

TURBULENCE AND TRANSFORMATION: CAREGIVING SPOUSES' USE OF  
COMMUNICATION IN MANAGING AND SUSTAINING RELATIONSHIP ACROSS THE  
PROLONGED TRANSITION OF ALZHEIMER'S DISEASE AND RELATED DEMENTIAS

by

R. Amanda Cooper

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As members of the Master's Committee, we certify that we have read the thesis prepared by:

R. Amanda Cooper

titled: Turbulence and Transformation: Caregiving Spouses' use of Communication in Managing and Sustaining Relationship Across the Prolonged Transition of Alzheimer's Disease and Related Dementias

and recommend that it be accepted as fulfilling the thesis requirement for the Master's Degree.

*Margaret J Pitts*

\_\_\_\_\_  
Margaret J Pitts

Date: Jul 13, 2020

*Jake Harwood*

\_\_\_\_\_  
Jake Harwood

Date: Jul 13, 2020

*Patricia M Sias*

\_\_\_\_\_  
Patricia M Sias

Date: Jul 14, 2020

Final approval and acceptance of this thesis is contingent upon the candidate's submission of the final copies of the thesis to the Graduate College.

I hereby certify that I have read this thesis prepared under my direction and recommend that it be accepted as fulfilling the Master's requirement.

*Margaret J Pitts*

\_\_\_\_\_  
Margaret J Pitts

Thesis Committee Chair

Department of Communication

Date: Jul 13, 2020

ARIZONA

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### **Abstract**

The degenerative nature of Alzheimer's disease and related dementias (ARD) poses incredible challenges to relating and maintaining relational connection for individuals living with the disease and their spouses/romantic partners. Alzheimer's disease creates a prolonged period of relational transition in which caregiving spouses must adapt to the ever-changing symptoms and behavior of their partner. Applying relational turbulence theory and relational turning points as sensitizing concepts, this study investigated the role of communication in shaping and navigating relational turning points and relational uncertainty across this prolonged relational transition. Data were collected through in-depth interviews with 18 caregiving spouses of people with ARD and were analyzed using the constant comparative method of thematic analysis. Analysis of four research questions regarding relational turning points, relational uncertainty, and the communication of caregiving spouses and their partners yielded 18 themes and 11 subthemes. Caregiving spouses experienced four relational changes (my spouse has Alzheimer's disease, from spouse to caregiver, my spouse is gone, and transcending through love) across the prolonged transition that were prompted by nine relational turning points (early symptoms shift the relationship, spouses' diagnosis, loss of driving privileges, shifting household responsibilities, no more romance, increasingly severe symptoms, no more deep conversations, didn't remember my name, and changes in living arrangements). These relational turning points provide detailed insight into the relational changes that occur across the disease trajectory. Experiences of relational uncertainty (I don't know who my partner will become, I don't know if I can make it through this, and relationship change and loss are certain) were shaped by the certainties of cognitive decline and death in ARD. These findings shed light on the unique experience of relational uncertainty in end of life transitions. Communication shaped the

relational turning points and in facilitating and interfering with relationships across this prolonged transition. Caregiving spouses employed six communication strategies to maintain companionship and closeness (daily conversations and activities, open and intimate conversations, and communicating love and affection) and to manage the challenges of the disease (direct and difficult conversations, avoiding confrontation, and avoiding talking about or bringing attention to Alzheimer's disease). Together, these findings shed light on the relational changes that occur in ADRD and the role of communication in shaping and navigating these changes.

*Keywords:* Alzheimer's disease, relational turbulence theory, relational turning points, relational uncertainty, partner interference, partner facilitation

## **Turbulence and Transformation: Caregiving Spouses' use of Communication in Managing and Sustaining Relationship Across the Prolonged Transition of Alzheimer's Disease and Related Dementias**

Approximately 5.8 million Americans are currently living with Alzheimer's disease (Alzheimer's Association, 2019). Alzheimer's disease (AD) is a degenerative terminal illness that causes gradual cognitive decline affecting individuals' daily functioning and their ability to relate with others (Jones, 2015; Klimova et al., 2015). Alzheimer's disease and related dementias (ADRD)<sup>1</sup> drastically affect the relationship between people with dementia (PWD) and their spouses or romantic partners. Spouses often provide informal care throughout the progression of the disease (Cash et al., 2019), and must work to maintain their relationships in the transitional time following a diagnosis and throughout the course of the disease (Ablitt et al., 2009; Hellström et al., 2007). Many couples affected by ADRD consider the disease to be a shared challenge which they must navigate together (Boylstein & Hayes, 2012; Davies, 2011). Communication between partners plays a key role in maintaining relational quality while adjusting to life with Alzheimer's disease; yet little research has investigated the ways in which these couples use communication to navigate challenges and preserve their relationship in AD. Rooted in relational turbulence theory (Solomon et al., 2016), the purpose of this study was to shed light on the communication practices that facilitate and interfere with relational functioning across the various relational turning points of this prolonged disease trajectory. In-depth

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<sup>1</sup> Although the focus on this paper centered on Alzheimer's disease, throughout the process of data collection, I became aware that some individuals with ADRD shared lived experiences with those with AD and I widened the focus of this paper to include those experiences as well. Literature on Alzheimer's disease and related dementias shows that there is considerable overlap between Alzheimer's disease and other forms of dementia such as vascular dementia and cerebrovascular disease (Kalaria, 2002). From a relational perspective, Alzheimer's disease and related dementias often progress in a similar pattern (see Ablitt et al., 2009).



retrospect interviews with caregiving spouses<sup>2</sup> of PWD provided insight into the relational turning points that shaped this transitional period.

This paper takes a lifespan approach by investigating both growth and decline in this end of life transition (Nussbaum et al., 2002) and the role of communication in contributing to relational growth and decline in AD. Alzheimer's disease creates a prolonged relational transition, a period of interruption and change, which requires couples to "adapt to changing roles, identities, and circumstances" (Solomon et al., 2016, p. 510). For couples affected by Alzheimer's disease, this transition spans the trajectory of the illness which lasts an average of four to eight years but can be as long as 20 years (Larson et al., 2004; Xie et al., 2008). Within this prolonged transition, couples are likely to experience several relational turning points, or events that change or shift the relationship (Baxter & Bullis, 1986). Communication facilitates the adaptive process; however, adapting to this relational transition is made more difficult by the degenerative nature of the disease. Individuals with ADRD become increasingly cognitively impaired as the disease progresses making relational maintenance more difficult. This paper provides insight into caregiving spouses' use of communication to navigate this relational transition and maintain their relationships across the various stages and turning points of the disease.

This study applied two sensitizing concepts, relational turning points and relational turbulence theory, to better understand the communication and relational change experienced across the trajectory of Alzheimer's disease. A sensitizing concept provides a theoretical foundation from which to start inquiry and guides the researcher in developing initial research questions without constraining qualitative findings (Charmaz, 2014; Glaser, 1978). Relational

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<sup>2</sup> The title "caregiving spouses" reflects participants' language in referring to themselves as caregivers to their spouses who have ADRD. This phrase will be used to refer to participants throughout the paper.

transitions create a sense of turbulence within the relationship which is characterized by tumultuousness, chaos, and fragility (Solomon & Knobloch, 2004). Couples affected by AD might be particularly susceptible to this sense of turbulence because of the ambiguous nature of life with Alzheimer's disease (Garwick et al., 1994) and uncertainties about how the disease will impact their relationship (Harris et al., 2011; O'Donnell, 2000). Communication between partners can contribute to or reduce the sense of turbulence by facilitating relational maintenance and goals, or by interfering with relational maintenance (Solomon et al., 2010). By using the lens of relational turbulence theory, this study sheds light on the ways communication between partners facilitates or interferes with the adaptive process required to maintain a sense of relationship in AD. Further, because Alzheimer's disease creates a prolonged relational transition, this study sheds light on the specific relational turning points that shape the relational changes experienced by caregiving spouses across the trajectory of the illness.

### **Alzheimer's Disease**

Alzheimer's disease is the most common form of dementia, accounting for 60-80% of all dementia cases (Alzheimer's Association, 2019). Dementia is a medical condition of the brain that causes detriments to memory, executive function, and awareness (Henderson & Jorm, 2002). The terms "dementia" and "Alzheimer's" have been used interchangeably; however, Alzheimer's disease refers to a specific type of dementia (Graff-Radford, 2018) that results from the abnormal formation of proteins in the brain (see Cataldo & Nixon, 2007). Alzheimer's disease is most commonly diagnosed in older adults (age 65 or older); however, the disease has been found in younger adults as well (Braak & Braak, 1997; Morris et al., 2004).

Alzheimer's disease develops and progresses gradually, creating a prolonged experience with the symptoms of the disease (Medina & Avila, 2014; Brookmeyer et al., 2002). Evidence

suggests that pathological markers of the disease are present in the brain many years before the development of symptoms or a diagnosis (Bennett et al., 2012; Sperling et al., 2011).

Alzheimer's disease affects the cellular level of the brain, damaging neuron cells which facilitate memory storage, visual processing, and emotion regulation by sending and receiving signals throughout the brain (Jellema & Perrett 2002; Rose, 2008; Smythies, 2002). The disease develops first in the temporal lobe, specifically in the hippocampus which controls memory storage and retrieval (Gómez-Isla et al., 1997). Damage in this region of the brain causes the gradual loss of memory and language functioning that are characteristic of Alzheimer's disease. Memory loss and impaired language functioning hinder PWD's ability to retain information and express themselves making relating with their spouse through communication more difficult.

The pathological development of Alzheimer's occurs in two ways (1) the abnormal buildup of plaques and tangles and (2) neuron atrophy. Plaques develop when beta-amyloid, a naturally occurring protein, accumulates *between* individual neuron cells blocking synaptic connections (Smythies, 2002; Thal et al., 2008). The approximately 100 trillion synaptic connections in the brain facilitate message processing across neurons (Markram, 2012). Blockage caused by plaque hinders this connection. Tangles develop *within* neuron cells when the naturally occurring tau protein breaks away from the inner structure of the neuron and binds with other tau molecules. These threads of tau then spread throughout the neuron cell and form complex patterns referred to as neurofibrillary tangles. These neurofibrillary tangles block the cell's inner transport system and impair the essential message processing function of the neuron. The development of neurofibrillary tangles is linked to the spread of Alzheimer's pathology throughout the brain (Guo & Lee, 2011; Iba et al., 2013). Damage caused by plaques and tangles leads to neuron atrophy or the loss of neurons and synaptic connections (Gili et al., 2011).

Atrophy is particularly focused in the hippocampus region of the brain and connecting areas (Attems & Jellinger, 2006; Fox et al., 1999). Together, plaques, tangles, and atrophy cause symptoms of cognitive decline (Giannakopoulos et al., 2003; Terry et al., 1991). The progression of these pathological markers throughout the brain shapes the experience of couples affected by AD over the course of the disease through the increasing severity of symptoms, including difficulty managing daily tasks and engaging in conversation.

