Lloyd and Stirling (2011) noted, “excessive ambiguity in social relations undermines the basic human need to impose meaning and order onto an otherwise chaotic world” (p. 910). Caregiving for a spouse with Alzheimer’s disease and related disorders can be demanding both physically and emotionally increasing the caregiver’s likelihood of declining health (Butcher et al., 2001; Harris et al., 2011).

The relationship between caregivers and the FTD diagnosed person is also taxed by the deterioration of the patient’s emotional, behavioral, and cognitive functioning (Caceres et al., 2016). FTD symptoms include but are not limited to the loss of empathy, disinhibition, apathy, repetitive behaviors, inappropriate sexual remarks, and mental rigidity (Bang et al., 2015). According to Lee and Tang (2015) caregiver roles and experiences differ based on gender and age. For many in the age group of 45 to 65 years of age, “working and caregiving is not a choice” (p. 466). The caregivers of FTD patients are often working spouses with school aged children therefore it is perceived that the overall stress of the situation is higher for these primary caregivers than those caregivers whose loved one is diagnosed with dementia at an older age (Freyne et al., 1999; Rosness et al., 2008).

The World Health Organization (WHO, 2020) projects that by the year 2030 over 82 million people will be diagnosed with dementia with FTD in the top three (Bang et al., 2015; Knopman & Roberts, 2011). Over the last 20 years there has been more awareness of people younger than 65 years old being diagnosed with dementia (Beattie et al., 2002). FTD affects both males and females equally and is thought to have a familial link in some cases while other diagnoses are not genetic or familial in nature (Onyike & Diehl-Schmid, 2013). The typical diagnosis age range is between 45 to 64 years (Bang et al., 2015; Knopman, 2011). And the course of the disease can last from 2 to 20 years with an average span of 7 to 13 years from the onset of symptoms (Onyike & Diehl-Schmid, 2013).

Even with the extensive research on caregivers and caregiving involving spouses and those diagnosed with any type of dementia, there are still gaps in the literature of males in committed relationships who are primary caregivers for those diagnosed with FTD. Several interests based on these gaps is what informed this current study.

First, this study sought to understand the male experience of being the primary caregiver, one who provides the majority of the in-home physical and emotional care, for a partner diagnosed with frontotemporal dementia (FTD). Second, the study intended to grasp and understand the male primary caregiver's level of commitment within the relationship defined as "a psychological state that globally represents the experience of dependence on a relationship, represents long-term orientation, including feelings of attachment to a partner and desire to maintain a relationship for better or worse," (Rusbult & Buunk, 1993, p. 180). And to further explore the experience of being a primary caregiver while maintaining relationship intimacy defined as “commitment and positive affective, cognitive, and physical closeness one experiences with a partner in a reciprocal relationship” (Moss & Schwebel, 1993). This study also sought to learn how the male primary caregiver for a partner diagnosed with FTD experienced the interdependence of the relationship. In other words, how “partners in a close relationship influence one another’s experiences and need each other to obtain valued outcomes such as instrumental support, affection, sexual fulfillment and emotional closeness” (Rusbult & Buunk, 1993, pp. 178-179). Additionally, this study explored how the male primary caregiver perceives ambiguous loss (Boss, 1999), a loss that remains unclear and the grief process frozen by ambiguity, along with the sensation of absent but present, when the diagnosis of FTD enters the committed, intimate, and interdependent relationship. Finally, this study sought to gain awareness and an understanding of the experiences of the male primary caregiver in a committed relationship for a partner with FTD to supervise counselors in training and seasoned counselors alike on the best counseling practices to work toward client wellness.

More research is needed to explore the experiences of males within a committed relationship who are the primary caregivers for a spouse or partner diagnosed with FTD. This research is necessary because FTD is diagnosed equally in males and females and will be one third of the 115 million diagnosed with dementia by 2050. This study is significant and will add to the extant literature.

Statement of the Problem

Although several studies look at caregiving and caregivers for those with dementia (K. Adams et al., 2008; Braun et al., 2009; Caceres et al., 2016; Eifert et al., 2015; Fauth et al., 2012), most focus on the female caregivers within a family system or society. Since FTD affects both males and females equally (Onyike & Diehl-Schmid, 2013), the assumption is that at least 50% of primary caregivers for those diagnosed with FTD are males. Therefore, more research is needed to explore how males view and experience the intimacy and interdependence of the committed relationship while being the primary caregiver for a partner diagnosed with dementia (Harris et al., 2011). This study looks specifically at male primary caregivers in a committed relationship and their experiences of intimacy and interdependence and how they experience ambiguous loss within the relationship with a partner diagnosed with FTD.

Significance of the Study

The significance of this study is to fill a gap in the extant literature regarding how male primary caregivers for a partner diagnosed with FTD experience intimacy, interdependence, and ambiguous loss within a committed relationship and how those experiences impact the caregiver personally. FTD affects caregivers who are often still in the work force and the caregivers of young children; therefore, it will be important to inform other caregivers in similar circumstances as well as those in the counseling field of this population’s experiences to better understand how to provide support.

This study attempts to capture the lived experiences of males within a committed relationship who are the primary caregivers for a partner/spouse diagnosed with FTD and how the intimacy and the interdependence within the relationship are perceived and how ambiguous loss is experienced, and additionally, how these changes and losses impact the caregiver personally.

Previous research indicates that male spouses who are caregivers showed lower levels of stress, anxiety, and depressive symptoms more so than female spouses who are caregivers (Braun et al., 2009; Gilhooly et al., 1994; Russel et al., 2004). However, according to Mourik et al. (2004), both male and female caregivers of those diagnosed with FTD were more stressed when the diagnosed person lived at home as opposed to living in nursing homes. Additionally, Braun et al. (2009, p. 434) stated that "detailed studies . . . that focus explicitly on one diagnosis and one caregiver group are needed to obtain better insight into dementia caregiving dyads." This study looks specifically at one diagnosis, FTD, and one caregiver group, males who are primary caregivers within a committed relationship for a partner or spouse diagnosed with FTD, and therefore this study adds to the current literature.

The Purpose of the Study and Research Questions

The purpose of this study is to explore the lived experiences of males within in a committed relationship who are the primary caregivers for a partner/spouse diagnosed with Frontotemporal Dementia (FTD).

The interests that led to this study were (a) to understand the male experience of being the primary caregiver for a partner diagnosed with FTD, (b) to explore the experience of being a male primary caregiver while maintaining relationship intimacy with a partner or spouse with FTD, (c) to explore the experience of the male primary caregiver of a partner or spouse diagnosed with FTD and the interdependence of the relationship, (d) to understand how the male primary caregiver in a committed relationship with a partner or spouse diagnosed with FTD perceives ambiguous loss, and (e) to gain an awareness of the experience of the male primary caregiver in a committed relationship with a partner diagnosed with FTD to use best practices in selection of counseling theories and techniques toward client wellness. All of which led to the following research questions:

1. How does being a male primary caregiver impact the intimacy and interdependence in the committed relationship?
2. How does the male primary caregiver of a partner diagnosed with FTD experience ambiguous loss within the relationship?
3. How does being a male primary caregiver to a partner with FTD impact the caregiver personally?

Theoretical Underpinning

The primary theoretical underpinnings for this study are Ambiguous Loss Theory (Boss, 1990, 1999) along with Interdependence Theory (Kelley & Thibaut, 1978) and the Investment Model of Commitment (Rusbult, 1983). These are conceptual models that are relevant to the discussion of the personal impact of males in committed relationships with partners or spouses who have been diagnosed with FTD.

Ambiguous Loss Theory

Ambiguous Loss Theory (Boss, 1990, 2006, 2007) has been used in earlier research to explain how loss is experienced within family systems, including couples, when there is no immediate closure or no closure at all. This current study (Boss, 2007; Boss & Carnes, 2012; Ford et al., 2012; Harris et al., 2011; Simpson & Acton, 2013;

Stephens & Qualls, 2007) will fall under this theory because with FTD there is a relational loss that is suspended in space and time.

Ambiguous Loss Theory (Boss, 1990, 1999) defined loss as: (a) psychological absence where the loved one is physically present but cognitively "absent" or impaired as in dementia, or as result of a stroke; and (b) physical absence where the loved one is missing in action, lost, and so forth (Boss, 1999).

"Ambiguous loss is a loss that remains unclear" (Boss, 2007, p. 105); symptoms can be missed or misdiagnosed (Boss, 1999). The grief process is frozen by the ambiguity and the decision-making process is halted and causes less coping abilities (Boss, 1999, 2007). It is the epitome of absent but present when a loved one is diagnosed with dementia (Boss, 2006, 2007).

The idea that ambiguous loss theory does not pathologize loss and grief is critical to this current study to gain knowledge of the male primary caregiver's experience in a committed relationship with a partner diagnosed with FTD and how those experiences impact the caregiver personally.

Interdependence Theory

Interdependence Theory (Rusbult & Buunk, 1993) has been used as an underpinning in previous research to explore the satisfaction of married couples (Givertz et al., 2016) by linking interdependence, defined as that which "implies that partners in a close relationship influence one another's experiences and need each other to obtain valued outcomes such as instrumental support, affection, sexual fulfillment and emotional closeness" (Rusbult & Buunk, 1993, pp. 178-179), to direct and indirect effects of commitment. This theory lends itself well as a supportive theoretical underpinning as well as the addition of the Investment Model of Commitment (Rusbult, 1980) due to how both relate to the strains of marriage and partnership when one partner has dementia (Braun et al., 2009; Tubbs & Boss, 2000).

Interdependence theory (Kelley & Thibaut, 1978; Rusbult & Buunk, 1993) centers on the interaction between partners as the focal point of all close relationships. According to Thibaut and Kelley (1959), “by interaction it is meant that individuals emit behavior in each other’s presence, they create products for each other, or they communicate with each other” (p. 10). According to this theory, interactions have results that are either costs or benefits for the individuals in the relationship (Rusbult & Buunk, 1993; Thibaut & Kelley, 1959). Interdependence theory suggests that the individuals enter and continue relationships partly because of the benefits of interactions within the relationship (Rusbult & Buunk, 1993).

Choices about relationships are not only made based on personal gain but also made with concerns and thoughts about a partner’s outcomes and goals for the future (McClintock & Liebrand, 1988; Rusbult & Buunk, 1993). The latter is known as transformation of motivation, which is when an individual will put his partner’s needs before his own for the good of the overall interactions within the relationship (Rusbult & Buunk, 1993).

The Investment Model of Commitment

The Investment Model of Commitment (Rusbult, 1980) has been used in previous research as a foundation to explore why and how people stay in long-term committed relationships regarding coping strategies in general without the presence of a life altering disease as a variable (Landis et al., 2014; Ogolsky, 2009; Rusbult et al., 1991; Wieselquist et al., 1999).

The Investment Model of Commitment (Rusbult & Buunk, 1993) expands the idea of Interdependence Theory (Kelley & Thibaut, 1978; Rusbult & Buunk, 1993) because it suggests that dependence is subjective and experienced as commitment (Rusbult & Buunk, 1993). Commitment level is defined as "a psychological state that globally represents the experience of dependence and direct reactions to new situations; it represents long-term orientation, including feelings of attachment to a partner and desire to maintain a relationship for better or worse" (Rusbult & Buunk, 1993, p. 180). Therefore, commitment is subjective and compromised of cognitive, emotional, and behavioral components that impact a relationship (Rusbult & Buunk, 1993).

A solid commitment to a relationship is a strong factor linked with free choice of continuity of the relationship (Agnew et al., 1998; Drigotas & Rusbult, 1992). Commitment is made up of "relationship maintenance acts" that include but are not limited to (a) a willingness to sacrifice for the good of the relationship (Agnew et al., 1998; Van Lange et al., 1997); (b) to be accommodative rather than retaliate when a partner behaves badly (Rusbult et al., 1991); and (c) tendencies to reject or dismiss alternative partners (Agnew et al., 1998; Johnson & Rusbult, 1989).

Agnew et al. (1998) suggested that as individuals become more committed in a relationship they start to think of their partners as a part of themselves and therefore see themselves as a part of a collective entity. It is a "pluralistic, collective mental representation of the self-in-relationship" (Agnew et al., 1998, p. 941). It becomes a way of thinking that "supports pro-relationship motivation and behavior by increasing accessibility of the partner and the relationship" (Agnew et al., 1998, p. 941). This is the "we" factor in a relationship that allows individuals to put their partners' needs before their own needs, wants, and desires to not only maintain the relationship but to preserve self within that relationship (Agnew et al., 1998; Rusbult & Buunk, 1993; Wieselquist et al., 1999).

Conceptual Framework

The conceptual framework of Existential-Phenomenology is the most beneficial method for understanding and highlighting the lived experiences of males who are the primary caregivers for a partner diagnosed with FTD without trying to objectify their experiences and by returning to the "primary source" (Van Manen, 2016; von Herrmann & Maly, 2013). "Phenomenological research is the study of lived experiences" (Van Manen, 1990, p. 9). It examines the lifeworld as it is immediately experienced before any preconceived reflecting about the phenomenon is done by the researcher (Husserl, 1970; Van Manen, 1990). Phenomenology is a thoughtful process that brings insight with "more direct contact with the world" (Van Manen, 1990, p. 9). Its structural purpose is to have a rich and "evocative description" of the human experience as evidenced by actions, behaviors, and intentions as met in the "lifeworld" (Van Manen, 1990, p. 19). Phenomenology is not a generalization; it is the process of describing a unique snap shot of an experience (Van Manen, 2016).

Definitions

Ambiguous loss: a loss that remains unclear, the grief process is frozen by the ambiguity, stopping the decision-making process and causing less coping abilities; absent but present (Boss, 1990, 2006, 2007).

Caregiving: "the process of helping another person who is unable to do for themselves in a 'holistic' (physically, mentally, emotionally, and socially) manner. Caregiving is facilitated by certain character traits, emotions, skills, knowledge, time, and an emotional connection with the care recipient" (Hermanns & Mastel-Smith, 2012, p. 15).

Cognitive interdependence: "a pluralistic, collective mental representation of the self-in-relationship" (Agnew et al., 1998, p. 941).

Commitment level: "a psychological state that globally represents the experience of dependence on a relationship; it represents long-term orientation, including feelings of attachment to a partner and desire to maintain a relationship for better or worse" (Rusbult & Buunk, 1993, p. 180).

Committed relationship: an intimate/romantic relationship of at least 7 consecutive years.

Interdependence: "implies that partners in a close relationship influence one another's experiences and need each other to obtain valued outcomes such as instrumental support, affection, sexual fulfillment and emotional closeness" (Rusbult & Buunk, 1993, pp. 178-179).

Intimate/Intimacy: "the level of commitment and positive affective, cognitive, and physical closeness one experiences with a partner in a reciprocal relationship" (Moss & Schwebel, 1993, p. 33).

Investment Model of Commitment: expands the idea of interdependence theory by suggesting that dependence is subjective and experienced as commitment (Rusbult & Buunk, 1993).

Noncorrespondence: “collective interest is better served if partners engage in prorelationship behavior than if they behave selfishly” (Van Lange et al., 1997, p. 1374).

Primary caregiver: the person providing most of the in-home physical and emotional care for someone diagnosed with frontotemporal dementia (FTD).

Spousal/Partner caregiver: a spouse or partner in a committed relationship that provides caregiving.

Willingness to sacrifice: “the propensity to forego immediate self-intent to promote the well-being of a partner or relationship” (Van Lange et al., 1997).

Summary

Chapter 1 includes the problem and the significance of the study, the theoretical underpinnings, and the conceptual framework for the study. Chapter 2 presents a literature review of the extant research regarding spousal caregivers of those with a chronic illness, caregiving, caregiving and intimacy, and the effects of spousal caregiving to a partner with dementia. The chapter closes with a discussion of the theoretical underpinning for the study. Chapter 3 explains the design and methodology of the study. Chapter 4 gives the results of the data collection. Chapter 5 gives the analysis of the data, implications for the counseling field, and suggestions for future research.

CHAPTER II

LITERATURE REVIEW

Additional knowledge and understanding of how being a male primary caregiver for a partner diagnosed with dementia impacts the caregiver personally within an intimate, interdependent, and committed relationship while experiencing ambiguous loss is what frames this study. Specifically, this study explores the lived experiences of males within a committed relationship who are the primary caregivers for a partner diagnosed with FTD.

This chapter is a review of the extant literature and includes (a) caregiving in the United States, (b) male versus female caregivers, (c) spousal caregivers, (d) caregiving when dementia is the diagnosis, (e) caregiving and intimacy, (f) caregiving and interdependence, and (g) caregiving and ambiguous loss.

Caring and Caregiving

Pearlin et al. (1990) defined informal caregiving as “activities and experiences involved in providing help and assistance to relatives or friends who are unable to provide for themselves” (p. 583). It is caring coupled with the behavioral act of giving care. These are the foundations for any close relationship (Pearlin et al., 1990). This is echoed by Hermanns and Mastel-Smith (2012) who defined caregiving as being “made up of actions one does on behalf of another individual who is unable to do those actions for himself or herself” (p. 5). The focus is on the needs of others at the expense of one’s own needs (Hermanns & Mastel-Smith, 2012).

The National Alliance for Caregiving (NAC) in conjunction with the American Association of Retired Persons (AARP) report 53 million Americans have volunteered as a caregiver over the last five years (National Alliance for Caregiving, 2020). This equates to one in five American adults who have served as caregivers. Of those caregivers, 26% are caring for others with dementia (National Alliance for Caregiving, 2020).

Male Caregivers Versus Female Caregivers

According to McDonell and Ryan (2013) many men enter the role of caregiver voluntarily for personal motivations, as a challenge, and therefore stay focused on the task. This finding is supported by previous research that found men tended to block emotion, focus on the job at hand, and minimize the interruptions of the daily routine (Calasanti & King, 2007). And moreover, current social norms put little pressure on men to be caregivers for relatives as compared to women (Campbell, 2010).

By contrast, women are expected to naturally fit into a caregiver role without choice. Women enter the role of caregiver due to social norms and family obligation (Calasanti & King, 2007; Gallicchio et al., 2002). In addition, Friedemann and Buckwalter (2016) found higher scores of depressive symptoms in female spousal caregivers that resulted in less overall wellness. Additionally, Seltzer and Li (1996) found female caregiver spouses experienced more burden stress than male spousal caregivers. However, Pinquart and Sorensen (2006) found only small variations in stressors, overall wellness, and resource outreach as related to gender in caregiving.

Spousal Caregivers and Caregiving

According to Carpenter and Mak (2007), intimate relationships often consist of patterns of support that ebb and flow between partners. These range from the everyday tasks like taking out the garbage to emotional support and a shared appreciation for the other’s love and affection. Caregiving affects and shifts the relationship between spouses or partners. This includes but is not limited to the independence and privacy of the individual within the relationship (Carpenter & Mak, 2007). It is a dyadic process in which the caregiver will likely encounter a multitude of trying situations (Carpenter & Mak, 2007; Hermanns & Mastel-Smith, 2012; Savundranayagam & Montgomery, 2010). Caregiving includes physical and emotional demands of the caregiver as accommodations are made based on the needs of the partner or spouse in need of care (Carpenter & Mak, 2007; Lee & Tang, 2015). The requirements of caregiving often take their toll on the caregiver's wellness (Lee & Tang, 2015).

Savundranayagam and Montgomery (2010) found an interface between spousal caregiver burden and the caregiver's changing identity in relation to the ill partner and caregiver identity theory. Their study consisted of 358 spouse caregivers with the task of helping a spouse with activities of daily living (ADLs) and found it is not stressful or burdensome unless it is viewed as "going beyond the call of duty" (Savundranayagam & Montgomery, 2010, p. 32). Spousal caregivers are usually more committed to giving many types of care (Marks et al., 2002). According to Savundranayagam and Montgomery (2010) caregiving for a spouse longer than two years normalizes the caregiving as part of the relationship identity.

According to Eifert et al. (2015), although most spouses share an identity as being a part of a couple, the loss of self and individual identity is greater as the intensity of the caring for a spouse increased. Often there is a renegotiation of the relationship by the couple that consists of learning new rules and a level of comfort about new norms so that a new shared identity is accepted (Coeling et al., 2003; Eifert et al., 2015). And moreover, Calasanti and King (2007) suggested this new normal lends caregiving husbands to be *stoic* and emotionally reserved while caregiving. By contrast, caregiving wives tend to not detach emotionally from the caring tasks. Their findings were focused on 9 male spousal caregivers out of 22 spousal caregivers in their study.

Spousal Caregiving and a Dementia Diagnosis

Caregiving for a spouse with Alzheimer's and other dementia related disorders can be demanding both physically and emotionally increasing the caregiver's likelihood of their own declining health (Butcher et al., 2001; Harris et al., 2011).

Dementia that has an onset before the age of 65 years takes longer to accurately diagnose and therefore creates more stress for the couple as they try to understand what is happening within the relationship (van Vliet et al., 2010, 2011). While the ill spouse will report feeling like something is not quite right with them, it is the well spouse that ultimately seeks out medical help and advocates for care (van Vliet et al., 2011). This includes being referred to several healthcare providers in search of an accurate diagnosis. Meanwhile, the ill spouse continues to exhibit symptoms that result in marital conflicts and stress (van Vliet et al., 2011). The relationship continues to be negatively affected as the illness progresses before and after an accurate diagnosis is made (Braun et al., 2009).

Spousal Caregiving and Frontotemporal Dementia

Frontotemporal Dementia (FTD) is the atrophy of white matter in the brain. It creates a loss of function within the frontal and temporal lobes of the brain which affects a person's emotions, social skills, and self-awareness. In addition, mood and behavioral changes include the need to always be right, emotional rigidity, and being selfish (Bang et al., 2015; Onyike & Diehl-Schmid, 2013).

Spousal caregivers of a partner with FTD often have school aged children that adds to the stressors of trying to manage both their children and spouse at the same developmental level (van Vliet et al., 2011; Williams et al., 2001). In addition, the caregivers are often still working fulltime while caring for their spouse and children. For these reasons, it is thought that the caregiver burden for those caring for a spouse diagnosed with FTD is higher than those diagnosed with dementia at an older age (Freyne et al., 1999; Rosness et al., 2008).

The diagnosis of FTD affects the relationship between the spousal caregiver and the ill spouse due to the deterioration of the emotional, behavioral, and cognitive functioning it causes (Caceres et al., 2016). The symptoms in early onset dementia are frequently attributed to mental health issues and a psychiatric diagnosis often precedes a dementia diagnosis in those 65 years or younger (Mendez, 2006; van Vliet et al., 2011). As a result, people diagnosed with early onset dementia and their caregivers may feel frustrated being bounced from one provider to the next while trying to gain an accurate diagnosis (van Vliet et al., 2011; Williams et al., 2001).

In addition, caregiver burden is associated with the loss of empathy and closeness in the relationship between the partner diagnosed with dementia and the caregiver (Fauth et al., 2012; Hsieh et al., 2013). Those diagnosed with FTD are characterized by loved ones as self-centered, selfish, and seem not to care about other’s feelings (Hsieh et al., 2013). Loss of empathy was especially noted and was associated with a less caring relationship between the diagnosed and the spousal caregiver (Hsieh et al., 2013).

Spousal Caregiving and Intimacy

Intimacy and interdependence in a relationship is the “instrumental support, affection, sexual fulfillment, and emotional closeness” as defined by Rusbult and Buunk (1993, p. 179). According to Harris et al. (2011) those diagnosed with Alzheimer’s and related disorders (ADRD) have deteriorating cognitive abilities that create constant transition and stress on emotional intimacy. However, caregivers who perceived high levels of intimacy within the relationship before the dementia diagnosis were more likely to have patience and be kind to their partners after the diagnosis of dementia (H. Davies et al., 1998; Fearon et al., 1998).

According to Duffy (1995) the “psycho-sexual health” of caregivers for a spouse diagnosed with Alzheimer’s disease is profoundly affected while caring for the diagnosed partner at home as a result of “the sexual behavior of an Alzheimer’s disease spouse” (p. 253). As the spouse’s disease progressed there was less ability to connect emotionally and cognitively, and therefore sexual intimacy decreased between spouses. Some of the female spouses described not wanting to have sexual relations with their spouse as his disease progressed, but feared he would get violent or angry if told no. The female spouse caregivers cited not feeling emotionally connected to their AD spouse but knew that sexual intercourse was a tension release for their spouse and wanted to do what made their spouse feel better. Male spouses did not report feeling it was their duty to have sex with their spouses diagnosed with Alzheimer’s disease and did not feel they needed to set boundaries. However, the male spouse caregivers did not find their spouses hypersexuality to be an issue.

Additionally, Youell et al. (2016) found continued loss of intimacy, both emotional and sexual, in long-term relationships where one partner has dementia. Participants reported due to their partner's dementia there was a feeling of sadness and loss at the "everydayness" of their lives. One participant described it as a "loss of mutual exchange" (p. 954). While questions about sexual intimacy were not specifically addressed, some participants reported sexual needs are often seen as problematic because a spouse diagnosed with dementia is either hypersexual or loses interest in sex within the relationship.

And moreover, Eifert et al. (2015) in a literature review of 23 sources analyzed caregiver identity and found female spouse caregivers were more inclined to view themselves as shifting from a wife and lover to a mother or provider. Whereas male spouse caregivers saw themselves as stepping up and doing their spousal duty with less emotional response.

The Spousal Caregiver and Ambiguous Loss

Ambiguous loss can explain what spousal caregivers experience when a partner or spouse is diagnosed with dementia (Boss, 2011). It is the psychological absence when a loved one is physically present but is cognitively impaired and therefore, not fully present as they once were (Boss, 1999, 2006, 2007, 2011). Loss can cause significant grief within the relationship when one spouse is caring for the other who has been diagnosed with dementia. Grief is a normal reaction to a loss and not a pathology; "Grief is not an illness" (Boss & Carnes, 2012, p. 462).

Ambiguous loss is "a relational disorder not a psychic dysfunction" (Boss, 2007, p. 106). It is the losses experienced within the intimate relationship between spouses or partners. Spousal caregivers who take the perspective of "my loved one is gone but she is still here, and I can learn to tolerate the stress of ambiguity" have better outcomes dealing with the strain of the situation (Boss, 1999, 2006, 2007). However, ambiguous loss can manifest as complicated grief which is seen as a pathology. The "pathology lies within the ambiguity, not in the person whose grief is frozen" (Boss & Carnes, 2012, p. 461). Therefore, the search for purpose and meaning becomes the end goal, not closure. "Lack of closure allows people the freedom to both remember the lost person and move forward with new hope and relationships" (p. 462).

According to Forsund et al. (2014), spouses experienced a sense of losing their couplehood when their partner was diagnosed with dementia. Couplehood refers to "the extent of which individuals perceive themselves as being an 'I' or having feelings of belonging to a 'we'" (Kaplan, 2001, p. 87; see also Forsund et al., 2014, p. 127). The loss of shared everyday life, the loss of a shared past, and the loss of a shared future were the combined sources of feelings of the lost couplehood.

In addition, Ford et al. (2012) conducted interviews with the spousal caregiver wives of three veterans diagnosed with dementia living at home to understand how the spousal "caregivers define, process, and grieve their losses" (p. 137). The most significant finding was related to the loss and grief the wives experienced caregiving for their spouse diagnosed with dementia. They all spoke of "their marriage as a partnership" (Ford et al., 2012, p. 143). It was the loss of the complementary unit that appeared to cause the most strain and stress on the wives both emotionally and physically. According to Hayes et al. (2009), identity shifts in many ways in the shared identity of a couple when a spouse has dementia.

Interdependence and Dementia

The reasons some couples who seem less committed stay together through trials and tribulations and others who appear to be “solid” do not can be explained by the Interdependence Theory (Kelley & Thibaut, 1978), specifically cognitive interdependence (Rusbult & Buunk, 1993).

Cognitive interdependence is defined as “a pluralistic, collective mental representation of the self-in-relationship” (Agnew et al., 1998, p. 941). This coupled with the “willingness to sacrifice” (Kelly & Thibaut, 1978) defined as “the propensity to forego immediate self-intent to promote the well-being of a partner or relationship,” could explain how couples continue to function when one is the other’s caregiver (Van Lange et al., 1997). Additionally, Interdependence Theory (Kelley & Thibaut, 1978) says that each person within a relationship must choose between the good of the self or self-sacrifice in situations where noncorrespondence is present (Kelley & Thibaut, 1978; Van Lange et al., 1997). “Noncorrespondent situations resemble social dilemmas” and is when “collective interest is better served if partners engage in pro-relationship behavior than if they behave selfishly” (Van Lange et al., 1997, p. 1374).

Research in the last 15 years has been exploring relationship-centered dementia caregiving and care (Davies, 2011; Nolan et al., 2004). Couples’ separate histories can be thought of as ‘interacting story lines’ more than existing independently (Davies, 2011; Forbat, 2005). In couples where dementia is present a “changelessness was experienced by both spouses in spite of the diagnosis” (Davies, 2011, p. 231). “The ‘us identity of the couple’ changed but remained intact” (Davies, 2011, p. 231).

Additionally, K. Adams et al. (2008) found caregivers experienced several losses within the relationship when a loved one is diagnosed with dementia. These losses include loss of sense of self, loss of intimacy, and change in the quality of the relationship. These losses significantly enhance the caregiver's sense of "role overload" and "depressive symptoms" (p. 313). However, no two couples will experience the effects of dementia in the same way based on the level of commitment and interdependence in each relationship.

Investment Model of Commitment and Dementia

The Investment Model of Commitment expands the idea of interdependence theory by suggesting that dependence is subjective and experienced as commitment (Rusbult & Buunk, 1993). Commitment in a close relationship as evidenced by the willingness to sacrifice for the other has been an instrumental component of a long term relationship (Bui et al., 1996; Lydon et al., 1997; Pierce et al., 2001; Rusbult, 1991; Van Lange et al., 1997).

Partners in a committed relationship identify as having "collectivist, communal orientation, including tendencies to respond to a partner's needs in a rather unconditional manner" (Van Lange et al., 1997, p. 1375). For example, the use of the words we, us, or our instead of individual recognition such as I, me, and mine (Agnew et al., 1998; Van Lange et al., 1997). Commitment level is defined as "a psychological state that globally represents the experience of dependence on a relationship; it represents long-term orientation, including feelings of attachment to a partner and desire to maintain a relationship for better or worse" (Rusbult & Buunk, 1993, p. 180).

Accommodation and willingness to sacrifice creates more positive regard and the caregiver chooses calmer and kinder responses when the ill partner behaves badly due to the dementia diagnosis (Menzies-Toman & Lydon, 2005; Rusbult et al., 1991).

Existential Phenomenology Conceptual Framework

Phenomenology provides a rich and "evocative description" of the human experience (Van Manen, 1990, p.19). Phenomenology is the process of describing a unique snap shot of an experience (Van Manen, 2016). Van Manen's (1990) four existentials of lived space, lived body, lived time, and lived human relation were used as a basis for reflection of the interview process and of the collected interview data.

Lived space or spatiality is the feeling or sense of a space (Van Manen, 1990). Lived space such as one's home as described by Van Manen (1990) and Heidegger (1975) is the feeling of inner sanctity and security where we feel protected and is essential to our sense of well-being. It is the feeling of safety and being "home" that we seek in the old, over-sized rocker on the front porch to watch a thunderstorm roll in and smell the wet cement as the rain hits the sidewalk.

Lived body or corporeality, according to Van Manen (1990), refers to the phenomenology that we are always bodily experiencing the world around us which includes how we experience other people. The lived body experience is sensual and tangible. It is shaking someone's hand and noticing how soft the other person's hand feels.

Lived time or temporality, according to Van Manen (1990), is subjective in nature depending on the activity. Lived time can be explained as how the hour massage felt as if only 10 minutes had elapsed, or the hour interview that felt like a lifetime.

Lived other or relationality according to Van Manen (1990) is how we relate and maintain shared space with others. It is a unique space with each encounter in which we experience ourselves with other people. It is a space that “allows us to transcend ourselves” (Van Manen, 1990, p. 105). It can be explained in a late-night discussion about one’s life purpose with close friends.

Van Manen (1990) explained the four existentials of lived body, lived space, lived time, and lived relation together create the “lifeworld” or the world in which we live. Van Manen stated that for the purposes of research the existentials can be temporarily independently studied with the understanding that one existential always brings about the whole.

Using the above framework, this study tried to capture and encapsulate the lived experience of male primary caregivers in a committed relationship with a partner that has been diagnosed with FTD and how those experiences impact the male primary caregiver by way of intimacy, interdependence, and ambiguous loss within the relationship.

Summary

Chapter 2 reviewed research studies that have explored the effects of being a spousal caregiver to partners with varied forms of dementia and other related diagnoses and illnesses and the effects on the relationship. This chapter included a representation of the meaning of caregiving. In addition, this chapter included a review of studies that explore ambiguous loss theory and the implication it has on spousal caregivers who are caregiving to a partner with dementia. This chapter included Interdependence Theory (Kelley & Thibaut, 1978) and the Investment Model of Commitment (Rusbult, 1983) and how these theories can explain specific dynamics within intimate relationships. This chapter included the background of what frontotemporal dementia (FTD) is and why it is important for professional counselors to understand. And finally, this chapter included Van Manen's phenomenology theory as it relates to the capture and validation of the lived experience.

CHAPTER III

METHODS

The purpose of this investigation was to examine the lived experiences of males within a committed relationship who are the primary caregivers for a partner diagnosed with FTD. The research approach was qualitative in nature with the foundations rooted in Van Manen's (1990) existential-phenomenological methodology and data analysis adapted from Hycner's (1985) guidelines for analyzing data.

Chapter 3 explains the methods of how this study was conducted via the research questions, the purpose and significance, research design and procedures, instruments used, sample size and selection, recruitment of subjects, and data collection and analysis.

The primary purpose of this study was to accurately describe the phenomenon by analyzing the rich content of the individual interviews of those who have first-hand experience and knowledge of the phenomenon in question.

Research Questions

The research questions for this study were:

1. How does being a male primary caregiver impact the intimacy and interdependence in the committed relationship?
2. How does the male primary caregiver of a partner diagnosed with FTD experience ambiguous loss within the relationship?
3. How does being a male primary caregiver to a partner with FTD impact the caregiver personally?

Research Design and Procedures

The data collected for this research study were qualitative and purposive. The general approach to this study was exploratory and data were gathered via 60 to 90 minute, in person or by phone individual interviews of the participants. The interviews were conducted at specific times and locations that were both convenient and private for the participants and the researcher. Individual interviews were the chosen method of gathering information for this study to stay close to the lived experience of the phenomenon being studied (Van Manen, 1990) and for the privacy of the sensitive nature of the issues and concerns that arose based on the questions asked.

The following questions were asked during the individual interviews:

1. From your perspective, how has being male and the primary caregiver for your partner or spouse diagnosed with FTD impacted your relationship?
    (a) Has it impacted how you feel emotionally connected to your spouse/partner?
    (b) Has it impacted how you have experienced loss within the relationship?
    (c) Has it impacted you regarding physical or sexual affection with your spouse/partner?
2. What, if any, impact has being a male primary caregiver for your spouse/partner had on you personally?
3. What, if any, impacts have there been on your social life?
4. If there were one way they could support you differently, what would you tell your:
    (a) doctors

   (b) family
   (c) friends

5. Your thoughts and feelings about being a male primary caregiver for a spouse or partner diagnosed with FTD will be useful to other male primary caregivers in similar situations. What additional thoughts or feelings do you have about being a male primary caregiver for a partner or spouse diagnosed FTD?

Recruitment of Subjects

The recruitment for this study required permission from the AFTD Director of Research. Once permission was granted from the AFTD Director of Research, the researcher was required to collaborate with the AFTD Director of Support Groups for all contact with potential participants. The AFTD Director of Support Groups disseminated the qualifying recruitment information to all the AFTD support group facilitators nationwide. The following steps were followed for recruitment:

1. A written description flier of the study and who qualifies to participate was sent to the AFTD Director of Support Groups to share with all AFTD support group facilitators. The AFTD facilitators then emailed all support group members as well as displayed the flier at the support group site.
2. A letter addressing caregivers explaining the nature of the study and who qualifies as a participant also was emailed to the AFTD Director of Support groups to share with support group facilitators to be shared with all support group members.

3. Both the flier and the letter included the name and contact information of the researcher and explained that the next step would be for those interested in participating to contact the researcher.
4. After an email of interest was received, the researcher contacted the interested party to verify he met the study's participant qualification criteria.
5. If the participant qualified for the study, the researcher scheduled a date and time to conduct the individual interview with the participant.
6. A copy of the participant's rights and confidentiality notice was emailed to the participant before the interview and signed and returned on the day of the interview before the interview began.

AFTD support group members were the sole population for subject recruitment in this study.

Sample Selection and Size

It was necessary for the purposes of phenomenological research to "seek out participants who not only have had the particular experience being investigated but also are able to articulate their experience" (Hycner, 1985, p. 294). Phenomenological research looks to "illuminate human phenomena and not in the strictest, sense to generalize findings" (Hycner, 1985, p. 294).

The participants in this study were males within a committed relationship who were currently or had been the primary caregivers for a partner or spouse who was diagnosed with FTD. The researcher had permission from the Director of Research at the Association for Frontotemporal Degeneration (AFTD) to recruit subjects from AFTD support groups.

The number of participants was contingent upon when the saturation point was reached. The saturation point was thought of in terms of the depth of data (Fusch & Ness, 2015). Saturation was reached once no new additional information could be gleaned and when analyzing the data was exhausted (Fusch & Ness, 2015). Seven participants were initially interviewed at different points in time and asked the same questions in semi-structured interviews to obtain rich and complex data. An eighth participant was interviewed to validate the saturation point was reached. Saturation was confirmed after the last interview.

Individual Interview Protocol

The researcher met each participant at an agreed upon, private location for the audio-recorded in-person interview. The researcher reviewed the participant's rights and confidentiality notice and had the client sign the consent to participate form before the interview began (See Appendix B). For phone interviews, the researcher reviewed the participant's rights and confidentiality notice and requested that the participant sign, scan, and return via email the signed consent form prior to the interview. The interviews averaged an hour and 20 minutes in length. After the interviews were completed, they were then transcribed for the purposes of analysis.

Transcription

All individual interviews were transcribed by professional transcriptionists through a HIPPA compliant professional company to ensure that the literal words of the participants were complete and accurate. I read the transcriptions several times and added my notes and comments in the margins while listening to the audio recordings to ensure accuracy. The transcriptions were sent to the respective participant to check for accuracy and member checking.

Validity and Member-Checking

Member-checking, collaborating with participants to ensure accuracy of data, was conducted. The transcriptions were sent to the participants with the request to review the transcript within a two-week timeframe. The participants were encouraged to send the researcher any additional information they felt was relevant and not included in the original interview, to note information that was incorrect, to clarify any statements as they felt necessary in the transcription of the interview, or to let the researcher know the transcription was accurate. It was communicated to the participants when the transcription was sent back for review, if the researcher did not hear back from the participant by the two-week deadline, the researcher would assume all information in the transcription of the interview was correct. The analysis of data began right away once the researcher heard from the participant or the deadline for the two-week timeframe had expired.

Confidentiality

The audio recordings of the interviews were stored in a password protected file and then transcribed. The transcription process removed any identifying information about the participant and his partner. All documents that contain any identifying information will be destroyed after five years.

Data Analysis

This qualitative investigation used individual interviews and researcher observations, journaling, notetaking, and bracketing as the qualitative methods of collecting and analyzing data. The transcribed interviews were analyzed by qualitative methods and included the adapted use of Hycner's (1985) guidelines for phenomenological analysis of the interview data. These guidelines were followed to accurately "be true to the phenomenon of interview data" (Hycner, 1985, p. 280).

Bracketing

Before beginning the analysis of data gathered in the interviews, this researcher first used bracketing, a methodological construct that required her to put aside her own beliefs and decenter as analyzing the phenomenon being studied to check for researcher bias (Chan et al., 2013). This researcher did this by journaling and reflecting her thoughts and feelings about each question that was asked of the participants during the individual interviews.

Listening for a Sense of the Whole

Next this researcher *listened to the interview for a sense of the whole.* After bracketing took place, the researcher wanted to "get a sense of the whole interview, a gestalt" (Giorgi, 1975, p. 87; Hycner, 1985). This entailed listening to the interview and reading the transcripts several times and highlighting salient text and taking notes. This allowed for "the emergence of specific units of meaning and themes" (Hycner, 1985, p. 281). This also entailed noted nonverbals such as silence, pressure in speech, and emphasis.

Delineating Units of Meaning

The next analysis step in this study was *delineating units of general meaning*. The researcher was "getting at the essence of the meaning expressed in a word, phrase, sentence, paragraph or significant non-verbal communication" (Hycner, 1985, p. 282). A unit of general meaning is defined as “those words, phrases, non-verbal or para-linguistic communications which express a unique and coherent meaning (irrespective of the research question) clearly differentiated from that which precedes and follows” (Hycner, 1985, p. 282). This was done by making a three-column table and listing the phrase, word, or sentence from the interview transcription in one column, this researcher’s notes and comments in the second, and the meaning in the third. If the researcher was not sure if it is a clear unit of meaning, it was included as well.

Delineating Units of Meaning Relevant to the Research Questions

The next step of data analysis of this study was *delineating units of meaning relevant to the research question*. After researcher had the units of general meaning documented, this researcher determined if it is relevant to the research questions (Hycner, 1985). Due to the nature of the interview questions, it was determined that all units of meaning were relevant to the research questions.

Clustering Units of Relevant Meaning

Next, the researcher *clustered units of relevant meaning* to decide if any meanings made sense in conjunction with each other (Hycner, 1985). The context was important and was kept in mind during this process. This step offered the researcher more “artistic” judgment. As stated by Colaizzi (1978, p. 59), “Particularly in this step is the phenomenological researcher engaged in something which cannot be precisely delineated, for here he is involved in then ineffable thing known as creative insight.” The researcher was careful to check in with her dissertation committee to keep vigilant with this process (Hycner, 1985).

Determining Central Themes

The next step in this analysis of data was *determining themes from clusters of meaning*. In this stage, this researcher determined if one or more themes emerged from each cluster of meaning (Hycner, 1985, p. 290). This researcher reflected thoughtfully and continued to check in with her dissertation committee to stay focused.

Summarizing of Each Individual Interview

Finally, the researcher *wrote a summary for each individual interview.* In this step, this researcher wrote a summary based on the interview transcript and researcher notes (Hycner, 1985). This allowed the researcher to get “a sense of the whole as well as providing the context for the emergence of the themes” (Hycner, 1985, p. 291). It allowed her to get a sense of each unique participant story and experiences with the phenomenon being studied.

Limitations

The main limitation of this study was the participant sample. It is likely that male primary caregivers for a partner or spouse diagnosed with FTD who are already willing to seek out support were overrepresented in this study. Other limitations are surrounding the way in which participants were recruited. The only means of recruitment were through the AFTD Support Groups via the AFTD Director of Support Groups and the AFTD Support Groups facilitators. Because the participants were already in a support group, their feelings may be different because support groups are therapeutic in nature. In addition, male primary caregivers who did not have access to this website or the internet were not represented in this study. Additionally, there were four participants that were widowers. Their perspectives of caring for their wives could have been looked back on with rose colored lenses. Whereas, the other four participants are currently caring for their spouses and their “in the moment” perspectives could be describing a different experience.

Chapter Summary

The methodology of this investigative qualitative approach was existential phenomenology and the purpose of the current study was to illuminate the lived experiences of males in a committed relationship who are the primary caregivers for a partner or spouse diagnosed with frontotemporal dementia (FTD) and how those experiences impact the male primary caregiver personally. This design used individual interviews, returned transcription summary of the interview to the participants for member checking, and a data analysis that extensively focused on the lived experience context and meaning gathered.

CHAPTER IV

FINDINGS

This chapter provides the findings of the data analysis based on the emergence of themes in each of the eight participants' transcribed individual interviews. Demographics of the participants are presented individually and compared with one another. In addition, snap shot descriptions of each participant and summaries of each individual participant interview are included to help the reader get a "sense of the whole" (Hycner, 1985) of participant data gathered. Lastly, this chapter presents the emergent themes in a cross-case analysis

Demographics

Eight participants in this study took part in individual, semi-structured, audio-recorded interviews. All participants were males in a committed relationship who were the primary caregiver to a partner/spouse diagnosed with frontotemporal dementia (FTD). All participants were at one point a member of an Association for Frontotemporal Dementia (AFTD) caregiver support group. The participants ranged in age from 60 to 80 years of age and the number of years married ranged from 17 years to 56 years wed. The amount of time spent being the primary caregiver for their spouse ranged from 3 to 10 years. Four of the participants' spouses were deceased at the time of the interview. See Table 1 for a Demographics reference.

Table 1

Participant Demographics

Participant	Age When Became a Primary Caregiver	Age of Spouse at Time of FTD Diagnosis	Age at time of Interview	Years in the Committed Relationship	Years as a Primary Caregiver To Date	Spouse Deceased at Time of Interview
Participant A	63 years	62 years	68 years	45 years	5 years	N/A
Participant B	62 years	52 years	69 years	17 years	7 years	1 Year Deceased
Participant C	60 years	58 years	64 years	37 years	4 years	N/A
Participant D	67 years	65 years	81 years	56 years	10 years	4 Years Deceased
Participant E	63 years	63 years	65 years	39 years	3 years	N/A
Participant F	60 years	61 years	62 years	38 years	2 years	N/A
Participant G	64 years	62 years	69 years	47 years	6 years	5 Months Deceased
Participant H	69 years	67 years	79 years	56 years	10 years	4 Months Deceased

Participant Snap Shots and Interview Summaries

The following are snap shots of each participant and summaries of the participant individual interviews. The snap shots give a brief description of each participant. The interview summaries allow for a sense of the whole for each participant during the individual interview. Each participant's story is unique to his lived experience as a male primary caregiver for a partner diagnosed with FTD.

Participant A Snap Shot: Strength in Numbers

Participant A was 63 years old and his wife was 62 years old when she was diagnosed with FTD. After his wife's diagnosis he experienced first-hand the ignorance and lack of empathy from medical professionals regarding FTD patients and their caregivers. He realized he needed help and immediately began to seek out people who understood what being a caregiver for his wife would entail. He wanted to be proactive, especially as a male in a new role. He found caregiver support groups but none that were specific to FTD caregivers. He decided, with the help of AFTD, to start and facilitate the first FTD caregiver support group in his region.

He suggested any male that finds himself in this exact role to immediately reach out to a FTD caregiver support group for help because as he stated, “I'm sorry, you cannot understand it unless you are in that role.”

Participant A Interview Summary

This interview was conducted as an in-person interview. Participant A began the interview by telling me a story of his wife’s uncle and his experiences with his wife who had been diagnosed with Alzheimer’s disease. He wanted to give examples of why male caregivers, in his opinion, are reluctant to say much about their role as caregiver. This story led Participant A to talk about how he thinks there is a major lack of understanding of what FTD is. He told me a story that really spoke about how he had to advocate for the dignity and personhood of his wife as her FTD progressed. He said:

> I took my wife to our PCP. She wanted to have some x-rays done to check for tuberculosis . . . The tech comes out to get her. I said, “My wife has dementia. She has PPA primary progressive aphasia. You can ask her questions but you’re probably not going to understand anything she says. If you need to get some clarification, I’m going to be right here, just come and get me. Well I tell you it wasn’t thirty seconds later that the door flies open and the tech’s going, “Yeah I need you.” So, I go in and the tech just literally throws this paper gown at me and says, “Get her in this, I am going back to my office and when you get her ready let me know.” . . . I’d have to say there is a lack of general understanding of what FTD is . . . I was steamed over that.

He continued to describe how he felt as a male caregiver for his wife at another doctor's appointment when there was no one to help his wife prepare for the medical procedure: "I just didn't feel comfortable going into the women's restroom with my wife." I continued to ask questions that followed up on Participant A's experiences as a primary caregiver. I asked him about how being a primary caregiver for his wife has impacted their relationship. He answered and was emotional but tried to keep composure:

> As for how it affected our relationship, it seems like from the very outset, right after her diagnosis, things started to fall apart very quickly, mostly because my wife was having more and more language difficulties . . . I don't want to keep harping on the loneliness aspect, but I think that is probably the most difficult challenge when you're dealing with dementia because you have that loss of companionship. You have the loss of your helpmate. You have the loss of intimacy; you're going through the grief process.

He continued and described what he was thinking and feeling after his wife was diagnosed:

> As far as the immediate realization for me upon the diagnosis (FTD) was that our lives were going to be forever changed and all of the sudden it started hitting me that I no longer had this companion that I depended on to help make decisions, major decisions.

Participant A was very heart felt and his sadness hung on his words as he answered my next question that pertained to his physical connection with his wife:

> I could tell you it's gone pretty much full circle. I won't say we had a perfect marriage, but we had a great marriage. I mean we were together for 45 years. From a physical standpoint, we were always very intimate. We used to say we'll be making love into our 80s. We were close, for the most part, and very intimate . . . We went (vacation) down there to celebrate our anniversary . . . it was a special place for us . . . and it was the first time I realized that her concept of what sex was had completely evaporated.

I then asked how being a primary caregiver for his wife impacted him personally. He commented:

> I think you have to learn to get in touch with your caring side because males are not really set up to be caregivers. We tend to be more on the—we're the provider and protector for the family. And when you're suddenly thrust into this role, you've got to be kind and compassionate and considerate. That touches on a different side of you that you're not used to putting on full display. So, it's been tough for me.

He continued to share more of his frustrations:

> I have my human moments where the frustrations of her lack of ability really drag me down and I can get angry and I've had to learn where my threshold is and walk away from it . . . and walk out of there and go do a primal scream in the backyard or something.

He poignantly added:

> I'm all alone . . . Here you've handed me this diagnosis for my wife, and I've got this hot potato, and I don't know what to do with it.

When he compared getting his wife's diagnosis to being handed a hot potato, I thought it was a perfect way to explain this sense of urgency and crisis he was experiencing. He added more about what helped him as a caregiver for his wife:

> I tried to seek help. And it wasn't easy at first, but wherever I could find information about FTD or Alzheimer's or anything in general dealing with dementia.

As we continued the interview, he said his dad would oftentimes joke with him and say he was going to one day be a facilitator of an FTD support group. He laughed and said:

> I am (now) co-facilitator of our FTD support group. We joke about it all the time. When we have our monthly FTD support group . . . this is our social interaction.

When I asked a follow up question about how friends and family could have helped him differently, he commented:

> Oftentimes, I would just appreciate if somebody would just pick up the phone and call me "How are you doing?" "What's going on?" Come by and visit. Don't just shut us out.

Toward the end of the interview he continued to speak about his relationship with his wife saying:

> So at this point in time, pretty much for the last five years, I felt as if I am living as a widower whose wife is still alive . . . I would go to places and see other couples enjoying each other's company or out on date nights . . . It used to bother me tremendously . . . But I am now at the point where I actually feel privileged to be able to care for her as she has declined. Sometimes I will be picking her up and getting her out of the car and she'll look at me and she'll pucker her lips and I'll kiss her and she'll say, "I love you." in her own way.

His final comment in the interview was:

> So, you do have that feeling that life is on pause and it used to kind of drag me down but I think the key to it is you got to learn just to live your life in the moment. And I try to put myself in my wife's head and think like she's thinking now. She lives strictly in the moment and I have to do the same.

The emotions of his experiences were palpable throughout the interview.

Participant B Snap Shot: Guidebook Needed

Participant B was 62 years old, and his wife was 52 years old when she was diagnosed with FTD. After two years, he retired and was his wife's fulltime primary caregiver and simultaneously cared for their school-aged child who had a debilitating disease.

As a spouse, he thought he was just supposed to know how to care for his wife. But he was in over his head and some days would hide away and listen to music to escape. Tragically, his wife was killed one afternoon when she was out for her daily run in the neighborhood. He had already been feeling overwhelmed, like he did not know what he was doing in the role of primary caregiver. His wife's death solidified those thoughts for him. He wished that there had been a FTD caregiver handbook to use as a "how to" guide for help and direction. His advice to other men in his position is to get help right away—do not wait.

Participant B Interview Summary

The interview with Participant B was an audio recorded phone interview. The interview began as Participant B shared how being a primary caregiver for his wife impacted their relationship. He immediately started to describe how things had been and how they had changed. He commented:

> I became sad for her seeing how sad and traumatizing, frustrating, the testing had become for her and the inability of herself to perform to the standards she had hoped and had always been able to perform . . . And so all of that made me sad for her. That's when I retired, I became a lot more of, I guess, a caregiver and doing a lot more things for her than I had ever done before.

He continued to talk and brought up their physical intimacy. He said:

> And I guess I should say our sex life became virtually non-existent, which wasn't necessarily a problem, it was just shocking to me, her inability to understand and know and lose understanding of parts of her body. There was not only watching her decline, but almost deteriorate. I mean her physical shell was still there and some of her mental acuity were still there.

It was quite apparent to me by the inflection in his voice, the strain, that this was an overwhelming transition in his relationship with his wife. He continued to talk about his caregiving experiences with his wife:

> And eventually because I had to physically keep her from going outside naked, she started getting angry . . . I had to sit on her with my back towards hers and she would pound on my back with her hands and I'd be able to put on her legging, workout pants. She would already have a shirt on, maybe the one she slept in . . . and so it was just exhausting.

Throughout the interview I listened attentively and verbalized hearing what he was saying while being empathetic. He then talked about his relationship with his family and added this glimpse into the relationships:

> And our son was very—he was a teenager going through a lot of disconnection or trying to separate from us, and so the last thing he wanted to do was be around us. So, he was shut in his room, but could hear. I mean being a small house he could hear all of the aggression and anger at times when she got agitated. And

> sometimes she and he would get into it, or sometimes he and I would get into it. Sometimes it would be me and her. And so, it was just this triad of chaos. So, it wasn't a good family unit. It wasn't a good husband and wife relationship. That had been going on for the last two years.

I asked Participant B how being a primary caregiver for his wife had impacted him personally. He responded:

> Some days . . . I retreated. I wasn't sleeping well. So, it was just . . . very stressful. Like I said early on I hid sometimes during the day . . . I just went into our separate house and laid down on the little bed we had there. Listened to the radio, drifted off.

While he seemed to be having difficulties finding time to decompress, he tried to make sure his wife was still connected to folks with whom she could go running: "She was an elite runner. She ran over 40 marathons. I always made sure she had running friends that would either train with her or run with her during races." I had noted during this comment in the interview that this was a way to keep a piece of her dignity intact with an activity that was so much a part of her identity. And it seemed to resemble some type of normalcy in their relationship before FTD entered the relationship. As he finished his comment about his wife's love of running, while trying to hold back tears, his voice cracked and he stated:

> Eventually, I didn't do such a good job with her because one day she ran away and I tried, in the afternoon, putting a missing person's report in . . . late that night she was hit by a car and killed.

I gasped as he described what happened to his wife. He had not disclosed this information to me in the initial screening and I was taken aback by his experience. I could feel a lump form in my throat as I tried to remain composed during the rest of the interview. Later in the interview he told me:

> What I would have liked to have done for me, at the time of my wife's diagnosis, to have an assessment of me as to my ability to be a caretaker . . . in hindsight I

> don't believe I was emotionally equipped to help . . . I really needed, sooner than later, to have someone that was emotionally attuned to be with her, to take over this aspect of caregiving . . . I was over my head and I didn't know it.
>
> I would tell people get into a caregiver support group. For me, it was really good in person. In hindsight, I should have probably retired a year earlier . . . I probably should have retired as soon as she was diagnosed . . . if I was going to have any quality of life with her before she went into a more severe state . . . But we had a son. It was complicated now because we had a son.

The interview jumped from topic to topic as Participant B thought about different aspects of being a primary caregiver for his wife. He made a profound statement about how it impacted him personally: " There's four or five times in my whole life when things have happened. It's not like something you gradually get used to. I am hugely affected. It's like a quantum step." This comment seemed to perfectly capture that loud clap that occurs in one's brain when trying to comprehend traumatic and life changing events. I followed up and asked about how being a primary caregiver for his wife impacted his social life:

> I didn't have a social life. It was between my son and getting him to school and taking care of our house—just all of the needs of being responsible for the house and taking care of our medical appointments between the three of us. And then when you retire, trying to manage medical coverage for all of us.

I could feel the pressure he had been under and the toll it had taken on him. He offered:

> Well, I felt a lot of guilt. And still do, and I feel—there's not a day that goes by that I don't remember, deeply, something about her, and so I have a lot of sadness on a daily basis.

He continued to talk about how his house, that space, how it made him feel, and what he wished he had known. He shared:

> And it's coupled with this house too. It was my second marriage and it was her second marriage and we'd been in the running club . . . I was with her when she first saw it (the little house) and we were dating. Eventually we got married and I bought half the equity, and then she and I did a total remodel of it. And there was a separate cottage that we did. And so, every aspect of the house and the cottage,

> I can't—and I don't want to, but there's not a place I go that I don't remember a single—I remember so many moments with her.
>
> I felt like at the end of my caregiving and her death, I wish there was a kind of handbook of things to do as a guy or whatever . . . I was at a loss.

The interview came to a natural conclusion after this comment.

Participant C Snap Shot: Self-Care Required

Participant C was 60 years old and his wife was 58 years old when she was diagnosed with FTD. He continues to work fulltime and starts his days by waking his wife so she can begin to get ready for the day. He has about 45 minutes of quiet time to himself until she comes downstairs for breakfast. The routine starts out the same each day, but how long it takes is dependent upon what his wife's obsession is that morning. It is stressful because he watches the clock knowing he needs to leave for work by a certain time. Each day brings a new issue and he constantly watches his wife as if watching a 2-year-old child.

He finds that he has less and less time to take care of himself, but he knows how essential it is to decompress from the daily stressors of caring for his wife. He would recommend that downtime be made a priority for others in his situation.

Participant C Interview Summary

This was an in-person interview. I began the interview by asking him about his experiences as being a primary caregiver for his wife and how it has impacted him personally. He answered:

> It's impacted me quite a bit. It's going from someone (wife) who was very independent, and we have been married for 36 years, to someone that, now, really needs assistance. So yes, it has kind of changed my life quite a bit. Sometimes I feel and a lot of times, and unfortunately, it's a constant thing, like somebody dies, you have a mourning period, right? But then you pick up the pieces and you move on and stuff.

He continued to talk about what an average day looks like for him. As he talked, he seemed frustrated as he described his experiences. He continued:

> Some days I wake up in the morning, and she's very confused and foggy in the morning. And it just takes a while to get her going . . . Basically, I can't do a lot of stuff. Basically, I have to do everything in the house.

He then offered more of a detailed daily morning routine:

> We can get, I mean, into a routine like in the morning I know what the routine is going to be. The question is how long is it going to be? She'll get up, I'll pour her coffee, she'll go out, have her cigarette out on the table. She'll go out and sometimes sit in the garage, she's just like sitting there. And so, I have to get her back into the house. Now what she does, even though she goes to the bathroom upstairs when she gets up, she'll go back into the bathroom downstairs and she'll just sit there. So, there's getting her up. And then she'll sit down . . . so it was this back and forth, back and forth. And then finally I got her to get the cereal in the bowl and get the milk, get the spoon . . .

As he finished with the description of his daily morning routine, he said:

> I just try to take time, even in the morning I'll get up at 6 am. My wife will get up at 7 am. I have 45 minutes of quiet time before she gets up. Because once she gets up and comes downstairs, I know it's a ritual we will have to go through.

I asked him how this impacts him personally and he said:

> Very stressful, very stressful because again, especially if in the car, if she gets in that zone, where she's just repeating herself over and over and over again, it's like you can't escape, you can only turn the radio up so loud. Emotionally, sometimes I'm drained. Especially if going in on Monday from a weekend, if I'm really by myself, I'm tired on a Monday.

I then asked him about how his relationship has been impacted by his wife's diagnosis of FTD and being her primary caregiver. He commented in a very heartfelt but matter of fact way:

> I mean there is no emotions on her face and stuff. When she kind of gets into that good zone, then you can see the love there. You can see the emotion, maybe crying a little bit, hold hands and stuff. So, it just depends.

During the interview he also warmly told me about him and his wife before FTD:

> We got married in 1982 and all that time she was my best friend. And then, we had three kids. She almost read my mind, I was thinking something, she could read my mind and stuff. So, you miss that because all of a sudden, it's all gone and so again, depending, most of the time I'm talking to someone who's not even listening to me because she zoned on something . . . So I definitely miss that. Because I knew who she was and now who she is and that really has changed dramatically.

I could hear the pain and longing of lost intimacy in his voice relationship with his wife.

He shared:

> Sometimes I sit there if all of the sudden she says okay, let's be intimate and stuff like that I think okay. But it's so sporadic . . . you kind of take what you can get. Because I always say that if you're just close and touch that kind of means a lot. At least you feel connected and stuff.

As the interview continued, he added more about his relationship with his wife:

> We used to love to be together, feed off each other and I think we had an excellent intimate relationship through those years and stuff and I realize raising kids, that always changes things from a standpoint. But we always tried to find time to go away by ourselves . . . Now . . . I said just do an overnight . . . So we test it. Sometimes I'll say let's go and let's go to a hotel and just spend the night there . . . we try it. If it works, great. We have a really good time and she's in a good zone, great. If not, I says, that well, then it's just like the same as being home.

After the interview was coming to a closure and I had turned off the computer audio recorder and my phone, Participant C started to talk more about his experience. I asked if I could continue to record and he agreed to it. I started to record again and while talking more he said:

> I always think—the good years that we had before she got sick is that you build up a tremendous amount of brownie points. And as things kind of don't go as well, when you're dealing with a disease that—you've got to be like, "Alright, she gave me a lot of quality years in there where we just loved to do things. Just had a lot of love there. And now, she might not be able to show that." So sometimes it's up to me to show more.

And fighting back tears he ended with: "And that's why I am here now, to help her. Because I know if something happened to me, she would be there helping me."

Participant D Snap Shot: Frozen in Time

Participant D was 67 years old and his wife was 65 years old when she was diagnosed with FTD and he became her primary caregiver. He was determined from day one to keep their daily life as normal as possible. He was steadfast in honoring their routine of eating dinners at the dining room table and keeping a weekly hair appointment for his wife. He continued to work part-time on contracted projects that included some travel. He continued this same routine for the 10 years he cared for his wife.

He was adamant that he had never identified himself as a caregiver. He was many things in life, but he never thought of himself as a caregiver. He also felt as a spouse, it is important to forget about yourself right away once your other half is in need. To him, he was doing what any spouse would do.

Participant D Interview Summary

The interview with Participant D was an audio recorded phone interview. I began the interview by asking him from his perspective how being the primary caregiver for his wife who was diagnosed with FTD impacted their relationship. He immediately responded with:

> When I thought about these things, probably one of the most important things was to have absolutely as little change as possible from our previous routine . . . I found the not talking, the habit of having interesting and lengthy discussions about all kinds of things, the things we were doing (difficult). And at first there would maybe be a little recognition, a blink or a nod or sometimes a few words, but then words gradually stopped, to the point where there was little conversation whatsoever. So that’s difficult to adjust to when you’re used to having pleasant and lively discussions.

As Participant D continued to talk about his wife’s diagnosis of FTD, I asked him how it had impacted him personally. He appeared to be matter of fact and even tempered and said: “I’m not sure it really did. That’s what I am saying. I think maybe I just blocked out everything like that.”

At several points during the interview he commented on how he tried to keep things the same as they had been previously before his wife’s diagnosis. He commented: “I tried as much as possible to for myself, to have as few changes as possible and trying to work around so that my life wasn’t dramatically affected, and the same thing for her.” He continued to talk about their life and before the disease entered their relationship. He said:

> I guess that was a different change with the disease, that it’d become had become apathetic and passive, which was in contrast to previous life where we took great pleasure in all the nice things we did. We did a lot of nice things and travels and recreation and social settings. And that always brought great pleasure. But that either went away completely or it was no longer expressed in a noticeable way.

He told me about how as a couple, they used to travel extensively to Europe and other places and how they both loved to sail and ski. I noticed his memories of times before FTD were told with a little more emotion and excitement. But he reiterated that keeping life as much the same for both was important to him. He commented:

> But all these little things. We would always sit at the dining room table for proper dinner and stuff like that. I guess that probably makes a difference. I have no idea. And some people of course, as quick as possible, ignore doing all those things because they say, “Well, the person doesn’t recognize” or “It’s just too much trouble for me.” And if you think that way, then you probably do nothing and you probably just sort of warehouse the person.

I next asked how being a primary caregiver for his wife after she was diagnosed with FTD impacted their physical or sexual relationship. He was thoughtful and answered: “Without any responses, that kind of drifted away . . . So it’s not a matter of necessarily not trying but not expecting any reaction or response. And I wasn’t comfortable with that.”

I then asked him about how being a primary caregiver for his wife had impacted him emotionally:

> I think where we were starting from is that the environment in the household was always very peaceful and calm and not all too emotional or anything anyway . . . I'm not sure I got too emotionally involved and was pragmatic . . . I just wondered whether what I had done was sort of compartmentalized and blocked out any emotional reaction to the point you deaden your emotions a little? But I never felt really, certainly never angry about any of this, never frustrated, or anything like that. I was just, "okay, this is the way things are."

I was intrigued that he had previously commented that he did not think he was emotionally taxed in his role of primary caregiver for his wife, yet he talked about how he compartmentalized his emotions. I followed up and asked him if he could explain what he meant by compartmentalized and he said:

> If I want to do something for recreation like sailing, I think about that only from my perspective, whereas in the past, that would have been something we would've done together. That's no longer possible, so I don't dwell on it and say, "Gee, this isn't as much fun as when we did it together." I just block out, and in a lot of ways, for the last several years I was living in my own little world and living alone just as much as I am right now. I mean, that didn't just start after she was gone. I mean, I was living in a lot of ways almost just as a lone individual, because the other person was not available.

I noticed his inflection in his voice changed slightly as he continued to talk about this topic and added:

> I am willing to share what worked or didn't work. Two things probably. One is whether they're used to it or not, it's probably necessary to a certain degree to compartmentalize the different parts of your life at that point because they'll be different. But probably the most significant thing you've got to do is forget about yourself. Don't think about you're frustrated or angry or anything, but you've got a job to do to take care of the person. You do that. In that sense though it does mean probably blocking out a lot of your own emotions, so that you don't get frustrated or angry.

As we continued to talk about his experiences, he began to talk about how others might have a different experience based on resources. He noted:

> Now I guess we were fortunate because we had a good caretaker and so I was free during the week to come and go and whatever . . . I can't imagine if you were confined to the house 24 hours a day to take care of somebody, that I think, would get you depressed pretty quickly.

Toward the end of the interview, Participant D brought up how being a male and a primary caregiver could affect a man's identity. He went on to say:

> As I thought about this a little bit, there's another thing that you probably have addressed, and it might be important. The difference between the male caregiver and the woman caregiver. A woman who—she had her own businesses and things like this until she retired . . . identifies herself as a caregiver. And I was a little surprised by that because, I mean, I didn't think of her as a caregiver. But when I thought about that, my reaction was—well, if I met somebody (and he) asked me what I was or something, I would have never in the furthest reaches of my imagination referred to myself as a caregiver. I was a retired engineer. I was a sailor. I was a skier. I was a musician. I was lots of other things but for a man—I don't think it's—even if they thought of themselves as a husband and a father, I don't think they're so quick to think of themselves and their identity as being a caregiver. I think this is important because for most men, their identity is tied up with their work and/or their hobbies and recreation, whereas often a woman, even if they're working professionally, still thinks of themselves as a homemaker and a mother and a caretaker . . . For a man, this is a major loss of identity and self-image.

It was interesting to hear how he identified as a man, retired engineer, skier, musician, and never as a caregiver. And he was his wife's primary caregiver for 10 years. We ended on this topic as he wondered if these were similar experiences of other male primary caregivers.

Participant E Snap Shot: Isolated and Detached

Participant E was 63 years old and his wife was 63 years old when she was diagnosed with FTD and he became her primary caregiver. As his wife's disease progressed, he started to view her as the person that *used* to be his wife. He feels he is honoring his wedding vows by taking care of her but equates it to caring for a giant toddler. He constantly reminds himself that it is the disease, not his wife's choice to act as she does.

He continues to feel isolated and alone as friends find it more awkward to visit and spend time with them. He would encourage others in his position to find a FTD caregiver support group so that you know you are not alone.

Participant E Interview Summary

The interview with Participant E was an audio recorded phone interview. I opened the interview and asked him if being a primary caregiver for his wife who had been diagnosed with FTD impacted their relationship. He very bluntly told me:

> I mean to be honest with you, there's really nothing that is the same. With FTD, they can no longer really comprehend anything, so for her to know what a relationship is or intimacy or any of that—none of that exists anymore. She's 65 years old, and I'm taking care of a two-year-old.

I was a little thrown off by the emotional negativity I felt from his first comment in the interview. His response sounded like one of frustration and anger versus one of sadness that I expected. I next asked specifically how his primary caregiving experiences had impacted him emotionally. He answered: "There is no longer an emotional tie of (her) being my wife. It's hard. You're isolated."

As Participant E spoke, I continued to sense his frustration and what seemed to be extreme anger at the situation, the disease, and how it impacted his relationship so profoundly. He shared:

> The emotional connection now is that was my wife. That was somebody that I had a commitment to take care of her, sickness and in health or whatever, and that's what I'm doing. So, the emotional part, that's pretty much it, is I have that emotional tie and commitment to her. I will take care of her, whatever she needs. Other than that, there really is no attachment any longer to—she's not my wife anymore.

He shared more of his experiences and thoughts around this topic throughout the interview. He added:

> You basically lose everything. First quarter, probably somewhere around 2017, I ceased mentally to view her as my wife anymore. At that point, I was more a widower. I viewed myself more as a widower than a spouse . . . You're a widower but your spouse is still there . . . You're a widower and a caregiver to a child. A big child.

As he shared his lived experiences of being a primary caregiver for his wife, I noticed my own anxiety increase. As I continued to listen to his emotions regarding his life before FTD compared to now, I became overwhelmed. I drank water during the interview to ground myself to continue the questions. I then asked if being the primary caregiver for his wife has impacted the physical affection or intimacy in their relationship and he shared:

> That ceased in 2016 about the time of the diagnosis. There was no longer—she could no longer really be intimate with you, both sexual and emotionally . . . And once you start doing the research on the disease and what's going on, to kind of relate it to something, it would be almost being intimate with a child, and that just totally ends it right there.

This comment was palpable and gave a concrete example of how having sexual relations with his wife would be taboo and compared it to having sex with a child. Later in the interview he circled back around to this topic:

> I started noticing change—just like intimacy or sexual or whatever, it was just not really the same prior to the diagnosis. Just things were just—it's like she's almost just kind of there and just not really fully mentally into the intimacy like she was. There's sex and there's making love. And the making love kind of almost seemed to dwindle away.

I followed this question and asked how his experiences as a primary caregiver for his wife had impacted him personally. He right away said:

> I have no free time. So, I had to take over all the business aspects. But not only that. On the personal side, I've had to take over everything too, so it leaves you

> virtually no time because you were splitting stuff up before. I now have to do everything. So, it's now to the point—she's in the final stage now, and it's at the point now she can't do anything for herself. I have to bathe her. All of her day to day activities that you would have to do, I now have to do all of those for her plus myself. So, I'm really doing the work of two people, brushing her teeth, bathing her, everything.

Later in the interview, Participant E continued to talk about how being his wife's primary caregiver impacted him:

> I knew something was going on (before the FTD diagnosis) . . . And it just kept getting worse and worse, and then we were fighting and stuff and then it was like—I would get in the car and just go for a ride to just vent and settle down, and bring your emotions back down so we could get back together and move on. And then like you'd find yourself out in the afternoon, here it is again and you're off in your car again. It's like holy crap. And it's every day. And it's like, okay. This is not how we're going to spend the rest of our life together. This isn't going to work. We're going to get a divorce or whatever it is, but this is not going to work. So yeah, it was really affecting every aspect of our life. It was affecting everything.

As the interview continued, he shared what has been one of the hardest things for him to deal with as a primary caregiver for his wife:

> Probably my biggest issue that I have is that it's so easy to lose your patience. It's easy to, "Come on. Help out" or whatever. She's like a blob or a zombie . . . Now I'm having to brush her teeth and it's "Come on, open your mouth. At least do that." "Open your mouth where I can see your teeth and brush your teeth." I have to force her mouth open.

As he explained this scenario, I found myself feeling both shocked and privileged that he shared so honestly what his existence and experiences have been as his wife's primary caregiver. He eventually commented:

> Emotionally it wears on you and you just have to walk away and take a break. And I know, personally, I don't say it enough, but I need to keep at the forefront of my mind it's not (my wife), it's the disease. A disease that's doing this . . . That's probably been the toughest thing, I personally have had to deal with.

Toward the end of the interview, Participant E concluded with a few statements about being male and a primary caregiver:

> And we males are not the one that's primarily looked to, or whatever, as being caregivers . . . because it's not an—I mean, it's nothing we've really had to do. And yet, all of a sudden, you're thrust right in the middle of it and now I've got to do everything for her.
>
> I think it has in a sense, that I look at my male friends and comments, whatever, that I get from males. And it's more of, "Gee, I'm sorry you're dealing with that," or whatever. But I know when I talk to females about what I'm going through, I get more empathy. More, "How can I help you?" or "What can I do?" Or more of that kind of stuff.

The interview ended shortly after this comment.

Participant F Snap Shot: Care and Flexibility

Participant F was 60 years old and his wife was 61 years old when she was diagnosed with FTD and he became her primary caregiver. He continues to work fulltime and considers himself fortunate that his employer is allowing him to work from home. This is critical because his wife continues to progress without any plateau in the progression of the disease.

Throughout the last three years, he has had to learn to ask for and accept help from others because he feels he is the best one to care for his wife. He is grateful for all the support he receives from his three grown children. His primary goals are to ensure that his wife has a meaningful existence and a good quality of life for her remaining time. He admits it has been a tough job and he has had to learn to be flexible, but he believes anyone could do it if it were your spouse.

Participant F Interview Summary

This was an in-person interview. I opened the interview and asked Participant F how being the primary caregiver for his wife has impacted their relationship. Right away he said:

> It’s completely turned around, okay. It’s completely turned around . . . In terms of our relationship, it’s more of an almost parent-child at this point, which is very painful, but we take heart in the fact she is not in physical pain.

As he answered this question, I could see from the tears in his eyes to the strain in his voice it was painful for him. He also talked about how their physical and sexual connection had changed:

> There probably isn’t much. She has lost some of the motor control, so she can’t kiss, she can’t stick out her tongue. It was a good ride. It still is a good ride, just a little different ride.

This led into him telling me about how being the primary caregiver for his wife changed how he works daily:

> She can’t be left alone. I’m fortunate my employer, when I told him about the diagnosis, said, “You now work from home.” So, I’m able to be with her 24/7, but that’s a tough job. So, we’ve been able to find an excellent adult day center that takes really good care of her and actively involves her. I wanted her to have a meaningful, as best we could, meaningful existence. She goes there four days a week from 9:00 am to 2:00 pm.

It was apparent that Participant F wanted to ensure he felt he was doing everything in his power to continue to provide for his wife. He added more on this as the interview continued:

> People come in (to visit), they’re so sad. I said, “Alright friend. This is the no crying zone for everybody. There’s no crying right now. She’s not sad. You can’t be sad.” So, the only rule we’ve had, if you come here and you’re sad, if you’re going to be sad, you be sad somewhere else. It impacts her. We always make sure (my wife) looks great every day. We’ve had to experiment with wardrobe because she has been a little weak. I said, “You’ve got to look good every day.”

> She always looked great before she got sick. And we will just try to continue that . . . (Dignity) that's the word. And I think we do a pretty good job of that.

I followed up with a question about how being a primary caregiver for his wife with FTD had impacted his social life. He told me a loving story how his children pitched in to help make socializing still happen. He said:

> (People from my FTD support group) we decided that we would go out together (spouses included). So, we did and we've done it two or three times and it's great because we understand what's going on, there's nothing that happens at the table that can shock us . . . in December one of the (spouse caregivers) mentioned her husband was having a little bit of stress. I said, "You know what? It's just more important we get together." So, my kids had dinner (made dinner) at our house and they came in and cooked a really nice dinner for us.

I asked him about how all of this, being a primary caregiver for his wife, has impacted him personally. He paused and said:

> Hugely. I'm just trying to find a place to start. Well, we never planned for Plan C. The reality is, I have to change, and I haven't been a flexible person in the past, so I've learned to just go with it for a lack of a better term and just make sure she is safe. So, in terms of me, I dream into the future of, quite frankly, what's left without her. Probably gets me through some days, quite frankly. As cold as it sounds, this isn't forever. I know that sounds pretty awful.

I was in awe by his raw honesty. I felt in that moment, with his comment, just how much he missed and loved his wife. He continued to talk about his tendency to become more easily frustrated with his wife and the situation they are in because of this disease: "I have a tendency now more to lose my patience, so I tend to leave the room a lot more than I used to because it's the best thing to do." Further into the interview he circled back around to this topic when asked what advice he might give to someone else in his situation:

> You need a really big bucket of patience. I think that's the biggest—it's not your spouse talking or acting. It's the disease talking or acting. Try to take that understanding with you every day. It is going to be probably the hardest thing you ever do. Understand that, reach out for help . . . Any help is good help.

This led me to ask more about his own experiences with being a caregiver and help received. He offered:

> I am at the point where I'm not afraid to ask for help, which has been the biggest hurdle for me. And I am getting better at it and people have responded well. I have 3 great children.

I then asked about if there is any activity or socialization, he does just for himself and he said:

> At the age of 62 I started taking piano lessons . . . I play piano. So that's half hour a week and all I can think of is do I have too many fingers in the wrong spots. But it's probably the only 30 minutes a week that I am not thinking, quite frankly, about what is happening to (my wife), and I know my daughter has her, and I know she is the best one besides me to have her, but at the same time I'm like, "What happens if?"

As Participant F continued to talk about his lived experiences, he began to talk about what it is like to be a male and take his wife shopping or other excursions:

> I go to Macy's and go with her to try on clothes . . . I need to be in there (dressing room) sometimes, I don't want to come in there, I am not a creep . . . That's something I have not been able to overcome. (When out) the bathroom is always scary to me because I can't be in there unless we've got a private family bathroom. So, most of our excursions I always try to think if there's going to one there. That's a little helpful.

As the interview was coming to its natural end, Participant # 6 made a profound statement that seemed to capture the urgency he was exhibiting during the interview. He quietly said: "I thought we had a little bit more time." The interview ended shortly after this comment.

Participant G Snap Shot: Faith Tested

Participant G was 64 years old and his wife was 62 years old when she was diagnosed with FTD and he became her primary caregiver. He had strong faith and was active in his church and believed that his wife would be saved from the fate of this disease. His wife had always been religious too and they both did community outreach based on their faith. When he realized that a miracle was not going to happen for them, it was emotionally devastating. He had to come to terms with what it all meant existentially.

He expressed being proud to be a part of this study to help others understand the role of primary caregiver for a spouse with FTD.

Participant G Interview Summary

The interview with Participant G was an audio recorded phone interview. I began the interview and asked him how being male and the primary caregiver for his wife who had been diagnosed with FTD impacted their relationship. He told me:

> I mean it's life changing and there is a lot of things that you used to do that you cannot do anymore. It just slowly takes away your relationship that you had with your wife, and you become just the caregiver . . . I would say (it) definitely impacted our relationship because you go from having a wife, to basically taking care of your wife, and eventually as the disease progresses, you wind up taking care of almost a toddler.