### **Symptoms and the Relational Transition**

The progression of Alzheimer's disease is often divided into three stages based on the severity of symptoms: mild, moderate, and severe (Alzheimer's Association, 2019). Although this division of the disease is somewhat artificial, it provides an easy heuristic for discussing the progression of AD. Spouses of PWD have also described moving through three relational phases over the course of the disease (Hellström et al., 2007; Wuest et al., 1994). Hellström et al. (2007) defined these phases as "sustaining couplehood," "maintaining involvement," and "moving on." Each stage of the disease poses new challenges for couples affected by AD who must shift their communication to accommodate the severity of symptoms. Despite the popularity of the three-phase model of Alzheimer's progression, many relational and communicative turning points may occur as PWD progress through these broad stages and symptoms become more severe. The investigation of relational turning points in this study is aimed to provide greater insight into the relational changes that occur as the symptoms of AD become increasingly severe in each stage of the disease, and to explore the role of communication in shaping and navigating these relational changes. In this section, I will review the symptoms associated with these three broad phases of Alzheimer's disease and implications of these symptoms for relational functioning.

## **Mild Alzheimer's Disease**

Mild Alzheimer's disease is characterized by challenges with language processing (Belleville et al., 2007; Taler & Phillips, 2008) and detriments to working memory (Huntley & Howard, 2010). One of the first symptoms to appear is difficulty with word recall (Henry et al., 2004; Kempler, 1995). This causes the "tip-of-the-tongue" problem in which PWD know what they want to say but cannot think of the right word (Klimova et al., 2015). Individuals experiencing this problem compensate by using non-specific language such as vague references (e.g., "that thing") and overuse of pronouns (Fraser et al., 2016; Taler & Phillips, 2008). This word-recall issue can make it more difficult for people with AD to express themselves and may complicate communication within the relationship. One individual described it this way, "For a while I'll search for a word and I can see it walking away from me. It gets littler and littler. It always comes back but at the wrong time" (Snyder et al., 1995, p. 694). Problems with word recall in mild stages of AD can make it difficult for PWD to express their thoughts, emotions, and ideas in conversation. This makes relating through conversation more difficult and may create distance within the relationship for couples living with AD.

Alzheimer's disease also impairs the executive control function of working memory, which limits individuals' ability to divide attention and block out distractions (Baddeley et al., 1991; Huntley & Howard, 2010). Impaired executive control creates challenges in following multi-step processes such as managing finances or following a recipe (Förstl & Kurz, 1999). It also makes it challenging to follow a conversation with multiple conversational partners because of the difficulty in dividing attention between speakers. This becomes increasingly problematic as more people join the conversation (Alberoni et al., 1992). One person living with AD in Phinney's (2002) interview study described this problem as "not following like you used to be

able to follow a conversation” (p. 64). Describing his reluctance to join in conversations another person said, “you get hung up on one thing, and their conversation has continued on” (Phinney, 2002, p. 65). Impaired working memory has also been linked to declines in episodic memory (Van Geldorp et al., 2015). This causes the forgetfulness that is associated with Alzheimer’s disease. Deficits in episodic memory can make it difficult to retain what has been spoken of in earlier conversations and can create an additional barrier to relating with others through communication.

These communication symptoms can be particularly frustrating for individuals with AD because, while AD affects their memory and their language, it does not destroy their knowledge of the conventions of conversation until late stages of the disease (Jones, 2015; Taler & Phillips, 2008). In the mild stage of Alzheimer’s disease people are often aware of their symptoms and the challenges of living with the disease (Sterin, 2002). PWD know how conversation should flow without always being able to perform according to their knowledge (Snyder, 2002). Difficulties with word recall and episodic memory can be frustrating and potentially embarrassing (Phinney, 2002). Holst and Hallberg (2003) found that PWD express anger, sadness, and shame about their difficulty with expressing themselves and socially connecting with others. Communication challenges caused by AD symptoms can create a sense of stigma which makes relating with others more challenging (O'Connor et al., 2018). These technical difficulties in conversation and a sense of stigma can lead individuals to withdraw from conversation and become less likely to ask for help (CDC, 2015; Snyder, 2006).

Communication between couples affected by AD can be particularly important in managing these symptoms to maintain relational satisfaction and a degree of independent functioning in the mild stage of AD. Anxiety, depression, grief, and fear can be common as

PWD begin to experience the symptoms of AD (Bender & Cheston, 1997; Di Iulio et al., 2010; Karttunen et al., 2011). Support provided by partners such as inclusion in social interactions, comfort, identity affirmation, and relational attachment can mitigate these challenges (Kitwood, 1997). Communication between relational partners can facilitate functioning for PWD and provide an antidote to social isolation. Enjoying shared activities and social connections together, as well as sharing affection, can be particularly beneficial (Conway et al., 2018). Social interactions and relationships help maintain cognitive functioning over the course of the disease and play a role in maintaining the independence of PWD (Balouch et al., 2019; Donovan et al., 2017). The interactions between PWD and their partners in the mild stage of the disease can be particularly important as Wright (1994) has found that the quality of interactions between couples partially predicts the state of future care.

Despite the challenges of living with Alzheimer's disease, couples affected by AD can maintain and potentially enhance their relationships during the mild stage of AD. A diagnosis with Alzheimer's disease can spark greater determination to maintain the relationship (Davies, 2011; Molyneaux et al., 2012). In a systematic review, Ablitt et al. (2009) found that despite some relational declines, couples affected with Alzheimer's disease report an increase in warmth, mutual affection, and closeness following the diagnosis. In this early stage of the disease, couples emphasized their commitment to the relationship and maintained relational closeness through reciprocity, resilience, forgiveness, and thinking of their relationship as a partnership for life (Davies, 2011). Molyneaux et al. (2012) found that couples framed Alzheimer's disease as 'just another life transition' and drew on past relational transitions to strengthen them in managing this one. Thus, despite challenging symptoms, couples may be able to maintain and even enhance their relationships during the mild stage of AD.

### **Moderate Alzheimer's Disease**

Alzheimer's symptoms progress from mild to moderate as the disease spreads to areas of the brain that control reasoning, emotion regulation, vision and auditory senses, and long-term memory (National Institute on Aging, 2019). During this stage, lapses in memory become more prominent. Autobiographical memory becomes impaired making it more difficult for PWD to accurately recall earlier life experiences and information such as their wedding date or places they have lived (Meeter et al., 2006). Disorientation about time and place become more common in this phase (Hirono et al., 1988), as do personality, mood, and behavioral changes (Devanand et al., 1997). Wandering, experiencing hallucinations, and sleep disturbances are most common in this phase of AD compared to the mild or severe stages of the disease (Chen et al., 2000). Memory impairments make communication more difficult causing PWD to forget what they want to say, misunderstand their communication partners, or jumble their words (Förstl & Kurz, 1999; Klimova et al., 2015).

Symptoms affecting cognition, personal functioning, and behavior create increased dependence (McLaughlin et al., 2010). These symptoms limit individuals' ability to manage the instrumental activities of daily living such as housekeeping, cooking, and grocery shopping (see Lawton & Brody, 1969). As the PWD loses the ability to perform the tasks of daily life, they often become more dependent on their partners (Vidoni et al., 2010). Greater dependence influences the quality of life for both PWD and their spouses (Jones et al., 2015; Quinn et al., 2009). For PWD, increased dependence can cause them to experience loss of identity and self-esteem (Hedman et al., 2019). In turn, greater dependence on the part of PWD puts greater burden on the spouse who provides care and can reduce their health and wellbeing (Etters et al.,



2008; Gallagher et al., 2011). In addition to impacting relational partners individually, this greater dependence on the caregiving spouse is likely to alter and possibly strain the relationship.

Loss of independence in the moderate stage of AD increases the difficulty of the relational transition because it causes changes to roles and responsibilities in the relationship and to the nature of the relationship itself (Harris et al., 2011; Molyneaux et al., 2012). Changes to the relationship and shifting roles are central to the experience of transition in AD (Evans & Lee, 2014) and may cause turbulence in the relationship. For some couples, changing roles within the relationship can reduce the overall quality of their relationship (Harris et al., 2011). Shifting roles caused by loss of independent function, coupled with the personality altering symptoms of the moderate stage of AD, can create a sense of loss in the relationship (Conway et al., 2018; Evans & Lee, 2014; Kaplan, 2001).

In the moderate stage of AD, caregiving spouses must work to maintain involvement with their partners despite the increasingly limiting symptoms (Hellström et al., 2007). One way that couples do this is by shifting focus away from changing roles and focusing more on loving and supporting one another to maintain the relationship (Molyneaux et al., 2012). Spouses of PWD have described experiencing both disruption and reconstruction in their relationship (Boylstein & Hayes 2012). Disruption experiences center on the drastic changes to the spouse with AD and to the relationship because of Alzheimer's disease, while reconstruction experiences emphasize recreating the relationship and maintaining connection despite increasingly severe symptoms. Communication may play a role in reconstructing relationships and assist couples affected by AD in maintaining relational closeness. Chesla et al. (1994) refer to relationships as "continuous but transformed" when couples exhibit strong commitment to maintain their relationship despite the changes caused by AD symptoms. Due to the drastic symptoms of the disease, the reframing

or transforming of the relationships is a necessary adaptation throughout out the course this prolonged relational transition. The moderate stage of AD as a phase of relational transition is marked by efforts to reframe and reconstruct the relationship to maintain connection.

### **Severe Alzheimer's Disease**

In the last stage of Alzheimer's disease, neuron atrophy becomes widespread, affecting both hemispheres of the brain including areas that control balance and coordination (Gómez-Isla et al., 1997; Thompson et al., 2003). Severe symptoms limit the ability of PWD to perform the activities of daily living including walking, bathing, and eating (see Katz et al., 1963). In the severe stage of the disease, PWD require professional care and often can no longer be cared for at home by their spouses. At this point in the disease, communicating and maintaining the relationship becomes much more challenging.

The severe physical and cognitive limitations at this stage of the relational transition make maintaining the relationship increasingly difficult. Talk in this stage often consists of disconnected words or phrases without logical flow, making it difficult to carry on a conversation (Förstl & Kurz, 1999; Klimova et al., 2015). Notwithstanding these severe symptoms, PWD may maintain some sense of self and an awareness of their surroundings (Ericsson et al., 2011; Tappen et al., 1999). Even in the severe stage of AD, caregiving spouses may be able to maintain the relationship through communication. While engaging in verbal dialogue becomes difficult in this stage, PWD continue to respond to communication through nonverbal cues such as touch, emotional expressions, and tone of voice (Hubbard et al., 2002; Luzzi et al., 2007). Speaking to PWD as equals, focusing on cooperation, establishing commonality, and encouraging self-expression all benefit PWD (Surr, 2006; Tappen et al.,

1997). This type of communication supports quality of life for PWD (Young et al., 2011) and may be beneficial in maintaining relational connection.

In the severe symptoms stage, the caregiving spouses relinquish care to trained professionals, yet this does not necessarily mean an end to relationship (Hellström et al., 2007). Couples experience varying degrees of continuity in this stage of the disease. Through her work with couples in the severe stage of AD, Kaplan (2001) created a typology of couplehood with levels of couplehood ranging from “we” to “I.” Some couples maintain a strong sense of “we” by continuing to take pleasure in each other’s company, exchanging affection, and making the best of the situation (Chesla et al., 1994). Kaplan (2001) refers to this type of couplehood as ‘til death do us part’ because partners with a strong sense of “we” still emphasized the importance of their relationship and couplehood. For others, relinquishing care to trained professional coincided with letting go of the relationship (Wuest et al., 1994). These partners described their relationship as one of “radical discontinuity” because they were no longer able to connect with their partners (Chesla et al., 1994, p. 7). Kaplan (2001) describes this type of couplehood as ‘unmarried marrieds.’ These spouses no longer had a sense of “we” and while they still cared about their partner, they did not feel as though they were part of a couple or relationship with them.