I next asked him about how it impacted him emotionally. He took a minute and then answered:

> Emotionally, I guess guys don't talk about emotions too well, but I don't know if it affected us, I don't know. Emotionally, it made some things harder, I guess as she progressed . . . So we're pretty much involved in our lives religiously. So, it was kind of hard with the emotions, say, coming across with the fact that 'Okay. We believe in God and we believe in miracles and praying for things to happen.' And then, eventually finding out that this probably is not going to be happening. I guess those things were the more emotional responses to the disease than anything. I guess you would say this is a downer. I definitely feel sad, but I guess it's one of those things it is what it is and so you just deal with it. I mean, I definitely have had my moments where I cried. But I knew there were times when the loss of her and her affection was definitely taking their toll on me. But it's something you kind of push back or over to the side because you've got a job to do that's more important than worrying about . . .

As Participant G answered the questions and shared his lived experiences, I felt the intense emotion in his voice. I then asked him about his physical relationship and affection with his wife. He told me:

> Well, the physical affection definitely was affected because she—one of the main symptoms is not having empathy and not having desires anymore. It was pretty much a deal that you just got to that point as well. You're not going to be having a sexual relationship anymore. I mean, when we first started in 2012, we were probably having some kind of relation at that point, but they were definitely becoming fewer and farther between. And then once she got to the point where it was apparent she could no longer make a decision about this type of thing, then I began to think . . . Well if she can't say yes or no and make that determination, I guess we're just going to have to go with no. So, we basically, after 2013, had no sexual relation.

He continued to talk about his relationship and how it had changed physically. He added:

> We had physical contact, but the thing when you have physical contact with your wife at that point, a lot of the times, I mean, it's like giving a hug to a person who doesn't know how to respond back. As far as giving her a kiss, it was not, anymore a passionate kiss. A lot of times it comes down to a kiss on the cheek. There was very little embracing.

As he continued to talk about his experiences and losses within the relationship with his wife, with conviction he said:

> And so all you do is carry what love you have for her into the job of taking care of her and being as kind and as helpful as you can to make her life as easy as possible and try to keep her without having pain or suffering during the process. I guess.

I then asked him about if there were any impacts on his or their social life. He shared:

> Her getting diagnosed with FTD basically impacted our future plans to the point where we had planned on as soon as she was ready to retire to start doing some traveling around the country. And once we got the diagnosis, I said, "Well, we are going to have to go to Hawaii now because we don't know when or if we'll ever be able to do it."

He gave another example of how being the primary caregiver for his wife impacted them. He told me about a scary event:

> But traveling became almost an impossibility because of things and what happened when we were in the car. She was trying to take off her seatbelt, open the door while we were going down the road at 60 miles per hour. I basically had tried, "Okay, let's move to the backseat so that I could use a childproof lock on the car to keep her from opening the doors."

It was clear from this story it was not only emotionally trying but a physical challenge to care for his wife.

I next asked Participant G about what he thought others in his same situation might need to know about being a primary caregiver for a spouse in a similar situation:

> Well, I guess the main one is be basically close enough with your wife to know what's going on with her. I think that my wife and I were close enough that I knew . . . for years we never had any pads around the house at all. All the sudden, I'm in the bathroom, "What are these pads for?" Well, she started to become incontinent and purchased the pads, and then I started talking to her about it. So, I know guys, husbands who couldn't tell you anything about their wife, let alone be able to read them and know something is wrong.

This was a concrete example of what he noticed in their bathroom that made him start to question if something was wrong with his wife. He continued to share:

> You learn to do all sorts of little things that you never dreamed of being able to do to take care of her to make sure she is not suffering and to make sure she is not in pain . . . You want to kind of be able to protect her dignity as much as possible.

After this, the interview came to a natural end.

Participant H Snap Shot: Transparency Needed

Participant H was 69 years old and his wife was 67 years old when she was diagnosed with FTD and he became her primary caregiver. Initially after his wife got the FTD diagnosis, he chose not to tell friends out of fear and embarrassment of how they might react. It was only after a close friend of theirs wrote a letter declaring their friendship was over, that he decided he had to be open and honest with her. He was surprised at the level of support and caring that friend expressed and it prompted him to continue to be transparent with all their friends. He believes that being part of a FTD caregiver support group is essential to understand that you are not alone and to gain reassurance in asking for help.

Participant H Interview Summary

This was an in-person interview. I began the interview and asked Participant H how being male and the primary caregiver for his wife who had been diagnosed with FTD impacted their relationship. He answered:

> Whereas we were co-equals before, and each had our likes and dislikes, and ways of doing things. As time went on, it became focused on her care . . . She had less empathy for what I needed. It was more focused on her. But the love never left, certainly on my part.

He continued to talk about the all the changes that occurred over a two-year period and noted how those experiences impacted him personally. He said:

> Yes. In fact, you know she died in March. And people talked to me about how devastating the loss must be, and it is of course. But it's not like she suddenly died, and I was mourning her for that. I was mourning for the last two or three years because I had lost the person that she was. So, it definitely impacted me from that standpoint.

He appeared deeply saddened as he told me about her smile:

> And that was—the smile—she had a beautiful smile. But the smile, the frequency of the smiles became fewer and fewer as time went on. . . . And I remember one of the things that we did is a funny story (at our 50th Wedding Anniversary Party about a year after the FTD diagnosis) about our wedding and honeymoon. We both related the story to the group. I gave her a script, and at that point, she could read from the script with a few mistakes, but she could still do that. And so we could still do that and laugh about things and remember things. We went on a cruise then . . . a month-long cruise.

I then asked if his physical relationship and affection had been impacted in his relationship with his wife since she was diagnosed with FTD and he became her primary caregiver. He told me:

> Well in terms of hugging, and kissing and touching, really no effect. Sex became a thing of the past . . . And she would have participated but I felt like if she didn't have the ability to say yes that it wasn't fair to her. So that was the consequence of the FTD.

As the interview continued, he shared more about how his wife's diagnosis impacted him personally:

> I think embarrassment, mainly. Anything that has to do with a mental condition. There's a tendency— it's not the same as having cancer or a broken leg or something that everybody understands. If it's mental condition or dementia , there's a fear that people aren't going to understand and you will be isolated in the community. And what I found out is that the opposite is true. The more open you are the more supportive people will be.

He later commented about the advice he would give other male caregivers for a spouse in similar situations. He offered:

> If you really love the person, even when it gets difficult, you want to be their primary caregiver. You want to be in charge of their health and to abandon that, I think, is abandoning the vows you took when you were married. They didn't say "in health" they said "in sickness and in health" . . . but the other part to that is when you get to a point where it starts to impact your own health, then you may need to find a different path. Maybe put the person into assisted living or a skilled nursing facility. And that was the most difficult decision I had to make.

The interview came to the natural endpoint.

Analyzing The Data

Hycner's (1985) phenomenological data analysis guidelines were adapted to analyze the transcribed individual participant interviews. The following are the steps the researcher followed:

1. The researcher first established *units of general meaning* by taking notes as the transcriptions were read to ensure clarity of meaning.

2. Once the units of general meaning were noted, the researcher then began bracketing. *Bracketing* included note taking while reading the individual interview transcriptions which allowed the researcher to de-center to ensure the meanings were derived from the participant's worldview and not the researcher's expectations based on preconceived ideas or opinions.

3. The researcher then *listened for the sense of the whole* while listening to the audio recorded individual interviews and rereading the individual interviews transcriptions. This step allowed for specific meanings and themes to emerge in each individual participant interview.

4. Next, the researcher *delineated general units of meaning* by using phrases or words that are unique irrespective of the research questions.

5. After this step, the researcher next *delineated the units of meaning relevant to the research questions*.

6. Then the researcher *eliminated redundancies and combined units of meaning according to the relevancy to the research questions.*

7. The researcher then *clustered units of meaning* which included examining if certain units of meaning naturally cluster together.

8. Then, the researcher *determined if the clustered units of meaning reflected more than one of the central themes* that were emerging.

9. The researcher then *wrote a summary of each individual participant interview* from researcher notes and observations to get a sense of the whole for each participant.

10. Lastly, the researcher *identified general and unique themes for all the interviews*. This included noted themes that contrasted the general identified themes.

Emerging Themes

After conducting a robust theme analysis of the individual participant interview transcriptions, 13 major themes emerged from this study.

The themes are as follows:

1. **Assault on the "We"**: the violation of connection, companionship, and being part of a team

2. **Lessening of the "I"**: the loss of independent activities within the relationship

3. **A Male Perspective**: on being a male primary caregiver which is not historically a male duty

4. **Rhythm of the Day**: day to day caregiving activities of daily living

5. **Shifting Roles:** role displacement and changes of the primary caregiver

6. **The Elusive Diagnosis:** FTD symptoms continue to stump medical professionals and makes getting an accurate diagnosis a long process

7. **FTD Caregiver Guidance:** more professional guidance needed to care for a spouse with FTD

8. **This Is Not My Wife Anymore:** the perception of their spouses changed due to the change in their wives' cognitive, emotional, and physical abilities as the disease progressed

9. **Religious Expectations:** religious views and beliefs that God would heal their spouse

10. **Find Your Tribe**: help needed from family, friends, doctors, self-help, support groups

11. **Shunned and Disregarded:** social isolation of the caregiver due to the perceived non-person stigma of mental/cognitive decline that FTD causes in the diagnosed partner

12. **Grief and FTD:** how caregivers understand and deal with the fatal FTD diagnosis of a spouse/partner

13. **Extinguished Sex Life**: the decrease and absence of sexual intimacy and physical closeness.

Emerging Themes Defined

The following are more in-depth definitions of the emergent themes and representative participant statements of each.

1. Assault on the "We"

The participants talked about how their experiences within the relationship with their wives changed once FTD was diagnosed. This included how the participants thought in terms of "we" when collectively speaking about their couplehood with their wives. Identifying as "we" seemed to give the participants confidence and security to know they were part of a "team" with their wives and not alone. As the disease progressed, the caregivers felt the disease violated the connection and companionship they once shared with their wives. The sense of "we" almost disappeared or was carried solely by the participant caregiver. Some representative statements include:

> As for how it affected our relationship, it seems like from the very outset, right after her diagnosis, things started to fall apart very quickly, mostly because my wife was having more and more language difficulties . . . I don't want to keep harping on the loneliness aspect, but I think that is probably the most difficult

> challenge when you're dealing with dementia because you have that loss of companionship. You have the loss of your helpmate. You have the loss of intimacy. (Participant A)

> Our connection was different, was severed. (Participant B)

> She almost read my mind. I was thinking of something, she could read my mind and stuff so, you miss that because all of a suddenly, it's all gone. (Participant C)

> I mean to be honest with you, there's really nothing that is the same. With FTD, they can no longer really comprehend anything, so for her to know what a relationship is or intimacy or any of that—none of that exists anymore. (Participant E)

2. Lessening of the "I"

The participants found they now had limited time for themselves or their individual interests. The majority of the participants' time was spent on the needs of their spouses. The participants' sense of individuality within the relationship seemed to be compromised due to all energy being directed to caring for their spouses. This appeared to add stress to the overall wellness of the participants. Some representative comments that evidence this theme follow:

> Some days I wake up in the morning, and she's very confused and foggy in the morning. And it just takes a while to get her going . . . Basically, I can't do a lot of stuff. Basically, I have to do everything in the house. (Participant C)

> But probably the most significant thing you've got to do is forget about yourself. Don't think about you're frustrated or angry or anything, but you've got a job to do to take care of the person. You do that. In that sense though it does mean probably blocking out a lot of your own emotions, so that you don't get frustrated or angry. (Participant D)

> I have no free time. So, I had to take over all the business aspects. But not only that. On the personal side, I've had to take over everything too, so it leaves you virtually no time because you were splitting stuff up before. I now have to do everything. So, it's now to the point—she's in the final stage now, and it's at the point now she can't do anything for herself. (Participant E)

> So, in terms of me, I dream into the future of, quite frankly, what's left without her. Probably gets me through some days, quite frankly. As cold as it sounds, this isn't forever. I know that sounds pretty awful. (Participant F)

> At the age of 62 I started taking piano lessons . . . I play piano. So that's half hour a week and all I can think of is do I have too many fingers in the wrong spots. But it's probably the only 30 minutes a week that I am not thinking, quite frankly, about what is happening to (my wife), and I know my daughter has her, and I know she is the best one besides me to have her, but at the same time I'm like, "What happens if?" (Participant F)

> Whereas we were co-equals before, and each had our likes and dislikes, and ways of doing things. As time went on, it became focused on her care . . . She had less empathy for what I needed. It was more focused on her. But the love never left, certainly on my part. (Participant H)

3. A Male Perspective

The participants' role of caregiver was experienced as feeling strange as a male. Most had never identified as a caregiver previously and had to learn what this meant for them personally. The participants expressed they wanted to help other males by giving a male perspective on being a caregiver for their wives. Several representative statements support this theme:

> I think you have to learn to get in touch with your caring side because males are not really set up to be caregivers. We tend to be more on the—we're the provider and protector for the family. And when you're suddenly thrust into this role, you've got to be kind and compassionate and considerate. That touches on a different side of you that you're not used to putting on full display. So, it's been tough for me. (Participant A)

> But when I thought about that, my reaction was-well, if I met somebody (and he) asked me what I was or something, I would have never in the furthest reaches of my imagination referred to myself as a caregiver. I was a retired engineer. I was a sailor. I was a skier. I was a musician. I was lots of other things but for a man-I don't think it's-even if they thought of themselves as a husband and a father, I don't think they're so quick to think of themselves and their identity as being a caregiver. I think this is important because for most men, their identity is tied up with their work and/or their hobbies and recreation, whereas often a woman, even if they're working professionally, still thinks of themselves as a homemaker and a

> mother and a caretaker . . . For a man, this is a major loss of identity and self-image. (Participant D)
>
> And we males are not the one that's primarily looked to, or whatever, as being caregivers . . . because it's not an—I mean, it's nothing we've really had to do. And yet, all of a sudden, you're thrust right in the middle of it and now I've got to do everything for her. (Participant E)
>
> I go to Macy's and go with her to try on clothes . . . I need to be in there (dressing room) sometimes, I don't want to come in there, I am not a creep . . . That's something I have not been able to overcome. (When out) the bathroom is always scary to me because I can't be in there unless we've got a private family bathroom. So, most of our excursions I always try to think if there's going to one there. That's a little helpful. (Participant F)
>
> Well, I guess the main one is be basically close enough with your wife to know what's going on with her. I think that my wife and I were close enough that I knew. . . . for years we never had any pads around the house at all. All the sudden, I'm in the bathroom, "What are these pads for?" Well, she started to become incontinent and purchased the pads, and then I started talking to her about it. So, I know guys, husbands who couldn't tell you anything about their wife, let alone be able to read them and know something is wrong. (Participant G)

4. Rhythm of the Day

The participants spoke of experiencing how they assisted their spouses with activities of daily living. They voiced the stressors of having to keep their partner fed, dressed, bathed, and ultimately safe. The following statements are representative:

> And eventually because I had to physically keep her from going outside naked, she started getting angry . . . I had to sit on her with my back towards hers and she would pound on my back with her hands and I'd be able to put on her legging, workout pants. She would already have a shirt on, maybe the one she slept in . . . and so it was just exhausting. (Participant B)
>
> We can get, I mean, into a routine like in the morning I know what the routine is going to be. The question is how long is it going to be? She'll get up, I'll pour her coffee, she'll go out, have her cigarette out on the table. She'll go out and sometimes sit in the garage, she's just like sitting there. And so, I have to get her back into the house. Now what she does, even though she goes to the bathroom upstairs when she gets up, she'll go back into the bathroom downstairs and she'll just sit there. So, there's getting her up. And then she'll sit down . . . so it was this back and forth, back and forth. And then finally I got her to get the cereal in the bowl and get the milk, get the spoon . . . (Participant C)

> Now I’m having to brush her teeth and it’s “Come on, open your mouth. At least do that.” “Open your mouth where I can see your teeth and brush your teeth.” I have to force her mouth open. (Participant E)

> But traveling became almost an impossibility because of things and what happened when we were in the car. She was trying to take off her seatbelt, open the door while we were going down the road at 60 miles per hour. I basically had tried, “Okay, let’s move to the backseat so that I could use a childproof lock on the car to keep her from opening the doors.” (Participant G)

5. Shifting Roles

The participants talked of experiences of role displacement and role changes while being the primary caregiver for their spouses. Many had to modify their employment to keep working or retired to become a fulltime caregiver. The shift was taxing but many found ways to manage the change. The following comments are representative examples:

> I became sad for her seeing how sad and traumatizing, frustrating, the testing had become for her and the inability of herself to perform to the standards she had hoped and had always been able to perform . . . And so all of that made me sad for her. That’s when I retired, I became a lot more of, I guess, a caregiver and doing a lot more things for her than I had ever done before. (Participant B)

> She can’t be left alone. I’m fortunate my employer, when I told him about the diagnosis, said, “You now work from home.” So, I’m able to be with her 24/7, but that’s a tough job. (Participant F)

> The reality is, I have to change, and I haven’t been a flexible person in the past, so I’ve learned to just go with it for a lack of a better term and just make sure she is safe. (Participant F)

> If you really love the person, even when it gets difficult, you want to be their primary caregiver. You want to be in charge of their health and to abandon that, I think, is abandoning the vows you took when you were married. (Participant H)

6. The Elusive Diagnosis

The participants were shocked by their experiences of how little knowledge the medical professionals knew about FTD and therefore it impeded an accurate diagnosis and often took years. In addition, once the accurate diagnosis was made, there seemed to be a lack of empathy toward both the person diagnosed with FTD and the spousal primary caregiver. The following statements represent this theme:

> I'd have to say there is a lack of general understanding of what FTD is . . . I was steamed over that. (Participant A)
>
> So, we went to one neurologist that I just basically said, "This guy doesn't know what he is talking about." And we went to her psychiatrist and, and (my wife) was on all these meds. Her doctor said, "We got to get her off of this stuff." . . . So, he did cognitive testing. They did the pet scan and they did a spinal tap and they basically ruled out Alzheimer's. (Participant C)
>
> My wife was diagnosed in May of 2013. And that was after we started seeing the doctor in 2012 and going through a lot of testing to finally see if they could figure out what was going on and doing a number of different things. We went through sleep apnea tests and a couple other things to see if those were the cause of what her problem was . . . Eventually we just finally had to say to the doctor, "We need to have a diagnosis and find out exactly what this is." And that's when they finally decided to send this to a neuropsych who did the testing on my wife. They determined that she had the FTD. (Participant G)

By contrast, two the participants' partners received a diagnosis of FTD quickly after seeing their Primary Care Physician and being referred to a neurologist:

> And so, we went to the neurologist. I took the exact same list to him. And his preliminary diagnosis—he did a few things in his office. And when I told him, he said my preliminary diagnosis is FTD, frontotemporal degeneration. I didn't have a clue what that was. And so, when he left and he said, "I want to do a MRI and more testing." (Participant E)
>
> When we arrived at the University of Pennsylvania FTD Center and between that and psychological exams and the like, they were able to come to a FTD diagnosis very quickly . . . We got our diagnosis within six months. (Participant F)

7. FTD Caregiver Guidance

The participants expressed genuine concern of not knowing what they did not know about being their partner's primary caregiver. There was a general desire and wish there had been some type of guidance from medical professionals on how to care for their spouse diagnosed with FTD. The participants felt they wanted to care for their wives but had some reservation that they were doing enough or caregiving in the best way. The following are representative statements:

> I'm all alone . . . Here you've handed me this diagnosis for my wife, and I've got this hot potato, and I don't know what to do with it. (Participant A)
>
> What I would have liked to have done for me, at the time of my wife's diagnosis, to have an assessment of me as to my ability to be a caretaker . . . in hindsight I don't believe I was emotionally equipped to help . . . I really needed, sooner than later, to have someone that was emotionally attuned to be with her, to take over this aspect of caregiving . . . I was over my head and I didn't know it. (Participant B)
>
> I felt like at the end of my caregiving and her death, I wish there was a kind of handbook of things to do as a guy or whatever . . . I was at a loss. (Participant B)
>
> Emotionally it wears on you and you just have to walk away and take a break. And I know, personally, I don't say it enough, but I need to keep at the forefront of my mind it's not (my wife), it's the disease. A disease that's doing this . . . That's probably been the toughest thing, I personally have had to deal with. (Participant E)
>
> And learning things that I would never have to learn before . . . You don't know what's coming. You never know what's going to happen next . . . Yeah. And so we as we go. We just learn as we go. (Participant F)

8. This Is Not My Wife Anymore

The participants expressed a change in their wives once FTD was diagnosed. They spoke of how FTD robbed them of the spouse they once knew and loved due to the disease altering their spouses' personalities, cognitive abilities, and emotional availability. Many described taking care of their wives like they would care for a child or toddler. Below are representative statement examples of this:

> So at this point in time, pretty much for the last five years, I felt as if I am living as a widower whose wife is still alive . . . I would go to places and see other couples enjoying each other's company or out on date nights . . . It used to bother me tremendously . . . But I am now at the point where I actually feel privileged to be able to care for her as she has declined.. Sometimes I will be picking her up

and getting her out of the car and she'll look at me and she'll pucker her lips and I'll kiss her and she'll say, "I love you" in her own way. (Participant A)

Yes. There was not only watching her decline, almost deteriorate. I mean her physical shell was there and in some aspects of her mental acuity were still there. (Participant B)

We got married in 1982 and all that time she was my best friend. And then, we had three kids. She almost read my mind, I was thinking something, she could read my mind and stuff. So, you miss that because all of a sudden, it's all gone and so again, depending, most of the time I'm talking to someone who's not even listening to me because she zoned on something . . . So I definitely miss that. Because I knew who she was and now who she is and that really has changed dramatically. (Participant C)

If I want to do something for recreation like sailing, I think about that only from my perspective, whereas in the past, that would have been something we would've done together. That's no longer possible, so I don't dwell on it and say, "Gee, this isn't as much fun as when we did it together." I just block out, and in a lot of ways, for the last several years I was living in my own little world and living alone just as much as I am right now. I mean, that didn't just start after she was gone. I mean, I was living in a lot of ways almost just as a lone individual, because the other person was not available. (Participant D)

You basically lose everything. First quarter, probably somewhere around 2017, I ceased mentally to view her as my wife anymore. At that point, I was more a widower. I viewed myself more as a widower than a spouse . . . You're a widower but your spouse is still there . . . You're a widower and a caregiver to a child. A big child . . . At that point, I was more a widow. I viewed myself more as a widower than I did a spouse. And yet, she's still here. She's still living. She still exists. (Participant E)

It's completely turned around, okay. It's completely turned around . . . In terms of our relationship, it's more of an almost parent-child at this point, which is very painful, but we take heart in the fact she is not in physical pain. (Participant F)

I mean it's life changing and there is a lot of things that you used to do that you cannot do anymore. It just slowly takes away your relationship that you had with your wife, and you become just the caregiver . . . I would say (it) definitely impacted our relationship because you go from having a wife, to basically taking care of your wife, and eventually as the disease progresses, you wind up taking care of almost a toddler. (Participant G)

And so all you do is carry what love you have for her into the job of taking care of her and being as kind and as helpful as you can to make her life as easy as

> possible and try to keep her without having pain or suffering during the process. I guess. (Participant G)
>
> Yes. In fact, you know she died in March. And people talked to me about how devastating the loss must be, and it is of course. But it's not like she suddenly died, and I was mourning her for that. I was mourning for the last two or three years because I had lost the person that she was. So, it definitely impacted me from that standpoint. (Participant H)

9. Religious Expectations

The religious practices and beliefs of the participants were called into question as they looked to God to heal their spouses. It seemed to shake the participants to their core when they realized a miracle was not going to take place. Representative statements are listed below:

> And as a Christian, I was angry with God at first. I was like, "Why are you taking my wife from me?" (Participant A)
>
> So, we're pretty much involved in our lives religiously. So, it was kind of hard with the emotions, say, coming across with the fact that "Okay. We believe in God and we believe in miracles and praying for things to happen." And then, eventually finding out that this probably is not going to be happening. I guess those things were the more emotional responses to the disease than anything. I guess you would say this is a downer. (Participant G)

10. Find Your Tribe

Participants reached out for some type of help or, in retrospect based on their experiences, believed they should have done so. The participants stressed how important it is to have people around that are positive, helpful, empathetic, and who truly cared. The following comments represent this theme:

> As far as friends, just call. I mean, people do not realize how lonely you are as a caregiver. And oftentimes, I would just appreciate if somebody would just pick up the phone and call me "How are you doing? What's going on?" (Participant A)
>
> I would just start going to a support group of caregivers once a month for FTD. And there was a couple of us. (Participant B)

> I deal with the AFTD, so it's just that they give me their support. My church, twice a year, they do a caregiver breakfast which I go to. But even my primary care physician, who's my wife's primary care physician, you just talk. Basically, you can kind of sit there and talk. (Participant C)

> Now I guess we were fortunate because we had a good caretaker and so I was free during the week to come and go and whatever . . . I can't imagine if you were confined to the house 24 hours a day to take care of somebody, that I think, would get you depressed pretty quickly. (Participant D)

> (People from my FTD support group) we decided that we would go out together (spouses included). So, we did and we've done it two or three times and it's great because we understand what's going on, there's nothing that happens at the table that can shock us . . . in December one of the (spouse caregivers) mentioned her husband was having a little bit of stress. I said, "You know what? It's just more important we get together." So, my kids had dinner (made dinner) at our house and they came in and cooked a really nice dinner for us. (Participant F)

> I am at the point where I'm not afraid to ask for help, which has been the biggest hurdle for me. And I am getting better at it and people have responded well.
> I have 3 great children. (Participant F)

11. Shunned and Disregarded

The participants experienced social isolation as the result of the "non-person stigma" associated with the mental/cognitive decline that FTD caused in their partners. Many had a myriad of feelings about being shunned and disregarded or a fear of that happening once others found out about the FTD diagnosis. At least one participant, seemed to view his wife in this manner, as a non-person as the disease progressed to the final stage. Below are some of the responses:

> And maybe it's partly the term dementia that just conjures up images of somebody who's delirious and out of their mind or whatever. Or they don't know how to talk to somebody who doesn't respond back. Oftentimes, I would just appreciate if somebody would just pick up the phone and call me "How are you doing?" "What's going on?" Come by and visit. Don't just shut us out. (Participant A)

> I always say selectively I would bring people into the inner circle with [spouse's] diagnosis on a need-to-know basis. So, I've said like, "I don't want to tell the

> world that my wife’s got FTD because nobody even knows what it is. (Participant C)
>
> Probably my biggest issue that I have is that it’s so easy to lose your patience. It’s easy to, “Come on. Help out” or whatever. She’s like a blob or a zombie. (Participant E)
>
> I think embarrassment, mainly. Anything that has to do with a mental condition. There’s a tendency—it’s not the same as having cancer or a broken leg or something that everybody understands. If it’s mental condition or dementia, there’s a fear that people aren’t going to understand, and you will be isolated in the community. And what I found out is that the opposite is true. The more open you are the more supportive people will be. (Participant H)

One participant began to view his wife as a thing or a non-person. He expressed:

> She’s like a blob or a zombie. Just she's gotten now to the point where she’s just sitting there like a zombie staring at you. (Participant E)

12. Grief and FTD

The participants were struck with grief when they learned that FTD is a fatal diagnosis and their spouses will not get better. Most participants recognized early in the diagnosis that their spouses had a limited amount of time left to live. There was a great sense of loss and an urgency to “get things in” before they ran out of time. The following are representative statements:

> As far as the immediate realization for me upon the diagnosis (FTD) was that our lives were going to be forever changed and all of the sudden it started hitting me that I no longer had this companion that I depended on to help make decisions, major decisions. (Participant A)
>
> There’s four or five times in my whole life when things have happened. It’s not like something you gradually get used to. I am hugely affected. It’s like a quantum step. (Participant B)
>
> It’s impacted me quite a bit. It’s going from someone (wife) who was very independent, and we have been married for 36 years, to someone that, now, really needs assistance. So yes, it has kind of changed my life quite a bit. Sometimes I feel and a lot of times, and unfortunately, it’s a constant thing, like somebody dies, you have a mourning period, right? But then you pick up the pieces and you move on and stuff. (Participant C)

> I thought we had a little bit more time. (Participant F)

13. Extinguished Sex Life

Participants experienced significant decrease in sex and physical affection with their spouse diagnosed with FTD. And most were unable to have any sex life at all with their spouses due to mental, emotional, and physical constraints as the disease progressed. The participants were open and honest about how lack of sex and physical contact affected them and the impact it had on their relationship with their wives. This is represented by the following:

> I could tell you it's gone pretty much full circle. I won't say we had a perfect marriage, but we had a great marriage. I mean we were together for 45 years. From a physical standpoint, we were always very intimate. We used to say we'll be making love into our 80s. We were close, for the most part, and very intimate . . . We went (vacation) down there to celebrate our anniversary . . . it was a special place for us . . . and it was the first time I realized that her concept of what sex was had completely evaporated. (Participant A)
>
> And I guess I should say our sex life became virtually non-existent, which wasn't necessarily a problem, it was just shocking to me, her inability to understand and know and lose understanding of parts of her body. (Participant B)
>
> Sometimes I sit there if all of the sudden she says okay, let's be intimate and stuff like that I think okay. But it's so sporadic . . . you kind of take what you can get. Because I always say that if you're just close and touch that kind of means a lot. At least you feel connected and stuff. (Participant C)
>
> Without any responses, that kind of drifted away . . . So it's not a matter of necessarily not trying but not expecting any reaction or response. And I wasn't comfortable with that. (Participant D).
>
> That ceased in 2016 about the time of the diagnosis. There was no longer—she could no longer really be intimate with you, both sexual and emotionally . . . And once you start doing the research on the disease and what's going on, to kind of relate it to something, it would be almost being intimate with a child, and that just totally ends it right there. (Participant E)
>
> I started noticing change—just like intimacy or sexual or whatever, it was just not really the same prior to the diagnosis. Just things were just—it's like she's almost

> just kind of there and just not really fully mentally into the intimacy like she was. There's sex and there's making love. And the making love kind of almost seemed to dwindle away. (Participant E)

> There probably isn't much. She has lost some of the motor control, so she can't kiss, she can't stick out her tongue. It was a good ride. It still is a good ride, just a little different ride. (Participant F)

> Well, the physical affection definitely was affected because she—one of the main symptoms is not having empathy and not having desires anymore. It was pretty much a deal that you just got to that point as well. You're not going to be having a sexual relationship anymore. I mean, when we first started in 2012, we were probably having some kind of relation at that point, but they were definitely becoming fewer and farther between. And then once she got to the point where it was apparent she could no longer make a decision about this type of thing, then I began to think . . . Well if she can't say yes or no and make that determination, I guess we're just going to have to go with no. So, we basically, after 2013, had no sexual relation. (Participant G)

> Well in terms of hugging, and kissing and touching, really no effect. Sex became a thing of the past . . . And she would have participated but I felt like if she didn't have the ability to say yes that is wasn't fair to her. So that was the consequence of the FTD. (Participant H)

Cross-Case Analysis

The participants during the individual interviews expressed many of the same thoughts and feelings regarding their experiences as male primary caregivers for a spouse diagnosed with FTD. However, not every participant experienced every theme that emerged in the data analysis. Table 2 presents the intersection of each emergent themes with each participant.

Table 2

Cross-Case Analysis

Analysis Category	P A	P B	P C	P D	P E	P F	P G	P H
Theme 1	X	X	X	X	X	X	X	X
Theme 2	X	X	X	X	X	X	X	X
Theme 3	X			X	X	X	X	X
Theme 4	X	X	X	X	X	X		X
Theme 5	X	X	X	X	X	X	X	X
Theme 6	X	X	X	X	X	X	X	X
Theme 7	X	X	X	X	X	X	X	X
Theme 8	X	X	X	X	X	X	X	X
Theme 9	X						X	
Theme 10	X	X	X	X	X	X	X	X
Theme 11	X		X	X	X	X	X	X
Theme 12	X	X	X		X	X	X	X
Theme 13	X	X	X	X	X	X	X	X

Summary

This chapter highlighted participant demographics, snap shots of each of the participant interviews, individual interview summaries, and the emerging themes with representative statements from the data gathered from the participant individual interviews.

CHAPTER V

DISCUSSION OF FINDINGS

For better or worse, in sickness and in health, spouses are expected to step into the caregiver role for one another. This significant role change within the committed relationship happens without “discreet demarcation” (Savundranayagam & Montgomery, 2010, p. 176). The role of spouse is already in existence and the primary caregiver role is just an add on to what was preexisting. However, many spouses overextend themselves and the burden of caregiving is felt more extremely (Marks et al., 2002). This is even more pronounced when the ill spouse is diagnosed with dementia. The behavioral issues associated with dementia can interfere with the natural ebb and flow within the relationship and can fracture the emotional bridge between the pair (Marks et al., 2002). This can lead to ambiguous loss within the relationship (Boss, 1999; Lloyd & Stirling, 2011). Ambiguous loss can present as a loss of connection between partners that presents as apathy from the partner with FTD to both partners no longer being able to “read each other.” The emotional and cognitive disconnection lead to a loss of physical and sexual connection. The spouses are still physically present but absent cognitively and not as available to their partners as they were before the FTD diagnosis.

Existing research is primarily focused on female caregivers. Less research is available regarding male primary caregivers, especially male primary caregivers who are caring for a spouse diagnosed with FTD. The research that does exist suggests that males do not have significant emotional distress from caring for a spouse with dementia because as males, they are task-oriented and gain a sense of accomplishment from caregiving (Calasanti & King, 2007; Eifert et al., 2015).

The findings in this study revealed males in committed relationships who are the primary caregivers for a spouse diagnosed with FTD experience significant emotional responses and even emotional upheaval. Surprisingly, and in contrast with extant literature, they did not hesitate to share their feelings and experiences in an honest, and at times, shockingly raw manner during the individual interviews. In addition, the participants freely and openly described their sex lives in terms of the relationship intimacy and the changes that occurred especially as the disease progressed. The findings are consistent with those of The Investment Model of Commitment (Agnew et al., 1998; Forsund et al., 2014; Rusbult & Buunk, 1993) that suggest individuals in a relationship begin to identify as a unified “we” instead of two separate “I’s” the more committed they are to the relationship. This allows the individuals to put their partners’ needs before their own for the good of relationship. The participants in this study echoed that sense of “we” within the relationship with their spouses before their spouse was diagnosed with FTD and they wanted to be their spouses’ primary caregiver even at their own expense. This finding supports The Investment Model of Commitment (Rusbult & Bunk 1993) that found transformation of motivation, when one spouse puts his partner’s needs before his own for the sake of the relationship, and one spouse is the caregiver for the other who has been diagnosed with dementia. However, this study did not align with Eifert et al. (2015) that found that most spouses’ shared identity affected the primary caregiver’s individual identity, specifically a loss of individual identity, as the magnitude of caring for the spouse increases. The participants in this study expressed having less time to do individual activities as the care for their spouse increased due to the progression of the disease. The participants in this study retained their individual identity within the relationship but expressed feeling lonely and all alone within the relationship as their spouse's FTD progressed. Moreover, this study did support the findings of Davies (2011) that found the "us identity of the couple" changed but endured even in the face of a dementia diagnosis. The participants in this study expressed being alone now in the relationship with their spouse due to the diagnosis of FTD. Therefore, the "us identity" significantly changed but endured. This is evidenced by the fact that the participants in this study stayed in the marriage and became primary caregivers for their spouses. In addition, the participants in this study tried to remain emotionally and physically connected to their spouses. The participants' commitment to the relationship and the vows of commitment to their spouse remained intact.

This study echoed the findings of Boss (1990, 1997) that ambiguous loss is experienced in the relationship by both males and females when one partner or spouse is diagnosed with dementia. In addition, the findings in this study support those of Forsund et al. (2014) that found the spouses experienced a loss of couplehood which entails the loss of everyday life, the loss of a shared past, and the loss of a shared future. The participants in this study spoke of no longer connecting in the same ways they did before their partner was diagnosed with FTD including feeling the loss of their couplehood.

The focus of this phenomenological qualitative study explored the lived experiences of males within a committed relationship who are the primary caregivers for a spouse or partner diagnosed with FTD. The research questions that led this investigation are:

1. How does being a male primary caregiver impact the intimacy and interdependence in the committed relationship?

2. How does the male primary caregiver of a partner diagnosed with FTD experience ambiguous loss within the relationship?
3. How does being a male primary caregiver to a partner with FTD impact the caregiver personally?

In phenomenological research, directly going to the source through interviews and capturing the perceptions of those experiencing the phenomena is key (Moustakas, 1994; Van Manen, 1990). In this current study, eight participants provided descriptive experiences of being primary caregivers for a spouse diagnosed with FTD through their own unique and individual lenses. It is the totality of all the individual voices that captures the essence of the phenomenon being studied (Husserl, 1970). Thematic analysis of each individual interview resulted in 13 emergent themes that both supported and added findings to extant literature.

This chapter provides a discussion of how the lived existentials of Van Manen (1990) were used to examine and give meaning to the findings in the study, a discussion of the themes that emerged from the data the significant emotional responses that emerged from the participants, the implications of the study, limitations of the study, and suggestions for further research and practice.

Conceptual Framework: Van Manen's Life World Existentials and the Findings

This study was framed using the conceptual framework of Van Manen's (1990) life world existentials of lived human relation, lived body, lived time, and lived space (Van Manen, 2009). Phenomenological research examines the life world as it is immediately experienced before any preconceived notions about the phenomenon by the researcher (Husserl, 1970; Van Manen, 1990). Its structural purpose is to have a rich and "evocative description" of the human experience as evidenced by actions, behaviors, and intentions as met in the "lifeworld" (Van Manen, 1990, p. 19). Phenomenology is not a generalization, it is the process of describing a unique snapshot of an experience (Van Manen, 2016). It was evident through the individual interviews conducted in this study the participants felt deeply about their surroundings through space, body, time, and human relation.

Lived Human Relation

The participants in this study expressed the lived relationship with their spouse as integral to their life experiences. Most discussed their relationship with their spouse as being equals, a team, and life partners prior to the FTD diagnosis. Comments from participants such as "She almost read my mind. I was thinking of something, she could read my mind and stuff so, you miss that because all of a suddenly, it's all gone" and "I mean to be honest with you, there's really nothing that is the same. With FTD, they can no longer really comprehend anything, so for her to know what a relationship is or intimacy or any of that—none of that exists anymore" are representative of the impact on the relationship. After their spouse was diagnosed with FTD, the participants discussed the ambiguous losses that occurred within the relationship as their spouse continued to decline due to the progression of the disease. They spoke of a loss of emotional, cognitive, and physical connections with their spouse within the relationship. This was evidenced by phrases such as "Our connection was different, severed" and "I think about that only from my perspective, whereas in the past, that would have been something we would've done together. That's no longer possible . . . I mean, I was living in a lot of ways almost just as a lone individual, because the other person was not available."

Lived Space

The lived space was expressed by the participants as the shared home they had created with their spouse and the changes in those experiences. Many discussed their role in the changes that had to take place as their spouse's disease progressed. Such statements as "Like I said early on I hid sometimes during the day . . . I just went into our separate house and laid down on the little bed we had there. Listened to the radio, drifted off" and "Basically, I have to do everything in the house." One participant discussed trying to keep the shared space without change as much as possible and commented, "We would always sit at the dining room table for proper dinner and stuff like that." It was his hope that by keeping the lived space the same it would help his wife remain perhaps unchanged. Most of the participants expressed having to take over all the household chores and maintenance that was previously shared with their spouse. Their shared lived space was not the same, familiar surrounding that they and their spouse worked to create for so many years.

Lived Body

Lived body was discussed by the participants as stressful and physically demanding. They expressed that physical demands became more intense as their spouse's disease progressed. Such comments as:

> And eventually because I had to physically keep her from going outside naked, she started getting angry . . . I had to sit on her with my back towards hers and she would pound on my back with her hands and I'd be able to put on her legging, workout pants. She would already have a shirt on, maybe the one she slept in . . . and so it was just exhausting.
>
> Now I'm having to brush her teeth and it's "Come on, open your mouth. At least do that. Open your mouth where I can see your teeth and brush your teeth." I have to force her mouth open.

Lived Time

Lived time was discussed with the participants as the day to day chore of trying to stay present with their spouse because that was the only time in space they both shared anymore. The participants' spouses were no longer able to reminisce about the past nor could they dream about the future. The present was the only lived time the participants and their spouses could experience together. Comments such as:

> So, you do have that feeling that life is on pause and it used to kind of drag me down but I think the key to it is you got to learn just to live your life in the moment. And I try to put myself in my wife's head and think like she's thinking now. She lives strictly in the moment and I have to do the same

Several participants expressed feeling sad about not being able to live out their futures with their spouses in the ways that they had planned as a couple before the FTD diagnosis. One participant summed it up with his simple statement of "I thought we had a little bit more time."

Discussion of the Emergent Themes Findings

Thirteen themes emerged in the data relevant to the research questions. These themes are discussed in relation to each research question.

Research Question 1: "How does being a male primary caregiver impact the intimacy and interdependence in the committed relationship?"

This question sought to elicit the male experience and perception of intimacy and interdependence within the committed relationship as the primary caregiver. The following themes emerged from the individual interview dialogues.

Assault on the "we": The violation of connection, companionship, and being part of a team. According to Interdependence Theory (Kelley, 1979; Kelley & Thibaut, 1978; Rusbult & Buunk, 1993) interaction between partners is the focal point of all close relationships. According to Thibaut and Kelley (1959), “individuals emit behavior in each other’s presence, they create products for each other, or they communicate with each other” (p. 10). Agnew et al. (1998) suggested that the more committed partners are to one another, the more they identify as a collective unit. The participants in this study had all been interacting and interdependent with their spouses for at least 15 years and, in some cases, for 38 years or longer. One participant even noted that his wife used to be able to read his mind—they were that in sync with each other before the FTD diagnosis.

According to Agnew et al. (1998) cognitive interdependence is “a pluralistic, collective mental representation of the self-in-relationship” (p. 941). Most of the participants in this study described feeling alone and the “we,” the pluralistic way they identified as a couple, no longer existed once their spouse was diagnosed with FTD. Almost all the participants in this study described an abrupt, severed cognitive and emotional connection with their spouses due to the progression of the disease. It is as if they had been gut-punched or physically assaulted. Several participants expressed feeling lost without the companionship of their spouse. There was a clear disconnection of the interdependence in the relationship.

Agnew et al. (1998) suggested that one partner will sacrifice for the other not only to preserve the “we” of a relationship but also to preserve a sense of the self within that relationship. Most of the participants in this study explained that their spouses’ inability to connect with them on a cognitive and emotional level evaporated due to the progression of their FTD diagnosis. However, most of the participants expressed a high level of continued independence even though they had less time to do independent activities as their spouse’s disease progressed.

Rusbult and Buunk (1993) as part of The Investment Model of Commitment (1980), defined commitment level as a “a psychological state that globally represents the experience of dependence and direct reactions to new situations; it represents long-term orientation, including feelings of attachment to a partner and desire to maintain a relationship for better or worse” (p. 180). Most of the participants in this study expressed a deep desire to ensure their spouses’ needs were met even at the expense of their own needs. They continued to be committed to their spouses as “we” of the relationship continued to be assaulted.

Lessening of the “I”: The loss of independent activities within the relationship. Most of the participants in this study expressed that they became more tied down with less time for independent activities as their spouses became more dependent as the disease progressed. They described limited or no time for self-care and wellness. Most of the participants noted having less time to go to the gym, see friends, or spend quiet time alone. Some participants said they had to “hide away” during the day whether it was 45 minutes in the morning before their spouse awoke or literally hiding from their spouse in the house during the day to decompress. This supports the findings of Carpenter and Mak (2007) that found caregiving often takes a toll on the caregivers’ wellness. It limits the privacy of the individual within the relationship (Lee & Tang, 2015).

Additionally, according to Eifert et al. (2015), most spouses share an identity as being a part of a couple, in turn the loss of self and individual identity is greater as the intensity of the caring for a spouse increase. Whereas the participants in this study certainly expressed an increase in the loss of individual activities as their spouse’s FTD progressed and more care was needed, they did not appear to lose their individual identity. Most of the participants in this study retained their sense of individual identity by having a perspective of what their lives will look like when they are no longer in the role of caregiver. This allowed them to continue to care for their spouses within the committed relationship. One participant summed up this concept poignantly and said:

> So, in terms of me, I dream into the future of, quite frankly, what's left without her. Probably gets me through some days, quite frankly. As cold as it sounds, this isn't forever. I know that sounds pretty awful.

Extinguished sex life: The decrease and absence of sexual intimacy and physical closeness. Intimacy in a relationship suggests "instrumental support, affection, sexual fulfillment, and emotional closeness" as defined by Rusbult and Buunk (1993, p. 179) as part of The Investment Model of Commitment, participants in this study were quick to express how their sex lives and intimate closeness were immediately affected once their spouse was diagnosed with FTD. Most noted that at the beginning of the diagnosis they still tried to be physically and sexually intimate with their spouse. However, as time went on and their spouse's FTD progressed, it became apparent their spouse was not capable of consenting and the default answer to sex was "no." One participant commented, "there is sex and then there is making love" to explain that while his spouse could still go through the motions of having sex, she was not able to make the emotional connection that they had shared in the past. This lack of emotional connection added to diminished sexual relations as a couple.

Several of the participants felt trying to have sex with their spouse in this cognitive state would equate to trying to have sex with a child. The thought of having sex with a child was repugnant, taboo, and off the table for the participants in this study.

Most of the participants expressed missing the tactile touch of their spouse coupled with the emotional affection that was part of their relationship foundation. They expressed significant emotional responses to the loss of sexual aspect of their relationship. Their emotions ranged from sadness to anger bordering on rage. This finding is this study is in contrast with earlier research. According to Eifert et al. (2015) female spousal caregivers were more emotional in their response to shifting roles within the relationship and often saw themselves as moving from wife and lover to mother and caregiver. Whereas male spousal caregivers saw their caregiving role as their spousal duty and therefore were less emotional. Most, if not all, of the participants expressed caring for their spouses was like taking care of a child. The males in this study expressed feeling more like a parent to a child especially as their spouses continued to decline as the disease progressed.

Shunned and disregarded: Social isolation of the caregiver due to the perceived non-person stigma of mental/cognitive decline that FTD causes in the diagnosed partner. Several participants in this study expressed their spouses were perceived as less than human in several situations. They experienced this within the medical community while at doctor’s appointments; this was felt while out in public by strangers; this was felt when friends no longer stopped by because they did not know how to act around a person with diminished cognitive abilities; and this was even the perception of some of the participants themselves. One participant described being treated with disrespect and his wife treated without dignity at several doctor’s appointments, but one stood out to him. He explained that his wife was treated like a thing to be dealt with rather than a person with cognitive decline. He recalled no empathy or kindness from a nurse that just threw the medical gown at him and told him to deal with his wife and get her dressed. This finding supports extant research that suggests people diagnosed with dementia are perceived and treated as less than human by healthcare workers (Bartlett & O'Connor, 2007; Gillies, 2000; Kitwood, 1997; Lyman, 1998).

Another participant described his wife as a "blob or a zombie" at this point in the progression of her disease. While this comparison of his wife to a zombie, a person who appears to be lifeless, apathetic, or totally lacking independent judgment (collinsdictionary.com), might be shocking, it gives a clear picture of how he is experiencing and conceptualizing what is happening to his wife due to FTD, and more importantly, how it is affecting how he now relates to his spouse at this point in time. It is a significant difference in how he and his wife related to one another before she was diagnosed with FTD.

Research question #1 sought to answer how being a male primary caregiver impacts the intimacy and interdependence in the committed relationship. The findings in this study suggest male primary caregivers are deeply impacted by the changes in the cognitive, emotional, physical, and sexual intimacy within the relationship when their spouse was diagnosed with FTD. These findings speak to the theoretical underpinning of The Investment Model of Commitment (Rusbult & Rusbult, 1980, 1993). The findings also suggest that male primary caregivers are significantly affected by the shift in interdependence within the relationship and affected by how the outside world views them and their spouse diagnosed with FTD. These findings are supported by the theoretical base of Interdependence Theory (Kelley & Thibaut, 1978).

Research Question 2: "How does the male primary caregiver of a partner diagnosed with FTD experience ambiguous loss within the relationship?"

This question intended to expose and understand the ambiguous losses that occur within the relationship and how the participants experienced those relational losses as the primary caregiver. The following themes emerged to answer this question:

This is not my wife anymore: The perception of their spouses changed due to the change in their wives' cognitive, emotional, and physical abilities as the disease progressed. According to Boss (1999) ambiguous loss is "a psychological absence where the loved one is physically present but cognitively 'absent' or impaired as in dementia" (p. 137). Ambiguous loss theory defines ambiguous loss as a relational loss and is not categorized as a pathological disease in the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (*DSM V*, APA, 2013; Boss, 1999, 2007). Most of the participants described a loss of connection both emotionally and cognitively with their spouses. Most of the participants felt this disintegration immediately after their spouses were diagnosed with FTD but all felt it eventually. It was an emotional upheaval to recognize that their life partner was now someone unavailable to them as they had been in the past. Most of the participants described their spouses as being child-like or functioning as a giant toddler due to the progression of the disease. It is a deeply painful reality with which the participants are learning to come to terms. Most of the participants viewed themselves as living as a widower whose wife was still alive. At least one participant remarked that the woman in front of him was no longer his wife. Some of the participants described compartmentalizing and blocking their feelings and emotions so that they could get through their days. The use of compartmentalizing was certainly not void of feelings and was not just going about business as usual in a nonaffected way. It was a purposeful setting aside of themselves to be the caregiver their spouses needed at that time. For most of the participants, caregiving is a way for to harness the energy of the love they have for their life- long partners and stay as connected as possible. One participant poignantly expressed he sometimes "dream(s) into the future of what's left without her . . . gets me through the days." This statement captures the daily pain of the relational losses. The participants' lives and relationships with their spouses have significantly been changed by the ambiguous loss within their relationship caused by the diagnosis of FTD.

The elusive diagnosis: FTD symptoms continue to stump medical professionals and makes getting an accurate diagnosis a long process. According to van Vliet et al. (2010; van Vliet et al., 2011) dementia that has an onset before the age of 65 takes longer to accurately diagnose. This causes more stress for the individual and couple as they are referred from one specialist to the next in search of what is causing the distressing symptoms. Many of the participants in this study expressed frustration at being either sent to multiple doctors for a diagnosis or being scheduled with the same doctor for periodic check-ups and check-ins without a true diagnosis. Participants expressed confusion pertaining to their spouses' initial diagnoses that ranged from sleep apnea, depression, anxiety, Alzheimer's disease. One participant finally decided the doctor his wife was seeing just did not know what he was talking about and sought other providers on their own. Another participant who lives in a more rural area expressed having less access to major medical facilities and therefore he had to do more research to find the right doctors to help he and his wife. He gave an example of an acquaintance, who lives in the same geographic location, whose wife was eventually diagnosed with

FTD but only after several years of searching for an answer from countless doctors. He eventually could no longer care for her at home and the only facility that would take his wife due to her diagnosis was several hours away from their home. Therefore, he only gets to visit his wife every few months due to financial and travel constraints. Access to medical care is not created equal for those diagnosed with FTD and their caregivers. This is especially true in more rural areas where larger medical facilities are not typically located.

The participants in this study also experienced having to be the ones that followed through with finding out what was happening with their spouses' health. Many expressed that while their spouse knew something was not right, most spouses refused to accept that it was any form of dementia. One participant described thinking that he and his wife might have to get a divorce based on his spouse's behavior. He thought she just stopped loving him and was not interested in the relationship anymore. This finding supports van Vliet et al. (2011) that found while the ill spouse knew something did not feel right, but it was the well spouse who had to advocate for finding an accurate diagnosis. Meanwhile, the ill spouse continues to exhibit symptoms that result in marital conflicts and stress. The relationship continues to be negatively affected as the illness progresses (Braun et al., 2009).

By contrast of extant research and the above findings of this study, other findings in this study found participants' spouses were diagnosed within six months of first seeing medical professionals. The participants' spouses that received an accurate diagnosis of FTD relatively quickly, were in larger cities with more access to larger, research medical facilities. One of the participants expressed not knowing what he would have done if he and his spouse had lived in another part of the country where access to first-rate medical care was not available.

Rhythm of the day: Day to day caregiving activities of daily living. According to Lee and Tang (2013) the requirements of caregiving often take their toll on the caregiver's wellness. In addition, Savundranayagam and Montgomery (2010) suggested helping a spouse with activities of daily living (ADLs) is not stressful or burdensome unless it is viewed as "going beyond the call of duty" (Savundranayagam & Montgomery, 2010, p. 32).

The vast majority of the participants in this study expressed the emotional and physical stressors of helping their spouses daily get bathed, dressed, fed, and stay safe. Most of the participants expressed that as their spouse's disease progressed, it became harder and more stressful to perform the ADLs for their spouse. This finding seemed to echo the stress that came with the help that was perceived as beyond the call of duty when helping a spouse with ADLs. One participant described having to sit backwards on his wife as he tried to put her pants on her so that she did not go out of the house naked. Another participant described how difficult it was to try and get is spouse to open her mouth as he was trying to brush her teeth.

FTD caregiver guidance: More professional guidance needed to care for a spouse with FTD. Most of participants in this study voiced not knowing what they did not know about being a primary caregiver for their spouse diagnosed with FTD. One participant thought it would be helpful to have a "handbook" on how to care for a spouse with FTD. He highlighted that medical professionals have handbooks on other diseases, such as diabetes, they disseminate to patients and caregivers with facts about the disease and how to handle certain situations. Another participant equated learning about his wife's diagnosis of FTD from the doctor as if he had "been handed a hot potato" and then sent on their way. In addition, one participant wished there had been an assessment of his ability to be an adequate caregiver for his wife. He expressed that in hindsight, he did not think he was emotionally equipped to be the primary caregiver for his wife. For many participants, it was "learn as you go" taking care of their spouse.

The vast majority of the participants expressed finding help and support through the FTD caregiver support groups. It was through hearing what other primary caregivers for those with FTD were experiencing and doing to ensure the best care was being given to their spouses. While the participants in this study recognize everyone's situation is different, there was a general feeling that having some guidance from medical professionals would have been better than none.

Research question #2 sought to understand how ambiguous loss within the committed relationship was experienced by the male primary caregivers in this study. The findings in this study suggest male primary caregivers experience significant ambiguous loss within the relationship as their spouses' FTD progressed. However, these ambiguous losses were experienced even before the accurate diagnosis of FTD was made. Participants expressed knowing something was wrong in the relationship and with their spouses long before seeking medical attention. One participant expressed he thought his wife wanted a divorce or was having an affair due to her lack of empathy and what he perceived as apathy for him and their relationship. Most of the participants voiced a diminished cognitive or emotional connection with their spouse or no connection at all as the disease progressed. The findings in this study also suggest the participants experienced having to take on more of their spouses' ADLs adding to the sense of the person in front of them was no longer their life partner but rather a dependent.

Research Question 3: "How does being a male primary caregiver to a partner with FTD impact the caregiver personally?"

This question sought to glean the male experience of being a caregiver and the personal impact that resulted. The following themes emerged to answer this question.

A male perspective: On being a male primary caregiver which is not historically a male duty. The participants in this study voiced their experiences of being male in a role that has historically been identified as a female role. Most of the participants expressed they never had identified as a caregiver in the past because they never were expected to be a caregiver. The finding in this study supports that of Campbell (2010) that suggests that current social norms put little pressure on males to be caregivers for loved ones or spouses as compared to females. Most participants in this study said they had to learn how to be a caregiver by joining a FTD caregiver support group, asking their primary care physicians how to care for their wives' female issues, but mostly they had to learn on the job.

Several participants shared that they still do not identify as a caregiver even though they are the primary person caring for their spouse. A couple of participants expressed being perceived as a "creep" when assisting their wives in the women's dressing room at a department store or taking their wives into the bathroom. One participant stated he always would carry a card that explained what FTD is and that his wife had the disease. This finding is not surprising but not reflected in the extant literature and is important to note. Several participants expressed having to get in touch with their feelings and “caring side” when they took on caregiving for their spouse. They reported an overall learning curve as males now being the primary caregiver for their spouses.

Shifting roles: Role displacement and changes of the primary caregiver. Most participants in this study had to adjust their lives significantly to take on the role of primary caregiver for their spouse. Several of the participants decided to retire once their spouse was diagnosed with FTD. Fortunately, those participants were able to retire and of retirement age and it did not affect their finances negatively. Other participants continued to work but with accommodations made by their employers. One participant was able to work from home noting that when he told his employer the diagnosis his wife was given told him, “You work from home now.” While being able to work from home enabled the participant to continue to provide financially for the family, it was not any less stressful of a situation. His day consists of caregiving for his wife during the day and working the night shift for his job. He expressed not needing a lot of sleep to function well daily. Another participant was able to modify his daily schedule to accommodate getting his wife ready in the morning and dropped at an adult day center before he went to the office for a full day of work. If he needed to leave work early to take care of his wife, he would finish his work at home after he got his wife settled for the night. Another participant expressed trying to keep things as “normal” as possible. Although he was already retired from his fulltime career at the time of his wife’s FTD diagnosis, he continued to work as a contracted consultant.

One of the participants continued to work for the first two years after his wife’s diagnosis because they had a child under 18 still at home. This finding supports other research that suggests spousal caregivers of a partner with FTD often have school aged children that adds to the stressors of trying to manage both their children and spouse at the same or similar developmental level (van Vliet et al., 2011; Williams et al., 2001). Overall, the participants' roles shifted due to being the primary caregiver for their spouses.

Religious expectations: Religious views and beliefs that God would heal their spouse. While many of the participants in this study might have used their religious beliefs and values to help them navigate the difficult role of being the primary caregiver for their spouse diagnosed with FTD, only two directly spoke of it. One participant expressed having a deep faith in God and strong religious convictions. He believes in the miracles of God and kept praying for a miracle for his wife. Once he realized that he was not going to get the miracle he had been praying for, he became more emotional about his and his wife's fate with FTD. Another participant expressed being angry with God and he could not understand why this was happening to him and his wife. He voiced that he and his wife were good Christians and getting the diagnosis of FTD was as if they were being punished for something. He eventually reckoned with the hand they had been dealt and continued to look to God and their religious community for help and support.

Find your tribe: Help needed from family, friends, doctors, self-help, support groups. The vast majority of the participants in this study expressed the significance of asking for and having help to some extent as they took on the role of primary caregiver for their spouse diagnosed with FTD. Many of the participants initially found it hard to ask for help. This was mainly because of preconceived notions that they could or should be able to care for their spouses single handedly. Most realized quickly upon assuming the role of the primary caregiver that it was almost impossible to do alone. One participant expressed he really did not have much help daily, but his daughter and her family provided the emotional and moral support that was so critical to his own survival. A few participants voiced not wanting anyone to help with the care of their spouses because they felt that is all they had left in the relationship. There seemed to be a sense of emotional connection through caregiving that was the last act of intimacy the participants could have with their spouses. It was hard to accept help due to this variable even though they knew help was needed.

Grief and FTD: How caregivers understand and deal with the fatal FTD diagnosis of a spouse/partner. Most of the participants in this study expressed immediately feeling and knowing that their lives with their spouse would never be the same once FTD was the diagnosis. Many of the participants voiced feeling sad and grief stricken when thinking about what their "golden years" would no longer be. They spoke of their lives forever being changed in that moment the doctor gave their spouse the FTD diagnosis. These findings support the current research that suggest caregivers of a spouse with a fatal illness experience grief over the inevitable loss of life (Ford et al., 2012).

Research question #3 sought to understand how being a male primary caregiver for a partner with FTD impacted the caregiver personally. The findings in this study suggest that male primary caregivers experience less social acceptance as a male caregiving for a female in public especially in situations where others might feel threatened by a male presence. This findings in this study also suggest that male primary caregivers had to learn how to give the care their partner needed by learning as they went because they were never expected to be a caregiver in the past. This included reaching out to medical professionals for guidance, friends and family members for support, and joining FTD caregiver support groups for the community support of those experiencing the same trials as a primary caregiver for a partner with FTD. Additionally, the findings in this current study suggest male primary caregivers relied on their religious beliefs and values to make sense of the "why is this happening to me and to my wife" existential question and to draw strength to persevere. And finally, the findings in this study suggest that male primary caregivers for a partner diagnosed with FTD understand from the day their partner got the diagnosis, their life would never be as they planned from that moment moving forward.

Limitations of the Study

The main limitation of this study is that the male participants were already members of a caregiver support group and perhaps more primed to readily discuss their caregiver experiences, including emotions and thoughts, freely as they had done in the caregiver support groups. Another limitation of this study are the demographics of the participants. The vast majority of the participants were self-described as middle to upper middle-class socioeconomic status and therefore had more access to medical care and support. In addition, four of the eight participants' spouses were already deceased at the time of this study. This is a limitation because the participants who are widowers could have memories of caregiving filtered through a positive lens. Another limitation to this study is that there was only one researcher and data analyzer who was female. An additional limitation was that member checking was done after the transcription of the interview was complete but not after the analysis of the data was completed to ensure the researcher captured the participant accurately. Finally, time and resources did not permit a prolonged engagement or more than one interview over time for this current study.

For future studies, it is suggested that a team of researchers consisting of both males and females conduct the study and analyze the findings for less potential gender bias. It is recommended that future research address the limitations of this study by collecting household income, ethnicity, and race. It is also recommended that all participants spouses still be living at the time of the interviews ensure the same lens is used to understand the phenomena. It is recommended for future studies that member checking be conducted at least twice for a more robust study. In addition, it is recommended that studies be conducted again with females to specifically look at how individual identity and self-awareness impacts their primary caregiver experiences.

Implications for Best Practices for Professional Counselors and Counselors-in-Training

Best practices implications for professional counselors and counselors-in-training were generated from this study. The participants expressed being deeply emotionally impacted regarding intimacy and commitment, interdependence, and ambiguous loss within the relationship in the role of primary caregiver for their spouse diagnosed with FTD. It would be beneficial to practicing counseling clinicians and counselors-in-training to realize male primary caregivers for spouses diagnosed with FTD do experience a myriad of deeply felt emotions regarding the changing relationship with their spouse. This is an important finding that challenges the stereotype of male caregivers as stoic and emotionally removed from the care recipient. The findings in this study illuminated that male spousal primary caregivers not only feel sad, angry, and experience daily ambiguous losses but they also feel deeply committed and vowed to take care of their spouse diagnosed with FTD and often find meaning and purpose in doing so. These findings should be considered for clinical supervision as well. Counseling supervisors should be aware of the emotional impacts that male primary caregivers for a partner with FTD experience so that it can be addressed with supervisees. This includes understanding that ambiguous loss is a relational loss and male primary caregivers experience ambiguous losses when a partner has FTD. Ambiguous loss is the epitome of absent but present (Boss, 1999). This will be imperative to consider when working with clients for couples counseling. The counselor will need to be empathetic and understanding of the relational losses that are occurring within the relationship including the emotional, cognitive, and physical connections that cause the spousal caregiver to experience anger, irritation, and feelings of resentment while still being committed to putting his partner's needs before his own. It is the commitment of marriage vows in the relationships that allow one spouse to stay and care for the other with dementia. This is supported by The Model of Commitment (Rusbult & Buunk, 1993) and Interdependence Theory (Kelley & Thibaut, 1978). This will be imperative to consider when working with clients for couples counseling.

In addition, the findings in this research suggest that being part of a caregiver support group for those caring for a loved one with FTD helped the participants process and understand what was happening to their spouse and within their relationship. This is an important factor for professional counselors and counselor supervisors to remember and refer clients to caregiver support groups for those caring for a loved one with FTD.

This would also be an opportunity for professional counselors to offer and facilitate a support group for caregivers for loved ones with FTD.

Implications for Counseling Programs and Counselor Educators

The findings in this study provide implications for graduate counseling programs and counselor educators to consider. It is recommended based on the findings of this study that counseling programs and counselor educators consider adding a dedicated course in adult development that includes caregiving for a spouse with dementia, specifically FTD. As the population continues to age and one new case of dementia is diagnosed every three seconds, it is expected that 82 million people will be diagnosed with dementia by 2030 (WHO, 2020). Those who are caring for a spouse with dementia of any type is only expanding. Without dedicated, formal training, counselors-in-training will be at a loss both practically and ethically when counseling those who are primary caregivers for a spouse with dementia, specifically FTD. Furthermore, the findings in this study confirm that male primary caregivers for a spouse with FTD are significantly emotionally impacted by this role they experience the committed vows of marriage strained, feel the changes in the interdependence and intimacy within the relationship, and live with the ambiguous loss of a lifetime partnership. Counselor training programs sometimes have dedicated courses to family and marriage counseling and human development across a lifespan. However, many spend a limited time on adult development regarding marriage and spousal caregiving for a partner with dementia, specifically FTD. This is a demographic that will continue to reach out for counseling over the next several decades. It is strongly suggested that counseling programs and counselor educators consider teaching the next generations of counselor-in-training about this population and to consider best practices for counseling.

Implications for Future Research

The findings in this study generated implications for future research. The participants voiced wishing a handbook for caregivers existed for those spouses caring for a spouse with FTD. This was coupled with the desire for medical providers to know more about FTD for a faster more accurate diagnosis and to communicate better with the caregivers. It would be beneficial for future research to include male and female spousal primary caregivers for those with FTD to compare and contrast unique and shared experiences. Further research would help to inform writing an FTD caregiver handbook that would guide primary spousal caregivers through their experiences and act as a lifeline when most are feeling adrift at sea. In addition, it is recommended that future research dives deeply into the loneliness and feeling of being alone while being in a committed relationship as a male primary caregiver of a partner diagnosed with FTD.

Conclusion

The participants in this study experienced an array of emotions can be seen throughout the themes that emerged and explicated from the conversations in the individual interviews. They described changes in the collective idea of “we” with their spouses as their individuality remained intact but “I” shrank within that team framework that causes feelings of being neglected and having less time to do independent activities. The participants often felt marginalized as they navigated society in the traditionally female role of caregiver. They spoke of how their daily routines are impacted by the needs of their spouses’ activities of daily living (ADLs) and their shifting role displacement at home and within the workplace. And how this caused them to feel stressed and burned out some days. They described being bounced from one medical professional to the next trying to get an accurate diagnosis for their spouse over a lengthy period that caused feelings of frustration, anger, and often resentment of one another.

Participants spoke of not knowing what they did not know about taking care of their spouses with FTD while concurrently experiencing the dramatic changes in their spouses' cognitive, emotional, and behavioral states. This caused immense anxiety and sadness. The participants expressed that religion, friends, and family are necessary help that comes in many forms including sitting with their spouse to provide time to themselves, prayer groups, dinner, to very simply calling to check in and see how they are doing. They found solace and a sense of connection and community through these forms of help. They spoke of the intense loss of the emotional and cognitive connection with their spouses. They described feeling as if their spouses were already deceased. This was confounded by the fact that their spouses were still physically present but often behaving like small children or toddlers due to the progression of the FTD. They expressed an extinguished sex life with their spouses primarily because the progression of the disease left their spouses child-like and therefore, sex felt taboo and forbidden. All these feelings occurred as the participants were coming to the realization that their spouses were diagnosed with a fatal illness and their lives were forever changed.

The purpose of this study was to examine the lived experiences of males within a committed relationship who are the primary caregivers for a partner diagnosed with frontotemporal dementia. All the participants in this study expressed being personally impacted by the experiences of being a male primary caregiver for their partners. The participants also voiced experiencing significant changes within the relationship and were deeply emotionally affected by the ambiguous losses and changes in the cognitive, emotional, and sexual intimacy within the relationship with their spouse as the disease progressed. And moreover, the participants were significantly impacted by the loss of the interdependence with their spouse causing them to feel alone within the relationship.

As the population continues to age and one new case of dementia is diagnosed every three seconds, it is expected that 82 million people will be diagnosed with dementia by 2030 (WHO, 2020). There will be an increased need to understand how spouses who care for their loved one with dementia experience the relational changes and how the caregiving phenomena impacts them personally while retaining their own health and wellness. This is especially true for those diagnosed with FTD since it will be the third leading diagnosis of dementia by the year 2050 (WHO, 2020). The findings in this study gave critical insight into how males in a committed relationship and who are the primary caregivers for a partner diagnosed with FTD experience the interdependence, intimacy and ambiguous loss within the relationship as their spouses' disease progressed.

It is recommended based on the findings of this study that counseling programs and counselor educators consider adding a dedicated course in adult development that includes caregiving for a spouse with dementia, specifically FTD. This is a demographic that will continue to reach out for counseling over the next several decades. It is strongly suggested that counseling programs and counselor educators consider teaching the next generations of counselor-in-training about this population and to consider best practices for counseling those spouses who are the primary caregiver of a partner with FTD.

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Appendix A

Participation Solicitation

DUQUESNE UNIVERSITY
600 FORBES AVENUE ♦ PITTSBURGH, PA 15282

Dear Caregiver:

I am attempting to understand the experiences of males within a committed relationship who are the primary caregivers for a partner diagnosed with frontotemporal dementia (FTD). It is my hope that the current study will help to inform other caregivers in similar circumstances and those in the counseling field to this populations' experiences to better understand how to provide support.

You are being asked to participate in a research project that seeks to understand how being a male primary caregiver for a partner diagnosed with frontotemporal dementia has impacted you personally.

I am currently seeking participants who are:

(1) male in an intimate/romantic relationship with the same partner for at least the past seven consecutive years
(2) the primary provider of most of the in- home physical and emotional care for your partner/spouse who is diagnosed with frontotemporal dementia.

Participants will be required to initially contact me via email or phone to ensure the participant meets the above requirements. After the participant meets requirements, an individual interview between 60-90 minutes in length will be scheduled. The interviews will be conducted at specific times and locations that are both convenient and confidential for the participants. The interviews will be audio recorded and transcribed for review. The transcribed interview will be returned to the participant to verify that the information is correct. The participant will be asked to email the researcher to let her know if the information is accurate or if changes are needed. You are under no obligation to participate.

If you are interested in participating in this research study, please contact me within two weeks at scanlon2@duq.edu. Should you have any further questions or concerns about this study, please contact me or my faculty advisor David Delmonico, PhD (delmonico@duq.edu).

Thank you for your time and consideration.
Sincerely,
Aniela (Nellie) Scanlon, M.Ed., NCC, LPC, ACS
PhD Candidate
Duquesne University

Appendix B

Informed Consent

DUQUESNE UNIVERSITY
600 FORBES AVENUE ♦ PITTSBURGH, PA 15282

CONSENT TO PARTICIPATE IN A RESEARCH STUDY

TITLE:
The lived experiences of males within a committed relationship who are the primary caregivers for a partner diagnosed with frontotemporal dementia (FTD)

INVESTIGATOR:
Aniela K. Scanlon, M.Ed., NCC, LPC, ACS
PhD Candidate
Counselor Education and Supervision Program
School of Education
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ADVISOR:
David Delmonico, PhD, NCC, ACS
Professor
School of Education
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(412) 396-4032

SOURCE OF SUPPORT:
This study is being performed as partial fulfillment of the requirements for the doctoral degree in the School of Education at Duquesne University.

PURPOSE:
You are being asked to participate in a research project that seeks to investigate how being a male primary caregiver to a partner diagnosed with frontotemporal dementia has impacted you personally.

In order to qualify for participation, you must be:

(1) male in an intimate/romantic relationship with the same partner for at least the past seven consecutive years
(2) the primary provider of most of the in- home physical and emotional care for your partner/spouse who is diagnosed with frontotemporal dementia.

PARTICIPANT PROCEDURES:

To participate in this study, you will be asked to talk about how your experiences as a male primary caregiver to a partner or spouse with FTD has impacted you mentally, emotionally, and physically.

Examples of the questions that you will be asked include:

1. How has being a primary caregiver impacted how you feel emotionally connected to your partner?

2. How have you experienced loss within the relationship since being the primary caregiver?

3. How has being a primary caregiver impacted you regarding physical affection with your partner?

You will be asked to allow me to interview you. The interviews will be audio recorded and transcribed. The interviews will last approximately 60 to 90 minutes, and you will only be interviewed once. The interviews will take place in a professional and confidential setting convenient for both you and the researcher.

After the interviews are transcribed you will be sent the transcript of the recording to edit, add or delete anything you wish. You will be asked to communicate your thoughts about the transcribed interviews through email, unless you prefer to speak by phone.

These are the only requests that will be made of you.

RISKS AND BENEFITS:

There are minimal risks associated with this participation but no greater than those encountered in everyday life. You may experience sadness or discomfort as you discuss your caregiver role, your partner's disease, and how both impact you personally. You will be provided the national crisis hotline number as well as local professional counseling resources and encouraged to follow up with a provider should you want to process your thoughts and feelings after this interview is concluded.

A benefit for participation in this study is how you can help to inform other people in similar situations by telling of your experiences. The information gained from this study will also help inform professional counselors when working with clients who present in clinical sessions with similar experiences.

COMPENSATION:

There will be no compensation for participating in this study.

Participation in this project will require no monetary cost to you.

CONFIDENTIALITY:

The audio recordings of the interviews will be stored in a password protected file and destroyed immediately after they are transcribed. The transcription process will remove any identifying information about you and/or your partner. Written documents will be stored in a locked filing cabinet only available to the research team. All documents that contain any identifying information will be destroyed after five years.

RIGHT TO WITHDRAW:
You are under no obligation to participate in this study. You are free to withdraw your consent to participate at any time by notifying the lead researcher. If you withdraw, you will be able to specify whether or not the researcher can use any data already collected.

SUMMARY OF RESULTS:
A summary of the results of this research will be supplied to you, at no cost, upon request.

VOLUNTARY CONSENT:
I have read the above statements and understand what is being requested of me. I also understand that my participation is voluntary and that I am free to withdraw my consent at any time, for any reason. On these terms, I certify that I am willing to participate in this research project.
I understand that should I have any further questions about my participation in this study, I may call Aniela (Nellie) Scanlon or David Delmonico, using the above contact information. Should I have any questions about the protection of human subjects in this study, I may contact Dr. Jim Phillips, from the Duquesne University Institutional Review Board, at 412.396.1886.

___________________________________	__________
Participant's Signature	Date
________________________________	___________
Researcher's Signature	Date

Appendix C

Participant A Analysis and Coding

Participant A Statement	*My observation during interview/reviewing interview*	*What is the meaning of the statement*	*Theme Code*
I was talking about with the male caregivers and the fact that I think that they are reluctant to say much about the situation they're in.:11	We had been talking before I had begun the interview and he was saying that he thinks males are less forth coming about their feelings as caregivers than females. I kind of had this thought before beginning this study too.	He thinks males are reluctant to talk about their caregiver situation Males are emotionally reserved	3
I have found—well, I was going to give the example, my wife's uncle. His wife had Alzheimer's and his immediate reaction to the diagnosis was to keep her hidden out of sight. He didn't want friends or family knowing that something was wrong. He thought it would be maybe embarrassing or shameful if others saw her in that condition. So he basically kept her in the house and didn't take her anywhere.:11	He was giving an example of how males as caregivers are embarrassed or ashamed of their spouse or of themselves. I hadn't thought about it in this same way before. I was interested in hearing his perspective	Male caregivers are embarrassed of their spouses Male caregivers are worried about being judged Male caregivers are insecure with that role	11
So I think that's fairly common with a lot of males.:11	He was giving an example of how males as caregivers are embarrassed or ashamed of their spouse or of themselves. I hadn't thought about it in this same way before. I was interested in hearing his perspective	Males are reluctant to share their situations as caregivers	3
I know the individual that I related to in (city) that I had wished he would be willing to come and interview, he I think stays in an extended state of denial.	He was continuing to give me examples of others and how being male caregivers is experienced. He has not yet told me about his own experiences but what he is saying is interesting and I don't want to interrupt him yet.	Some Male caregivers stay in state of denial	3
He's in a situation. It's a very difficult situation because they have a son, they only have one son, but he has cerebral palsy and when he was born the umbilical cord was wrapped around his neck, and so his mother cared for him basically all of his life. And of course, he's quadriplegic. He's in motorized wheelchair, and the	I wondered how I would react to a life like the one he was describing? I don't know that I am strong enough to handle what that person has been dealt.	FTD affects those who are still caregivers to their children and their parents	5

mother was the primary caregiver until she got the diagnosis with FTD.:11			
And he has not been very proactive about looking for help.	I was also wondering if he was making a generalization about all male caregivers? But then again, in his experience of male caregivers it has been that they don't reach out for help or let anyone know what they are going through.	He is not like other male caregivers he knows Other male caregivers don't look for help Other male caregivers don't ask for help	5
And I have some mutual friends through our church that were very concerned about him and they asked if I would call him. So I did one day. This is a couple years back. And I told him about hospice care, which he had never even considered hospice care. And I told him about the benefits of the hospice care, and I said, "You know, the worst that can happen is that you ask for an evaluation. They come evaluate." I said, "It's no cost to you. They're going to come to your house." I said, "They come and evaluate, and they say that your wife does not qualify, I mean that's the worst that's going to happen. And then you can always go to another hospice provider and ask them to do an evaluation. There's no time limit on it.":11	He was explaining to me how he and other church members and friends reached out to help this man. It seemed to me that perhaps this participant feels like "other" when it comes to his identity as a male and caregiver. He might end up being the outlier? Something to keep in mind.	He is unlike other male caregivers He created an outreach to help a fellow male caregiver Males are uncomfortable asking for help typically.	7
And he took my advice:11	I thought this was pretty amazing that one male caregiver reaching out to another male caregiver was the catalyst for getting help with caretaking.	One male caregiver reaching out to another male caregiver allowed for the first to ask for help Male caregiver to male caregiver outreach works	10
He had her evaluated. She was approved. He found out about the respite care, which I had told him about that, so he took advantage of that, the temporary five day respite, put her in a skilled nursing facility. And something [perhaps?] transpired when she was there at the nursing facility that the social worker was able to get her on a long-term placement in the facility. And I think	It seemed to me that just by this participant reaching out to another male caregiver in the same situation he was able to help that other caregiver, the caregiver's spouse and family. I wonder what would have happened if he had not reached out to this other caregiver?	Additional help was achieved by male caregiver to male caregiver outreach Males do accept help when they know what finally what they didn't know	7

from financial standpoint they didn't have too much trouble getting him through on the Medicaid because I think they were basically living on his social security:11			
So everything was going along pretty well for them for a while and then all of a sudden, the nursing home started having issues with her being a younger patient3:59	I had read about this very issue in the documented research on FTD and caregiving and medical assistance and Medicare.	Asking for help is only the first step in getting help FTD is a difficult diagnosis per current policies and regulations in the healthcare world	6
She was in the lock down dementia unit of the nursing home but because she was 65 years old, they were afraid that she would be a combative risk to the other patients who are mostly in their late70s and 80s being that they were mostly--the dementia they had was Alzheimer's and not frontotemporal which frontotemporal is an early onset dementia.3:59	I felt very sad for the man who had risked reaching out for help only to be turned away based on lawyers and current Medicare policies.	Those diagnosed with FTD are discriminated against Caregivers of loved ones with FTD are in a unique and lonely situation Help for caregivers with loved ones with FTD is limited by policy and procedures and Medicare	6
So I think what it really came down to is that the nursing homes are understaffed. They go with minimum staffing, state requirements since you have to have two [inaudible] for every patient. If you've got a ward that's got 16 dementia patients and you've only got two people in there, that's not nearly enough3:59I think they are more content if you've got a patient who is docile, can be sit in a wheelchair, just wheeled around, stuck in front of a TV and [inaudible] the way they do. But because this particular individual was active and mobile and younger, they were fearful of her.	I know that through the research, that this is exactly true and something that is not related to those with FTD. Medicare only covers so much of the nursing home cost especially if folks have money in the bank. I think there needs to be more education around this type of medical information	A FTD diagnosis might get that person fast tracked to S SD/Medicare but what does that really mean?	6
And so, what happened is they kept sending her over to the hospital to the psych ward to get her on some kind of adjustment meds and they would prescribe the antipsychotics in the psych ward, and she'd be perfectly fine in the hospital. They	I was really pissed at hearing this. The advocate in me came forward and I was thinking of ways that I could use this information for future research to advocate for caregivers and those diagnosed with FTD so that a vegetative state will not be the only way long term facilities will	Medication management is the answer against potential law suits for FTD patients in long term facilities	6

wouldn't have better trouble with her. They'd send her back to the nursing home and the nursing home would put her back on the regular regimen of meds which is the prescribed,3:59	care for those with this diagnosis.		
They take her off that. So she's going from being on these anti-psych drugs for two, three days then [inaudible] off of them. They did this five times to this man. And after the fifth time, they called him one afternoon, it was a Friday morning, they called him and they said, "You need to come get your wife. She can't stay here anymore."6:07	I was just appalled at the thought of getting a call to come and get my loved one Friday afternoon. How devastating to the caregiver and his spouse diagnosed with FTD. I feel like that would be more of a law suit potential? I can't believe more places haven't been sued over neglect and abandonment? Something to look into for future research.	Long term facilities are not equipped to care for the average FTD patient FTD caregivers, male or female, have few options for long term facility care. Abandonment and neglect are real concerns for caregivers and their FTD diagnosed spouses	6
Of course, he's in a panic, "What do I do now? I can't keep her at home anymore." So he told the nursing home, "Please send her back to the psych ward." So they sent her back to the hospital. And in the meantime, they wrote her up and blacklisted her.6:07	I was thinking that even if this is only 75% accurate, it is a terrible thing for this caregiver and his wife to experience. I wonder how many other families this has happened to? Just because people don't report it doesn't mean it isn't happening widespread. I feel very motivated to publish this current study and work on another study to expose this issue in FTD caregiving needs.	The caregiver for a spouse with FTD was abandoned by the long term facility FTD patients are being blacklisted for long term facility care based on their age and symptoms	6
Now, I only have his side of the story so I don't know the whole version but his side of the story was that she was sitting next to another patient one day and that patient pulled out a can of snuff. Now, tobacco products are not allowed in the nursing home and she had enough presence of mind, even with her dementia. She knew that that tobacco was not allowed. So she reached and grabbed his can of snuff and took it away from him. Well, the aide saw it, went running over there, grabbed the can of snuff, gave it back to the man and then wrote her out for stealing. Now, I always thought that was ridiculous because if you're in a dementia unit in a nursing home, you know full	This participant was just supporting his previous story about the other male caregiver and his experience with his wife at a long- term facility.	FTD patients are discriminated against out of fear and ignorance of the diseased patients and their caregivers need a voice at the healthcare table	10

well there's no such thing as private property.6:07			
My wife stayed four times from respite in a nursing home and she's lost articles of clothing every time even though I mark everything and I tell him, "Don't mix it in with the laundry. I'll take care of it by staying there five, seven days.6:07	He was telling me his own experiences with things getting lost or misplaced when his wife was staying at a nursing home for a respite stay. I just keep thinking about how hard all of this must be on the caregivers and the relationship itself. Everything thing has changed so drastically	His experience of a nursing home was that nothing is private and what's yours is everyone's. **N/A**	N/A
What ended up happening was this individual is-- I got called back in. "Can you please call him? See if you can help him. "I'm like, "I don't know what I can tell him at this point." So I called him.8:10	He is navigating his own journey with a spouse with FTD while advocating and helping other male caregivers in his same situation. It felt purposeful to him as he explained how he was helpful. I have to wonder if finding this purpose is helping him with his own journey? I would imagine that will come up soon.	He reached out to another male caregiver to offer support Male caregiver to male caregiver support seems to be received well	5
So I called him. And I said, "I think you need legal advice." I said, "I can't give you legal advice." I said, "But I do think you need to contact an attorney."8:10	Yes, as I was thinking earlier, an advocate is needed. And an attorney seems like a reasonable and necessary means of help. If long term facilities are worried about law suits from one side they should be worried from all sides. It is a tough situation to be in .	Spouse who are caregivers for a spouse with FTD should seek legal advice for healthcare rights and responsibilities Male caregiver to male caregiver outreach is received well	7
Because what had happened with the hospital is the director of the psychiatry had told him that they cannot keep his wife there. She's not an acute care patient. They have no reason to keep her in the hospital. They can't keep her. And so they had called around to all of the available nursing homes. And everyone had said no. Because she had been blacklisted.8:10	I continued to feel sad and mad at what had happened to this participant's friend. Someone finally reaches out for help and then is met with abandonment and judgment. It makes it hard to not be ashamed of a the diagnosis or blamed for something that is out of the caregiver/patient's control.	FTD patients and their caregivers are discriminated against in the long term health care world/facilities FTD patients don't fit anywhere within the current Medicare driven healthcare system	6
This one particular nursing home had put her on this blacklist. And all the nursing homes had access to it. And they were saying, "No. We can't take her." So the psychiatrist told my friend that-- he said, "Either you can call probate court or I can call them." And he had no idea what he was talking about. He	It seems to me that caregivers are confused about what their rights are and where to go for help and guidance. I am wondering if male caregivers, in particular, feel more reluctant to seek the information they need because caregiving is not a role or identity they relate to?	Caregivers for spouses diagnosed with FTD are a marginalized population in the healthcare system He didn't know what he didn't know	67

was like, "Why would I call probate court? For what?" And he said, "I guess you need to call." So the next thing he knows he gets a phone call or he gets a summons from the court in his wife's name. She is supposed to appear before a judge. And so he calls the court and he says, "How is my wife supposed to appear before a judge? She has dementia. She can't go to a courtroom?" "Well, I'm sorry sir. She haste appear. She's on the summons. She has to appear." 9:01			
But he calls the psych ward and the psych ward said, "Well, we cannot send her to the court in an ambulance. Because she's not acute care. We're not allowed to do that. The only way we could get her to the court is you'll have to have a sheriff would come and pick her up." And he's going, "A sheriff come and pick her up? She'll think she's being arrested and taken to jail."10:02	I couldn't believe what I was hearing. It reminded me of when I was a school counselor at a school for at risk and adjudicated youth. They didn't have a chance at being heard based on how people perceived them and judged them. I feel the same is happening to at least some patients with FTD and their caregivers. They need a voice. It seems that in more rural areas it is worse than in larger metro areas where access to care might be different.	FTD patients and their spouses who are their caregivers are marginalized FTD patients and their caregivers are discriminated against by the healthcare system and the courts FTD is a disease not a choice	6 11
And so I tell him. I said, "You need to get some legal advice. And you need to get it fast." Because this was the week before all this was supposed to take place in court. And he goes, "Oh." He says, "I've got a friend who's a probate attorney." And I said, "Well, you get off the phone with me [laughter] and you call him [laughter]." And sure enough, he did. And the attorney was able to rush through paperwork and get him a legal guardianship So that he could appear in court before the judge and not drag her in10:29	We live in a sad state of affairs when it comes to caring for the weak in our society. If you can't give us something, you don't count. I am worried and sad. I am wondering why this participant is starting with someone else's story? I am sure we will get to that reason by the end of the interview.	Caregivers for a spouse with FTD need to seek out legal advice Caregivers with FTD need to gain legal guardianship of their spouse The healthcare system and legal system don't know how to handle a diagnosis like FTD He didn't know what he didn't know	7
The judge ruled that she would be placed temporarily in a rehab center here in (county) for two weeks to be assessed. And then she would be sent to the state facility up in (city) for a long-term assessment before	I was thinking the participant was telling me about his friend to showcase how most folks who are caregivers for a spouse with FTD in rural America are treated when seeking the best care for themselves and their spouses.	Spouses that are caregivers for a partner with FTD in rural areas are more marginalized then their peers in bigger cities FTD is a disease not a choice	6

they could find placement and get her back here in (city)10:29		Male caregivers for a spouse with FTD are marginalized just as much as their spouses are	
And so she spent probably about six weeks up in (city) 11:30 And she did fine up there. But of course, he couldn't go up there to see her. Because he's got this quadriplegic son.11:37	He just continued the story. I was really actively listening to him and I think he felt heard for the first time in a long time.	Long term care and help for people diagnosed with FTD is not supported by the current healthcare system and legal system in the USA **6**Males who are the primary caregivers for a spouse are often the primary caregivers for their children too	6
And so they eventually got her a placement a nursing home in (city). They sent her back to (city). She was there all of two weeks. And they I'm sorry. She can't stay here long-term. And they sent her back to (city) where she still resides to this day. and he goes up there maybe once or twice a year to see her11:46	I could feel myself become overwhelmed with sadness and emotion hearing the end result of the man he was telling me about. How unfortunate that he had to send his wife so far away to get the care the “system” said she had to have based on her diagnosis and age and nothing else.	People diagnosed with FTD are discriminated against in the healthcare system and legal system in the USA	6
The facilities themselves, I think, there is a major lack of understanding about what FTD is. They know all about Alzheimer’s. They've heard about Alzheimer's. Everybody's heard about Alzheimer’s. But they don't understand what frontotemporal degeneration is all about12:40	This is what I had been thinking and he stated just that. It is important to hear from his lived experience so that others can be informed.	The healthcare facilities don’t know what FTD is FTD is an unfamiliar disease to the majority of healthcare providers FTD is a disease not a choice	6
I found there's a lot of neurologists who don't understand what FTD is all about. I have even had a situation myself where my wife was hospitalized in the neuro ward of a hospital, where you would think they would have some understanding of the entire dementia spectrum, but I basically had to train and educate every nurse that came in on the new shifts, because they didn't understand how to deal with my wife12:40	As this participant began to start to talk about his experience as a male primary caregiver and his spouse, I believe he now feels comfortable with me and not judged. I believe his story about his friend was not only to inform me of different caregiver situations but to “feel me out” to see if I would judge him and his decisions as a caregiver for his wife.	The medical community does not understand FTD. FTD is not fully understood by experts in the field of neurology Spousal caregivers have to inform and educate some healthcare providers on what FTD is and how to treat their loved one. His life has changed drastically	6

And it really basically started with the neurologist that was assigned to her when she went in the hospital. And neurologists can be kind of strange people. It's a different field of medicine. But this particular doctor, he comes bounding in the room like we're supposed to know who he is. He's not even wearing a white coat, so I wasn't even sure he was a doctor at first. But give him credit, it was a Sunday night so he wasn't prepared to be in a hospital, but my wife had been there all day Saturday and then got admitted early Sunday morning. So he came bounding in there late that evening. And anyway, he immediately is telling me, "Oh, we're going to put her in adult diapers, because she's incontinent."12:40	As I listened to his talk and tell his story of not being marginalized by the medical profession, I couldn't help but think of how it must feel to be a white male in America and be treated as if you don't have a voice. To be told what will happen…to not be included in the conversation. Being marginalized is devasting…but I wonder if this is the first time he has felt this way?	Healthcare professionals, such as neurologists, sometimes do not have a good understanding of what FTD is or how it progresses differently for each person diagnosed. FTD is a diagnosis not a choice. His life has changed dramatically and drastically He was traumatized by the medical community as a male primary caregiver for a spouse with FTD	6
And I'm going, "Wait a minute, wait a minute. She's not incontinent. She does have control, and she wears Pull-ups." Oh, now we're going to put her in adult diapers. Well, so he wrote the order up.12:40	I felt so appalled at what he was telling me about how he and his wife were treated by the medical profession to this point. I was thinking that the caregiver has to be an advocate as well. I wonder if being male makes it easier or harder to be an advocate for a spouse's healthcare?	He was bullied as his wife's caregiver by medical professionals. He was ignored by healthcare providers as his wife's primary caregiver He and his wife were marginalized 6, 14	6
And the nurse would come in and they would check her to see if she was wet. And they would find her dry. And I looked at the nurse when they came in and I said, "She's going to be dry." And I said, "She holds it in." I said, "You're going to have to get her out of the bed and walk her to the bathroom."12:40	I couldn't help but feel terrible for how he and his wife were treated. I felt embarrassed for them. Where was the dignity and compassion from these medical providers? It was hard to hear. As he talked, he was speaking louder and gesturing as if to say can you believe this?	He was treated disrespectfully His wife was treated like an object He and his wife were not treated with dignity	6
I said, "But, the doctor wrote that she's incontinent." And I said, "She has bladder control issues," but that point in time she was not incontinent. And I said, "You're going to have to get her out of the bed and take her to the bathroom." And she got some help, they got her out, got her in the bathroom.	I couldn't help but feel terrible for how he and his wife were treated. I felt embarrassed for them. Where was the dignity and compassion from these medical providers? It was hard to hear. As he talked, he was speaking louder and gesturing as if to say can you believe this	He had to fight for his wife's rights He had to educate medical providers about his wife's behavior and condition	6

Sure enough, she had a flood in there. And she'd been holding it several hours while they come in and check. “Oh, she's dry, she's dry.”12:40			
But I mean, it's just a continuing education process.12:40	I was thinking how he appears to be taking everything in stride. I could not imagine their situation.	He had to educate the medical professions on his wife’s diagnosis of FTD He had to educate the medical professions on how FTD is affecting his wife specifically	6
I can give you another example in a medical office. Took my wife to our primary care doctor. She wanted to have some X-rays done for check for tuberculosis. She just wanted to check her lungs. I forget. It wasn't tuberculosis per se, but the Xray room was on the same floor just outside of our doctor's office. It was a little office to the side. So we get through with our doctor. We go out there. I go to the sign-up ward. I sign my wife in. The tech comes out to get her, and I went to the door and I explained to the tech. I said, “My wife has dementia. She has PPA, primary progressive aphasia.” I said, “You can ask her questions. You're probably not going to understand anything she says.” I said, “If you need to get some clarification, I'm going to be right here, just come and get me.”16:03	He was giving another example of how he had to educate the medical profession about his wife’s diagnosis and what that means for her and what that means for how to best interact with her. He appeared to have the explanation down and was saying it in a plain and easy to understand way. How different his life is now with his wife.	He educates the medical professionals about his wife’s diagnosis to ensure the best treatment for his wife	6
Well, I tell you. It wasn't 30 seconds later that door flies open and tech's going, “Yeah [laughter].” So, I go in, and the tech just literally throws this paper gown at me, and she says, “Get her in this, and I'm going to go back to my office and when you get her ready you let me know.”16:03	As he was telling me another example of how he and his wife were not treated with care or dignity, it was painful to hear and be witness to.	He was treated disrespectfully and undignified by a medical professional	11
You're the medical professional here, and you're telling me I have to get her ready.17:34	He was frustrated even as he was recounting the story to me.	His role as a caregiver was to sometimes do the job of a medical professional	6

So that's what I did. And when I get finished, I call the tech, and she comes back out there. Well, she wants her to stand with her back flat up against the wall, and she aims the x-ray machine. Well, as soon as she gets my wife positioned on the wall, she steps forward. And so she goes back there. She does this three times, and my wife just won't stand there with her back up against the wall17:34	It seemed to me that he had to shift roles several times in just this one story. He was his wife's husband, caregiver, advocate, and the medical professional's support with her patient. I was thinking that if I were in that same situation I might have taken my loved one and just walked out. It seems like he has a lot of patience for this situation.	He had to support the medical professional in her job duties in regard to his wife **5.6**	6
Probably cold. Exactly. She's wearing this paper gown, and her back's exposed [laughter], and she won't stand there. And she says, "Well, you're going to have to stand here and hold her." And I said, "You mean I got to stand here in front of this x-ray machine while you put your leaded suit on and go back there [laughter]."18:13	He was kind of laughing as he told me this story but was able to convey the humiliation and disbelief he felt from this encounter with the medical field as the caregiver, spouse, and advocate for his wife.	He was discounted by the medical professional He and his were not treated with dignity He and his wife were marginalized by the medical professional	6
So that's another example. I can give you a third example, too. It was actually in that same office complex. We had been sent to get some lab work. The lab was also on that same floor. I had gone into the lab, and they wanted to do a urine culture, and I told the tech that you're going to have to get a nurse to come help because I'm not comfortable going in there in the women's restroom with my wife. I said, "You need to get a nurse to come help her with this."18:34	He was saying he was uncomfortable going into the women's restroom with his wife for several reasons. I do believe it might be more embarrassing for a male to go into a female restroom than the other way around. Maybe because the male might be seen as a pervert or predator were as a female would not be seen in that same light if she were in a male restroom with a spouse? Just the thoughts I was having as he was describing this event.	He is a male primary caregiver He is uncomfortable taking his wife in the women's restroom as a male	3
Because they have the restrooms are set up next to the lab where they have a little door. You just put the sample in. But I just didn't feel comfortable going in the women's restroom. I mean, it was a single person restroom, but still. I mean, there's a lot of people in the waiting room and all that. And I'm a male and I just didn't want to do it,18:34	His role has changed so much as a spouse/caregiver/advocate and it seemed that his last bit of dignity was being called into question. He seemed to draw the line with his male identity to not go into the restroom with his wife in public. I could certainly see his point.	His male identity is challenged as a male primary caregiver	3
They got all these nurses and techs there. Somebody can do it.18:34	He certainly has a point. There are medical staff hired to help	His identity as a male is challenged as a primary caregiver for	N/A

	patients with these type of things.	his wife He and his wife are not being treated with dignity by the medical staff/community	
So they get the nurse. The nurse comes in there, and I mean the nurse was in there just a short time, and she opens the door and motions me over, and she said, “Your wife soiled herself. I’m not going to be able to get a urine culture.” I'm like really? “You don't have any way to clean her up here?”, “We don’t have anything here that we can clean her up. You're going to have to take her home. And try to get her rescheduled for another culture.”18:34	I couldn’t believe what I was hearing when he told me this story. I have heard of bad professionals in every field but this must have been so humiliating and embarrassing and just horrible. For both he and his wife.	He and his wife were stripped of their dignity He was marginalized as a male primary caregiver	6
I got to take her home soiled, and then try to reschedule a urine culture to see if she's got a UTI?20:19I was steamed over that20:29	I was trying to put myself in his shoes as I was listening. I don’t know what I would have done. and I don’t know what would be the final incident that would push me over the edge	He was treated without regard or caring by the medical staff His wife was treated without care of concern by the medical staff	6
Next time we went back to our doctor, I told her about that incident, and she said, “I'm going to send my nurse in with her this time.” And the nurse they had called from the lab was just the nurse they found on call that was not wanting to deal with it 20:35	It sounded like he kind of got an apology from his doctor but more of an excuse for poor medical staff behavior instead.	He was given excuses why he and his wife were humiliated and not treated with dignity	6
And I learned from that experience too, always take an emergency bag with you. So I have this little kit that I keep in the trunk. So that if I have situations where I need some clean pull-ups and some wipes, and that I've got them with me. Because I never would have thought being in a medical facility they wouldn't have a way to clean her up.20:3521:06	As he continued to say he learned from that experience I could only imagine how much of a learning curve his entire experience as his wife’s primary caregiver has been for both of them.	He is learning as he goes how to be the primary caregiver for his wife	7
So next time that happened, and she did have her nurse go in there. Her nurse had me go in with her to keep my wife calm so she wouldn't get upset being in there with somebody she didn't know. But she did	He sounded relieved when he told me that he had help the next time his wife needed to have a urine culture. It sounded like he and his wife were treated with respect and dignity. But I wondered how the other	He advocated for respect and dignity for he and his wife	6

all of the work, and I just was there for my wife's-- to keep her settled down.21:33	experience had affected him still?		
And that went fine, but it's a-- I'd have to say there's a lack of general understanding. There's a lack of understanding about what FTD is,22:02	Again, it sounded like he and his wife have been treated like her diagnosis is a choice not a disease. It is especially hard to know that the medical community is one of the biggest offenders.	He has to educate the medical community about what FTD is He has to advocate for himself and his wife with medical professionals	6
I think then there's a lack of understanding of what the caregiver goes through. And I think that goes both male or female22:02	He answered the question I was wondering about in one of his earlier statements.	His role as the primary caregiver for his wife is not understood by the medical community	6
If you're a caregiver, you're going to run into situations like that, and I think maybe it's maybe even a little bit more embarrassing for a male caregiver because you're dealing with some intimate issues that you're not used to dealing with.22:02	He said what I was thinking, that it might be more embarrassing for a male caregiver since that role has historically been a female role and maybe being in the bathroom taking care of your husband is easier for a female than a male in the bathroom taking care of his wife.	He is uncomfortable with intimate issues as a male primary caregiver. Male caregivers are not used to dealing with intimate issues	3
Absolutely. Yeah. From day one, (spouse) was diagnosed in February of 2014. So we're right at 5 years post-diagnosis. She likely had early symptoms dating back as far as 9 to 10 years ago.23:03	When asked if FTD had impacted their relationship.	FTD changed their relationship drastically	1
She is now 67.She was 62 at diagnosis.23:30		His wife was diagnosed at age 62 with FTD His life changed drastically 5 years ago	N/A
And that was critical in the probable diagnosis of FTD was the age factor because, as I'm sure you're well aware with FTD, there is no specific marker that they can look at and go, “Yeah. It's definitely FTD.”23:34	It is amazing that with FTD being the 3rd leading cause of dementia in the USA, that more research hasn’t gone into diagnosis and causes of FTD. I realize while it is the 3rd leading cause, the numbers are still relatively small…but maybe because diagnosis has been underreported or missed	His wife’s age was critical factor in FTD as a diagnosis His wife was diagnosed with FTD	6
Now, they're getting better. Since 5 years ago, they're getting better with the diagnosis where the PET scans are more accurate, and they can they can pinpoint areas of activity in the brain, and if they find there's lack of activity in the frontal lobes and		Since his wife was diagnosed with FTD, the medical field has gotten better at methods/tests of diagnosing FTD	6

temporal lobes, it's a pretty good indicator that it's frontotemporal23:34			
In my wife's case, she was denied twice having PET scans by insurance companies that thought there was not enough empirical evidence, even though we had one very arrogant neurologist say, "Oh, I can get one no problem," and then he couldn't 23:34	Even though the medical field has gotten better at ways to diagnose FTD, the insurance companies still hold all the cards in how these tests are paid for and when.	He had a struggle getting a diagnosis for his wife initially due to insurance companies denying critical tests.	6
But at that point in time he was like, "A PET scan really isn't going to establish anything more than what we already know,"23:34	He was just saying that even if the tests were paid for by insurance it wouldn't really tell them anymore than they already suspected. I was thinking it must be frustrating to know something is wrong but not what.	He was told more testing doesn't always mean more of an exact diagnosis	6
because what I learned from experience is that the caregiver's very critical in the diagnosis. You've got to go into the doctor with notes in hand and all of your observations because that's going to carry a whole lot more weight than any tests they can run23:34	It seemed like a lot of pressure was on him not only as the spouse, caregiver, but also as the guardian of the diagnosis. I could not imagine the stress and pressure.	He was critical in his wife's diagnosis of FTD He had to advocate for his wife's health care	6
MRIs are not going to show [FDE?]. PET scan is the closest you can come to it, and everything else is kind of a-- it's a process of elimination. You eliminate all the bad stuff like tumors and brain bleed and stroke, and then you go, "Oh, well. The age and the behaviors," and so forth and so on.23:34	He was being matter of fact with me as he described this part of the diagnosis process. I wondered if that is because the medical community was matter of fact with him?	He was a vital part of his wife's diagnosis of FTD His wife's FTD diagnosis was a process of elimination of other diseases	6
As for how it affected our relationship, it seems like, from the very outset, right after her diagnosis, things started to fall apart very quickly, mostly because my wife was having more and more language difficulties25:26	This was his initial response to how his wife's diagnosis has impacted their relationship. I was expecting him to say what he did.	His relationship with his wife changed drastically with his wife	13
And right after her diagnosis-- she had been in the hospital for four days, following what-- well, the hospital team determined it was a near fainting incident which never	He was a little scattered as he began to talk about how his relationship had changed almost right after his wife was diagnosed	He didn't think the medical professionals knew what was wrong with his wife	6

really explained much of anything25:26			
I was very hopeful at the time she was hospitalized that they would really find something. The hospitalization resulted from an incident where she had literally frozen at the table.25:26	As he was telling me this story about his wife I was thinking that if my loved one just froze at the table I would have been really freaked out. And he was just telling me the story like it was the norm.	He was hopeful the medical community could help him	6
I mean she was sitting at the kitchen table, and she was drinking a protein shake that this neurologist had prescribed for her that was being used as a brain food for Alzheimer's, and he said we might try this with her because she wouldn't take the (medication). She thought it was a black box drug, so she wouldn't take it. So he said, “Well, let's try this (medication),” which was a protein shake that was being developed for Alzheimer's, had just come on the market.25:26	It sounded like it must have been scary to think that perhaps the shake his wife was drinking was causing her seizure like symptoms if not full on seizures.	His wife was taking new to the market medicine for Alzheimer’s although she doesn’t have that disease	6
Anyway, she was drinking that and she just suddenly froze in place.26:56mean it was like she was in a state of suspended animation. She was just leaning forward, her eyes were glazed over, and she was stiff, wasn't moving her limbs I immediately thought stroke, grabbed the phone, called 9-1-1.26:56	He was very animated and talked louder as he told this part of the story. I could feel my own anxiety level rise just listening and thinking about his situation	He didn’t know what do to. He knew his wife was having a medical emergency N/A, He thought his wife was having a stroke N/A, He was scared by his wife’s symptoms	7
Of course, they started asking me all the stroke-related questions, and while I'm on the phone, she started moving, so I was able to get her into a more comfortable chair, and within 5 minutes they had EMS out there. And they took her to the hospital. The hospital kept her for four days of observation. We had an entire team of doctors looking at her. Primary care was in charge, and then they had a cardiologist, a gastroenterologist, had a psychiatrist, had a neurologist. They did EKGs, ECGs. They did MRIs, and all they could conclude was she had a near fainting incident.26:56	The way he described what his wife was doing before he called 911 it didn’t sound like she was fainting? But after hearing him describe every test that was done his wife it sounded like doctors couldn’t explain what actually caused these symptoms so just gave a generalized diagnosis.	He was not given an exact reason for his wife’s medical episode at the dinner table. N/A	6

It did lead to us going to a different neurologist because he was appalled that she was taking this protein drink. He said, “Why is she taking that?” and I said, “Because that's what her neurologist put her on,” 28:27		He was sent to another expert for his wife’s symptoms	6
and anyway, from that point forward, things started to break down as far as our relationship because she was less and less aware of things, and that was in February.28:27	He was telling me about all the incidents that seemed to lead up to the break-down of his relationship with wife. Although I almost forgot why he was telling this latest story. He seems to be good at intellectualizing things related to his intimate relationship with his wife.	The progression of his wife’s disease started to break down their relationship	1
As a result of the GI doctor checking her out, they did find that her gallbladder was not functioning correctly and that it needed to come out. So she had gallbladder surgery in April28:07	He just jumped around the topic of his relationship with his wife and how it was rapidly deteriorating. He went back to her physical ailments. It seemed that was easier for him to discuss with me.	His wife had gallbladder surgery N/A. His wife had many physical ailments that accompanied her diagnosis of FTD N/A	N/A
And, when she had the gallbladder surgery, I did not, at that point, have a durable POA or a healthcare POA, and in fact, I'd never really even considered such, didn't really know what they were, and when she was in the hospital for her procedure and they were getting her prepped, they had called me back there to answer questions because she was notable to communicate all of the answers, and when they asked her what procedure she was in there for, she couldn't tell them.28:59	As he was talking I was thinking I don’t think anyone really things about a POA until it is almost too late. It is something that everyone should probably have done along with a will sooner than later. As he was talking he was using hand gestures to emphasize just how overwhelming things were at that time in space.	He had to advocate for his wife’s medical care He didn’t know what he didn’t know	7
And I thought then and there, I said, “They're going to say she can't have it.” And they did go ahead and allow me to sign the paperwork and the release forms, but that kind of was like an “Aha” moment for me because like, “I'd better do something about this.” Because if she gets in a situation like this again, they might not let me sign the papers and then what’s going to happen?28:59	It sounded like everything that was happening to him as his wife’s disease progressed was a true learning curve. As he was telling me this story I got the feeling he was warning me that I too should be prepared for a crisis like this in my own life.	He didn’t know what he didn’t know He had to advocate on behalf of his wife	75

I sought out an attorney and we had our wills updated. We had living wills done, the advanced directive. We had both a healthcare POA and a durable POA. And it was still while she was cognitive enough that she could sign and she knew what she was signing. And I'm so thankful that we did that.28:59 Otherwise, I'd be looking at legal guardianship or surrender-ship or something like that at this point.28:59	It sounded like he knew what he had to do to get things legally updated so that he could guarantee that his wife got the medical treatment that was best for her from this point forward. I am wondering if every caregiver is so knowledgeable about where they need to turn and what they need to get done?	He sought legal advice for what he didn't know	7
I always tell other caregivers, that's one of the first things you need to do. Go see an attorney, get those papers done while they're cognitive because once they're not cognitive anymore, they can't sign those papers.28:59	He was very emphatic when telling this to me. It might just be good advice for all couples?	He advises all caregivers to get the POA while your spouse is still cognitively able to sign off	7
I got that taken care of, but my immediate realization was our retirement is going to be 100% different than what we had planned28:59	He swung the conversation back around to how this all has impacted his relationship with his wife. It was a very impactful statement.	His relationship with his wife had changed drastically His idea of retirement with his wife changed 100%	1
We were both pre-retirement at the time. She had been forced into an early retirement.28:59		Their lives as a couple had drastically changed.	1
She was a speech pathologist if you can believe it28:59	It seemed like a cruel joke that his wife who no longer can speak, was a speech therapist by profession. I got chills as he told me this. His voice became lower.	His wife was a speech pathologist by profession and diagnosed with FTD the PPA type	N/A
Works 30 years in public schools. She had a double major. She had a major in both speech and in math. She was certified to teach math, but she never had the desire to teach math in the school system. Her passion was working with the special ed population and working with the speech students.31:25	As he was telling me about his wife he was both sad and proud of the woman she was and what the disease has done to her now.	His wife was a speech pathologist for over 30 years in the public school system	N/A
And it was very gratifying to her to see the progress that she could make with these children and really help them to have a better life. But she would do that during the day, during the regular school day. Then she'd	He was beaming with pride as he told me about how hard his wife worked and was independent and motivated by the people she helped. I could see his love for his wife in his non-verbals.	He was proud of his wife's life accomplishments	N/A

come home and for like two hours in the late afternoon, she would tutor students inmate at our house.31:25			
And I'd come home for dinner and I'd say, "What's for dinner?" And she'd say, "We're going out (laughing)32:14	He was laughing and clapping his hands as he recounted what his wife used to say to him after a long day of work for both of them.	He and his wife shared humor before her diagnosis	1
I was a marketing communications manager. I worked in advertising for some 40 years.32:24		He was a professional communications manager for over forty years. He relates to his professional identity	5
I am now retired. I retired at 65. The company I last worked for, I was with a startup division of a company that, the owner of the company didn't think we were making fast enough progress after three years and he decided to pull out funding.32:32	He was telling me his professional background	His professional identity has changed He is now retired	5
So, at that point in time, I was 65 and I was paying for help to take care of my wife, and I thought, "Well, I might as well just retire and be her full-time caregiver." So, I have been ever since.32:53	He seemed matter of fact when he was telling me how he decided to retire since he was 65 at the time it made the decision a little easier.	He retired to take care of his wife fulltime His role drastically changed. His life changed dramatically. His relationship with his wife changed dramatically	5
So, as far as the immediate realization for me upon the diagnosis was that our lives were going to be forever changed33:10	He was sad and holding back tears as he was telling me of when he realized their lives were forever changed. I was thinking in our culture we work all our lives to save for retirement but that doesn't always play out that way. I was looking at him and thinking life is short…enjoy the now	Their lives were going to change forever. His relationship with his wife has dramatically changed	1
all of a sudden it started hitting me that I no longer had this companion that I depended upon to help make decisions, major decisions.33:10	He again was very somber and sad as he was telling me this. I felt sad for them both and for the life they didn't get to continue to live together in the way they had planned	His relationship with his wife had changed drastically He lost the companion he had once known	8
She was always the logical side of our marriage. I was always the more emotional side.33:10	I just listened quietly as he continued to tell me about his relationship with his wife over the years.	He and his wife balanced each other	1
And she was famous for pulling out her sheet of legal paper and putting pros and cons and we'd list things out,	I definitely got a visual of how they handled things in their relationship. It sounded very different from how it is today	His wife was logical in the relationship He was emotional in the relationship	1

and I'd go, “Yeah, I guess you're right.”33:10			
But we were that way about buying cars. IWars the one who'd go in and I'd go all ape over a car and she'd go, “Do we really need all these extra options. We could get this basic car and it'll--.”33:10		He was emotional in the relationship He depended on her	1
she was always the voice of reason, and I was very dependent on that33:10		His role in his relationship with his wife has drastically changed	1
I think the second thing I realized is I'm losing the best cook I know because she was a fabulous cook.33:10		His wife took care of him His wife is no longer available to him in the ways she used to be	1
And the only cooking I ever did was I was the outdoor grill man33:10And we had our divisions of responsibilities34:44		He and his wife had their distinct roles within the relationship	
I'd take care of the outside of the house, and she took care of the inside and did the laundry and the cleaning, and I occasionally vacuumed. But we had our split responsibilities34:44	I just continued to sit quietly and actively listen as he continued to recount his life with his wife. I would occasionally nod my head or gesture that I was interested and listening. I thought they had a relationship that sounded like much of a typical relationship	He and his wife had distinct roles within the relationship	5
and all of a sudden I started realizing I've got to do everything.34:44	This statement hit me hard to hear him say. I imagine it’s because it was one of the hardest realizations he had to make for himself.	His role completely and drastically changed	5
I've got to do all the finances, I've got to do the cooking, the cleaning, the laundry, major financial decisions. And all this stuff starts hitting me.33:44		He is responsible for everything now in the relationship and around the house	5
I'm all alone34:44	This was the most haunting thing he said in the interview.	He is “alone” in the relationship but not physically alone	8
I mean, I think that becomes the overwhelming feeling is I don't have any help.34:44	I imagined him out to sea without his life line or anchor he relied on in his wife all those years before.	He is overwhelmed He is alone in his relationship with his wife	8
Here you've handed me this diagnosis for my wife, and I've got this hot potato, and I don't know what to do with it.34:44	I certainly go the visual as he was gesturing passing a hot potato from one hand to the other. I got a sense of the urgency he was feeling	His life changed drastically when his wife was diagnosed with FTD. He doesn’t know what to do	7

And I think that was the thing that struck me that most is the neurologists are great, they can do all the diagnosis and tell you this is what you've got, but then they don't tell you how to handle it34:44	He continued to talk freely and I continued to listen and try to put myself in his shoes a bit	He didn't know how to handle the news that his wife had FTD	7
And I walk out of their office and it took a while for all this to sink in.34:44	I really couldn't imagine what hearing that news must have been like for him and for his wife.	He was shocked by the news of his wife's diagnosis of FTD	12
Obviously, it wasn't the same day she got the diagnosis because it'd been kind of a progress anyway. We knew that something was coming down the pike, but once it finally got to the diagnosis, and then I started realizing all the implications, I was like, "I'm all alone in this. There's nobody here to help me.34:44	Again, he was really stressing how alone he was.	He is alone in the battle with his wife's diagnosis	7
I can't even ask my wife because she can't help me anymore."34:44	The person he depended on for 30+ years is no longer able to help him. He was tearing up when he was telling me this. I could feel his emotion. I felt sad for him	He could no longer depend on his wife	8
I guess that's where I took a different approach than a lot of men do.34:44	After he was done talking about what he had lost he began to talk about what he chose to do differently that other male caregivers he had known of…	He chose to be different in his caregiver role	3
Instead of becoming internal and internalizing it, and I think that would have been the biggest mistake I could have made because I would have gone into a state of depression at that point, I tried to seek help. And it wasn't easy at first34:44	As he was comparing what he did as a male versus what, in his experience is vastly different from other male caregivers, I wondered what made him so different?	As a male caregiver he reached out for help	10
but wherever I could find information about FTD or Alzheimer's or anything in general dealing with dementia. I started signing up to go to seminars and different groups34:44	He continued to explain what help he was seeking. I just listened quietly.	He signed up for educational seminars for help. He began reading any information on FTD to help him	10
I was somewhat limited because I was working and I didn't have the time to go to things, so a lot of my research relied on what I could find online at first34:44	I was reminded that he was working full time when his wife was first diagnosed with FTD	His resources were online at first due to his time constraints of still working full time. He educated himself about FTD	10

Later on, after I retired I was able to get involved with support groups and so forth but.34:44	After he retired he had more time to join support groups etc. I also reminded me that not everyone who is a primary caregiver can or wants to retire from working full time which might make reaching out to certain kinds of help hard or impossible.	After he retired he had more time to join support groups for help	10
2016, after I retired, I started going to a support group that was offered at the daycare where my wife was going. I had her enrolled in a hospital-sponsored daycare. We've got a wonderful facility here in [inaudible]. It's dedicated strictly to dementia patients, it's called the (center). It's over at (hospital) which is the big hospital in (city) 37:37	I thought it was good that they had resources available for the caregivers at the site where he had his wife in care during the day.	He joined a support group after he retired and had more time. He joined a support group for caregivers of loved ones with dementia at the same hospital where his wife was in adult daycare	10
It was established back in the early 2000s by a family. They had no children. The man was an executive in one of the steamship companies in(city) years back and family had money and his wife had Alzheimer's. So he wanted to establish an ongoing fund that would support a facility. So they've got a five-acre piece of land over there. It's a beautiful facility. A couple of buildings on there. It's all a lockdown facility. So once you get in there, it requires one of the aides or nurse to come and let you out or let you in. But I had her enrolled over there and she was doing well there.37:37	As he was describing the facility where he had enrolled his wife for daycare, I knew he seemed to have more resources in a metropolis than other people who live more in more rural places. I was thinking what a difference it would make having access to better help.	He had access to better resources to care for his with and help for him	10
Yes. I didn't want to go down the rabbit trailer39:28	This was his response to me asking about if support groups were helpful to him.	He wanted help so he didn't become depressed	10
At that time, they were having a monthly support group that had met in the morning. So when I was still working, I could never go to it. But once I was retired, I started going to the support group.39:28		He was able to attend support groups after he retired He was unable to attend support groups when he was still working due to the time of day they met	10
It was not a sharing type of support group it was an educational support group and they would bring in different representatives to come in and talk about different aspects of	I was listening quietly as he told me about his support group experience.	He joined an educational support group for caregivers of those with dementia	10

dementia or dementia care.39:28			
They brought in a whole different range of people. They had an attorney come in and actually ended up being the attorney that I used for elder care advice later on.39:28		He used an attorney for elder cared advice. The educational support group brought in different speakers to help the group members in the care of their loved ones	10
Anyway, during this same period of time, I was trying to keep my wife as active as possible.39:28		He was seeking support at he was trying to keep his wife as active as possible	5
I want to do as many normal things as possible. And I came across a program that the (museum) was doing which they had developed a couple of years previous where they had trained a staff of volunteers to be able to give what they call memory tutors for people suffering with dementia.39:28	As he was telling me about the program at the museum he seemed a little more energized.	He sought out activities that he could do with his wife **1**He was the “we” and the “I” of the relationship	1 8
And I had called the museum and told that I wanted to schedule a tour for my wife. And they were a little bit back and forth with me at first because they said, “Well, it's been two years since we trained our volunteers and nobody's called. And we'll have to see if we could find somebody.” Well, they did eventually find it first and then they got scheduled and they do it on a Monday when the museum is closed to the public, so you basically got the museum to yourself.39:28		He and his wife were the first people to take the museum on the offer of the program for people with dementia. He was persistent with trying to find ways to help his wife He was an advocated for his wife	N/A
And so I took (spouse) up there and we met this person. She turned out to be a nurse herself and she has her own company that provides in-home nursing care. And she was our guide for this private tour in the museum and it was very well done. She was very animated and she had a lot of objects. She had this big bag with her and she would take things out. She said, “And this is what this feels like in our--”39:28	It seemed like he was very happy with the experience at the museum.	He and his wife were able to enjoy an activity together outside of the house. He was trying to provide new activities for his wife His role changed within the relationship His life changed drastically	1

So my wife was walking around in the exhibit, but she would have little samples of things and she did a very good job with it. [inaudible] I met this-- her name was (name), and it's a name you don't forget [laughter].42:15	I wasn't sure if he was talking about the nurse or he met another woman at the museum. I was quietly listening and waiting to see if he would clarify before I interrupted him.	He met a woman in the museum while his wife was walking around. He was alone. N/A	
But I started going to this support group at the (center), and this (name) also would go to that support group, and oftentimes she would sit at the same table with me and ask about my wife, and we got to be friends.42:47	As he was talking about this woman who he met at the museum and now is going to the same support group he was going to, I thought for sure he was going to say that more than a friendship was happening between them. I was waiting patiently for that to be said.	He formed a friendship with a woman in the same support group. He was lonely His role had changed	10
And she mentioned to me one time-- she said, "Are you going to the seminar in (city) next week?" And I said, "I don't know anything about the seminar in Fairhope." And she said, "Well, I'm going to send you materials on it." So she emailed me the application form and I start reading through this thing and it says CEU credits for healthcare professionals. And I wrote her back and I said, "(name), I'm not a healthcare professional. I can't go to this thing." And she writes me back and she says, "Yes, you are [laughter]."42:47	I started to wonder if he knew/felt that India was having an emotional connection with him that perhaps she wasn't getting elsewhere? I wondered if he knew that it appeared he was getting the emotional connection from India that he was no longer able to get from his wife? I wanted him to continue talking and I didn't want to interrupt his story.	He formed a friendship with a woman from his support group He was identified by others as a health care professional His identity had changed His role was drastically different.	5
Yeah, and I don't say this to brag, but honestly, I have learned through five years that in many cases I have more knowledge on the subject than many medical professionals43:51	I could tell he was proud of his knowledge and skill set of how to care for his wife. And how to advocate for his wife with the medical community. I think he was flattered that this woman was impressed with him perhaps.	He is an expert in how to take care of his wife more so than the medical professionals He is very knowledgeable about FTD and how it has affected his wife	6
But I got on the phone and I called the sponsor of this seminar, and it was a local hospice provider based out of (city). And when I called - I didn't know it at the time - but they put me through to the executive director, and I'm talking to this woman and I'm telling her that it's been suggested to me that I attend this seminar next week. And	It was great to hear how empowered he had become by this woman from his support group. He was reaching out to become more educated and perhaps share with others what he already knew about being a primary caregiver for a loved one diagnosed with FTD.	He was proactive in his outreach for help and education about being a primary caregiver His role had changed He was an advocate for his wife and for himself as a caregiver He found connection with other primary caregivers whose loved ones had FTD	N/A

she said, “Well,” she said, “It's already booked out.” She said, “We've got another one coming up in (city) next month if you can come to that one.” And I said, “Well, I could probably do that.” And she wanted to know a little bit about why I was interested and I told her about my wife, and as soon as I mentioned FTD, it was like, “Oh. FTD,” because she had been a caregiver for her mother who had suffered with FTD for eight years.44:07			
So she had a special place in her heart for FTD, and she says, “If you don't tell anybody [laughter]” she says, “I'm going to pencil you in.” And I was like-- who was I going to tell [laughter]? But she says, “If you don't tell anybody,” she says, “I’m going to pencil you in and you come to the seminar next week.”45:10	I was happy to hear he had a “win” in his reaching out for help. It appeared to really lift his spirits as he was telling me how things happened.	He was able to connect on a personal level with others who were caregivers for loved ones with FTD He is an advocate for himself as a caregiver His role has drastically changed.	N/A
So I went to the seminar and I am sitting there listening toa professor from the (university) talking about all of the new research that's being done on Alzheimer's.45:10And he opens it up for questions at the end of his presentation. So I raise my hand and I go, “You've talked all about Alzheimer’s research, what can you tell me about current research on FTD?” And he kind of hems and haws and he says, “Well, there is research being done but that's about as far as they would go.”	As he was talking he was conveying that the seminar wasn’t maybe exactly what they had advertised. r	He wanted more information on FTD in a seminar about dementia and caregivers	6
And so, a little later one when they had a break, one of the nurses who's attending this event sought me out and she said, “Are you the guy that asked the question about FTD?” And I said, “Yeah, that was me.” And [laughter] she says, “Oh, my husband has FTD.”45:10	Even though FTD is not as diagnosed as Alzheimer’s, he still found another person who was a caregiver for her husband who had been diagnosed with FTD. He was not alone.	He was not alone in his role of caregiver for a spouse diagnosed with FTD	N/A
And she lives down in (city) which is south of here. And she said, “I've been going to a	He was really emphasizing the fact that a lot of caregiver groups that focus on caregivers whose	Support groups rarely include caregivers who	6

support group." But she says, "Everybody that's in that support group is dealing with Alzheimer's." And she said, "None of what they say really relates to me because the thing is with FTD, it's younger onset and some people dealing with FTD still have children in the house."45:10	loved ones have been diagnosed with dementia very rarely are focused on FTD. Those caregivers have different concerns since those diagnosed are younger and may still have children at home.	spouse is diagnosed with FTD	
Well anyway, she said, "I don't get a lot out of going to his Alzheimer's support group. Do you know of an FTD support group?" And I said, "Unfortunately, I don't. Because the only one I'm aware of is in (city) and that's a little far for us to go[laughter]."45:10	I could see he was enjoying telling me about his experiences and the journey of advocating for FTD support groups. It seemed as those this was his purpose now. I wondered if it helped support his identity as a male?	There were no local FTD groups in his region at one time	10
So that got me to thinking, why not? Why couldn't we have an FTD support group here?45:10		He is an advocate for caregivers for loved ones with FTD	6
So I called AFTD and I told them that I was interested in finding out more about how to get a support group going and that I was working with this executive director with this hospice company down here. And I think she might be interested inworking with me on this if you would send us information.47:28	He was again energized when he was telling me about how he was proactive and involved in getting a FTD support group activated.	He was proactive in reaching out for help specifically with FTD support and education	10
So I got in touch with the executive director at the hospice company and she was all on board. She says, "I've been wanting to do this for a long time." Because that hospice company was starting-- they were sponsoring support groups all over the area but they're all Alzheimer's support groups and I was actually attending one that she was facilitating at the facility here where her mother used to be. So she had started this support group but it was an Alzheimer's support group. But I would go to her group and she kept encouraging me, "Keep coming because I want more males to come."47:28	It was good to hear that he was able to find purpose by advocating for FTD support groups in his area. He seems to be the epitome of activist.		N/A

And at first, I was the only one and then there were a couple of others. So there are about three of us in this group that--and I got a lot out of the group just because it gave me an outlet47:28	He was explaining that he continued to go to the support group that was primarily for caregivers for those diagnosed with Alzheimer's because it did serve as an outlet to vent.	He found the support group for mainly Alzheimer's caregivers still helpful	10
So by February of the following year, I think it was 2017, we started our first support group.47:28We've been meeting ever since	It was great to hear that he had started the first FTD support group in his area. He had advocated for this and got it going.	He was an advocate and activist for a FTD support group in his area His role changed	10
The only downside on that was her name was (name). She left that company. She had been the executive director there 10 years. She left that company right at the same point that we started our support crew. And so I was kind of left holding the bag49:57		His role changed within the FTD support group He is a leader for FTD caregiver support group	5
My dad kept telling me, she said, "You're going to end up being the facilitator of that group." I said, "No, dad." I told him, I said, "I can't do it. I'm a full-time caregiver. I can't run a support group at the same time."49:57	He was laughing as he was telling me what his dad told him about being the group leader. It seemed that he was happy that his dad was right. And that his dad was proud of him.	He is a fulltime caregiver He is a leader for caregiver support	10
And sure enough, I'm co-facilitator. The lady who works with me, she is on our end and she has been a director of [inaudible] care facility herself. So she's very good to have as a co-facilitator49:57		He is a leader for caregiver support	10
For me, the support groups have been very good.49:57		He asked for help through the support groups and it helped Him to help others	10
I'm disappointed now that they seem to be kind of shrinking in this area49:57		He is disappointed that support groups for FTD caregivers are shrinking	10
We still have our FTD group but the company that originally was our local sponsor has kind of-- they've gone through some management changes and they don't have-- they're not supporting the support groups anymore. And I know that from a fact because I had actually registered with them	He appeared to feel responsible for the groups not continuing on in his area. He really explained that it was helpful to him. I think it not helped him process his new role as a caregiver but it seemed to give him a new purpose for his life without the life partner he once had.	He feels responsible His role has changed	10

as a volunteer for their hospice company so that I could be-- so that we could be listed as one of their support groups. I used to have to send them monthly reports after our meeting, listing any new members and information sheet.49:57			
They got rid of the position of the woman who I was sending those reports to and they've never asked me for another report. So like, okay, they don't care. If I don't send them reports anymore-- I mean we're affiliated with AFTD and we're both certified, myself and my co-facilitator. We're both certified with AFTD. So I mean, we get our support through AFTD51:40was disappointed that they've pulled the plug on all these other support groups too because the one I was going to over this memory care facility is no more because the woman who is facilitating, taking over facilitating that, that's the person who's job they eliminated. And then there was a social worker before who left. I mean it's just been a revolving door. You know how companies do sometimes. Management changes aren't alwaysgood51:40		He was disappointed that the FTD caregiver support groups fell by the wayside His role changed His purpose was in question again His life changed drastically He was disappointed that the FTD caregiver support groups fell by the wayside His role changed His purpose was in question again His life changed drastically	10
I could tell you, it's pretty much gone full cycle.53:17	This was in response to me asking about the changes in his partnership with his wife since her diagnosis and how that has affected their physical relationship.	His relationship with his wife has changed drastically	13
I won't say we had a perfect marriage, I don't think anybody has a perfect marriage but we had a great marriage.53:17	He became visibly emotional, tearful as he was telling me about his relationship/marriage with his wife.	He had a good marriage	1
I mean we were together for 45 years53:17	I could feel myself well up with tears as I was reacting to his emotionality while he was remembering and telling me of their marriage	He was married for most of his life He and his wife were together for 45 year she was part of a “we” longer than he was an “I”	1

We have two children53:17		He and his wife have two children as a result of their 45- year marriage	N/A
We both had careers pretty much our whole marriage. And I think maybe sometimes careers maybe got in the way of us being as close as we could've been.53:17	As he was saying this it made me for an instant think that about my own marriage and time spent doing things that don't really matter in the long run.	He and his wife had independence within their marriage He and his wife were "I's" within the "we" of their relationship	12
From a physical standpoint, we were always very intimate. We used to say that we'll still be making love when we're in our 80s.53:17	He laughed as he said this to me. And then his laugh faded as tears came to his eyes. I again, could feel his emotion and I reacted with teary eyes too.	He and his wife always had a healthy sex life He and his wife were always very physically intimate	13
Divorce was never in our vocabulary54:18	I thought this was a very poignant statement. I perhaps a reason he has remained in the relationship and has become his wife's full time caregiver. I was just quiet and waiting to see what else he had to say.	He and his wife never spoke of divorce He and his wife were a committed couple	1
We made that pact with each other when we first married that we would never even use that word. I'm not saying that we never fought. We were close, for the most part, and very intimate.54:18	I just listened and tried not to interrupt as he continued to tell me about their relationship. I paid attention to what he stressed.	He and his wife were very close	1
The intimacy started to fall apart-- in November of 2010, I had surgery to remove my prostate.54:18So I had limited function after that but my wife was very understanding and we were working through those issues.		His physicality changed their sex life	13
Then along comes FTD starting to enter the picture.54:18	He was explaining the physical relationship with his wife and how it had started to change after his prostate surgery and then was further complicated when his wife was diagnosed with FTD.	His intimacy with his wife was significantly impacted by the diagnosis of FTD	13
We didn't know it was FTD. I can remember taking a trip with her down to (city) where we had lived in (city), (state) for 13 years and we had a lot of ties to that area is where we first lived right after we were married. And then we came back up here for a couple of years and then went back down there with the company I	He was reliving a romantic trip he and his wife took not so long ago.	He and his wife made time for romantic couple time He and his wife were intimately close	1

was with. So it was a special place to us.54:18			
But we went down there to celebrate our anniversary and it was the first time I realized that her concept of what sex was had completely evaporated.54:18	He was telling me the story of the exact time he realized his wife's concept of sexual intimacy had disappeared.	His sexual intimacy with his wife had drastically changed	13
And what normally would've been an intimate time for the both of us ended up being pretty much a bust. And because it's like she just didn't-- she was getting to the point where she was apathetic and she just didn't have that [inaudible] same kind of drive that she once had which is kind of disappointing54:18	It was sad to hear how they had enjoyed their sex life, at least by his account, and then to have it disappear was hard to hear.	His wife became apathetic to sex with him	13
So at this point in time, pretty much for the last five years, I felt as if I'm living as a widower whose wife is still alive.56:55	I found it interesting that he was equating loss of sexual/physical intimacy with being a widower. It does make sense because he also used words such as close and intimate to mean more than just sex.	He felt like a widower whose wife is still alive	8
It used to bother me tremendously when I first started going places alone and I'd go to a restaurant or I'd go to an antique gallery or somewhere. This is once I started having additional help and I could do that. I would go to places and I would see other couples enjoying each other's company or out on date nights.56:55	I could really get the sense of loss he was experiencing. He had lost several things within the relationship along with the loss of part of his own identity.	He was "I" not "we" in his relationship with his wife	1
It would depress me because I was like, "That should be (spouse) and me. Why am I being denied this?"56:55		He felt alone He felt denied his relationship with his wife	8
And as a Christian, I was angry with God at first. I was like, "Why are you taking my wife from me?"56:55		He was angry with God	9
But I said it came full circle because I am at the point where I actually feel privileged to be able to care for as she has declined. She's very dependent on me. She's been dependent on me all throughout this ordeal.56:55	He said he feel privileged to be taking care of her now but I wondered if that was actually the truth? I believe he believes what he is saying is true but I wonder if he has to believe that in order to keep going?	He feels privileged to be his wife's caregiver His wife is dependent on him He is the "we" for both he and his wife His life has changed drastically	1

But now, she's been on hospice for two years. She's just got a sweet sweet spirit about her. I'm very thankful she does not have the behavioral variant. She has the language variant with the PPA but she retains her sweet spirit.56:55	As he was talking about his wife’s sweet spirit, it seemed to me he is trying to keep something he remembered about her and their relationship alive and the same as it was for 45 years.	His wife has been on hospice for the last 2 years 12	12
I'll pick her up sometimes and I'll be getting her out of the car and she'll look at me and she'll pucker her lips and I'll kiss her and she'll say, I love you”[inaudible].” She can't enunciate very well but I know what she's saying. So I mean, she's still got that emotional attachment with me and—56:55	He began to cry as he told me how his wife still tells him she loves him. He believes it is a true emotional attachment she has with him. I am not sure if that is still possible due to the nature of FTD but it appears to be happening with them. I could feel his love for his wife as he told me this story	He still feels some emotional connection with his wife	8
Yes. Yeah. I have my human moments where the frustrations of her lack of ability really dragged me down and I can get angry and I've had to learn where my threshold is and walk away from it.59:30	He was really engaged in the conversation and honestly opening up about his frustration and angry with his situation and with his wife. I could not imagine how I would handle this exact situation if it were me? I can’t say I would handle it with as much grace, dignity and love.	His relationship with his wife has changed drastically	8
If I've got her in the bathroom and I'm struggling to try to get her cleaned up and she's fighting me all the way, not because she's really fighting me, but she has Parkinsonism too. So her arms get stiff and she grabs on and you're trying to get her cleaned up and she's resisting and-- I'm using every ounce of physical strength I've got. You wouldn't believe that she's 85 pounds but I mean, she had--when those muscles stiffen, they're stiff, they're locked in place. And when I'm trying to keep her balanced, get her cleaned up and she's trying to pull off on her pull-ups and stuff's dropping on the floor, “I can't take this.” And I just have to set her down and walk out of there and go do a primal scream in the backyard or something [laughter].59:30	As he was describing just the physicality of having to take care of his wife, I thought how strong he has to be. Not just physically, but emotionally and mentally. And that the vow they took, and the fact that they never spoke of divorce, must be what gets him through all of this. I don’t know that I would be able to do it.	He is struggling on a daily basis with ADLs for his wife His wife if struggling	4
But I have learned to cope with that. It used to bother me a lot to do the cleanups	As he was talking about having to clean up after his wife has accidents with being incontinent,	He has learned to cope with being a caregiver	5

because I mean, that is wasn't something I was used to doing1:00:59	I was thinking is anyone really used to cleaning up those types of accidents? And it reminded me of my time as a nurse's aide and how I had to clean up folks that were incontinent and what that feeling was like. I then compared what I felt like when I had to help take care of my mom in the last year of her life. It was a very different feeling. I was more hurt at how I knew she felt as her daughter was taking care of her versus someone else that was not so connected to her in that same way. I wondered if it is the same type of feeling he is feeling about taking care of his wife?		
that touches on another issue with male caregivers as the-- I think you have to learn to get in touch with your caring side because males are not really set up to be caregivers. We tend to be more on the--we're the provider and the protector for the family.1:00:59	He was really giving evidence of how males are not set up in our culture/society to be caregivers. And that male are more set up to have roles as the provider and protector for the family. I would not disagree with how our American Culture has labeled male and female roles.	He thinks males are set up as protectors and providers for their families in our society He thinks males are not naturally geared for the role of caregiver He thinks males have to learn how to be caregivers	3
And when you're suddenly thrusted to this role, you've got to be kind and compassionate and considerate.1:00:59	I was wondering if he was not kind, compassionate, and considerate before his role shift? I find it hard to believe a person can learn to have these types of characteristics…maybe he had to practice them more? I just continued to listen.	His was thrust into a new role of caregiver as a male	3
That touches on a different side of you that you're not used to putting on full display.1:00:59	I think I received my answer to my previous question. it's not that he didn't feel these ways before, he just felt he couldn't show that side of him before because it did not fit his role or identity as being male in our society. Perhaps the label of caregiver gave him permission to be wholly who is truly is? It is a great thing to think about as far as male identity and male role in our society.	He was not used to showing his caring and compassionate side in public	3
So, it's been tough for me. Patience has been the biggest thing. Learning to be patient1:00:59	He seemed to get saddened as he was thinking about how and why he has had to learn to be patient. I wondered if being patient was part of how he had to learn how to be compassionate? Or kind?	He has had to learn how to be patient as a male in the role of caregiver	3

	Because he didn’t mention patience earlier when he was talking about how as a male, you have to learn how to be more caring.		
Yeah [laughter]. I had a woman that worked for me at one time and she used to always say, “Hey, patience is a virtue. Possess it if you can. Always in a woman but seldom in man [laughter].” 1:01:59	Again, he was really hitting it home the difference he really saw and felt as a male caregiver in comparison to a female caregiver. And the fact that it was a female coworker that seemed to validate his feelings and thoughts seemed to make it truer for him.	His role within his relationship with his wife changed significantly His identity as a male and caregiver was being challenged	3
Well, basically, I don't have a social life1:02:45	In response to my question about his social life now.	He does not have a social life anymore	2
I mean, I very much adhere to keeping with my wedding vows and to not trying to look for relationships. I'm not saying that I have not had that temptation, but I try to avoid it.1:02:45	I didn’t specifically ask him about extra marital relationships, but he must have thought that was what I was implying. I was wondering about it and would have eventually asked. I could not imagine having some type of physical, tactile relationship with someone for over 5 years. Not to mention an emotional and cognitive relationship with someone.	He has adhered to his wedding vow he has remained committed to his wife. He still identifies with the “we” of the relationship He has not sought out other extra marital relationships to meet his physical or sexual needs	13
Actually though, I have to make opportunities to have social interaction. I have some male friends who are widowers, who are my age, unfortunately, but I do call them from time to time, go to lunch with them.1:02:45	I found it interesting but not surprising that he feels more comfortable with widowers in a social situation. It gives way to the ambiguous loss theory of absent but present that is created with dementia and specifically FTD within a relationship.	He identifies as a widower	2
And most recently, I have a troupe of widow ladies who are all mostly in their 80s, who go out to church after-- or go out to lunch after church, and they've invited me to join their group, so I've started going to the restaurant after church with them.1:02:45	We laughed as he told me about going out with the group of 80-year old widows from his church. But after thinking about it a little more I wondered what need of his was being met with these relationship/social interactions.	He identifies with widows His social interactions are with older widows	8
When we have our monthly FTD support group, there's one other lady that comes. She says, “This is our social interaction.”1:04:10	All his “social” interactions are with people who have lost their significant emotional, cognitive, social, physical, and sexual relationship.	His social life has changed significantly	2
So, because we often times at support group don't even talk about FTD, we just share a lot what's going on in our lives, so. That is a social outlet that--	It seemed like he gets some relief from talking about other things with folks who know about what it means to be a caregiver for a spouse with FTD…so they don’t	He has found connection with others in the FTD support group His social life has changed drastically	2

beyond that, it's not much to it because most of my evenings are spent in the house.1:04:23	always have to mention it…they can just "socialize" about other "normal" life problems or successes with each other.		
I do have paid caregivers that come three nights a week that-- like tonight, and it gives me a little bit of an outlet, but I'm basically alone when I go out. I go out to eat, and we've got a nice pier down here that I go down to, and it's a lot of park area, and I go [renting?], and walk when the weather gets nicer, so, lighter a little longer.1:04:23	It was sad to hear that his time out is usually by himself. I did wonder if he was being completely honest with me. Perhaps there was more to his social life but he did not want to tell me or maybe he was telling the truth but I just can't imagine it is true? It just seems such a lonely existence.	He has scheduled times to get out of the house but it is spent alone. His social life is not social	10
I think with the doctor it comes down to education. I think the doctors need to have the materials on hand about what this disease is1:05:49	This was in response to me asking him about what doctors/medical community could have done differently to help with his experience as a caregiver for his wife.	He believes the medical community/doctors need to be better educated about what FTD	10
And I think when you get a diagnosis, they need to have those readily available to offer their patients or their patient's caregivers. Because basically when you're dealing with a dementia, you're dealing with a caregiver, it's not so much the patient-doctor relationship, it's more the doctor-caregiverrelationship.1:05:49	I believe his perspective of when it's any form of dementia as the diagnosis it's really about the relationship with the doctor and the caregiver. This makes sense to me.	He believes when dementia is the diagnosis the relationship is really between the caregiver and the doctor He believes having information about FTD from the doctor to the caregiver is paramount in helping the caregiver understand and have resources right away	10
But I think that along with any support materials, like a list of available support groups, and some possible books that you can read because there are some good books. There's a book called What If It's Not Alzheimer's? which specifically addresses FTD.		He believes having information about FTD from the doctor to the caregiver is paramount in helping the caregiver understand and have resources right away He didn't know what he didn't know	7
And also, any kind of connection or literature or just a link to AFTD because AFTD has a wealth of information that most people find stumble on my accident then I think if the doctors had that initially, that would be very helpful.1:05:49And it needs to be in every neurologist's office. A lot of neurologists don't have a lot of working		He is an advocate for caregivers of loved ones diagnosed with FTD He promotes any connection with the AFTD. His role has changed significantly	7

knowledge of this disease. But that education needs to be-- it needs to be out there.			
As far as family and friends, family is difficult because family tends to be the worst about being in denial.1:05:49	His response to me asking him about what he would want to be different when asking for help from family and friends.	His family was in denial of his wife's diagnosis	10
I made the mistake with my mother-in-law of telling her that early on I had done research and found that dementia can be reversed if they can determine that it's caused bydepression.1:05:49	As he was saying this during the interview, I really didn't think anything about it. But after listening to the recording and reading the transcript I wondered if his family was just reflecting his own denial in the beginning?	He was in denial about his wife's diagnosis initially He didn't know what he didn't know	7
We had gone through a particular trying time with one of our daughters prior to my wife's diagnosis, so she kind of clung on to the idea that they could determine that it was depression, treat the depression, and she'd be well1:05:49And I shouldn't have ever told my mother-in-law that because she was always going to look on the bright side of things, and everything's going to be well, and she's going to get better.1:05:49		He shared his worries and hopes with his family	7
And it wasn't going to happen and of course, when she found out that (spouse) was having her neuro-psyche testing, and I had told her that's the purpose of neuro-psyche testing is to determine if it's organically based or if it caused by some kind of emotional trauma. And she clung on to that. "Oh, well, how did the neuro-psyche testing come out?"1:05:49	He was continuing to tell me about how his family was in denial initially with his wife's diagnosis. Again, now I can see how perhaps he was hopeful along with them in that regard.	His family was in denial of his wife's diagnosis initially	10
Of course, I had to tell her the neuro-psychologist found that her findings were consistent with what the neurologist was seeing. And so, family, you would want the family to be supportive, but a lot of family tends to back away when they hear it's a dementia1:05:49		He had to tell his family about his wife's diagnosis His family was not as supportive as he would have liked them to be	11
I think a lot of it's just because they don't know how to react to somebody who's got dementia.1:09:01	I thought about this statement. I agree with him. In our culture being young and vibrant is attractive and being young and "demented" is taboo. It had to be	He had to tell his family about his wife's diagnosis He didn't know how to respond to them not knowing	11

	the one to break the news to the family while still trying to wrap his mind around exactly what this all meant for him.	how to respond to his news	
And maybe it's partly the term dementia that just conjures up images of somebody who's delirious and out of their mind or whatever. Or they don't know how to talk to somebody who doesn't respond back1:09:01	Again, I think his comments mirror how he might have felt at first or possibly still might be feeling on some days.	He believes dementia conjures feelings of anxiety about how to communicate with someone who can't respond back	11
Honestly, I really don't have any advice for family except stayinvolved.1:09:01		He needed support from his family once his wife was diagnosed with FTD	10
And that's hard to do because most family members have a difficult time with it. It has taken a long process with(spouse)'s sister who lives here in [inaudible]. She at first, well, (spouse) was going and staying with her mother during that period of time when I was still working. One of the days of the week I was dropping her off at her mother's house. And we did that until her mother passed in March of 2016. And that's when I started putting her more full-time into the (center). But up until that point of time, she'd been seeing her there and her sister who'd come up occasionally and visit with her while she was at her mothers. And every once in a while her sister would ask me, "Do you think she's going to get better?" And I said, "No, it's a progressive disease. It's just going to get worse." And so she stayed in that denial state. Well, after her mother passed, my sister-in-law started coming up every Friday to take (spouse) out to lunch. And it's been a really good thing because all throughout their adult years, they have not been close. And so ironically, this disease brought them together, but at first she would come to the house and she	This was his story about how his wife's sister stayed in denial of her disease.	His experience is that family stay in denial of a FTD diagnosis	10

would be critical of me and things I was doing.1:09:49			
And I would react with, "Well, if you think you could do it better, you just take her and you live with her for a while and you see how it is," because nobody understands what a caregiver goes through unless you are a caregiver.1:11:01	To his point, I believe what he was saying and understood to a certain degree that no one knows what it was like to be him, in his relationship, as a male caregiver for his wife who was diagnosed with FTD.	His role has changed He didn't know what he didn't know and nobody else does either	7
I'm sorry, you cannot understand it unless you are in that role. But she would come in, and she criticized what clothes I put on her "OH, well, that's dirty." "No. It's not. I just put it on clean, and she just spilled on herself. I'm not going to take her back and change her again. It's an ordeal. Do you want to do it [laughter]?" I didn't tell her that, but that was my thought process1:11:10		Help from others is often misguided by what they don't know they don't know	7
And I think the aha moment for her was she took her out to lunch one day and she took her over to a park to eat their lunch and they got out of the car and there were some kids playing in the park there. And (spouse), she's always happy to see kids because she worked with kids her whole life. And (spouse) sits down on the ground, and her sister cannot get her up. And she came this close to calling me to come and help pick her up. And finally, I think (spouse) did pick herself up, but I think that was her watershed moment where she finally realized that everything I was doing was as best I knew how todo.1:11;10		The family help finally realized they didn't know what it was like to be a caregiver for their loved one with FTD. They didn't know what they didn't know.	10 7
And she stopped being critical after that. And she and I have actually developed a closeness, which I never thought would happen because she's always had a hard edge about her, and she's not [laughter] been a sister-in-law that I would have felt close to. But through this disease, she's become close to her sister--1:12:51	It was a good perspective and hope filled about FTD as a vehicle for reconnecting family relationships	He experienced FTD as a relationship connector	10

As far as friends, just call. I mean, people do not realize how lonely you are as a caregiver. And often times, I would just appreciate if somebody would just pick up the phone and call me "How are you doing? What's going on?"		He needed support from friends His life changed drastically	10
Come by and visit. Don't just shut us out.1:13:19			11
My wife taught school for 30 years, and I thought she would have a community of support among her former peers. She was forced into an early retirement. There were a lot of people that were still working in the school system that she knew, that she worked with. As a speech pathologist, she was assigned all over this county. I mean, she worked in multiple schools over the time period, and she knew a lot of people.1:13:54	He was explaining the lengths he went to try and have friends or coworkers from his wife's work come and visit her. I was thinking that is a lot of work on his part. And I was thinking it was sad that he had to put that much effort into trying to get folks to visit them and keep them included.	His wife had a lot of social connections before she became sick with FTD	10
So what I did one day is I went to the school website and I looked up every school where she had previously worked, and I composed an email and sent it to the principals of those schools. Now, I know most of those principals were different than the ones that were there when she was there, but I sent them to those principals and I explained (spouse)'s situation and that she would love to have company. And I gave my contact info and I said, "If anybody would like to come by and visit, we'd be glad to have visitors.		He reached out to friends and colleagues for social support.	10
Well, I got one phone call from a woman who worked at a school office with her and knew her and she was wanting to come by but it never worked out. Had two other ladies who she had worked with professionally who came to the house.1:13:54		Social supports were contacted to visit he and his wife.	10
They spent about two hours with (spouse). And (spouse), at	I could feel his disappointment in even telling me the story	He experienced friends not understanding the	11

that point, she was kind of borderline being able to talk and not talk and they were able to draw her out and they actually talked about old times and reminisced and had a great time. They were there for two hours. And they left the house saying, “We're going to do this every week.” I've never seen those two women again.1;15:29	about the two women that came to visit with his wife. And then when they never came back it seemed to hurt him on behalf of his wife immensely.	disease or how to remain in the relationship	
I had (spouse) with me and we were in a (store). Saw her friend and she, “Hi. How are you? Oh, I need to come by.” Never did.1:15:29		He experienced friends not understanding the disease He experienced friends being uncomfortable with seeing his wife deteriorating cognitively	11
She also had a work associate she worked with who was a fellow speech pathologist at one of the schools actually here in (city) who now has a private practice. We had run into her and her husband a couple times in a local restaurant back when I was still taking (spouse) places and she would come over and talk to us. And she gave me her card and she said, “You call me.” She says, “I want to come to the house. I'm going to visit (spouse).” Well, I actually did call her a couple times. And she always had some excuse, some reason why she couldn't come. In fact, I called her one time and I said, “This house is full of teaching materials that my wife got from a school that closed.” She was working at one of the schools here that they shut down because it was small school in the system. And they told the teachers, “You take whatever you want. We’re not going to move this stuff.” So we took a pickup truck up there and filled it. We had two [inaudible] filing cabinets.	It was heartbreaking to hear him talk about their social isolation and being shunned and disregarded due to his wife’s diagnosis. It really highlighted for me the true stigma and taboo associated with cognitive decline		11
“Oh, I'd love to do that.” And she never has. Never has		He realized he couldn’t force people to remain	11

called me. Never has come. So you can't make people-- you can't force people to have relationships. But I think that's something that needs to be encouraged is that don't leave people out of your lives just because you're dealing with a brain disorder.1:15:20		in a relationship with he and his wife	
I think some of it's fear and reluctance because they don't know what to say. Now we're fortunate we have a couple from our church that comes and eats dinner with us one night every month1;18:30		He and his wife have one couple who socializes with them once a month	11
At first, they were a little bit-- they didn't quite know how to deal with(spouse). And they've seen me working with her and they're comfortable with her now. I think they were a little bit uncomfortable at first. But I I'll tell you I've gone and visited some of these—1:18:45		He had to educate friends on his wife's disease	6 11
I've gone and visited some of these locked down memory facilities and I've seen residents in there. I've had (spouse) in a dementia care unit myself for respite care. And I'll have to admit, the first time I went in I was a little bit uncomfortable too around some of the people. They'd come up to you and they'd say weird things and all right, "I don't think I know what you're saying." But it's just a matter of your comfort level but I encourage people to stay involved. I think too, a lot of times people don't want to call because they're afraid they'll interrupt something. And I've told them and I said, "If you call me and I'm in the middle of doing something with (name) and I can't take the call, I'll just tell you to call me back in a few minutes."1:19:11	I think it is interesting that even he felt uncomfortable going to a locked dementia unit in the past. It can be shocking on many different levels. Having worked on one such unit myself years ago, it does take a little getting used to. Not just the patients with dementia, but learning to be an advocate for people that can't speak for themselves. I often would speak up for the residents to administration and would find myself at the end of a shitty mess by another coworker.	He was uncomfortable at first with visiting locked dementia units	6