### **Relational Turning Points**

Although these three stages of AD paint a broad picture of the symptomatic and relational experience of Alzheimer’s disease and related dementias, they provide less insight into the turning point events, conversations, and behaviors that lead to these relational changes. Considering the shifting nature of life with Alzheimer’s disease and the increasing severity of symptoms, couples affected by AD are likely to experience several relational turning points throughout the course of the disease. Investigating the relational turning points that occur across

these three stages of AD provides a nuanced perspective of the relational changes prompted by the disease and caregiving spouses' experiences adapting to this prolonged transition. Relational turning points are part of a larger body of research focused on relationship development and dissolution (Baxter & Bullis, 1986). Relational turning points illuminate the specific experiences or events that changed the trajectory of the relationship including instances of relational growth or decline (Johnson et al., 2003). Identifying relational turning points may be particularly beneficial in the context of ADRD because the symptoms are likely to change the trajectory of the relationship and dramatically impact relational development for couples affected by the disease. Investigating the specific relational turning points caregiving spouses experience sheds light on the factors and experiences they perceive as causing change in their relationships. Individuals may attribute relational turning points to factors within their relationship, themselves, their social networks, or circumstances outside of their control (Lloyd & Cate, 1985). Thus, the investigation of relational turning points may provide a detailed look at the relational changes experienced within the three broad stages of the disease and the factors that shape these relational changes.

Analyzing relational turning points sheds light on the role of communication in shaping relational change (Baxter & Bullis, 1986). Relational turning points are often inherently communicative and shaped by communication between partners (Braithwaite et al., 2018; Wang, 2014). Communication strategies may facilitate adaptation to the symptoms in each phase of the disease and enable relational maintenance throughout the various turning points of this prolonged relational transition. Yet, the communication behaviors that provided relational maintenance for couples prior to the disease may not be as beneficial in the context of ADRD. The communication of caregiving spouses may shift across the disease progression as they adapt to

various relational changes and turning points. Thus, to identify the relational turning points that shape relational change in ADRD, and to explore caregiving spouses' use of communication in navigating these turning points, I constructed the following research questions to guide this inquiry:

RQ1: What relational and communicative turning points do caregiving spouses describe across the trajectory Alzheimer's disease and related dementias?

RQ2: What communication strategies do caregiving spouses use to maintain relationship and navigate challenges across the prolonged relational transition and turning points of Alzheimer's disease and related dementias?

### **Relational Turbulence Theory**

In addition to exploring relational turning points, I also employ relational turbulence theory as a theoretical framework to understand the ways relational transitions influence communication. This theory centers on the experience of uncertainty and influence from relational partners during times of relational transition (Solomon & Knobloch, 2004). In times of transition, communication between partners becomes essential in shaping relationship outcomes as couples adapt to changing circumstances and roles (Solomon et al., 2010). Changes to the relational environment in transition can lead to relational turbulence, or a sense of fragility, within the relationship (Solomon & Knobloch, 2004; Solomon et al., 2016). Relational turbulence causes people to become more sensitive and reactive to the communication and behaviors of their partner (Knobloch et al., 2018). Individuals experiencing relational turbulence are more likely to view the actions of their partner and social network members as a hindrance (Knobloch & Donovan-Kicken, 2006) and are more likely to perceive their partner's behaviors as intentionally hurtful (McLaren et al., 2012; Theiss et al., 2009). Turbulence is manifested by

greater emotional reactivity and an increase in negative emotions such as anger, fear, sadness, and jealousy (Knobloch et al., 2007; Knobloch & Solomon, 2002b; Theiss & Solomon, 2006b). This makes relational communication more difficult and increases the likelihood of relational partners engaging in indirect communication or topic avoidance (Knobloch & Carpenter-Theune, 2004; Knobloch & Solomon, 2005; Theiss & Solomon, 2006a). This can be particularly challenging for couples affected by Alzheimer's disease because they must adapt to the relational transition while also coping with language impairing symptoms.

Relational transitions can shift individuals' perceptions of the relationship in two ways that lead to increased relational turbulence. First, transitions create uncertainty about the relationship. This relational uncertainty can make it difficult for relational partners to interpret specific communicative interactions with their partners (Solomon et al., 2016). This leads to stronger emotional reactions to a partner's behavior and the use of more indirect relational communication (McLaren et al., 2012; Theiss & Solomon, 2006b). Second, transitions can make individuals more sensitive to their partner's influence on their daily activities and routine (Solomon & Knobloch, 2001). Partner influence, which comes in the form of facilitation or interference with daily goals, creates emotional reactivity to specific communication episodes (see Solomon & Theiss, 2011). Together, relational uncertainty and increased sensitivity to partner influence coalesce to create a sense of the relationship as turbulent (Solomon et al., 2016). Relational uncertainty and partner interference/facilitation are likely to be acutely felt by couples affected by ADRD because of the uncertain nature of the relationship across the disease trajectory and the greater reliance of PWD on their partners.

Relational turbulence theory is particularly fitting for examining the relational experience of the Alzheimer's disease transition because of its focus on the relational effects of uncertainty,

partner interference/facilitation, and turbulence. Relational turbulence is particularly likely to occur when one relational partner is experiencing health challenges (see Knobloch & Delaney, 2012; Knobloch & Knobloch-Fedders, 2010; Weber & Solomon, 2008). In their study of relational turbulence across marital relationships, Brisini et al. (2018) found that health issues were the most frequently reported turbulent transitions recalled by their participants. Alzheimer's disease is likely to be a particularly turbulent relational transition because of the drastic changes to cognitive functioning. The gradually developing and prolonged nature of the disease requires these couples to be continuously adapting as the symptoms become increasingly severe.

### **Historical Development of Relational Turbulence Theory**

Relational turbulence theory began as the relational turbulence model and was originally positioned to explain relational turbulence during the transition from casually dating to serious courtship. Solomon and Knobloch (2004) proposed that relational turbulence would peak at moderate levels of intimacy during relational development, because the increase in interdependence and the undefined nature of the relationship would lead to greater relational uncertainty and partner influence. Early tests of the model found mixed support for the idea of increased relational turbulence at moderate levels of intimacy in relational development (Knobloch et al., 2007; Knobloch & Donovan-Kicken, 2006). Longitudinal tests of the model suggested that relational turbulence was not related to intimacy but rather that uncertainty and partner influence were mechanisms of relational turbulence and could occur throughout the relationship (Solomon & Theiss, 2008). These findings led to a greater focus on relational uncertainty and partner influence as mechanisms for relational turbulence across relationships (Knobloch & Theiss, 2010). This opened the door for broader investigations of relational turbulence in varied relational transitions (Solomon et al., 2010).

Scholars have demonstrated the effectiveness of relational turbulence model/theory in providing insight into diverse types of relational transitions. Early research focused on transitions inherent to relational development (Knobloch & Carpenter-Theune, 2004; Knobloch et al., 2007), which has continued to be a point of interest in RTT work (Brisini & Solomon, 2019; Mikucki-Enyart & Caughlin, 2018). RTT has also been applied to common life-course transitions that create dramatic changes to the relationship but are marked by discrete events such as the birth of a child (Theiss et al., 2013) or becoming empty nesters (King & Theiss, 2016; Nagy & Theiss, 2013). Other work has demonstrated the relevance of relational turbulence during dramatic yet potentially reoccurring transitions such as the return of military personnel after deployment (Knobloch et al., 2016; Knobloch & Theiss, 2012). Yet other work has centered on more extended transitional periods such as maintaining long-distance relationships (Ellis & Ledbetter, 2015). The relational transition prompted by Alzheimer's disease and related dementias is best categorized as a prolonged relational transition with the transition potentially beginning before the diagnosis when couples first notice something might be wrong (Garwick et al., 1994) until the final stages of the disease and death of the partner with ADRD.

Relational turbulence theory extends the relational turbulence model by investigating the experiences of relational uncertainty and partner influence in creating relational outcomes (Solomon et al., 2016). Work with this theory has established relational uncertainty and facilitation/interference as distinct relational constructs that can be experienced across relational contexts (Solomon & Brisini, 2017). Yet, little work has been done to investigate how these constructs shape prolonged relational transitions. Building on this foundation, this study applied relational turbulence theory as a framework for understanding the relational experiences of



caregiving spouses, centering on the experiences of relational uncertainty and partner interference and facilitation.

### **Relational Uncertainty**

Relational uncertainty occurs when individuals have questions about the nature of, and involvement in, their relationships (Knobloch & Solomon, 2002a; Solomon & Knobloch, 2004). Relational uncertainty can be observed in three forms: self-uncertainty, partner-uncertainty, and relationship-uncertainty. Self-uncertainty occurs when individuals have questions about their own involvement in the relationship; partner-uncertainty occurs when individuals have questions about their partner's involvement in the relationship; and relationship uncertainty occurs when individuals have questions about the nature of the relationship itself (Knobloch & Theiss, 2010; Solomon et al., 2016). Together, these three types of relational uncertainty create a sense of ambiguity in the relationship.

Relational uncertainty hinders individuals' ability to interpret the behavior of their partner and in turn constrains their communication. This creates several issues that make maintenance behaviors difficult and might be particularly difficult for couples who are contending with the symptoms of ADRD. Individuals experiencing relational uncertainty are likely to view their partners as less responsive to their needs (Theiss & Knobloch, 2014) and to perceive communication about relational issues to be more threatening (Theiss & Estlein, 2014; Theiss & Nagy, 2013). In the context of illness, relational uncertainty can make communication about the illness more threatening (Leustek & Theiss, 2018). Unsurprisingly, individuals experiencing relational uncertainty are likely to avoid communicating about sensitive matters in their relationship (Theiss, 2011; Theiss & Nagy, 2012; Theiss & Solomon, 2006b). While direct communication within relationships can decrease uncertainty (Theiss & Solomon, 2006a, 2008),

this lack of directness is likely to propagate uncertainty further complicating relational maintenance and communication (Theiss & Knobloch, 2014). Thus, understanding the relational uncertainty experiences of couples affected by ADRD might shed light on some of the communicative constraints that affect their relationship within the prolonged relational transition of Alzheimer's disease and related dementias.

Uncertainty plays a role in shaping the experience of illness and is likely to be a prominent feature of the disease experience for couples affected by Alzheimer's or related dementias (Babrow et al., 1998). Uncertainty plays a role in a broad range of diseases including cancer (Iannarino, 2018), type 2 diabetes (& Theiss, 2018), depression (Knobloch et al., 2016), and stroke (Byun et al., 2017). In the context of illness, uncertainty has been shown to increase anxiety about illness (Kai & Wilson, 2017) and threaten people's ability to engage in illness related coping behaviors (Leustek & Theiss, 2018). Couples affected by Alzheimer's are particularly likely to experience relational uncertainty due to the drastic changes caused by the disease and the prolonged disease trajectory. Previous research has found that spouses of PWD do experience uncertainty about their relationships (Harris et al., 2011; O'Donnell, 2000), however further research is needed to elucidate which aspects of relational uncertainty shape the experiences of caregiving spouses in AD. To this end, I constructed the following research question:

RQ3: How do caregiving spouses experience relational uncertainty related to long-term adaptation to living with Alzheimer's disease and related dementias in their relationship (e.g., partner, self, and relationship uncertainty)?

## **Partner Interference and Facilitation**

Interdependence, which requires the “coordination of mutually beneficial systems of behavior between partners,” creates the potential for partners to influence one another’s daily activities (Solomon & Knobloch, 2004, p. 798). This influence can either enhance or constrain each person’s ability to pursue their daily activities and goals. Partner facilitation occurs when individuals’ communication and behaviors make it easier for their partners to pursue their daily activities, while partner interference occurs when their communication and behaviors make it more difficult for their partners to pursue their daily activities (Solomon & Knobloch, 2004). Repeated interference or facilitation of daily activities and goals coalesce to create a global sense of interference or facilitation within the relationship (Solomon et al., 2016). Partner influence is inherent to interdependent relationship, and partners influence one another in both facilitative and interfering ways.

Partner influence might be a particularly important aspect of relating within relationships affected by Alzheimer’s disease and related dementias because of the shifts in interdependence caused by the disease. Gradually increasing symptoms of cognitive decline lead PWD to become more dependent on their partner in enacting their daily routines and accomplishing their goals (Cash et al., 2019; Vidoni et al., 2010). Over time, the greater dependence of PWD can completely change the roles and dynamics of the relationship (Harris et al., 2011). Although changes from interdependence to dependence have not been studied within RTT, it is likely that this trajectory of increasing dependence uniquely shapes the experience of interdependence and partner influence for caregiving spouses. In this study, the use of in-depth qualitative interviews provides needed insight into the experience of partner influence during this unique transition from interdependence to dependence.

While partner interference has been the focus of many RTT investigations, partner facilitation has been less well studied. This is unfortunate because facilitation may provide an opportunity for growth through difficulty in the relational transition. Partner interference and facilitation have been linked with emotional reactance, with interference increasing negative emotions and facilitation decreasing negative emotions (Knobloch et al., 2007; McLaren et al., 2012). Further Solomon and Priem (2016) found that relational turbulence amplified the effects of an individual's supportive messages in improving their relational partner's emotional state after a stressor. Building off this research, I argue that facilitative communication might be especially important for couples affected by Alzheimer's disease and related dementias in managing their relationships and adapting to the relational transition of the disease.

Understanding the communication of couples affected by ADRD can provide insight into the ways they manage and maintain their relationships in the face of the disease. In-depth qualitative inquiry is invaluable here as little is known about PWD's ability to facilitate or interfere with daily activities and relational goals. Thus, to ascertain caregiving spouses' perceptions of their partners' interfering and facilitative behavior, I constructed the following research question:

RQ4: What communication practices and behaviors do caregiving spouses report as (a) interference and (b) facilitation throughout the relational transition of Alzheimer's disease and related dementias?

### **Methodology**

The central purpose of this study was to investigate the role of communication in shaping and navigating the relational turning points and uncertainties that comprise the prolonged relational transition of Alzheimer's disease and related dementias. This research falls squarely in the interpretive paradigm, focusing on the lived experiences of caregiving spouses to PWD and

the ways that communication shapes their relationships. Researchers in the interpretive paradigm seek to provide rich descriptions of experiences or phenomenon with the goal of illuminating the subjective realities of a specific group or community (Droser, 2017). This paradigm operates under the assumption that social realities are pluralistic and emerge through communicative interaction (Lindlof & Taylor, 2011). As such, scholars in this paradigm privilege participants' perspectives and seek to find meaning in the words and language used by the participants themselves (Baxter & Babbie, 2004; Braithwaite et al., 2018). I applied relational turning points and constructs from RTT as sensitizing concepts to gain insight into caregiving spouses' experiences of relational change across the trajectory of ADRD. These concepts guided me in designing a semi-structured interview guide to elicit the lived experiences and perspectives of caregiving spouses.

Sensitizing concepts inform preliminary thinking about a phenomenon or process and can help guide initial qualitative inquiry (Blumer, 1969; van den Hoonaard, 1997). In using constructs from a theory as sensitizing concepts, the goal is not to test the theory, but to use the theoretical framework to direct initial inquiry. The sensitizing concept provides a "point of departure" to guide the researcher in developing research questions and structuring the initial interview guide (Charmaz, 2014). This enables the researcher to build from past research and theory in developing a line of inquiry (Glaser, 1978). Sensitizing concepts are tentative and flexible and do not constrain the emergent approach of interpretive qualitative research (Marsiglio, 2004). For this study, the following sensitizing concepts guided the development of the research questions and interview guide: relational turning points, relational transition, partner interference, partner facilitation, and relational uncertainty. These provided a launching point for investigating the relational experience of Alzheimer's disease and related dementias through in-depth interviews.

I used in-depth semi-structured interviews to create a space for caregiving spouses to share their relational experience with AD. In-depth semi-structured interviews offer a fruitful strategy for seeking the actors' point of view because they provide insight into individuals' personal realities and identities (Kleinman et al., 1994). This method of data collection is particularly useful in understanding lived experiences because it provides a space for participants to tell their stories and make sense of their experiences through talk (Gerson & Horowitz, 2002). Charmaz (2014) describes semi-structured "intensive" interviews as "gently guided one-sided conversations" in which the researcher guides the flow of talk to help the individual share their lived experiences (p. 56). In this type of interviewing, the researcher uses a set of questions and potential probes to guide the interview conversation but retains the flexibility to adjust the questions to adapt to the needs of the interviewee or probe for further insight into their experiences (Brenner, 1985). This approach allowed me to make participants comfortable in telling their stories and to gain richer insight into their experiences than could be gained through other forms of inquiry.

## **Method**

### **Recruitment**

I recruited participants through gatekeepers, direct and mediated contact, and snowball sampling. Gatekeepers are individuals and organizations that either formally or informally have power to grant access to a group of interest (Wanat, 2008). Between the months of June 2019 and March 2020, I worked to build rapport with leaders in the local Alzheimer's community including managers of several memory care units, support group facilitators, and administrators of local Alzheimer's disease centered nonprofit organizations including the Banner Alzheimer's Institute and the Alzheimer's Association Desert Southwest Chapter. This process included

attending events, seeking introductions through network members, calling organizations directly, and meeting personally with program coordinators and others. Administrators at local memory care centers and the Banner Alzheimer's Institute distributed the recruitment flier (see Appendix A) through their front offices and shared the flier with individuals they thought might be interested in participating in an interview. This led to the recruitment of one participant. I also met with organizational leaders and visited support groups to recruit through the Alzheimer's Association. With the consent of the support group facilitators, I took the first five minutes of these meeting to introduce myself and my project and then shared the recruitment flier with individuals interested in participating in the interview. Through this method, I recruited 11 participants from five support groups.

I also used social media and snowball sampling to spread information about my study and recruit participants. Social media recruiting involved first seeking the support of Facebook group administrators who were the gatekeepers of their online communities. To do this, I requested permission to join Alzheimer's focused Facebook groups and sent a message directly to the administrators introducing my project and explaining my purpose for requesting to join. After being granted access and permission to post, I created a standardized post that included the recruitment flier and an invitation to participate in an interview. I recruited four participants through this process. I used snowball sampling to recruit two additional participants. In snowball sampling, the participants become gatekeepers of their social networks and are asked to share details about the study with their friends and acquaintances who might also be eligible to participate (Biernacki & Waldorf, 1981). This method is particularly useful in reaching a "hard-to-recruit" population (Lindlof & Taylor, 2011). At the end of each interview I asked participants if they would be willing to share information about the study with other caregiving spouses to

PWD who might be interested in participating in an interview. If they desired to share information about the study with members of their social networks, I provided them with a recruitment flier to share.

All potential participants were informed that they would receive \$10 at the completion of the interview. I included this information in the recruitment flier, social media posts, and in verbal descriptions of the research project. These payments were funded by a research grant through the University of Arizona Graduate and Professional Student Council. Participants who completed in-person interviews received a check for \$10 at the conclusion of their interview. Those participating online received a check in the mail a few days after the completion of their interview. Six participants politely refused to accept payment.

### **Participants**

Eighteen participants (11 women, 7 men) completed interviews. In order to participate, individuals must have self-identified as having been in a marital or romantic relationship with an individual who has Alzheimer's disease or related dementia.<sup>3</sup> Three participants' spouses had passed away within three months of the interview. Because these participants continued to identify with the experience of providing care to their partners, and to gain a full perspective of the prolonged relational transition of AD, these individuals were included in this study.

Participants were between 49 and 88 years of age ( $M = 69.39$ ,  $SD = 10.17$ ), and all of them shared the experience of providing care to their spouses. Thirteen participants identified as

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<sup>3</sup> Four participants' spouses were not diagnosed with Alzheimer's disease. Two explained that their partners were unwilling to engage in thorough testing, and physicians were unable to determine the specific type of dementia. Two participants reported that their partners had been diagnosed with vascular dementia. There is considerable overlap in the symptoms of Alzheimer's disease and vascular dementia and many individuals have a mix of both pathologies (Kalaria, 2002). The same treatments are often used to address these two types of dementia (Kalaria & Ballard, 1999; Xing et al., 2014). Because this study was focused on the relational aspects of Alzheimer's disease rather than the pathology of Alzheimer's, these participants' interviews were included in data analysis and there were no noticeable difference in their experiences. All four of these participants were recruited through the Alzheimer's Association support groups and identified with being a part of a community of Alzheimer's caregivers.



white/Caucasian, two identified as Black/African American, two identified as Native American, and one identified as Hispanic. The majority of participants were retired ( $N = 12$ ), five were working, and one was unemployed for the purpose of caregiving. Most participants reported an annual income over \$40,000 (83%); the lowest reported annual income was between \$20,000-\$30,000 and the highest was between \$140,000-\$150,000. Five participants completed some college, two completed vocational training, seven had a bachelor's degree, and four had a graduate/professional degree. For additional demographic information see Table 1.

### **Data Collection**

Individuals who were interested in participating in an interview contacted me via phone, email, or Facebook message to schedule an interview. I scheduled and conducted the interviews with the goal of creating a comfortable interactional space in which participants could share their stories. To facilitate this, I invited participants to choose the location/medium for the interview with which they felt most comfortable. Of the nine in-person interviews, six took place in participants' homes and the others were held in public spaces including a campus common area, a cafe, and a public library study room. Eight interviews took place over the phone, and one was completed via Zoom. Before each interview, the participant was given an interview packet containing a brief description of the interview procedure, the consent form, a short demographic questionnaire, a blank relational timeline with instructions for filling it out, an example relational timeline, and an interview reminder card (see Appendix B). Participants completed these packets and brought them to the interview. Individuals participating via phone/Zoom received their packets through email and returned them before the interview. I recorded all interviews using a hand-held audio recording device. I was able to complete 16 interviews before the Coronavirus

pandemic began and the remaining two interviews were completed over the phone. See Appendix C for the complete recruitment schedule.

**Table 1**

*Participant Demographics*

<b>Pseudonym</b>	<b>Gender</b>	<b>Age</b>	<b>Ethnicity</b>	<b>Years Married</b>	<b>Partner's Diagnosis</b>	<b>Disease Length</b>
Jennifer	Female	62	White/Caucasian	29	Alzheimer's	1 year
Michael	Male	76	White/Caucasian	56	Alzheimer's	6 years
Cheryl	Female	79	Native American	57	Alzheimer's	3 years
William	Male	88	White/Caucasian	63	Alzheimer's	7-8 years
Carol	Female	80	Hispanic/Latino	50	Alzheimer's	9 years
Annie	Female	68	African American	42	Alzheimer's	4 years
Kevin	Male	83	White/Caucasian	62	Alzheimer's	2 years
Joni	Female	56	African American	27	Early Onset Alzheimer's	2-4 years
Wendy	Female	73	White/Caucasian	30	Unspecified Dementia	4 years
Jane	Female	71	White/Caucasian	11	Alzheimer's	7 years*
Emily	Female	49	White/Caucasian	17	Early Onset Alzheimer's	4 years
Bella	Female	62	White/Caucasian	39	Early Onset Alzheimer's	10 years*
Eleanor	Female	59	White/Caucasian	14	Vascular Dementia	3 years
Robert	Male	70	White/Caucasian	36	Alzheimer's	3 years
Frank	Male	64	Native American	34	Early Onset Alzheimer's	10 years*
Connie	Female	70	White/Caucasian	45	Unspecified Dementia	4 years
Tom	Male	59	White/Caucasian	20	Early Onset Alzheimer's	3 years
Garth	Male	80	White/Caucasian	59	Vascular Dementia	7 years

*Note.* \* indicates that the spouse with Alzheimer's disease passed away within the three months

prior to the interview.