Appendix D

Participant B Analysis and Coding

Participant B Statement	*My observation during interview/reviewing interview*	*What is the meaning of the statement*	*Theme code*
Well, initially because she, my wife, was still generally healthy at least as far as I could tell and we could carry on conversations and she was still able to thrive other than the initial shock of what the heck is FTD [inaudible] either of us had heard of it before.00:49Besides that shock, our lives continued for about two years in a similar fashion that it had.	As I opened up the interview I just asked how he has been impacted as a male caregiver for his wife. He started by saying at first things were ok because his wife was still able to be the same. But that they did not know what FTD was.	He did not know what FTD was His role did not change much initially after his wife was diagnosed	6
About a year after our initial diagnosis or her initial diagnosis we had submitted her to participate in an observation trial study for FTD at (university clinic) under (doctor). She was accepted and we started. And so the first two years she spent-- I spent with her taking her down to (university clinic) about five or six days each year, and then the third year she had declined enough and the testing was stressful enough that she removed herself from the study and it was about-- it was during that phase that I became much more aware of her decline:49	As he was telling me about this I wondered how those first two years really were as they made their several trips to San Fran. This was a phone interview so I could only hear his emotion.	He and his wife sought out FTD research to participate for 2 years	1
and I can't say that--look, I became sad for her seeing how sad and traumatizing, frustrating, the testing had become for her and the inability of herself to perform to the standards she had hoped [inaudible] had always been able to perform. She had a masters in English Literature, she had taught, she had set up her own business, she traveled around the United States with her own business before we had	As he was telling this, within the first minute of speaking with him, his voice became a little shaky and he was talking a little faster.	He was sad for his wife and sad for who she was now and who she had been	8

her son teaching to how to write for business.			
And so to see her noticeably decline both with her physical attributes, a lot, of course, motor functions were starting to decline. She would drop food, was becoming harder to dress herself, and her word finding capability became a lot more challenging. And so all of that made me sad for her:49	He continued to tell me about his experiences watching his wife decline as the disease progressed.	He was sad to see what FTD was taking away the wife he had known.	8
After about two to two and a half years, that's when I retired, I became a lot more of, I guess, a caregiver and doing a lot more things for her than I had ever done for her before:49	He sounded shaky and emotional on the phone. But I just listened and I wondered if I would have to stop the interview and call him back and try again at a later date. But I wanted to get more than a minute in before I made that decision.	Two years after the diagnosis, he became his wife’s full -time caregiver	5
And I guess I should say that our sex life became virtually non-existent, which wasn't necessarily a problem, it was just shocking to me - her inability to understand and know and lose understanding of parts of her body.5:18	He sounded absolutely devasted as he was continuing to tell me about his how the disease took his wife away from him.	His sex life with this wife changed significantly	13
She was diagnosed at the end of June, in 2011, and she was accepted into Dr. [inaudible] study in around October of 2012, and so it was over a year before she got a really, really thorough evaluation. And by the end of 2012 was given a diagnosis of logopenic primary progressive aphasia.5:59	I had asked when she was diagnosed	His life changed drastically	N/A
When she was initially diagnosed by a neurologist here in (city) in June of 2011, she was 52, and I was 62. 6:38	I was really struck by how young she was and he was too. I was thinking she was really in the prime of her career and her life. I felt a rush of sadness…I think I was “catching” his feelings through the phone.	His wife was 52 when she was diagnosed with FTD. He was 62 when his wife was diagnosed with FTD. His life changed drastically. His role changed	N/A
It did. The doctors told me--I'm not sure of the exact timeframe, and it wasn't immediately. It was probably around two years to three years that they told me that she had lost her cognitive, her logic reasoning, and she	This was in response to me asking him about emotional connection since the diagnosis. It was hard to hear.	His wife was unable to be emotionally and cognitively available to him even though she was present physically	8

was functioning at an emotional level, and her emotional level wasn't one necessarily of an attachment.7:20			
And she became more childlike in a number of ways.7:20	This statement really stood out to me.	His wife was childlike as the disease progressed	8
I'm still in dismay to this day with regards to the conundrum of it all with regard to her physically being able to walk. Even until the last six months, she would run in races. She was an elite runner. She, when she was younger, ran a sub-three-hour marathon. She ran over 40 marathons. She won money racing. She ran a sub three-hour marathon in (city). She wrote a column for The (newspaper), part of the [?] newspaper. She wrote a biweekly column for eight years. So it was ingrained in her physically to be able to continue to run, and that was one of the things that she had set in stone that the doctors had told her that if she could run, it would help with her mental health.7:20	He just seemed to rattle these facts out as he started with an emotional statement of the fact he is still in dismay about it all.	He is in dismay about the course of his wife's disease and how physically she was still as before the disease	8
And I always made sure that she had running friends that would either train with her or run with her during the races so that she-- because she had gotten to the point where even though she could run, she would get sidetracked by engaging with people during the run9:50	He was very adamant that he tell me about her running history and what he did to support that based on what the experts were telling him to do.	He tried to keep his wife's life as meaningful as possible with friends who would run with her.	10
She maintained to a lot of people, especially people that she considered more disadvantaged than her or she maintained a very cheerful, positive attitude. And specifically, there was a woman in our neighborhood that she bumped into that walked every day at 3:00. She had MS. She used a walker. She could talk very well and so (spouse) would	Again, he just kept talking without me prompting him really. And he continued to tell me about how his wife continued to be sweet and look after folks in her neighborhood and even would walk with one neighbor who had MS. I just kept quietly listening. Periodically validating his comments.	His wife maintained relationships with others His wife lost parts of who she used to be. His relationship with his wife changed drastically	N/A

sometimes walk with her just to make sure she didn't fall.9:50			
But her personal hygiene fell apart.11:10	This statement felt powerful to me. It felt like this is where is role and identity as a caregiver really will be talked about	His wife's hygiene fell apart. His wife was losing part of herself. He was losing his wife as he knew her. His life was changing	4
She started thinking, well, hand lotion was shampoo. She'd take showers with the clothes on, get frustrated with getting dressed, and try to leave the house partially clothed or not clothed11:10	His voice was shaky again and I felt his stress level as he was talking about this. I could not imagine watching a spouse/life partner go through this.	His wife was losing her ability to function independently with ADLs	4
Over the course of the year prior to her death, she lost the ability to give herself her medicine or swallow it. And so I had to eventually crush it and put it into yogurt when I made her [crushed?] with yogurt and fresh fruit.11:10	He definitely went from just telling me general things to how being her caregiver affected him too.	His wife was losing her ability to function independently with ADLs	4
Some days, because she could still go outside when I retired, to walk around the neighborhood and come back, I retreated.12:24	This was his response to me asking him how he was affected emotionally.	He became less independent as his wife became more dependent on him	2
I wasn't sleeping well12:24		He was exhausted from not getting enough down time	2
And we have a little separate cottage and I would just go into it and I knew - this sounds terrible - I knew that she had difficulty opening doors or whatever. And I just retreated.12:24	I felt bad that he felt bad about telling me he would literally hide from his wife to get some time away.	He had to hide and retreat from his wife to keep part of himself He needed a break	2
And she would hang out with maybe an older guy across the street and just sit and enjoy watching people go by. We live in a neighborhood next to a hospital and there's a lot of people that take walks, that walk with their dogs.12:24	It seemed like he wanted me to know that he knew she would be "ok" as he retreated for his own sanity. I just listened quietly.	He relied on neighbors to watch his wife when he retreated	10
So I don't know how to put a name on it other than that I retreated.12:24		He retreated emotionally, physically, and mentally from his wife He needed	2

		downtime His life changed drastically	
I did the necessary things like feeding her. Eventually, I was able to start bathing her when she-- it was five or six months she would go a couple of weeks sometimes without showering. I mean, she did get in the shower. She didn't know how to use soap or shampoo herself and so it was just letting the water run over her.12;24And it was hard for her to brush her teeth. There'd be toothpaste everywhere.	I got the sense that he was almost traumatized by how much he had to do for his wife as her primary caregiver. It seemed like he was just trying to get through the days one minute at a time while trying to get a few minutes to himself every day. I felt like he was drowning…I felt some anxiety as he was continuing to tell me his lived experiences.	He was helping his wife with all her ADLs. His wife was almost completely dependent on him as her caregiver His role changed. His life changed drastically. He had no down time to himself. He became less independent (free) as she became more dependent	4
So I helped her with eating and making sure she ate.12:24	As he was just telling me facts about his caregiving it struck me that he was just all over the place with how he was telling me. His speech was faster and his voice was shakier. I was hoping he could continue the interview but I wasn't sure at this point.	He was truly his wife's primary caregiver. His wife was totally dependent on him. His role changed. His life changed drastically. He became less independent as his wife became more dependent on him. He had no down time	4
And then, like I said, eventually I was able to tell her we were having a spa day and be able to clean her up. We had a deep bathtub so it was hard for her to get in and out of so eventually-- that was my plan, and it worked. I eventually got her from the bathtub into taking showers together so I could make sure that she would be clean.12:24	As he was telling me how he helped to keep his wife's hygiene up, I wondered if the taking showers together helped him feel closer to her as he remembered their relationship before her diagnosis? I didn't want to interrupt because he was already shaky in his voice. I just continued to listen and thought he would eventually let me know.	His wife was completely dependent on him for her hygiene	4
And then eventually, because I had to physically keep her from going outside naked, she started getting [angry?] with me so showers were kind of iffy.12;24	I could sense he was still feeling lost and abandoned as a result of his wife's illness. I just listened quietly as he continued to tell his story.	He was her caregiver for all her ADLs and keeping her safe	4
So it was just-- besides retreating and after making sure that her basic needs were taken care of, that she'd eaten and that she was	I just kept listening quietly	His role as primary caregiver was very stressful	5

dressed, it was very stressful.12:24			
And to add to the stress, was every day we had to get our son to high school by 8:15. And [he?] had (medical condition), or he still does. And sometimes he was very low. He was nonresponsive. And it was a struggle to get him alert. I'd have to do intervention with him. That added to my stress.12:24	I could hear the stress in his voice as he described what it was like to be a caregiver for a child with severe health issues who was still a dependent and trying to be a caregiver for his wife who now needed more care and attention than their child. I could not imagine trying to do all that on my own. And he was doing just that.	He was a caregiver for a dependent child and for a dependent spouse.	5
And then trying to get him ready and driving him, making sure that she was dressed. Sometimes, [to adapt] physically I had a technique for-- it sounds terrible.12:24	He sounded desperate as he was telling me about how he had to manage his caregiving in the morning to ensure his wife was dressed, his son was to school, and everyone was ok. I felt my own anxiety increase as I was listening to his anxiety through the phone.	He had a daily routine of care for his son and wife	4
Some people might think it was physical abuse, but it wasn't.12:24	It was apparent he thought he needed to preface how he gets his wife dressed	He thought other people judged him in his caregiving	5
I would just sit on her with my back towards hers and she would pound on my back with her hands and I'd be able to put on her stretch kind of legging, workout pants.12:24	I was trying to envision what he was explaining. I couldn't imagine how he went from being independent and having a partner who was equally independent working together to having to be the responsible one that everyone depended on without an equally strong life partner. I could only imagine that it must have started to feel like he was drowning…alone, without his strong partner.	He had to physically restrain his wife to get her dressed	4
Then, I'd be able to stand up and she'd already had a shirt on that she maybe slept in and then I would-- she needed to go with us or if she was upset enough, she would just either stay on the couch or go outside go and for a walk. That was the way she would calm herself down. But at least I knew that she was decent12:24		He had to get his wife physically dressed to make sure she was decent to leave the house	4
And so, it was just exhausting and stressful from the standpoint of making sure, not only her but my son were physically--	He started to cry as he was telling me this and I felt the emotion well up. I was feeling a little shaky too as I was listening.	He was physically exhausted from taking care of his wife and his son	5

that they were not in danger, I guess.12:24			
Eventually, I didn't do a good job with her because one day she ran away and I tried, in the afternoon, putting a missing person's report.12:24	He had a sense that he was doing a better job of taking care of his wife before now. He really sounded distraught new. I was just about to interrupt him and ask if he needed to take a break and then he said the following statement…	He failed in his primary caregiving	5
Late that night she was hit by a car and killed12:24	I was in total shock by this information. When I initially did the prescreening phone call to make sure participants qualified for the study	His wife was hit and killed by a car	12
And that was when she was 59. She'd just turned 59.17:58	I was still in shock and glad that the call was being recorded because I was still trying to process what he just told me.	His wife was 59 when she was killed His life changed forever His life will never be the same His wife's life tragically ended when she was 59	N/A
And when she ate, she ate with her fingers. She couldn't use utensils anymore.17:58	Again, I was still trying to listen but was unable to completely. I don't know if he picked up on that? He then started to talk about her inability to eat with utensils.	His wife lost ability to perform ADLs by herself	4
I'm told that eventually, it could have gotten to the point where I needed to slurry food for her because it might have been difficult for her to swallow. But we didn't get to that point, so. 17:58	I was still wondering how he jumped from telling me his wife was hit and killed by a car one night to going back to her inability to feed herself and how it would have gotten worse. I think he was just rambling at this point and I was just listening until he finished.	His wife would have gotten worse as time progressed	12
Yes. There was not only watching her decline, almost deteriorate. I mean her physical shell was there and in some aspects of her mental acuity were still there.18:58	This was in response to me asking his about the loss and the loss in the relationship. I guess I was trying to recover from the shocking news of his wife's death and to learn about their relationship from the time of her diagnosis until her death.	His wife was there physically but not completely her cognitive ability	8
We lost the ability to go out and I tried a number of times.18:58There was a group of graduate people that she graduated with some 20 years ago and so they would meet. We would meet a couple of times a year.18:58	He sounded so sad as he was remembering things to tell me. I felt bad and was still in shock	His social life with his wife changed significantly	1

And the last time we were at a restaurant and she was hearing voices going into the restaurant. And after or just as our food was arriving, she got up and left the restaurant. And we were in a community 20 miles away that she had no idea where she was, and luckily, she just stayed outside in the restaurant.18:58And I went out and stood with her and coaxed her back to the car. We came home.18:58	I wondered if he was telling me this to let me know what his wife's behaviors were with leaving and running away so that I could understand how she ended up getting hit and killed? I just continued to listen quietly	He tried to have things remain the same socially for his wife	7
And I think that was, maybe, about 10 months before she died18:58	I did think at this point it sounded like his wife's behaviors were ramping up due to the progression of her disease. But I also think he was telling me this so that I could see that things were quickly getting out of hand for him too	His wife died 10 months after her behavior to run away increased due to her disease progression His wife died from FTD	7
And her best friends would come over, and she would refuse to go out with them to maybe go for a walk or go to a coffee shop for an hour or two, which she had done previously with them just a few months before that.18:58	He was letting me know how his wife's behavior continued to change for the worse even with her best friends.	His wife's behavior changed even with her best friends as they tried to visit with her	10
So [he?] was [inaudible] worked with the outside agency that provided caregivers to try to get some respite. And she was distrustful of men so we tried women18:58		He tried to get help and support as the primary caregiver for his wife He reached out for help	10
And she, for our whole marriage, was very distrustful of women. She was veryjealous.18:58	I believe he was telling me this to give some history to their relationship	His wife was distrustful and jealous of other women throughout their entire marriage	N/A
She had come to the United States, and the man she came to the United States with from (country)-- she graduated college in (country). He left her in (city). Her father had abandoned the family when she was young. So it was difficult.18:58	More background offered on his wife's background to help understand their relationship and how the disease intensified some of the issues	He had always taken care of his wife to some degree since they were married His wife was distrustful of people even before they got married	N/A
I mean, we had a woman in the house that came for four hours, once a week to try and	I could hear his exhaustion through the phone as if he was still caring for his wife as her	He asked for help His wife was completely	2

give me a break, and I never got the break because (spouse) would get up and leave the house.18:58	primary caregiver. I wondered if he had PTSD from his wife's death?	dependent on his for her care and safety He had no down time He became less independent as his wife became more dependent	
I'd just hang around waiting for her to come back before I could leave.18:58		He became less independent as his wife became more dependent	2
So after about four or five months trying that on a weekly basis and trying to acclimate, trying to reassure (spouse) that-- we tried to tell her that this woman was there in our house to help with household duties, rather than to help with her.18:58	It seemed that the more the disease progressed the more he tried to reason with his wife. However, his wife was losing her ability to reason about anything.	He tried to keep help with care for his wife He needed down time from being his wife's primary caregiver	10
And we have a tiny house, only 1,000 square feet. So it was really-- it became very stressful for me to try and figure out things for her to do so that she would just be present doing something, and (spouse) would stay in the house.18:58	He seemed desperate to get down time away from his wife at this point. It sounded like it was get time away or risk his own health, mental, physical and emotional health.	He was stressed out trying to make sure his wife was safe with hired help while he got his down time His wife was completely dependent on him	2
Sometimes she would-- when the woman came to the front door, she would recognize that this was the weekly visit, and she would leave the house.18:58	I found it curious that his wife was still able to feel something about another woman coming to the house. I wondered if that was the case of if she was just afraid of everyone?	His wife was afraid of everyone but him His wife was completely dependent on him His wife would run away out of the house because that's what she knew how to do	N/A
Sometimes she would stay and get angry18:58	He seemed to think that his wife was still getting jealous or being unreasonable regarding another woman. It seemed to me as an outsider that perhaps his wife was afraid constantly. And any changed was scary.	His wife would get angry if he tried to leave her with someone else	N/A
So it just didn't work out, so it was just left for me.18:58	He was alone in caring for his wife	He was alone in his caregiving role He had no downtime to himself	2
And our son was very-- he was a teenager going through a lot of disconnection or trying to separate from us, and so the last thing he	It seemed like his family was in complete upheaval and chaos. I could hear it as he continued to talk…his sadness and	He was responsible for his son and his wife His son was a teenager and trying to become	5

wanted to do was be around us.23:23	desperation to understand what happened.	independent of his parents	
So, he was shut in in his room, but he could hear. I mean, being a small house, he could hear all of the aggression and anger at times when she got agitated.23:23	It sounded like his household was totally disrupted by his wife's disease and his son's quest for teenage independence and push back	His son was aware of the anger and aggression between his parents His house was full of stressful situations He was frustrated, his wife was frustrated, and his son was isolating himself	4
And sometimes she and he would get into it, or sometimes he and I would get into it. Sometimes it would be me and her. And so it was just this triad of chaos.23:23So it wasn't a good family unit23:23	He continued to sound sad and disappointed in himself and in the outcome of his wife's death.	His household was full of emotional chaos on a daily basis	4
It wasn't a good husband and wife relationship23:23 That had been going on for the last two years		His relationship with his wife deteriorated	1
And through the decline too, then she started having run-ins with neighbors. She would imagine that the women were trying to take me away or that the men were harmful to her in some way23:23	He was just really saying whatever was coming to his mind. I listened quietly because it seemed like he wanted to tell me as quickly as possible so that he didn't have to sit with these memories too long.	He had to manage his wife's behavior as her caregiver more and more as her disease progressed	5
Yes. I'd say everybody on either side of us and directly across the street and a couple of others down the street knew and I had printed out the cards from the AFTD website and I could have given her cards, but she wouldn't have known what to do with them.25:15	He seemed to try and put protective factors in place for his wife throughout their neighborhood. It seemed like he was doing everything right. It just seemed like it was so overwhelming especially for one person to manage 24/7	He informed his neighbors about his wife's disease He tried to educate neighbors about FTD and how the disease is affecting his wife	10
So I just printed out the ones that's the caregiver card to be able to hand to people. But, yes. The people around, they were helpful in spending time with (spouse) or if she came to her house and they were outside, that they would, I guess, just sit or walk with her because I was going through some physical difficulties25:15	He didn't have exact help set up with his neighbors but it sounded like they pitched in to help even if it was just to sit and talk with his wife is she was around or showed up on their porches.	He tried to educate his neighbors about his wife's disease He counted on his neighbors to help watch her in the neighborhood He needed support physically too	10

See she was diagnosed in 2011. 2014, I had my left hip replaced, so prior to that, it was difficult for a year, year and a half, for me to move around as quickly as she could. And then I had my recovery and then my other hip started going bad and I had my other hip replaced last summer.25:15	I was thinking how in the world did they all manage as long as they did? As an outsider, it seemed like it was a recipe for disaster. Of course knowing the outcome, it appears that is what happened.	He was physically unable to take care of her for a bit He had his own health issues that required attention	7
And I should also say, during this period of time, first two or three years of her diagnosis she had stopped driving so she had to pretty much go where we went whenever we left the house.25:15	This statement really drove home how much time they all spent together whereas I am sure there was independence in the relationship prior to her diagnosis.	He was less independent as his wife became more dependent	2
My son was playing competitive soccer and so we would go to a lot of practices and drive weekends out of town.25:15		His son needed to be driven to lots of soccer practices during the week and games on the weekends He was responsible for his son's transportation for sports He was always busy with family events	5
And that became really stressful for us because initially, the first day of travel would be okay, she'd be okay with it. Then once we got to playing the soccer, we got to the games or even the hotel, then she'd sometimes become agitated because she realized, well, she wasn't at home and she was going to be somewhere she didn't want to be:25:15	It must have been difficult to try and reassure his wife that she was safe. It also would have been difficult to be the only one that was responsible for 2 adults and one child. It sounded very stressful.	It was stressful traveling with his wife and his son for soccer He still tried to give their son some sense of normalcy with playing soccer	4
and the only people to socialize with were parents on the soccer team, which she got more distant from, so eventually, we stopped doing that25:15		His wife could no longer socialize Their social life changed drastically His wife was no able to handle time away from home socializing with other soccer parents	11
Oh, it was impossible to have (a social life)28:34	His life just seemed so stressful and overwhelming from every aspect. It was emotionally taxing	His social life changed significantly He and	2

	for me just hearing what his experiences have been over the last few years.	his wife’s social life changed completely as a couple	
from the time I retired, May 2015, I was home full-time. It was difficult.28:34	He went from being full time at work to being full time at home. It sounded like the full time at home was exponentially more difficult and stressful.	He retired to be home full time It was difficult being a full time caregiver for his wife	5
if I arranged for friends to go by the house. She would get up and leave because of the primary progressive aphasia. She was the kind of person that was so knowledgeable. She loved conversation. She would do deep-dives in conversation with friends. She couldn't do that anymore. She could not. And so, she would just be sitting in the group, and then you could see her physically just lean back, and then, eventually, because she was so frustrated and sad, she would just get up and leave.28:34	He was explaining how the disease robbed his wife of her love of conversation with friends. I could not imagine knowing that I was losing my ability to converse. It had to be so frustrating and sad for her and sad and frustrating for him to watch happen to her.	His wife became more socially frustrated as her disease progressed His wife would leave the situation if her agitation became too great He became more responsible for her safety as she kept leaving the house or wherever they were at the time she would become agitated	10
And when I mean leave, she'd get up and leave the house and wouldn't come back for a couple of hours.28:34	I really don’t know what I would do if my loved one with FTD got up and left for hours? I would imagine it was scary and anxiety filled. I might have to just get up and follow that person every time or think about safeguards to keep that person in the safe space of the house. I don’t know though…I have not been in that situation.	His wife would leave the house for hours when she was agitated He was stressed out over his wife’s urge to run away from the house/situation and his inability to stop her as her caregiver	7
It was just the neighborhood. She would comeback; she'd always come back, so.28:34	Of course we know that she didn’t always come back. I wonder if he just thought she would continue to always come back even though it appeared her disease was progressing? Maybe he was hopeful she would plateau for a while?	His wife always came back after leaving the house in agitation His wife only ran in the neighborhood when she would leave the house	7
And the irony of it was sometimes she would ask me, “Where are my friends? Where are my friends? Why aren't they here?” And then when they came, she would leave28:34	It sounded so hard for him to keep trying everything to keep his family going. I could not imagine doing all of that alone without significant help somewhere	He tried to honor his wife’s requests His wife was no longer able to socialize	N/A
So the only social-- and so she and I together did not		He and his wife no longer had a social life together His role	1

have a social life with anybody else30:24		had changed in the relationship	
The little bit of social life she had was two girlfriends that would come maybe once a week. They would alternate. They would pick her up and take her to their house for three or four hours for just girly time, maybe doing facials or walking, watching a TV show or listening to music and laughing. But that was as much as her social life was30:24	He was telling me that he and his wife no longer have a social life together. I took that to mean that he just couldn't relax and enjoy his time with her anymore because she took a lot of effort.	He no longer had a social life with his wife His wife's social life consisted of two female friends for spa days	1
I'll take that back. Up until about eight months, the last year I started taking her to her runs, and I would wait and then bring her home.30:24	He was still trying to give his wife a quality of life/interaction. I did wonder if it was more for him or for her or for both?	He tried to help with his wife's quality of life by keeping her involved in activities she used to love He tried to keep her socially connected	10
But between the beginning of her run when she was excited and the end of the run-- at the end of the run, a lot of the times she would still place, but she was kind of bewildered as to what was going on.30:24	It seemed that he was trying to do things for her that used to be meaningful to her but now they just seemed to overwhelm them both.	His wife was often confused as to what was going on after a race/run His wife was still a great runner	N/A
No, I didn't have a social life. So I'm sorry to have kind of laughed a little bit.32:01	His reaction to me asking him if he had a social life was to laugh. I guess it must have sounded insensitive or like I wasn't listening to him. But he never directly answered my question so I asked it again.	He did not have his own social life	2
No, I didn't have a social life32:10	He sounded bewildered himself as he was telling me about his daily routine with medical care and caregiving. It didn't sound like there was much time left for his own social life and well-being.	He did not have a social life	2
It was between my son and getting him to school and taking care of our house-- just all of the needs of being responsible for the house32:10	He sounded bewildered himself as he was telling me about his daily routine with medical care and caregiving. It didn't sound like there was much time left for his own social life and well-being.	He was responsible for all household duties	4
and taking care of our house-- just all of the needs of being responsible for the house and taking care of our	He sounded bewildered himself as he was telling me about his daily routine with medical care and caregiving. It didn't sound	He spent all his time taking care of his son, his wife, and his own medical needs	

medical appointments between the three of us32:10	like there was much time left for his own social life and well-being.		
And then when you retire, trying to arrange medical coverage for all of us. She and him have pre-existing conditions32:10	He was trying to manage everyone's medical issues and insurance coverage. I am sure things became very expensive once he retired. It seemed very stressful.	He had to manage his family's medical insurance once he retired His wife and his son had preexisting medical conditions	5
And so just being responsible for the household became added to the stress32:10		He was responsible for all the household duties He had added stress from being the only responsible one in the family	4
So she had one of the group in her college friends who--his workload for a while got [refused?], so he was only working four days. So he came by a couple of times and stayed with her on the day that he didn't work.33:03	I occurred to me that he kept trying to find ways/people to come and help with his wife so he could get a little down time or free time to himself. I give him credit for his persistence.	He continued to ask for help His wife had a friend that would come and stay with her on his day off a couple times	10
And then, I left the house--I think at least one of those times, I went to a movie, but that was by myself33:03	Even when he did get a little time away from caregiving for his wife, he still sounded stressed and lonely. So all that effort to get help and some time to himself wasn't as great as maybe he had hoped it would be?	His down time was spent alone	2
It's hard because a lot of my friends were still working.33:03	He was retired but essentially working full time as his wife's caregiver. Even though he was retired most of his friends were still working full time. He sounded lonely and burnt out	He was retired but his friends were still working full time He had a hard time socializing because he was retired and his friends were still working full time	5
She'd be in her 50s, her friends were always working, and so that made it difficult even when she was early in her diagnosis.33:03	It seemed that he and his wife were both alienated by FTD. He was retired and his friends were still working and his wife was only in her 50's so her friends were working too even when she could have still enjoyed socialization in the beginning of her diagnosis	His wife was only in her 50's so all her friends were still working and busy with their lives Even in the early stages of his wife's diagnosis, socializing was hard because all her friends were still working and busy with their own lives	10
It was difficult to do things for her because her friends		It was hard for his wife to go and do things with her	10

were working and she couldn't drive33:03		friends because she was no longer able to drive	
She lost her Independence33:03	This statement struck me. He also lost his independence as she lost hers and became more dependent on him for everything.	His wife lost her independence and he lost his too	2
she couldn't drive anymore, so she couldn't go near her friends anywhere. She had to depend on them coming.33:03		His wife had to depend on friends coming to her	10
So, our social life, ours together and mine separately, just changed.33:03	I think this was the understatement of the interview. It seemed to me as an outsider like a nuclear bomb went off in their lives. Nothing would ever be the same. Everything was affected and impacted.	His social life changed drastically His social life with his wife changed drastically	2 1
It was primarily driven by needing to be the primary caregiver. And I probably should have-- at hindsight, I should have retired a year earlier34:26	This was in answer to if he retired to become his wife's primary caregiver.	He retired to become his wife's primary caregiver He felt he should have retired a year earlier to become his wife's primary caregiver	7
And in technicality, I didn't retire.34:26		He didn't technically retire from his job	5
I worked in my place-- a business for my whole career. So, I worked there when I retired for 43 years. And we were going through significant downsizing, and so there were layoff severance packages being given, and I was trying to-- essentially, I was a technical. I worked in science and there was almost like the equivalent of a vice president, and so the people above me were high-levels. So, we did coordinate, but it took about a year so that I could give in a nonvoluntary layoff.34:26	It seemed what he was trying to say was that he worked it out with the higher ups or HR that he would be one of the casualties so that he could still qualify for a severance package and insurance coverage.	He was a casualty of downsizing	5
So that qualified for the severance package and then avowed into having medical coverage for my family for another year and having, basically, a year's worth of salary34:26	It seemed that he was smart about how to take care of his family for a year while he tried to figure out finances and health care for them all.	He had a full salary and medical coverage for a year after he "retired"	N/A

So that was stressful and anxiety-ridden for both her and for me because she wasn't driving; she was getting more and more impaired.35:58	He continued to flip flop back and forth between topics. But I followed him and knew where he was going. But I had to really listen.	He was more stressed and anxious as his wife became more and more impaired His wife wasn't driving anymore	2
And she was home a lot by herself because I was so at work [inaudible] was at school.35:58	I believe he was going back to why he should have retired a year earlier than he did	His wife was home a lot by herself before he retired	7
And so that last year was just-- and I was able to work half days sometimes from home; telecommute. And so that helped her35:58		He was able to modify his work schedule to be home more the year before he retired He was home more to help his wife	5
but really, I probably should have retired as soon as she was diagnosed.35:58	He truly felt things would have happened differently if he had retired a year earlier. Or perhaps he could have had a good last year with his wife before she completely declined.	He felt he should have retired as soon as his wife was diagnosed	7
And if I was going to have any kind of quality of life with her before she went into-- at about year three, a more severe [inaudible].35:58	I felt bad as he was rethinking about what that quality year would have been like for them as a couple if he had retired earlier.	He would have had a quality year with his wife if he had retired a year earlier than he did	7
But we had a son with it. It was complicated now because we had a son.35:58	It seemed that even if he had retired earlier they would still have had their son to look after too. So it could not have been just them as a couple to travel etc. to enjoy their time together.	He had a son who was a dependent	5
If I had to-- even when I retired and once my medical coverage stopped, our insurance premium that I was paying for her and for him was about $1,500 a month35:58	It seemed that they were paying so much for insurance that he might not have been able to retire a year earlier…I wasn't sure if he was telling me this to justify not retiring a year earlier or why? I hope I didn't sound judgy over the phone.	He had to pay $1500 a month for medical insurance for his wife and son combined	N/A
And so I was able to-- when I did have a severance package, I was able to delay taking my retirement for another year and my retirement grew by another 12%.37:26	He was very smart with his money so that he could provide the care and medical insurance for his family.	He delayed his retirement for another year and his money grew by 12%	N/A
So economically and with my son's pre-existing condition it just made it such that being able to put it off	He had definitely been thoughtful about how to best take care of his family financially and as a full time	He made the best choice for retirement based on how to	5

when I did and not have to take retirement till later and then when I did have to start paying for medical I could pay, by then, $2,000 a month for the medical coverage37:26	caregiver. I don't know that others in his position would have had the same options.	finance his family's medical needs	
and we still had a house mortgage payment of, I don't know, $2,300 a month.37:26	He had a lot of expenses to consider when thinking about retiring	He still had to pay a monthly mortgage of $2300 in addition to his medical insurance and expenses	5
And the last year I was looking into the independent group that had helped me with the caregiver, which didn't work out, also had assessed her, come to the house and assessed her and seen some of her more frantic and irritable and aggressive moments.37:26	It seemed like he had so many things to consider and think about for his wife's care while making sure his son was medically ok and thriving in his teenage life as well.	He researched independent group facilities for his wife His wife was assessed for how much help she would need to live in a residential facility	10
They had recommended three places and so they were within about a 40-mile radius.37:26		3 facilities were recommended for his wife within a 40 mile radius	10
And I didn't have anybody to watch (spouse) and that was going to-- and I found the place and about two months before she died.37:26	He finally found a facility that would be able to take care of his wife to his standards. But it was only right before she died.	He had a difficult time getting to the facilities to check them out because he had no one to watch his wife while he went He found a facility for his wife that was up to his standards 2 months before she died	10
And that was very stressful too. Not only trying to find a place in (city) but the cost because she was ambulatory, she was not going to qualify for any kind of Medicare or Medicaid help.37:26	It was surprising to hear that because his wife was ambulatory she didn't qualify for Medicare or Medicaid help. I guess unless a person can truly be ware housed they want cash…	He found it difficult to find a facility for his wife because she was ambulatory His wife did not qualify for Medicare or Medicaid assistance because she was ambulatory	6
So, it was going to be all out of pocket and our family was going to have to take 8 to 10 thousand dollars a month for her care.37:26	I couldn't believe how expensive monthly care was out of pocket because his wife was not bed ridden.	He had to pay out of pocket for any facility for his wife because she was ambulatory and therefore didn't qualify for Medicaid or Medicare coverage	6

And so, I had wrapped my arms around that once I realized all that and my 401(k) was going to be able to take care of that for maybe 8 to 10 years37:26	He was fortunate enough to be able to pay for care for his wife out of pocket for 8-10 years if needed. Of course that did not come to fruition but he had resources others would not have	He had financial means to pay out of pocket for his wife to live in a facility for 8-10 years	5
Oh well, so what? So, the household, everything, it just I got to the point too where I didn't know what the hell to do37:26	He sounded distraught and so sad and so sorry for what had happened to his wife.	He got to the point that he did not know what to do He was distraught with taking care of the household and everything else	7
We started doing telecoms for her neurology39:57 It was mostly me giving them information.40:21	He was trying to make somethings less stressful for he and his wife.	He started doing neurology appointments via telecoms for his wife	6
And basically whenever we drove [inaudible] too. We would try and sidetrack her because otherwise, it was difficult to get information and then he'd look to me for side comments or whatever and then it led to a lot of disagreements. So we just started sidetrack her and I would give him an update of what her current symptoms were, and that's what it all became, just treating her symptoms, so40:21	I think he was just rambling again about how things would go at doctor's appointments. I just continued to listen and find out where he was going next and how this possibly linked to what he said next.	Telecom doctor's appointments were better because going to the doctor in person led to disagreements	6
Well, I felt a lot of guilt41:31	I had thanked him at this point for doing this interview and sharing his experiences with me. I stated that it must be hard for him. I wanted to acknowledge that I could feel his anxiety. He was rambling so much prior to this I felt like I had to say something.	He felt a lot of guilt	7
I still do, and I feel-- there's not a day go by that I don't remember, deeply, something about her41:31	I wonder if he would feel so much guilt if she had not died tragically? I would imagine that it would still be hard losing your spouse to FTD?	He intensely remembers something about his wife everyday	12
I have a lot of sadness on a daily basis.41:31		He is sad on a daily basis	12
And it's coupled too with this house41:31	It sounded like cell memory is what he was talking about.	His house held so many memories of his wife for him	N/A

It was my second marriage to her and it was her second marriage41:31	Knowing that it was the second marriage for each of them made me wonder if taking care of her was different than someone who had been with their spouse for longer?	This was his second marriage This was his wife's second marriage	N/A
we'd been in the running club (together)41:31	I was transported thinking about how they met…so active and full of independence… it was sad to think how things ended up	He met his wife in a running club	N/A
She had fled from (country) with nothing. She grew up in a version of the projects, so she saved and saved over here, bought this little house.41:31	He was back to talking about why the house held so many memories of her for him	His wife fled England with nothing His wife saved to buy the house they lived in	N/A
I was with her when she first saw it and we were dating.41:31	It was interesting that she bought the house herself even though they were dating already…it just says how independent she really was at that time. He was too.	His wife first looked at the house when they were first dating	N/A
Eventually, we got married and I bought half the equity, and then she and I did a total remodel of it 41:31		They got married and he bought half the house equity from his wife then	N/A
And there was a separate cottage that we did. And so every aspect of the house and the cottage, I can't--and I don't want to, but there's not a place I go that I don't remember a single-- I remember so many moments with her41:31	He is grieving her death seems to be reminded of their life together before FTD entered the picture. It sounded like they were really working well together as a couple and making the house their own.	He remembers so many moments with his wife in their house He and his wife made their house their own	12
And then, being (ethnicity), I helped her. She did most of the work but we just-- she tore apart the whole back and front yard and made it into fabulous gardens.41:31	It sounds like they have lovely gardens that she started and he still maintains. Just more ways that their house and surroundings were made their own.	His wife was English and loved to create gardens at their house He maintains the gardens he and his wife started	N/A
It is awesome. Her passions were writing, running, her garden43:47	It sounds like most folks when they miss a loved one, return to things that remind them of that person. It sounds like taking care of the gardens is what he does to be around his wife	His wife's passions were writing, running, her garden	N/A
And her son…And then at about the age of 10, her disease was kicking in and his desire to separate, and so that was fading from her43:47	I could not imagine how a child who is 10 could process his mother not being emotionally available for him. I currently have a 10 year old daughter and I feel overcome with sadness	His wife was not able to remain emotionally connected to her young son His son was becoming a teen	8

	thinking about how hard that must have been for everyone.	as his wife's disease was progressing; both were becoming less emotionally available to each other	
About two years after that her ability to work in the garden, maybe three years, she didn't know how to dig a hole. She couldn't dig a hole to put a plant in43:47	I just kept thinking about how hands on he remained with his wife. It seemed like he truly took the role of primary caregiver to an entirely different level than others perhaps? Right down to digging holes with her to plant trees/plants.	His wife lost the ability to even dig a hole in her garden due to the progression of her FTD 2 years after diagnosis	N/A
But I would take her to the nursery and she would walk around the nursery and she would pick out plants that she liked and we would buy them.43:47	I thought it was a lovely idea that she still was able to pick out what plants and flowers she liked for the garden even if she could no longer plant them herself.	He took his wife to pick out what plants and flowers she liked to plant in their garden	1
But then she couldn't figure out how to plant them, but she didn't want me to help her at all. She thought I was going to take over the garden, which ultimately I did.43:47	He was backtracking a bit but I understood and was following what he was saying.	His wife couldn't garden anymore but didn't want him to do it because it was hers	1
And so what I'm getting to is just that, yeah, I forget your exact question, but I'm hugely affected now.43;47	He kept getting lost in his memories of his wife and their life and his emotions then and now	He is hugely affected	12
It's not like it was two years ago when I was just [inaudible] beside myself now I can function.43:47	I was thinking he is more affected because of his wife's tragic death. But I would imagine some of the trauma is a result of how the disease took his wife away from the point of diagnosis. FTD completely disrupted their lives and how they lived as a couple and a family.	He was beside himself and unable to function 2 years ago after his wife's death He is able to function now	12
I can talk to people, and I can sort of detach from her in many ways when I talk to them43:47	I felt honored that he wanted to talk to me and be a part of this study.	He can talk to people now about his experiences He can talk about his wife now	12
Some aspect of her might come up because I'll be out in the front yard, or people walking by, and I'll be working in the garden doing this or that, trimming something or repotting something, or fertilizing the ground.43:47	I wonder if he keeps up the garden out of guilt along with keeping her memory alive	He honors his wife's memory by tending to her garden	N/A

I mean, it's a full-time job, the front and the back yard, so.43:47So it's kind of comforting, but at the same time, it's very sad.43:47	I think it is a lot he went from working full time, to be a full time primary caregiver for his wife to now being a full time caregiver of her garden.	He tends his wife's garden like it's a full- time job	12
Yeah. I was with a couple of friends the other day, and I was talking to them, and I said, "There's four or five times in my whole life when things have happened. It's not like something that you gradually get used to.46:03	He was trying to explain to me the magnitude of his experiences with his wife, her disease, and her death.	He has had 4 or 5 times in his life where single events happened that were life altering and not gradual	12
It's like this-- I'm a scientist, so hopefully you understand.46;03	He is attempting to help me understand how impactful these events have been to him in an instant from a scientific point of view	He is a scientist	N/A
It's like a quantum step46:03	This statement says it all	He has experienced a quantum step	12
It's like I'm going along and all of a sudden our son is sick, and we take him to an emergency, and he's diagnosed in ten seconds with type 1 diabetes.46:03		His first quantum step was when his son was diagnosed with type 1 diabetes in 10 seconds in the ER	12
And so it's like going from this idyllic situation to we have a child with a life-threatening illness for the rest of his life."46:03	I was just quietly listening and completely understanding what he was saying	He went from one minute from having an idyllic family life to the next minute having a child with a life -threatening disease for the rest of his life	12
Going with her to a neurologist because she'd just had her first physical in about five years and she talked to him, her GP, about her inability to find words, and that's the common first symptom in PTA is-- she said, "I'm losing my words," 46:03	He seemed like he was trying to reason away her symptoms of not being able to find her words. At 40 something that doesn't seem normal. No matter how much stress someone is under.	His wife's first symptom was the inability to find words	12
and I just thought it was one of those things because she wasn't writing much, that it was, "Well, yeah, it's natural because you haven't been using such a large vocabulary. You've been dealing with a toddler, and then a five-year-old, and whatever."46:03	He seemed like he was trying to reason away her symptoms of not being able to find her words. At 40 something that doesn't seem normal. No matter how much stress someone is under.	He thought his wife's inability to find words was due to the stress of a having a toddler and not writing much He was trying to reason away his wife's symptom of the inability to find words	12

So, when the neurologist said, “You have this,” and then he explained-- he showed me that she couldn't do the clock test.46:03	He was told by the neurologist about his wife’s diagnosis and shown assessments as evidence	He was told his wife’s diagnosis by the neurologist evidenced by the clock test	12
And they're supposed to draw the clock face, put all the numbers in, put the two hands of the clock in to designate a certain time, and when the doctor-- she thought she did fabulously, and then the doctor showed us separately that the hands were outside the clock. Most of the numbers were there. Some of them were written backwards. Some of them were out of place. And she had no idea that she had-- she thought that she'd done great.47:59	This sounded like the first time he had true confirmation about his wife’s	His wife’s diagnosis was supported by her results on cognitive assessments His wife thought she had done well on the cognitive assessments	12
So I think on the MME score of about 33, she had about a 15 or a 16. And so again, that was more than a step.47:59	He was realizing that what his wife had was not stress related evidenced by more low scores on cognitive assessments	His wife continued to score low on cognitive assessments	12
That was life-changing47:59		Getting his wife’s diagnosis was life-changing	12
So, it was this quantum step from, “Well, I'm losing my words,” to, “You have this incurable death sentence.”47:59	This statement was very heavy to here. That they were given a death sentence. I had not heard anyone else put it quite that way	His wife given a death sentence	12
And then it became-- it was gradual because it didn't happen. 47:59	I was thinking knowing that you were given essentially a death sentence but not knowing the timeframe is so cruel. None of us know how much time we have but not knowing how long before all our cognitive abilities will disappear is way worse in my mind	His wife’s decline was gradual.	5
She didn't die the next day47:59		His wife didn’t die the day after her diagnosis	8
It was just watching certain-- or becoming 47:59	He was explaining that it was just watching and becoming aware of behavioral or cognitive changes in his wife.	He watched for certain changes in his wife	88
I kick myself so many times that I'd continue to try and be logical with her or even correct her, and that's the	It seems that denial would be part of this process too. The person looks the same and sometimes even act like they	He felt guilty for trying to reason or correct his wife as	8

farthest thing away from what I should have been doing.47:59	used to but in the end, the disease does take over and the person is a shell of who they used to be. The epitome of ambiguous loss.	her disease progressed	
And I'm happy that things like what you're doing are taking place47:59	This was in reference to me doing this study	He felt validated by being part of this study	5
I've even seen with the AFTD now there's a one- or two-page list of, for lack of a better term, a lot of helpful hints, a lot of directions, for caregivers, to help us.47:59		He has seen resources now for primary caregivers for partners with FTD via AFTD	10
But for me, it's a little too late47:59	There wasn't info for caregivers in the past that might have been helpful for him and ultimately for his wife.	He did not have the primary caregiver resources he needed	12
The doctor eventually said-- in (university clinic), "Well, you need to get help."47:59		He was told by doctors that he needed to get help to take care of his wife	6
And he connected me with some-- or his assistant would connect me with some people up here, and it was just so difficult running the household. And then figuring out well, what kind of help do I need?47:59	It seemed that he was told he would need help but he didn't know what he didn't know. It seemed like he might have needed more concrete suggestions of what type of help he needed	His wife's doctor connected him with some resources in his area but he didn't know what kind of help he needed	7
I just couldn't really ever grasp really what help I needed47:59	It was simple but profound: he didn't know what help he really needed.	He didn't know what help he needed	7
But in hindsight, I really needed somebody I-- what I really needed is what I tell people now is put your loved one if you can afford it. Put your loved one in the memory-impaired facility as soon aspossible.47:59	He was still so affected and traumatized by his wife's diagnosis, being a primary caregiver for her, and her tragic death that I think he feels that a facility is better than trying to take care of a loved one at home…the progression of the disease is different for everyone. So the sooner the better to put a loved one in a facility where they can be taken care of 24/7	His advice is to put the loved one diagnosed with FTD in a memory facility as soon as possible	7
Well, some families are lucky. Because they have a large extended family.47:59 So people can come over. You could have two or three days.50:42	It seemed he was implying that if he had a larger family that maybe others could have helped him and maybe a facility wouldn't have been the only option	He did not have family members from whom to ask for help	10
I would just start going to a support group of caregivers once a month for FTD. And	It seemed that he needed more support than caregiver support group once a month. But at least	He got help from a FTD caregiver	10

there was a couple of us that was just us.50:42		support group once a month	
when I got married I was 52.She was 42. And I was 52 when I got Ian50:42		He was 52 and his wife was 42 when they got married and became a stepdad	N/A
Wow. Her parents were dead. My parents were dead. All her family was in either (country) or (country) 50:42	It was really telling that they literally had no family to reach out to for help once his wife got sick	He had no extended family to ask for help	10
Her uncles and aunts that she never-- because she grew up poor she never visited them. She was in (country). They were in (country) 50:42		His wife had no family members to reach out for help	10
I have an older son. I have an older daughter. But they aren't nearby.50:42		He has 2 older children but they do not live near him	10
So we had no family support50:42		He had no family support to help take care of his wife when she got sick	10
It was just me, her, and our son.50:42		His family consisted of his wife and his son	5
So, I tell people that if they're similar to my situation is, I tell them as hard as it may be and if you can afford it (choose a memory facility) So that you don't suffer51:55	I think he has a very real, valid point that might need to be mentioned spouses sooner than later when talking about resources	He would advocate a memory care facility for a spouse diagnosed with FTD to those in his exact situation.	7
I mean there’s no way around guilt51:55		He felt guilty	12
Because that much [inaudible] put a person-- my grief counselor who has also worked with caregivers for FTD or Alzheimer's, she worked in institutions. She said, “if you [inaudible] it's not.” You'd like to think maybe it's safe in that facility. People get out. They're still [hit?] or get hurt. They may have a lot of aggressive or behaviors. And so they [inaudible] constantly with the doctors. They're just medicated to numbness. And she would have been far enough away. It would have been harder to get there on a regular basis.51:55		He was advised by his grief counselor that his wife would not have been 100% safe at a facility either	12

So I would have been feeling really guilty about not seeing her. And so it—wasn't easy 53:09	No matter what the decision for caregiving, the hard fact was that his wife was actively dying from FTD and there were a lot of unknowns	He would have felt guilty about his wife's health no matter where she lived or who took primary care of her	7
It was life-changing. Huge life-changing 53:09	He was reiterating how life changing this disease was for him	What he experienced was hugely life changing	5
And a lot of aspects of it I just didn't comprehend or I refused to see it.5 3:09	What he was describing almost sounded like an out of body experience sometimes.	He was in denial or uncertain about aspects of what was happening around him with his wife	7
Like I said early on [inaudible] hid sometimes during the day I just went into our separate house and laid down on the little bed we had there. Listened to the radio, drifted off 53:09	As he was talking, I was imaging what it would be like to walk in his shoes and escape to the little house and drift off for a bit. I really couldn't imagine what his experience was like.	He hid sometimes in their separate house and drifted off listening to the radio	2
That's really hard for me to answer. I guess one thing is I would have liked to have known better what to expect 54:33	His answer when I asked what the doctors could have done better for him	He would have wanted doctors to tell him more of what to expect as the disease progressed	10
I didn't know what to expect and in my support group, I came to find out that every day-- so it was difficult as much as I wanted now for the doctors to tell me what to expect, I realized that that's almost impossible.54:33		He knows it would have been impossible for the doctors to tell him how the disease would affect his wife	7
Not only is every person different even with the same diagnosis. 54:33		He now knew that the disease affected everyone differently	6
That they change in a different pattern5 4:33		He knew the progression of FTD was different for everyone diagnosed with it	6
One day can be good. One day can be not so good. So it's all unpredictable. 54:33		He experienced his wife having good days, bad days and no exact formula for one or the other	6
I guess thinking a little bit more now about your question they could have somehow I could have been forced into somebody would have just-- like I just said, somebody here almost full-time to take care of her and I	He was rambling again about not getting someone to stay with his wife in the house even though his wife was having a hard time having anyone but him take care of her. I can't imagine having to make that decision and worse, thinking	He feels guilty he didn't get the level of care and help he needed sooner	7

feel guilty that I didn't go out and get that person sooner instead of waiting to talk to an independent agency.54:33	about what could have been done so that his wife didn't die tragically as she did.		
One time when I was trying to give her a bath and she had been incontinent and she was just all-- it was all over her and I was trying to clean her up and she was fighting with me and fell in the bathtub and so I had to take her to emergency.56:42	This was just the second time in the entire interview he had talked specifically about how it was for him to physically take care of her. And how demanding it was on both of them.	It was physically demanding and sometimes unsafe to take care of his wife at home	7
So true, the social worker with her doctor that had come to the emergency, they set me up with this independent help that and I was given a grant for the woman that I told you about I tried to have help me.56:42		He was given a grant and connected with in home care for his wife	7
But I guess what I'm saying is when the doctor started telling me--her neurologist maybe a year before that, a year and a half, I wish that they would have just said, no. Stop. Don't go past go. Here's this organization. We're going to have them send over or come over with somebody that you're going to start having in the home support.56:42	It sounded like he was doing what he thought he was supposed to do as a good husband…take care of his wife by himself at home. But in reality, he wishes the medical professionals would have given him "permission" to get help right away in the home or through a facility. I am not sure that is a role the doctor's would have wanted but perhaps a counselor or social worker could have helped his with that decision?	He wishes the doctors would have stressed to him he would need in home care right away for his wife	710
But that's because there was just me and her and our son. So because I guess I felt I was worried about our finances58:28	It must have been a hard decision to hire in help especially when trying to determine finances and being retired	He was worried about the financial strain hiring in home help for his wife	5
thought, well, I can do it58:28		He thought he could take care of his wife by himself	7
yet I couldn't58:28		He could not take care of his wife all by himself	7
we all suffered because of that58:28	Again, it seemed like he was really concentrated on how he thought he was supposed to be or what he was supposed to do versus what the reality was…	He, his wife, and his son all suffered because of lack of help with the level of care his wife needed	7
And so that's the one thing is get outside help, maybe as		His advice to others in his	7

soon as you get the diagnosis.58:28		situation is to get outside help upon the diagnosis	
Start bringing somebody in. And you may have to go through two or three people before your impaired partner accepts them58:28	It sounded like a good plan of action. To start introducing caregivers from the outside sooner than later to make sure a good fit is found for the partner diagnosed and the family as well.	He advises bringing care in right away because it take working with 2 or 3 caregivers before the right match is found	10
Well, what I did ask for, and what some of them were able to do a little bit, was you'd come over and be with (spouse) or take her somewhere and god bless her, she really started that because she was getting antsy here at home, she couldn't drive, had no independence.59:40		He asked friends to stop by and see his wife and some did a little	10
Our connection was different, was severed,59:40	This really spoke volumes about how he and his wife had become due to the progression of her disease	His connection with his wife was severed	1
she was angry with me,59:40	He knew or thought he knew his wife was angry at him. I wonder if she was angry at him or at the situation? maybe both?	He felt his wife was angry with him	1
she was still able to use her phone just to make calls. She had a smartphone but she couldn't do anything with it other than make calls, and she had a few friends on speed dial.59:40		His wife was able to make phone calls to friends	N/A
She called one of her friends and said, "Can you come get me to take me to your house?"59:40And so that's what initiated me reaching out to a few of her friends. We then also posted on Facebook to our running friends asking for them to take (spouse) for runs59:40	It would be hard feeling trapped…I would imagine she might have felt that way just as he did sometimes. They were both used to being independent within their relationship	His wife would call friends to come and get her He reached out to his wife's friends to keep her connected to them	1
Everybody was working, so it was either-- A lot of them being runners would get up a		His wife's friends were still working and would	N/A

5:00 in the morning before work and go running1:01:12		get up and run at 5 am	
And with our son, I tried that once or twice. I took her out to someplace. I got up at 4:00 in the morning. I got ready. We got to wherever they were running at 5:00 in the morning. Got home here in time to then get my son ready for school and help him because sometimes he wouldn't wake up because of his (medical condition)1:01:12	It sounded like he tried to meet his wife's friends at their scheduled runs but it was just too much at that time in the morning with trying to get his son ready for school too while trying to manage his son's diabetes too	He tried to take his wife to meet her running friends in the morning but it became too difficult to manage that and trying to take care of their son and get him to school	4
So then it just became reaching out to-- asking a few friends can you come by?1:01:55		He tried to reach out to his wife's friends to stop by and visit	10
And we tried to set up a routine of on Wednesday evening, once a week, can you come by and take her for four hours and go do something with her1:01:55		He tried to set up a routine for friends to stop by and visit	4
And once or twice, I took her somewhere to be with her friend. And then she got in the car with her friends, and then, she became really suspicious or paranoid because she thought that the reason that we were doing this is so I can go have an affair. 1:01:55		His wife became suspicious of he was having an affair when he tried to take her to meet up with her friends He tried to keep connections with friends for his wife and would take her to her friends	1
So she would get out-- she would jump out of the car, scared the heck out of her friends. And it was hard for them to get her back in the car. So that eventually started eliminating people who were willing to help		His wife would try and jump out her friend's car and wouldn't get back into the friend's car	10
So that eventually started eliminating people who were willing to help1:01:55		His wife's behavior of trying to run away from friends eventually eliminated people who were willing to help spend time with her	10
I guess get help as soon as possible1:03	His answer to what he would tell others in his situation	He would advise other's in his situation to get help right away	7

Look into a residential facility sooner than later1:03		He would advise researching a residential facility sooner than later	7
I felt, toward the end of my caregiving with her and her death, I told my grief counselor, “I wish that there was kind of a handbook of things to do as a guy or whatever.”1:03:39		He wishes there was a handbook of caregiving for guys	7
For instance, when our son was diagnosed, we were given a book that was about 300 pages that went through various age groups, because people are diagnosed from age of 1 to 40 or 50 with (medical condition)1:03:39	He had a really good point. that other illnesses have literature for those diagnosed and their caregivers about what to expect in general	He was given a handbook when his son was diagnosed with Diabetes that went through various issues for different age groups diagnosed	7
So there was all kinds of aspects of the effect of (medical conditions) on one's life that was in that book. So it was this reference book.1:03:39		It was helpful to him to have a type of reference book for his son’s illness	N/A
I would hope that your works coupled with other people's works-- I would hope that there would be a handbook, so to speak, that could be put together to help.1:03:39		He hopes that this study plus other studies about caregivers can act like a type of primary caregiver handbook for caregivers for loved ones with FTD	7
I was a scientist and I worked, not only in R&D, but in developing processes. And it was really helpful for me always to have a roadmap, a plan to get from A to B.1:03:39	It did seem like a logical way to think about how to know about what to expect as a primary caregiver for a spouse with FTD. I wondered myself why there isn’t something like that already established?	He was a scientist used to following a road map to get from A to B.	5
And I know it's really hard with the disease, these types of dementia, but their system kind of-- so I just didn't know who—1:03:39I was at a loss1:03:39		He did not know who to ask about guidance as a primary caregiver for his spouse who was diagnosed with FTD	7
I don't know if there's maybe videos put together, but just if I had some kind of handbook1:03:39	It did seem like a logical way to think about how to know about what to expect as a primary caregiver for a spouse with FTD. I wondered myself why there isn’t something like that already established?	He thought a handbook for primary caregivers for spouses with FTD would have been helpful	7

I said I thought I could take care of it, and I was the one that was ready for it.1:03:39	Interesting that he thought he was prepared or ready to be his wife's primary caregiver. I am not sure why he thought that? Maybe because he loved her and thought that would be enough?	He thought he was prepared and the one that was ready to be a primary caregiver for his wife	7
It was always work, work, work, and so our relationship wasn't as we had a lot of fun times, and we played a lot and we traveled a lot.1:03:39	Maybe he was in denial or his expectation of what his wife was going to be like as her FTD progressed was off. Maybe he thought he would get to have fun with her a little more?	He worked hard and many a lot and his relationship with his was fun. They played a lot, had fun times, and traveled a lot.	1
And I wish that I could have allowed myself to play a little bit more. 1:03:39	This did answer my question a little. He did think he was going to be able to have more fun times with his wife even if in different ways than before. It sounded like he really didn't realize how hard being a primary caregiver for his wife and their son would be. And how time consuming it is.	He wished he could have played more with his wife in his role as her primary caregiver. It was hard for him to play the last couple of years	12
And I guess even-- I'd seen recently where if you can try and bring play and laughter and music in, with your partner-- so it was hard for me to play the last couple of years1:03:39		It was hard for him to play the last couple of years	7
I was so stressed out with all the aspects of our life, but not on her disease.1:03:39	I believe he meant he thought he could have been more focused on ways to help her with music and other things that could have helped them play together more	He was so stressed out with all aspects of their life together but not on her disease	7
And so that's where you have to have that help, and as much as full-time help as possible1:03:39	In retrospect, he now knows that he needed help. A lot of help that he originally didn't think he needed. And by the time he realized he needed so much help it was almost too late	He knows now that he should have had as much help as possible from the beginning.	10 7
This is one thing that we didn't touch on, but again, like I said about her earlier intervention, not looking for help, but looking for a residential facility would be to get all of your legal and financial affairs in place as soon as possible1:03:39	He broke down sobbing as he finished saying this. I can't imagine looking back and thinking that had you done something differently the outcome would have been less tragic. I asked him if he was ok and he just kept talk a little more.	He would suggest earlier intervention in finding a facility and getting all legal and financial affairs in order	7
And I guess, depending upon where you live-- I don't know if—(state) has in a few counties, pilot programs for		He knows now has pilot programs for the kind of care his wife would have needed	N/A

the kind of care that she needed.1;08:58		as her disease progressed	
They were providing waivers to get Medicaid at the facilities that I looked at, because of her aggressive-- I don't know.1:08:58	He kind of stopped after he said this but continued on…	He knew CA was providing waivers for Medicaid at facilities he looked at for FTD/dementia patients with aggressive behaviors	7
I hate to categorize her as just always being this aggressive person, because she still had a sweet side to her [inaudible] times too 1:08:58	It was hard to talk about his wife's aggressive behavior. It was hard for him to separate her disease and who she was before the disease	He hated to categorize his wife as her aggressive behavior because she was still sweet sometimes	N/A
There's some county programs that are giving waivers in providing Medicaid, so--I could have gotten Medicaid help for her if she would have been bedridden, but she wasn't bedridden1:08:58	It is beyond frustrating that is a person is bedridden Medicaid will pick up care in a facility but if they are still mobile they don't qualify for health insurance. This seems to be the epitome of warehousing the vulnerable.	If his wife was bedridden she would have qualified for Medicaid	7
so yeah and I guess the early intervention, the help, you can if you've got family. Get help from them as soon as possible1:08:59		He advises get help as soon as possible	10
I know one woman with her husband moved to a house right next to their son so that the son could be there to help every other day or part every day with his mom helping their dad who was dying from dementia, so1:08:58	I think he wished he had either looked into a facility sooner or wished he had family to help him keep her at home. It seemed he felt bad that he didn't have family to help and saw what a difference that could have made for them.	He knew someone who moved to live next to her son so he could help take care of his dad who was dying of dementia	10
I did not feel like it. I was getting a little bit sad and maybe not able to answer1:11:02	I thanked him and let him know he did a great job with the interview. This was his response		N/A
Well, it's you're right and in some ways, it feels like it was yesterday and in some ways, there's a number of things that I know I've forgotten whether they were good or bad. I don't know. I've forgotten because it was chaos here for so long it seemed like		His life was chaotic for so long in his role of primary caregiver for his wife and for his son at the same time	12
I would tell people should get into a caregiver support group.1:11:56	I asked if there was anything else he wanted to add and he said one more thing.	He would highly suggest getting into a	10

		caregiver support group	
For me, it was really good in person1:11:58		He liked the in person group	10
I know there are online kind of chat groups. They may even do them by Skype. I don't know. I didn't participate because I found through the Alzheimer's Organization here they're connected with the FTD group.		There are online caregiver support groups	10
I wish my support group had been more frequently instead of once a month for two hours.		He wanted to meet more than once a month for 2 hours with his FTD caregiver support group	10
But I did it because the dementia, this FTD type, there's what 60,000 they say that have it? So when you look at the demographics there won't be that many people in your community and some of the people in my support group traveled one and a half or two hours to come.		He thinks meeting more often might be difficulty due to not as many caregivers for loved ones with FTD	6
I was lucky that it was just across the street from me literally. So and people in my support group had found that the FTD support group were going to Alzheimer's and so they were spending the time but it wasn't helpful because their loved one was acting much differently than the way someone with Alzheimer's behaves.1:13:18		Alzheimer's caregiver support groups were not helpful for those caregivers taking care of loved ones with FTD	1010
Is if you're a caregiver get into a support group right away. As soon as possible		He advises getting into a caregiver support group right away	10

Appendix E

Participant C Analysis and Coding

Participant C Statement	*My observation during interview/reviewing interview*	*What is the meaning of the statement*	*Theme Code*
It has impacted me quite a bit. (00:46)	This was the first response he had to me asking how being the primary caregiver for his wife who was diagnosed with FTD impacted him personally.	He was personally affected significantly by being the primary caregiver for his wife.	5
I'm a CPA and a firm director here in our firm. I have a lot of client responsibility. (00:46)	He was telling me about his responsibilities outside of the home and outside of caregiving.	He has a lot of responsibility and is in a leadership role at work.	5
And since my wife's got diagnosed, she, basically, needs a lot of assistance. (00:46)	As he was telling me this, only 2 minutes into the interview, he already was sighing, and making hand gestures to indicate he was/is feeling the stress and pressure at home and at work with trying to find a good balance.	He now has added responsibility and a leadership role at home.	5
Every day during the week, Monday through Friday, she goes to the adult day center, and I get up, I get her fed, showered, dressed, and driving her to the day center. (00:46)	He was explaining the sequence of his weekdays during the work week. I could feel his exhaustion as he was telling me the schedule of activities of daily living he does now not only for himself but for his wife too.	His work week daily schedule has completely changed since becoming his wife's primary caregiver. He is now in charge of his wife's activities of daily living.	4
And so, basically, I'll be coming into the office quarter after 9:00, 9:30 - but the firm's been great and they just say do what you have to do - and then I try to stay a bit later. (00:46)	As he was explaining what time he gets to the office now, after having to get his wife ready for the day, he seemed tired but grateful that his place of employment values his work and leadership enough to accommodate his caregiving needs. Mainly needing extra time in the mornings.	He now gets to work later than he used to in order to take care of his wife every morning during the work week. His place of employment has allowed him the flexibility in the workplace to be able to be a caregiver for his wife	4
Weekends, my wife, when she wakes up in the morning, she's a little bit more on the confused side so it's a lot of repetition and you've got to be	He was describing how the weekend schedule is stressful in a different way than the weekday schedule. He seemed like he was patient with his	His weekends are just as stressful as his work days as the primary caregiver for his wife.	4

constantly answering her questions, helping her do things. (00:46)	wife even though it seems frustrating at times.		
Today, she was going to put stuff in the washer, but what she ends up doing-- she puts the dirty stuff in the dryer thinking she already washed them. So, it's constantly watching what she's doing, try to get her involved, but to try to also watch what she's doing (00:46)	He was giving an example of how his wife performs household chores. He almost gets it correct but doesn't. His voice was calm but had a tone of frustration as he described an average Saturday now at his house. He was explaining how he tries to keep her involved and doing things but that he has to constantly be "on" and watching her.	Every day he wears the caregiver hat and more so on weekends. Weekends are not a time of rest from the work week for him. He is tired	4
Most of her behaviors are OCD-type behavior so, again, a lot of Repetition constantly putting hand lotion on, constantly looking for a razor to shave because she thinks that her hair on her face grows every two minutes. (00:46)	As he was explaining his wife's behaviors and how repetition is a big part of her compulsions, I was thinking it not only sounded exhausting for her but equally exhausting for him too. I could envision her repeatedly putting on lotion and he trying get her to stop and put the lotion away. Or her looking for razors frantically while he is trying to get her to focus on something else.	He has to constantly watch his wife and her repetitive behaviors He does not have breathing room He is constantly engaged	4
So yes, it's from someone who was very independent - and we've been married for 36 years - to someone that, now, really needs assistance (00:46)	He was describing how his wife went from being very independent and an equal to him for 36 years to now someone who needs constant attention for everyday tasks. I could feel his emotion as he was talking about this. I felt he really loves his wife and misses their relationship before she became ill.	His wife went from being independent and his equal for 36 years, to now needing constant oversight.	1
So yes, it has kind of changed my life quite a bit. 00:46	He ended this statement the same way he started it, his life has changed quite a bit. He sounded as though he has come to accept this as his life now but is still frustrated and sad for what has been lost or sad for what he thought his life with his wife would be in retirement.	His life has significantly changed. His relationship with his wife has significantly changed His wife has significantly changed	5

She got diagnosed in the summer of 2015 so, basically, we're heading into year four with the diagnosis. And it takes a while to kind of figure out what's going on because, sometimes, there's change in behaviors, but they're so subtle you don't really think about it. 2:43	He stared to explain that this is his 4th year of taking care of his wife since diagnosis. He mentioned that trying to figure out what was going on was difficult at first because some of the behavior his wife was having was so subtle that it could be attributed to a number of things.	He has been a caregiver for 4 years Diagnosis was hard to pinpoint at first	6
But one of the things about FTD is that if you go back five or six years, you start to see these little changes. Because my wife's got the behavior variant FTD, and we start going back when she got the-- once it really manifest itself, we went back and we said, "God. You remember four years ago she did this or four years ago she did that?" 2:43	He was explaining that looking back over the last 5 or 6 years and they could really start to see a pattern of behavior changes that were small at the time but now having knowledge about FTD, it all fit. It seemed that he was sad thinking about what they might have missed back then while realizing there was really nothing they could have done to stop where his wife is today in the progression of the disease. I wonder if they had known sooner what they would have done differently with their time together?	Life is busy and signs of the disease were missed in real time. Time is of the essence when a loved one has been diagnosed with FTD	6
And they realized that little changes in behavior, which you kind of just chalk to something else-- and then all of a suddenly, when it really gets a little crazy, then that's when we said, "We better go to a doctor and figure out what's going on." 2:43	As he was describing how little changes in his wife, or really anyone, can be chalked up to stress, hormones, lack of sleep, normal aging process it seemed he was thinking of himself too. so maybe he was comparing the little behavioral changes in his wife to his own at that time. But once her behaviors became truly alarming, they decided they needed to get medical attention. He had a calm tone but a nervous laugh as he was telling me about his experiences.	Truly alarming behavior was reason to seek out medical attention Subtle behavior changes were normalized	6
Both her father and her grandmother had early	It seemed that maybe due to his wife's familial	Early onset Alzheimer's was ruled out FTD was the diagnosis	6

onset Alzheimer's so we thought that's what we were dealing with. But they did a bunch of tests, they kind of ruled out Alzheimer's, and then they focused on the FTD until the neurologist said, "I think that's what we're dealing with." 2:43	history with early onset Alzheimer's, they were a little prepared emotionally to hear the possible diagnosis. But once that was ruled out by the neurologist and FTD was the front runner as an explanation that seemed to changed that little bit of preparedness they might have had as a cushion.		
Depending on what her obsession of the day is. Some days I wake up in the morning, and she-- again, she's very confused, foggy in the morning. And it's just like, it takes a while to get her going. 4:25	This was his response to how the last 4 years has been for him and what changes he has been through. He started by saying well it really depends on the kind of day she is having as to how his day will go. As he was explaining this, he was using his hands like maybe he would trying to hurry her along some mornings. His frustration was showing.	Obsessions are a part of his wife's routine now. His days are dictated by her obsession of the day. Mornings are long getting prepared for the day.	4
You try to get her outside of the house, you try to take her places and stuff, but what happened with me is that basically I can't do a lot of stuff. 4:25	He was voicing his frustrations about trying to take his wife places but after a while it didn't work out too well for him.	He was limited in what he could do independently of his wife. He was limited in what he could do as a couple outside of the house. He was now an "I" and not part of a "we" anymore. His wife didn't know the difference anymore.	2
Basically, I have to do everything in the house. 4:24	He is alone but not alone. He is now taking on the role that used to be his wife's along with still doing tasks that have always fallen under his role in the couple/house/life.	His role changed. His part of "we" changed to "I." He had to do everything in the house himself.	1
My son's not home that much. My two daughters are out of the house, so when he is home he helps out. 4:25	He was conveying that his "help" from his kids is not that much. Although I didn't get the sense he expected more or even wanted them to be more involved with helping?	He is the primary caregiver for his wife and himself. He gets sporadic help.	10
But every time I try to do a little project in the house, then my wife will want to help, and then she kind of peters out. 4:24	He was voicing his frustration with having to do everything by himself and then added that even when his wife does try to help, she can't last very long.	He gets limited help from his wife. His role has changed from "we" to "I" He is worn out	1

She kind of focuses on some obsession like smoking or chewing gum, and then she just can't do anything. 4:25	He was adding the reason she "peters out" is because her obsessions take over and she gets distracted with those.	He is frustrated with her obsessions. He is overwhelmed by her obsessions. His role has changed.	5
So she's put on a lot of weight, so that kind of hampers her. She gets tired 4:25	Again, he was adding why she can't be of help like she was before the disease of FTD. He was making gestures with his arms to show how much weight she had gained while talking of her weight. For the first time in the interview, he seemed ashamed of his wife and her weight gain.	His wife has physically changed along with cognitive and emotional changes. He is overburdened with his own physicality and emotionality.	1
So, I try to just take the time, even in the morning I'll get up at 6 AM. My wife will get up around a quarter to 7 AM. I have that 45 minutes of quiet time before she gets up. Because once she gets up and comes downstairs, I know it's going to be this ritual that we have to go through 4:25	He was saying that he needs to get up early so that he can just have some quiet time to himself and get gathered emotionally and mentally for the day. He seemed exhausted just telling about what his mornings are like. I could feel his sadness as he was trying to hold his emotions in check.	He takes time for himself. He needs quite time in the mornings to collect himself. He gets 45 min of quiet time a day at home, away from his wife and her chaos.	2
And my wife goes upstairs after dinner to kind of go to bed, watch some TV, and I stay downstairs. So it's quiet time for me. So I try to find that quiet time, because depending on how long 'm with her, for let's say, the bulk of a Saturday, it starts to get to you. 4:24	He continued to tell me that he gets a little more quiet time in after dinner when she goes upstairs to get ready for bed and relax. His tone of voice and the way he was saying how it gets to him really conveyed how frustrating and sad the situation is…	He gets a little more quiet time in the evenings after dinner when his wife goes upstairs. He is irritated by his wife's behavior He is angry at the entire situation His role has significantly changed in the relationship	2
Because the fact is, you're trying to get her to do things, and it's just repetition. When we take our car ride, and let's say we visit my daughter down in (state), nine hours in the car, you're ready to-- and you can't escape, right? You're ready to bang your head against	He became more animated and his voice tensed as he described being with his wife for 9 hours in the confined space of the car. I could visualize him literally banging his head on the steering wheel out of frustration because of his wife's behavior…and because of what they had	His life has significantly changed His role in the relationship has changed His role as a male has changed His role as man of the house has changed His wife has changed and therefore the "we" has disappeared.	2

the windshield and stuff. So, it's changed my life. 4:25	become…what he had become.		
Again, my wife was very independent. We loved doing things together. She would be very proactive with things. That's all gone 4:25	He just got more saddened as he continued to talk about how things used to be with his wife and their relationship. I could feel myself becoming emotional, I was saddened for them both.	His independence is personally gone. His wife's independence is gone Their lack of independence has significantly affected their identity as a couple.	8
At certain times during the day, I call it sunsetting, where all of a sudden, she can have a normal conversation with you and remember things, and you say, "Wow. I'm enjoying this conversation."	His facial expression lightened and he smiled as he was telling me about when his wife can recall things and when she is in a good frame of mind. I could tell he really enjoyed talking about those times. I felt he really still loves his wife in those moments.	He gets moments of the "we" with his wife His role is briefly restored in moments of his wife's clarity His role has changed significantly in the relationship	1
I love it. I mean, sometimes when-- and one of the interesting things is when she goes out in public. So if we go out to dinner with some friends, the two couples that I know through the FTD group, we've gone out to dinner with the spouses of FTD, and my wife will just carry on a conversation. The other two spouses are starting to lose some of their verbal ability, so they don't say too much at the table, but my wife will just be talking talking talking. And they think it's so opposite what they're going through. But I always say when we go out socially and to dinner or for the show, she can just carry on a conversation. 6:59	He was excited to talk about when he takes his wife out for dinner with friends whose spouses have the same disease. He really likes it because she is able to be social and talk to them like she used to do. It seemed to make him happy and proud that that is something his wife can still do…it feels like the "we" again.	His social life with his wife has remained somewhat intact. His social life has changed drastically He is proud that his wife is able to maintain appearances to some degree.	1
It just seems that when she's out of that environment, like she's back in the car, it was like she flips a switch.	He seemed to flip that same switch as he was telling me about how things are "good" in a social environment and	He flips a switch when his wife does the same behaviorally/emotionally/cognitively He feels normal when his wife is acting socially acceptable socially.	8

And then she goes back to the way she normally is. 6:59	then back to the same FTD "normal" once they get back in the car. It seems like it is a nice escape for both he and his wife when he can relax and she can be herself out with company.		
So just depending on what's happening and stuff, I really enjoy. We're taking the trip and she's in the zone, she's good, she'll start talking about things, her long-term memory's phenomenal. She'll start telling me something about 25 years ago, and I know [it's true?], and we'll just carry on the conversation. 6:59	He was sort of lost in his more lovely memories of his wife when they were "we." He was smiling and living in that moment during the interview. I was feeling his joy as he remembered how they were in those few moments of clarity that his wife has.	He lives for the moments of clarity and the "we" with his wife He misses his partner in life These moments of clarity are bitter- sweet for him and perhaps his wife too	1 8
And then, it's like a switch gets flipped, and then, all of a sudden, she goes, when are we stopping for lunch, where are we going to stop. And you try to answer, well, when we need gas, we'll stop for lunch. And then, two seconds later, she asks the same questions. So, you kind of go from one extreme to the other. 6:59	He appeared to be actually deflated as he was telling me about his experience with his wife while traveling. It was reminding me of my own 9 year old daughter who on long car trips wants to know when we will be there…and asks every 5-10 minutes for the 7 hour ride. I could empathize with him in that moment. But I couldn't imagine those types of questions coming from my life partner and best friend.	His role has significantly changed. He is just as lost as she is in the relationship He is frustrated with his situation	8
Very stressful [laughter], very stressful because, again, especially in a car, if she gets into that zone, where she's just repeating herself over and over and over again, it's like, you can't escape, you can only turn the radio up so loud. try to get her to read a book in the car. 8:44	As he was telling me about his experiences with his wife in the car, I could feel my anxiety increase as his did while he was telling the story. And the fact that he turned up the radio so loud that he could literally "tune" her out felt painful.	His role in the relationship has forever been changed. His wife is no longer his partner He treats his wife as if she is a child His wife is not capable of being his partner anymore	8
And I actually, like the next time we're going to go see my daughter, my	He seemed to be exhausted telling me this story about traveling with	He needs to gain some sense of independence again He needs to experience the "I" independently from	2

daughter maybe wants to do some things, like maybe go do a little hiking, and my wife cannot do that, I just said to my wife and my daughter, you know what, next time, I'm coming down by myself. 8:44	his wife. There seemed to be some sense of relief when telling me about traveling by himself to see his daughter in NC. And at the same time irritated that his wife can't keep herself together enough to join him to see their daughter.	the role of caregiver His role has significantly changed within the relationship His role has changed significantly in general: provider, friend, man, lover, partner	
I'm going to leave mom home, and this way, my daughter, I say, this way, if we want to go to some big trail or some big park, we can do some hiking and stuff, we can do it because (spouse) just can't do it. 8:44	It seemed he wanted to have some sense of normalcy for his relationship with his adult daughter too. Maybe it was becoming a burden, physical and emotional, for his daughter to have her mom there for an extended stay. The trips to see his daughter seemed to become his respite from his new role as caregiver…	He wants some degree of family relationship normalcy He is looking to his daughter for additional support	2
And (spouse) understood that. She's like, well, I don't want to do that and stuff. 8:44	He said his wife, (spouse), understood that he needed to go by himself on these trips to see their daughter. I am not sure what he meant. I am not entirely sure based on the previous statements about his wife's cognitive state, that she completely understood. But I wonder if she felt the sadness of not being included anymore.	He needed to believe his wife "understood" his needs His life had changed significantly	1
I kind of look forward to taking these trips but we even had a wedding up in (state) and I decided not to go because I said, it was a Friday, come home on a Sunday, and I said, I can't deal with the car ride up there and the car ride back because it's such a short period of time. And sometimes I need a couple of days. You know, when we go to (state), we stay a couple of days. So we'll go on a Friday, come	He continued to tell me about how his life has changed. How he can't travel to places they used to or events because it is to exhaustive for him. I would imagine it is exhaustive for his wife too. I got a sense of feeling trapped in a car without being able to escape His frustration really came through as he was telling me more about traveling with his wife now. It is sad to think that the person he wanted to spend the most time with,	He used to like to travel with his wife for weekend trips with his wife before she got sick His life has changed significantly His role in his relationship with his wife has changed drastically He needs time to decompress He needs an escape route from his wife His role in their relationship has changed dramatically His "I" independent time in the relationship has changed significantly	2

home on a Monday. I get a couple of days to decompress basically. So when you're in the car, it's so hard when you're in the car because you can't do anything about-- at least at home, I can go upstairs, you know? I can go outside and cut the grass, I can try to find something where I can get away from her for about an hour. 8:44	is the one he is trying to escape from now. The image of him going upstairs to get away from her made me sad for them both. When he asked me, “You know?” I really don’t’ know. I know what it’s like to fight with a partner and to go in another room for a bit but them come back together eventually as a team. I can’t imagine what it is like to not have that second step. Especially after doing that very thing for over 38 years.		
Yes. I mean, before FTD, there was some evidence of, I would say, OCD like behavior. Going back and realizing that, like spending money. She got into a lot of trouble with credit cards. She did some weight swings and weight gain and then losing it and weight gains and stuff. 10:41	I had asked him if he had traveled independently before now. He responded by telling me about some strange behavior his wife exhibited before she got the diagnosis.	He noticed a change in his wife’s behavior before she was diagnosed with FTD	6
But we always did stuff together, vacation together, had a good time. And then in late 2014, the early part of 2015, started noticing a real change in her. 10:41	He was remembering his life with his wife, as the “we” and how he was as an “I” as part of the “we” before her diagnosis. I started to realize that was only 3 years ago that his life as he knew it was pretty much still intact. And now, there is not much left of what they had built together over the last 38 years	His relationship is no longer the “we” it was 3 years ago. His “we” has significantly changed in the relationship with his wife His wife’s significant life changes were his significant life changes	8
And so that's what got us very concerned to the point where, walking through the house naked, going outside, actually she would go outside and pee on the deck. This was the behavior that was going crazy. 10:41	As he was describing his wife’s extreme behavior, he seemed to almost whisper. I saw him become embarrassed to tell me these facts of how the disease effected his wife, and ultimately, affected him.	He is embarrassed by his wife His role as provider has changed significantly His role as partner has changed drastically He was shocked by his wife’s behavior	6