### ***Building Rapport***

Rapport building was essential to creating an interactional space where participants could feel comfortable talking freely about their experiences. Building rapport means communicating respect and creating a sense of safety and trust in conversation (Patton, 1990). Although strong rapport is built over time, rapport can be built in the first moments of an interview through communicated warmth, reciprocity, and respect (Pitts & Miller-Day, 2007). For this study I began building rapport through the first interactions with potential participants both in person and on social media. During my brief time at support groups I built trust through expressing genuine interest in the experiences of Alzheimer's caregivers, by being respectful of their time and concerns about confidentiality, and through my professional recruitment flier and articulation of my research. I made an effort to exude a friendly and open persona to ease concerns and help potential participants feel comfortable around me. Similarly, in recruiting online professionalism and transparency about the interview purpose and processes helped me gain trust and interest in my research. During the interviews, I made participants feel comfortable by explaining the confidentiality procedures in place to protect their data and by expressing gratitude for their participation. I also assured them that they could skip any questions they did not feel comfortable answering. I continued building rapport throughout the interview by actively listening, making eye-contact when possible, asking thoughtful questions, and being sensitive of their emotions in sharing their stories of this difficult experience.

### ***Conducting the Interviews***

To make relational turning points salient across the prolonged transition of Alzheimer's disease, I incorporated a modified version of the retrospective interviewing technique (RIT) to guide the conversation (Huston et al., 1981). In RIT, the interviewer asks the participant to plot

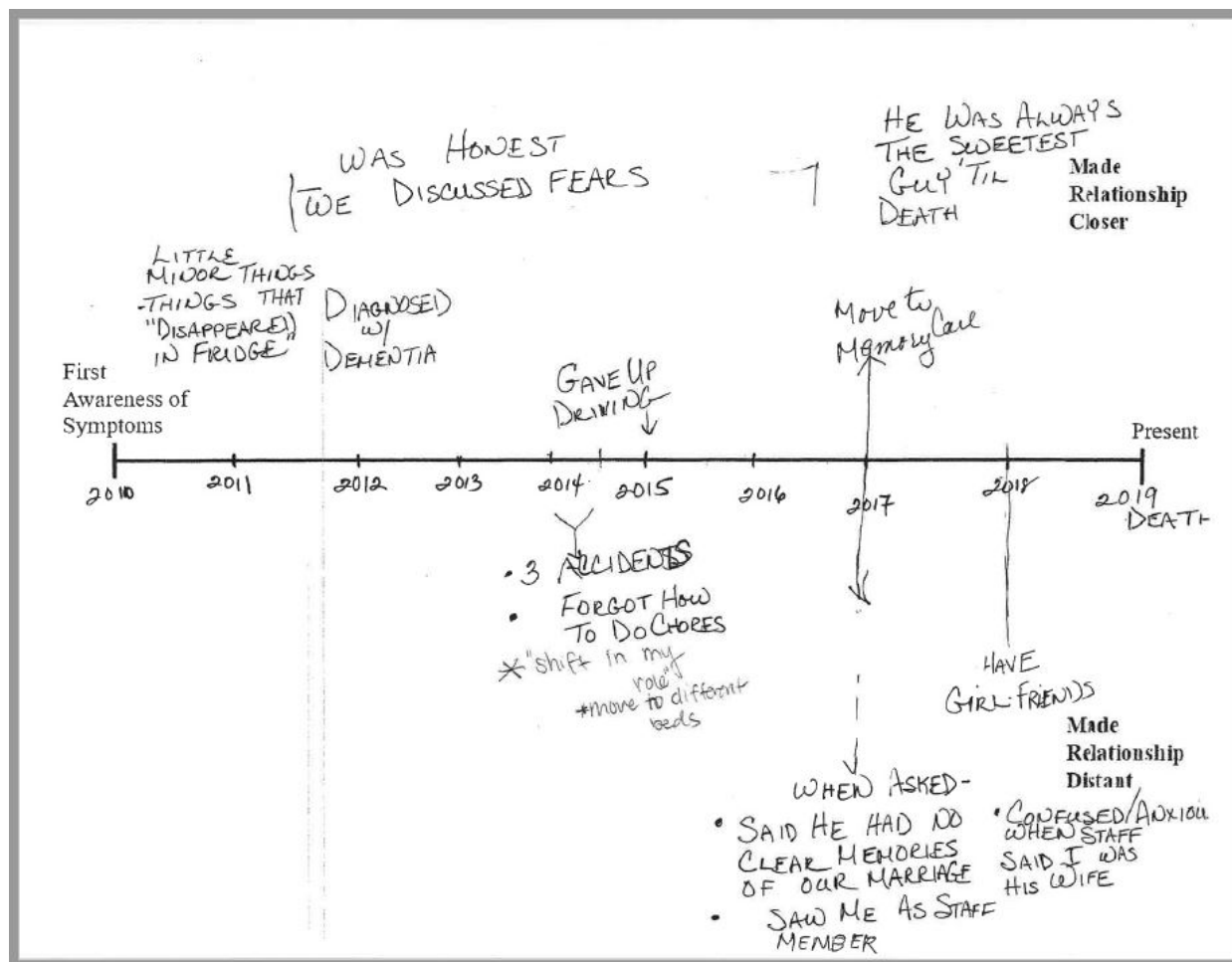
experiences or events that created a shift in their relationship on a graph/timeline (see Baxter & Bullis, 1986). In plotting relational turning points on their timelines, participants are asked to indicate how the event affected their relationship on a marker of relational development such as the level of commitment (Baxter & Pittman, 2001), partnership (Pitts & Miller-Day, 2007), or closeness (Golish, 2000). In this study, I asked participants to plot turning points that made them feel closer to their partners above the timeline, and those that made them feel more distant from their partner below the line (see Appendix B for blank timeline). Participants completed their timelines prior to the interview and returned them to me at the start of the interview. For mediated interviews, timelines and consent forms were returned via email before the scheduled interview time.

I opened the interviews by asking participants to describe their relationship with their partner since they had become aware of Alzheimer's disease. This question gave participants the opportunity to speak freely about their experiences and to give me necessary background information. Next, I invited participants to walk me through each event on their timeline and to explain how the event impacted their relationship. I used additional probes such as "Please tell me what communication was like with your partner in the time surrounding this event" to get further details about the role of communication in creating and navigating each turning point (see Figures 1-2 for examples of participants' timelines). After discussing their timelines, I asked participants to tell me about the relational uncertainties they experienced at different points on the timeline, and to share the ways they experienced facilitation and interference from their partners throughout the disease trajectory. The interview guide provided an adaptable framework to direct the interview conversations and gave me the flexibility to ask questions in my own

words and to ask additional follow up questions as needed (see Appendix D for the full interview guide). The interviews ranged from 47-90 minutes in length.

**Figure 1**

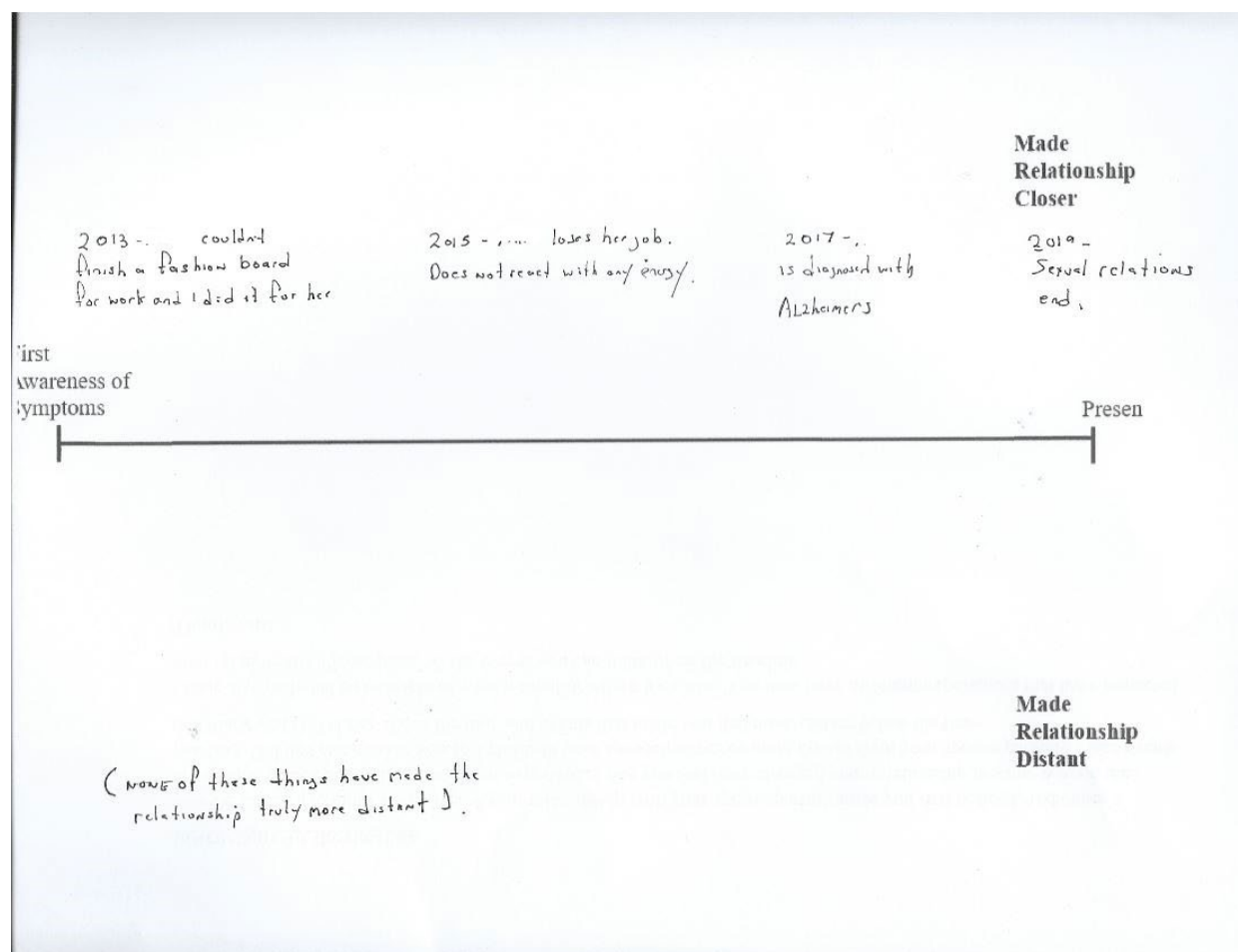
*Participant Timeline for Participant whose Spouse Passed Away*



*Note.* This timeline was completed by Jane. This timeline shows the full relational transition, from early symptoms to death, and is similar to the timelines of most participants whose spouses were in late phases of ADRD.

**Figure 2**

*Participant Timeline for Participant whose Spouse is in the Early Stage of Alzheimer's disease*



*Note.* This timeline was completed by Tom. This timeline includes many of the common turning points plotted by participants whose spouses were in the early stage of ADRD. The note, “none of these things have made the relationship truly more distant” is similar to notes left on two other participants’ timelines.

### **Data Analysis**

Data analysis began with theoretical sampling and transcription. In theoretical sampling, data analysis and data collection occur simultaneously. Analysis of the initial interviews provides

insight that guides and focuses further data collection (Strauss & Corbin, 1998). This process enables the researcher to concentrate data collection on emerging patterns or themes, and to adapt the interview guide to saturate and refine the emerging themes (Glaser, 1978). Theoretical sampling leads to richer, more robust data. To facilitate theoretical sampling, I wrote detailed memos after each interview and throughout data collection. This helped me identify patterns in the initial data and guided me in adapting and conducting later interviews. The transcription process also helps familiarize the researcher with the data and facilitates initial analysis through theoretical sampling (Charmaz, 2014). I used Temi software services to transfer my audio recorded interviews into written transcripts through speech recognition software. Temi software provides transcripts with 90% accuracy and a secure platform for easily reviewing and correcting the transcription (see [temi.com](https://www.temi.com)). I reviewed the transcripts for accuracy by listening through each interview recording to correct mistakes made by the software and remove major speech disfluencies. I also assigned a pseudonym to each participant and replaced the names of participants' family and friends with generic labels such as "[wife]" or "[friend]." Thoroughly reviewing the interview transcripts helped me gain greater familiarity with the experiences of my participants and enabled me to identify initial patterns in the data that guided data collection. The transcription process yielded 284 pages of single-spaced text.

Working in Nvivo12 to organize the data, I analyzed the transcripts using the iterative comparative process of thematic analysis (Glaser & Strauss, 1967). Braun and Clarke (2006) proposed six interconnected phases for conducting thematic analysis which I have used to structure the discussion of my analytic process. The first phase of analysis involved gaining familiarity with the data which I accomplished by reading and rereading the transcripts. Initial coding marked the second phase of analysis. Codes are descriptive labels that summarize and

illustrate the meaning of a short excerpt of text (Strauss & Corbin, 1998). Open or emergent coding requires going through each interview line by line and assigning codes that are representative of the meaning in the data rather than a preconceived meaning or idea (Glaser, 1978). Guided by my research questions, I identified meaningful chunks of data and assigned emergent codes. When possible, I assigned in vivo codes, using the exact wording of the participant to label the code (Creswell, 2013). Labeling codes with participants' words keeps the coding grounded in participants' experiences and meaning. When a section of the data addressed multiple research questions, I assigned multiple nuanced codes that related to each research question. I used a similar method to code the timeline data. I made unique codes for each of the turning points on the timelines and labeled them with the participants' words. I added the words "distant" or "close" in parentheses to identify what side of the timeline the turning point was on: "diagnosed with dementia (close)." This process of initial open coding yielded 1255 codes. Identifying and summarizing meaningful portions of the interviews through initial open coding enabled me to compare meanings across interviews (Strauss, 1987).

The third phase of analysis involved comparing and grouping codes with similar meanings into categories. This process of clustering codes gave an initial look at how data fit together and provided the foundation for early themes (Charmaz, 2014). During this phase I grouped codes that seemed to represent the same or similar experience. For example, in coding for relational turning points I found that many participants described their partner's difficulty with driving. I created several codes representing these incidents: "turned the wrong way on a divided highway," "husband in accident and didn't get any information from the other person," "she veered off the road on the way home from vacation twice." I grouped these codes into an initial category labeled "driving mishaps." The fourth phase involved comparing and combining



codes and categories into broader themes or patterns across the dataset. This process required constant comparison to refine themes until they accurately represented the data and the experiences of participants. Glaser and Strauss (1967) proposed constant comparison as a method for finding similarities and distinguishing theoretical differences between emerging themes. Like solving a puzzle, this process requires repeated comparison of pieces until they fit together to reveal a coherent picture (Strauss & Corbin, 1998). Through constant comparison I combined, or sometimes divided and realigned, the initial categories to fit the emerging picture. Returning to the driving example, through continued comparison with additional data and other initial categories, I combined the category of “driving mishaps” into a broader turning point category labeled “loss of ability to drive.”

Once the themes and subthemes were satisfactorily refined, phase five required defining and naming each one. Theme definitions and names “[identify] the ‘essence’ of what each theme is about” (Braun & Clarke, 2006, p. 92). This phase enabled me to clearly define each theme and to demonstrate how it addressed the research question and provided insight into the ADRD experience. During this phase I renamed the category “loss of ability to drive” to “Losing Driving Privileges” and concretely defined aspects of this experience that created a relational turning point for caregiving spouses. In the sixth and final phase, evocative exemplars were selected from the data to illustrate each theme. This is a key part of reporting qualitative analysis and demonstrating qualitative trustworthiness. Vivid exemplars allow the voice of the participants to be heard. These exemplars pull the reader into the participants’ experiences while also helping them gain a full picture of the conceptual boundaries of the theme (Geertz, 1973; Lindlof & Taylor, 2011). At its completion, this process of thematic analysis yielded 18 themes

and 11 subthemes that together paint a picture of the experience of relational change in Alzheimer's disease and related dementias (see Tables 2-5).

### *Establishing Qualitative Trustworthiness*

Throughout data analysis, I engaged in verification procedures to increase the trustworthiness of the analysis. Lincoln and Guba (1985) describe four criteria of qualitative trustworthiness: credibility, dependability, confirmability, and transferability. I conducted procedures that meet each trustworthiness criteria. First, credibility was established through extended engagement in the field by collecting in-depth interviews until each theme was saturated, or fully and robustly defined, with no new meanings emerging in subsequent interviews (Glaser & Strauss, 1967). I also engaged in negative case analysis, which requires looking for “disconfirming data” or cases that contradict initial themes (Lincoln & Guba, 1985, p. 310). For example, early in my data collection and analysis several participants mentioned avoiding confrontation with their partners and this emerged as an early theme. Almost halfway through data collection a participant described her use of direct confrontation to manage her husband's difficult behavior. This contradicted my early theme of “avoid confrontation.” Through continued theoretical sampling focused on participants' use of confrontation, I found that participants used both avoiding confrontation and direct confrontation as means of managing their partner's challenging behaviors. This negative case illuminated the varying communication strategies participants used to address challenges in their relationships, and both were incorporated into my findings.

Second, to demonstrate the dependability or consistency of findings I kept detailed memos throughout every stage of the project which were compiled into an audit trail creating a comprehensive record of the analytical process. My audit trail includes field notes, analytic

memos, codes, written decisions about how to combine codes, notes about themes or patterns in the data, and explicit tracking of decisions made about how to treat the data (Rodgers & Cowles, 1993). Keeping detailed memos in the audit trail also provides “an interactive space” for the researcher to make sense of the data, compare codes and categories, and document themes and patterns as they emerge (Charmaz, 2014, p. 163). The audit trail helps develop qualitative findings and demonstrates the dependability of qualitative findings by providing a detailed record of the analytical process (see Appendix E for an excerpt of my audit trail). This thorough and detailed audit trail enabled me to construct a coherent and comprehensive report of the qualitative findings.

The third trustworthiness criteria, confirmability, demonstrates that findings are observable and consistent with the experiences of the group being studied. For confirmability, I engaged in member checking, which involves sharing qualitative findings with participants to ensure the analysis and themes are representative of their lived experiences. Member checking allows the researcher to gauge if the findings “ring true” for participants and provides an opportunity for further refining of the themes (Lincoln & Guba, 1985). To do this, I sent the initial write up of the findings section to five participants and invited them to send feedback about the findings. Specifically, I asked them to respond to these two questions: (1) “Does this resonate with your experience?” and (2) “Are there parts you disagree with or would change?” Three out of the five participants responded, and each confirmed that the findings resonated with their experiences. These participants did not recommend any changes.

The fourth and final trustworthiness criteria, transferability, refers to the ability of qualitative findings to speak to the experiences of people not in the sample and transfer to similar samples or contexts. To increase transferability, I selected exemplars with thick description of

participants' experiences. Thick description provides vivid detail and gives the reader a rich understanding of the experience (Geertz, 1973). These exemplars "paint a verbal picture so rich that readers of the study feel as if they had walked that mile in the shoes of the [participants]" (Baxter & Babbie, 2004, p. 62). These rich descriptions provide a clear and detailed understanding of participants' experiences and how findings about their experiences relate to other contexts. Exemplars are used throughout the findings section and in Tables 2-5. I also provided descriptive detail of my sample so that other researchers can compare their sample to determine if findings might be likely to transfer. These procedures for establishing qualitative trustworthiness increased the reliability of my qualitative analysis and enabled me to explore and present the lived experiences of my participants more fully.

### **Findings**

The purpose of this study was to investigate the experiences of caregiving spouses during the prolonged relational transition of Alzheimer disease and the role of communication in shaping and navigating this transition. Sensitizing concepts from relational turbulence theory and relational turning points inspired four research questions which guided this inquiry in exploring (RQ1) the relational turning points that shape this prolonged transition, (RQ2) caregiving spouses' communication strategies for maintaining connection and managing challenges, (RQ3) the experience of relational uncertainty, and (RQ4) the facilitative and interfering effects of the communication and behavior of the partners with ADRD. Data analysis yielded four themes and nine subthemes for RQ1, six themes for RQ2, three themes for RQ3, and five themes and two subthemes for RQ4. These 18 themes and 11 subthemes provide insight into the prolonged relational transition of Alzheimer's disease and related dementias.