And then, that behavior sometimes disappears and it gets replaced with other behavior. That's what I'm saying, you wake up in the morning and say, what are we going to deal with? 10:41	As he was telling me about how he never knows what his day holds in store for him based on his wife's behavior, he seemed far away as he was talking. He would occasionally take a sip of water and it would seem he was back in the room again. I felt a heaviness in my stomach	Nothing is the same His routine has forever been changed His role in the relationship has significantly changed He has to always be on	4
So now, her big behavior is, she has to chew gum. It's like she's obsessed with chewing gum. And, of course, like a two-year-old, and I was kind of like dealing with a two-year-old. She takes the gum out, she puts it on the table. And I say to her, I go, well, we least not putting it under the table like you did in school.	He was physically showing me how his wife chews her gum…chomping his teeth, with his mouth open. And he seemed annoyed with how she chews it, let alone what she does with it when she is finished chewing it. He kind of found some humor by saying at least she doesn't put it under the table…she puts it on top so at least he can find it and discard it.	He no longer is in an equal relationship His relationship has changed dramatically He is alone	4
But yeah, prior to that, I mean-- so my wife's had some-- all of these compulsive things and again, prior to her diagnosis, but maybe there was a little [inaudible] because of the fact is you're spending money, you're buying stuff. It's in the basement still in the boxes. She's just compulsively buying stuff And that caused arguments because she was saying-- she was working 10:41	He was explaining that even before the more extreme behavior started to happen, his wife was spending money recklessly and it was not like her to do so. It seemed that this behavior was more tolerated than the other behaviors like peeing off the deck, and running naked outside	He no longer trusted his wife's judgment His relationship began to change long before his wife's diagnosis His wife's compulsive spending was the initial red flag His wife wanted to have her continued sense of independence	6
then she stopped working. And then she actually was able to get on disability. By trade, she's a nurse. And so she was always the caregiving type person, taking care of her father when he was sick, taking care of her mother, taking care of	He let me know that his wife tried to justify her spending by saying that she was working to be able to spend what she wanted. It seemed that even when she would buy things in the past, this extreme buying was really out of character for her. He continued by saying	His wife's role changed significantly His role changed significantly His wife went from being the caregiver to needing care His caregiver is gone His security is gone	8

three kids. And that's all kind of gone. 12:29	she eventually couldn't work and went on disability. and that she was caregiver by nature and by profession, being a nurse. And now that is all gone. She is now the one that needs taken care of…		
So there was a big change from what I-- who I knew (spouse) as and now because you could just see that she struggles just doing a lot of things. Like I mentioned this morning about just putting stuff in the washer was a big deal for her. Okay. 12:29	I could sense that he felt so badly for his wife. Who she used to be and who she was becoming because of this disease. He seemed imply that maybe she knew she was changing in the beginning which was so sad for them both to realize. I also got the sense that he felt bad for himself and the hand he/they had been dealt. No one plans for this type of dramatic change in a relationship. One that is not caused by choice. Not like an affair or falling out of love.	He has changed His wife has changed significantly. She is there but not as she was in the past.	8
Since she got diagnosed, I would say that the-- she doesn't have that emotion anymore. 13:45	I had asked him how things had changed emotionally for him/them since her diagnosis. He was sad as he said that she really doesn't have emotion anymore. I took that to mean emotion for him…caring for him.	He misses the emotional connection with his wife Without the emotional component of his relationship with his wife, things are forever changed	8
She also has some anxiety and depression, so she's been on some medication for that. But what I just kind of notice when she's not in-- when's she in the bad zone [inaudible] she-- no eye contact or the looking down, doesn't-- sitting on the couch very rigid. I mean, there's no emotion, no emotions on her face and stuff 13:45	As he was telling me about how his wife is no longer emotional with him, he looked down at the table as he was saying that she often has no eye contact and is very rigid. Almost mirroring what he experiences with her in those moments.	He is isolated He is lonely He is emotionally abandoned His wife is emotionally unavailable	8
When she kind of gets into that good zone, then you can see the love there. You can see	He was describing how he feels when his wife is in the "good zone" and he can connect a little	He is isolated He is emotionally isolated He is alone	8

the emotion, maybe crying a little bit, hold hands and stuff. So it just depends on what zone she's in. 13:45	emotionally with her. He was smiling but almost crying as he told me about how he can see the love. It is devastating to see how much he loves his wife yet how overwhelmed he is by her as she is now.		
Sometimes I feel and a lot of times, and unfortunately, it's a constant thing, like somebody dies, you have a mourning period, right? But then you get-- you pick up the pieces and you move on and stuff. 14:56	As he was describing his relationship with his wife as a death and mourning period, I couldn't help but think about the continued ambiguous loss he experiences on a daily basis. I wondered if his wife, on some level, was experiencing the same ambiguous loss as she could understand it? I felt sad and my heart was heavy for them both.	He is grieving the loss of his relationship He is grieving the loss of his wife as he knew her He is grieving who he used to be He is grieving his independence He is unable to completely grieve He is alone His life has significantly changed	8
I mean, (spouse) is sometimes to me emotionally dead when she's just kind of very rigid, showing no signs of and no eye contact. And it's almost you're constantly going through a state of mourning 14:56		His wife is emotionally dead to him He is emotionally dead He is lonely He is mourning his life His life has drastically changed The "we" has changed meaning The "I" has changed meaning His role has significantly changed	8
you kind of know when she does show it, you go, "Wow," how great it is so maybe we'll continue, right? And then, boom, the switch gets flipped again and she gets back to the FTD piece of it. 14:56	It seemed to me that no matter how much he realizes cognitively, his wife is not going to get better and will never be consistent, he still has that hope each time she "comes through" and connects emotionally with him. That has to be so hard. He is being raked over the coals each and every time this occurs. I can't help but think and feel this has to be one of the worst ways for a relationship to change/end.	He continues to have hope He is alone His life has changed significantly He wants a connection with his wife	8
No, I said, "I miss it," because you just don't know when it's going to happen and where you're going to be. And so when it does happen,	He became tearful when he was telling me about the fleeting moments of emotional connection with his wife…and the moment when it's gone. Reading	He misses his wife He is desperate for emotional connection with his wife His life has drastically changed His identity has significantly changed His needs are not being met	8 1

you take it and stuff but-- and I say to her, I go, “Wow, you're smiling, you're laughing, we're kidding around. We're making [inaudible], what, we're joking I see the laughter, the emotion there and then boom, it's gone. so. 14:56	through this again is making just as sad, and heavy-hearted as I was when I heard him say it in the interview.		
That's what makes this disease so tough. It's just that you don't know at any 5 minutes, 10 minutes could be a change, and-- 16:07	He was almost distraught telling me this statement. He took a minute to gather himself, take a sip of water, blow his nose. It was hard for me to remain composed at points too. This was a very emotional interview.	His is constantly experiencing ambiguous loss of his relationship His life is a series of disruptions His is in a state of constant chaos His life has drastically changed	8
Stressful in a way that it's a little bit different than maybe what people would assume the stresses would be. 16:21	It seemed to me that he must have folks say things to him like they know what he is going through. Or say things to him like it has to be so difficult to have to do more around the house. I certainly got the feeling that he feels misunderstood, or has no one really to relate to regarding his experiences.	He is alone He feels misunderstood He is emotionally taxed His life has changed significantly	5
I guess if you're afflicted with-- as in my father-in-law had Alzheimer's. I know what that was like because I was there for that. Her grandmother had Alzheimer's. Again experienced that. Her mom died in '91. So she had a great life until maybe couple two or three years prior to the time she died that she was actually living in her own apartment, and we would bring her down to our house every other week. So it was fun. There was a little stress there because my mother-in-law had 24-hour care at that point in time 16:28	As he was explaining his experiences with loved ones who had Alzheimer’s, he was noting the facts those people had lived long lives and were independent, with help, until the time of their passing. He was still able to be around them and bring them to his house for visits. He called it fun.	His experience with loved ones diagnosed with Alzheimer’s was less stressful Those diagnosed with Alzheimer’s live long, productive lives before diagnosis The stress he experienced as being a loved one versus a caregiver was less	N/A

it's stressful to the point that says-- I see it in the faces of the people I go to the support group with. It's just that it's a constant, you're on edge. 16:28	He was continuing to describe his stress level and those in the FTD caregiver group. The stress is constant, there is no real reprieve from being on edge and being “on.”	His stress level is constant His life is not his He has to be “on” all the time	5
My wife doesn't walk out of the house and disappear like some other people do, but it's almost kind of like when she's home for an hour, an hour and a half before my son gets home from work, and sometimes I don't mind her calling me because at least I know where she is. But she really never wanders. She did that twice on us but basically it's very rare that she does that. 16:28	It seemed like he was trying to convey to me that others have it worse than he does as a caregiver because his wife, at this point in time anyway, is able to be home by herself for about an hour before someone gets home from work and she gets home from the adult day center.	His life has drastically changed His independence has been compromised His relationship is no longer equal He is now the “we” for both in the relationship	4
it's just constantly almost taking care of a two-year old. You're constantly watching. 16:28	As he was saying the words, it’s like taking care of a 2 yr. old, I could sense that was painful for him to say and realize. It made me feel a sense of anxiety and was thinking this is what he must feel every minute of every day	He is always on His wife is like a 2 yr. old His life has significantly changed	8
My son's a teacher. So he has some compassion. My other daughter is a teacher. But, as I said, a lot of times, the girls are out of the house. My son isn't home that much. And so it's really, as I said kind of me 16:28	He was saying that is really the only one that “watches” and takes care of his wife. So while he has help, it is limited by time limited to his children.	He is alone He is lonely His time is not his own	2
I don't look forward to the weekends because if basically my son's not home, then it's me. 16:28	I could feel his desperation as he described what weekends are like for him when he is home alone with his wife. He was kind of half smiling as he was telling me about it but I think that is his resting face now because the alternative would be to cry. Just what I was sensing.	He is alone even when his wife is around He is the “we” alone but is no longer an “I” as part of the “we” His existence is constantly in a state of ambiguous loss He is lonely	2

And I start saying, "I got to figure out things to do for her with her routine" so I say that we can get out of the house because in the house, it's kind of a disaster emotionally because you just aren't able do anything. "Well, at least, if we get out sometimes, she focuses on something else." 16:28	It appeared that even simple things like looking forward to Friday of the work week and looking forward to the weekend is no longer a luxury. He views the weekend with dread and tries to find ways to escape his wife while still having to take care of her.	He tries to emotionally escape from his wife He is the "we" without being able to be "I" in the relationship He is constantly in a state of ambiguous loss He is in crisis mode especially on the weekends	2
I mean we got married in '82. I started dating [inaudible] when she was a senior in high school. It kind of was Love at First Sight. 19:00	He was starting to answer my question about how things have changed in their relationship. He gave me their history as a couple. It was fun to hear and honestly, I welcomed the break from the feeling of dread, suffocation, and sadness.	He loves his wife He loves who he was then He loves who they were then He was an "I" in a joint "we" for over 35 years	N/A
I saw her. We were at the [inaudible] Polish folk dancing as we did when we were growing up. And then, men were at the dance. We kind of danced talked and stuff. And I was like, "Wow. [inaudible] she's really, really nice." Went out on our first date 19:00	As he was talking, I was imagining them at the dance, the music, the energy, and the two of them as equals in a relationship.	He loved his wife at first sight He was part of a mutual relationship His wife was an equal part of the "we" equation He was happy He was not alone	N/A
And then, we both went to college. She went to [inaudible]. I went to (university), but we still got to see each other during the week and both got through school. We graduated and then we got engaged and then we got married. 19:00	It was apparent from the beginning of their relationship they put the work into seeing each other. They followed a natural course of events…engagement and marriage after college graduation	His relationship was significant He identified as "we" while still maintaining his "I" individuality	N/A
And since '82, and all that time she was my best friend. My wife, my best friend. 19:00	He teared up as he was saying this sentence. He apologized for being emotional. I felt the exact same way as he did.	He and his wife were "we" for over 3 decades He was an "I" in the "we" for over 3 decades He has lost his best friend	1
And then, we had three kids, but we always just loved people we loved the social lives and our	His energy was high as he was telling me about their lives in the beginning of their couple-hood. It was	He and his wife, the "we", always enjoyed a full social life.	1

neighbors loved us. 19:00	fun to hear him tell their story.		
She almost read my mind. I was thinking of something, she could read my mind and stuff. 19:00	His energy started to get low as he continued to tell me of his relationship with his wife in the beginning	His wife was part of who he was He was truly part of a “we” His wife knew what he was thinking and could read his mind His wife was in tune with him perfectly…cognitively and emotionally	1
So, you miss that because all of a suddenly, it's all gone and so again, most of the time I'm talking to someone who's not even listening to me. 19:00	I felt a sense of loss and sorrow from him as he is made this statement.	He no longer has his life mind reader He no longer feels heard	8
Because she's zoned in on something. That's what her brain is thinking about. So, I will keep talking to her and I don't get a response or definitely get a confused response and stuff. 19:00	I felt a sense of loss and sorrow from him as he is made this statement.	He still tries to find a connection with his wife He talks to his wife without response He talks to his wife and she answers in a confused response	8 1
So, it's I definitely do miss that. Because I knew who she was and now who she is and that really has changed dramatically. 19:00	I was thinking he is the epitome of the definition of ambiguous loss. His wife is still physically present but cognitively and emotionally gone. At least gone as she used to be as he knew her before to be.	He misses his wife His wife has changed dramatically He knew who she was and who she now is	8
I always tell people that when they see her, I guess it was Thursday we went out to dinner with some friends who hasn't actually seen (spouse)e in a year and they know that she's got FTD and so (spouse)e went up to go to the bathroom. They said to me, “Wow. She's doing so much better than she did a year ago.” and I can always tell them. I said, “You've got to be with her 24 hours.” 20:56	He was frustrated as he told me people want to believe his wife has an illness that she will recover from and get better. I would imagine they know she will never get better but just don’t know what else to say to him.	He is frustrated with the perception of his wife’s prognosis He is the only one that knows the truth about his wife’s disease He has to re-educate friends/acquaintances continually about his wife’s prognosis He is constantly reminded of being alone	6
Even my sister-in-law finally actually took her for an overnight because I had to go on a	He sounded vindicated a bit as he told me that finally, his sister in law	He has one person that has slight insight into his role as caregiver for his wife	10

business trip and my sister-in-law's texting me. She said, “I know what you're talking about now.” 20:56	got it. How difficult it is to take care of his wife.		
She said because she doesn't see it. She sees her for a couple hours, three hours and sometimes it doesn't show itself. But if you're with her for 24 hours you start to see the behavior and so I have a laugh when I get a text from my sister-in-law saying, “Yeah. Welcome to my world. 20:56	He sounded vindicated a bit as he told me that finally, his sister in law got it. How difficult it is to take care of his wife.	At least his sister in law knows a little of his caregiving role with his wife	10
And I know it's the disease 21:58	He was verifying with me that he knows it is not his wife intentionally acting this way. That it is the disease that is causing her significant behavior changes. I was thinking even knowing what the cause is doesn’t seem to help with the stress and hurt that he is experiencing.	He knows it is the disease that is causing his wife’s behavior He knows it is the disease that has changed his life drastically	6
They're still not sure. They have a good inclination of what's causes it but it's not genetic. For her at least, it's not genetic which was I guess good. But it's trial and error and you go to the doctors and sometimes you wonder I said, does she really have this or does she have something else? But it's just you kind of go with the diagnosis that you have. There's no treatment for it. 21:58	As he was explaining why his wife might have this disease or one similar to it, it seemed to really not matter the why. It seemed to only matter that she has changed and because of that he has changed dramatically/drastically.	His wife’s diagnosis is not genetic His wife could possibly have another diagnosis but there would still be no treatment He just has to go with the diagnosis and the fact there is no treatment for it	6
Maybe someday they'll come out with some drug but right now it's just constantly going for checkups and stuff and MRI's and trying to see what's going on in	He was matter of fact when telling me that until they come up with new medications to slow the disease of cure it, he just continues to do the status	He takes his wife for MRIs and check-ups to monitor her progression with the disease He knows it is only a matter of time before his wife gets worse He does what he can do and takes one day at a time	6

the frontal lobe of the brain and see is it. So I think based on other people whose spouses have it, I said (spouse)e's kind of plateaued a little bit. You don't see her really getting worse, worse as getting into these other stages. But I know that any given day that can change. So I said, take it one day at a time. That's all we can do 21:58	quo and take his wife for MRIs and check- ups.		
if you do have that moment where you can that she seems to be in the good space and stuff and you can kind of lay there. It could just be you could be close. You can kid around with each other 23:28	This was in response to me asking about their physical affection in the relationship. He had started to say at this point none but then said this.	He has rare moments with his wife where he can connect with her physically He has had moments where he can lay with his wife and be physically close to her	13
. A good laugh and any physical aspects is not really there. Sometimes I sit there if all a suddenly she says, okay. Let's be intimate and stuff like that, I think like, okay. Right and but it's so sporadic You kind of take what you can get. Because I always say that if you're just close and just touch and that kind of means a lot 23:28	He was just adding to the previous comment that being able to joke with his wife and flirt and have physical affection with his wife is basically gone. This is really an echo from what he had said before. Again, this is a big shift in their relationship	His emotional and physical aspect of his relationship with his wife is limited but meaningful His sex life with his wife is sporadic His life has changed dramatically His role has changed significantly	13
At least you kind of feel connected and stuff and she'll remember that too. Because she will say, wow, it was really nice last night. We're kind of sitting there just kind of close and talking and stuff. So sometimes the next day she'll remember that which sometimes I think is good. But as I said, if the moment is	He seemed slightly embarrassed to talk to me about his sex life and the frequency of the physical affection with his wife. But I sensed he felt it was something that would be necessary for others to hear that were in his same situation. I was aware of his uncomfortableness and just let him talk without interrupting	He and his wife have rare moments of intimacy and closeness He has a glimpse of the “we” at fleeting moments with his wife	13

there it is there. If it's not it's not. 23:28			
Yes. I think so. Because we just loved to be together and feed off of each other and I think we had an excellent intimate relationship through the years and stuff 25:15	This was his response to me asking him about loss within the relationship and if this was a part of that loss. It seemed as if they had a really close relationship and this was so far from what it used to be. I was thinking about myself at that point and wondering how I would feel if this happened to me and my spouse. I also wondered if his wife would have felt the same sentiment about their past?	He and his wife loved spending time together through the years He and his wife used to have an excellent intimate relationship He and his wife were the epitome of "we" in the past	13
I realize raising kids, that always changes things from a standpoint [laughter]. But we always tried to find time to go away by ourselves. My sister-in-law maybe would watch the kids or my parents were alive. When my mother-in-law was alive she would watch the kids and we can go away for a weekend because you always need to recharge the battery. 25:15	He was just emphasizing the previous statement with the evidence that he and his wife used to make time for themselves as a couple even after having children. It sounded to me like they indeed did have a healthy relationship filled with friendship and intimacy.	He and his wife always made time as a couple in the past He and his wife were the epitome of "we" in the past His life has changed drastically His role within the relationship has changed drastically	13
Now basically I said and we have done it. I kind of said just do an overnight. I always try to avoid three or four days and stuff. But maybe we do an overnight. A lot of times she's like am I just going to deal with the same stuff I got at home where she's just going to be in the bad zone and then I could have just stayed home for this. So we test it. Sometimes I'll say let's go and let's go to a hotel and just spend the night there and stuff	He was basically saying that going away now as a couple isn't the same as it was before. He tests it. They might go over night. Sometimes it is a good time but most times it is just like being at home as far as behavior goes just a different location. I felt sad and happy that he still tries to have that couple time of significance with his wife now.	He tries to recapture the meaning of going away as a couple as they did in the past He has lost a significant component of is relationship with his wife He and his wife now have rare moments of sexual and emotional intimacy	13

and then she'll go and I say to myself, we try it. If it works great. We have a really good time and she's in the good zone, great. If not, I says that well, then it's just like the same thing as being home. 25:15			
so I'm always looking to do things with her. Valentine's Day's coming up, so I'd like to go to shows in (city). There's the local and Performing Arts Center there. And I get emails about new shows, so there's a show there, the 16th. And I go, "Oh, I think that you would really like the show [that kind of talks?] about this person." And so then I said, "I'll get tickets [to?] surprise you. And [inaudible] go at the dinner after that." So that's kind of the [stop?], maybe I'll try to do just to get her out of the house. Then I'll take her to the movies. It's date night. But she seems to relax and enjoy that show, watch a movie and actually watch a show. 26:47	He continued to tell me things that they are still capable of doing as a couple. Activities they also enjoyed from their past. Like watching a movie or going to a play. It seemed a bit haunting to hear him say it like it was the same as in the past.	He and his wife do some similar activities as a couple now as in the past He continues to try and have some sense of the "we" in their relationship He has rare times that his relationship feels as it was in the past	1
Yes, because when she's doing that, she's focused on what's on stage or what's on the screen. And so it's very enjoyable 27:32	This was his response when I asked him if he enjoys these dates with his wife.	He is social with his wife at times He enjoys his social dates with his wife He still experiences the "we" with his wife at times socially He get to have some semblance of couple hood still with his wife	1
I mean, because she's not going to sit there and talk about, "Well, I need a shaver," or, "I need a lotion." She'll kind of be quiet. 27:32	He was continuing to explain why it is enjoyable for him to go to movies or plays with his wife. It almost seemed to me that because she would be quiet during these types of outings he could pretend things were ok or he could escape the reality of their collective life as it is now	His social life enjoyment involves his wife being quiet. He no longer enjoys the "we" of his social life his wife as he had in the past His social life with his wife has drastically changed	1

And going out to eat. Like today I told her, I said, "We'll go out for a bite to eat maybe like 5 o'clock [inaudible]." And she looks forward to that. She's [always?] able to go out to eat. And so we will pick any local place and just sit in there and then she'll eat. 27:32	It seemed to me that it wasn't really that he enjoyed going out with her, it was he could still go out and take her with him so that he didn't have to miss out on going out to eat.	The "we" in his relationship with his wife has changed dramatically. The "I" within the relationship has changed drastically for both His life has changed drastically.	1
One of the things that-- [what I heard?] at sessions is binge eating, snacking at night. So that kind of drives me crazy because I come upstairs, then she's eating popcorn [inaudible] on the bed. Okay? And she'll make a bag of popcorn, she'll go upstairs. So, I got the popcorn in the bed. 27:32	He seemed very irritated by his wife's new eating habits. While he was saying earlier he knows it is the disease he really seemed to blame her not the disease regarding her eating/over eating.	He is irritated with his wife's eating habit	4
And I keep telling her, I said, "You're eating salt [inaudible] the popcorn." And then you're always telling, "You're very thirsty." So you constantly drink [inaudible]. But I go, "Why don't you give up the popcorn for a day? Have it a few times a week instead of every day." But no, she'll come downstairs, she'll grab the popcorn and make a pretzel, whatever's in the house. 27:32	It occurred to me that he was trying to reason with his wife about her food choices when she is not capable of reasoning and her food choice is more about her obsessions and compulsions related to the disease. I wonder if he has an issue with her weight gain not just the popcorn in the bed?	He is losing patience with his wife's behavior He is trying to reason with his wife who cannot reason anymore His life and his relationship with his wife have changed drastically	5
But I heard [inaudible] [FTDs?] like this calorie craving, the sugar craving that they go through. So I guess that's you're sitting there and you're watching her come downstairs and you try to plead with her, "Don't eat the cookies. Don't make the	He seemed embarrassed to tell me how his wife eats and seems to have no self- control that perhaps she had at one time? He stressed that it's the disease and "they", those diagnosed with FTD, have extreme sugar and carb cravings. It was as if he identified with the "we" of the relationship and felt	His role has changed in the relationship His relationship has drastically changed with his wife His role as part of the "we" in the relationship with his wife has changed dramatically His role as the "I" in the relationship has changed dramatically	5

popcorn." But she goes, "No. I'm making the popcorn." And then you sit like, "Well, [inaudible] gain some weight and you don't want to gain [weight?]." And it just doesn't connect. 27:32	responsible for her weight gain and bad habits?		
I mean, there are certain things I know are not going to stop. She smokes and if we left the carton of cigarettes on the table, she'll probably smoke the whole carton. So, we have a lock box at home. And it's a double combination, so you've got two different combinations. We have to lock her meds up. We have to lock the cigarettes up. I just lock the gum up. And I just put the body lotion in there because she'll constantly be putting lotion on. And I said, "They got this boxes as big as it is. So [inaudible]," because if we just left this stuff out, she'll take meds at the wrong time. And we were finding my son's meds [inaudible] he hid them, he's on (medication). All of a sudden, he was missing like 30 pills. So, we know she took them. And so, it's just like she goes around looking for stuff and especially when nobody's home and she'll find something and she'll start taking a look [inaudible] her meds or find the shaver and constantly she would shave herself. We're all like, everything's kind of has to be hidden or	I asked him if he had to pick his battles and he said yeah, but then continued to add all the behaviors he and his son have to watch with his wife and the lengths they have to go to in order to keep her safe. It sounded lengthy and exhausting for them and for his wife.	He has to take drastic measures to ensure his wife's safety His life has changed drastically His relationship with his wife has changed drastically His wife is no longer an independent "I" in the relationship He is the "we" of the relationship by himself	4

locked up in the house. 29:22			
I mean, we can get into-- I think the routine like in the morning I know what the routine is going to be. It's just always the question is how long is it going-- yeah. Yeah, how long's it going to take, let's say, (spouse) to get out of the house to bring her to the day [inaudible]. But then I said, “No.” Then I have to go to the office. But she'll get up, I'll pour her coffee, she'll go out, have her cigarette out on the table. She'll go out and then she sometimes sits in the garage, just like she's [inaudible] she's sitting there. And so I have to get her back into the house. Now what she does, even though she goes to the bathroom upstairs when she first gets up, she'll go back into the bathroom downstairs and she'll just sit there. So there's getting her up. And then she'll sit down, she'll take her meds with her coffee, and then I usually make her breakfast because I try to get her on Friday-- yeah, I think it was Friday, tried to tell her, “Why don't you get yourself a cereal?” So she got up, she had the bowl and she had the cereal, and she's walking back into the family room. And I said, “No, you've got to pour it in--” Oh, she had the cereal and she had the milk, but she	Just in the way he was telling this story about his wife’s routine in the morning, it felt burdensome even as he was trying to allow her to be as independent as she possible can be at this point. I was wondering if it would be less exhaustive if he were to just get the bowl of cereal for her? But since I am not there or in this relationship that is unfair of me to question. I would guess that at some point you hope for something to change?	His wife is dependent on him for activities of daily living He is his wife’s daily caregiver His role in the relationship has changed His role has changed He is less independent as his wife becomes more dependent on him	4

didn't have the bowl. 30;34			
So it was this back and forth, back and forth, back and forth. And then finally I got her to get the cereal in the bowl and get the milk, get the spoon. 31:56	He was continuing to tell me about their “routine” in the morning. It doesn’t sound like much of a routine other than it is breakfast time.	His morning routine is spent attending to his wife His morning routine has changed drastically His role has changed drastically	4
And then I'm looking at the time because we just wasted 20 minutes now. And then try to get her upstairs into the shower, and I constantly have to go in and see what she's doing because she'll wash her hair three times or she won't use soap on her little sponge there And I have to put her clothes out because that-- then at least I know she'll kind of get dressed. And then she dries her hair and she's got to put her makeup on and stuff. So a lot of times I'll tell her, “do it-- do the makeup in the car.” But I said, “God, could take her an hour and a half to get her out of the house, could take an hour.” So the routine is definitely there. It's just how long it takes to do the routine. 31:56	I was thinking this is every day for them. I was looking at him talking and I wondered what their mornings used to look like? I could imagine they were very independent and had great respect for each other. I couldn’t imagine how this change has interrupted their lives.	He is his wife’s primary caregiver His role has changed drastically within their relationship Her dependence on him has changed his independence within the relationship	4
That's what drives me crazy because I try to watch the clock and stuff. I said, “We need to really be out of here by this time.” And then I always got to put a-- when she comes off the bus, when she comes home from the day [center?] I have to try to have stuff out so when she comes into the house she'll say, “Oh, there's my cigarette.” So she smokes a	As he was explaining his daily routine with his wife, I thought about how it sounds like what I kind of go through with my young daughter…making sure she is getting washed in the shower, checking on her, telling her to hurry up, putting her clothes out so that she can just get dressed…and then thinking about what she will need after school. It really hit home with me	He is his wife’s caregiver His wife is dependent on him His relationship with his wife has changed drastically His role has changed drastically He is frustrated	4

cigarette in the last afternoon. And then I'll try to make a little list of things for her to do, like clean the kitchen, clean this, maybe start to do some laundry. But it is a world of-- it is a routine basically. 31:56	that his wife has really become his dependent.		
I think socially it hasn't impacted me as much because I'm not embarrassed to take (spouse) out. 33:31	This was in response to me asking how his/their social life has been impacted. I wonder how much insight and perspective he really has on this? As an outsider, it seems as if it has been impacted greatly.	He is not embarrassed of his wife He thinks his social life has not been impacted	11
So we go to a show, we go to dinner. We go to church every Sunday, even though last week we were at church and she's-- again, she's got this thing about appearance and makeup. So she'll be kneeling there and she takes her pocketbook, and during the most important of the mass, right, she's almost taking makeup out and she's putting makeup on. And I'm looking at her, I'm saying, “No, this is not the place to do this.” 33:31	This seems to contradict his pervious statement that he is not embarrassed by his wife’s behavior. Perhaps it just depends on who or where they are out together.	He is embarrassed of his wife’s behavior sometimes His socialization with his wife has changed while some of the activities have remained the same His life has changed drastically	11
But we get together with people who go out, I says, “Go out to dinner,” and she-- I love that time because she's normal. She's absolutely normal. And she talks a little too much but she's normal. So that really doesn't embarrass me. 33:31	I thought as he talked that he previously said he wasn’t embarrassed of his wife then it seemed like he was and now he says he is not embarrassed of her because she acts normal. So I guess there would be nothing to be embarrassed of…	He is not embarrassed of his wife when she acts normal He can still have a social life with others when his wife acts normal	11
know the other two couples that we go out to dinner with, I think the last time we actually just went to (friend) house because	I think this was his way of conveying to me he might not have it as bad as another person and that his wife is not to that point yet…so he is not	His friend’s wife behavior is more embarrassing than his wife’s behavior in public. He understands his friend’s predicament with his wife’s behavior He is empathetic to his friend’s	11

his wife likes-- just constantly will be getting up and going to the bathroom. (Friend's) husband would get up, he'll start banging the table [know is?] that, so they get a little embarrassed about it if you go into a place and it's crowded. T 33:31	worried about being embarrassed by hen public.	situation with his wife's behavior due to FTD	
Maybe coming here is a little bit of a relief because I'm kind of away from (spouse). I know she's at the day center, and she's being well taken care of there. So I like to come in because it challenges me here, kind of stimulates my brain. 35:07	His response to me asking him about how it affects his work. He just seemed matter of fact	He gets relief going to work and getting away from his wife He feels free when he goes to work He is independent when he goes to work	5
The only thing I sometimes-- I get very, very busy, and if I'm walking in the door at 9:30, then I kind of work through my lunch hour, then I'll probably stay here say to 6:00 to 6:30, and then I may not even finish something, so I come home, and it's like, “Nah. I'm not even going to turn on my computer,” and stuff. 35:07	He seemed to be honest in his account of what work does for his own mental and emotional health	He gets lost in his work He is independent in his work environment His role has changed	5
So I think, workwise, even trying to destress with being here, it definitely has affected me because, emotionally, sometimes, I'm drained. 35:07	I could feel how tired he was by the inflection in his voice and the way he gestured	He is emotionally drained His life has changed drastically He is personally impacted	5
Especially if going in on a Monday from a weekend, if I'm really by myself routine, I'm tired of a Monday. And I also noticed that I used to go to the health club during the week,	His life has definitely changed in regard to his own health and wellness. He seemed a bit dejected as he was talking about it all	He is tired His own mental health and wellness is no longer a priority His life has changed drastically His independence has decreased as his wife's dependence has increased	5

get up 5:30, quarter to 6:00 - It's right on my corner, so it's two minutes away - go, do cross trainer, do a spin class, and now, I get there on the weekends, I'll do a class on a Saturday or on a Sunday, but I can't get to that during the week. It just seems-- I always think that I don't have enough time. 35:07			
So I think not exercising during the week is a little bit of a stressor. I probably put on some weight, too. The fact is that I'm out of a routine, so that definitely has affected me. 35:07	He was just saying again that he is definitely affected by being the primary caregiver for his wife. His own physical, mental, and emotional health is less than before.	He is not exercising as much which is causing more stress He is out of his independent health routine He has personally been impacted by his role as primary caregiver	2
That's why you say about caregivers if you really don't take the time for yourself, caregivers usually die before their people who are-- or get sick because of the stress, before their loved ones, who have whatever particular disorder, get worse and stuff. 37:23	His response to me asking him about his own health as a caregiver. I could tell he knew it cognitively but he felt compelled to continue to put his wife's needs first	He is putting his wife's health needs before his own health needs His is less independent as his wife becomes more dependent His life has changed drastically	2
Or our support group leader constantly is harping at us is that you got to take care of yourself, because you're going to get all stressed out and then, all of a sudden this pops up on you and that pops up, and it's true. It's really, really true. 37:23	I just listened to him tell me why it is so important to take care of himself as a caregiver. I agreed with what he had to say	He knows he has to take care of himself as a caregiver His role has drastically changed	2
That's a tough question. I mean (spouse), she's got a psychiatrist that we go to once a month. We kind of just tell her how she's doing. It's probably more medication management at this point. People at	In response to my question of what would he have liked the doctors to do better, more, less…	His wife sees doctors for medication management His wife is part of a study He is content with how the doctors have handled his wife	10

(hospital) are great because that's part of the research studies that she's in, so we go to the (hospital) 38:22			
I deal with the AFTD, so it's just that they give me their support. My church, twice a year, they do a caregiver breakfast which I go to. But even my primary care physician, who's my wife's primary care physician, you just talk. Basically, you can kind of sit there and talk how you're doing, you don't try to-- make sure your blood pressure doesn't go up. I'm trying to take care of myself and stuff. So I mean they're supportive, but sometimes they really don't know what to do. You, unfortunately, can't prescribe a magic pill. So they understand probably, what I'm going through and some other patients are going through, and they're there if I need them, but basically, it's more just being there, talking, or-- I've known my primary care physician very, very well for a long time, and we talk all the time, so I'll always be asking. And even clients who know, family knows and stuff, that always kind of reaching out and seeing how things are going. 38:22	He was explaining to me that the doctors really don't give support because there is not much they can to help with this disease. he was telling me that it's the AFTD, his church that he gets support from. Although he did mention that his PCP allows him to talk for his 15 min at an appointment.	He feels as supported by his wife's doctors as he can with what little they can do He feels listened to by his PCP He feels supported by his connections at the AFTD He feels supported by his church	10
So I think what I just need to do… So, every once in a while, when I do these trips with the firm, I took (spouse) a couple times, and it was just a disaster her being in a hotel and then me	He was talking about needing respite care for himself but he tied it to going away for work instead of just going away for pleasure and a break. I felt that maybe he needed to go away more often for	He needs time away alone, without his wife He needs respite care from being a caregiver He needs support from family members to take time away from his wife	2 10

being in a conference room someplace and then not knowing what she's doing was too stressful. So, I just talked to my sister-in-law, I talked to my daughter, my son, and I said, “Listen.” I go, “I need to go by myself,” and I said, “Somehow we'll just have (spouse) covered,” and the last time I had to go [for that?], and they had her covered. So that started to work, and I had to kind of almost give in to some taking (spouse) with me because I had no other choice, and then I said, “You know what--” I just needed some help, so then I give them enough time, and I say, “Listen, this is two days I'm going to be gone, and then we all figure it out,” so. 40:08	the sake of everyone’s mental health.		
Yep. Yeah. As long as I give them the time frame and-- we even used to-- before my wife went to the day center five days a week, she was going two days a week, and then I had, well, an aide come in who was a family friend and lives in the next town, so she would come in and stuff. So now that we've flipped to five days a week, the aide, even though she's working someplace else, she is always available, so if I really get into a bind where my son is not going to be home, I have to go to work, and (spouse) happens to be home because the day center's closed, I could call her	He continued to say that he knows he needs some time away and was letting me know exactly how he manages it with help and support from family and other folks. And he realizes that he needs help even though his wife goes to an adult day center 5 days a week now.	He needs family support to help with his wife’s caregiving He has a support system He is ok asking for help His life has changed drastically	10

up and say, "Hey, can you and your daughter come and just have a sit with (spouse)? So at least there's usually some options out there. 41:31			
I think it's already there. They're just a phone call away. 42:39	This was his response to me asking about friends who might help out. It was an instant, immediate response which seemed like he really appreciated his friends.	He has friends He has a support system of friends	10
If my neighbors across the street that we get together with four times a year, five times a year. Just go out maybe for dinner and is usually-- he works from home and stuff so if there's a situation where maybe I'm not sure something's going on in the house, I can call them up. They'll just run over there. So all the neighbors around-- they all know. 42:39	It felt like he knew he had a community of friends and neighbors that would spring into action if he called and needed help. Even hearing him talk about it, I could feel his worry and concern if he had to call on them to help with his wife.	He has neighbors that will help He has a supportive community His life has changed drastically	10
Fortunately, (spouse) doesn't wander. She doesn't walk out the door and just [inaudible]. But they're always kind of watching the house. And then (spouse)'s not really home until three o'clock, so at least I don't have to worry about her being in the house by herself. Yeah. It's just maybe an hour window, hour and a half window, so. But, yeah. They've been great. Even saw neighbors a pasta dinner at the church on Friday and they-- she was asking me how (spouse) was doing and stuff. 42:39	He was justifying why his wife is at home by herself sometimes given what her disease and prognosis is… I felt bad for him that he feels perhaps judged.	He has a support system He has become more dependent on others as his wife has become dependent on him for her care His independence has become less as his wife has become more dependent on him His life has drastically changed	10
And they always say, "My God. You're going	As he was telling me what his friends, neighbors, and	He is doing the best he can He knows others recognize how difficult his	7

to go to heaven," or "You deserve a medal for what you're going through here," and stuff. I kind of feel is big because I say-- they see I'm doing the best I can. 42:39	acquaintances say about him having almost saint status based on how he tries to take care of his wife, it seemed to me he needed that reassurance because this level of caregiving is all new to him.	situation is His life has changed drastically He is personally impacted	
And everybody's got family members getting sick, parents getting sick, kids getting-- I mean, everybody goes through their crisis period and stuff. And hopefully, it gets resolved and everything goes back to normal 44:04	As he acknowledged that most people have their own share of sick parents, and other family members getting sick most folks have the crisis period and then it goes back to normal pretty quickly. I was thinking about my own family and he was right.	He knows illness is part of life His wife will never get better Every day is harder than the last	12
I guess my biggest fear, which is probably the one you're questioning, is all right, things have plateaued. I'm dealing with what I'm dealing with. In a lot of routine, lot of repetition. But then I see what my support group members are going through right now and it's just saying, "You know what? She's probably going to be there. At some point this thing's going to progress." Could be five years from-- nobody knows, right? 44:04	He seemed to nervously laugh as he was saying what might be coming down the road very quickly. I just listened because I didn't have anything to add or any way to ease what he was saying. It was all true.	He is scared He is alone in his life journey His wife is going to get worse His wife will become more dependent on him He will become less independent His life will continue to change drastically	12
But it's almost kind of like, wow. How am I going to-- that's a whole different plateau with what they're going through, so. I always get a little thinking out there. They start saying assisted living, nursing home. And I just don't know. I say that kind of gets you scared a little bit. And try to get out of that thinking. Because I say, "It's not today. It's not	He was getting teary eyed as he was telling me what might be coming down the road soon. I could feel myself getting emotional too. Feelings are contagious	He is scared His wife will get worse His wife will never get better He lives day to day His life has drastically changed He gets less independent as his wife gets more dependent on him	12

tomorrow." I say, "Guess we'll deal with it when we have to deal with it." 44:04			
Yeah. And that's why I say, now this is not doing me any good. Even though they tell you you always got to be prepared, especially if a disease all of a suddenly start to progress. 45:20	I was commenting that it must cause anxiety to think about when things start to progress with his wife's disease. I could feel his anxiety at just describing it to me.	He doesn't like to think about his wife getting worse He is scared He is lonely He is alone in his relationship	12
And sometimes it could-- I've seen it already in other people where it progressed almost rapidly. And don't get caught short where all of a suddenly you're in the situation where, oh my gosh. You need assisted living. And you haven't even started the process. And then you find out it's a year and a half wait. Or two years to get into a place. Sometimes I think about that. 45:20	I just listened as he continued to tell me what he thinks about regarding the progression of his wife's disease and dependence on him for care.	He is scared He doesn't want to think about his wife getting worse He is less independent as his wife becomes more dependent on him His life has changed drastically	7
And then you say, no she's really been the same. It's not progressing. And then you kind of go back and say, well, I don't have to deal with it today. I'll deal with it tomorrow. But it's kind of just-- definitely out there where all a sudden I start thinking about what would I do though? 45:20	It seemed to really cause him great stress to even talk about his wife getting worse…almost like if he spoke it, it would happen	He is living in the present He is in denial He is scared His life has changed drastically	8
When they do the cognitive testing, there's a whole caregiver questionnaire I got to go through every time. And that's one of the questions about do you feel you'll be able to handle the caregiving three years from now or two years	I couldn't help but try and put myself in his shoes when a medical professional is asking him if he is ready for what will come in the next two years? I felt trapped in that thought.	He is scared He lives in the present for self -preservation He is less independent His wife will become more dependent His life has changed drastically	7

from now? It's a hard question to answer. 45:20			
That's right. And plus I said two years from here I'm going to be 64, could be retired in two years. We're kind of talking about downsizing, get out of a house because I got to do everything basically. And they said, "You're getting into a townhouse, you don't really have to do anything that was kind of done for you." Two years, maybe three years, kind of thinking that that way. And I guess getting older, your energy level is less. Thinking that I was doing this at 40 is a lot different than doing it at 64. That kind of adds to it, it's just that you don't have the energy to do some of the stuff that they have to do. 46:46		He will be retired in 2 years He doesn't have the energy he once did He doesn't know what 2 years will look like	5
So she was, let's see, 2015, so 58 and I was 60. [inaudible] able to get this summertime. So she was 50. she's going to be 62. So, yeah, 50. Yeah. Well, FPDs early onset, you're [inaudible] 65, 40 to 65 age group. 47:41	He was answering my question of when/how old he and his wife were when she was diagnosed	His wife was diagnosed at age 58 He was 60 when his wife was diagnosed His life has changed drastically in 2 years	N/A
As I say, you go back and you start the money thing, definitely the OCD behavior. Trying to think some of the other things that she-- not being honest. There's probably a couple of things as I slip in my mind, but then there was a few things in that five or six year window said that,	I just listened quietly as he tried to remember when they first started to notice when his wife started to show symptoms.	He noticed his wife's OCD symptoms with money His wife was symptomatic 5-6 years before she was diagnosed He noticed his wife had changed in small ways before she was diagnosed	6

"Yeah. She did little weird things. But just not enough just to say like, "[We have?] this major problem." 48:19			
We all think the trigger was when her mom died, very peacefully in her apartment in October, 2014. And we went up there and my father died 10 years before that. So [inaudible] 15 years before that. So after my mother died [inaudible] that we had them move everything out of the apartment. So I think (spouse) was very busy because she was not being [inaudible] and stuff. She was kind of like always an that caregiver mode and, yeah, every week, every other week we would go up there and burger down to our house and stuff until that last couple of years. But my sister lived a little closer. So she was probably over there more dealing with the professional caregivers. And I think after my mother died, (spouse) never filled that void and [inaudible], right? Because she was home, she wasn't working. 48:19	I just listened quietly as he tried to remember when they first started to notice when his wife started to show symptoms.	His wife as a caregiver for the last 15 years prior to her diagnosis He needs to explain why his wife is sick His life has changed drastically	N/A
And so we started noticing maybe December, January, and she was home. We found that she was abusing antihistamines, she was just taking anti-histamine made absolutely no sense, right? We would just find a little stashes of these things. And then she was like doing	I was thinking to myself I couldn't imagine having a life partner all of the sudden start to exhibit these types of behaviors.	He is worried He was scared His life has changed drastically His wife is dependent on him	6

other weird things again about just going through the door with no clothes on and confusion. She'll go in the kitchen, you can see there's all this confusion. 49:59			
So we went to one neurologist that I did basically said, “This guy doesn't always talking about.” And we went to her psychiatrist and, and (spouse) was on all these meds. Her doctor said, “We got to get her off of this stuff.” She'll go the doctors, but nobody was talking to each other. So this one is prescribing, that one is prescribing. And so my psychiatrist kind of said, “We've got to get rid of these meds, she should only be on this stuff.” And then we put her into the carrier, which is a carrier clinic in (city) for just kind of like a break. I never know what you need to detox from the anti-histamines, but they put her on a mood stabilizer. And as she kind of came home and we still noticed there was this confusion and we're thinking Alzheimer's, right? Because we're her parents. I found a doctor neurologist that specializes in Alzheimer's. So we went there and we kind of told him what she was doing and stuff. So he did cognitive testing. They did the pet scan, they did a spinal tap and they basically ruled out Alzheimer's	The lack of direction and urgency in the medical community was in direct contrast to his sense of crisis and the chaos he was experiencing at home with his wife. I know in my own experience what it feels like to see many different doctors and get different opinions about medications and diagnoses but no real help or relief.	He was desperate to find help His wife didn’t have Alzheimer’s. He took his wife to many health care providers to find the correct diagnosis	6

because I guess there are certain proteins that are associated with that.			
So he said sometimes you have depression, there's something called pseudodementia. Where I guess it's a form of depression, but it's almost like you have Alzheimer's and stuff. So he just said, based on everything we're talking about and then the behavior changes and stuff, that's the first time I ever heard of FTD and that's when we got the diagnosis. And since then we've been working with the doctors in UK. And they did another pet scan and they do MRIs and stuff. And they definitely see in the frontal lobe, that's in two areas. One is reasoning and the other one is I guess eating, and they see definitely there's a decreased activity in those two areas. And they said exactly what she's going through with these behaviors like overeating, doing reputation and stuff. They say those are the two areas that kind of control. So like I say, this makes sense why we're seeing this with the MRI. Doesn't have [inaudible] protein buildup, which is one of the big things. But they said there's five proteins that has been associated with this though, one of them probably kind of got out of control. . 51:56	How he described how they got his wife's diagnosis seemed anticlimactic and not very scientific.	His wife was diagnosed with FTD based on her behavioral symptoms His wife's diagnosis was confirmed by an MRI and pet scan His wife's over eating behavior and lack of reasoning were the areas being affected in the frontal lobe based on imaging tests His wife's MRI didn't show protein buildup as it would if Alzheimer's was the cause	6
But yeah, I guess the other thing too was	It seemed like not only was his wife finally	His wife's FTD was probably present 5 to 6 years before she was diagnosed	6

when that five, six-year period, she [inaudible] was complaining about being in pain. So she'll go to a pain specialist. Given these symptoms and going for tasks, putting the oxycodone or something. Yeah. And I know which was not good. 51:56	diagnosed with FTD but she was also have a lot of other things going on such as chronic pain. To complicate matters, she was put on opiates which seemed questionable in my mind. Why would doctors do that? Wouldn't that complicate things?	His wife was in physical pain His wife was prescribed opiates for pain	
And when she started realizing she was going to an orthopedic, she was going to a rheumatologist, she was-- and it was all these doctors, oh boy, prescribing stuff. And I said to her, I said, "You know why," I go-- at that time she weighed maybe about 260, 265. And I said, "You know what? You're just carrying a lot of weight." And then after her mom died she all of a sudden dropped to 195. It was like she just kind of stopped eating. And all of a sudden all the aches and pains went away. I said, "Wow. How about that?" Right? And then within six months a swing back up when actually she was 270, so. We have these swings. So I even think that back then besides spending money and stuff it was-- she also had the thing where she was constantly thinking that there was something wrong with her. She thought she had cancer. She was telling everybody she's got cancer. I was like, "Don't [inaudible] you've got cancer, okay?" And so that was another thing that was	He seemed to be frustrated with his wife's obsession with food and at the amount of weight she had gained since being diagnosed. It seemed he was again trying to reason with his wife in the past when she probably wasn't able to reason as well anymore.	He realized his wife was going to many different doctors for pain He thought her weight gain was causing a lot of her issues He noticed weight fluctuations with his in the past and now thinks it was the beginning of the disease. His wife became paranoid there was something wrong with her 5-6 years before she was diagnosed. (maybe she was correct)	6

kind of crazy during that five- or six-year period of time. 53:65			
Oh, she went to a lot of doctors just because she had all of these [clinical?] ailments going on. We found this doctor, he was out of (city) and that was over at (university). So he's the one who gave us the diagnosis. At that time there was no research studies into FTD. Everything was Alzheimer's. And then I found the AFTD, found the support group. And it was the AFTD that told me about this research study that was going on from (university clinic). And that (university clinic) was one of the sites, also (university clinic). So it took a long time but we finally got into the research [inaudible](university clinic). And they've been taking great care of her. Taking great care of her. So now we're just locked into (university clinic). (doctor) there and staff is great and we're going to go see him again in March and stuff, so. And she's just finishing up a pharmaceutical company study, which is cognitive testing every month. They're just trying to get a baseline when someone's been diagnosed with early-stage FTD. And I see no-- [inaudible] testing is good. It stimulates the brain. Because her psychiatrist is always saying, “You've got to		Getting the correct diagnosis took a long time His wife eventually had great doctors His wife gets brain testing though a clinical study once a month currently	6

stimulate the brain.” So that's why I say doing the testing once a month is not the worst thing in the world. 54:46			
Well, I think one of the important things is-- your spouse has something going on - like I said, (spouse) had something going on - is get the right diagnosis 56:34	I asked him about something he would to say additionally to someone in his caregiving shoes. He was very adamant about getting the right diagnosis	He advises get the right diagnosis His wife was not accurately diagnosed in the beginning He felt lost	6
Because people coming to our support group where a doctor would say, “You've got FTD.” But don't run any tests, right? And then they find out she's got a brain tumor or something like that. So I think it's to get the right diagnosis. “What are we dealing with?” Right? And then learn as much as you can about it. I just read so much about FTD and so I said, “Okay. I think I've got an understanding.” 56:34	He was emphasizing that ruling out other diagnoses was imperative in determining if FTD is the correct diagnosis.	Education is key to understanding what FTD is He needed to understand the disease He needed tests to be done to make sure FTD was his wife’s diagnosis	6
And then find an organization like [inaudible] and AFTD. They're there to help. Get into a support group and stuff. 56:34	He really seemed to appreciate the FTD support group especially in the beginning.	He needed the FTD support group He was supported He was not alone	10
I always say selectively I would bring people into the inner circle with (spouse)'s diagnosis on a need-to-know basis. So I've said like, “ I don't want to tell the world that my wife's got FTD because nobody even knows what it is. 56:34	As I was listening I got why he would only want certain people in his inner circle but it could also backfire I would imagine.	He needed to be protective of himself and his wife He only wanted certain people to know about his wife’s diagnosis Nobody knows what FTD is	11
But tell family members and just that this is going to be a process. Things might be doing okay now but it may not be a month		He needed family support He needed to communicate his wife will not get better His life drastically changed	11

from now, two months from now. 56:34			
And the last thing is, I mentioned before, try to find time for yourself. Because you got to decompress, basically. Even though it's really, really hard. Decompress and try to find just whatever works. Some time for yourself. 56:34	He appeared exhausted and a bit sad as he said self-care is so important	He needs to decompress He needs time to himself He needs to be independent He is exhausted His life has drastically changed	2
Yeah. It's trying to get up, having the cup of coffee, and just kind of relax a little bit. It could be even at night if (spouse)'s upstairs watching TV until she comes down for the snacks. But I can be watching TV downstairs and she's watching it upstairs. And again, it's kind of like quiet time. And then if I get to the gym and I do a spin class for an hour that's nice. You can sit in the whirlpool, take a shower there, that makes me feel really, really good. There's probably other things I can try to do. Sometimes I'll pick up a book and start reading but then I don't finish it. Then I just kind of put it down. We did a lot of stuff around the house maybe in the last couple months though so kind of it was really in sync with trying to get the stuff done. End of the day it was good that it got done. Throw a lot of that old stuff out. But, it was also not fun stuff. So it's almost you're exhausted because that's all I'm doing is filling trash bags and stuff like that.	More about self-care. I just listened as he kept telling me how important it was. I wondered if he really took as much time for himself as he was saying he did/does?	He needs self-care He has coffee time by himself in the mornings He watches tv by himself He gets to the gym by himself He reads by himself, but never finishes the book He is lonely He needs space He needs to be independent He is depended on His life has changed drastically He is exhausted He has to schedule time to practice self-care He tries to get minutes here and there in while taking care of his wife on a daily basis He is not a priority His wife is his top priority His life has changed drastically	4 2

Yeah, I got to find other things too to do because I just don't think it's enough. I got to really just try and pick a day, say Tuesday. And get up and maybe go to the health club, do 20 minutes on the cross trainer, maybe shower there so when I come home and let's say it's quarter to 7:00, 10 to 7:00. I'm already showered. I just have to get dressed. So I don't have to think about, and let's say it's quarter to 7:00, 10 to 7:00. I'm already showered. I just have to get dressed. So I don't have to think about, "Okay, (spouse)'s got to go in the shower. And I've got to go in the shower." And then maybe I can get her to the day set up earlier. And then I can kind of get here earlier and start my day earlier. So that's why I said I've got just do it once and say, "Hey, I can do it." Then I can maybe do it twice a week and during the week. I'm always constantly trying to retool what I can do for myself. 58:23			
When you first get the diagnosis. You always ask that question, first try and digest what it is you're dealing with. And then, you always ask that question like, "What's the life expectancy?" 1:13:00	As we were finishing up the interview it seemed as if he didn't want it to end. I got the sense that for once someone was asking about what this disease had done to him not just to his wife. Afterall he is part of the "we" he is and "I" of the "we." Although lately he is more of the "we" of the "we."	He wanted to know if his wife was going to die from her diagnosis He needed to know how long his wife had to live He was scared to hear the diagnosis His life changed drastically with his wife's diagnosis of FTD	12

Appendix F

Participant D Analysis and Coding

Participant D Statement	*My observation during interview/reviewing interview*	*What is the meaning of the statement*	*Theme Code*
I think the main things it affected was, as the time went on, from the beginning, it started-- [first things were strange?] in August of 2005 and then she died in 2015. :52	I asked how being his wife's primary caregiver has impacted their relationship.	His wife was diagnosed in 2005 and died in 2015.	5
Probably the most noticeable things were, as the time went on, less and less responsiveness. :52	In the first minute he seemed to be very matter of fact but caring.	His wife was less and less responsive as time went on.	8
In the last several years, the thing I found most troubling was the not talking. [inaudible] the habit of having interesting and lengthy discussions about all kinds of things as we were doing things. :52		Not being able to talk with his wife was the most troubling for him.	1
And at first there would be maybe a little recognition, a blink or a nod or sometimes a few words, :52	This was a phone interview, so I was listening quietly.	His wife used to blink or nod or use a few words to talk with him.	1
but then words gradually stopped, to the point where there was no conversation whatsoever. :52	Hearing this I felt sad for them both.	His wife was unable to speak anymore and then there was no conversation at all.	8
So that's difficult to adjust to when you're used to having pleasant and lively discussions :52		He found it hard to adjust to not having pleasant and lively discussions with his wife anymore.	1
I first started noticing strange things in around 2005. I noticed a few things like - what'd they call it now - low-quality decisions 2:19		He first noticed low quality decisions his wife was making in 2005.	6
And it was just a few incidents and I started keeping a daily log and kept track, 2:19	I thought he was so smart to start keep a journal of how his wife was behaving. I don't know that most people would do that.	He started keeping a daily log of his wife's behaviors.	4
then I first shared that with a primary care doctor who immediately sent us to (hospital), medical school, memory clinic 2:19		He shared the log with their primary care doctor who sent them to Georgetown Hospital Medical School Memory Clinic	6

And things were still functioning well enough for several years after that. 2:19	It is great that they sought out help early but then just kept living every day.	His wife continued to function well enough for several years after the first memory clinic appointment.	N/A
We would carry on pretty much your normal activities, just that once in a while something strange might happen, or unusual decision made, 2:19	I couldn't imagine having a spouse diagnosed with some kind of cognitive disorder and then going on with everyday life. It sounded like so far, he did a good job of that.	He and his wife continued on with their normal activities with something strange or unusual decisions being made once in a while.	4
I just had to start being more careful to watch out. 2:19		He was more careful and watched out for his wife.	5
I would say that that went on for four or five years before things got to the point where we had to change a lot of the normal activities. 2:19	I thought that 4 or 5 years was really a gift knowing how a lot of people diagnosed with FTD progress rather quickly.	He and his wife had 4 or 5 years after her initial diagnosis of living normally as they always had.	4
She was born 1939, so that would've been, what, 65, 66, [inaudible] like that. I'm just two years older. I'm 81 now this year. 3:39 She died when she was 75. 3:57	I had asked how old she was when she was diagnosed.	He was 77 years old and his wife was 65 years old when she was diagnosed. His wife died when she was 75 years old.	N/A
Well, once we had the diagnosis, I mean some various brain scans, PET scans, MRIs and that, I mean we knew it was a real issue. 4:17	I asked him about his emotional connectedness since his wife's diagnosis.	He knew he and his wife had a real issue after the results of his wife's PET scans and MRIs.	6
It wasn't just a change in habits or attitudes 4:17		It was more to him than just a change in habits or attitudes.	8
I tried as much as possible the whole time to keep things as normal as possible 4:17	I found this very interesting. I was wondering what he meant. But I just kept listening quietly.	He tried as much as possible, to keep things as normal as possible.	8
Everything was always pretty--the household was always very calm and orderly and disciplined and that. 4:17		He and his wife had always had a calm, orderly, and disciplined household.	4
And as much as possible, I tried to keep things normal. 4:17		He tried to keep things as normal as possible.	8
And for a few years, we were still able to do our social and recreational things and some travel. 4:17	I really think it was great that they continued to enjoy themselves. And that he had the time and resources to do that for them as a couple.	He and his wife were still social and participated in recreational activities including some travel.	1
And then gradually, that became more and more complicated 4:17		Gradually it became more and more complicated to continue to socialize, participate in recreational activities, and travel for them as a couple.	1
But even right up to the end, I always tried to keep the normal	It became clear that it was beyond important to him that	It was important for him right up to the end, that he	8

life pattern, even when it came-- it wasn't clear whether she was responding to this or recognized it or anything like that 4:17	he keep things “normal” as they were and had always been before his wife was diagnosed with FTD. He was really stressing that point. I wondered if someone from the medical community had suggested that to him?	kept their normal life pattern whether she was responding to it or not.	
I mean, for example, we always went once a week on Thursday to-- as she had always done and went and had her hair done properly. And then it was a nice place next door to go for lunch and that. And that was true right up to within the last year she was in the hospital and rehab and then in hospice 4:17	I thought this was so sweet and spoke volumes about how much he loved and respected her.	He continued to take her for her hair appointment every Thursday and then to lunch right up until she was in hospice in her last year.	4
So things like that that just-- I never could tell whether she recognized or responded, liked or didn't like 4:17	It seemed to me he was erring on the side of caution. He was hoping that she still enjoyed getting her hair done and looking nice. I wondered how it made him feel to do this for her still?	He never knew if she recognized or even like or didn’t like having her hair done every week as she had always done before.	8
There was just no, at least the last few years, no emotional reaction or no indication. 4:17	This must have been so hard to live with for 10 years or at least the last 6 years.	He didn’t get any emotional reaction or indication from his wife about anything in the last few years of her life.	1
So, in a sense, it was going through the motions and saying, “Well, I don't know whether it makes any difference or not. But it doesn't cost me anything to spend a little time that way.” 4:17	Even though he wasn’t sure what his wife recognized or not, in his mind it was little cost to him to continue to try.	He didn’t know whether it made a difference or not but he felt it didn’t cost him anything to do those things for his wife.	8
And the same thing, like on any of the holidays, birthdays and stuff like that. 6:29		He tried to keep holidays and birthdays the same way as before she was diagnosed.	8
I always make a formal dinner and set flowers in the dining room because that's what-- she was an extraordinary cook and always would make very special formal dinners for any of the special occasions. 6:29		He continued to make formal dinners and set flowers for special birthday and holiday dinners just as she had always done for them.	1
So, I kept that up, again, just in a way going through the motions. 6:29		He kept going through the motions	8
But it seemed to-- she was always very calm and there was never any anxiety, wasn't any striking out or anything. 6:29		His wife was always calm, never anxious, and never had any striking out behaviors.	N/A

But that was true even over all the time. She was always very disciplined and calm and we never had very-- we've never really had emotional kinds of things and arguments and stuff like that. 6:29	It seemed that his attempt was to keep thing the same as before and remain calm as it had always been before the diagnosis.	He and his wife were always calm and disciplined and rarely had emotional arguments.	1
So the home environment was kept peaceful and calm. 6:29		Their home was always peaceful and calm.	1
And then when she got sick, [there was?] little emotional reaction to anything 6:29		As his wife's disease progressed, she had little emotional reaction to anything.	1
There were a few things I could see would bring a little pleasure 6:29		He could see a few things would bring his wife some pleasure	1
But otherwise, you can't really tell whether the person is recognizing what's going on or liking or [inaudible], but there was no resistance or anything like that. 6:29		He really couldn't tell if his wife was enjoying anything but there wasn't any resistance either.	8
Another thing I discovered that we did was that we had a keyboard that you didn't have to play the songs yourself. Push in the number and it plays songs. And I printed out the words to the songs and so we do singalong every day. 6:29	I thought this was a very lovely thing he did for his wife too. He was really trying to preserve their life. It was almost trying too much. I don't know why I feel that way?	He had a singalong every day for his wife with their keyboard as they had done in the past	4
The caretaker we had for many years that we [inaudible] during the week, we do the same thing. So there was certain routines like that 6:29		He still had the house caretaker come in during the week.	4
And then for several years she went two days a week to an adult day program, which was really wonderful, stimulating and activities and things like that. 8:41	I thought this was a great idea not only for his wife but for him to get a bit of time for himself as well.	His wife went to an adult day center 2 days a week that was stimulating for her.	4 10
So that was kind of the routine that we developed, I would say in that last two, three years, three, four years. 8:41		Their routine was the same for the last several years of his wife's life.	4
We didn't go traveling anymore 8:41	When he said this, I felt an immense amount of sadness for him. I am not sure exactly what I was picking up on from him.	He and his wife did not travel together the last several years of her life.	1
We'd always done a great deal of traveling. Both of us had work traveled as well. [inaudible] would travel well.		They had always traveled a great deal together in the past. He and his wife used to do a lot of skiing and sailing together.	1

8:41 We did a lot of skiing and sailing and stuff like that 8:41			
I would say - I have detailed notes, I can always check - but three or four years where those things just were not either safe or possible 8:41		For the last several years of his wife's life, it was unsafe or impossible to ski or sail for them.	1
I kept very detailed notes. I almost kept a daily log so I could remember what was changing. 8:41	Again, I was really impressed that he kept a daily journal about all the changes that were going on.	He kept a daily log of detailed notes to remember what was changing with his wife.	6
And I was surprised when I showed those to the doctors, those notes. I think that was more important than what their tests were showing 8:41 But that helped big time to see what was changing or what needed more attention or what	Since most FTD is diagnosed based on symptoms and patient/family report it only makes sense that his daily log was so vital to getting a diagnosis from the doctors.	His daily journal of detailed notes proved to be more important to his wife's disease than the tests the doctors were running.	6
Everything was pretty orderly and calm. 8:41		Everything was fairly orderly and calm with he and his wife over the course of her disease progression.	4
We did have a caretaker every day. It worked out very, very well. The caretaker would take her to the day program and help her with everything 8:41	I thought it was so wise that he hired a caretaker on a daily basis. I also thought how lucky they were to be able to afford a daily caretaker.	He hired a caretaker that came to the house every day and would also take his wife to the adult day program.	10
So, my time was pretty much free. 8:41	While he had "free" time, I am sure he was still weighed down by what was happening to his wife and them as a couple. That at least is what I assumed was happening. I just continued to listen quietly.	He had time to himself on a daily basis.	2
I was still doing quite a bit of work independently in projects. And I had some travel, maybe once a month or so, and sometimes for a week or so if I went to [inaudible] for something. 8:41	It was interesting to me that he continued to keep a sense of independence within the relationship with his wife. He didn't necessarily take on the "we" for both he and his wife. He was still an "I" within the relationship.	He was still working from home doing independent projects and traveling a little every month for those projects.	5
And I kept all of that up so that-- I kept my routine, as little change as possible. 8:41	He was literally keeping everything as "normal and the same" as possible for himself.	He kept his routine and had as little change as possible.	4
And her regular life was the same except that she was no longer working 8:41	He was literally keeping everything as "normal and the same" as possible for his wife.	His wife's life was the same except she was no longer working.	4 8
I think where we were starting from is that the environment in the household was always very peaceful and calm and not all	I was trying to really understand how calm and peaceful he and his wife had always been with each other. That is a foreign concept to me	He and his wife always had a peaceful, calm, and emotionally even relationship and household.	1

too emotional or anything anyway. 11:06	because while I have periods of calm in my relationship with my husband, we are definitely emotional at times whether happy, mad or sad with each other or at each other.		
She was on faculty at (university) until she retired and then for a year or so was working as a certified financial planner, which was related to her work. 11:06		His wife was a professor and then worked briefly as a financial planner	N/A
So, it was a case of probably being more orderly and disciplined than average people. 11:06	This might be true.	He thought that his wife was more orderly and disciplined	N/A
And otherwise, I'm not sure where I got too emotionally involved 11:56	I am not sure that this statement will hold true. I continued to listen quietly.	He doesn't think was too emotionally involved more so once his wife was diagnosed with FTD	8
These were all little projects to be solved and things like that. And I had some thoughts more recently and I wonder-- and I thought I would answer to this. I just wondered whether what I had done was sort of compartmentalized and block out any emotional reaction to the point you're getting your emotions a little. 11:56	He has now said what I was thinking since he first started talking during this interview. From an outside viewpoint it does appear that this might have very well happened.	He wondered if what he had done was to compartmentalize and block out any emotional reaction to what was happening to his wife.	8
But I never felt really-- certainly never angry about any of this, never frustrated, or anything like that. 11:56		He never felt angry or frustrated about anything that was happening	5
I was just, "Okay, this is the way things are. 11:56	It seems that he saw this as more of a small shift in their lives	He chose to see things as just the way things were now	5
And we make some little changes to make the house better for living with some safety things," 11:56		He made little changes around the house for the safety of his wife	4
some of the routines we did, we're trying to always not stop doing things that we had done that were pleasant and pleasurable. 11:56		He and his wife kept their routines of doing things that were pleasant and pleasurable as they always did.	8
And I think that worked pretty well. 11:56	Again, it worked well from his perspective. I wonder if it helped him in his grieving of the loss of his wife as he once knew her?	He thinks keeping similar routines as always worked pretty well for them.	NA

We'd go to music concerts quite often 11:56		He and his wife still would go to music concerts often	4
Pretty near to the end, that was impossible. But there was little, if any, what I would call interaction. 11:56	He was skipping around a bit but I listened quietly because it seemed like some of this he just thought about for the first time ever or at least in a long time.	He and his wife had little interaction like they used to as her disease progressed towards the end	1
Certainly, no talking and discussion and stuff like that. 11:56		He and his wife were not able to carry on talks or discussions like they used to before she got sick	1
I guess that may be typical of FTD that eventually they go mute and become very passive. 11:56	Although it has been a few years since his wife's passing, it seems that just now he is able to understand how it really impacted him.	He knows that it is typical that FTD patients eventually can't speak and become passive.	6
I guess that was a different--the change was that with the disease, that she'd become particularly apathetic and passive, which was in contrast to previous life where she took great pleasure in all of the nice things we did 11:56	It seemed that they truly had a life together full of travel, work, recreation and most importantly, conversations and discussions that were meaningful.	His wife was now apathetic and passive from FTD which was in contrast to their previous life where he and his wife really enjoyed all the great things they did.	1 8
We did a lot of nice things and travels and recreation and social settings. And that always brought great pleasure. 11:56	As he was talking I could imagine some of their sailing trips and I was thinking how wonderful their life before together really was.	He and his wife enjoyed a nice life of travel, recreation, and social settings that always brought them great pleasure.	1
But that either went away completely or it was no longer expressed in any noticeable way. 11:56	It really seems to me that he missed his wife so much and that he was trying to keep things the same so that he didn't feel the loss so much. Truly heart breaking.	His wife was no longer able to express her pleasure in their shared travel, recreation, or social activities anymore towards the end.	8
I'm not sure it really did. 14:45	This was his response to me asking if/how all this impacted him. This was at least the second time I had asked him about how things impacted him and he again said he didn't think it really did.	He wasn't sure if his wife's disease, and her decline really impacted him.	5
That's what I'm saying. I think maybe I just blocked out everything like that 14:45	This was a really profound statement. Because to block things out implies it really did affect him…greatly.	He thinks maybe be blocked everything out that might have impacted him.	8
The main thing being, of course, not having an adult to talk to within the family. 14:45	It seemed to me that his relationship with his wife was very cerebral and conversations, discussions, and debates where so imperative to their being a couple. And it	His wife could no longer talk to him like she had for so long in the past.	1

	seemed that they stuck together and didn't really have many outside friends like they were to one another.		
But, again, I wasn't confined to the house or anything. 14:45	It seemed to me he was making sure that he wasn't implying he had it worse than others. I would disagree. It seems to me he lost quite a great deal to FTD.	He was not confined to the house during his wife's illness.	2
I had quite a bit of external activities with my work. So I had interaction too with companies and people I worked with as well 14:45		He had interactions with people through work.	2
Even when she wasn't able to go on trips, I can still do the trips and be out with other people like them. 14:45		He was still continued to travel for work by himself.	2
So, I wasn't totally isolated 14:45	I disagree with him on this statement. While he was around other people, they paled in comparison to his wife based on his description so far of his relationship with her.	He was not totally isolated.	5
I can imagine some people, depending on their circumstances, would be confined to the home to take care of the sick person. And that would be very, very difficult, not having any interaction with other people 14:45	He did have a point. There are some people who are really disconnected from all others and are truly isolated and alone.	He thought it would be difficult to be a primary caregiver and be confined to the home.	10
Now, I guess we were fortunate because we did have a good caretaker and I worked full time 14:45 But that helped big time to see what was changing or what needed more attention or what	He was still home every day and his wife lived at home most of the 10 years she had FTD He was right. He changed things as little as possible for both he and his wife. He continued to travel for work as needed. And he was free to come and go during the week. He held onto the "I" within the relationship and did not become the "we" only.	He felt fortunate because they had a good caretaker and he was able to continue to work full time. He was free to come and go for work and travel as he had always done.	10
I can't imagine if you're confined to the house 24 hours a day to take care of somebody that, I would think, you would get depressed pretty quickly. 14:45		He couldn't imagine being confined to the house 24/7 to take care of somebody and he imagined that a person would get depressed quickly.	2

Yeah. Without any responses, that kind of just drifted away. 16:44	This was his initial response to me asking about physical affection in their relationship once FTD entered their relationship.	The physical affection between he and his wife drifted away as she became unresponsive.	13
There was no interaction that way in the sense of no feedback in them. 16:44	It must have been so sad when she was no longer to have any emotional connection to him.	He did not feel any sense of emotional connection in the physical interaction with his wife as the disease progressed.	13
So it's not a matter of necessarily not trying, but at most, it would be described as just [inaudible] emotions, not expecting any reaction or response. 16:44	It seemed that he probably did try to connect physically with his wife but in the end he had to expect that there would be no reaction or emotional response.	He tried to be physically affectionate with his wife but he had to know she would not react or respond in an emotional manner.	1 13
And I wasn't uncomfortable with that. I mean, again, it could be a matter of blocking out if something that you wanted wasn't quite there. 16:44	I felt very sad at this statement.	He had gotten used to blocking out his emotions regarding the relationship with his wife pertaining to how she was now emotionally and physically unavailable to him.	8
And just think there was-- in that sense, I think people more prone to this than other people, just compartmentalizing 16:44		He thinks that some people are more prone than others to naturally compartmentalizing.	8
And I had to do it to take care of things, what I think of as projects-to-be. 16:44	This was an interesting way to think about his wife and how her disease had disrupted their full lives together. Now things are seen as projects to be?	He had to compartmentalize to take care of things as projects-to-be	8
So often, and [inaudible], that was in one box and then, perhaps--even in the past, it wasn't what I would call it always intense. 16:44	He was uncomfortable talking about their sex life it seemed and just skimmed around the details. I didn't push him.	He and his wife's sex life was never intense in the past and now it was just in a box.	13
And so it just went along very comfortable, well-controlled faction with lots of variety and stimulus, stuff like that. 16:44		He and his wife did enjoy their physicality and sex life with each other and were very comfortable with each other.	13
So, yeah, things just kind of drifted away. 16:44		He and his wife's sex life drifted away as her disease progressed.	13
I can't think of anything that stands out that really would make a dramatic difference 18:40	This was his initial response as I asked him how his wife's disease and their situation has impacted him personally.	He does not think he has been personally impacted by his wife's diagnosis of FTD	5
I mean, the impact was largely-- control of my time 18:40	He was impacted but he just seemed to be in denial or thought maybe that if he admitted some things he might feel worse?	His time was the thing most impacted	2

and more of my time being devoted to taking care of running the house and to the extra attention needed for taking care of her and her [inaudible] and, obviously, some medical appointments. 18:40		He was spending more time taking care of the house and taking his wife to medical appointments	2
But just some things that were in the past, we wouldn't have had those. We've been out doing things in various--actively involved in all kinds of professional, social, recreational scenes. 18:40	It seemed to me that he and his wife were perfectly matched from every angle. And because of that this must have been exceptionally hard for him to handle and adjust to…the ambiguous loss factor.	He and his wife used to be very involved in professional, social, and recreational scenes	1
So those things were moderated 18:40		He had to adjust to the changes in their social, professional, and recreational activities	1
Even though I tried as much as possible, for myself, to have as few changes as possible and trying to work around so that my life wasn't really dramatically affected, and the same thing for her. 18:40	Again, he is saying that even though he had to make adjustments to their life happenings, he tried really hard to keep things the same. I would imagine that must have taken a ton of energy because the fact of the matter was that everything was in a constant state of change for them over a 10 year period.	He continued to try to have a few changes as possible for himself and his wife even though there were obvious moderations being made.	8
Other than not working anymore, trying to keep everything as normal as possible without making any changes wasn't at home all the time. 18:40		Other than not working anymore, he felt he was keeping everything as normal as possible for his wife at home.	8
So, even until the last couple of years when she's been really sick we went out and did things or what we putz around here. 18:40	He really tried to keep her life full of meaning and how he thought she would want to live if she still had a voice in the matter. It felt dignified but lonely.	He still wanted to and managed to take his wife to outings up until the last couple of years of her life.	4
Yeah. Around about the beginning time, I had retired from my first job. 20:36	The fact that he had already retired from his primary job was probably a factor in how he took care of his wife as he did.	He retired from his first job right around the time his wife was diagnosed with FTD.	5
I worked here in (city) at the government laboratory. It's now called (institution). It was called (institution). 20:36		He worked for the US Government in DC	N/A
And so, as I had planned, I had retired. 20:36	He had already planned to retire and that is what he in fact did. I wonder what they	He had already planned to retire and so he did retire.	5

	had planned for retirement before FTD entered their lives?		
But then, I've kept a very, very active contract project work for companies and government agencies and a lot of work on the technical standards committees and most US and some overseas. 20:36	I wonder if that was the plan in the beginning? I wonder if his wife hadn't gotten sick if he would have continued to work so much on projects?	He continued to keep busy with contract project work for companies and government agencies in the US and abroad.	5
So I was working pretty-- during most of that time, I probably wasn't working like-- I had been 50 or 60 hours a week. 20:36		He was working almost full time but not 50-60 hour weeks as he used to do.	5
But I was certainly working probably not quite full time because I kept time to myself for my recreational things and that-- so that did not really change the whole time. 20:36	Again, he is stressing that nothing really changed that much for him and his routine. When I first talked with him, I thought he was the one participant who really had it together. But not what I reflect on his interview and the transcript, I wonder if it is just the opposite? I feel sad for this participant more now than I did before.	He was not working full time because he left time for recreational things but for the most part nothing really changed for him.	2
I'm still doing a little but I'm having more trouble getting motivated to do technical work now. 20:36	I know his age might play a role in that, but I wonder if it's because his wife has passed and he doesn't have to keep things the same as much for himself anymore? As a means of distraction that things were in fact changing?	He is still doing a little technical work now but finds it more difficult to be motivated by this type of work.	N/A
Well our social life pretty much revolved around our travel and a couple of yacht clubs, and stuff like that, and I still maintain and still do today 22:00	I asked how their/his social life was impacted if at all? This was his initial response. I have to admit, I was a bit transported to sailing on a yacht for a minute.	Their social life revolved around travel and a couple of yacht clubs of which he still maintains membership to this day.	1
I go to their activities at least a couple of times a month and some special things 22:00	It is great to hear that he is not isolated or isolating himself. I feel glad for him.	He still goes to club activities a couple times a month for special events.	N/A
Probably the big difference at least the last five or six years, we no longer went on the week-long ski trips 22:00	They really seemed to have a wonderful life together from an outsider point of view.	The last 5 or 6 years of his wife's life, they no longer were able to go on week-long ski trips.	1
the last one we went would have been maybe 2007, 2008, somewhere [inaudible]. And it had a little problem with getting lost and stuff like that, so it wasn't something we could readily do. 22:00	I wondered how the "in your face" changes affected his need to keep things the same and as normal as possible? I remained quiet and actively listening and figured he would eventually, hopefully get to that point.	He and his wife stopped going on week-long skiing trips because she was getting lost and having other difficulties.	1

	Also, his time frame seemed a bit off.		
I mean, it wasn't safe anymore, and [inaudible] that I didn't go on the week-long ski trips. I just went locally here. 22:00	I am amazed at what activities his wife was still able to continue to do. And the fact that he just kept taking her as if things were the same and normal as before. Maybe he is on to something here?	He knew it wasn't safe anymore for week-long ski trips for his wife. They chose to ski locally.	5
I always arranged for the ski club to go for the day skiing. We went already last Friday, but now it's getting too warm, but we'd get out every week with a group of people 22:00		He is the one that always arranged the local skiing arrangements and still does. He and his wife would get out every week with a group of people to ski	N/A
And I'm not sure of the time. I'd have to look that up, but there was a point pretty late in the game where it was no longer really safe to go to the boats. 22:00 We'd done this since 1970's, and I have a sailboat now still sail. 22:00	It just is a giant reminder that no matter how much he tried to keep things calm and the same, things were changing for his wife and ultimately for him and for their relationship	Eventually, his wife was not able to go boating due to safety issues. He and his wife had sailed together since the 1970's until she became too sick to sail safely. He still sails now	1
With a partner we had another boat, a trawler-type other boat that we had [inaudible] for a while, and then the other guy lived there, and then he decided it was too hot here in the summer, so we took that up to (state), and then I would go back [inaudible]. 23:56	He and his wife lived what appears to be a life of privilege afforded to them by hard work and being a team for many years. This was my thought as I reflect on this particular comment.	He and his wife owned one boat with another person who moved to Maine. They would sail from DC to Maine and then fly home.	N/A
And I don't remember if she went to (state) or not. It might have been getting late in the game like 2011 or something probably. 23:56		His wife might not have sailed to Maine because in 2011 her disease had progressed quite a bit.	N/A
When the boat was local up until 2011, then she always went on the boat, but then there's a point where she was just moving around and doing things 23:56		His wife continued to go boating until about 2011. Her behavior of roaming became a safety issue while boating.	1
She was very, very experienced, but that went away when her memory went away or something 23:56		His wife was very experienced with boating but that all went away when her disease progressed and affected her memory.	N/A
and I watched carefully 23:56	He seemed like he did a spectacular job of paying attention to his wife's behavior and watched for signs of the disease progressing. It seemed	He watched his wife carefully for signs of decline for her safety.	5

	to me that they might have known each other better than most.		
so I didn't think it was safe to be around the boats very much. So that stopped in the last certainly three or four years. 23:56		He didn’t think it was safe for his wife to be around boats in the last few years of her life.	5
Yeah, I consciously tried to change as little as possible [inaudible] here to continue on. 25:21	It must have been hard for him to continue on with the motions and activities they used to do but to not have his wife as she used to be with him. I still wonder if this was better or not? I guess no one really has the answers to that question.	He consciously tried to change as little as possible and tried to continue on in that fashion.	8
It wasn't a matter of trying to ignore that there was anything different so much as [inaudible] I have to look out for yourself and I still keep reasonably healthy personal [inaudible] and that sort of thing 25:21	I am not sure that seems like what he was doing? Healthy in what sense?	He kept things the same as much as possible to keep himself reasonably personally healthy.	2
The only thing we still did quite a bit together would be we'd go off into music concerts especially in the summer outdoors. 25:53	He has not once mentioned that he is doing this out of obligation or because of wedding vows. It seems from an outsider perspective it’s because he truly cares for her and misses her.	He and his wife still went to outdoor music concerts together even as her disease progressed.	N/A
There are really nice things around here and [if she could?] do that [inaudible] again I think the last two years she got into rehab for three months or so and then came home for [inaudible] three or six months and then went into [hospital?] so the last roughly a year and a half things pretty much stopped because it wasn't easy or safe to be going out. 25:23		It wasn’t until the last year of his wife’s life that they could no longer go out together because she was in and out of rehab and the hospital.	1
We still go out to lunch or to go get her hair done 25:23		He did continue to take her to get her hair done weekly and then to lunch	4
but other things-- I mean one of the things that a couple of— usually she never had any acting out or inappropriate behavior which is sometimes common with this disease 25:23	It seemed important that he let me know that his wife usually never acted out as if typical with this disease much of the time.	His wife usually never acted out with inappropriate behavior that is a common symptom of FTD	11
I mean the only thing a couple of times-- not regularly but a		There were only a few times when they were at	11

couple of times we went to the music and she would get [inaudible] and start singing when it wasn't appropriate. 25:23		the outdoor music concerts that his wife would sing at inappropriate times.	
A couple of times we left a bit early because she would be annoying people 25:23	I wonder how he felt when this happened? Was he embarrassed by her behavior? Pissed off at others intolerance? Sad at the fact that things had changed so much for them?	He and his wife left outdoor music concerts a couple of times because her inappropriate behavior was annoying other people.	11
That was really the only thing that ever was inappropriate but mostly she always liked to go to music concerts and stuff like that and then every day she did the sing-along 25:53		His wife continued to enjoy music concerts and her sing along every day at home.	N/A
I learned later that music therapy is very important. 25:23		He learned later that music therapy is important for people diagnosed with FTD	6
it's hard to say whether she really got excited and enthused about it because it was so little interaction because she was so passive but that was part of every day's routine to do the sing-along for her that was so— 25:23	I guess it makes sense to include music whether it is know for sure if it helps. If nothing else, at least doesn't seem to be harmful.	He made sure music was a part of his wife's daily routine even though due to the progression of her disease, she could not express if she enjoyed it or not.	4
No. I just played the keyboard or the-- I think the caretakers would sing along too. 28:02	I asked if he sang along too. He laughed and was quick to say no. He just turned the keyboard on and the caretaker would sing with his wife.	He did not participate in the daily sing along with his wife	5
No. Maybe I wasn't so enthused about the singing [laughter]. I know once I had to sing a long time ago and I did sing but they then [inaudible] because it was not [inaudible] [laughter 28:18		He was not as enthused to sing anytime not just the sing along with his wife.	N/A
I played music professionally back in the early '50s and so I was familiar with all these kinds of things so. 28:18	I thought it was interesting that he played music in the 50's and so that made sense why he continued to have music in their lives	He played music professionally in the 1950's so he was comfortable going to concerts and having music in the house.	N/A
But that was the kind of thing-- we didn't go to theatre very much. I'm not sure why. 28:18		He and his wife did not go to the theatre much but he did not know exactly why.	N/A
Maybe, well, a lot of the time when we were working there wasn't too much time then on weekends we usually went away to the recreation 28:18		He and his wife worked a lot during the week and on the weekends, often would out of town for recreation.	N/A

but we went to the theatre a lot when lived in (city) because she was teaching at (university) and they had an especially good theatre school there 28:18	He and his wife had outstanding careers it seems. Again, from an outside perspective, it seems they knew each other and enjoyed each other more than most. I realize this is just his perspective of things and she might remember things differently if she were here to also do the interview.	When they lived in Pittsburgh, they went to the theater a lot because his wife taught at a local university that had an exceptional theatre school.	N/A
but when we moved down here I don't remember not-- a couple [inaudible] but nothing special like that. Mostly just we would go to the music 28:18		When they moved to the DC area they mainly went to music concerts	N/A
I don't know. I never-- there was always the time element, but by being able to have the hired caregiver for whenever we wanted, that basically wasn't an issue. 29:48	This was his response to asking how the doctors could have been more helpful to him as a male primary caregiver. He was a little off topic but I just listened.	His time was spent differently as his wife's primary caregiver but since he had hired a caregiver to help, his time was still ok	2
If I wanted, we could have had somebody 24 hours a day, but it wasn't necessary. 29:48	He had the financial means to hire an in home caregiver for 24 hours a day but he didn't thing that was necessary.	He could have hired a caregiver to help 24 hours a day but he did not think that was necessary	10
So that alone-- okay, having access to the caregiver was very important because it could free up your time to run the household and to do work if you wanted to do hobbies and that. 29:48	He had a very different primary caregiving experience than others that were interviewed for this study thus far.	He hired a caregiver during the week and that freed his time to do household chores, work projects, and hobbies.	2
The other thing that was extremely was the adult medical day care. We only did it twice a week. It's at [inaudible] (hospital), but it was a wonderful program 29:48	This was yet another resource that he had access to and could afford for his wife. And he seemed to know that it was there and available to her. These are things that would have been so important for others to know about.	His wife went to an adult medical day care twice a week.	10
You'd go there about 10:00 and then come home about 3:00 and the caretaker always drove her to there and then picked her up 29:48	He was really "free" to do what he wanted. Although I would imagine that he was never really "free" from worrying or thinking about how his wife was doing. Or thinking about how different his life really was even though he tried desperately to keep things the same.	The caretaker he hired would take his wife to the adult day at 10 am and then pick her up at 3 pm two days a week.	10 4
so again, I was free all that time to do whatever I wanted 29:48		He was free to do whatever he wanted to do most of the time.	2