**Table 2**

*Findings from Research Question 1: What relational and communicative turning points do caregiving spouses describe across the trajectory Alzheimer's disease and related dementias?*

<b>Theme/Turning Point</b>	<b>Description</b>	<b>Exemplars</b>
<b>Relational Change 1: My Spouse has Alzheimer's Disease</b>		
<i>Early Symptoms Shift the Relationship</i>	Early symptoms shifted the relationship because caregiving spouses could not understand their partners' behavior.	"It strained the relationship because if you're not familiar with this disease, you just don't get it. You're just like, how the hell can you not do this thing that you've done a thousand times and that I'm showing you with my hand? We didn't know what the illness was." - Tom
<i>Spouse's Diagnosis</i>	The diagnosis was a positive turning point for caregiving spouses because it helped them understand their partners' behavior and have greater patience with them.	"Getting the diagnosis actually helped cause then I could realize, well there's a reason for that behavior... So instead of getting angry, I could try to be more relaxed and just accept it and try to be more understanding." - Robert
<b>Relational Change 2: From Spouse to Caregiver</b>		
<i>Losing Driving Privileges</i>	The loss of driving privileges was a turning point that shifted the relationship toward caregiving because questions about driving put caregiving spouses in a position of monitoring/regulating their partners.	"I took the car away from her last spring. That was a blow to her... and then we came back from the summer and I sold the car, and she was in a dither, and then she sort of got used to it." - Kevin
<i>Shifting Household Responsibilities</i>	The relationship moved further toward caregiving as caregiving spouses took on more household	"The relationship is impacted so deeply because there was so much he suddenly couldn't do anymore. We were pretty even in what our

	responsibilities because they were no longer able to rely on their partners to complete household tasks.	responsibilities were, and I just had to take everything over... So I was like scrambling to understand all the things that had once been his arena, which was now my arena cause he couldn't grasp things anymore." - Emily
<b><i>No More Romance</i></b>	Romance was an important aspect of the marital relationship, and the loss of romance shifted the relationship further toward one of caregiving.	"That's when intimacy was gone. Um, other than the basic, you know, handholding or hugs, but not the romantic side of a marriage relationship. And a lot of that was me too, because, you know, I felt I became his mother." - Jane
<b><i>Increasingly Severe Symptoms</i></b>	Severe symptoms such as hallucinations and incontinence made the partner with ADRD fully dependent on the caregiving spouse and solidified the change from spouse to caregiver.	"The relationship has changed; it's now being the person who takes care of her. That's my role in the relationship right now. There's no reciprocal part on hers." - Garth
<b>Relational Change 3: My Spouse is Gone</b>		
<b><i>No More Deep Conversations</i></b>	Caregiving spouses felt the loss of their spouse in the lack of deep and meaningful conversation in their relationships.	"He couldn't do a give and take conversation anymore." - Bella  "That's the thing I miss the most that, you know, we talk everything over kind of thing." - Carol
<b><i>Didn't Remember my Name</i></b>	The moment when the partner with ADRD forgot their spouse's name or other aspects of the relationship made caregiving spouses realize just how much their partner had changed and how much they had forgotten about the relationship.	"That's when he said he didn't even remember our marriage; he didn't remember our dating and that was hard. Definitely. I counted on him losing memories, but what I didn't count on was the disconnect." - Jane

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***Changes in Living Arrangements***

The move to memory care and similar changes in living arrangements were physical manifestations of the loss of the partner and distance in the relationship caused by the symptoms of Alzheimer's disease.

“I don't like going to bed alone at night. I mean, you live with somebody for 60 years, why, it's different. But I don't love her any less. We just can't be together all the time now. We can't be.”  
- William

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**Relational Change 4: Transcending through Love**

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Caregiving spouses described continued and even increasing love for their partners across AD. For them, love changed to be less about romance and more about friendship and selfless commitment.

“[Regarding] feelings of loving somebody or something like that, it had really no effect except that she was going to need a different kind of caring.” - Michael

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**Table 3**

*Findings from Research Question 2: What communication strategies do caregiving spouses use to maintain relationship and navigate challenges across the prolonged relational transition and turning points of Alzheimer’s disease and related dementias?*

Theme	Description	Exemplars
<b>Addressing the Challenges of Alzheimer’s Disease</b>		
<b><i>Direct and Difficult Conversations</i></b>	Caregiving spouses strategically addressed concerns about sensitive topics with their partners through direct conversation.	“I just said to my husband, we need to talk about this, whatever you’re comfortable with. And I also tried to keep open the lines of communication, you know, ‘let me know how you feel about things.’ Um, because I feel that communication even uncomfortable is important. ‘Sometimes you have to put your big boy pants on and just talk to me and if you’re scared it’s okay, I’m here for you. We’ll get through this together’... So there were those just touch base check-in type conversations” - Jennifer
<b><i>Avoiding Confrontation</i></b>	Caregiving spouses were strategic about when to engage with their partners and when to avoid confrontation about specific issues. They “held their tongue,” walked away, and put up with some behaviors to avoid unnecessary confrontations.	“I leave things alone, you know, things that would bring up bad feelings or arguing I try to stay clear of it.” - Annie



<b><i>Avoiding Talking about or Bringing Attention to Alzheimer's Disease</i></b>	Caregiving spouses tried not to bring attention to the effects of the disease in daily life to shield their partners from the painful recognition of AD and to help them maintain a level of independence.	“I never said to him, well, you can't do things like that. No. I just kind of, kind of worked around it” – Carol  “When we see stuff now, we just cover up for her or we don't let her know that she's done it. We just address it as we can.” - Tom
<b>Maintaining Companionship and Closeness</b>		
<b><i>Daily Conversations and Activities</i></b>	Positive shared activities and daily conversations helped couples maintain a sense of connection and relationship across the trajectory of AD.	“It's great that we can do things that we love to do together... just keeping us social and outgoing and communicating with friends that we've made. It's great. That's how we cope with things... I think that's kind of a saving grace for our relationship.” - Cheryl
<b><i>Open and Intimate Conversations</i></b>	Open and intimate conversations about the disease and their relationships helped solidify couples love and commitment to the relationship early in disease progression.	“I think [conversation about end of life care] is kind of what brought us closer during that time. ‘What do you want to do when it comes time?’ ...It made our conversations, um, just kind of brought us together. We're all on the same page.” - Eleanor
<b><i>Communicating Love and Affection</i></b>	Caregiving spouses communicated love and affection through words, touch, and acts of care. These expressions of love helped them feel closer to their partners.	My husband loved to be hugged. And that to me was a sense of intimacy... I wanted him to know that he was loved. And I told him, you know, I love you and I'm sorry that you're going through this” - Bella

**Table 4**

*Findings from Research Question 3: How do caregiving spouses experience relational uncertainty related to long-term adaptation to living with Alzheimer's disease and related dementias in their relationship (e.g., partner, self, and relationship uncertainty)?*

<b>Theme</b>	<b>Description</b>	<b>Exemplars</b>
<b><i>Partner-Uncertainty: I Don't Know who my Partner will Become</i></b>	Caregiving spouses experienced uncertainty about who their partners would become with Alzheimer's disease and how these changes would impact their interest and ability to engage in the relationship.	<p>"My biggest fear was that I didn't know how it was going to affect her." - Frank</p> <p>"What will this look like? It's the unknown... and I had that at that question too. How long would he love me?" - Jane</p>
<b><i>Self-Uncertainty: I Don't Know if I can Make it Through This</i></b>	Caregiving spouses were uncertain about their ability to face the changes in their spouses and relationships.	<p>"I don't know if I have the ability. I've never been without her. She was always the stronger one... Every day I worry. I'm more in love with her and want to take care of her and do different things, but I hear that at some point you got to change their diapers and all of that. I wouldn't be able to do that. I don't think I could. I want to..."</p> <p>- Kevin</p>
<b><i>Relationship (un)Certainty: Relationship Change and Loss are Certain</i></b>	Caregiving spouses described their relationship certainty that the effects of the disease would change their partners and relationship, and that this transition would end with the death of their partners.	<p>"It's very upsetting because the end of this is death, and you know, institutionalization." - Tom</p> <p>"You see the good, the bad, the ugly, you know what the end results are." - Frank</p>

**Table 5**

*Findings from Research Question 4: What communication practices and behaviors do caregiving spouses report as (a) interference and (b) facilitation throughout the relational transition of Alzheimer's disease and related dementias?*

Theme	Description	Exemplars
<b>Communicating Love and Affection</b>		
	Caregiving spouses found their partners' expressions of love and affection drew them closer and facilitated the goal of continuing sense of relationship in AD.	"He tells me how much he loves me, and holds my hands when we go to bed" - Carol
<b>Symptoms Create Distance in the Relationship</b>		
	The symptoms of AD interfered with daily tasks and made it difficult to communicate. These created distance in the relationship.	"Sometimes she'll have problems just understanding things. Um, her memory gets confused, you know. One thing is the constant repetition of questions. That makes it difficult to carry on a conversation because she keeps on asking the same question over and over again." - Robert
<b>Facilitating Daily Tasks</b>		
<b><i>Expressing Appreciation and Helping Out</i></b>	Early in disease progression partners with ADRD facilitated daily tasks and preserved goodwill in the relationship by expressing appreciation and helping around the house as they were able.	"He'll help me. He takes out the trash for me each day, his chore is to take it out, you know." - Annie  "Whenever I help her into her wheelchairs, she says, thank you... there's always the thank you." - Garth

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***Cooperative (Not Combative)***

Caregiving spouses considered their partners' cooperative behavior as facilitative in comparison with what it could be.

“She didn't get antagonistic or anything from the standpoint of the what you might see, and I do see it in a lot of other people, the confrontational kind of things that you would suspect would come from the disease and the challenge to communicate.” - Michael

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**Aggressive Behaviors Strain the Relationship**

Aggressive behavior from partners with ADRD interfered with daily tasks and were hurtful to caregiving spouses. These behaviors damaged the relationship.

“That's all he does is attack me, attack me, attack me... So, um, it's just, it's made it really, really difficult.” - Connie

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**Preserving the Past**

Caregiving spouses appreciated moments when their partners could remember the past or behave in ways they would have before AD. For caregiving spouses, these moments were facilitative in preserving the relationship.

“When he can reminisce in a way, or talk about projects that we worked on, or just industry in general, it makes me feel more strongly towards him because that's where it all started. It's sort of like getting the old person back when they can sort of suddenly kick into awareness or that wisdom shows up.” - Emily

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Although I addressed each of these research questions individually, through the process of analysis it became clear that each research question represents only a small part of the relational experience. When viewed as a whole, these findings paint a rich picture of the relational transition of AD and the role of communication in shifting the relationship, maintaining connection, and addressing challenges and uncertainty across the trajectory of the disease. As such, in presenting these findings I hope to provide a detailed picture of the relational experience of Alzheimer's disease. I have organized this section with this in mind and begin by presenting the findings related to the experience of relational uncertainty in AD (RQ3). The relational turning points that shape this prolonged transition are presented second (RQ1), followed by findings about caregiving spouses' communication strategies (RQ2). I conclude this section by addressing the findings regarding partner facilitation and interference (RQ4).

### **The Experience of Relational Uncertainty in Alzheimer's Disease**

Caregiving spouses shared a unique experience of relational uncertainty shaped by the all-consuming symptoms and terminal nature of Alzheimer's disease and related dementias. Although people affected by Alzheimer's often have uncertainty about the disease itself (Stone & Jones, 2009), this inquiry focused specifically on the uncertainty caregiving spouses had about their relationships. The three sources of relational uncertainty from RTT (partner-, self-, and relationship-uncertainty) provide insight into the relational transformation caused by AD and caregiving spouses' experiences of relating with their partners throughout this transition. Because caregiving spouses anticipated their partners' symptoms of decline, the experience of relational uncertainty in AD must be understood within the context to two relational *certainties*: (1) that the relationship would be changed completely as the disease transformed the spouse with ADRD and (2) that the relationship and the relational transition would end with the death of their

spouse. Relational uncertainty generally revolves around both partners' involvement in the relationship and the nature and future of the relationship (Solomon & Knobloch, 2004), but for caregiving spouses, the certainty of relational change and death shifted the experiences of relational uncertainty. Across the trajectory of the disease caregiving spouses' experiences with relational uncertainty reflected a tension between certainty and uncertainty. This was seen in their experiences of partner-uncertainty (I don't know who my partner will become), self-uncertainty (I don't know if I can make it through this), and relationship-(un)certainty (relationship change and loss are certain).

***Partner-Uncertainty: I Don't Know who my Partner will Become***

Caregiving spouses' expressed uncertainty about who their partner would become as the symptoms of Alzheimer's disease took effect. "My biggest fear was that I didn't know how it was going to affect her" (Frank). This type of partner uncertainty was most common early in disease progression when the symptoms were mild. Eleanor explained, "I don't know where it's gonna lead. I don't know that because we're still pretty early here." As they looked toward a future with the disease, caregiving spouses felt concern about how their partners would change and how this would affect the relationship:

There's so much unknown. How to anticipate what of his personality traits are going to shift? ... when is he going to turn into the angry person that I hear about that happens to many other people? I've heard of people getting angry and getting irritable and getting combative. You know, is that going to happen to him? (Emily)

Knowing the symptoms of AD, caregiving spouses anticipated that their partners' personalities would shift due to the disease. Emily was concerned that her husband might become "the angry person" or that his personality traits might shift in other ways. Concern about who the partner

would become was closely linked to concern about how the changes would affect the relationship. Caregiving spouses were concerned about what it would be like to be in a relationship with a “completely different person.”