Sometimes it was a matter of sitting at home and doing my desk work, but the adult day care program was extremely important, both for me and for her. 29:48		He would sometimes use his free time to stay home and do desk work when his wife was at the adult day center.	2
And it was very good. They'd do singing, they'd do exercise, they'd have lectures or showing things and that and then they'd give them lunch and that and it was socializing, 29:48		He felt the adult day center days were very good for his wife. They would sing, exercise, have lectures, and lunch daily. It was a way for his wife to socialize.	N/A
and that seemed to be very, very effective for a long time. I would say almost up to where she then finally stopped eating and got sick	"finally stopped eating and got sick"…I wonder if he never viewed her as sick before she became physically compromised?	He thought the adult day center was very effective for his wife until the end when she stopped eating and became sick.	N/A
So certainly, I don't know if it's available in all places, but the services around this area, (county), are wonderful. 31:41	One of the may perks to living in a metropolis.	He had resources available to him because of his geographic location and wondered if others had the same kind of resources.	10
But the county has an enormous amount of services for the older people and for sick people. 31:41		The county where he lives has a tremendous amount of services for the elderly and those that are sick.	10
And (hospital) has a senior program, just wonderful, both for advice and getting help and all of that, as well as their day program 31:41		His local hospital has many resources for seniors and is a great place to get advice on caring for a loved one who Is not well.	10
So those things are-- without that, for example, if we didn't have the day program, we didn't have the caretaker, and I had to be here all the time to look after and take care, I can't really almost imagine how horrible that would be. 31:41	This is exactly what I was thinking. He has taking advantage of help just as all the experts suggest and he is in a large area where services are an option. It seems to have made a significant difference in his experience as a primary caregiver for his wife.	He can't imagine how horrible it would be if he didn't have daily help with his wife and was stuck at his house all the time looking after her	10 7
She didn't wander very much. There were just two or three incidents where she wandered out and then we fixed the house so it wasn't possible. 31:41		His wife only wandered out a few times but after that he fixed the house so that wasn't possible anymore.	5
So I know some cases, the people wander a lot. Other cases, they're aggressive or even violent and that, but we had none of that. 31:41	It sounds like she might have had the Progressive aphasia type of FTD that comes with less aggressiveness and more loss of words	His wife was not aggressive or violent at all through the progression of her disease	N/A
And I had thought about that from the point of view, if there	This seemed to be a direct decision he made when she	He made the decision from the start if there was	7

was a substantial problem with wandering, if there was any aggressiveness or violence, then right away she would have had to go into an assisted living facility 31:41	first got the diagnosis. this seemed to be a matter of fact decision on his part. It seemed that he knew what he was able to handle/deal with/take care of her and what he could not deal with or handle or take care of her well.	significant wandering, aggressiveness, or violence, then his wife would have had to go right away to assisted living.	
But we never had that. 31:41		His wife was never aggressive or violent and only wandered a few times	N/A
And again, this may be related to the prior personality of somebody who isn't volatile or emotional or stuff like that, and they get sick, then they're less likely to strike out like that. 31:41	I am not sure that I agree with his reasoning of why she was not aggressive. It seems to me like it was just a different type of FTD she had not the behavioral type.	He thought maybe his wife was not violent or aggressive even though she is diagnosed with FTD because she was never volatile or emotional before she became ill.	N/A
I don't know the answer to those things, but I went to a discussion group once a month, and there were maybe 15 or so people there. And some of the discussions, it sounded like many of the households I don't think would be pleasant to live in. 33:42	I would imagine that he heard what most folks encounter when a spouse has FTD. I would also imagine that those folks though he had it easy in comparison. It seems like he even thinks that way about some of the things.	He went to a caregiver support group once a month and it seemed to him based on the discussions, that many of the households were not pleasant for the caregiver or the spouse diagnosed with FTD	10
From some of the discussion, I think that was true before the person got sick [laughter]. They were highly emotional, argumentative, and all kinds of things like that. 33:42	It makes sense that relationships would not get better once FTD was introduced in the relationship. So he is probably correct, if couples were already emotional and argumentative with each other before the diagnosis, it only stands to reason that would continue.	Based on the group discussions, he thought some of the couples were argumentative and emotional even before FTD came into the relationship.	6
But we never had that. We had very pleasant, respectful--maybe a little less emotional than would be appropriate, but it worked. 33:42	I thought it was interesting that he did not think he and his wife were emotional enough perhaps even before she became sick	He and his wife always had a respectful and pleasant relationship. Even though he thinks it was less emotional than most and it worked for them.	1
I think you have to fit it into the larger context. 33:42		He believes in the bigger picture of things.	N/A
And again, if it's only two people involved, that's one thing. If there are more people in the household, then of course that gets more complex. 33:42	I think his statement makes sense. And the fact that it was just the two of them in the household. They did not have kids and no immediate family to content with once she became sick.	He believe if it is only two people involved that is entirely different than if there are more people in the household which would make it more complicated.	1

I don't know if I could say I even depended at all on friends and acquaintances 35”02	I asked if there was anything friends could have done differently to support him as a male primary caregiver.	He did not depend on any friends or acquaintances at all while he was taking care of his wife.	10
We have no relatives at all around here. Her family was from (city). My brother lives in western (state) and my sister and her family and children live up near (city). But we have no relatives at all for support. 35:02		He and his wife had no relatives at all for support	10
I don't think I've depended much on friends and acquaintances other than they were people to go out and socialize with. 35:02	He was truly alone in his caregiving decisions. He seems to have made some wise choices in how to stay healthy as he continued to care for his wife at home.	He did not depend on friends for help other than to go out and socialize with them.	10
But nobody came and helped at home 35:02		His friends did not come and help at his home	10
It wasn't necessary because I could do most and then with the caretaker support, everything was pretty well taken care of. 35:02	I wondered if he wanted them to stop anyway? I don’t think it sounded like they had the kind of friends that came to their house to socialize even before his wife was diagnosed. So friends not stopping by might have been part of the normal routine he was trying to keep for them both.	He didn’t need friends to help because with the hired caretaker he was able to take care of everything on his own.	10
No. 35:56	His answer when I asked if friends visit the them at the house.	Friends did not come and visit at the house.	10
That was not true even before very much. We didn't do much entertainment 35:58	It seemed that he and his wife were only social with others through clubs. I am trying to get a feel for what kind of relationship they had with each other and others around them.	He and his wife did not due much entertaining at their house even before she was diagnosed with FTD	N/A
Most of the things we did were out and about in other places. We were almost always away on weekends 35:58		He and his wife always out doing things and most weekends they were away	N/A
And then a few times a month it'd be social gatherings, and some of our professional clubs would have special events and that. It's common here for the local professional societies would visit embassies once a year And those were always wonderful things. 35:58	I was thinking I don’t know any professional clubs that visit embassies. He and his wife had a special life together.	The professional clubs he and his wife belonged to would have special events during the year such as visiting embassies	N/A
So we didn't really do home entertaining hardly at all. We		They never did home entertaining because they	N/A

would be out with groups some place 35:58		were always out with groups some place	
Yeah. When I thought about how to handle these things, probably almost one of the most important things was to have as absolutely little change as possible from our previous routine. 37:02	This was his initial response when I said it sounds like they continued to do these things as a couple as long as she could, and it sounds like he still continues some of these activities	He thought about how to handle things after his wife's diagnosis of FTD. He decided that it is most important to have as little change as possible from their previous routine.	8
Even though that may take some extra effort, you obviously have to do some things different, and then drop some things But mostly the emphasis for both of us was, let's see how important it is to try to keep the routine unchanged. 37:02		Even though it was an added effort, and he had to do some things differently and drop others, it was important to him to keep as much as the same routine as before his wife was diagnosed with FTD	8
Now again I don't know if I can judge how effective that was because, at least in the later years, there was no clear reaction, even smiling or speaking or anything. 37:02	This must have been difficult for him because he put so much effort into keeping things the same and to not have her be able to react in a positive way must have been disappointing to say the least.	He doesn't know if keeping the same routine as before was effective because his wife was unable to communicate with words or react with emotion.	1
But my sense is that some of those things brought whatever level of pleasure and awareness that was possible. 37:02	By his account so far, they definitely knew each other and got each other so I would take his sense of things to be meaningful.	His sense what that keeping things the same brought his wife whatever level of pleasure that was possible for her.	4
But I can't prove that. I mean that was, for example, it was certainly unnecessary to go once a week to have the hair done and go to lunch, but she'd been going to the same person for 20 years or so and that was an important part of her life. 37:02	I was thinking that not only was this keeping the routine but it seemed that by doing this he was ensuring her dignity too. Even though he didn't say that I would imagine that was part of his plan of keeping the same routine as much as possible.	Even though he can't prove his wife still got pleasure from having her hair done every week, she had been going to get her hair done every Thursday by the same person for the last 20 years so he assumed it did.	8
And I mean, certainly, you could forgo that and say, "Well, look. It doesn't make any difference anymore because what the hair looks like isn't important." 37:02	Again, I think that he wanted to continue to have her hair done to continue on with dignity…for them both	He thought he could have chosen to forgo getting her hair done every week because what hair looks like isn't too important	8
But that seemed to be something that, I could guess at least, she looked forward to going out and doing that. 37:02	I would assume that this was something he felt good about doing for her too. She was still his wife and he wanted to do nice things for her as he had always done.	He wanted to continue to have her hair done weekly because she always used to look forward to doing that.	4
Again, you may know more from other experiences. Is it important to try and keep the life as normal as possible? Or is	He was asking me if I thought making major adjustments or keeping things the same…which one was better	He asked if it was better to make major life readjustments or to keep the same routine and keep	N/A

it better to make major readjustments?	based on my findings talking to other participants. I answered him by saying what he did seemed to work well for he and his wife. I don’t think there is a one answer fits all couples/individuals. I don’t know what is a better way to cope with a fatal disease like FTD.	things as normal as possible.	
Yeah. I mean, it didn't bother me that say, I would take time and effort to do something without getting a response. 39:10	It might not have bothered him in the sense it made him angry but I wonder if he felt sad, not seen, and lonely as a result of not getting a response from his wife?	He was not bothered that his wife did not respond to his continued efforts to make her life meaningful and pleasurable as much as possible.	1
It was like, “Oh, yeah. That's wonderful. Thank you.” I mean, I didn't care. I mean, my feeling on that was I'll go through the motions of keeping things the way they always have been. 39:10		He did not care that his wife wasn’t able to respond with “thank you” or “that’s wonderful” as he continued his efforts to keep things as they always had been.	1
If it works, fine. 39:10		If his efforts worked, he was fine with all he was doing.	5
But if it doesn't, if the person is oblivious to this, so what? It doesn't cost me that much. 39:10	He was doing this even if it might not be helping his wife because on the off chance it was helping he was going to continue to put in the added extra effort and time.	He thought if his wife is truly oblivious to what he is doing, it doesn’t matter because it hadn’t cost him that much.	1
I wasn't thinking of myself that way. 39:10	He wasn’t thinking of himself, as the “I” in the relationship only, he was thinking of the “we” that made up the relationship.	He was not thinking of himself	1
It was, well, this is the life we live. And this is the way we do things. 39:10		He thought of how to handle things just as he and his wife always had lived life together before she was diagnosed with FTD.	4 8
And this is the way we do things. We got to keep things orderly and nice and have some [stimulus?] and like that. 39:10		He thought they had to keep things orderly and nice	4 8
But I don't know how effective these things were. 39:10	.	He doesn’t know how effective it was keeping the same routine	4
I had one thing, though, that we would go about once a month up to (hospital clinic) to the FTD center there. 39:10		He would take his wife once a month to the Johns Hopkins FTD center	4

And we go there and things were, they were slowly deteriorating, but nothing was coming apart. 39:10	He continued to take her to Johns Hopkins for consultation and medical appointments. It seemed that the doctors there followed her progress even though they only saw her once a month.	His wife was slowly deteriorating over the course of time.	8
Well, she had [one point?] stopped eating, went in the hospital, and then rehab and then came back around and was quite good for another year 39:10		His wife had stopped eating at one point and had to be hospitalized and then to rehab. But she rallied and was good for another year.	5
And the Dr. [inaudible] at one point said to me, "Well, what are you people doing? Because usually when the person stops eating, then they quickly die. But she's come back around and is functioning." 39:10	It sounds like this might have been the reassurance he had been looking for to know he was proceeding the right way for his wife. This seemed to be towards the end of her life but nevertheless, it was said to him by a FTD medical expert.	He was asked by a medical expert in FTD what he had been doing to keep his wife alive and functioning after she had stopped eating and then recovered and didn't die.	6
And he's asking me, "Well, what are you doing?" I thought that was funny. 39:10		He thought it was funny that a medical expert in FTD was asking him for advice	6
And all I can say, "Well, we have the life as normal as possible." 39:10		His answer to the medial expert in FTD was that they were keeping their life as normal as possible	8
And there was a lot of emphasis on the day program and the singing and going to music or stuff like that. 39:10		He also mentioned the importance of the adult day program and daily singing and going to music concerts	10
Oh, and she would watch the old movies on television a lot. 39:10		His wife would watch old movies on the tv a lot	N/A
Somewhere along she was reading a great deal the first few years but then the reading stopped. And I just think the attention span wasn't there, so. 39:10		His wife used to read a lot in the first few years too	N/A
But all these little things. 41:38	He ended this section by saying it was all these little things. He saw them as little things but to an outsider it seemed more like things that took time and effort to appear like they were just little things…	He thought that all the little things he had kept the same were helping his wife	8
We always would sit at the dining room table for proper dinner and stuff like that. 41:38	This was an example of the "little things" he kept the same. On one hand I felt a sense of the dignity he was	He and his wife continued to have a proper dinner at the dining room table just as they had always done.	8

	trying to hold on to and on the other hand I felt extremely sad as I pictured the two of them sitting at the dining room table as they always had but without the lively discussions and conversations and The deafening sound of silence.		
I guess that probably makes a difference. I have no idea. I have nothing to compare with. 41:38	Because there is so little literature about FTD and caregiving experiences he doesn't have much to compare his experience to at this time other than talking with folks at a caregivers' support group	He only can guess if having a proper dinner at the dining room table as they always had done helped to make a difference for his wife. He had nothing else to compare it with.	8
And some people, of course, would as quick as possible ignore doing all those things because they say, "Well, the person doesn't recognize," or, "It's too much trouble for me." 41:38	He seemed to be the most emotional as he said this statement. Which really told me that all the "little things" he was doing to keep the same routine for he and his wife was a lot of effort and a true labor of love.	He thought some people would be quick to not do the little things for their loved one because the person might be oblivious to the efforts or because the caregiver would see it as too much trouble.	1
And if you think that way, then you probably do nothing and you just sort of warehouse the person 41:38	Now it is clear, he was trying to make his and his wife's life as meaningful as it had always been by keeping things as normal or the same as they had always been. This was in an effort to make sure he wasn't warehousing his wife because of her disease	He believes if someone thinks that way, that the little things don't matter anymore to the person with FTD, then the caregiver probably does nothing and essentially just warehouses their loved one.	7
So that's, again, everybody has to do what they're comfortable with. I was comfortable with what I did. 41:38		He believes everyone has to do what they are comfortable with doing. And he was comfortable with what he did.	7
Well, I would certainly be willing to share with anybody my experiences, what I did, and how it worked or didn't work. 43:13	This was his initial response to my asking him what he would want other male primary caregivers to know.	He is willing to share his primary caregiving experiences, things that worked and didn't work, with anybody.	7
To probably two things. 43:13		He would suggest two things to other male primary caregivers.	N/A
One is whether they're used to it or not, it's probably necessary to a certain degree to compartmentalize the different parts of your life at that point, because they'll be different. 43:13	I thought this was interesting that he had been questioning whether or not he had compartmentalized things and now he is suggesting that others will definitely need to do that.	He believes it is necessary to some degree to compartmentalize the different parts of one's life because they will be different.	8
But probably the most significant thing when	This is also an interesting statement because his	He believes the most important thing to do	2

[inaudible]-- the first thing you've got to do is forget about yourself. 43:13	caregiving experiences as he told shows him practicing good self-care that so many caregivers don't do because they do forget about themselves.	when one is the primary caregiver for a spouse, is to forget about yourself.	
Don't think about you're frustrated, or angry, or anything, but you've got a job to do to take care of the person. 43:13		He believes as the primary caregiver for a spouse, one should not think about being angry or frustrated but should be focused on the job at hand of taking care of his spouse.	2
You do that. 43:13		He feels he primary caregiver should focus on his spouse not on himself.	5
In that sense though it does mean probably blocking out a lot of your own emotions, so that you don't get frustrated or angry. 43:13	So he was having the emotional reaction but he chose to consciously block them out and compartmentalize it all.	He does admit that in order to do that, one has to block out his own emotions so that anger and frustration don't happen	8
Now, I went to this discussion group at a memory care facility once a month, and we had 15 or 20 people. And I went there, because I felt well it's a discussion group. It sounds good. I will learn from them what works and what doesn't. 43:13		He used to go to a support group once a month at a local memory care facility to try and learn from other's stories.	10
I found that was really not very successful. I still went, but I didn't learn much from them. 43:13		He did not find the support group at the memory care facility helpful.	10
It seemed to be a bunch of people sitting around wanting to feel sorry for themselves… "Oh it wasn't supposed to be this way. We were supposed to have this glorious retirement," 43:13	I wondered why he still went if it was an irritant for him? Maybe so he could feel validated about his decisions?	He did not like to go to support groups where he felt like people were sitting around feeling sorry for themselves.	7
and many of them, even in the group, seemed to be very angry, where they would describe how they were angry at their partner and, "I told you to do this, and you didn't do it," screaming at each other some of them. 43:13	When he was telling me this he was audibly upset and disgusted by some of their interactions with their spouses who were ill.	He was appalled that some caregivers described yelling and screaming at their partners in anger.	7
I was surprised at some of this 45:19	He was really caught up with this…he was the most emotional thus far in the interview. And I was thinking because of his lifestyle with	He was surprised at how people talked and acted in a relationship with one another.	7

	his wife for over 40 years, he had never interacted with people who were more emotional in their relationships with each other?		
(I) didn't learn very much 45:19	I was thinking I don't exactly agree with him. I think he learned a great deal but not in the way or about the things he expected to learn.	He didn't learn much from the caregiver support group	10
most of the people, at least in the context of the discussion group - and they probably were this was 24 hours a day - I would say predominantly thinking about themselves, maybe 80% to 20%, 45:19	He was really upset about how he perceived the others' character to be in regard to thinking more about themselves than about their ill loved one.	He thought the others in the caregiver support group were thinking more about themselves than about their ill loved one.	7
rather than thinking about the other person and what they could do to make the other person's life as good as it could possibly be, even if that wasn't very good. 45:19		He thought that caregivers for spouses should be thinking about that person more and how they could make her life as good as it could be, even if it's not very good.	5
And so. I guess from that I learned how most of the people were interacting. 45:19	He does finally realize here that he in fact, did learn something from the group…just not what he had expected to learn.	He did learn something from the caregiver support group, how most other people interact with each other.	7
Now, most people, I'd only picture maybe of the people that came very often, maybe only two others were men. 45:19	I was wondering if he was going to imply that women were the more noncaring gender?	He noted that most of the people in the caregiver support group were women. Only two other members were men.	3
They were mostly women caring for older husbands 45:19	I was also wondering if he thought maybe he was doing a better job as a male primary caregiver?	He noted the caregiver support members were mostly women caring for older husbands	3
So you didn't get-- there was one interesting guy here, and maybe from the context you'd [inaudible]. He was younger, and his wife apparently was [inaudible] in her 50's, and they still had children at home 45:19		He met a younger man in the caregiver support group whose wife was in her 50's and they still had children living at home.	3
it was the only one he could talk a little bit about, but he was mostly-- I don't think they had any caretakers, so he was working full time but still having to take care of the family [inaudible] 45:19 That sounded like a real burden and pretty horrible. 45:19	He seemed really dismayed that this guy didn't have any caretakers and that in addition to working full-time, he had to take care of his wife and his family too.	He was dismayed to learn that the male caregiver he met was still working full-time while taking care of his wife and family without any caretakers to help.	3 7

I don't remember any other specific men. don't think there [inaudible 45:19		He didn’t remember any other males from the caregiver groups specifically	3
It seems to be there aren't too many men that are the primary caretakers, 45:19	Of course, that might be because men were not going to support groups.	In his experience with caregiver support groups, there didn’t seem to be many men that were primary caregivers.	3
but there was one incident there that was sort of toward the end And maybe because of that, I kind of lost it. 47:33	I was curious to see what would make this participant really emotionally upset because so far by his account, he was fairly even with no extreme emotions. At least in the caregiver role.	There was one incident that he remembers during a caregiver support group that made him angry.	N/A
[Before?] the young woman came through the discussion group and we would [inaudible] we were just telling the stories and that. And the young woman, she was maybe in her 20s or 30. She let me get home, to the family home with the father and the mother. And the mother had gotten six or seven [more?] years. And father was taking care. And then for whatever reason, the father went on a dating site, found somebody, [a?] woman who've been to the family house with his daughter and wife [laughter]. I was a bit startled by that 47:33	I was a little amazed that he was so shocked that someone would seek out sex or companionship while their spouse was ill or dying. Not that I agree one way or the other, but I don’t think I would have been shocked to hear it was happening. His reaction was interesting to me for that reason.	He was startled that a male caregiver started dating another woman while his wife was ill at home.	7
And they went around the room [inaudible]. And [inaudible] people say, “I can understand that. Okay. Okay.” And I found that a little-- I guess after that, I thought, “Well, I'm not learning much, 47:33		`He was even more shocked at the fact the other members of the caregiver support group seemed to understand and empathize with the situation	7
I wanted to say, “Look, you mean if your spouse has dementia, then polygamy becomes acceptable [laughter].” 47:33	So a couple thoughts ran through my head: one, he was truly appalled at this type of behavior, or two, he hadn’t thought about it before and was actually curious and maybe interested in learning more but was embarrassed or ashamed?	He wanted to say to the group that polygamy was not okay just because your spouse has dementia.	7
That's my personal thing. I mean, I can understand some people feel they don't want to be alone and they have their	I don’t know that he really was understanding of how most others live because he and his wife appeared to have lived	He understands that some people don’t want to be alone and they put their personal needs first.	2

personal needs that come first. 47:33	what most others would call a charmed life.		
But everybody has to approach these things from whatever direction. 47:33		He thinks everyone has to do what is right for his situation.	7
Well, only for example, okay, if I'm doing my work, just what I'm doing, these are words and that's all I think about. 49:39	I asked him about what he means when he says he compartmentalizes. He agreed to try and explain it more to me. Somehow in the transcript that came out to look like "tell me about lies"…	If he is working, he only thinks about the work he is doing.	5
If I want to do something for recreation like [bowling?], I think about that only from my own perspective 49:39	This made me think about the "I" in the relationship versus the "we" in the relationship and how 2 people are interdependent on one another.	If he wants to do something recreationally, he only thinks about it from his own perspective now.	1
whereas in the past, that would [inaudible] we would've done together. 49:39		In the past, recreation was something he and his wife would have done together.	1
That's no longer possible 49:39		It is no longer possible for he and his wife to get out together	1
, so I don't dwell on that to say, "Gee, this isn't as much fun as when we did it together." 49:39	I was thinking this has to be one of the hardest thing about having a spouse with FTD	He doesn't dwell on what used to be with his wife.	1
I just block (it) out 49:39	This was a truly enlightening statement…his idea of compartmentalizing was really to block out his emotions and thoughts about what it used to be like with he and his wife before she got sick.	He just blocked out thinking about how things used to be when he and his wife did things together	8
in a lot of ways for the last several years, I was living in my own little world and living alone just as much as I am right now 49:39	His wife in now deceased but the fact that he felt that way while she was still alive is the epitome of ambiguous loss in a nutshell. Some of what I thought might be happening.	For the last several years while his wife was still alive, he was living in his own world, alone as he is now as a widower	8
I mean, that didn't just start after she was gone. 49:39	I felt sad for him as he was remembering and coming to a few realizations just through this interview.	He didn't just start living alone once his wife died.	8 12
I mean, I was living in a lot of ways almost just a lone individual, because the other person was not available. 49:39	I was starting to realize he had kept the routine the same maybe in case his wife "came back" she would know where she was? Maybe it was his hope? And because she had enjoyed these things in the past it stood to reason she would still enjoy them now.	He was living as a lone individual because his wife was not available as she once was.	1 8
I guess that's what I was thinking about that I didn't when I say [inaudible] I didn't		He compartmentalized his feelings and thoughts about how things used to	8

comingle my feelings about it. What's missing with the other person what I'm doing right now. 49:39		be with his wife and how they were as her FTD progressed.	
I was just focusing on what's here and now. 49:39	He was trying to remain in the present, each day with his wife instead of thinking about what life used to be for him and for them as a couple.	He focused on the here and now, the present.	8
I mean, maybe I'm just being too pragmatic, but I didn't get involved with having a lot of emotional reactions or wishes or thoughts and about what wasn't possible because of the person not being available 49:39	I didn't think he was being too pragmatic I just wondered if he ever, eventually, felt the feelings he had pushed to the side for over5-6 years?	He thinks he might have been too pragmatic but he didn't want to get caught up in emotions or wishes about what things his wife was just not available for anymore.	8
But again, that was not a change from the last 70 years or something 51:36	This was his initial response to me saying that he was staying in the present and going from day to day.	He has tried to live his life in the present for the last 70 years and this was not a change for him.	5
One thing at a time, focusing on one thing then another. 51:36		He has always focused on one thing at a time.	5
I sometimes describe it as I'm living in my own little world, almost blocking out any external reactions or stimulus. 51:36	He seemed to me to be a well-disciplined professional and person in many aspects of his life previous to the role of caregiver for his wife. I would imagine that helped him compartmentalize in that role too.	He lived in his own world blocking out all external distractions.	5
But that wasn't something that just came in recent years. 51:36		He has always been able to focus on one thing at a time and block out other distractions.	n/a
It's probably a way of coping 51:36	I thought this was very insightful	He thinks focusing on one thing at a time and staying in the present is his way of coping	5
But it makes for a certain amount of effectiveness and efficiency. 51:36	I was thinking I should adopt his way of doing things. I might get a lot more done that way.	His way of focusing on one thing at a time has proven to be effective and efficient for him.	5
You don't get distracted by too many other things when you've got something to focus on or do. 51:36		He wasn't distracted by other things when he stayed present and focused on one thing at a time.	5
I mean, everybody has different ways of handling these things. 51:36		He believes everybody has his own way of handling situations.	5
I know some people are [dealing with it?], anything they're doing or anything they		He thinks that some people react with	5

say always has an intense emotional content, even when that's not necessarily appropriate or necessary. 51:36		inappropriate emotional intensity.	
And other people-- it isn't a matter of saying, “You don't have emotions.” It's a matter of saying, “Well, you're trying to do something pragmatic or a project or something, it's just not relevant. 51:36	I realized I am probably both when he was saying this. I react and then tackle the problem with action.	He thinks other people are more pragmatic, not unfeeling, and tackle the project in front of them.	5
Save it for the time when it's better to have intense emotional interactions 51:36		He thinks there is a time and place for intense emotional reactions	5
There are two things. And the one, I'm not sure you're making a distinction or how you handled this. I think there's a big difference for where you're the caregiver when the person is still living in the home full-time compared with you're a caregiver where the person is in an assisted living facility. 53:38	This was his answer to me asking him if there was anything else he wanted to say that I hadn’t asked or he hadn’t said yet.	He wanted to make sure there is a differential made between the caregiver whose loved one is at home still compared with the caregiver whose loved one is in a living facility.	5
Do you make a distinction for the men who are the home caregivers compared with caregiver for somebody that's in a facility? 53:38	He was asking me about this current study.		N/A
I thought so, but that's a big difference. I think the people in the discussion group, almost all of them were still at home 54:22		He thinks there is a big difference between the experiences of caregivers whose loved ones are still at home and those caregivers whose loved ones are in living facilities.	N/A
A couple of them I remember mentioning where they'd moved into a facility. That's a whole different thing because then, effectively, you're living as a single individual for all practical purposes 54:22		He thought caregivers whose loved one was in a living facility was essentially living as a single person and not part of a couple.	5
As I thought about this a little bit, there's another thing that you probably have addressed, but it may be important 54:22		He wanted to address another important point about caregivers	N/A
And the difference between the male caregiver and the woman caregiver 54:22	This was something different that had been said by other participants. I was interested to hear his perspective based on his experience.	He believes there is a difference between the male and female caregiver	3
And I was reminded of this because one of the couples that		He knows a couple that reminded of the	3

I know, the man is-- he's in his 90s and he has some limitations like this. 54:22		differences between male and female caregivers.	
the man is-- he's in his 90s and he has some limitations like this. 54:22		The man in the couple he is reminded of has some limitations.	N/A
But a woman who - she had her own businesses and things like this until she retired. 54:22		The woman in the couple had owned her own business until she retired	3
She was in her 80s - identifies herself - I think I saw it on something - as a caregiver. 54:22		The woman in the couple now identifies herself as a caregiver.	3
And I was a little surprised by that because, I mean, I didn't think of her as a caregiver 54:22		He was surprised the woman identified herself as a caregiver because he did not think of her that way.	3
I think of her as sort of a retired professional person. 54:22		He thought of her as a retired professional person.	5
But when I thought about that, my reaction was-- well, if I met somebody asked me what I was or something, I would have never in the furthest reaches of my imagination referred to myself as a caregiver. 54:22	This was a very important point: he did not identify as a caregiver when he thinks of himself and his identity. Caregiving was an action he did not who he was.	If someone were to ask his what he was or what he did he would never refer to himself as a caregiver.	5
I was a retired engineer. I was a sailor. I was a skier. I was a musician. I was lots of other things 54:22		He is a retired engineer, he was a sailor, he was a skier and he was a musician.	5
but for a man-- I don't think it's-- even if they thought of themselves as a husband and a father, I don't think they're so quick to think of themselves and their identity being a [caregiver?]. 54:22		He doesn't think males are quick to name themselves as caregivers as part of their identities in their lifetime	3
And I think this is important because for most men, their identity is tied up with their work and/or their hobbies and Recreation 56:44	This is interesting to me. He was so adamant that this was the case. It was as if he was really wondering if he was right?	He believes that most men align their identity with their work or hobbies.	3
whereas often a woman, even if they're working professionally, still thinks of themselves as a homemaker and a mother and a caretaker. 56:44		He believes women, even those who worked professionally, identify as homemakers, mothers, and caregivers	3
And so the loss of identity when you go, and this is especially true, for example, if because of the person getting		He believes there is a loss of identity if a spouse gets sick and the other has to	5

sick, you had to change your employment or retire 56:44		retire or change employment as a result.	
For a man, this is a major loss of identity and self-image. 56:44		He believes that for a man, this is a major loss of identity and self-image.	3
And I don't think most of us would, even then, jump to say, "Well, I used to be an engineer, but now I'm a caretaker." 56:44		He does not think that most men would ever identity as a caregiver but instead identify with what they were in their career role	3 5
Somehow, that connection or concept, [not maybe?] with me, but [laughter] that's how most men identify themselves by what they did in the world. 56:44	I am not sure if this is only true for men or if it is true at all for the general population?	He believes that most men identify with what they did in the world.	5
Is that an issue? The loss of identity or the change in identity, whether you're still working or had to quit working or whatever? 56:44		He wondered if loss of identity or change in identity whether you are still working or had to quit working to take care of a spouse, was an issue?	5
Yeah, I think you want to try to address the issue of the person's personal identity and who they are and what they think of themselves 58:21		He thinks it's important to address a person's personal identity and how they think of themselves (as they take on a caregiver role)	5
I mean, during all of this time, I still thought of myself as, "Well, I'm an engineer. I mean, that's what I do." I never thought of myself as a caregiver. 58:21		All the time he was caring for his wife he never thought of himself as a caregiver. He thought of himself as an engineer.	5
And it just startled me when I happened to see this note from this woman who was doing the same thing and right up front, "Who am I? I'm a caregiver." 58:21		He could not understand how this retired professional woman now identified herself as a caregiver only	3
I would have never conceived of identifying myself as that even if somebody asked very directly and pointedly because that was not my personal identity. 58:21		He would never identify himself as a caregiver because that is not his personal identity.	3
And that influenced an awful lot of your view on who you are and how you function and all of that. 58:21		He believes that how one identifies influences how that person views himself and affects how that person functions	5

So I didn't know where this came in. [inaudible] which is very different, for example, this one case I mentioned where the man was a caregiver but still then had to take over running the family where there were dependent children 58:21		He imagined that being a male primary caregiver who still worked full-time and had dependent children at home would be a very different experience than he had.	3
And that's probably pretty rare, but with FTD sometimes it's fairly young. People in their 50's or even 40's or 50's. 58:21	I was thinking it is not rare that people from this age group are diagnosed with FTD. By the very definition, FTD hits people who are younger than 65.	He thinks that it's rare that people in their 40's and 50's get diagnosed with FTD	N/A
They may be the whole family that suddenly where there's no shared responsibility it's all sole responsibility of the man. 58:21		He would imagine the entire family would rely on the male primary caregiver for everything with no shared responsibilities.	3
That would seem like an enormous burned especially if you're actively working. 58:21		He believed that would be an enormous burden for the male primary caregiver that was still working full-time	3
I think it could easily be overlooked that the change in the man's identity and self-image changes drastically even if—most of the men would not even recognize that. 1:00:35		He believes that the changes in a man's identity and self-image could be overlooked because most men would not recognize it was happening at the time.	3
And it could have a big effect on their whole outlook on the world and on themselves and where they're going and things like that. 1:00:35	It seemed like maybe he had given this some thought between the time we set up the time to talk and this interview. I thought he had some good points and things to continue to research.	He thought changes in identity for primary male caregivers would have a big effect on their outlook on the world and themselves.	3
It's easy to overlook that because our identity is tied up in not only what we do working, but what we do within the personal relationship and the family. 1:00:35	This seemed to contradict what he had said previously. I got the feeling this might have been one of the only times he talked about this and what he thinks and feels.	He thinks how being a caregiver can affect a man's identity can be easily overlooked based on how the man relates his identity to his work and his relationship with his family.	3
And obviously some of these people-- I know of one other case like that where I think the woman was in a facility and, I don't know, the man just went off functioning as if he was a single individual. That was his identity 1:00:35		He knew a man whose wife was in a facility and the man went on living as a single individual and that was his identity.	53

I mean, I can understand why certainly this happened after the things went on for many years. 1:00:35		He understands why it happened, the man whose wife was in a facility lived alone for so many years his identity changed to a single individual	7
But they no longer think of themselves as a partner 1:00:35	This was in relation to the man whose wife was in the nursing home	He believes they no longer see themselves as a partner.	7
And the one with the young woman describing her husband (father) having somebody come and live with him. Clearly, I mean, he no longer that he was [helping?] as a partner with a sick wife. 1:00:35		The one young woman he met whose father had met another woman and brought her to their house clearly no longer saw himself as a partner with his sick wife.	7
Yeah. I never felt any real change in my personal outlook for myself and for us. 1:02		He never felt any change in his personal identity or his identity with his relationship with his wife.	5
To me, it went on just the way it always was even though there were certain things missing a little bit. 1:02		He went on as he always had realizing certain things were missing in the relationship.	8
And I think it has a lot to do with the way that you're more primarily focused on yourself and your wants and needs. Or whether you're more thinking a little more broadly in terms of a couple or whatever. 1:02		He believes that his identity did not shift so much because it has to do with thinking in terms of a couple instead of being focused primarily on yourself.	5
That's not something that just comes about just when the person gets sick, I mean, that was there from the beginning. 1:02		He believes that thinking in terms of a couple and not just an individual doesn't just happen when one person in the couple gets sick. It had to be that way from the beginning of the relationship.	1
Whether you think of yourself as an independent individual that just happens to be sort of connected to somebody else or whether you're really in a functioning, effective, healthy relationship. 1:02		He believes it depends on if a person sees himself as an individual just connected to another or if he sees himself as a part of a healthy, effective relationship with another person.	1 2
And I'm sure that when you talk to people whether it's explicit or not you will get a sense of what things were like before. 1:02	This is a good point and I think it is worth keeping in mind	He thinks the researcher will be able to get a sense of what a couple was like before the disease entered the relationship	1
In the discussion group, some of the discussions were such I		He observed how couples were before the disease	7

can only conclude these were pretty horrible relationships to start with and getting sick just exaggerates them. That's my own personal observation. 1:02		entered the relationship through the exaggerated behavior described now.	

Appendix G

Participant E Analysis and Coding

Participant E Statement	*My observation during interview/reviewing interview*	*What is the meaning of the statement*	*Theme Code*
Oh, absolutely. Yeah. No. I mean, to be honest with you, there's really nothing that's the same (2:00:39-2:00:44)	The participant's voice was very strong and forceful and he was emphatic, almost angry in his response to the question of how FTD has impacted his relationship.	Nothing is the same	1
With FTD, they can no longer really comprehend anything, so for her to know what a relationship is or intimacy or any of that—none of that exists anymore. 1:00:44)	I started to feel anxious as he continued to explain how he felt about his relationship and how his wife is no longer how she was before FTD.	His wife can no longer comprehend what a relationship is Intimacy does not exists anymore He said, "She's 65 years old and I'm taking care of a two year old."	13
She's 65 years old, and I'm taking care of a two-year old.1:00:44			8
She was diagnosed in the Fall of 2016 (1:01)	I was thinking it had been 2 years roughly since her diagnosis.	2 years of being a primary caregiver	N/A
Wow. The emotional connection now is that was my wife. (1:01:41)	I felt empathy for him because he seemed so angry and hurt.	No emotional connection That was his wife.	1 8
That was somebody that I had a commitment to take care of her, sickness and in health or whatever, and that's what I'm doing. (1:01:41)	He continues to seem so hurt and pissed off that FTD has entered his life and their relationship. He appears to be almost numb and detached from his wife.	Commitment to take care of his wife in sickness and health and that is what he is doing	1
So, the emotional part, that's pretty much it, is I have that emotional tie and commitment to her. I will take care of her whatever she needs. Other than that, there's really no attachment any longer to—she's not my wife anymore (2:01:41)	He was very matter of fact and straight forward with his thoughts about what is keeping him with his wife, who he considers not his "wife."	No attachment She's not his wife anymore He made a commitment to her	1
She probably ceased being my wife probably about the beginning of 2017 to where she's no longer—any of the reasons you're married to somebody anymore, the emotion tie, the partnership, none of that's there anymore. (2:01:41)	I realized that only a little over 2 minutes into the interview he had intensely vented all of his thoughts and feelings, mainly anger and I was feeling it in my body. I began to feel overwhelmed with what I was hearing in his blunt expression.	She ceased being his wife The emotional tie, the partnership is not there anymore The marriage is gone	8

Once you become a caregiver, it's purely that. You're a caregiver of someone, and that someone just happens to be your spouse, your former wife. (2:01:41)	I felt his sadness and disgust come through. I felt sad and nauseated. I drank some water to try and stay grounded and present and continue the interview.	He is a caregiver only He is a caregiver to his spouse, his former wife and he makes a distinction between the two	5
She was diagnosed in 2016(2:01:14)	I asked this question since he said 2017 was when things really changed in their relationship	He has been a caregiver for at least 3 years to date	N/A
1980, so we are 38 years. This is our 39th year.(3:01)	I was amazed that they were married for 38 years and he sounded so detached.	He was married for 38 years	N/A
There's no longer an emotional tie of (spouse) being my wife.(3:15)	As much as he has said there is no emotional tie to (spouse), seemed angry and frustrated with her and with the situation they are in. He definitely has made a distinction between spouse and wife	He has no emotional tie to (spouse) as his wife	1
Really, everything has changed, even simple stuff. Like any marriage, you split up responsibilities and duties. She handled the grocery shopping. She handled the majority of meal prep. She did the laundry, some of those kinds of things. I now do all the stuff she used to do plus what I did. I've had to learn to do the laundry, to do the shopping, to do different things. So, all of that has totally changed. (3:46)	He seemed frustrated and very overwhelmed when explaining how much he has to do now that his wife is unable to function as she did before.	Everything has changed Marriage includes splitting up responsibilities and duties He now does everything she used to do like grocery shopping, meal prep, laundry in addition to what he was already doing	4
She was diagnosed in 2016. But once we got the diagnosis and I knew what I was looking at, I could look back, and I could see where the FTD has been there for several years prior to 2016. And there would be just simple stuff like meals. She would go prepare a meal or whatever and she would be missing items and ingredients or whatever, and I'd say, "Why are you not—use your brain." I probably said to her, "Use your brain," a 1000 times a day, and I just thought she was	I felt his pain come through the phone. He was explaining how he had thought his marriage was dissolving due to his wife not caring about him anymore and then realizing that it was the disease causing all the changes. I am not sure that made him feel better?	His wife was diagnosed with FTD in 2016 He realized FTD had been in their relationship prior to 2016 His wife would miss items or ingredients preparing a meal He would say, "Why are you not—use your brain." He would say "Use your brain" a 1,000 times a day He though she did not care anymore He thought she was getting lax	6

getting lax or not caring anymore or whatever, just totally changing. (3:46)			
But I know now it's the disease that was causing this. For example, grocery shopping, she was making so many mistakes and errors and stuff on grocery shopping probably at least two or three years prior to her diagnosis and I would say, "(spouse), I'll take over the grocery shopping," and she would come back, "No, no, no. I got it. I'm going to handle that." So, I said, "Okay." and at least every other month, I was saying to her, "How about letting me take over the grocery shopping?" And simple things like that even. So, there's really nothing in the relationship as far as what you would do, husband and wife, who does what duties and that. That kind of ceased to exist. You, as the caregiver, end up doing both parts. (3:46)	It seemed very important to him that he explain and give concrete examples of how the duties and responsibilities of their marriage had changed and seemed to cause so much stress. This seemed to be especially true before he realized it was the disease causing his wife to act this way and not that she was just not caring about him or their relationship anymore.	It's FTD causing changes not his wife's choice He noticed changes in his wife 2 or 3 years prior to diagnosis She was making so many mistakes and errors on grocery shopping He would say, "(spouse), I'll take over the grocery shopping," and she would come back, "No, no, no. I got it. I'm going to handle that." Nothing in the relationship of husband and wife duties exists. He, as the caregiver, is now both	8
That ceased in 2016 about the time of the diagnosis. There was no longer—she could no longer really be intimate with you, both sexual or emotionally. You could just kind of see it's just not there. And once you start doing the research on the disease and what's going on, to kind of relate it to something, it would be almost being intimate with a child, and that just totally ends it right there. (6:18)	Again, I could feel how upset he was and missed the sexual and emotional intimacy with his wife. And his disgust at the thought of having sex with his wife because it would be like having sex with a child. I took this to mean she could no longer consent and without the emotional connection it just wasn't the same as having sex with his wife before FTD	Sex ceased with his wife around the time of her FTD diagnosis Sexual and emotional intimacy was not possible with his wife Sex with wife violates taboo of with sex with children	13
I have no free time. Both (spouse) and I owned a business together. We were both equals in the business. We're both financial planners, and we both had clients. We both	I could sense his total loss of partnership in business and in everyday life. He again talked about having to do everything. I took this to mean he truly relied on his wife to be his equal and perhaps his rock. He now has no	He has no free time "We" is now me. He runs the business and everyday life for both He and his wife are no longer splitting up stuff. He does everything	2

dealt with stuff, and I started noticing changes in when we would do joint meetings with clients. and I started noticing things just weren't right, and just one thing kind of led to another. I had to take over all the business aspects, but not only that. On the personal side, I've had to take over everything too. So, it leaves you virtually with no time because where you were splitting up stuff before, I now have to do everything. So, it's now to the point—she's in the final stage now, and it's at the point now she can't do anything for herself. I have to bathe her. All of her day to day activities that you would have to do, I now have to do all of those for her plus myself. So, I'm really doing the work of two people, brushing her teeth, bathing her, everything. (7:23)	free time and sounds totally exhausted and done. Ready for things to be done. Ready for this final stage to be over. Ready to be done bathing her, brushing her teeth, taking care of the business they used to run together. It seemed "we" is not just him and he is overwhelmed and tired and even mean to her now?		
Going to the gym for one. I find I don't have the time to really take the time for me. Personal entertainment, I like to go fishing or to do stuff on my own. I no longer have the time for that. So really, all of the stuff I would—all of the discretionary time I had before, you no longer have because your spouse takes up that time. (8:47)	It seemed like he resents his wife who he now refers to as his spouse for being sick. He says he realizes it's the disease, but he presents like he feels she chose to leave the relationship.	He does not have "me" time. He can't have his own time because his spouse takes up all his time	2
We would get together with friends and stuff, which now we can't. So, as the disease progresses, your social life and really all your activity and time starts changing. Back in 2016, I could go to the gym. I could still do some stuff. I just had to kind of keep an eye on her---but	As he was describing his/their social life as the disease has progressed to the point it is now, I began to feel closed in and claustrophobic. As he said, "Outside activities became smaller, and smaller, and smaller…" I began to feel almost squeezed. I can only imagine he might be feeling pressurized. Going out to eat	He/we can no longer have friends He can't leave her alone He can't have alone time He said, "She was just there but not really existing," As the disease progresses, outside activities get smaller, and smaller, and smaller When his wife was	2

she could be left on her own and she could be responsible. So, she did some activities on her own. She stopped driving but she could still do activities. She did pool aerobics, and she'd go up to the pool. She would do different activities and so would I and we were okay. As the disease has progressed, we have gotten to the point where—you get to the point where you can't leave her alone. I can't leave her alone for an hour and go to the gym like I could before.,	seemed to be the one thing that might have resembled the "we" of he and his wife and now that too is gone. I imagined someone gasping for air.	continent. things were okay His wife is incontinent now and things are not okay	
We can no longer get together with friends because of her behavior. She has behavioral FTD which is you don't know what she's liable to say or do, and there's no empathy or anything. So, getting together with friends or whatever or even family,. So, you would kind of—so if kind of makes it harder and harder to where you can get together with other people. 9:42			11
it go to be to where she was just there but not really existing			8
She has now progressed all the way to where the temporal part of her brain, her language skills she no longer talks anymore. So in the last couple months, she's progressed down to—you just keep progressing and as you progress, your outside activities and your outside stuff gets smaller and smaller and smaller,9:42			11
and we're now to the point to where we can't even go out to eat—she's incontinent—where up until the beginning of this year, we could still go out			11

to eat. She was continent. Things were okay. (9:42)			
Once she became incontinent—and she could also not sit still. So, we had to go to a restaurant almost like a buffet type where she could get the food immediately, and she could do stuff. We could eat, and then we could leave. But she has no—patience isn't really the right word. She's antsy. She just can't sit still or can't whatever. And she'd have to keep getting up and drumming her fingers, or that kind of stuff. So, to go to a restaurant and order food and wait for your food to get there and have a social conversation and stuff, that seized probably about a year after diagnosis.	I thought and felt that he is traumatized by having to watch his wife deteriorate right in front of his eyes. He now purees her food himself in the blender. He mentioned several times she has swallowing issues and it came across that her choking scares him. The fact that they no longer have connection and community with friends over shared meals seemed to be sad for him but his tone came across angry and frustrated. And as he described her being antsy and almost hurried and anxious it struck me that he seemed to be the same way.	His wife was incontinent and could not sit still He was irritated that his wife always antsy He has to puree her food in their blender He and his wife can no longer have shared meals with friends	11
So now we're at the point where we can't even go out to eat anymore, even simple stuff. She has swallowing issues, which is common. So she now cannot—I pretty much got her on liquids or puree-type food. I put in the blender and blend up her food. She had a smoothie today for lunch. She has swallowing issues. So, going out to eat, or going out to a restaurant, or getting together with friends and have a meal, or something like that doesn't exist anymore. (11:43)			1
It is hard. You're isolated. Your friends will stop by, but after a while that will slow down. Because they really don't know what to say, or do, or whatever. So, it puts friends in an awkward position. So that slows almost to a stop.(13:09)	I could feel myself start to tear up and I had to take a drink of water to keep composure. His isolation and loneliness were palpable even through the phone. I also felt a heaviness and sadness for his wife and for her losses.	He is isolated Friends eventually don't visit	11

Listen. It's good to have somebody to vent to, from time to time. To just, "Hey. this is what I'm dealing with."		He needs to be heard and have people check in with him.	5
To be honest with you, probably the best ones to deal with are fellow people that are going through it. That has by far been the most help. I belong to a local FTD caregivers' group. We meet once a month so we can kind of talk about what's going on. Or in the meantime. we can talk by phone. But we meet as a group once a month. I'm on—it's a closed Facebook group. The FTD Spouses. That has been probably the biggest help, being on that. And as changes come along, you can, "Hey, my loved one is now experiencing this. How are you guys handling this?" or whatever. And you can get 20, 30 different responses of what people are doing to handle that.(14:47)	I felt a sense of relief that he did have a connection to someone, something. I had the sense he was reminded during these group meetings that his spouse is his "loved one." Not just a chore.		10
The medical staff. Well, obviously never dealing with this before, it was a big learning curve for me. and I did a lot of research. And initially, we went to her primary care doctor who has known (spouse) personally, even outside being her doctor, has known her personally probably for 20 years. And actually, how is started how all of that started, is we live in (state). (16;10)	It struck me just how close he and his wife had been for so many years. To live the summers together in an RV is a true testament to their partnership and intimacy. To be close to a divorce and not really know why or what is going on had to be extremely heart breaking for both of them especially in the beginning when she might have had some insight into the fact that something might be wrong with her even though she was denying it to him. I again felt an overwhelming sadness and sinking feeling in my stomach.	He knew something was wrong with his wife He needed space from his wife He sought out medical advice . He was frustrated with her denial that nothing was wrong with her He knew things were bad and going to get worse He needed a break from his relationship He thought about divorce	6
And the last 10 years up to 2016, we would leave and go to the mountains of North Carolina during the summer. We would spend			1

the summers in (state). We had an RV and we would go up there. And when you're in an RV, you're in very close quarters. You're very intimate with each other because you're right there with—and everything you do is with each other. So, things just started really appearing to where "What's going on with you?" And it got to the point where we were heading for a divorce here. This is not looking good. This is bad. And things aren't good. And we were in (state) at the time. And I said to (spouse), I said, "Look. We need a break. Somebody needs to go home and somebody stay here. And let's take a break and see if we can figure out what's going on here because this is not good." And so, she decided to come home. She came home and I stayed. And after a couple of weeks in thinking of that, I said, "Okay, look. Maybe there was some hormonal or chemical problem going on." So I called her and I said, "Schedule an appointment with your doctor. And let's go talk to your doctor." And her response to was, "I just had my physical. Everything is fine. I don't need to see my doctor. I don't have a problem. You have the problem. (16;10)			
So, I said, "Well schedule the appointment for me. I want to go in and talk to your doctor." And so, I had a whole list of all the stuff that's going on with (spouse). And we went and met with her doctor. And I went down the whole list, and he said, "Well, let me		He sought a medical explanation for how the long list of his wife's concerning behaviors His wife denied the doctor's original diagnosis of depression	6

run some more tests and see if I can find what's causing this. Or what the problem is." I said, "What do you think the initial diagnosis says?" And he says, "Well I think it might be depression or something." And she goes, "No, no, no, I don't think it's that at all." But I want you to go to a neurologist. "It's not a problem. There's nothing wrong with me." (18:19)			
And so, we went to the neurologist. I took the exact same list to him. And his preliminary diagnosis—he did a few things in his office. And when I told him, he said my preliminary diagnosis is FTD, frontotemporal degeneration. I didn't have a clue what that was. And so, when he left and he said, "I want to do a MRI and more testing." And so, we came home and I jumped on the computer to find out what the heck FTD is. And I said, "(spouse), do you want to know anything/" And she said, "No, I don't have that." (18:19)	It seemed that he was slightly relieved to finally have something, a tentative diagnosis, that would explain what was going on with his wife. It might explain why their partnership was falling apart to the point of needing space and possibly divorce. And once FTD was the possibility he rushed to find out what that meant by looking it up on the computer. It felt like it only deflated him even more to know what the prognosis is of those diagnosed with FTD. I felt his frustration come through the phone as he told me that his wife did not want to know about the disease because she knew she didn't have that disease.	He was given FTD as the preliminary diagnosis for his wife's list of behaviors He did not have a clue what FTD was and relied on what he found on the internet He was scared about what he found on FTD His wife knew she didn't have FTD	6
The minute he said a form of dementia, she totally shut it out. "Because that's not my problem at all. My doctor's going to find I've got some vitamin deficiency or something." So she just went on with life like it was nothing…(20:15)	I felt this further confirmed she was scared and in denial about the diagnosis. It seemed that maybe she already had an inkling that something was going on with her thought process. And she was hoping the doctor was wrong. I could feel his anger start to well again as he said she just went on with life like nothing was wrong.	The minute dementia was mentioned his wife shut that diagnosis down His wife knew the doctor would find another reason He was frustrated as his wife went on with life like nothing was wrong	6
I read the stuff on FTD and just about fell out of my chair. Everything fit her. All the criteria, all the stuff fit her to a T. (20:15)	I could literally feel his physical reaction to how he felt as he read about FTD and is wife resembled the symptoms. He was emphatic and demonstrative as he spoke these words. He was blowing his breath as he spoke.	He was shocked and just about fell out of his chair reading about FTD He realized FTD was the reason his wife was changing	6

And then when I saw the life expectancy and that this was a terminal disease, it was very devastating. (20:15)	It seemed like he was reliving how he felt the day he discovered his wife was terminal. I was thinking I didn't know what to say to him. I didn't say anything, I just listened.	He knew his life with his wife would be over sooner than he thought He was devastated	12
We did the MRI and all that. The MRI actually showed when we went back in to see him, he changed it from a primary of FTD. He said there's a lot of vascular dementia damage done to the brain and he said, "So I'm going to change it to vascular dementia and by the way, I'm retiring." So that was that. (20:15)	I got the sense that he felt as if no one else could understand how his entire life had changed with the 3 letters, FTD. And the way in which he described the visit with the neurologist, seemed as if he felt even the doctor was cavalier about the diagnosis that had completely changed his life. It seemed as if this was the first moment, he was alone, truly alone without his wife.	The neurologist changed the primary diagnosis, but that didn't change his reality with his wife He experienced a change in his wife's diagnosis and learned the neurologist was retiring in the same breath He was treated with matter of fact not with empathy	6
We went to see his replacement neurologist, and the replacement neurologist looked at the file and said, you know everything I am seeing here I'm leaning towards, and we discussed what changes had taken effect and he said, "I'm leaning towards FTD as primary and the vascular dementia as a tagalong." So, at this point, I'm totally confused. Two different neurologists. Two different ways of looking at it (20:15)	I could hear his frustration and he came across almost aloof as he described his experience in trying to get a correct diagnosis. Because even with the "correct" diagnosis it would not change the outcome that his wife's time with him is short-lived.	He took his wife to the replacement neurologist to follow up He was confused by the reversal of diagnosis. What did that mean for him?	6
They were both single person neurologists and I thought, I am going to get another opinion and I want to go to a group of neurologists where they can collaborate or talk about her or whatever and see if I can get a consensus of what's going on here (20:15) because when I looked at vascular dementia, absolutely nothing fit (spouse). None of the descriptions, none of the side effects. Nothing fit (spouse). (spouse) is a marathon runner, physically fit, top-notch	I think he wanted to make it know he was in shock with his wife's diagnosis and the fact the doctors couldn't agree on a diagnosis was frustrating. He didn't say it, but he came across as desperate to find answers and perhaps felt the doctors were guessing and it was his life at stake. It seemed like he started to focus on finding the right diagnosis. Maybe that helped him stay grounded as he tried to wrap his mind around what was happening to him. It felt like this was happening to him. Of course, it was his wife with the disease but when he talked it was in reference to himself.	He wanted more opinions from doctors that worked and collaborated in an attempt to get an accurate diagnosis He did not agree with the previous doctors' diagnosis of vascular dementia Vascular dementia did not fit his wife's symptoms	6

physical health and everything under the vascular was overweight, diabetes, no exercise. Nothing fit. (22:03)	Granted that is probably because I was asking about how all this affected him.		
I scheduled with a group of neurologists. They looked at the file. They looked at the MRI. They let me look at everything. They did more testing on her. They came back with primary FTD and vascular dementia as a tagalong. They said it is quite common to have tagalongs with it. (22:03)	Again, it seemed important to him to try and get the most accurate diagnosis and to talk about what was found repeatedly during this interview.	He went to a group of neurologists to get more testing done on his wife He was given a definite primary diagnosis of FTD	6
So, trying to get the diagnosis or what and from the group, I'm all in, that's the hard part is getting it because it is hard getting a diagnosis on it. But we got the diagnosis. (22:03)	His words should signal a sense of relief that he finally got a diagnosis. But again, it was a diagnosis that was terminal for his wife and ultimately for himself. I could sense anger and disgust with what his life was going to be. And it was not what he had been planning.	It took considerable time and energy to finally get an accurate diagnosis It was hard for him to get a diagnosis for his wife	6
That was done and what I didn't know, I thought from that point on the neurologist being the brain doctor would be the one who would take you from here on out and basically what the neurologist said was there's no treatment. (22:03)	As he said this he sounded put off. I found myself sympathizing with him even though his overall demeanor throughout the interview was rough and disturbing to me.	He thought he would have support from the neurologist on his wife's treatment The reality that there is no treatment for his wife hit him hard	6
There's no cure. There's nothing I can do other than give you some medicines to counter some of the side effects of the things that are going on. But there's nothing I can do to treat FTD. There's no treatment.	He really stressed this part again, that the doctor just handed him the diagnosis and said sorry but it's terminal, no treatment, no cure. It felt like he was handed a death sentence with a "good luck" handshake.	He was beginning to understand there really was no cure and no treatment for his wife He was beginning to realize he had his own life sentence being handed to him	12
So you can come back and see me if you want but as far as you could really pick back up with your pcp and he could give you whatever prescriptions you need for agitation or you can't sleep or whatever the side effects due to FTD and so the neurologist was pretty much done with you	As he was explaining this, he had the tone that I suspect he felt the doctor had with him, dismissive.	He was alone with the diagnosis	6

once they have the diagnosis. (23:51)			
That part of the medical part I didn’t understand and being a part of the Facebook group, I noticed that’s overwhelmingly the situation. Once the neurologists diagnosed—there are some neurologists that will keep most of them, once you’re diagnosed, they’re done because there is nothing else they can do. (23:51)	He was again repeating the experience of once being given the FTD diagnosis being “dropped” by the neurologist because this disease is terminal and has no treatment. Because he repeated the information for several minutes, it seemed this might have been traumatizing for him.	He felt abandoned by the medical community He felt isolated	6
The primary key person to then take care of your needs from that point on would be a neuropsychiatrist. So, I looked around, found a neuropsychologist, and I actually found one that was training. He had just moved here. He had only been here for a couple of years. And he did his fellowship training and stuff under doctors who did research in FTD at (hospital). So, he actually had FTD listed under his expertise or whatever [dealing?]. So, we started going with him in November of '18. So we've been with him three or four months now, and he's been perfect. (23:51) (25:07)	He seemed to be hopeful that he might get some kind of “real” help from a doctor trained in FTD. But he still sounded dejected from what he has experienced so far with his wife.	He felt a sense of hope	6
He's got her on-- (spouse) has developed, as the disease has progressed, she got to the point-- we weren't needing any medicine until [end of?] '18. She started hallucinating, and she started being delusional. Somebody's going to shoot us and this and that. She had all kinds of delusions and stuff that were just totally off the wall, so it was time to get her on antipsychotic medicine.	I was listening to him and at the same time imagining what his wife must be going through and wondering if she knew in the beginning she was changing? I concentrated on listening and remaining present as he kept explaining his experiences.	He needed help He was frustrated with his wife’s behavior He was annoyed by his wife’s hallucinations and delusions He was scared	6

But you got to be very careful on that for FTD people. (25:07)			
So, we went to her primary care. Her primary care doctor was not comfortable giving her medicines for her problem-- prescribing her drugs for her problem. So, we found the neuropsych and went to him. He got her on medicine. We got the hallucinations and delusions stopped. And that medicine caused some side effects, and we've now got on a medicine that has now cause that to stop. So, we've got her on the right meds, and actually, we're due to see him tomorrow. So as far as the medical profession, that one's been a surprise and been quite eye-opening	He seemed thankful that he was able to find a doctor that helped with his wife's severe symptoms so that he could deal with her better.	He was helped He was surprised with the medical community	6
The neurologist should've really-- well, she did refer us to (spouse)'s primary care, which I know, in the group, quite a few of the neurologists refer you back to your primary care. That seems to be quite common. But I think the main one to really probably take care of you the best would be a neuropsych. And nobody really mentioned neuropsych (26:25)	The way he describes this, at this point as so many months later, it just seems like more of the same for him, being alone in his life without his wife or without any real support from anyone else.	He feels more informed than some of the doctors He found some help with a neuropsychologist He had to find his own way through the medical system to find help	6
I didn't even know what a neuropsych was, but I found out about neuropsychs through the Facebook spouses' group. That's how I found out about trying to find a neuropsych. And that, by far, that was the right move.	He was matter of fact and talked about why a neurologist would be done with someone once FTD was the diagnosis. And he reasoned why a neuropsych of some type would be better to manage the psychological side effects of the disease. I felt less uncomfortable as he described the relationship he had with the medical community. He was less corrosive.	He found working with a doctor to manage his wife's psychological effects of FTD to be good for him	6
. I just wish we had found that out and gone there sooner. So, I don't know if-- it's not really abandoned.			7

I can kind of see it from the neurologist's standpoint. There's really nothing more-- the neurologist is, really, strictly the medical aspects of the brain, and what happens with FTD, it becomes psychological side-effects. 26:52			
As the brain's being destroyed, you exhibit psychological issues. Some are giving money away. Some have all kinds of different issues or sexual issues or inappropriateness or hallucinations and delusions or whatever. But you develop psychological problems. So really, that is correct that the neuropsych is the right one to handle you, but it would have been better if that had come from the neurologist. I think the biggest problem is FTD is so rare that it's not run across that often. (26:52)	As he was describing how FTD affects a person psychologically, I wondered if he was trying to convince me or himself? He was calmer during this explanation than when he was talking more personally. Therefore, I was calmer.	He knows cognitively that FTD destroys the brain and causes psychological issues He thought this information would have been better coming from the neurologist FTD is rare	7
It's definitely not recognized. It's highly, highly missed by the primary care. The number one thing that I've seen is the primary care. (28:48)	It was as if he was wearing the "rareness" and missed diagnosis as an additional cross to bear.	FTD is not recognized by primary care physicians	6
Depression. That's the number one thing that the primary care comes up with is you're suffering from some kind of depression. They put you on medicine six months or a year, there's no change. (29:13)	He again was calm when he was talking about how PCP's miss FTD and think it is depression or anxiety. He was just matter of fact. It was easy for me to listen to him during this description. It was not terribly interesting and didn't really add to the interview, but it was a nice break from his anger.	He thought depression would be the diagnosis most often made instead of FTD	6
Then they refer you to a neurologist and say it must be something different. So that's very, very common. Luckily, we didn't go down that road. But that's very common with FTD. And that does nothing	Even though he didn't go down this road he knew about it in depth and wanted to let me know that he knew about it. It seemed important for him to let me know these facts.	He was able to get an accurate diagnosis for his wife faster than most	6

because it doesn't address the problem. (29:13)			
Probably not in the sense that-- other than maybe the neurologist contact the primary care directly and say, “Look, you've probably never seen an FTD or whatever. I'm going to refer you to some sites you can go to like The Association for FTD, or whatever, and you can learn a little bit more about it and know how to handle this patient of yours.” I think that would have been very beneficial. Probably coming from the Neurologist to the primary care would have been the right move there because primary cares really don't-- they don't see it. They don't face it. They really don't know how to deal with it. (29:56)	He was just reiterating what he had just said in response to me asking if he had anything else to say about the topic. Looking back and reviewing this interview I wonder if I wanted him to keep talking about this so that I didn’t have to hear more anger and disgust he had towards his wife and his situation?	He thought being referred to AFTD by the primary care physician would have been helpful	6
In that category, I couldn't be any better. I have a son and daughter-in-law that live five minutes away from me, and they're very involved. If I need to go somewhere or do something, I can drop her off there, and they can come over. They come over. They visit. They're involved with her. (31:03)	His voice was softer as he talked about his son and daughter -in- law and how they help him with his wife. It was good to hear he had help and that his wife had a break from him too.	He has help from his family	10
They have two small kids, our grandkids. They're three and five, and they talk good around the grandkids towards her. “Go give Nana a hug,” that kind of thing. So it's been very good as very as the family side. That parts been very good. I couldn't have asked for more. (31:03)	It seemed that he could appreciate that even though he wasn’t attached to his wife at this point his son allowed children to show love and affection to their grandma. It made me feel good to know that someone was able to do this for his wife.	His family is good to him His family is good to his wife	
Time has been the biggest thing. (32:07)	He started to amp back up with his tone and disgust.	He has no time	2
But I'm 65, and we've been kind of semi-retired for probably the last 10 years.	He was talking about how he and his wife had things set up in such a way that they could work	He is 65 and has been semi-retired for the last 10 years He and his wife	5

So, we don't solicit for new clients. We've got the clientele that we want, and we've kind of had it on cruise control. We kind of set everything up knowing that we wanted to be able to travel and to do some things and stuff on our own. (32:07)	part-time and make room in their lives for travel together and doing some things on their own as well. He seemed resentful that his time is being used for other things that what the plan was. He now had to take care of his spouse he was committed to but not attached to as his wife anymore.	had plans for their time after retiring He and his wife planned on traveling together He and his wife planned to travel alone	
So, let's make the amount of money we need to make to live comfortably. We don't need to make a ton of money. Let's live comfortably. And let's be able to do everything we want to do. So as far as workload, for probably the last 10 years, each of us individually has probably had the workload of half of a workload. (32:07)	He was describing how things had been over the last 10 years. He and his wife had worked equal amounts in order to live comfortably and to do the things they wanted to do.	He and his wife were beginning to live the life they had envisioned for last several years	5
So now that I've had to take over her half plus my half, I've got a full workload and less time. (32:07)	He started to get more pressured in his speech and his angry tone came back.	He has had to take over his wife's duties at work He has a full workload and less time	5
But with the job that I can do, luckily, I can work from home. So, I work from home probably three-- I come into the office maybe two to three times a week. And when I come in, I do what I need to do, but a lot of the stuff I can do at home; I can do after hours. So, when I come to the office, it's pretty much to meet with clients or that kind of thing. So, I'm lucky that I'm in the career and in the position that I'm in. Both (spouse) and I own the-- now, I solely own the company, but we jointly owned the company before. So, I've got a lot of flexibility. I've got support, stuff like that, work-wise. So, I'm okay. (33:00)	As he was talking about his career and how being a caregiver for his wife affected his work, he was less emotional and more matter of fact and his tone was even.	His career was not affected too much He is now the sole owner of his once shared business with his wife	5
If I'm in a regular 9 to 5 job and I work for somebody 40 hours a week, I probably would've	He continued to in a matter of fact tone about how if he had a regular 40- hour job he would have had to retire. This	He did not have to retire to be a caregiver for his wife	5

had to take retirement. And to be able to be a caregiver for (spouse). (33:51)	continued to be easy for me hear.		
So, I'm able to do it now. Like right now, (spouse) is at a daycare so I'm able to drop her off on my way to the office. I drop her off at a daycare. I come to the office. I do what I need to do. (33:51)	His voice was a little more pressured as he began to describe his day. He drops off his wife at a day care while he goes to the office.	He continues to be able to work He drops his wife at a day care when he needs to go to the office to work	4
And at 4:30, I pick her up from the daycare and we go home. So, whether I work from home or I work at the office or whatever, I drop her off at the daycare five days a week. So, I've got a lot of support. (33:51)	He was less calm and more pressured in his tone as he talked about taking his wife to day care every day until 4:30. and then having to take her home every day at 4:30. And that he does have support.	He has help taking care of his wife He is supported	10
Luckily, I live in a metro area. There's a lot of facilities, a lot of different things like a more rural area or not as natural of an area may not have. So, I've got a lot of flexibility that I think a lot of people would not have.	He sounded like he knew he had it better than other caregivers who do not have the supportive resources he has for help with his wife's care. And as a result, it is better for his own self- care too.	He lives in a metro area where he has access to support with care for his wife He has flexibility due to living in a metro area	10
And also owning my own company and having the flexibility of being able to work from home. But when we would go to (state) for six months, due to technology, we could-- as long as I had internet hook up and a phone, I'm in business. I could deal with the client no matter where I am. (33:51)	He was just describing their flexibility with work even when they traveled and lived in NC for 6 months out of the year. It was more matter of fact in tone.	He has/had flexibility to work from anywhere with the internet and a phone.	5
So that part of it really made it nice. So, for 10 years, we dealt with our clients. So, for 6 months, while we're here in (state), we had all of our client needs. We would meet with the clients. Everything that needed to be done face to face or whatever, we did while we were here. The 6 months that we would be gone, whatever we needed to	He again felt the need to make sure he explained how he and his wife ran their business. I believe he was doing this, so I knew just how much flexibility they had to move around and still work. It seemed important to him to tell me again.	He had work flexibility for the last 10 years He had a flexible work schedule to accommodate his lifestyle	5

deal with the clients, we talked by phone or over the internet and I could do everything. They could call in and I could talk to them just like I was sitting in my office. Had I not told them anything, they would've never known I was out of town. So due to technology, due to owning my own company and not having the 40 hour, 9 to 5, I had it quite easy, to be honest with you. (36:10)			
It's not. It's really not. I've referenced several times the Facebook spouse thing. Probably 90% of the spouses that are on there are female, the wives. And there are some men but by far the majority of it is women. I think the males, on the FTD side, I think male caregivers have it easier than female caregivers in this case. But women, it's tough. I mean men weigh more for them to pick them up and move them. And with FTD, they could be violent. (spouse)'s never been violent but a lot of these men are violent. (36:50)	I got the sense that he thought maybe he was complaining too much about his duties as a caregiver for his wife…so he began to talk about how the women who care for their husbands have it harder…at least from a physical standpoint	He felt female caregivers had it harder than male caregivers from a physical standpoint	3
And to have somebody bigger than you and violent, that's got to be scary and tough. (36:50)	He was referring to female caregivers taking care of males with FTD who are prone to violent outbursts. But I couldn't help but see the irony of how it seemed he was treating his wife sometimes. I wonder if she feels he is somebody bigger than her and violent, and is scared sometimes?	He was realizing that female caregivers might feel scared taking care of males who are bigger than they and violent	3
Yes, physically to be a caregiver to FTD, I think there is definitely an advantage to being the male caregiver. (38:00)	I wondered as he said this if he was thinking what it would be like for his wife to take care of him if roles were reversed?	There is a physical advantage to being a male caregiver for someone diagnosed with FTD	3
Yeah. I mean the men, they're violent, whatever they have them. They have called the cops on them or they fall and they can't	As he was talking about how society looks to the female as the primary caregiver he acknowledged he had always felt that way too. I wondered if	He had always thought of caregivers as primarily female	3

pick them up or they can't move them or scoot them. Or even when they become incontinent, (spouse)'s incontinent but I think it's easier with the female dealing with it than the male incontinence. I think it's harder on the female. And yet, as a society, the inclusion [inaudible] always look at the female as the primary caregiver and I did too. (38:24)	he is harboring resentment towards his wife for not only having to take care of her but for almost humiliating him by forcing him into a historically female role? Was this emasculating for him?		
And I think in this case, actually, the reverse role. If one of us had to end up with the FTD, I'm kind of glad the way it did end up, not necessarily on a selfish point but I think I can care for her easier than probably she could've cared for me. (38:24)	He was speaking from a purely physical standpoint as he was making this statement. I was sure to clarify that point with him. It seemed like maybe her would have been scared for her to take of him? I am wondering if he thinks about how well she would take care of him?	He is glad that it is he who is the caregiver for his wife and not the other way around. He thinks it is easier for him than it would have been for her to be the caregiver in the relationship based on gender	3
It's definitely going to get worse how it is today. It will definitely get worse. Get the right support. Get the right team to gather around you. (40:26)	I had asked him if there was anything else he would like to about being a male primary caregiver for a spouse/partner diagnosed with FTD that others in similar situations might find useful. This was is initial response and the uncomfortable feeling I had in the beginning of the interview returned. A type of icky feeling in my gut.	He wanted others to know if will get worse definitely. And to get the right support team gathered around you	7
If they're not exhibiting it now, they are going to start exhibiting psychological issues. So, you're going to need meds. I don't know any person that has FTD that's not on some kind of meds for some kind of psychological problem so I would definitely find you a good neuropsych. (40:26)	It seemed like he was really trying to be helpful to other folks that might be in his shoes one day but I just couldn't help but pick up on his disgust and resentment he had not only for the life situation he is in but also for his wife.	He wants other caregivers of someone with FTD to know having a neuropsychologist as part of the care team is essential.	10
Find you a good-- find you a good support group for you. If there's one around, get in an FTD support group (40:26)	It has seemed throughout the interview it has been the FTD support group that has essentially kept him afloat with advice, sympathy, empathy, and human connection during a situation that seems like the twilight zone a bit.	He felt a FTD support group is essential for those who are caregivers	10

I highly recommend the FTD spouse support group that's on Facebook. Being a closed group like that, you're actually vetted to be able to get into it, which is good because everybody can't just get in there and look around. So, you can say what's truly on your mind, and that kind of means there's some very intimate responses.	It seemed that he was really saying he found intimacy within this group and that is what he was missing from his relationship as a caregiver for his wife. While I understood cognitively what he was saying, I had some level of discomfort with hearing him express this.	He recommended a closed FTD Facebook group because of the discussions and intimate responses	10
Like we we're talking before about, "How's your intimacy, or whatever, with the spouse?" And by far, every person on there has stated, "There is no intimacy anymore." They're dealing with a child, and it's now an adult-child relationship. And that's a drastic change. (40:26)	When I hear him talk about intimacy, I assume he is talking about sexual intimacy based on his previous comments. It makes me cringe a bit when he compares the adult-child relationship and no intimacy anymore. I just didn't know how he really felt about that even though it is taboo and considered a crime in this country. Perhaps I am reading too much into his responses and should be taking them for face value?	He said no more intimacy exists due to the adult-child relationship that FTD has now caused	8
I started noticing change-- just like intimacy or sexual or whatever, it was just not really the same prior to the diagnosis. Just things were just-- it's like she's almost just kind of there and just not really fully mentally into the intimacy like she was. (42:25)	He started to notice more than her forgetfulness at work or with cooking etc. He started to notice how she was with him intimately. It had changed somehow and it really bothered him that she was not into him or their sexual intimacy.	He noticed change in the sexual intimacy with his wife after her FTD diagnosis	13
There's sex and there's making love. And the making love kind of almost seemed to dwindle away (42:25)	He seemed to be missing the emotional availability his wife was unable to give. Even though it sounded like she was going through the motions of physical sexual intimacy with him still.	He said there is a difference between sex and making love. The making love dwindled away as his wife's FTD progressed.	13
It was like kind of, "What's going on here?" And all spouses, you're going to have your ups and downs, and this kind of stuff, and all of that. But then it's kind of more and more of that, and it's, "Gee, we don't have any strains now. We don't have anything. The kids are	He was just explaining why he was so disturbed by her lack of ability to be emotionally present during sex. His explanation here seemed genuine and I was sympathizing for him rather than being bothered by what he was saying.	He couldn't understand why they were not as close as he thought they should be since the kids were grown, finances were good, and they were traveling and on top of the world as they had planned.	13

grown. It's just us. We're on top of the world. We're traveling. We don't have a care in the world. And yet, why are things like this? (42:25)			
And why do you have to bring something up? Or why do you have to keep saying something like"-- many times I'd say to her, "Mentally, you're not into it." And that really was-- I mean, I didn't know it at the time, but, I mean, that really was the case. So, this was all pre-diagnosis. (42:25)	He again seemed genuine as he continued to explain what he thought was going on in his marriage. This was pre diagnosis of his wife. He didn't include her response to his constant questions of what was going on. I wonder what she told him?	He knew something was wrong pre diagnosis of his wife's FTD because she was not mentally into making love to him.	13
I would say, once you get the diagnosis and you get online and you do the research and you find out, really, about this disease, if the intimacy is not gone by that point, it's going to go very fast because once you really see what you're dealing with, it changes your mental perception. (43:50)	He was pointing out to others who might find themselves in his situation one day, that if the emotional, mental, and sexual intimacy is not gone it will be gone quickly. And he continued with the fact they will really see what they are dealing with…and it changes the caregivers' perspective. I began to feel his anger and disgust creep back into the conversation. It's not that I have never had hard and disturbing conversations with people but he was so raw and the pain was palpable. I felt for him but more for his wife.	He wanted other caregivers to know intimacy goes quickly after the FTD diagnosis. He experienced that once intimacy goes in the relationship it changes the mental perception of the well spouse.	13
The intimacy. Just even day-to-day-- yes. That was part-- but, I mean, everything about the relationship together. (44:29)	I had asked him if he only meant the sexual intimacy was lost. He clarified that yes, he meant that but also every other part of the relationship together.	He experienced a changed in intimacy in the day to day relationship of what it meant to be together.	13
Whether it's preparing a meal, and it's like-- when you have FTD and you're losing your executive functioning, you can't really follow a recipe anymore or you can't-- Step A, Step B, Step C. You can't do that kind of stuff anymore	He was just simply continuing to explain the changes he experienced in his relationship with his wife after the diagnosis. I felt like he was calm as he described this part.	He experienced changes even in the mundane task of preparing a meal with his wife after FTD entered the relationship.	8
We were both professionals and on equal ground and equal terms, I could see changes in her	He was again describing their proximity in the relationship. The lived together 6 months out the year in a RV in North	He knew there was something going on based on his relationship with his wife not only	1

professionally too. So not only on the personal relationship but on the business relationship I could see changes, so I knew something was going on. More than just-- but it was every aspect. It was from intimacy to husband and wife to business partner to business equal to all of that, from one end to the other. (44:29)	Carolina, they worked and ran a business together, they essentially were joined at the hip.	from a personal perspective but from a professional standpoint as well.	
My initial thought was, gee. We're getting on near retirement. Are you just getting tired of it and you don't like it anymore? Or you're just getting, you're not applying-- I took it as she wasn't applying herself anymore. Just kind of copping out and copping out on everything.	He was talking in terms of their business, but it felt like he was wondering that about their lack of intimacy too. Was she just getting tired of him and not applying herself to loving him anymore? He didn't say that, but it felt like that is in part what he was implying.	He wondered if his wife was just getting tired of their life together?	1
And it just kept getting worse and worse, and then we were fighting and stuff and then it was like-- I would get in the car and just go for a ride to just vent and settle down and bring your emotions back down so we could get back together and move on. (45:21)	He was having a hard time trying to wrap his mind around why his wife was seemingly rejecting him and the life they had built together. He began to get ramped up emotionally again as he was describing this memory. I was quiet and listened.	He was confused and hurt by what he perceived as his Wife's rejection of him and their life together.	1
And then you'd find out in the afternoon, here it is again and you're off in the car again. It's like, holy crap. And it's every day	He was very intense as he explained what is was like to have to keep taking drives to calm down during the period of time he felt rejected pre diagnosis. He didn't want to fight with his wife so he would go for drives	He would find himself in the car everyday trying to calm down.	1
And it's like, okay. This is not how we're going to spend the rest of our life together. This isn't going to work.	As he was explaining how hurtful these times were for him, he again, didn't describe how his wife was answering him. It seems like he was continually met with her inability to meet his emotional needs.	He did not want to spend the rest of their life together the way it had been going.	1
We're going to get a divorce or whatever it is, but this is not going to work. So yeah, it was really every aspect of our	He had contemplated divorce based on how he perceived his wife and her lack of caring about him and other aspects of their relationship. I could tell he	He was thinking about divorce.	1

life. It was affecting everything. (45:21)	still is emotionally bitter and traumatized by his lot in life. I vacillate between sympathy and feeling disturbed by what he has to say.		
It's been straight downhill. And see that was another thing (46:52)	He was explaining his experience with his wife's FTD diagnosis. It has been straight downhill…not plateaus. He sounded irritated and almost cheated out of life.	He was amazed at how straight downhill his wife went after being diagnosed with FTD.	1
When the initial doctor did the vascular, came back with the vascular and I looked on line and stuff, I said nothing fits. I mean, even as time progressed I could see nothing that fits, because the vascular was more of a stair step decline. They would drop down, and then they would level out (46:25)	He was explaining that the original diagnosis of vascular dementia didn't fit his wife based on the progression of her symptoms. He was very adamant that he just knew the diagnosis was wrong. He seemed to pride himself in finding the correct diagnosis. But unfortunately that didn't change the trajectory of his wife's outcome.	He knew that the initial diagnosis was wrong.	6
(spouse) from day one never levelled out. Every month was worse than the preceding month. So she has gone straight downhill prior to diagnosis, through diagnosis, and right on up to today. (46:25)	He was telling me how his wife never levelled out but just kept/keeps progressing and getting worse every month. Again, as he is describing this process he sounds disgusted and tired and done.	His wife never plateaued in her progression of the disease.	12
We're about at the point for a hospice to come in. So, she has progressed downhill every month worse than the preceding. 46:25	He was explaining that his wife is at the point of actively dying and it is time for hospice. He did start to break down and sounded as if he was crying as he was telling me this. I was still uneasy as I actively listened to his story.	His wife progressed every month downhill and is at the point for hospice now.	12
Probably my biggest issue that I have is that it's so easy to lose your patience. It's easy to yell at her, it's easy to, "Come on. Help out," or whatever. (48:15)	He became more agitated as he explained how he sometimes loses his patience with his wife and continually tells her to help out or whatever. My feeling of the ick factor returned as I couldn't help but think of his wife.	He knew his biggest issue was having patience with his wife.	5
She's like a blob or a zombie. (48:15)	When he described his wife as a blob or a zombie I didn't know what to say so I remained silent and let him continue to talk. I felt uncomfortable and worried for both he and his wife. And yet I was grateful for his honesty in explaining his lived experience.	He saw his wife as a blob or a zombie.	11

Just she's gotten now to the point where she's just sitting there like a zombie staring at you. (48:15)	I was wondering if he even sees her as a human being? Let alone his spouse? I know he doesn't see her as his wife anymore because he stated that earlier in the interview.	When his wife looks at him all he sees is a zombie staring at him.		11
And it's like, "Help me out. Pick your feet up." Or now I'm having to brush her teeth, and it's, "Come on. Just open your mouth. At least do that.	As he was telling me these details of what is like for him to take care of his wife, I felt his frustration and it seemed like maybe she was his penance in his mind? Whatever he had done in this life or the one before, he was paying for by taking care of her in the state she was currently in.	He said "help me out. Pick up your feet." Comments he made while trying to dress his wife. He said, "Come on. Just open your mouth. At least do that." Comments he made while trying to brush his wife's teeth.		4
And I know, personally, I don't say it enough, but I need to keep at the forefront of my mind it's not (spouse), it's the disease. A disease is what's doing this. Not (spouse). (48:15)	He was explaining that he constantly has to remind himself that it's the disease, not (spouse) being difficult towards him purposely. He was getting louder and sounded frustrated as he might feel in the moment with his wife.	He had to tell himself constantly it is the disease acting, not his wife.		1
And it's too easy-- I mean, every day I'm blaming-- blaming's not the right word. I'm on (spouse)'s case because it's so easy to say it's (spouse)'s-- "(spouse), lift your foot up so I can put your pants leg on," or whatever. "Do this." "Do that." "Help me out." "Do this." "Do that." "Open your mouth," or whatever. (48:15)	I believe his raw experiences came through clearly when describing how he is to his wife when he forgets it's not her fault she can't lift her foot, open her mouth, or do things she used to be able to do on her own. It was hard for me to hear his words and I felt a deep pit in my stomach. An uneasiness. I wanted the conversation to be over. But I also wanted to know what it was really like for him as a primary caregiver.	He was frustrated and at times took it out on his wife verbally. He forgot it was not his wife "doing" this to him. He blamed his wife.	8	1
And it's easy to yell at her, to blame her, to whatever. "Sit down," or "Don't do that," or "Why did you do that?" or. It's very, very, very easy to blame your spouse or to take it out on your spouse rather than to keep at the front of your mind it is the disease. It's not your spouse. That's probably been the toughest thing I, personally, have had to deal with. (48:15)	He continued to give examples of how he blames his wife sometimes and yells directives at her. He tried to say that he tries to remember it's the disease and not his wife trying to be difficult. However, I got the feeling that even if he did remember it's the disease he would still yell directives at her out of his own frustration and feeling like a victim.	He would blame his wife. It was the hardest thing for him, to keep at the forefront of his mind, it is the disease making his wife behave this way; it is not his wife willing trying to upset him.		11
I look back on the pre-diagnosis relationship and I look at how I treated her and dealt with her and I	He was upset as he was telling this information. It was apparent he believed that his wife was trying to hurt him prior to both	He would get upset with his wife all the time and ask her what was her problem.		1

would just-- I mean, I would jump her case all the time 50:37	of them knowing that a brain disorder was in play. I can’t help but wonder if he was ever able to get over those feelings of betrayal and hurt even after he knew she had a form of dementia?		
“(spouse), use your brain. What are you doing? Use your brain. You're very intelligent.” She went through college with straight A's. She went to social work for a year and decided she didn't like graduate social work and switched to law. She got her law degree and she's got an MBA. She's [inaudible] as a corporate attorney. (50:37)	As he was telling me all his wife’s credentials, it seemed like he was scared; He was angry and scared that his very intelligent wife, who might have been the driving force of their business, at least the brains, might not be able to keep things going for the both of them. I started to understand his anger better. However, he still struck me as at least verbally abusive to his wife. That continued to make me uncomfortable.	He knew his wife was very intelligent. He could not understand how his wife, who had multiple advanced degrees, could not get simple tasks done.	1
She's very, very intelligent. Very smart. Very knowledgeable. And yet, over and over and over I keep saying to her, “(spouse), use your brain. Use your brain.” (51:18)	He was again portraying how smart and capable his wife was and yet he kept telling her to use her brain over and over and over. I couldn’t help but think how she must have felt to be keep being told to use her brain while knowing she was trying. I wondered if she was aware what was happening on some level and perhaps felt her husband wasn’t being a good husband or friend to her? Did he really think she was trying to piss him off for that long? And if so, why did she stay? I felt like his anger was transferring to me a bit.	He knew his wife was very intelligent. He kept telling her to use her brain repeatedly. He was frustrated with her lack of caring about him and his feelings.	1
So, for probably at least two years pre-diagnosis, I was on her case all the time. “What are you doing?” “Why are you saying that?” “What's going on?” “Don't do that. Use your brain.” 51:18	His frustration level over the years of being a caregiver and even pre diagnosis was coming through the phone line. For 2 years he was on his wife’s case all the time. I don’t know if I could have taken him for 2 years on my case…dementia or not? Maybe she was afraid to ask someone else for help? And why did he stay? If he truly thought she was doing this to him purposely, why did he stay? I know he had talked about divorce but 2 years of “being on his wife’s case” is extreme. Why did they both stay? I wonder if she ever used that	He was on his wife’s case for 2 years pre diagnosis about all of her actions He was trying to make his wife act differently He was trying to make his wife use her brain	1

	phrase with him . . . use your brain? He uses it so often it made me wonder if that was her way to get at him when she was well?		
And come to find out, she was using the best part of her brain that she had. It's just the brain was going away. 51:18	I couldn't tell if that helped him handle the change in the relationship or not? it didn't seem to help because he was already hurt and resentment had already been built up.	He realized his wife was using her brain to the best of her ability He learned his wife had a brain disorder that was causing her behavior	8
And neither of us knew it. She couldn't tell me there was stuff going on because she doesn't know it. And that's probably the only good part of this disease is I don't think she has ever really fully comprehended what's going on. 51:18	I still wonder as he is saying this if she did know? I have heard other accounts from people diagnosed with FTD and they have said they did know in the beginning. I wonder if she was afraid to tell him based on his behavior and reactions to her not being well? At this point, I felt less affected by what he was saying because I started to wonder about his wife.	He realized his wife had a brain disorder He thought neither he or his wife knew she had a brain disorder	7
So, I look back on the pre-diagnosis and how I treated her back then and I feel guilty and stuff about that 52:09	He was saying he felt guilty about he treated her pre diagnosis. I was wondering if he feels guilty now about how he is treating her? When he tells her to lift her leg, open your mouth…? I definitely felt torn by his responses. I am wondering if that is how he is feeling too?	He felt guilty about how he treated his wife pre diagnosis.	7
But I've had to kind of just accept it and move on and say, well, that's-- we didn't know it and that's life. And I'm sorry about it, but let's move forward. 52:09	Would his behavior been ok if she didn't have brain disease? She probably would have been treating him the way he was used to so maybe his behavior would have been better too? It seems like his feelings were extremely hurt by her actions that were caused by FTD. I am not sure he was able to get past that and move on?	He is sorry about how he treated his wife pre diagnosis. He has to accept his behavior and move on with his life	7
Right. And it's so easy to blame them and to take it out on them because they cease to properly function 52:44	This was his response to me saying to him it seemed like he took things personally while not knowing what was happening to his wife. His answer of "it's easy to blame them." In the sense that there is a them and the rest of the "normal" population. Saying they cease to function properly really seemed to dehumanize his wife completely. I thought maybe I	It was easy to blame his wife for not functioning properly due to her illness	11

	put him on the defensive and that cause his more severe answer?		
You basically really lose everything 53:46	He was just reiterating and summing up towards the end of the interview the take home points for me. He seemed genuine and sincere. He also seemed hurt, bitter, and angry. It felt like he was a victim of FTD caregiving	He lost everything.	12
She was diagnosed probably from about, mentally, I would say probably the first part of 2017. First quarter, probably, somewhere of 2017 I ceased mentally to view her as my wife anymore. 53:46	He continued to talk about how he lost everything as a result of his wife's diagnosis of FTD. He on to give a timeline of when he stopped viewing his wife as his wife.	He stopped viewing his wife as his wife. He mentally no longer saw his wife as a wife.	8
At that point, I was more a widow. I viewed myself more as a widower than I did a spouse. 53:46	He was being honest and said he viewed himself as a widower than as a spouse. This was one step	He viewed himself as a widower not a spouse	8
And yet, she's still here. She's still living. She still exists. 54:25	He was acknowledging while he views himself as a widower his wife is still alive, still exists in body, still living. Yet he has had to view her as other or technically dead to be able to cope as her primary caregiver	He views himself as a widower but his wife still exists, is still living, and is still here in body	8
But, yeah, to me-- and it's quite common. I've noticed through the group, too, it's not just me, but it's quite common to where you stop viewing them as your spouse. And that was tough. That was tough to stop-- to start viewing you as a widower. 54:25	It seemed like he was trying to normalize how he feels more like a widower than a spouse. He said it was tough to start viewing himself that way. This was the first time something other than anger came through in the interview. I felt more empathy for his at this point. Although, I was still concerned for his wife	He thought it was common for spouses of someone diagnosed with FTD to identify as a widower It was tough to identify as a widower	8
You're a widower, but the spouse is still there. So emotionally, mentally you're a widower 54:57	It seemed important to him to state again how he feels and identifies more as a widower because his spouse is emotionally and mentally unavailable.	He identifies as a widower from an emotional and mental point of view.	8
And you're a caregiver to a child. You're a widower and a caregiver to a child. A big child. 54:57	He really stressed this: he is a caregiver to a child and a widower at the same time. He sounded stressed out and frustrated and angry. I felt sad as I listened to him bring home	He identifies as a widower and a caregiver to a child He is a caregiver for a big child not for a spouse	8

	the main take-aways from the interview.		
And we males are not the one that's primarily looked to, or whatever, as being caregivers. 55:20	He was adding that he has a lot on his plate as a caregiver especially since males are not primarily supposed to be caregivers.	He is more stressed out as a male caregiver since males are not usually the ones looked to for caregiving.	3
think it has in the sense that I look at my male friends and comments, or whatever, that I get from males. And it's more a, "Gee. I'm sorry what you're dealing with," or whatever.	He was telling me the difference in advice, empathy, and sympathy he gets from his male friends versus his female friends or acquaintances. He said he felt more real emotion from the females. At least that is what I was taking away from this statement.	His male friends could not connect with him on the emotional level that he needed as a primary caregiver for his spouse.	3

Appendix H

Participant F Analysis and Coding

Participant F Statement	*My observation during interview/reviewing interview*	*What is the meaning of the statement*	*Theme Code*
It's completely turned around, okay? :41	I asked if being his wife's primary caregiver has impacted their relationship. This was the beginning of his answer. He was very matter of fact in his answers but his non- verbal communication was that of irritation or anger. He was irritated a bit when he arrived because he said I did not tell him which Panera bread we were meeting at…that there were 2. I double checked my email and I had…I apologized anyway and thanked him for being there.	His relationship with his wife has completely turned around since he is now her primary caregiver	1
My wife was a kindergarten teacher until the end of 2016. Went to work every day, was very good at her job. Took care of her children. :41	He was explaining how independent and how much of a caregiver his was in her life before FTD.	His wife was a kindergarten teacher, went to work every day and was good at her job. She was a great caregiver for her students.	N/A
[Ran into?] somebody and we had a situation, and I had noticed it at home, that she was saying things that didn't quite fit the conversation we're in and that's just not like her. :41	He was saying other folks noticed some of the same behavior they had noticed at home with his wife. She had been saying things that didn't quite fit the conversation and it wasn't like her. As he was talking he was antsy.	He and others noticed his wife was saying things that didn't quite fit the conversation and that wasn't like her.	N/A
She's very precise, worked in the box because structure as a kindergarten teacher worked very well, okay? :41	As he was remembering the course of events he seemed to be mad.	His wife was always precise and structured especially as a kindergarten teacher.	N/A
And I said, "Are you sure you're--" it'd been going on for a few weeks. I said, "Are you sure things don't happen to you at work like this?" :41	I just listened quietly as he continued to tell me about how things happened to his wife and how that all has impacted him and their relationship	He questioned his wife if she was answering things not quite right at work the same as she was doing at home	N/A
And she said, "No." I said, "Okay." :41		His wife said she was fine at work and he accepted that	N/A
And then she came home one evening and said, "I didn't want to show you this, but I'm going to." :41		His wife shared with him something from work	N/A
So this [inaudible] she had a very difficult class. And one of the administrators wrote, "You said something that was	This was evidence that his wife in fact was having the same issues at work that she was having at home.	His wife's administrator wrote her a note to ask if she was okay due to	N/A

kind of out of context. Are you okay?" :41		saying things out of context	
So she declined pretty rapidly, okay? :41	It seemed that his wife didn't plateau in the beginning like sometimes is the case with others diagnosed with FTD	His wife declined rapidly	N/A
We went and did-- which they were very aggressive in trying to find a diagnosis. I think that probably to a T with FTD, probably not well known to others. But we were very lucky we were able to find a few local neurologists. :41	His wife got the diagnosis of FTD faster than most. I noticed he was talking fast, and the diagnosis was fast, and his wife's progression was fast. I felt like he wanted to be in the study but didn't like being away from his wife for this long.	His wife was diagnosed with FTD quickly	6
We know a lot of people who are able to expedite our appointments. 2:26 I have greater flexibility at work, so I said, "Any cancellation you have, I will take, no matter what it is," so we were able to push our appointments up 2:26	This was important to note because not all situations are created equally. He was very determined to get his wife the best care he could and in a timely manner. I was thinking how scary it must have been for him to know this was happening and having no control over any of it besides getting appointments faster.	He had connections and was able to get his wife's doctor's appointments expedited He had flexibility at work and took any appointments that he was offered to push up the appointment	6
When we arrived at the (name) FTD Center and between that [inaudible] psychological exams and the like, they were able to come to a FTD diagnosis very quickly. 2:36		His wife's doctors were at the University of Pennsylvania FTD Center and a diagnosis of FTD was made quickly	6
I understand from other people and the people I'm exposed to that this takes a very long time usually. 2:36	I knew this to be true based on my research and speaking with other caregivers for this study. He did everything right for this to happen so quickly…flexible for appointments, access to experts in dementia/FTD, and high awareness of his wife's behavior	He knew most of the time getting a diagnosis of FTD takes a lot longer	6
We got our diagnosis within six months 2:36	I noticed he used "we" instead of saying his wife got the diagnosis. I really started to get the sense of how much he loves his wife and is still in love with her	*They* got the diagnosis within six months	6
So as for the relationship with my wife, she has progressed, unfortunately, very quickly 3:21	He has repeated some of the same statements in just the first 3 minutes. I was thinking he must be traumatized to a certain degree. I was picking up on his anxiety as he continued to tell me about his experiences.	His wife progressed very quickly	1
She is pretty much non-verbal now, okay? 3:21	He was very open but at the same time guarded in a pissed off manner. As if he was just pissed at this disease and at the way his wife was going to die. How hard	His wife is now non-verbal	1

	this all must be for he and his wife.		
But she's quite happy 3:21	I was wondering how he knew she was happy? But after so many years being married maybe it was just a matter of knowing the other person that well even if the brain disease is in charge of her now.	He believes his wife is quite happy	N/A
In terms of our relationship, it's more of an almost parent-child at this point, which is very painful 3:21	I could see how painful it is for him. It felt like he didn't want to be talking to me but was doing it for the sake of helping others by telling his story. It was visibly noticeable that he was uncomfortable talking about it all.	His relationship was almost parent-child with his wife which is very painful for him	8
we take heart in the fact that she's in no physical pain. She is very happy 3:21	He again is talking about her happiness. This must be what keeps him going emotionally…is to believe she is happy and in no physical pain.	His wife is in no physical pain and is happy based on his observation.	N/A
Very little medication probably just a small dose of antidepressant, which may not even be necessary. 3:21	He seemed to be proud of the fact that his wife needed little medication. Or perhaps it was that he didn't want her on a ton of medication in hopes to keep his wife present longer?	His wife is on very little medication just a small dose of an antidepressant.	N/A
more parent/child [inaudible], okay? And that's where we are. 3:21		He and his wife's relationship is more parent/child now	1 8
She can't be left alone. 3:21		His wife can't be left alone	5
I'm fortunate that my employer, when I told him about the diagnosis, said, "You now work from home." 3:21	I thought how fortunate he was that his employer was flexible which allowed him to be more flexible in the type of care he can provide for his wife	He was fortunate that when he told his employer about his wife's diagnosis he was told, "You work from home now."	5
So I'm able to be with her 24/7, but that's a tough job. 3:21		He was able to be with his wife 24/7 but that was a tough job	5
So we've been able to find an excellent adult day center that takes really good care of her and actively involves her. 3:21	I thought it was so important that he knew that getting outside help was integral to everyone.	He found an adult day center for his wife that takes great care of her and actively involves her	10
I wanted her to have a meaningful, as best we could, a meaningful existence 3:21	It made me think this could almost simulate her going to work everyday	He wanted her to have a meaningful existence	5
She goes there four days a week from-- now we've extended her hours, so she goes from 9:00 to 2:00. 3:21		His wife goes to the adult day center 4 days a week from 9 am to 2 pm	4
She can go [inaudible] for-- [inaudible] extend her hours. She can go in the-- they call it		His wife could go for the medical program at the adult day center	10 4

the medical program, from 8:00 to 4:00, but I chose to stay with the 9:00 to 2:00. 3:21		from 8 am to 4 pm but he chose 9 am to 2 pm for his wife	
She was going 9:00 to 2:00 before in more of a-- they call it the social club, 5:10	He was telling me about how the day center has different levels of care. It seemed very important to him that his wife be taken care of well and according to her cognitive abilities while still being safe	His wife went for more of the day center social club at first	10
but now she requires a little bit-- she likes to wander. So she's in that locked down part of the facility which is much bigger 5:10	As he continued to tell me his wife's weekly routine at the day center I just listened and hoped that this wasn't' too much for him	His wife eventually needed more care at the day center due to her tendency to wander. She was not in the locked unit of the facility	10
She wants to get up and walk, they let her walk. So she's good there. 5:10		The day center his wife goes to allows her walk around the locked unit. He believes she is good there.	10
And I've hired two young ladies to stay with [(spouse)?] on Mondays from-- those hours plus [inaudible] 3:00 to 6:00. 5:10	He really seemed to understand what he needed in order to keep his wife at home instead of placed in a facility. He seemed to understand that he needed a break and help too. Not something that every caregiver I have met with seemed to know or realize. Or were able to set aside guilt.	He hired two women to stay with his wife on Mondays from 3-6 after she gets home from the adult day center	10
It's a long weekend for me: Saturday, Sunday [laughter], 24/7. 5:10	He laughed as he said the weekends are long since he is taking care of his wife 24/7 mostly by himself at home.	Weekends are long and exhaustive because of he is with his wife 24/7 taking care of her mostly by himself	5
I realized I needed a little-- plus I'm working from home. 5:10		He realized he needed a little time for himself…by himself.	2
I've just started taking piano lessons at the age of 62. 5:10	I thought this was a great way to create and reduce some stress. He seemed to lighten up a little as he was telling me about his piano playing.	He started taking piano lessons at the age of 62	2
So, I have someone cover piano lessons 5:10	He is employing good self-care.	He has someone stay with his wife while he goes to piano lessons	2
My children are excellent [inaudible] they have full-time jobs, and I can usually call on them for most, but [inaudible] cover piano lessons [inaudible] end their day early 5:10	He was saying his kids are great and help out but they have full time jobs and they would have to leave work early to stay with their mom while he goes to piano so he just hires someone to come and stay while he goes.	His children are great with helping out but they work full time and would have to leave work early to cover his piano lessons	10

I said, “No, we'll just pay somebody to come in.” 5:10	He sounded disheartened as he said it really is a parent/child relationship now between he and his wife.	He pays for someone to stay with his wife while he goes to piano lessons.	10
So [inaudible] it's more of parent/child 5:10		He views his relationship with his wife as a parent/child relationship now	1 8
It'll be 38 years in September 6:22	I asked how long he and his wife had been married.	He has been married for almost 38 years	N/A
Thanks. It was a good ride. It still is a good ride, just a little different ride. 6:32	He was kind of smiling as he said it was a good ride and still is but just different. I wondered if he really meant that it was still good?	He thought his 38 year marriage was a good ride and still a good ride but just a little different now.	1
Yeah, there probably isn't much (emotional connection) 6:47	This was his response to me asking about his emotional connection to his wife now. Again, he was pretty matter of fact in how he answered but it was all done with an overtone of anxiety as we sat there talking.	He doesn’t have much of an emotional connection now with his wife	1
There probably isn't much [inaudible] just, it's a caregiver role, okay? 6:47	This statement really struck me. I had not heard anyone say it like this before…very blunt and honest without trying to dress it up.	He had no emotional connection to his wife other than his caregiver role for her	1
she's lost some of the motor control, so she can't kiss, she can't stick out her tongue [laughter] 6:47	As he was giving me a concrete example of how they used to connect physically and emotionally he laughed nervously….it seemed so perhaps he would cry?	His wife has lost some motor control and can’t stick out her tongue to kiss anymore.	13
We were just at a swallow test this week to make sure that at least the function's there. 7:08	He went from talking about his emotional connection to back to talking about other health aspects about his wife that are quickly changing. I just continued to listen because I didn’t want to interrupt his flow and his story.	His wife had a swallow test recently to make sure she still has that function.	N/A
There's going to be-- the pneumonia factor with FTD is horrible, so we're trying to [give it?] everything we can between pneumonia shots, between trying to prevent aspiration any way we can. But the mechanism is in place, it's more of a slowdown thing. [inaudible] and she forgets to swallow 7:08	I couldn’t imagine watching a spouse for choking and aspirating because she has forgotten how to swallow. It sounds scary and very anxiety provoking not to mention so sad.	He know there is a real risk for pneumonia with FTD. He gets her pneumonia shots to help prevent it His wife sometimes forgets to swallow	12
So 2017. February, right about two years ago, we got the official diagnosis 7:44	He was telling me she was diagnosed about two years ago around this time.	His wife was diagnosed 2 years ago to the month	N/A

It was shocking when they said, “She has FTD,” and I said, “She's getting flowers?” I literally said that 7:44	As he was talking I was very aware of how painful it was for his to share his story and the story of his relationship with his wife.	He was shocked when doctors said his wife had FTD. He asked if she was getting flowers.	12
Who will hear about this? Who will hear about this? Who would know about this? 8:01	I wasn’t sure if he was asking about my study or if he was talking about not knowing what FTD was/is? I just kept listening.	He wondered who had heard about FTD? Or who knew about it?	6
Yep. Yeah. Communication is just so difficult now. 8:17	His initial response to me saying it sounded like so much was at a loss in the relationship.	Communication with his wife is so difficult now.	1 8
Up until recently, she would answer and have a [inaudible], or at least she would have a way to give us her thoughts. 8:17		His wife had been able to at least have a way to communicate her thoughts but not anymore	1
at least she used to react most of the time, too. “(spouse), would you like this or this?” or “(spouse), what would you like to have for dinner?” And she would give some kind of response, 8:17		His wife used to be able to respond to simple questions like what did she want for dinner.	1
But we're at the point where but now it's-- sometimes it's no response, and other times we can't figure out what she's trying to say, which is hard. 8:17		He can no longer figure out what his wife is saying His wife often does not respond to him	12
We thought we had-- we all went to the Catholic school, so she has that perfect Catholic school citizenship [laughter]. So that's interesting. And I thought that we had a kind of way to communicate. I just remember sitting at the table and just could not figure out what she wanted to eat. So I'm like, “All right. [inaudible].” And she wrote down apple sauce. 8:17	I was kind of lost as he was sort of rambling about things but I knew he was going to get back to what he was trying to say soon. Talking about his experiences had to be a little stressful so I didn’t want to seem ungrateful or like I was trying to rush him. and I didn’t want him to think I thought I knew what he was going to say.	His wife was able at first, to write down what she wanted to eat.	N/A
Okay. So I thought, “Okay. Here is a way to communicate.” 8:17	It seemed he was trying so hard to get to his wife as he remembered her being. It felt like out of his	He thought he had a new way for his wife to communicate through writing.	N/A
Unfortunately, that made it the last thing we could read. Now she writes. She writes, but except for her name, it's-- so I'm considering getting a storyboard. 8:17		His wife’s ability to communicate through writing was short lived. He can no longer read what she writes other than her name.	N/A
Is that what you call it? Just point to the item? Yeah, I've got that somewhere 9:40	He is so desperate to continue to communicate with his wife. I can’t imagine what this must be	He is considering getting a storyboard to see if his wife can at	N/A

	like for him. To see his wife but not have the same relationship with her because she is incapable of it now.	least point to pictures to try and communicate with him	
We talk like five-year-olds in the past years. 10:03		He communicated with his wife in a way she could understand him. They talked like 5 year old's would	8
And as I talk to people who have worked with her before, they said, "Oh, you know, she'd miss meetings. That's not her. She just sort of-- she'd go over to the wrong spot." 10:03	He is now getting information about how others at his wife's place of employment noticed her odd behavior while she was still working. it seemed to annoy him that he is just now finding out this information.	His wife's former coworkers told him they noticed her odd behaviors while she was still working. she would miss meetings or go to the wrong locations.	N/A
I'm like, "Well, you know." I wish I would have kind of known this. How would they know? 10:03	He sounded frustrated but at the same time knew that nothing could have been done to stop the final diagnosis outcome.	He wished his wife's co-workers would have shared sooner how his wife was behaving at work.	N/A
And I know them. I know that it's not just colleagues. 10:31		His wife's co-workers where not just colleagues but friends too.	10
I mean, I work hard to make sure she has social engagement. So on Tuesday nights, two of her former colleagues, who are our teachers and neighbors, come over to spend time with her. 10:31	He seems to be trying really hard to keep his wife's full and meaningful as it was before she was diagnosed with FTD. It seemed to me again that he really loves and respects his wife.	He works hard to make sure his wife still has social engagements. Two of her former colleagues come over one night a week to visit.	10
And we still try to get out socially, but the choking thing, being out in a restaurant setting, is a little difficult 10:31		He tries to get out socially with his wife but the real hazard of her choking makes it difficult to go out to a restaurant	1
I've got to make sure everything is cut. And kind of [meter?] the food she eats, so. [inaudible] on a fork, is the most we can do without choking 10:31	He was explaining how careful he has to be with her when it comes to eating. I was trying to imagine what the social outing would be like for them both if he is spending a lot of time cutting her food and making sure she only takes a bite that fits on the fork. I started to wonder if it was a social outing at all? Or if it was just being out instead of being home?	He has to cut his wife's food and monitor her bites so that they fit on the fork. Otherwise, she is at risk of choking.	5
So if that takes an hour to eat dinner, it takes an hour to eat dinner. 10:31	Again, I was thinking how enjoyable would going out to eat really be for him? She might not know the difference but it doesn't seem relaxing for him at all.	He knows that it could take an hour to eat dinner and he is fine with that.	5

But it's those kinds of things that we have to adjust to 10:31		These are kinds of things he just has to adjust to now.	5
And then, again, one of her colleagues also comes in on Monday wanting to have lunch with her, on the day that she's not at the day center, so. We try to make sure-- although, it takes a little bit of work, have to make sure that she's got something and-- she doesn't really communicate anymore. But I think it's good they're there 10:31		One of his wife's former colleagues comes on Mondays to have lunch with his wife. He has to make sure there is something appropriate and safe for his wife to eat so she doesn't choke. He thinks it is good that friends still visit	10
So now I have to sit in on lunchtime, and [inaudible] talking to and I get what's going on 10:31	Even though this might be more inconvenient for him, he still encourages people to stop by and visit with his wife.	He has to monitor meals so that his wife doesn't choke when friends come for lunch with his wife	5
Again, I encourage people to come and visit. 10:31		He always encourages people to come and visit his wife	10
We've managed to assemble a great team around this. I think that's one of the keys to my survival, my friend. 11:54	He does seem to have a great support system and team of people to keep him connected	He had a great group of friends and family before his wife was diagnosed and they are still there now to help out and keep connected with he and his wife	10
So I'm at a point where I'm not afraid to ask for help, which is the biggest hurdle for me. 12:31	This was a profound statement because I would imagine for someone like this, asking for help seems like a sign of weakness. He is very confident and capable but human too. We all need help	He is at a point where he is not afraid to ask for help which has been the biggest hurdle for him.	10
And people have responded very well. 12:31		He has found that people have responded well to him asking for help	10
Because nobody does it better than me, that. 12:49	His response when I asked why it was difficult for him to ask for help. This is kind of what I was thinking previously	He feels that nobody does things better than he does them which made it harder to ask for and accept help	5
Nobody can do it better than me, and I could do this, and just-- I could take care of her, so. 12:52	It seemed to me that his role as his wife's primary caregiver was tied to his identity as her provider too.	He felt nobody could take care of his wife better than he could.	5
A bunch of excellent social workers we work with kind of anticipate my need before I need it and suggest things like, "Maybe you should be a better companion. Get a little bit	There was some information lost in the translation of the transcription. But after listening to the recording again, this is what I heard. He needs reminded that he can ask for help and take a break	He needs reminded to use the help he has to take time for himself so that he remains a good companion for his wife	10

more care.” Yeah. That's a great idea. And those two ladies that I have are-- they will do what they need to. 12:52	so that he can be a better companion for his wife and family. That is why he has agreed to hire to the women that come and stay with his wife a few hours on Mondays and when he has piano lessons.		
Just things like that. They know this like they said, “The earned so that they think about-- so you let her hair grow [laughter]?” Because they're all very-- back then, we always make sure (spouse) looks great every day. 13:33	He wants to make sure his wife is still treated with dignity and respect. He wants to make sure she still looks the way she would want to look based on her previous ways she did things before FTD	He makes sure his wife looks good everyday	5
We've had to experiment with wardrobe because of-- she's been a little weak. So we've had to change what she 13:49		Because his wife is physically weaker now, he has had to experiment with her wardrobe and what she can wear to look good	5
I said, “You've got to look good every day.” 13:49	He wants to make sure his wife is still treated with dignity and respect. He wants to make sure she still looks the way she would want to look based on her previous ways she did things before FTD	He told his wife she has to still look good everyday	5
Because I think a lot of people that are unfortunately disabled end up looking disabled because nobody's taking care of them. And that's just my take on it. 13:49	He was very adamant that he get the point across to me that he wants his wife to still look like she did in the past. And be treated with dignity and respect	He thinks that a lot of people that are unfortunately disabled end up looking disabled because no one takes care of them	11
So she always looked great before she got sick. And we'll just try to continue that [laughter] 13:49	It seemed to me that it not only reflected his care for her dignity but it was also a reflection of how he was viewed in how he was taking care of his wife. Maybe part of his was afraid to be judged too?	His wife always looked good before she got sick so he wants to continue to make sure she looks good now	5
And learning things that I would never have to learn before [laughter] 14:19		He had to learn things about taking care of his wife that he never thought he would have to know	7
And bra sizes, geez [laughter]. I would do that. I think one of the things that I found difficult in terms with going to stores and not as a creep, just- 14:34	He had to go to historically women’s stores or into the bra section to try and find the right sizes for his wife. And he either was made to feel like a creep or he just felt that way because he was uncomfortable .	He had to learn about bra sizes by going to stores like Victoria Secret. He often felt like a creep doing that.	3
But if I go into a (department store) and try to help her try	He gets treated like he is either a creep or abusive if he goes into a	He has to help his wife try on clothes at	3

on clothes, I explain the situation. I need to be in there sometimes like-- I'm just not prepared for us. I'm not here to act as the devil, but I don't want to come here. 14:52	department store dressing room to help his wife try on clothes	departments stores and always has to explain the situation because he feels like people see him as a creep or the devil.	
But it was just something like a family dressing room, like a family bathroom 15:15		He tries to find a family dressing room or family bathroom when they are out so that he can help his wife without issue	3
I haven't been able to overcome, even when I was in that situation. I have the FTD cards to excuse the person was-- they have these if they can't help themselves. 15:22		He hands out the FTD cards that explain the disease and his wife's behavior when needed.	3
The bathroom is always scary to me because I can't be in there unless we've got a private family bathroom. So most of our excursions-- I was trying to think if there's going to be one there. That's a little helpful. 15:38		He has to plan excursions with his wife based on what bathroom options allow him to be in there to help his wife	3
we've traveled…She's great. She had a problem getting through TSA because she doesn't speak, so if I'm there, I just have to answer the questions for her. 16:04		He has to speak for his wife when going through TSA when traveling because she can't speak	N/A
The other time it's come up is that she decided it was a good idea to pack the very large bottle of shampoo [inaudible] [laughter]. And I'm like, "Why are they pulling her bag aside?" And sure enough . . . I said, "Okay. I'm sorry." He said, "It's okay." [inaudible] so I'm getting better at anticipating what could happen. That's part of the deal. 16:04	Traveling sounds like it could be a challenge at times, but it seems he has been able to handle things in stride and stay present as much as possible to enjoy what he still can with his wife	He has had some challenges traveling with his wife in regard to items she has packed	N/A
We've gone to Florida. I've taken her to Myrtle Beach. I think those were the last two for air travel 17:00	I had asked him where they had traveled and he was telling me where. I could feel his anxiety increasing the longer we kept talking. I could feel he just wanted to be done and out of there to get back home. I didn't blame him. I appreciated his time and his experiences he was sharing with me.	He and his wife last traveled by air to Florida and Myrtle Beach	N/A

and it may be the last two for air travel. It's just not fair for everybody around us It's a lot (laughter) 17:00		He thinks they are done traveling by plane because it's not fair to the people around them	N/A
Coming back, when she could speak, many of the filters went away. 17:00		When his wife could still speak, she had lost the ability to filter what she said	N/A
So we're sitting on the end seats on the flight to Myrtle Beach and the flight attendants make sure that you're ok to sit in the exit row. Even though she probably shouldn't be sitting there, we sat there, though. The last person to get on the plane, I could tell that she was frazzled. Something was going on. So she sits down and my wife asks her, "Oh, are you pregnant?" And the lady says, "Oh, no. I'm just fat [laughter]." So, there's no place to go. 17:00		His wife once asked a woman who sat next to her on a flight if she was pregnant. The lady replied by saying no she was just fat. His wife had lost the ability to filter what she said when she could still speak	N/A
Yeah. But the woman was so kind. She had seen us, the interaction. I kind of said something. She happened to be a nurse at the local hospitals here, so she completely understood. 18:05	He was embarrassed by his wife's inability to filter what she said as the disease progressed. He seemed to do a good job of explaining the situation but I could imagine it would get exhausting to have to keep doing that and being on edge wondering what was going to be said or done next.	He found most people were kind in awkward situations with his wife.	10
I'm like, "Thank God. Thank God." So that now, fortunately or unfortunately, she can't speak or doesn't. Can't speak so she doesn't say a word [laughter] 18:23		His wife now can't speak so she doesn't say a word when they travel	
She wanted to go back to Hawaii before she couldn't talk and I said, "I just can't do that. It would be too much. We'd have to take an army with us So, yeah. We're not going to do that. 18:23		He could not travel great distances with his wife unless he had a lot of people going to help.	5
I think in terms of traveling, it's going to be by car because the bathroom needs 18:51	I was thinking I give him credit for still attempting to travel with his wife only because it sounded more stressful than fun.	He has limited travel with his wife to going by car based on bathroom needs	N/A
Just if you're going to go to the bathroom and the seatbelt sign's on, then we got a problem. (if traveling by plane) 18:51		He stopped traveling by plane with his wife because of bathroom issues.	N/A

Hugely. 19:29	His word for how this has impacted him personally. I just listened quietly because he was very intense and I wanted to really hear what he was going to say.	He was personally impacted hugely	5
I'm just trying to find a place to start 19:29		He had to find a place to start after learning of his wife's diagnosis	5
Well, we never planned for this. 19:29		He and his wife never planned for this	1
You can never plan for Plan C. 19:29		He never planned for this type of situation	1
She was supposed to retire in two years 19:29		His wife was supposed to retire in 2 years	N/A
now it's going to be cut back however gradually on our happily ever after 19:29		He and his wife's happily ever after has been cut short	12
The places we want to travel. 19:29		He and his wife will never get to travel to the places there were planning on after retiring	12
My daughter hinted about having children. And she also wanted to have grandkids. So, she would have been a great grandmother 19:29	When he said this I could feel myself become emotional and tears welled up in my eyes. Perhaps I know this feeling as a daughter whose own mother never got to meet my daughter?	His wife will never get to be a grandmother	12
Now she can't be by herself let alone watching a child 19:29		Even if his daughter has a child before his wife dies, his wife can't take care of herself let alone a child	12
So, in terms of me, I dream into the future of, quite frankly, what's left without her 19:29	This struck me as very harsh but the most honest answer I had heard to date of any of the participants. It made me sad because it seemed to me that he was the one participant that might actually still be in love with his wife…not just love her.	He keeps going by dreaming of what's left of the future without his wife	12
I'm able to do that. Probably gets me through some days, quite frankly. 19:29	It made me think about how long a person who is emotionally attached can continue to watch their spouse decline and be the primary caregiver? How do they make it through? maybe this is the answer?	Some days he gets through by thinking about the future without his wife	5
As cold as it sounds, this isn't forever 19:29		He knows this isn't forever	12
I know that sounds pretty awful. 19:29		He thinks it sounds awful that he says he gets through knowing this is not forever	12

So I look to see what it will be 20:24		He looks to the future to what will be for him	5
I have a tendency now more to lose my patience 20:24	It seemed to me that he has to look to the future because the person he used to know as his wife is now gone. I wonder if that is why he tends to lose his patience more now? Of if it is just being burnt out?	He loses his patience more now as time goes on	5
I tend on leaving the room a lot more than I used to because it's the best thing to do 20:24		He leaves the room more now because it's the best thing for everyone	5
And she's not going to change 20:24	It seems he knows this cognitively but his emotions are still trying to catch up	He knows his wife is not going to change	N/A
The reality is, I have to change 20:24		He knows it is he that has to change	5
I haven't been a flexible person in the past 20:24		He has not had to be flexible in the past	5
so I've learned to just go with it for lack of a better term and just make sure she's safe 20:24	He seemed defeated in the sense that he is angry and hurt because of what is happening to his wife, their relationship, and their family but he can't or wouldn't let it out because he is still responsible for taking care of his wife.	He has learned to just go with the flow and make sure his wife is safe.5	5
So there's no time to dwell on 20:24		He doesn't have time to dwell on they why	12
it's just more of a read and react at this point 20:24		He just has to read each situation and react	5
You don't know what's coming. You never know what's going to happen next 20:24	He seemed irritated as he was telling me this. Annoyed that he was with me for the interview and anxious to get back home.	He never knows what's coming or going to happen next.	7
But she's happier being free and that's why the latitude 20:24		His wife is happier being free at home and that's why he is trying to be so flexible	N/A
People come in, they're so sad 20:24		He sees people become so sad when they come to visit his wife	10
said, "All right, friend. This is the no crying zone, everybody. There's no crying right now. She's not sad. You can't be sad." 20:24	He set boundaries for people visiting his wife at their house. That must have been hard to keep it all together to ensure his wife's existence	He made sure that whoever came to visit his wife made sure they knew his wife is not sad so they are not allowed to be sad around her	10
So the only rule we've had, if you come here and you're sad, if you're going to be sad, you be sad somewhere else. 20:24		He had one rule. If you were going to be sad, be sad somewhere else other than in front of his wife	10

It impacts her. That's what people tell me, 20:24		He believes other's sadness will negatively impact his wife	10
I have three children that are great Okay. 1982, so (daughter) will be 37 this year. So my daughter will be 37, so he'll be 35, and a son that will be 33 in a month 21:53	He seems to be uplifted when he talks about his children	He has three children, now in their 30's, that have been great	10
So they're a very close line of offense or defense for me. 21:53	I think that he is lucky to have strong adult children to help him stay strong for their mom. This might be the link to resiliency for primary caregivers for a spouse with FTD.	His children are his very close line of defense or offense	5
Like I said, I had to get a sitter this morning and my daughter was more than willing to and said, "Dad, you go do that and I'll be there." 21:53		His daughter stays with her mom when he needs her to	10
And I make time for myself 21:53	This seemed like he does this out of necessity not out of really wanting to be alone.	He makes time for himself	2
sometimes I go out socially alone now. 21:53		Sometimes he goes out socially alone	2
Interesting, I have a couple high school people from a long time ago that encouraged me to have dinner with them every month. 21:53		He has dinner once a month with old friends from high school	n/a
Yeah. And we try to stay off this topic and we just talk about other stuff. The first two minutes of how (spouse) is and then we don't have the conversation, 21:53	It must be a relief to go out and not have to talk about what is happening to his wife	When he socialized with friends from high school, they only talk about his wife for the first few minutes	n/a
so I get that escape a little bit 21:53		He gets an escape when he goes out with his friends from high school	2
One was in my wedding actually 23:14	This was his response to me asking if those friends knew them as a couple. He said yes.	One of his friends from high school was in his wedding	N/A
It hasn't because my employer's been letting me work from home 23:53	This was his response to me asking how it all has impacted his work/career	His work has not been impacted because his employee has allowed him to work from home	5
And so my boss says, "Oh, you work from home now." 23:53		His employer told him he works from home now as soon as it was known about the health of his wife	N/A
I think that's the biggest thing that's allowed me to take care	That was a big statement on many different levels. From a financial standpoint, to keeping his identity	He thinks that being able to work from home has allowed him to take care	5

of my wife the way I want to without a doubt. 23:53	as the family provider to keeping his purpose. At least, that is what I was thinking about that statement	of his wife how he wanted to care for her	
So I'm a project manager. I work for a company and we contract back to (company). I just take care of the database of data, of course [laughter]. It's a very big database of stuff. I'm quality gatekeeper for certain inputs and outputs and just make sure things are correct 23:53		He is a project manager of database data for a large company	5
Unfortunately, most of the time, I don't have any deadlines because the deadline is now. When it comes in, I go through it, sort it, and do it now my work is dependent on other people's upstream from me 23:53		He doesn't have deadlines because everything he does is needed now	5
So I said, "As long as you don't mind this stuff getting done at two o'clock in the morning," he said, "No, that's fine." 23:53		He cleared with his employer that as long as he can submit work at 2 am if needed that is acceptable.	5
So sometimes that happens, though, that in order to compensate for the day for me if I need to take care of (spouse) during the day then I'll just work at night. 23:53	I wondered when he sleeps? Maybe working through the night eases his own anxiety and fears.	Sometimes he works in the middle of the night because he has to take care of his wife during the day.	4
So in terms of work quality and ability, it has not been bad, it's just the schedule has changed a little bit, 23:53		His work quality and ability has not changed just his schedule	5
I don't require a lot of sleep and that's good. Probably four or five hours 25:03	This was his response to me asking if he sleeps	He doesn't require a lot of sleep and get about 4 or 5 hours of sleep a night	5
and I'm probably okay. I think I'm okay [laughter 25:09	I don't know that with all that's going that he could be relaxed enough to sleep any longer	He thinks he is okay	5
I take care of myself 25:09		He takes care of himself	5
I go to my cardiologist who's my primary care physician and I don't have any other issues other than the high blood pressure and stuff like that 25:09	He takes care of himself by going to his doctors to ensure his health is ok.	He sees his cardiologist who is his PCP to ensure his health is good	5
So, yeah. I've been able to have the work flexibility that's allowed me to do this. I think that's really important 25:33		His work has not been impacted because his employee has allowed him to work from home	5

But, in my defense, I think I earned because all the stuff they've brought in the past you just don't give that anybody to do. 25:56		He feels he has earned this privilege to work from home because of his past work history	5
We used to have fun 26:23	This was his answer to how his wife's diagnosis and his role as primary caregiver has impacted their social life	He and his wife used to have fun together	1
We used to have Friday night date night 26:23		He and his wife used to have date night every Friday	1
We would go out every Friday night for dinner and usually a movie. So we'd seen all the movies 26:23		He and his wife would go to dinner and a movie every Friday night	1
I realize this year we didn't see any other movies until the week before the Academy Awards 26:23		He realized he and his wife didn't see any movies during the year except right before the Academy Awards	N/A
Going out is a little bit more difficult 26:23		Going out with his wife is a little more difficult now	1
(A friend's) wife and another lady who we've met at our FTD support group decided that we would go out together. 26:23		He and his wife get together with other couples who have been impacted by the diagnosis of FTD	1 11
So we did and we've done it two or three times and it's great because we understand what's going nothing that happens at the table that can shock us 26:56		When he and his wife get together with these couples impacted by FTD it's great because everyone understands and nothing is shocking	11
If a situation arises, we get it, really good, good idea 26:56		It has been a good idea for he and his wife to get together with like couples to socialize	11
So then in December, we had our first issue going out and (friend) had mentioned that her husband was having a little bit of stress 26:56		Eventually, it was becoming more stressful for the couples to go out for dinner	11
I said, "You know what? It's just more important we get together." So my kids have had dinner at our house and they came in and cooked a really nice dinner for us 26:56		He felt it was more important that they all still get together so his children hosted a dinner party at his house for all the couples	11
And then last weekend (friend's) sister who was		Another time, one of the spouses' sister	N/A

sleeping in for us brought in a guitar player. It was really great 27:33		brought in a guitar player for entertainment	
So we're able to do that. That's a very comfortable situation, okay, for us, get out and socialize 27:39		He and his wife are able to still socialize with other couples going through the same situation. It is comfortable for him.	11
We try to stay off this topic as best we can 27:39		They try to stay off the topic of FTD and just enjoy the evening together and socialize	N/A
Things happen and it's okay. So in terms of that group, it's fine 27:39		Things happen with the couples get together and that’s fine with him and the others because they all understand the situation.	11
In terms of us going out together, I've been more hesitant and we'll go to simple places that if anything happens it's okay. 27:39		If he does take his wife out socially, it is to simple places where is something happens it will typically be okay.	11
So a (fast food restaurant) is fine, the local diner is fine, and that's okay. 27:39		He is okay with taking his wife out to McDonald’s or a local diner	11
I'm more worried about her choking so I'm very, very on her plate to mention that we're not going to have it, and it's happened. It’s tough 27:39		He is worried about his wife choking when they are out to eat	5
It's horrible, and I think I'm a little bit more petrified now when she starts to gasp. I'm like, “You can't lose your stuff right now, but this is horrible.” 28:31		He becomes petrified when his wife starts to gasp while eating. He has to tell himself to keep it together	5
We used to go out a lot. We used to go out way too much, okay? 28:31	It was sad to hear that they used to enjoy going out for dinner together to the point where it was almost too much. And now, he can’t enjoy going out with her anymore because he is worried to death about her choking to death.	He and his wife used to go out often together for dinner and to socialize	1
Yeah, we don't go out as much as we used to. 28:31		He and his wife don’t go out as much as they used to go out	1
Our socialization is different 28:31		Their socialization as a couple is different now	1
I think I found out who my friends are 28:31	As he was talking about friends, he just shook his head.	He found out who his true friends are through this situation	11

is just a difficult thing for-- people say you learn who your friends are, and I think they're still our friends. It's just a difficult situation 28:31	It seemed like he realized this situation is difficult for people to understand. And that people are still his friends but that maybe there is a level of friendship he didn't realize was in place before this happened to them.	He knows it is difficult for people and that he still has friends but there are just different level of friendships since this has happened to them	11
I mean, a friend came over and then we were talking about (spouse) but we don't have much else to talk about when you think about it because we're just consumed by the monster. 28:31	Even if friends do stop by, there doesn't seem like there is much else to talk about other than what is going on with his wife and the disease. I thought he labeled it correctly as a monster	There isn't much else to talk about when friends visit but the all - consuming monster of FTD	11
So yeah, we go out less. We spend a lot less money going out, so that's a plus 28:31	He still has a sense of humor to some degree about what life has handed them.	He and his wife go out a lot less and that has saved them money	1
Play piano. So that's a half hour a week [that that's?] all I can think of [because I always have?] too many fingers [or they're in?] the wrong spot. 30:18	This was his response to me asking what he does just for him. I play piano so I get that it can be an escape from your brain and your thoughts about life.	He plays piano 30 min a week at a lesson and that's all he thinks about in that time. What fingers go on what keys. He is able to escape for that 30 minute lesson.	2
So that's going to be relaxing for me, all in the moment 30:18		He gets to be present and in the moment when he is playing the piano	5
But it's probably only 30 minutes a week that I am not thinking, quite frankly, about what's happening to (spouse) 30:18	I thought this was probably correct. He gets 30 minutes a week where his mind can rest completely and focus on his fingers and playing the right keys. this is probably better for him than an extra couple hours of sleep.	He gets 30 minutes a week, when at his piano lesson, where he doesn't think about what is happening to his wife	2
And right now, I know that my daughter has her, and she's the best one besides me with her [laughter], but at the same time, I'm like, "What happens if?" 30:18	It seems that I was on the money when I though he was a little irritated and anxious to be sitting with me telling his story instead of being home with his wife.	Even when his daughter has his wife, and he trusts his daughter the most, he still worries about what could happen with his wife because he is not there with her.	10
Because I think I've become oversensitized to the choking thing 30:18		He has become over sensitized to his wife's choking issues	5
I'm used to the opposite 31:07	He was starting to tell me about his own downtime or own socialization just for him	He is used to the opposite. He is used to spending more time on his own	2
So it was a great year no matter what happened at the end. 31:07	He kind of skipped around to talking about what else he did	He has had a great year no matter what has happened	5

	during the year that was just for him.		
So I was able to-- I have some family on the West Coast, so I was able to make some time for me, and I went out and bought a [inaudible] in September 31:07		He went to visit family on the West Coast in September by himself	5 2
I also went to the (football team) play-off game. 31:07		He went to a Dallas Cowboys play off game this year too.	N/A
But I have to plan that 31:07		He has to plan in advance time away by himself.	10
I have to make sure it's okay, and the kids are all going to say yes, but at the same time, I have to see what the situation is at home in terms of how she's doing 31:07	He can make all the plans and arrangements but in the end if something new or more serious comes up with his wife's health he would change plans to stay home	He has to plan his time away to make sure his kids can stay with his wife. And he has to make sure his wife is stable enough for him to leave.	10
So I've made time for that. 31:07		He has made time to travel by himself for himself	N/A
A friend comes up Tuesday nights. One of those ladies come over, I get out, whether it's to go play a local trivia game or catch up on shopping that I do for her. 31:07		He makes sure to take a little time to get out the house each week.	10
But I have a lot of help, so that helps me— 31:07		He has a lot of help and that helps him	10
even if I don't take advantage of it, it helps me know that that's not in it alone. 31:07	This comment stood out to me. Because I know that myself and my control issues, it is still nice for people to offer to help me even though I need to do things myself.	Even if he does not take people up on their offer to help, it helps him know he is not alone.	10
So again, I have a great support system. 31:07		He knows he has a great support system	10
I take advantage when I can without abusing it 31:07		He takes advantage of his support system when he can and tries not to abuse it	10
socializing is a little bit more difficult 31:07		He finds socializing more difficult now	5
I do have some buddies that I make sure they have lunch with me once a month 31:07		He does have some buddies he has lunch with once a month	N/A
My high school buddy, I had dinner with the other night 31:07		He and a high school friend had dinner last week	N/A
So I do get out, as much as sometimes it's an effort 31:07		He tries to get out and socialize but sometimes it is an effort	5

Sometimes you just want to sit and not do anything because that's a luxury in itself 31:07		He sometimes wants to just sit and do nothing because that is a luxury right now	5
Yeah. Because it's just like people coming in to spend time, it's a little bit of extra work 32:59	I can understand where he is coming from. I would imagine as much as he wants to keep his wife connected and her life as meaningful as possible, that would tend to lessen his time to decompress and relax from always being "on"	It is more work for him when people come to the house to spend time with them	5
I don't know, maybe it sounds a little selfish, but at the same time, true 32:59		He thinks it might sound selfish that having people visit is more work. But it is just his reality right now	5
Yeah. And so we learn as we go. We just learn as we go. 33:30		He and those around him just learn as they go	7
That's a really good question. How could they support me better? I kind of reached out. It hasn't helped me with the stuff that I've got 33:59	This was his initial response to me asking him how doctors could have supported him better	He reached out to medical professionals for help but it hasn't helped him with what he is dealing with as a primary caregiver	10
But in terms of overall, what I've seen, people don't know the services, in general, that are available at the local hospital 33:59		He feels that overall people don't know the services that are available at the local hospital	7
So those support groups I go to [inaudible] is actually sponsored by the [inaudible] facility my wife goes to. I know not many people [inaudible] know about them. 33:59		He goes to support groups that are offered by the facility his wife goes to during the day. He knows not many people know about those meetings	10
They're doing as best job they can with the resources they have to get the word out 33:59		He feels the facility that offers the support groups do the best they can to advertise with the resources they have	10
But people come at their first time and they're mystified we're actually talking about this in the open 33:59		He has experienced people being mystified by the support group because they talk about it all in the open	10
And especially in the FTD group, there's a lot of guessing going on, in terms of diagnosis. 33:59		He has experienced this feeling of people being mystified in the support group, especially the FTD group because of all the guess work that	10

		goes on in getting the right diagnosis	
I don't think the medical profession is maybe up on it because it's so relatively rare. Only 60,000 people in the USA 33:59		He thinks there is a lot of lag time in getting a FTD diagnosis because the medical professionals don't consider it because it is relatively rare	6
Lot of misdiagnosis going on. 33:59		He believes a lot of misdiagnosis is going on in regard to FTD	6
So I think from an overall perspective, just letting people know this disease exists is important and it sounds like the AFTD mission, right? 33:59		He thinks that overall, people need to learn that FTD exists.	6
And letting people know there are resources are available 35:44		He thinks that letting people know there are resources through the AFTD is important	6
Yeah. I've actually handed some literature to my wife's PCP 35:55		He has handed out literature from the AFTD to his wife's PCP	5
Oh, absolutely. Compared to other people, really quick 36:12		Compared to other people, he and his wife got the FTD diagnosis quick	6
Yeah. So [inaudible] I called my cardiologist. I said, "Doc, this is what's happening. Okay, I need you to get me to somebody to give me the symptoms. He said, "All right." I said, "Give me some [inaudible] first." And he said, "All right." And so they went, "This is the practice I'd recommend, and this is the doctor." No, I said, "Which doctor should I go--?" "They're all great." I said, "No, I want the greatest one [laughter]." 36:20	I really could feel his passion in how he went about finding THE best care for his wife that he could find. He was a true advocate and proactive for her diagnosis and for her care.	He went above and beyond to find the best medical care for his wife in order to get the correct diagnosis.	6
I'm very aggressive when it comes to that 36:20		He was aggressive in his search for the best medical attention for his wife	5
And so I just got one, what do you call it? Differential diagnosis. Just a [inaudible] to eliminate everything. 36:20	It seemed that he had really good direction to getting the correct diagnosis and care for his wife. On top of that, he really advocated well for himself and his wife. He	He received a differential diagnosis to rule out other possible diagnoses based on his wife's symptoms	6

	was on a mission and nothing was going to stop him.		
So we went through psych factors, we went through a neurologist, we went through numerous neurologists 36:20		His wife was seen by many neurologists for psychological evaluations	6
Okay, and then we got to a point after we did number four that they're all the same results 36:20		He and his wife got the same results from all 4 neurologists	6
Now I'm wasting people's time and money 36:20		He felt like he was wasting peoples time and money to keep going to different neurologists to get the same answers	5
So between the, it's not this, this, and this. And another psych exam, they came to a diagnosis. Almost at 58 and I think the PET scan was the determinate. 36:20		He believes between ruling out different diagnoses, the PET scan was the determinate factor in his wife's FTD diagnosis at 58 years old.	6
And that's where we went. But we were very aggressive with our time, and again as I had mentioned earlier, I had a very flexible schedule 37:49	He was very anxious as we reached over a half hour of meeting. I feel like he just wanted to get everything out as fast as possible so he could get back home. I wanted to make sure I asked what I needed to ask but was very aware to not keep him any longer than necessary.	He and his wife could be aggressive with their time due to his flexible schedule to get to appointments	5
So I said if you have any cancellations, just let me know the day before and I'll be there. That came up a couple times where we were able to get that slot [right away?]. 37:49		He let the doctors' offices know if cancellations happened they were available.	5
In the meantime, our insurance [coverage?] declined the PET scan. So I get it when you're an insurance [37:49		His insurance company declined to pay for his wife's PET scan.	6
No, I get it [inaudible]. I see both sides of it. 38:18		He can see the point of view from the insurance company too	N/A
So I'm starting it off like I've said, and my pledge to my wife was you are going to get the very best care that we can find you. And it's never going to be a money issue 38:18		He pledged to his wife she would get the very best medical care and it would never be an issue of money	5
We'll figure it out 38:18		He told his wife they would figure it out	5

So I found out at the insurance declined test. In the meantime, our great doctor [inaudible] went to bat for this test. And I'm not getting stupid, or crazy [laughter]. 38:18	I could feel myself getting emotional as he was explaining how he had struggled to get tests run for his wife.	His doctor advocated for having the test with the insurance company	10
I'm standing in the neurologist office, and I said, “Hey, how much is the test?” They said, “Nobody asks us that question.” I said, “Just tell me how much the test is, and then we can do it.” And I said, “I need the test, okay. It's not that it doesn't matter, but we need the test.” 38:18	He was keeping his word to his wife and willing to pay out of pocket for the test that his wife needed in order to get the help she needed	He was willing to pay for the test the insurance company declined to pay because it is what his wife needed.	5
So I said, “Okay.” She said, “Can't you just wait one more day?” I said, “One more day, yeah.”38:18		He was asked to wait one more day before paying out of pocket for the test. He agreed to waiting one more day	5
I'm always polite, I'm just firm. No cursing, no jumping up and Down… 38:18		He was always polite but firm when asking for what his wife needed.	5
Okay, but at the same time, this is what I want, this is what we need to have, and we need to get to it. 38:18		He remained focused on what he wanted and what they needed and how to get it.	5
So despite the insurance, I'm not going to say we can't go there because the insurance. 38:18		He was adamant that insurance coverage was not going to dictate his wife’s medical care	5
I need the best facility, doctors, that's it. 38:18		He needed the best facility and the best doctors for his wife.	5
You approve the tests for nothing [laughter?. But that's the determinate-- that was our determinate, definitive tests and at that point, it was pretty much to differentiate that it was Alzheimer's or FTD. And it came out as FTD. 38:18		The test concluded his wife had FTD not Alzheimer’s disease	6
Okay and I know this monster kind of changes its course and it could be something different down the road. But when we're getting it from three sources all saying the same thing, I think that's enough. There's no more picking and prodding and not necessary, just beating the dead horse I mean. 40:17	It sounded like he really wanted her diagnosis to be different any one of the times she was tested. But after so many times people all saying the same diagnosis how much more does that need to happen before you start to plan and stop assessing.	He felt that after getting the same diagnosis from all sources it was time to stop the poking and prodding.	6

Yes. We're the only ones we have 40:50	This was his response to me saying he has been an awesome advocate for his wife in all of this.	He is the only one his wife has to advocate on her behalf	5
I was never going to do that again unless it's going to save your life, you're never going to do that again. So at that moment, we chose that she's not going to be one that participates in any study that requires a spinal tap, that's the bottom line. And most of them start with a spinal tap, but the tradeoff is that we will do our best to advocate for the disease and raise as much money as we can, so that's our part. 40:50		He will never allow his wife to be part of a study that involves a spinal tap and most start that way. So they chose to advocate and raise money and awareness about FTD as their contribution.	5
It seems that it's gone pretty well. We know a lot of generous people and I tell them, I said, "I'd rather have 25 $5 donations [inaudible] site, okay, than one $1,000." Let's have both, but just the awareness piece is what we're working on now 41:45		He has raised money for the AFTD by asking friends and the community to support AFTD $5 at a time.	5
My daughter was just named to the AFTD board 41:45		His daughter has just been named to the AFTD Board	N/A
So we have a seat at the table. So I thought that was a good outcome for us 41:45	I commend his entire family for taking up the FTD cause to support not only their mom/wife but others in the same situation	He feels they have a seat at the FTD advocacy table.	5
We've raised the money because we think it's important, we weren't buying a seat. It just happened like that. 41:45		He and his family and friends has raised money for AFTD/FTD because it's important. He wasn't trying to buy a seat at the AFTD advocacy table.	5
But that's how we do our part. We get between the awareness piece and the raise the money part 42:28		He and his family do their part to get between FTD awareness and raising money for FTD research.	5
I only let them in so far, selfishly 42:52	His answer when I asked how other family members could have helped more/differently.	He only lets extended family help so much for his own sake	10
Fortunately, (spouse)'s parents are alive. They're 90-years-old. They're 90-years-old, they're in pretty good shape. They're self-sufficient. 42:28		His wife's parents are in their 90' s and in good health.	N/A

I make a point to see them every week either we bring dinner there or-- the driving leads to a ton of issues, so (spouse)'s brother or sister need to bring her whatever place we're meeting at. So we can't prevent him from driving locally, but we can prevent him from driving distance [laughter]. So 42:28		He makes it a point to take them dinner and see them every week. He goes to them so they don't have to drive.	10
I give it to them straight 43:29	He was still talking about his wife's parents and how he keeps them at a distance	He tells his wife's parents the straight truth.	5
Whenever we've had a doctors' appointment, I write a up a little few sentence memo and tell them exactly what happened, what's going on, and this is what to expect. 43:29	When he said this, I thought it was a really kind thing he does for his in laws. But perhaps this also is an easier way to share information without having to repeat himself to them.	After every one of his wife's doctors' appointments, he writes a small note to his in-laws explaining exactly what is going on with their daughter.	5
I told them right from the beginning, "So I'm going to give it to you straight. You're not going to like it sometimes, but I'm not going to mince words 43:29	I wondered what his relationship was with them before his wife became ill? It sounded to me like he had had it with them a long time ago on some level, and now he could just be short with them while he kept them in the loop about their daughter.	He told his wife's parents that he going to be straight and honest with them and not mince words regarding his wife's disease.	5
I don't have time to coddle you. That's for somebody else. We used to be able to coddle you. We don't have time to coddle you anymore." 43:29		He told his in-laws he didn't have time to coddle them anymore.	5
So in terms of what they could do for me more, they do as much as I let them. 43:29		He is in control of how much help he wants/gets from his in-laws	10
As selfish as that sounds, and I know selfish is not a four-letter word, there are just sort of things that I don't need an opinion on. 43:29	As he was talking about this I knew exactly what he was talking about from my own experiences	He needed to control who he let in because he didn't need others' opinions on how he was taking care of his wife.	5
I just don't need advice 43:29		He didn't need advice from family on how to care for his wife	5
And her parents want to help, but they can't 43:29		His wife's parents want to help but they can't	10
And for them, it will be [inaudible] quicker. They go through [inaudible] Park, which is about an hour to the house. Her parents live halfway between, so that scenario, there are lots of ways	He was explaining that his in laws live half way between his house and his sister in laws house so it would easier to drop his wife at her parents and one or the other would pick her up there. but because his wife wanders they	His wife's parents would not be able to stop her from wandering out of their house if she decided to go.	10

to be able to drop (spouse) there and then continue on and come back and get her. But (spouse) wanders, so if she decides that she's going through the house, they're not stopping her [inaudible] [laughter] 43:29	would never be able to stop her from going		
But I think they know and they've known me for 40 years, that there's a certain line, an invisible line. And you probably shouldn't go across that line. 45:36	He was very matter of fact about this statement. It just solidified how determined he has been to take care of his wife the very best he knows how to do.	His in laws have known him for 40 years and they know there is a line that they shouldn't cross with him.	5
The Asian culture has that filial piety thing in terms of honoring your parents. And I do that and they're not Asian [laughter] 45:36 So they're taking advantage of my marriage 45:36	He is Asian and so he was explaining how his culture that he identifies with has played a role in his relationship with his in laws.	He honors the Asian cultural tradition of filial piety of honoring your parents with his in-laws even though they aren't Asian. His in laws would take advantage of his marriage to their daughter.	5
So we're always very respectful, always-- we used to really take really good care of them 45:36		He and his wife were always very respectful of her parents and always took really good care of them.	N/A
And we still do but just from a distance, 45:36		He still does take care of his in-laws, but from a distance now.	5
It's got to be hellish for them to watch this happen Because they're seeing it happen right before their eyes 45:36	I was thinking that the entire time he was talking about his wife's parents.	He realizes it must be hell for his wife's parents to watch what is happening to her.	10
So that's a whole other level of stuff … this is the craziest thing they've had so far. 45:36	It makes sense why he keeps them at a certain distance. I would imagine it is hard for him to see her parents so sad and devastated by what is happening to their daughter.	Watching his wife's parents watch what is happening to her is a whole other level of stuff.	10
I sat on the [inaudible] and said, "So, Mom, if you could, what would do you miss that you could do before?" 45:36	While he was saying how selfish he is, I found him to be just the opposite. in the middle of taking care of his wife he took the time to ask his mother in law what she missed the most that she used to be able to do. It was like he was asking her what he maybe wished he could ask his wife…	He asked his mother in law what she misses now that she could do before.	5
Just like that, she said, "You want to know what I want to do? I'd like to go to the beach." 45:36		His mother in law told him she wants to go to the beach.	N/A

So being that we can't travel too far, I'm planning in the next month, taking them on a beach vacation to the Jersey Shore. But even for all of those, it's got to be someplace I can drive with them in two hours. 45:36		He is planning a trip to take his in-laws to the Jersey Shore since it is within a 2 hour driving trip.	5
(spouse)'s of course going obviously, because it's so I can't make that drive too far. 45:36		His wife is going to the beach too, so the drive can't be too long.	5
My mother-in-law only can sleep if she has a recliner so either the [inaudible] has to have a recliner or bring one with me. Also, they're tough on steps so I need [inaudible] elevator. I'm going to get someplace close to the beach so we can put them on wheelchair [inaudible] [laughter] beach. So a lot of planning going into that one 45:36		He has to plan carefully for the trip because of all the needs of his in-laws and his wife.	5
Oh. I haven't given them the choice. They're coming [laughter It's going to take a team. It's going to take an advanced team. So my children are all going to come 47:45	His response to me asking if his children are going to the beach too.	He isn't giving his children a choice, they are all coming on the family beach trip because it's going to take a team to pull it off.	10
So, yeah. I mean, I try to plan adventures with a group. 47:45		He always plans adventures as a group now.	5
I'm going to drive a minivan now. Because I need to cart everybody around. But that's okay 47:45		He has to drive minivan now to cart everyone around and that's just fine.	5
I'm like [laughter]. I didn't have to say anything. They're like, "I know, Dad." Okay. Okay 48:13		His kids just knew that they were going on the beach trip to help out.	10
So I try to make sure life goes on just to make sure enough help. 48:13		He tries to make sure life goes on but with help.	5
Somehow (spouse) has an existence every day with just a smile, or a laugh. She just laughs, a lot of the time. 48:13	This almost seemed to piss him off. Like what the hell is so funny or wonderful about what is going on and with what is happening to her or their relationship.	His wife smiles or laughs a lot of the time now.	8
Even when inappropriate. I'm like, "That is not funny." She'd laugh anyway 48:13		His wife laughs even when he points out to her things are not funny.	1

I'm thinking of the progression, like I said, a little quicker than I thought. But things have to keep going. 48:13		He knows that the disease is progressing faster than he thought it would.	12
I thought we had a little bit more time. 49:17	His response to me asking what he was told about timeline and the progression of the disease.	He thought they had a little bit more time before the disease progressed.	12
I just wish she would plateau 49:17		He wishes his wife's disease would plateau	12
But just the language is going away so quickly, it's just startling. 49:17		His wife's language is going away so quickly it is shocking.	12
But at the same time she doesn't seem-- in the past, I've asked her to repeat whatever she's saying, 10 times, she would just keep doing it until she got tired 49:17	It seemed that maybe he was more frustrated with her when she could speak because his expectations of understanding her or knowing what she was trying to say was too high.	When his wife could still speak he would ask her to repeat herself many times and she would just keep doing it until she got tired.	1
And so she didn't have the ability to, "Come on. That's enough." She would just keep doing it and after a while she just got tired and say, "I can't figure it out." 49:17		His wife didn't have the ability to say quit asking me to repeat myself.	1
Not like anybody knows. What does the website say, 7 to 12 years from the time she--? 49:17		He doesn't think anybody really knows the disease timeline.	12
So the first signs were, probably, a long time before we realized anything might've been going on at all, so. I don't know 50:07		He thinks his wife first showed signs long before they realized what was going on.	6
61. She was still actively teaching Kindergarten at 61. 50:19	His response to me asking at what age his wife was when she was officially diagnosed.	His wife was 61 years old and still actively teaching Kindergarten when she was officially diagnosed with FTD.	N/A
I said, "My God. What happened if one the kids left the room and she didn't know it?" That's just so horrible on a whole lot of levels. 50:19		He thought how horrible it would have been if one of the students left his wife's room and she didn't know it.	N/A
So I said, "I don't think you need to work anymore," which was a really hard pill for her to swallow. 50:19	He has really had to become the manager of their relationship and of his wife. He seemed to step into that role with a fierce sense of determination and love.	He had to tell his wife she should not work anymore and that was hard for her to hear.	5
Because originally, I had said something terrible is wrong. 50:19		He knew something was really wrong with his wife.	5

So fortunately or unfortunately, we were able to extend her payout through, I guess, May of that year. There was a contract she had. 50:19		His wife was able to extend her payout through May of that school year according to her contract.	N/A
But you know, fortunately, because FTD is on the-- what is that, Social Security, whatever that express line is for disability? I don't know much about it, but all of that process went very smoothly. 50:19		Because FTD is on the Social Security fast-track list of disabilities, getting his wife disability was a smooth process.	6
But there's certain diseases that get fast-tracked. FTD is one of them 50:19	I did not know that FTD was on the list of fast-tracked diseases to qualify for disability benefits.	He knew that FTD was a disease on the fast-track to disability benefits	6
And the federal government is going to be an absolute monster. Well, the federal government because of that. Social Security is [inaudible]. I still want to reach over and grab that woman [laughter] 51:46	It sounded really stressful trying to worry about and figure out all the insurance and disability and state pension stuff for his wife on top of taking care of her everyday needs.	He was frustrated working with the federal and state programs his wife qualified for based on her disease.	6
I would get a call two weeks after I called. And I maybe press things a little hard. And I would get a call two weeks after I called to talk to her, asking, “Mr. [inaudible], did you want to speak to me about something?” I'm like, “Mrs. X, we talked about this two weeks ago and we're no further than my [inaudible].” 51:46		He was frustrated with the number of calls he had to make to state agencies in order to get answers about benefits for his wife.	5
And the kicker was that I called, and I didn't hear from her for a really long time. And I'm calling her almost every day. So, she calls me one day. ,I said, “Oh my God. I [inaudible]. I thought you died [laughter].” 51:46		He was finally called back by the state agency regarding his wife’s disability benefits and he joked with the representative that he thought she had died.	N/A
That's called a squeaky wheel. The squeaky wheel theory unfortunately works. 53:08	He was referring to all the persistent calling he had done to eventually get a call back from the agency he was trying to get a hold of for his wife’s benefits. I couldn’t imagine having to deal with all the red tape and incompetence on top of losing your spouse.	He believes the squeaky wheel theory works.	5

Just continue to call me. Don't be afraid just to call and ask how things are 53:40	His response to me asking about his friends and how they could have been more supportive.	He wants his friend to not be afraid to continue to call and ask how things are	5
It's okay. I'm okay to do that. I'll give it to you straight. 53:40	He was emphatic that he would be just fine and would welcome friends calling to check on him	He wants his friends to call and he will let them know honestly how he is doing.	5
Understand that if I-- I'm really bad at returning phone calls, not so much now just because I said--understand that it might take a couple days to get back to you now [inaudible] in the next five minutes just because I've got a lot going on. 53:40	This sounded reasonable to me that friends have to give some leeway and understand that he appreciates them calling and he wants to talk to them but it might take a few days to return a call…but keep calling anyway.	He wants his friends to understand that it might take longer for him to get back to them and it's not going to be in the next five minutes now.	5
I'm not trying to make an excuse, I'm just telling you how it is. It's just a lot some days. 53:40		He is not making an excuse because he doesn't want to talk to his friends but because it's a lot some days his wife's primary caregiver	5
Continue to ask me to socialize, but don't be offended if I can't do it or won't do it because sometimes, I just need air. 53:40		He wants his friends to continue to ask him to socialize but also wants them to understand that sometimes he can't because he just needs room to breathe	10
I'm very fortunate that we have a lot of friends and acquaintances that I know I can call on, and I won't hesitate to call if I need something 53:40		He knows he is very fortunate to have friends and acquaintances that he can call on and he would if he needed anything	10
In any case, I have neighbors that are always willing to help, and it's just a great comfort knowing that- 53:40		He finds great comfort in knowing his neighbors are always willing to help too.	10
I know people that try to do this by themselves that have no support whatsoever. 53:40		He knows there are people that try to do all this by themselves with no support at all.	7
And some of that, as I sit back and pontificate, it's almost self-inflicted. 53:40	His response to thinking about why some people choose to not ask for help in taking care of a loved one with FTD	He thinks that caregivers that don't have help or support is because it is self-inflicted.	7
I used to be like, "I won't take help." There's nobody] that's better than me. 53:40		He used to think the same way, that no one can take care of his wife	7

		better than he can take care of her	
But once you really get across that line life becomes a lot easier. 53:40		He feels that once a primary caregiver finally lets himself ask for help life becomes a lot easier.	7
Even just mentally, that I can call them if I'm stuck as opposed to what do I do if I fall down the steps or whatever the case may be 53:40		He feels better just knowing he can call if he is stuck as opposed to not having anyone to call.	10
So we've actively built a team of people to help us. 55:03		He and his wife and their kids have built a team of people to help them: organizations, people, doctors…	10
Her doctors, because of persistence-- is that a nice word? My persistence, are always responsive 55:03		He believes his persistence with people, organizations, and doctors are always responsive to me	5
But I think that especially (FTD clinic), they're really good at it. They're really good at returning phone calls, answering questions 55:03		He is grateful that UPenn was really good at returning his phone calls.	10
30% of the battle is to get the people to pay attention and call you back and care on some level 55:03		In his experience, 30% of the is to get people to pay attention and call you back and care on some level	5
Yes. And either we accidentally came on the right the doctors within the organizations we chose to put on our team but they're really, really good at-- every doctor we deal with is very good at following up, answering our questions. 55:41		He believes by luck they found the best doctors who always call them back and answer all their questions.	6
If I don't have an answer that I don't understand before I leave the office, that's on me. Okay. That's my fault. 55:41	It seemed like because he had found the right doctors and lived in an area where those doctors practiced, he was lucky in a sense to get a fast diagnosis and get answers	He knows that if he leaves a doctor's and doesn't understand something that is on him for not asking.	6
So I expect them, as professionals, not [inaudible] preferred, they need to be more engaging. And they are. I've had instances where I forgot to bring the spinal tap results with me to the (FTD		His doctor's work with him and support him as he needs it.	6

clinic) appointment. Got on the phone with the neurologist office and within two [minutes?] she had it faxed to me. I mean, you don't get that. And that's the answer 55:41			
I've established a really good relationship with (spouse)'s caretakers, all the way down the line. The people at the day center, they know we're engaged, so maybe that's why they give us a little bit more, not service 56:55	I believe that is probably true. The folks also taking of his wife can see how much he loves her and is willing to advocate and is involved hands on in her care…that they take more time with her and with him…and care more.	He has established good relationships with everyone who takes care of his wife from the doctors to the day center workers. He believes that is why they get the extra level of care and attention.	10
I'm not a good waiter. I'm not patient when it comes to this, especially when it's for my wife, in this situation 57:34	I was saying that his persistence seems to be paying off for them. He agreed.	He is not a good waiter or patient when it comes to getting care for his wife in this situation.	5
So yeah, persistence, but also, for my part, have a little knowledge before you get in the room, okay? So they can't-- number one, so they can't talk by you, okay? And if you have any questions, make sure you ask one. But that's always been my approach, I think, for anything critical like this**.** 57:34		He advises having some knowledge of what you want to ask or want to know before you walk into any appointment.	7
I don't want to be sold a bill of goods. And maybe the medical professionals aren't equipped or knowledgeable about this disease to begin with, and that's nobody's fault. That's just that's where we're at, and I get that 58:07		He wants doctors to be honest with him and maybe the medical professions aren't as knowledgeable about this disease to begin with.	7
And I also understand mistakes can be made. And you have to-- it's not a perfect world. This is such an unknown that-- you might will say, "Oh, I have a [vaccine?] [inaudible] tomorrow." Well, that'd be great. 58:20	I think this was at an honest comment about the fact that nothing is perfect, but you have to keep trying.	He knows mistakes can be made and nothing perfect but the hope is that there will be a vaccine tomorrow.	6
You need a really big bucket of patience 59:04	His response to me asking what else he would want to tell other caregivers in his situation.	His advice to other male primary caregivers is to have a big bucket of patience.	5
I think that's the biggest-- it's not your spouse talking or acting, it's the disease talking or acting. 59:04		He would remind other male primary caregivers that it's the disease	8

		acting or talking this way not their spouse.	
Try to take that understanding with you every day. 59:04		He would suggest that they try to remember that every day.	N/A
It is going to be probably the hardest thing you'll ever do. Understand that. 59:04		He would say to other male primary caregivers that this will be the hardest thing you will ever do, please understand that.	5
Reach out for help, even though it may not be your fit. 59:29		He advises to reach out for help	10
Learn to reach out for help and accept it. It may not be the way that you would do it or the way you want it to be, 59:29		He would advise other to learn to reach out for help. It might not be the way you would do things.	7
but any help is good help 59:29		He believes that any help is good help.	10
Yeah. Yeah, you get mad a lot. Like, "How did I get-- who dealt me this deck?" 59:57	This was response to me asking about emotions that he would want to let others know might come up often.	He advises other male primary caregivers that they will get mad and wonder why this happened to them.	12
But I have a-- my life history-- so I lost both my parents when I was very young 59:47		He has a history of loss of both of his parents when he was very young.	N/A
My mother when she was 40 years old-- I was 13. My dad died - and he was sick for a long time - when I was like 27 years. 59:47		He was 13 when his mother died, she was 40. And he was 27 when his dad died.	N/A
So I buried both my parents before I was 30 years old. 59:47	59:47	He buried both his parents before he was 30 years old.	N/A
So it's always been My normal, so I'm a little bit, maybe, less emotional than most people. 59:47	I wondered if he is realizing now how losing his parents really formed who he is now…as his wife's primary caregiver?	He thinks he might be less emotional about his losses now due to his experience with loss in the past.	5
Unfortunately, that's helped me, like, "Sh-- I've done that before," so [laughter]. 59:47		He believes his past losses has helped him deal with what is going on with his wife now	5
You know, a lot of people say, "You know, I could not do what you're doing." 59:47		He has had many people say they could not do what he is doing as his wife's primary caregiver.	5
I say, "Oh yeah, you could. If you had to you would. You would." 59:47		He tells people they could do what he is doing as a primary	5

		caregiver if they had to do it.	
Maybe it's just a compliment, backwards compliment. But at the same time, what choice do I have? 59:47		He is not sure if people are giving him a back handed compliment or not , but he doesn't see he had any other choice.	5
You know I can't-- certainly not going to walk away 59:47		He was not certainly going to walk away	5
although probably people have because it's a tough job. 59:47		He thinks there probably been some people who have walked away because it's a tough job.	7
It's a tough job, but I think the key is get yourself a support group. 59:47		He knows it's a tough job but the key is having a good support group.	10

Appendix I

Participant G Analysis and Coding

Participant G Statement	*My observation during interview/reviewing interview*	*What is the meaning of the statement*	*Theme code*
I would say definitely impacted the relationship because you go from having a wife to basically then taking care of your wife, and eventually as the disease progresses, you winding up taking care of almost a toddler :43	I had asked in general if being primary caregiver for his spouse impacted their relationship. It seemed to me he go to the heart of the matter in one sentence within 43 seconds of this interview.	He went from having a partner in his wife to taking care of his wife to basically taking care of a toddler as his wife's disease progressed	8
So there's definitely a change :43		There was definitely a change in his relationship with his wife.	1
when it first started, when you didn't know exactly what was going on but something was happening, you're taking care of your wife just like if she had the flu or something :43	I thought this was a really concrete way to explain what it must have seemed like in the beginning of symptoms	When his wife's symptoms first appeared and they didn't know what was going on, it was like taking care of his wife like if she had the flu	5
then all of a sudden it starts progressing into something more than just a momentary illness :43	I was thinking he really put it well based on what I have learned so far about how the disease progresses and how it affects spouses.	His wife symptoms then all of a sudden started progressing into something more than a transient illness	12
I mean, it's life changing :43		His wife being diagnosed with FTD and becoming her primary caregiver has been life changing.	12
there is a lot of things that you used to do that you cannot do anymore. :43		There are a lot of things he and his wife used to do that they can't do anymore.	12
It just slowly takes away your relationship that you had with your wife :43	I felt sad for him as he struggled a bit saying this.	He feels as FTD progressed it slowly took away the relationship he had previously with his wife	1
you become just the caregiver. :43		He became just the caregiver	5
My wife was diagnosed in May of 2013. And that was after we started seeing the doctor in 2012 and going through a lot of testing to finally see if they could figure out what was going on and doing a number of different things 2:04		His wife was diagnosed with FTD in 2013 after starting to see doctors in 2012 for testing to see what was going on with her	6

We went through sleep apnea tests and a couple other things to see if those were the cause of what her problem was 2:04	It seems that a myriad of tests are done just to make sure that all other things are ruled out before looking at FTD as a diagnosis. It must be nerve wracking and anxiety provoking during this time for couples.	His wife was tested for sleep apnea as a possible diagnosis for her symptoms originally.	6
Eventually we just finally had to say to the doctor, “We need to have a diagnosis and find out exactly what this is.” 2:04		He and his wife were eventually stressed out and told the doctors they just need a diagnosis to figure out what it is that is causing his wife’s symptoms	6
And that's when they finally decided to send this to a neuropsych who did the testing on my wife 2:04		He and his wife were directed to see a neuropsychologist who tested his wife	6
They determined that she had the FTD. 2:04	Again, it seems after everything else is ruled out by other doctors, it is the neuropsychologists that make the FTD diagnosis	The neuropsychologist determined his wife had FTD	6
My wife was, say, 62 so that makes me 64. 3:10		His wife was 62 and he was 64 when she was diagnosed with FTD	N/A
Emotionally, I guess guys don't talk about emotions too well 3:51	I asked how it impacted them/him emotionally	He doesn’t think men talk about emotions too well	3
but I don't know as if it affected us-- I don't know 3:51	I don’t know that he thought about this before or realized it had affected them to the point of impacting them/him	He is not sure how it affected he and his wife	1
Emotionally, it made some things harder, I guess, as she progressed 3:51		HE felt things were harder emotionally as his wife’s illness progressed	1
There definitely were times when we were basically, what I would consider fairly religious and we'd go to church constantly 3:51	I was curious what their religiosity had to do with the emotional impact of his wife’s disease and his role as primary caregiver. I just listened quietly.	He and his wife were very religious at one point and went to church regularly.	9
My wife worked with a prison congregation... 3:51	I did not see that coming…	His wife worked with a prison congregation and that national organization.	9
So, we're pretty much involved in our lives religiously. 3:51		Religion was a big part of their lives	9
So, it was kind of hard with the emotions, say, coming across with the fact that, “Okay. We believe in God and we believe in miracles and praying for things to happen.” 3:51	This really caught me by surprise. They were actually hoping for Divine intervention from his wife’s disease. And then to not get it, had to be devastating…	He and his wife believed in the miracles of God and were used to praying for things to happen.	9

And then, eventually finding out that this probably is not going to be happening. 3:51	My heart sank for him as I heard this. I have faith but to have such faith that they were banking on a miracle must have been a hard realization.	He and his wife eventually realized a miracle was not going to be happening for them	9
I guess those things were the more emotional responses to the disease than anything 3:51		He had more emotional responses to not having a miracle cure his wife than anything else.	9
As far as my taking care of her, I mean, we were pretty close and took care of each other, were parts of each other's lives constantly 3:51	It sounded like he and his wife were very close before she started having symptoms and then being diagnosed with FTD. It seems like this just continued for them	He and his wife were always close and constantly in each other's lives	1
So I guess I'm not sure what else I would say about emotions. 3:51		He is not sure how else he was affected emotionally by his wife's illness and his role as her caregiver	5
It was just there and it was something I had to do to complete the job and take care of her. 3:51		He saw being his wife's primary caregiver as a job he had to complete to take care of her.	5
Well, the physical affection definitely was affected 6:11	I asked about how this all impacted their physical affection	His physical affection with his wife was definitely affected.	13
one of the main symptoms is not having empathy and not having desires anymore. 6:11	He sounded sad and a little irritated as he told me this. From his tone it sounded like his wife no longer could care about his wants or about his feelings. And on top of that, she had no sexual desires as the disease progressed.	His wife's diagnosis of FTD left her without empathy for him and without any sexual desires of her own.	13
It was pretty much a deal that you just kind of got to the point as well, you're not going to be having a sexual type relation anymore. 6:11		He knew he and his wife would no longer have any type of a sexual relationship anymore.	13
I mean, when we first started in 2012, we were probably having some kind of relation at that point, but they were definitely becoming fewer and far between 6:11		When his wife was first diagnosed with FTD, they still had an active sexual relationship even though their interactions were becoming less often.	13
And then, once she got to the point where it was apparent she could no longer make a decision about this type of thing, then I began to think, "Okay." You get to the arguments about, "Well. They can't say no or whatever." And my feeling was, "Well, I guess	I thought this must have been a difficult realization to come to for him. I had read about a court case regarding a husband that was being charged with rape because he had sex with his wife, but she was not cognitively able to say yes or no. So, he has a real legal concern as well as making	He felt that once his wife could no longer make decisions for herself, and she couldn't say yes or no to sex with him, he had to assume her answer was no.	13

if she can't say yes or no, make that determination, I guess that we're just going to have to go with no." 6:11	a choice out of care and dignity for his wife and for himself.		
So we basically, after 2013, we basically had no sexual relation, physical type relations other— 6:11		He and his wife stopped having a sexual relationship or any physical affection a year after she was diagnosed.	13
I mean, we had physical contact, but the thing when you have physical contact with your wife at that point, a lot of the times, I mean, it's like giving a hug to a person who doesn't know how to respond back 8:01	It seemed what he was really saying is that her ability to be emotionally and cognitively connected to her physical actions was gone. And it seemed that is what he really missed, not just the physicality or sex.	He and his wife had physical contact, but she was unable to respond to him in the emotional way she used to respond to him.	13
As far as by giving her a kiss, it was not anymore a passionate kiss. 8:01		He and his wife no longer had passionate kisses between them	13
A lot of times it may have come down to just like a kiss on the cheek or something 8:01		He and his wife now just kissed each other on the cheek	13
There was very little embracing 8:01Like, okay, she would put her arms around me and I put my arms around her 8:01		He and his wife would sometimes hug	13
very little of that with me or with anybody like our daughter or son. They might give her a hug and she'd probably just stand there like, "Well, I don't know what else to do." 8:01	It sounds like he and his family were used to being affectionate with each other…hugs and kisses with kids too. It sounded like this was so very hard for his entire family as well.	His wife would allow him and their children to hug her but just stand there not knowing how to respond.	N/A
So they would hug her and then that would be it 8:01		His children would hug his wife and that would be it	N/A
So the physical part definitely was lost probably early in the stages by, say, 2013. And so from there on, there was very little real physical contact except once in a while holding hands when we walked. 8:01		His physical relationship with his wife diminished after the first year of her diagnosis to holding hands as they walked	13
I might give her a hug for a reason or something, but it wasn't a loving [inaudible]. I guess loving isn't kind of the word. But it wasn't a physical attraction hug type thing 8:01		He would still give his wife a hug in a loving way not in a way to connect on a sexual intimacy level as they had done in the past.	13
Well, I guess, I mean, some of the losses is being able to come home and to give her a hug and to get a hug back 10:34	I asked about how all of this impacted their relationship…if there was loss?	He missed being able to give his wife a hug and get a hug back	13

to be able to talk to her and get feedback on what went on during the day. 10:34		He missed being able to talk to his wife about his day and get her feedback	1
You basically, at the point you realize that, “Okay. She's progressed far enough that no matter what you say, it isn't going to mean anything to her because she's not going to be able to interpret what you're saying and relate to it.” 10:34	Again, it seemed like he really lost his best friend in every sense of the word. He lost being able to be emotionally, intellectually, and sexually intimate with his wife as her disease progressed.	He realized as his wife’s disease progressed, that she was no longer able to comprehend and respond in a meaningful way to him	1 8
So, a lot of it is just caring for this person who no longer is able to respond back to you. 10:34	This seemed like it was hard for him to shift his thinking. It had to be a complete paradigm shift	He was caring for a person, his wife, who was no longer able to respond to him	8
And so all you do is basically carry what love you have for her into the job of taking care of Her 10:34	This must the way he was able to accept the paradigm shift that occurred within their relationship. I wondered what or where his motivation came from to be his wife’s primary caregiver was.	He carried the love he had for his wife into his role as her caregiver	8
…being as kind and as helpful as you can to make her life as easy as possible and try to keep her without having pain or suffering during the process, I guess. 10:34	I thought that this was not only so that his wife’s life was as easy as possible but so that his life in turn was a little bit easier as he also adjusted to all the changes	He was kind and tried to be as helpful as he could to make his wife’s life as easy as possible for her	5
and try to keep her without having pain or suffering during the process, I guess 10:34		He tried to keep his wife’s life as pain free and free of suffering as possible	5
Well, it definitely is-- I guess you would say is a downer 12:22	I asked how it all has impacted him personally. I thought this was very honest way to describe how he it has impacted him.	He described his life situation as personally being a downer	5
I definitely feel sad 12:22		He is sad	5
I guess it's one of those things it is what it is and so you just deal with it. 12:22		He had to just deal with what was happening to him	5
I mean, I definitely had my moments where I cried. 12:22	I thought this was an interesting time for him to mention this. This came up as a result of me asking him how all of this has impacted him personally. This implies to me that he realizes he is crying for himself too…not just for what is happening to his wife.	He had moments that he cried for himself	12
I didn't really become-- I don't feel like I've become depressed. 12:22	I wonder if he associates crying with depression? Instead of crying when it is a normal and acceptable response to feeling sad? I wonder if in our culture,	He was sad but not depressed	5

	we have pathologized crying for males?		
But I knew there were times when the loss of her and her affection was definitely taking its toll on me. 12:22		He was affected by the loss of his wife and her affection	8
But it's something that you kind of push back or over to the side because you've got a job to do that's more important than worrying about, “She isn't going to give you a hug.” 12:22		He could not spend time thinking about his wife’s inability to give him the affection and attention she used to give him	8
But you give her a hug and then you go from there just to take care of her. 12:22		He would give her a hug and just take care of her	8
We were married for 47 years and we had started dating in high school, so we had actually been together 51 years 13:45	I had asked how long they had been married	He and his wife had been married for 47 years and together for 51 years	N/A
Yeah. It's hard to get over that many years and just kind of push them aside and say, “Well, she's gone and now I've got to do something else. 13:45	It struck me they had been together longer than they had been separate. It had to be so hard to not have that part of yourself anymore. They must have identified as “we” more than ‘I” I would imagine.	He found it hard to push what used to be in the relationship aside to now accept the wife he knew is gone. It was hard for him to accept his role in the relationship has completely changed.	8
There's a lot of memories to get over first. 13:45		He felt the loss of his relationship as he thought about past memories	1
Yes. Yes. I retired early, so I was lucky enough to be able to retire before her disease started 14:36	I asked about work and his social life impacts	He retired early before his wife was diagnosed with FTD	5
And after I retired, I got several part-time jobs that basically I loved doing, and were doing those different part-time jobs, 14:36	He seemed happy that he finally got to do jobs that brought him joy that maybe his full-time job did not.	He continued to work part-time doing jobs he enjoyed	5
but then as she became sick, then I started giving those up. 14:36	His joy was impacted by having to give up his jobs that seemed to bring him joy and purpose	He had to give up his part-time jobs slowly as his wife became sick	5
And once she was diagnosed in 2013, then I basically retired from all of the part-time jobs 14:36		When is wife was diagnosed with FTD he quit his part time jobs	5
and just became a full-time caregiver. 14:36	He gave up the “I” in the relationship and took on the role “we” for he and his wife once this happened.	He became his wife’s primary caregiver only once she was diagnosed with FTD	5
So, the impact was somewhat minimal because of the fact that I wasn't having to have a	He says the impact was minimal regarding finances. I was patiently listening to see if he	He thought the impact to his work was minimal since he was	5

full-time job to earn money for our home or our living expenses 14:36	would talk about the impact personally too.	wasn't working full-time to earn money for living expenses.	
I had my pension and was able to draw that when I retired the first time from my main profession. 14:36		He had a pension they lived on from his main profession.	5
And then, those part-time jobs were mainly just to pass the time until she was ready to 14:36		He worked part-time jobs after retiring to pass time until his wife retired	5
and then we could go do some travelling 14:36		He and his wife planned on traveling together once she retired too	1
So, her getting FTD basically impacted our future plans 16:02	He did get to how her disease impacted them as a couple and their future plans of enjoying life together.	His wife begin diagnosed with FTD impacted their future plans as a couple	1
we had planned on as soon as she was ready to retire to start doing some traveling around the country and possibly going to maybe a foreign country or so 16:02		He and his wife had planned on significant traveling together once she retired	1
And the one trip we had planned for a long time to take was a trip to Hawaii. 16:02	This made me think about all the things my husband and I put off for a future time citing we don't have time for It now because of work, kids, family, no money etc.	He and his wife had always wanted to travel to Hawaii together.	N/A
And once we got the diagnosis, I says, "Well, we are going to have to go to Hawaii now because we don't know when or if we'll ever be able to do it." 16:02		Once his wife got her FTD diagnosis, he decided they needed to travel to Hawaii right away because he did not know how much longer they would be able to travel	1
And the way it worked out, we went to Hawaii in 2013 right after the diagnosis. And it really impacted the trip 16:02		Even though he and his wife went to Hawaii right after she was diagnosed, their trip was still impacted by her disease	N/A
she was already to the point where her stamina was pretty much hampered. She would tire easily and after the first three days I was ready to bring her home. 16:02	I felt bad and sad to hear they had waited their entire lives to go to Hawaii and when they finally made it there, her disease had progressed to the point it was not the lifelong dream they had planned it to be.	His wife had no stamina and would tire easily and after 3 days he was ready to go home	1
But then we moved on to a different part of Hawaii which we weren't doing as much touristy type things and so it	I was happy to hear they had a few days of a good Hawaiian vacation together even if it	He and his wife enjoyed the last few days of their Hawaiian vacation once they moved to a less	1

was calmer, and things were more laid back, and we had a great last four days. 16:02	wasn’t the dream vacation he had dreamed of with her in the past	touristy part of the island	
But after that, travelling became almost an impossibility because of things 17:38		He and his wife did not travel after their trip to Hawaii	1
…and what happened when we were in the car She was trying to take off her seatbelt, open the door while we were going down the road at 60 miles an hour 17:38	He was very emphatic when he was telling me this story. He must have been really frightened when this happened. I felt nervous just hearing about it	His wife tried to take her seatbelt off and open the car door when he was driving at about 60mph	7
That basically became a deal where we can't have that type of thing and we tried different things towards before she moved to a memory care unit. 17:38		He moved his wife to a memory care unity when what he was trying was not enough to keep her safe	7
I basically had tried, “Okay. Let's put her in the back seat so that I could use a childproof lock on the car to keep her from opening the doors.” And there was an [old?] device I got that we could use to keep her from being able to take her seatbelt off. And that helped some traveling 17:38		He tried different tactics to allow his wife to still travel safely by car	5
but then you can't travel very long when she would become agitated to a certain extent and started kicking on the back of the front seat and a few things like that 17:38		He and his wife could not travel long distances in the car because she would become agitated and start kicking the back of his seat	5
So travel became basically just trips around town and not anything-- I mean, we used to go out, go down into our hometown and see relatives, my mother and my sisters and other relatives 17:38	.	His travel with his wife was limited to just around town and no trip to see family	1
And that just became an impossibility to do because of safety for her and the ability to do that. She became a wanderer at one point where if you weren't constantly next to her or watching her, then she could go off and go walking any place. And sometimes it was hard to find her. 17:38	As he was telling me about their limitations of traveling he sounded sad as he was recounting what could have been in comparison to what was	Travel became impossible as his wife’s disease progressed and she started to wander if he didn’t watch her closely. Sometimes it was hard for him to find her	1
So it definitely impacted the ability to do things like, say, travel and that type of thing,		Their ability to travel as a couple was greatly impacted by his wife’s disease	1

were definitely impacted by the disease 17:38			
We did very little until she got-- well, I did some-- while she was home right after the diagnosis, I got some in-home help. 20:19	I asked about his social life	He hired some in-home help right after his wife was diagnosed with FTD which allowed him some time to himself	10
And people would come in maybe two or three times during the month so I could go out in the evening and go to-- I was a member of a computer club and so I would have somebody come stay with her while I went to the computer club 20:19	He still had some social interactions with others outside of his home	He would go to computer club a few times a month	2
And a couple of minor things like that, but for the most part we stayed home taking care of her. 20:19	He really seemed to be okay being home mainly with his wife…taking care of her	He mainly stayed home taking care of his wife	5
The big problem came as the other people who I was hiring, they basically were no longer available. 20:19	I wondered why they were no longer available to take care of his wife? Perhaps she became too much of behavioral problem for them?	The help he had hired to help in-home with his wife were no longer available to help anymore	10
And then that's when I says, “Okay. If I can't get any help, then I'm going to have to try looking at finding a memory care unit for her to move into 20:19	He had not said yet why he couldn’t get help but I had to assume that if he couldn’t take care of his wife she had to have progressed behaviorally to the point she was a danger to herself and to him	He knew he could not take care of his wife without help and decided to look to move her to a memory care unit	10
And that's in 2015 basically because I didn't have any help in the home. I moved her into a memory care unit to help. 20:19	The way he was telling me it happened makes me think he thought maybe I would or was judging him for his decision. I was trying hard not to stand in any judgment because I have never been in this situation	He moved his wife to a memory care unit 2 years after she was diagnosed because he no longer had in-home help available to him	10
And then, once she was there, then that gave me a little more opportunity to like go to church and do some other Activities 21:46	He didn’t spend much time on descriptions of what was going on in his house with his wife before he had to place her. But I assume it was very difficult for one person to manage in a safe way for her and others	He was more independent to do the activities he wanted to do when is wife was living in the memory care unit.	2
but I spent several hours a day over at the memory care unit helping to take care of her because basically the people at the memory care unit did not understand FTD and how it affects my wife and/or other clients. 21:46	It seemed important to him that I know he spent many hours every day at the nursing home. He did not want to place his wife, but he was unable to continue to take care of her on his own. I did find myself judging him slightly. I tried to	He spent several hours a day with his wife at the memory care unit to ensure they care providers knew how to take care of his wife.	5

I mean, the thing is she was the only one in the memory care unit when she moved in that had FTD. 21:46		His wife was the only one at the memory care unit with FTD	6
All the rest of the people basically were Alzheimer's or other types of dementia 21:46		The other residents at the memory care unit where his wife lived had Alzheimer's or other types of dementia, not FTD.	6
So, I spent probably eight hours a day at least at the memory care unit to begin with 21:46	I wondered if he spent 8hrs a day everyday with his wife? That is a long time to spend with a spouse even in good health. Perhaps it was most of the day with lunch breaks and other errands?	He spent 8hrs a day with his wife at the memory care unit when she first was admitted	5
as the disease progressed, I was even spending more time at the memory care unit to help take care of her. 21:46	I found this surprising. I would have guessed he would have spent less time with her as her disease progressed. But maybe it was to make sure she was being taken care of appropriately since she could no longer speak for herself.	He spent even more time at with his wife at the memory care unit as her disease progressed	5
Well, I guess the main thing for the doctors would have been to be able to, one, recognize the FTD part, the frontal temporal lobe dementia 23:23	I had asked if he could tell doctors what they could have done differently to help him.	He wished doctors would have been able to recognize FTD	10
whereas when we first went to our family doctor, at least he listened and he says-- when we were talking with him he says, “Well, I'm not sure. I don't really see this.” 23:23	I think it is important that he was listened to	He felt listened to by his wife’s primary care doctor even though he did not recognize FTD as the diagnosis	10
And I explained a few other things and talked to him a little more. And he says, “Okay. Well, let's do the test, the 30-question memory test.” 23:23		His wife’s primary care doctor did a 30-question memory test to start to rule things out	N/A
And my wife got 26, and he says, “Well, that's borderline.” And he says, “What we need to do is to make sure all of her meds are straightened out and do a few other things and then, in a few months, we will do another test.” 23:23		His wife scored high enough on the memory test to be sent away with a suggestion of doing another test in a few months	N /A
And so that's what we did. And I didn't mind that process. I mean, I can understand having to eliminate a lot of things. 23:23		He did not mind the process of ruling out other diagnoses to find what was wrong with his wife	N/A
We went through the sleep apnea test, and I mean, it was	It seemed like at this point he knew that sleep apnea was the	His wife was diagnosed with mild sleep apnea	N/A

quite evident that during that test there was something really wrong because as I left my wife there to do the test, came back in the morning, and the gal says, well, about halfway through the test, my wife got up, took all the leads off to all the sensors, and went to the bathroom. And she says, "We got enough data to know that she has a mild sleep apnea." 24:39	lone culprit of what was going on with his wife. I guess I would be hoping that's all it was too if it were my loved one.		
Well, then moving on to the CPAP machine, and it was obvious that that wasn't the answer because before the CPAP machine, she might get up maybe once or twice during the night. But with the CPAP machine, she was getting up five or six times during the night She would forget she was wearing the CPAP and drag it off of the nightstand. And it was a nightmare. 24:39		His wife did not do well with the CPAP and was actually sleeping less throughout the night.	N/A
So basically the sleep doctor didn't understand dementia and the problems that were going to be happening with the CPAP machine. 24:39b	It did seem like it would be counterproductive to use a CPAP on a person with certain types of dementia. I would imagine it would be confusing and scary for the person with dementia.	He didn't think the sleep doctor understood dementia and how the CPAP machine would not be useful	6
So after three months of the CPAP, four months of the CPAP machine, we gave it up. Because it was causing more problems. She was getting less sleep with it than we had before 24:39		His wife stopped trying to use the CPAP machine after 3 months	N/A
So, then the neurologist that we went to, I mean, he understood dementia, but he was basically treating her as an Alzheimer's patient 26:10	It amazed me that neurologists in general, don't seem to know about FTD. And treat all dementia like it's Alzheimer's. That has to be frustrating to patients and their families.	His wife's neurologist treated her as if her dementia was Alzheimer's disease	6
And he says, "Well, come back in three months." And well, every three months we go through the same 30-question test, the memory test deal. 26:10	As he was telling me this he sounded frustrated with the way things went in the beginning of trying to figure out what was going on with his wife	His wife's neurologist wanted her to have a memory test check every 3 months	N/A
The thing is that that test basically showed her declining, but it didn't give us a diagnosis. 26:10		The memory test showed every three months that is wife was declining but the	6

		neurologist gave no diagnosis	
And the thing for us to go to Social Security and say, "Hey, she needs to be on the Social Security disability," we needed to have a diagnosis. 26:10	It's unbelievable that the neurologist did not give a diagnosis. In order to bill insurance, there had to be a diagnosis of some kind. Maybe this participant was confused?	He knew without a diagnosis, his wife could not apply for SSD	6
So, basically after a year or so with a neurologist, I just basically says, "We can't do this anymore. We need a diagnosis. Period. 26:10		After a year of seeing the neurologist, he insisted that his wife be diagnosed finally	6
And then that's when they finally says, "Okay. We'll line you up with a neuropsych." 26:10	I don't understand why the neurologist couldn't give the diagnosis and this participant and his wife were sent elsewhere? Maybe this doctor just didn't know what was going on?	His wife was finally referred to a neuropsychiatrist for a diagnosis and second opinion	6
And they gave us the diagnosis we needed so that we could go to Social Security and get it taken care of. 26:10		His wife was diagnosed by the neuropsychiatrist with FTD which made her eligible for SSD.	6
But I don't know how long we would have gone to the neurologist if I hadn't finally just says, "Hey, this has got to stop. We're not doing anything." 26:10	It sounded like it would have just gone on and on until his wife died. I feel frustrated just listening to how things went for them medically.	He wonders how long, if he hadn't put a stop to the visits, the neurologist would have continued the memory tests without any real diagnosis	6
A lot of people with FTD, they've gone through MRIs, they've gone through PET scans, a whole bunch of other tests that we never did, but once we went to the neuropsych and they said that they were 100% sure it's FTD, that's all I needed 27:53	I found it shocking that his wife was only given memory tests for a year and then the 3rd doctor, without MRI, PET and other exams, diagnosed her with FTD. I wonder if that is what her true diagnosis was? Based on her behavior and symptoms it sounds appropriate but who knows?	His wife was diagnosed with FTD based on her symptoms without an MRI or PET to confirm the diagnosis	6
I mean, I didn't see a need for going through a PET scan or MRI or anything like that, but at least we have the diagnosis. We could go to Social Security. 27:53	As I heard him say this, initially I was taken aback. But as he explained it more, I realized he needed the money from SSD in order to help take care of his wife's medical and behavioral health needs. No matter what the PET or MRI would have said, nothing would change for him or his wife	He didn't need the confirmation from a PET or MRI that his wife had FTD because as long as she had that diagnosis, she qualified for SSD and for help.	6
But we needed a neurologist that was probably a little more attuned to other dementias,		He thought his wife's neurologist knew more about FTD, a diagnosis	6

other than Alzheimer's, and would have been a little more aggressive on getting a diagnosis. I mean, until I said, “We need it. We need to do this,” he was willing to have us come in every three months and take the same 30-question test. I mean, it just didn't make any sense, so. 27:53		could have been a lot sooner	
And he said they-- I mean, they had said that-- I mean, I know some people from other support groups where doctors have says, “Well, don't come back because there's nothing I can do for you.” 27:53		He knows other’s in his wife’s situation that were told not to come back for appointments because they could do nothing for her	6
I mean, the guy was saying at least, “Well, there's nothing really we can do, but we can continue to watch and monitor the progress.” 27:53	It struck me that he was okay that the doctor was trying to be honest even if it isn’t what he wanted to hear.	He was okay with his wife’s doctor saying nothing more could be done other than monitoring her disease progression.	6
But again, some doctors were a whole lot worse than the ones we had 27:53		He thought other’s had doctors that were a lot worse than their doctors had been.	6
And our primary care physician was excellent. And the neurologist was okay. The neuropsych was great. 27:53		He thought their doctors were all above average to excellent.	10
But I can't fault our family doctor or our primary care physician because I think he did an excellent job of getting us to where we needed to go and help us out throughout the whole process. I mean, any time she had a problem and I needed to get in to see him, he was right there to help us out, so. 27:53		He felt like their primary care doctor was by their side and there when they needed him	10
Well. It's a process and I don't know. 30:39	I asked about how his family might have helped differently to help him better.	He doesn’t know how his family could have helped him differently	10
I have a daughter who's a female. But I can guarantee you that as being a primary caregiver, I don't know what part of the family would have been more helpful. 30:39	It seemed to me thought at first that another female could help his wife better than he could as a male. But it seems now he isn’t sure about that especially as he thinks about his family, specifically how his daughter would have been as a caregiver.	He isn’t sure his daughter would have been any better of a help even though she is a female.	10
But I learned a lot of things about a female and doing	I thought this was a good point he brough up. I had never	He learned a lot about being female as his	3

things for a female that I had no clue what to do or how to do it. 30:39	thought about husbands not knowing about all the things that females deal with daily.	wife's primary caregiver	
And so it was a deal where I, again, my primary care doctor helped me, especially when my wife got to the point where she would no longer clean herself after going to the bathroom. He instructed me on what to do and how to do it 30:39	I found it interesting that it was his PCP that instructed him on the female anatomy and how to clean his wife after a bathroom mishap. I am not sure how I feel about it either?	His PCP helped him learn how to clean his wife properly after using the bathroom or when she was incontinent.	3
And I don't know if it would have been-- if my daughter would have been helpful in that or not. 30:39	Maybe he didn't feel comfortable asking his daughter about the female anatomy or how to take care of her mother? Maybe his daughter didn't feel comfortable with him asking either?	He didn't think his daughter would have been helpful in that situation.	10
But since she's not close enough, I really didn't have much help from her. 30:39	It seems that his children did not help in the physical sense with their mother at all. It sounds like he was on his own along with whatever help he hired at the time before his wife went into the memory care unit. I feel like I am being judgmental but trying not to be	His daughter didn't live close and he didn't have much help from her.	10
And I know my son wouldn't have been of any help at all. 30:39		His son would not have been any help.	10
There is, I mean, other things. Luckily I just became kind of aware of this problem the other night on Facebook on the FTD Facebook page. A lady was asking-- or the daughter was asking, "Well, what do you do when your mother who isn't through menopause, and she's still having her period?" Luckily, my wife was through the menopause stage. And I didn't have to worry about the tampon, pads, that kind of stuff. 32:11	This is a real concern for those who are diagnosed with FTD in their 40's. He has a good point. He sounded grateful that he didn't have to worry about that with his wife.	His wife was already in menopause so he didn't have to worry about feminine hygiene products for her.	3
It was enough of a worry to worry about cleaning after she urinated and after she had a bowel movement so that we didn't cause her to have UTIs by improper cleaning 32:11	I would imagine it was difficult to change roles within the relationship and become a caregiver that has to know how to clean his wife properly so that she doesn't get a UTI.	He already worried enough about cleaning his wife properly so that she didn't get a UTI	3
Luckily, I didn't have to go through the process of having a wife who was still menstruating 32:11		He felt lucky his wife was not still menstruating	5

Other things still that women do and things, luckily my wife kind of gave up wearing makeup before I had to start taking over things, so I didn't really have to worry about putting on makeup for her. 33:25		His wife stopped wearing makeup before he became her primary caregiver, so he didn't have to worry about learning how to apply make up	7
I mean, I took care of her skin as much as possible with lotions and that kind of stuff, but I don't know who you would go to get that information other than our primary care doctor who, like I said, he helped quite a bit on that end 33:25		He took care of his wife's skin with lotion	3
but I don't know who you would go to get that information other than our primary care doctor who, like I said, he helped quite a bit on that end 33:25		He asked his PCP for help and guidance on how to take care of his wife physically.	7
But I don't know if I could have asked that question—excuse me, I could have asked that question to my daughter. "Okay. But how do you wipe [laughter]?" I think that she might have been embarrassed and I might have been too embarrassed to ask, I guess. I don't know. 33:25	This is what I had suspected earlier. However, I think he would be more embarrassed than his daughter would have been . . . just my own thoughts on that.	He thought it would embarrass his daughter if he asked her how to clean or wipe her mother	7
But it's something I basically told a lot of guys. I says, "You better talk to your wife about these things so you can learn how to do it just in case you have to because when you have to learn on the fly it's a different ballgame." 34:32	I thought this was an important comment. It is so true, that most men don't know their wives' daily rituals for beauty and everyday up keep.	He tells men to talk to their wives about their daily beauty upkeep because learning on the fly is hard	3
If you have a husband, talk to him [35:01	He suggested I talk to my husband now just in case something happens. Not bad advice.	He suggested if you have a husband, talk to him about these daily beauty rituals now	N/A
I would say most of our close friends were excellent Our very closest friends from church, they were very supportive of me. 35:21	I had asked about how his friends could have helped his differently	His close friends were an excellent support to him	10
Several of her friends were able to come over and sit with her and do things so that I could go out and take care of things in the yard or something like that		His wife's friends would come and sit with her so that he could go grocery shopping or do yard work	10

or maybe go grocery shopping. 35:21			
Then there's the opposite where some of her best friends basically like they dropped off the end of the earth and never saw her again 35:21		Some of his wife's best friends dropped her completely	11
I know I talked to one of them and was asking her maybe she would like to come visit and she says, "I can't handle it." 35:21		One of his wife's best friends did not visit her because it was too hard for her	11
She basically would say-- now we're getting to the emotional part, but- 35:21	He became very emotional and began to cry as he tried to continue telling me about what her best friend said…I felt said for them both	He felt very emotional about his wife's friends not coming to visit her	11
She just basically says that, "I remember (spouse) the way she was and I can't go see her now." 36:31		His wife's friend does not visit because she prefers to remember his wife as she was in the past	11
This particular friend, the ironic part here is that she didn't want to come visit and (spouse) see her the way she is, but now her husband has developed dementia. 36:31		The friend that couldn't bear to see his wife now that she has FTD, now has a spouse with dementia	N/A
So I don't know how she's going to be able to handle some of this if his friends basically say, "Well, I don't want to come see him anymore or have anything to do with it because I want to remember him the way he is." 36:31		He doesn't know if this same friend will be able to handle it when friends don't visit her husband because they want to remember him as he used to be	N/A
But I've been out. I visit with him and talk to him and took him some material on dementia things that they could use to kind of be aware of what they're going to be possibly going through and hopefully I'll still be able to help them 36:31		He has visited the husband of his wife's friend and tried to be helpful to them both even though that same kindness was not extended to him from them	N/A
But friends basically ran the whole gamut from very supportive to me and (spouse), to basically not wanting anything to do with the situation. 37:41		His friends and how involved they stayed ran the gamut from very involved to not at all	10
think I'm over that part. I don't know what other questions you got but at least I know that one elicited a little bit of emotion. I	He did very upset as he was telling me about their friends who didn't want to spend time with them anymore. I couldn't imagine being at that stage in my	He felt very overwhelmed and sad when thinking about how some friends wanted nothing to with	N/A

think I should be all right. 38:21	life and finding out who my true friends really are.	them once his wife got sick.	
Well, I guess the main one is be basically close enough to your wife to know what's going on with her. 39:56	I asked what advice he would give other males in the primary caregiver role for their spouse.	He would advise other male primary caregivers to be close enough to really know what's going on with their spouse	3
I think that my wife and I were close enough that-- and I'm sure that this played out as she became basically-- she couldn't speak [inaudible 39:56	He felt close enough with his wife to make this comment, but he also said previously he had to ask his PCP how to physically clean his wife. I am not exactly sure what he is really trying to imply here. I waited quietly to see what else he said.	He felt close to his wife to know what she needed and wanted especially once she was unable to speak	1
And if and when she did speak, most of it was basically garbled or she might be able to put two or three words together that most of the time didn't have anything to do with the situation. 39:56		His wife was unable to speak clearly and when she did speak, it often was not on topic	1
So, you need to be able to be close enough to your wife to understand when she's in pain, when something's wrong, to be able to sense that there's a change going on, and then again, to be able to take care of her. 39:56	Again, I am not sure he had the most realistic perspective on this? But it is interesting that he thought he did.	He believes that male caregivers need to be close enough to their wives to know how best to care for them	1
I mean, my wife had hard contacts that she put in and out every day. She got to the point where she could not do that, and I can guarantee you, being able to put contacts into another person's eye is a learning experience. 39:56		He had to learn how to put his wife's contacts in for her	5
And then, the other thing happens is that if she would rub her eye and the contact would come off, then you'd have to retrieve the contact from the back part of her eyeball. 39:56		He had to learn how to retrieve her contacts when they would move to the back part of her eyes.	5
You learn to do all sorts of little things that you never dreamed of being able to do to take care of her and make sure that she is taken care of so that she's not suffering or in pain or— 39:56		He had to do many things for his wife he never dreamed he would have to do in order to take care of her well.	7
You want to kind of be able to protect her dignity as much as possible 42:23	I am glad he said this outright because it seemed like what he	He wanted to protect his wife's dignity as much as possible.	5

	had been trying to tell by his stories.		
I mean, when she was in the first stages, and before we kind of really even knew that things were happening, and it was just little things were happening and I was just like kind of going back to the menstruation part, but my wife had tampons and a combination of that and pads. And for years we never had any pads around the house at all. All the sudden, I'm in the [inaudible] "What are these pads for?" 42:23		He knew his wife well enough to know she was in menopause. And he questioned why after years of never seeing pads in the house all of the sudden his wife had them	1
Well, she had started to become incontinent and then purchased some pads and was using them, 42:23		His wife had started buying and using menstrual pads when she started to become incontinent	7
I didn't know until I found these pads, and then I started talking to her about it. 42:23		He did not know about his wife's incontinence until he found the menstrual pads and asked her about them	7
But you got to notice these little things going on to start putting the pieces of the puzzle together, then watching her do other things. You start to say, "Okay. Now what's really going on here? This is happening. This is happening." 42:23		He believes that because he knew his wife so well, he was able to notice little changes to know something was wrong	7
So I know guys, husbands who couldn't tell you anything about their wife, let alone be able to read them and know when something's happening 42:23	As I was listening to him say all of this, I wondered if he learned the most about his wife as he became her primary caregiver? I am sure he knew a lot about her before this, but he really got to know her intimately once he had to feed her, clean her, and watch her	He knows some husbands who don't know their wives at all and wouldn't know if something was wrong.	3
A man and a woman who have separate bathrooms, how is a guy ever going to know what's happening in there or be able to monitor? My wife and I shared the same bathroom so it was easy for me to monitor and to see and talk to her and do things together 44:07	He again, really was stressing the fact that he knew his wife and knew her habits. I wondered again, if he really knew her that well? It sounded more like he was having some PTSD symptoms from learning as much as he did about her in a very short amount of time? Perhaps I am reading too much into his comments and he is just a little	It's important for a man and a woman to share space to know each other and each other's habits.	3

	anxious and nervous as he talks to me about it all.		
I mean, well, I don't know if it makes a whole lot of difference but I mean, a lot of the times we took showers together. 44:07 It was good for her to wash my back. I washed her back	It seemed important to him to talk about what their physical intimacy was like before his wife was diagnosed with FTD	He and his wife were very intimate with each other in the past, often taking showers together.	13
But eventually, it got to the point well, because it was natural for us to take a shower together, it was easy for me to shower her when it came to the point of having to do that, to be able to wash her hair, to wash her body, and then to dry her off and put the lotion on 44:07	He was sad as he told me about what they used to do together. I felt sad for their loses too.	He was still able to shower his wife when her disease progressed because of their past intimacy and showering habits.	13
I mean, being that close together over the years, I think, made a big difference in being able to take care of her. 44:07		He was able to better care for his wife because they were so close and intimate over the years	5
Because if a guy doesn't know, he's never taken a shower with his wife or a bath or something, it's going to be impossible almost for him to understand what you've got to do to get that done. 44:07	It really seemed to me that he missed that aspect of his relationship with his wife. And it was important for him to let me know that he and his wife did, at one time, have a good physical and sexual intimacy that had helped him take care of her throughout her illness and the progression of her disease.	He knew his wife intimately which helped him to care for her when she could no longer care for herself.	5
Well, I guess it's kind of a deal from one of the guys following a little bit on FTD Facebook page, and I know I did this, but he's probably doing it a lot more than my-- but his wife it's a little different situation than my wife was, but know like playing your favorite music together when you can be together, holding hands. 46:01	He thought it was important that other's in his situation look to the AFTD Facebook page to get ideas of how to help your loved one.	He believes that getting ideas from the AFTD could help caregivers with quality time with their loved one.	3
Just try to remember those things that you did together when you were younger, and try to do the same things if at all possible once your wife has the disease 46:01	He said this and it seemed to echo what others have said about quality time with your spouse who was diagnosed with FTD.	He felt it was important to try and do things with your spouse now that you used to do together before FTD entered the relationship.	1 8
And maybe somewhere along the line, it will spark a moment whether you're dancing together, holding her. I mean, you don't have to be doing the	This was a very moving statement. I felt his extreme sadness and longing for his relationship with his wife, and best friend.	He was hoping for a spark of clarity from his wife by doing some of the same things they used to do before she	1 138

foxtrot or something really fast, but just kind of standing in the middle of the floor rocking back and forth to the music. 46:01		became sick. He was always waiting for a glimpse of his wife he knew.	
It's a lot of things that since I knew my wife for a long time, I mean, we started in high school, and I knew some of the things that went on with her, talking with her parents about things that happened in her childhood, some of those things, if you can get that kind of information from your wife's parents or cousins or things like that, those types of things you can use once your wife begins to—the disease begins to progress and she begins to go basically backwards. 47:23		He believes that knowing your wife’s childhood from her parents, cousins, etc. can help you when she starts to regress as her disease progresses	8
I mean, some of the things she did as a child, you might be able to do now once she's regressed back into almost a child to try and spark her mind a little bit 47:23		He believes that knowing your wife’s childhood from her parents, cousins, etc. can help you when she starts to regress as her disease progresses	8
So the more you know, the easier your job is going to be to take care of her and to maintain her dignity 47:23		He believes the more you know about your spouse from childhood through the present, will help a spouse caregiver take care of and maintain your loved one’s dignity	5
It's something that you don't necessarily ever figure on doing but some of the things you just have to do whether you're ready for it or not 48:57		He believes that being a primary caregiver for a spouse is not something anyone figures on doing. But it might be one thing you have to do whether you are ready for it or not.	5
And like I said, the more things you can do to get prepared, the better off it's going to be. 48:57		He believes the more you know about your spouse, the better you will be at taking care of that person when they can no longer take care of themselves	5
I don't know what-- I mean, I guess the one thing that is very evident to me is that every person with FTD, the progression is different. And		He wants other caregivers to know the progression of FTD is different for every person.	7

when I read some of the posts from the other FTD people on the Facebook page, their process, to me, is an extreme nightmare. And so people are going to have to be aware of that 50:11			
My wife's progression, she basically was a pretty gentle and calm person and remained that throughout the progression.50:11		His wife was always a gentle and calm person and remained so throughout her disease's progression.	N/A
I mean, she had moments that they were extremely violent. I mean, we had a time back probably in 2013, 2014 before she went to the memory care unit that one of the things she started doing at night was she would just start hitting the bed with her fists. 50:11	It seemed to me that he had to explain why he had to put his wife in a memory care unit was because his wife started to have a violent tendency that she had never had before…ever.	His wife started to have extreme violent tendencies as her disease progressed.	7
And if I was in the way, I might get hit. But then you know you move over to your side of the bed and eventually I got something to put between us that solved that problem. Then pretty soon she stopped that. 50:11	This really hit me…no pun intended. He was talking about not being physically hit by his wife and moving out of the way…but it seemed that is what he had been doing from an emotional standpoint too…putting something between them so he didn't get hurt. I thought this was really powerful.	He would put something between them so he didn't get hurt.	7
But as a caregiver for your loved one, whether it's male or female, you've got to learn right away that you can't sit there and argue with them. 52:08 You can't sit there and try to tell them that there's no reason why you can't understand me. There's no reason why you can't do this.		He believes you cannot argue with your spouse that has FTD.	7
You've got to learn to be able to accept the disease is doing what it is and that you've got to get away from trying to-- I don't really know how to say it. It's just you've got to accept what the disease is and just be the best caregiver you can be 52:08 You're going to waste so much time if you argue and try to make things that are never going to happen. You just got to accept what it is.	Acceptance is so hard. I wonder if he has come to this epiphany now that his wife has passed?	He believes as a primary caregiver, one has to accept what FTD is as a disease and still be the best caregiver you can be.	7
And once you realize that that person is no longer there, but	This really says it all…	He believes once you realize and accept that	7 8

you need to take that person, protect their dignity, to protect them and keep them safe as much and as well as you can, that's about all you can do 52:08.		your spouse is no longer there, your job is to protect her dignity and keep them safe.	
But I see on Facebook on the FTD pages that I'm on, they [inaudible] “Well, I tried to explain her about daylight savings time.” Really? Seriously, I mean, they have no concept of that. It doesn't mean a thing to them. There is no use trying to explain to them. 53:58 If somebody close to them dies, there you might say to them, “Your aunt died,” or your uncle, aunt, but don't try to sit there and try to evoke some emotion out of them because they have it no longer there. You're going to either slowly learn that process or you're going to go crazy trying to take care of them explaining things like that to them that they'll never understand anymore. I don't know. I don't know if that helps or not.		He thought this it is ridiculous to try and reason with someone with FTD because they have lost that ability.	8
But I mean, if a doctor or a counselor could say, “Hey, I know that at some point you're not going to be able to explain all these little details to your spouse, so don't let it get to you because you're going to drive yourself crazy trying to do it.” You got to learn right away that as things go, you got to let it go and just take care of your loved one the best you can. 55:34	I thought this was insightful. giving caregivers permission from an outside source, that you don’t have to be perfect to be a great and loving caregiver.	He thought that words from a doctor or counselor that being a loving caregiver doesn’t mean being perfect.	710
Oh. I know. I'm grateful that my wife's FTD wasn't as bad as some. But in the end the result is the same, and you still have to spend the time to take care of them. You can't just say, “Well, I can't do anything,” and lock them up or-- one of the employees that I had at our memory care unit, in my estimation she basically should never have been an employee there, but her attitude was, “All the people with Alzheimer's, all		He believes that everyone deserves to be taken care of well and with dignity.	5

these people, we should just drug them to the point they're zombies, and my job will be easy." 57:30			

Appendix J

Participant H Analysis and Coding

Participant H Statement	*My observation during interview/reviewing interview*	*What is the meaning of the statement*	*Theme Code*
Well, certainly. Not in a bad way :42	I asked how being the primary caregiver of a spouse diagnosed with FTD impacted their relationship.	His relationship with his wife was impacted by her diagnosis of FTD and his new role as primary caregiver but not in a negative way.	1
But whereas, we were co-equal before, and each had our likes and dislikes, and ways of doing things. :42	In the past they were co equals and so I assumed that now they are not so much so… which right off the bat seems to be impactful and not really in a great way.	He and his wife were co-equals before FTD entered the relationship.	1
As time went on, it became focused on her care. It was more focused on her :42	It was clear in the first 42 seconds of this interview his wife's disease was very impactful to their relationship.	As time went on, the focus in the relationship became more on his wife.	2
And what as you probably know, one of the things that happens with FTD is a loss of empathy. So, she had less empathy for what I needed. 42	Within the first 42 seconds of the interview he was already talking about his wife's inability to have empathy for his needs.		2
But the love never left, certainly on my part. :42		His love for his wife remained constant.	5
It got toward the end. She really didn't know who I was. So it's like that impacts the relationship as well. :42	I would imagine that when a spouse no longer knows who you are that would significantly impact the relationship.	His wife eventually didn't know who he was and that impacted their relationship.	8
56 years 2:13	This was his response when I asked how long they had been married.	He and his wife had been married 56 years	N/A
Yes, and even though things were different, but it didn't change. My devotion to her, that was not affected 2:13	I asked about how this all impacted their emotional connection to each other	His devotion to her didn't changed no matter how the disease changed her individually in the relationship	5
I never felt bitter or disappointed that this problem was thrust upon us unexpectedly. 2:13	I did not believe him. I know that is my issue not his. But when he said this I just thought immediately he is trying to not have me judge him for being human.	He never felt bitter or disappointed that this problem was thrust upon them.	12
But yeah. If anything, I probably loved her more 2:13	I wondered if it was because she truly needed him now? but I don't know why I was thinking that as he said this.	He believed he loved her more once she was sick	5
Just because I was focused on taking care of		He was focused on taking care of her since she took care of him for	1

her. Then, I often told people that she took care of me for 50 years, I could take care of her for a few years. 2:13		50 years throughout their relationship	
She was diagnosed in 2009. I would have been 69. She would've been 67 3:38		He was 69 years old and his wife was 67 years old when she was diagnosed with FTD	N/A
she noticed it more than I did That something wasn't right 3:59	I asked about what they were noticing that made them go to the doctor	His wife noticed her changes more than he noticed her changes	6
And so she went to the doctor and he gave her a brief test and diagnosed her with mild cognitive impairment. 4:05		His wife went to the doctor when she noticed changes in herself and she was diagnosed with mild cognitive impairment	6
It was—We began treatment which included. Namenda and Aricept and something else. And I could see that really wasn't helping at all because things were getting worse. 4:05	I thought it was interesting that the doctors and they went right to medications.	His wife was prescribed 3 medications for dementia that did not work and made things worse	6
And I was the one who discovered that it was FTD 4:05	This statement did not surprise me.	He was the one who diagnosed his wife with FTD	6
Because I was on the internet and I came across a FTD website. And I looked at the symptoms for primary progressive aphasia and if fit her exactly. So I took her to a neurologist then and he did an MRI and confirmed that it was FTD 4:05	Again, this is not surprising.	He took his findings about FTD to the neurologist and an MRI confirmed the FTD diagnosis	6
Yes. Yes. Not the original doctor 5:18 The original doctor was our primary care physician 5:25 So. And then we went to a gerontologist. But I didn't like what he was doing. So that's when I discovered it was FTD	I had just reiterated that he had taken what he found back to the doctor	He took the information he learned about FTD back to other doctors not to their PCP	6

than I went to a neurologist. That we got confirmed. 5:30			
About two years 6:02 It was 2011 when we got that diagnosed 6:04	I asked how long it took to get the official diagnosis	It took his wife 2 years to get the official diagnosis	6
Yes. In fact, as you know she died in March. And people talked to me about how devastating the loss must be, and it is of course. 6:36	I asked about loss in the relationship and how or if this impacted them	His wife died 2 months ago and people are talking to him about how devasted he must be now with that loss.	12
But it's not like she suddenly died and then I was mourning her for that. I was mourning for the last two or three years because I had lost the person that she was. 6:36	I really felt this from him when he said it. I can't imagine being in his shoes and reliving this hell every day.	He has been mourning the loss of his wife and who she used to be for at least the last 3 years.	8
So it definitely impacted me from that standpoint. Knowing that she wasn't the same person. 6:36	I felt sad for him as he became teary eyed. It has only been about 2 months since his wife died as we sit here for the interview	He was significantly impacted by knowing his wife was not the same person he used to know anymore.	8
And I could still give her a hug and give her a kiss and she wouldn't-- Up until the last six months, I could still get a smile out of her by giving her a kiss 6:36	I thought it was lovely that he still wanted to get a smile from his wife and make that connection with her.	He was still able to connect with his wife by kissing her and watching her smile.	13
And that was-- the smile--- she had a beautiful smile 7:37	He started to cry as he told me this about his wife.	He loved his wife's beautiful smile.	1
But the smile-- the frequency of the smiles became fewer and fewer as time went on. 7:37		His wife's smiles became fewer and fewer as her disease progressed	1
Yes. Yes. In fact, in 2012, which was a year after the FTD diagnosis was out 50th wedding anniversary so we had a party with several hundred of our closest friends. 8:03	I asked if there were things there were still able to do as a couple once she got diagnosed	He and his wife were able to celebrate their 50th wedding anniversary together with friends and family	1
And I remember one of the things that we did is kind of a funny story about our wedding and	As he was telling me he was smiling as he was thinking about how he and his wife performed their skit for friends and family. It	Even three years after diagnosis, his wife was still mostly present even though the disease was there too.	1

our honeymoon. And so she and I related that story to the group and I gave here-- I wrote out a script and, at that point, she could read from the script and make a few mistakes but she can still do that. And so we could still laugh about things and remember things. 8:28	seemed at that time, his wife was mostly still present even though the disease was too.		
We went on a cruise then, a month-long cruise. 8:28 In northern Europe and then across the Atlantic. And that was our last real-- we have done a lot of world traveling. That was our last big trip together. But I figured, on a ship, if I lost track of her, she can't get away. I'll find here. 9:25		He and his wife traveled for a month while she was still mostly present.	1
And we continued to go to the theater, go to concerts. 9:48	They tried to continue to enjoy each other as they had always done before she was completely gone	He and his wife continued to enjoy social activities together as much as possible.	1
So I would say that up until the last, maybe three years, we tried to live as much as of a normal life and activities that we would both participate in. We did that as much as possible. 9:48		He and his wife tried to live as normal as possible as they had done before FTD	8
Well, in terms of hugging, and kissing, and touching, really, no effect. 10:59	I had asked about how/if his situation has had an impact on their physical affection	He and his wife continued physical affection throughout her disease	13
Sex became a thing of the past-- 10:59 probably after about five years. 11:15	This was not surprising, but I was surprised how straightforward he was about it	He and his wife no longer had a sex life.	13
And she would have participated but I felt like she didn't have the [inaudible] ability to say yes and that it wasn't fair to her. So that was the	I thought this was also something that has been echoed by other participants so far.	He stopped having sex with his wife because she couldn't consent.	13

consequence of the FTD 11:22			
But we never lost the ability to touch, kiss, and hug, the affection with each other. 11:40	I wondered how different it was for him and for her? I find it hard to imagine it was/felt the same?	He and his wife continued their physical affection with each other throughout her disease progression.	13
It never seemed strange to me, being her caregiver even though that's not always a male trait. 12:18	I wondered if he felt less male somehow because it felt “normal” to care for his wife?	He felt comfortable taking care of his wife	3
But it's something I felt I needed to do, I wanted to do and I wanted to keep her at home as long as I possibly could 12:18	He wanted and needed to do… again the question of where does one put all his energy of love towards someone when the relationship shifts? Is it put towards caregiving for the loved one?	He wanted and needed to care for his wife at home	5
Eventually, it became too difficult for me to physically take care of her. 12:18	It seemed to pain him that he had to eventually put his wife in a memory care unit. I could feel his guilt/shame as he talked about it.	He was eventually unable to care for his wife at home	5
Yes, I did. For one thing, I do a lot of music things. Direct choirs and musical groups and so forth and [active?] things. So I would need to go to rehearsals and for some time I would take her with me and she'd be fine with that. And eventually, that wasn't going to work so I did two things. I hired a caregiver who could come in and stay with her while I was the meeting or rehearsal. That, of course, gets expensive 13:08	I asked about his time for himself as a caretaker.	He found time for his hobbies by hiring caretakers as needed	2
. We live in a 55 and better community with very close-knit relationships so I had about 12 people that volunteered to, you know, “Anytime you need somebody to come in and just stay with her, give me a call.” 13:08 It's fascinating that (spouse) was the one that wanted to move into this community. I was kind of		He and his wife are part of a tight nit living community that was a great support system for them.	10

lukewarm about it. I was happy where we were. But it turned out to be the best thing we could have possibly done, because of the closeness of the community. 14:17 There's a lodge and there's lots of activities and so you get to know people really well. And so it's different from a normal neighborhood where you're friendly with people but you don't really know much about them or- 14:41-			
By the time we got the mild cognitive impairment, I had been retired for three years. So that made it easier, obviously, for me to be a primary caregiver. 15:08	I had asked about whether he was still working or not when his wife was diagnosed/he was her caregiver	He was already retired when his wife was diagnosed with mild cognitive impairment. He was already retired when he became his wife's primary caregiver	5
I wouldn't say it inhibited, maybe doing that, I mean. There's a golf group that goes out once a week and I could do that. So it didn't impact us other than I had to make sure that there was somebody to stay with her because she could wander 16:03	He was talking about how he was still able to be social by himself without his wife	He was still able to be social with others as long as he had someone stay with his wife during his time out	10
When that was happening, she didn't need a lot of physical care, so I didn't need a nurse like a caregiver, just needed a companion to stay with her and make sure she was okay. 16:03		He was still able to be social with others as long as he had someone stay with his wife during his time out	10
I don't think I have a good answer to that 17:21	I asked what doctors could have done better/differently that would have helped him as a primary caregiver	He is not sure what doctors could have done differently to help him as a primary caregiver	N/A
The neurologist that we had was extremely helpful. He was the kind of doctor that would take the time to talk and give advice. He was in session by saying, "You're doing		He had one doctor that took time to talk to him and give advice	10

a great job." And really encouraging and very helpful. And he would say, after the examination, [he would say to us?], "Here's what your life will [receive?] in the next six months." So he would watch with us, make sure she's swallowing okay. So I couldn't have asked for any better care 17:21			
have a daughter who lives globally and a son who lives out of town. And in the video you saw my daughter. They're both extremely supportive. In fact, they were once-- when it came time to make a decision - do I continue to care for her at home or put her in assisted living? - they were the ones who said, "Dad, you've got to protect your health." So it's time. 19:23	I asked what his family could have done differently to help him better as the primary caregiver	His family was extremely supportive and helpful to him as his wife's primary caregiver He would not have asked for things to have been done differently by his family	10
My daughter was not able to help with a lot of time, which would have been nice, but she has five kids And she's a teacher, a school teacher, so in summer, she could help out but otherwise, she just didn't have much time to help. My son actually doesn't really like to my being a caregiver, but after (spouse) went into assisted living, he had actually helped financially [inaudible]. So again, I couldn't have asked for anything more. 20;02 Not locally. I have a brother who lives out of town and a sister who lives out of town, so they really couldn't provide any help. (spouse)'s brother does live locally.		Some of their family members were able to offer more support than others and in different ways	10

And he was one of the people that I could call on to stay with her. So he provided good support. 20:52			
Well, it's interesting. One of the things that we learned sort of early on is that we needed to be open with our friends exactly what's going on. 21:41 What she has--because we had her best friend who now lives in (out of town), this was about six years ago, came up for a concert that one of my choirs was putting on. The time before the concert, people were talking and (spouse)'s friend noticed (spouse) wasn't spending much time with her. She was talking to other people and (spouse)'s friend got--she was the kind of person who would get upset about things like that. And so, she sent me an email the next day and said, "Well, it's been a nice friendship but things move on. See ya." And (spouse) was still talking at that time, so I said, "Look at this. What's going on here?" (spouse) was enough self-aware still at that point to say, "Well, she doesn't know what's happening with me." And so I sent an email back to the friend and said, "She has FTD," and explained what FTD is. So her friend wrote back and said, "Well, I wish I had known because nobody [had rather?] sit and be quiet with (spouse)." 21:41	It seemed like he had an experience that prompted him to say this. I was listening quietly as he told his story	He learned that being open with friends early about what was going on with his wife was the best plan	11 7
Yeah. So that taught us a lesson, taught me a lesson, that don't hide it,		He learned not to hide what was going on with his wife so that	10

let your friends and family know exactly what the situation is. And most of them will bend over backwards to support you, and the ones who don't, aren't really your friends. 23:28		others could offer help and support	
There were a few that just kind of shied away and so-- but there was so many that did support that didn't bother me. 23:59	I liked how he reframed and was able to look at the positives of the friends that were still around	He and his wife had more friends be supportive than friends that were not	11
think one of the most important things is to find a support group because males are not sort of natural caregivers, I think. 25:00	Again, he doesn't think males are natural caregivers. Although, he doesn't necessarily see himself in that same light as a male caregiver	He thinks finding a caregiver support group is essential for male primary caregivers	10 3
Maybe that's an over-generalization, but even if you're a woman there's-- when you're first faced with this disease that you've never heard of before, and you feel like you're all alone and what do I do next? 25:00	I thought it was insightful to realize that this disease, FTD is a game changer for most spouses regardless if male or female	He believes that not matter if male or female, primary caregivers for spouses diagnosed with FTD must find a support group	7
What are the legal implications or the medical implications? All these things that you have to learn. If it hadn't been for basically, Alzheimer's Association, I would have been lost 25:00		He found being part of a support group specific to dementia and FTD necessary for his new role as a primary caregiver for his wife	7
So, the most important advice I would give is either the Alzheimer's Association or the AFTD. It just so happened that the (city) Alzheimer's Association have an [FTV?] support group. But for a year I went to a general dimension sort of training for caregivers. And then I started I going to the [FTV?] specifically support group. And as you go around the room and you tell stories of		He found that through a FTD specific caregiver support group he was not alone and got to share experiences	7

what's happening, they say, "I found this thing that works a lot better than what we were doing before," or, "Here's a good place to find caregivers." How to deal with incompetence, which becomes a big issue. So I wanted as much from other people, other caregivers - both male and female - as I could [inaudible] from what was being presented by the people who were running the [crosstalk].			
Better ideas. More confidence so I would be able to deal with the situation 27:36	This was in regard to why support groups specific to dementia or FTD was helpful and important	He became more confident in his abilities as a caregiver by hearing others' experience in the FTD caregiver support group	7
I could see, since we're talking about male caregivers, I could see other male caregivers being successful in doing that. 27:36		He could learn from and model other male primary caregivers in the support groups	3
And as time went on, I did a turnaround, and I was one of those who was giving advice from the years of experience that I had. 27:36	I thought this was so important to know. It really speaks to perhaps identity and experience as a caregiver?	He eventually became the one teacher others in the caregiver support group about best caregiver practices	3
I would say, I gave the example that I was talking about earlier where I had a group of people that would volunteer to come in and stay. And the thing I mentioned earlier about, be sure to be open with everybody, I would advise them to do that. Because everybody's first thought is, "Let's hide it," so we can keep things going the way they were 27:36		He believes that being honest about the loved one's diagnosis is important	11
I think embarrassment, mainly. Anything that has to do with mental health, the condition 29:31	I asked why he thought people are not honest with friends and families about loved ones diagnosis of FTD	He thinks since FTD is a form of dementia, caregivers want to hide the diagnosis out of embarrassment and stigma	11

There's a tendency to-- it's not the same as having cancer or a broken leg or something, which is obvious, everybody understands 29:31	Important point.	He believes that having a cognitive disease is not seen as the same as a physical disease.	11
If it's mental [inaudible], mental illness or dementia, there's the fear that people aren't going to understand that you have be isolated in the community and what I found out is that the opposite is true. 29:31	He still was either experiencing the stigma of mental illness/cognitive decline/dementia or he felt that way about it himself and just assumed others would/did feel that same way too.	He realized most people wanted to help him not shun them based on his wife's disease	11
The more open you are, the more supportive people will be. And so that's the advice I was giving. 29:31		He advised other male caregivers to be open and honest about what disease their partners had	7
And that's especially true of guys. I mean, never wanting to ask directions when you're driving, that's kind of the same. You don't want to reveal how little you know about caregiving so you tend to hide it. 30:43	There is an assumption here that females know how to be caregivers and males do not know how to be caregivers.	He believes that males tend to hide the fact they don't know how to be caregivers	3
And so sitting in a group and hearing other guys say, now you can be open and you really should be doing this. 30:43	Having other males model how to be an effective caregiver was crucial for him even though he stated before that he was never uncomfortable in the caregiving role. I found this interesting. Was he hiding the fact from the beginning that he was nervous in the role of caregiver? Not a judgment, just an observation.	He thought hearing other male caregivers voice their experiences and give advice during a support group meeting was critical.	3
The first thing is that because of the apathy that comes with FTD. 31:41	I was asking about his normal day as a primary caregiver. I guess I was getting at how it impacted him personally.	It was hard for him to deal with his wife's apathy due to her diagnosis of FTD	5
If I'm going to get her on a bed and she would not get on a bed so I would have to get her up. I would have to give her a shower, I would have to dress her. Initially, I would [inaudible] but eventually, I just had to dress her. I had to do the	He had to assume the role of both he and his wife in the household chores and in both their ADLs	He had to assume to role of "we" for both of them in their daily lives	4

cooking and food preparations, laundry, making the bed. 31:41			
Before, I withheld with those things. They weren't my responsibility, they were her responsibility and because she'd lay a guilt trip on me or tell me that I need to be a modern male and do half the work. 32:44	This really magnified how much he has taken on the “we” role in the relationship. Although, I don’t think he has completely lessened his “I” role in the relationship. but it has definitely diminished	He has had to assume both his and her responsibilities of daily living now. He has become the “we” for both he and his wife.	34
But again, there's a big difference between doing half the work and not being responsible for it. 32:44 Now if I don't do it, it doesn't get done. If I don't do the laundry, it doesn't get done. If I don't clean the house, it doesn't get done. It's kind of funny that early on she was still doing the cooking but I noticed that more and more frequently we were having peanut butter and jelly sandwiches for a meal and I thought, “Okay, it's time for me to take over the cooking.” 32:44	He sounded like taking over the household responsibilities were stressful for him in ways maybe he wasn’t expecting.	He felt pressure to assume the roles his wife once held within the relationship	4
I would say toileting was especially important and she was incontinent, urinary incontinence, not so much bowel movements. Although occasionally that was a problem. And when that happened, that was really-- it's on the floor and it's just really hard to deal with. 34:34 They say that dealing with incontinence is one of the things that really impacts the caregiver [yourself?] because it's such a difficult problem to deal with.	I don’t know if this is unique to males? I would imagine female caregivers don’t like this part either the most	He found dealing with his wife’s incontinence issues the most stressful for him.	4

But I would set my-- I've got an iPhone, so I'd set the alarm for two hours so that I would know that it's time to take her to the bathroom. And that was really important because, obviously, if I forgot-- and she wore disposable underwear, but if I would forget and she'd be wet for a long time, it's dangerous . . . what's it called? 34:34 UTI. That what it was called. I couldn't come up with-- which she did have 2 to 3 times. So that was really important. To be aware that-- how long has it been since the last time she went to the bathroom. 36:11	He had a system that sounded like it worked for him as best it could. As I listened to him tell this story I could feel his sense of anxiety about it but also a little bit of pride that he was able to accomplish this task for his wife's care.	He had a timed bathroom schedule for his wife to help with her incontinence	4
For a long time, in terms of doing things together in the house, we would do jigsaw puzzles. [inaudible] simple jigsaw puzzles, so that entertainment for her. And television, what I would try to do there is come up with the old-time television, find that because it was going to bring back memories of the shows that she watched when she was younger. 36:11		He and his wife continued to do leisure activities together in the home	1
But no matter what was on television, she would watch it. I think just the color and motion, even after she lost the ability to understand words, I think that she liked to watch television. 36:11	I wonder if this was used sometimes like parents to with kids to get a break…"go watch tv"?	His wife would watch tv and stay focused on it no matter what was on it.	N/A
And then put her to bed at night, which got increasingly difficult. Our bed was a little bit high, so I had to have a step that she could step up on and then have her sit	Again, this reminds me of when I put my daughter to bed at night…I have some free time to myself that I don't have to worry about her as much. Parent/child relationship	He would have some free time to himself once he put his wife to bed for the night. Parent/child relationship	4

down and then have her lie down and pull the covers over 36:11 And then I could go do something on my own for a couple hours while she began her sleeping			
Well, the only thing I can think of is that it's really important-- if you really love the person, even when it's difficult, you want to be their primary caregiver 38:39	This was in response to me asking if there was anything else he wanted to add that he hadn't said yet	He feels that if someone really love your spouse, you will want to be that person's primary caregiver	1
You want to be in charge of their care and their health and to abandon that, I think, is abandoning the vows that you took when you were married. They didn't say, "In health," they said, "In sickness and health." 38:39	This was not shocking to hear as a primary caregiver and spouse.	He feels that not being a partner's primary caregiver is not honoring their wedding vows.	1
But the other part of that is when you get to a point where it starts to impact your health, then you may need to find a different path. 38:39	I think this is something that is subjective because I think this implies physical health and not emotional health.	He believes even though spouses want to be primary caregivers for each other, other options have to be considered when the caregiver's health is impacted	7
Maybe to put the person into assisted living, skilled nursing. And that was the most difficult decision I had to make. When it got to that point. That's about all I can think of. 38:39		Deciding to place his wife in a memory care unit was the hardest decision he has ever had to make. He had to put "I" before "we" for survival	5
Yes. And we were fortunate enough to have long-term care. Insurance, which couldn't cover all of the assisted living but it covered a major portion of it. 40:08	This was in response to me asking the exact number of years he cared for his wife at home versus when she was in the memory care unit.	He cared for his wife at home as her primary caregiver for 8 of the 10 years she lived with FTD His wife's medical insurance paid for most of her memory care unit expenses	5
Yeah. Because the thing that determines whether they will cover it or not is-- there's the activities of daily living. Ability to eat, ability to take care of yourself, to [inaudible]	This was news to me because I had understood that if someone is diagnosed with FTD that they did not qualify for long term care.	His wife qualified based on assessments for her long term care to be covered	6

getting up from a chair and so forth. So there's this list of things. And if there's two of those things that you can't do, then she's eligible for long-term care. And I think, in our case, all of that aside, dementia automatically gave her coverage, gave us coverage. 40:35			
Yeah, and [that?] we were lucky [then?] that we got the policies probably 25 years ago. And they were fairly new at that time. And insurance companies, I don't think that experienced-- they didn't have good actuarial [inaudible]. So they probably lost money and so they began typing up the insurance policies. In fact, the one that we have, there's no time limitation or dollar limitation, which you can't buy a policy like that today 42:12		He and his wife had an insurance policy from 25 years ago that allowed their coverage for long term care	6
So I have to say we were lucky we had a financial planner and in fact a couple of years ago I thanked him from the bottom of my heart for recommending that we do that [basically?]. I'm never sure whether I'm selling snake oil when I sell long-term period insurance but it's really good to hear it was the right thing for you. 43:00		He and his wife were given good financial advice a few years ago that helped them plan for her care	N/A
Yeah. He's more [a bit of ?] financial planner than an insurance. The insurance is kind of just on the side. But yeah, and I think that's another thing that people need to do, is definitely read all the fine print and before buying a long-term period		He would advise couples to do financial planning long before a health crisis happens	10

insurance policy. And [then?] of course, at the time we bought it, she was in perfect health at that point and that was years before she got dementia. 43:31			
No. I guess the short answer is no. Her mother died at 93 and she-- the last year or so, she was not in full [guardian?] control. But that wasn't FTD. It was just old age. 44:26	I asked if FTD ran in his wife's family. I am not sure why I asked that question? I must have been just in the moment and wanted to know. but I appreciate his answer which speaks to about 80% of FTD cases…just random.	FTD or dementia did not run in his wife's family	N/A
My son, in particular, is concerned about could it be genetic. But they thought about getting genetic testing but I actually advised against it. If they weren't here, it would make sense there's not a cure. You might give yourself 10 years to worry about it. 45:46		His son is concerned if FTD is genetic in their family	N/A
(spouse) participated in one clinical trial. Well, not a trial but a clinical examination of symptoms. And I did a thing with the (clinic). Being, not the victim of cognitive difficulties, took the cognitive test. I didn't feel like I did very well on it but they did it with healthy people to establish a baseline. 46:42		He knows that some clinical research is being done to have a baseline for FTD and genetics	6
Yeah. And I raise . . . I participate in an Alzheimer's, Walk to End Alzheimer's. 47:23 In the past three years, I've raised $20,000. 47:37 The first year, I set a goal of $1000 and said, "Well that's going to be a stretch." And it was $6000 47:45		He participates in raising funds for Alzheimer's and has raised significant funds of 20K	6

But it's amazing that people want to give money to dementia research, because almost everyone has been affected at one time or another, with a relative or friend. Just so pervasive. 47:54		He is amazed at how people are generous in their giving to dementia research	N/A
So (spouse) was diagnosed when she was, well, 69 when FTD was diagnosed. Which I guess is late in terms of FTD. Often it's earlier by 10 or more years and then . . . 48:41		His wife was diagnosed with FTD at 69 years old which is an advanced age for initial diagnosis for most people with this disease	N/A
I would mention too that my son and daughter noticed things before I did. They noticed that she-- when we'd have dinner together she would be the conversation starter. She would ask questions and get the conversation going. And they noticed that she wasn't doing that anymore. And when either one of them needed some help with something, she would just right in and help, and that gradually went away. And I wasn't seeing that and they were. They didn't tell me at the time, but they noticed. 49:42	I wondered if she was showing signs of the disease long before she was diagnosed officially.	His children noticed his wife’s changing behaviors long before she was officially diagnosed with FTD	N/A
Right. Yeah like the frog in the pan on the stove that is gradually heated up 50:55		His wife’s behavioral changes were slow in the beginning before she was diagnosed	N/A
In the same sense that it's not hard for me to talk about her and her death, when you have a disease it's a fact of life. And we need to talk about it. Because otherwise, it works on your own mind. So no, it's not hard for me. 51:32		He finds strength in talking about his wife’s life and her death	12