In addition to experiencing uncertainty about personality changes, caregiving spouses were uncertain about how their partners would feel about them and the relationship once when the symptoms became more severe. Jane recalled feeling this uncertainty shortly after her husband was diagnosed, “I had that question too, how long would he love me?” The question “how long will they love me” is at the heart of partner uncertainty in AD. Caregiving spouses were concerned about how their spouses’ feelings toward them and the relationship might change when memory impairment became more severe. Many caregiving spouses expressed concern that their partner would forget who they were or forget about their relationship. For Kevin, this was at the heart of relational change in Alzheimer’s disease, “We won’t be together... [she will] not know who I am.” Caregiving spouses were uncertain about who their partners would become, whether they would remember or care about the relationship, and how willing or able they would be to engage in the relationship.

Later in disease progression, when symptoms became more intense, some caregiving spouses experienced uncertainty about who their partner might become throughout the day. “That uncertainty is just, like I said, you don’t know what’s going to happen, sometimes it’s moment by moment” (Annie). Wendy explained that she feels uncertainty about her husband “every single day” because his behavior can change quickly and unpredictably:

Some days he’s perfectly fine and happy go lucky and he’s a joy to be around and everything’s fine and God’s in his heaven and all is right with the world. Ten minutes later he’s in a bad mood and you never know why.

For caregiving spouses, this tendency to shift personality and behavior unpredictably throughout the day created daily uncertainty about how AD might affect their partners moment to moment. Joni described these rapid changes as “a Jekyll and Hyde kind of thing.” These daily partner-uncertainties made it difficult for caregiving spouses to know how to relate with their partner on a day to day basis and created broader uncertainties about how the changes in their partner’s personality would impact their relationship.

***Self-Uncertainty: I Don’t Know if I can Make it Through This***

The heart of self-uncertainty for caregiving spouses was concern about their ability to endure these relational changes. For some, this was about their ability to be what their partner needed them to be through caregiving. For caregiving spouses like Kevin this uncertainty was about their ability to perform the tasks required to provide care, “I’m always questioning my ability. Can I do this? Can I do that?” For others, this uncertainty was more about being able to carry the load that fell to them as their partner’s symptoms become more severe. Emily expressed this aspect of uncertainty, “there's so many roles I’m dealing with now, from parent, to employee, to spouse, I think it’s more like how much longer can I endure this?” These caregiving spouses were uncertain about their *ability* to support their partner throughout the disease. Some caregiving spouses expressed uncertainty about their *willingness* to provide the care their partner needed. Wendy described this aspect of self-uncertainty in reference to the more demanding aspects of care, “I’m not saying I *can’t* do it. I don’t *want* to do that kind of thing. That just is not where my head is.” Like Wendy, some caregiving spouses were uncertain about how willing they would be to provide more intense care when it was needed. This first aspect of caregiving spouses’ self-uncertainty was about their ability, stamina, and willingness to support their partner through providing care.



Another aspect of self-uncertainty was centered on caregiving spouses' emotional responses to the changes in their partners and their relationships. Caregiving spouses felt uncertain about how they would feel about their partners as they became more dependent. Jane explained, "I knew at some point there would be that role change and I didn't know, I mean, I'm a mother and I love my children, but would I be capable of loving a grown man like that?" Knowing that their partners would change created uncertainty about how they would feel toward them as they changed. This aspect of self-uncertainty was less about caregiving spouses' ability or willingness to *provide* care, and more about their ability to *feel* care for their partner as they changed. Caregiving spouses also experienced uncertainty about how they would react emotionally to watching their spouses change. Bella said, "I didn't want him to suffer. I didn't know if I could take him suffering and watching him transition." As caregiving spouses anticipated the difficulty of watching their spouse deteriorate with Alzheimer's disease, they felt uncertain about whether they could make it through the challenge of the transition. Kevin reflected this uncertainty when he said, "I am completely lost. I'm scared stiff and more in love with my wife. I don't want to see us parting... I just can't accept change." At its core, caregiving spouses' self-uncertainty in AD was about their ability to manage the difficult relational transition of Alzheimer's disease.

***Relationship (un)Certainty: Relationship Change and Loss are Certain***

Many caregiving spouses were hesitant to discuss relational uncertainty. A few went so far as to say that they did not have any uncertainty. While it may be possible to have no uncertainty in the face of AD, it is more likely that they chose to focus on something other than their uncertainties. When it came to relationship uncertainty, which centers on the nature and future of the relationship (Solomon & Knobloch, 2004), caregiving spouses focused on their

certainties. Caregiving spouses were certain that the nature of their relationships would change as their partners were impacted by the disease. Jennifer explained, “I know at some point it’s going to become one-sided.” Although they did not know exactly what their relationships would look like, they knew that because of the changes to their partners, the relationship would be completely different. Due to the terminal nature of Alzheimer’s disease and related dementias, caregiving spouses were also certain that this relational transition would end with the death of their partner. “The end result is death. That’s it. Period. It’s going to happen sooner or later” (Garth). Although they did not know how long this period would last or exactly what these changes would look like, caregiving spouses had little relationship-uncertainty because they knew the relationship would decline and end in death.

These two certainties shaped the prolonged relational transition of Alzheimer’s disease and related dementias and created unique challenges for caregiving spouses. The knowledge that they would lose their partners and relationships led to a prolonged experience of loss. Emily said, “We are sort of grieving someone while they’re still here and then it’s like a marathon of grief cause you don’t know how long they’re going to live.” This marathon of grief made the relational transition more difficult. Jane, whose husband had passed away three months before the interview, described the waves of loss experienced in AD, “The first death is when they lose the memory and then the second is when they actually pass, and the biggest challenge is the period of time between the two.” The certainty of relational decline and death created a profound and prolonged sense of loss throughout the relational transition of AD.

Faced with the grim reality of these relationship-*certainties* caregiving spouses may have found it easier to avoid thinking about their uncertainties about Alzheimer’s disease. This was reflected in their claims of “no uncertainty” during the interviews. Instead of discussing their

certainties or uncertainties, caregiving spouses focused on the day to day aspects of care. Bella explained, “We have to live in the moment... don’t worry about the future or how they’re going to be or how you’re going to be when they reach a certain stage because there’s no sense in worrying about it.” Bella’s statement hints at both the certainty of relational change and the uncertainty of how that change would look for the caregiving spouse and their partner, yet she focuses attention away from the future and onto the present moment. Similarly, Annie said, “I don’t want to worry about what may be down the pike right now... I can’t do nothing about what’s ahead and I can’t do nothing about the past... We’re dealing with this thing a day at a time.” Because they knew Alzheimer’s disease would eventually radically change their relationships, focusing on the present moment helped caregiving spouses avoid the certainties and uncertainties of future relational changes and turning points.

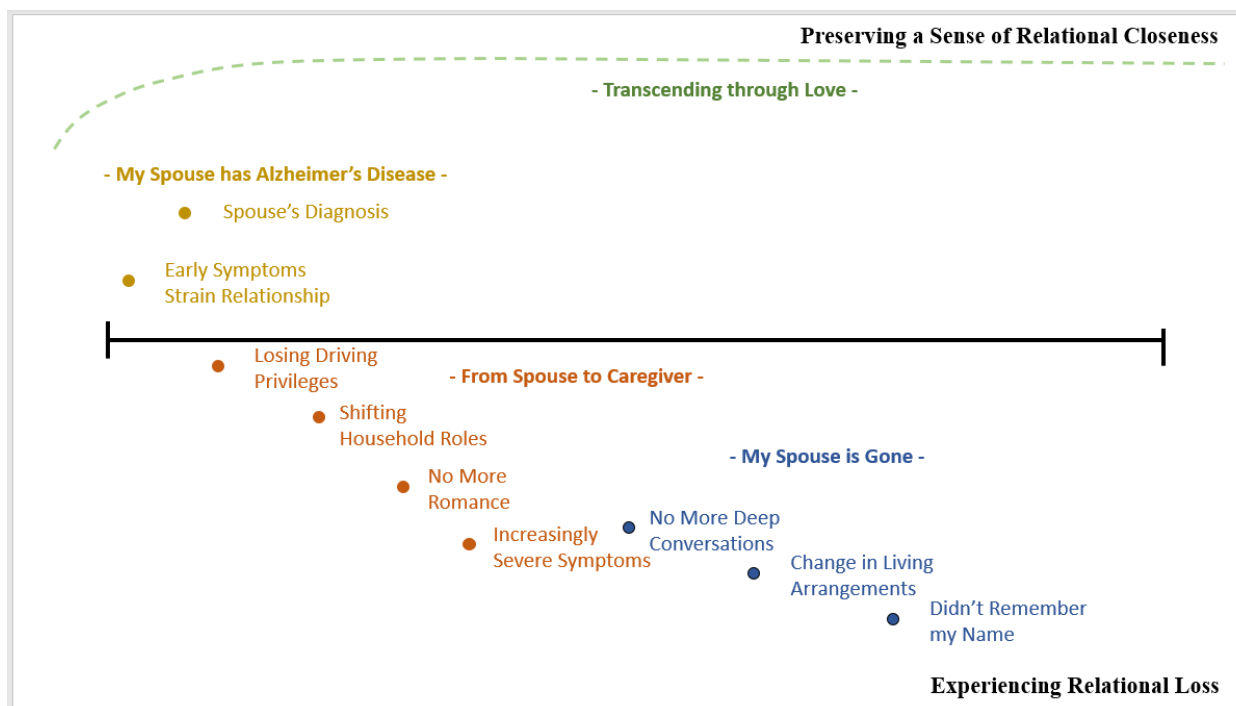
### **Relational Turning Points and Changes to the Relationship**

The increasing deterioration caused by Alzheimer’s disease creates continual change in relationships affected by AD. These relational changes can be mapped through discrete relational and communicative turning points that impacted the relationship across the disease trajectory. In total, there were 10 common turning points that caregiving spouses experienced throughout the prolonged relational transition of Alzheimer’s disease. I have grouped these turning points into four broad relational changes: (1) my spouse has Alzheimer’s disease, (2) from spouse to caregiver, (3) my spouse is gone, and (4) transcending through love. Although many of these turning points were marked by changes in the disease, changes caused by the disease shifted the relationship. “Whenever you change the material circumstances, you change the relationship” (Tom). These turning point experiences shifted the relationship by drawing partners together, creating strain in the relationship, or by changing the nature of the relationship. Relational

turning points will be presented in conjunction with the broader relational change they produce and approximately as they occur chronologically in the progression of Alzheimer's disease (See Figure 3).

**Figure 3**

*Relational Changes and Turning Points Across Alzheimer's Disease and Related Dementias*



*Note.* This relational turning points timeline includes all the relational turning points and relational changes identified through data analysis. Turning points are plotted in approximately the order they occur throughout the relational transition and at the point above or below the timeline that is most representative of participants' experiences. Each color represents a unique relational change, My Spouse has Alzheimer's (yellow), From Spouse to Caregiver (orange), My Spouse is Gone (blue), and Transcending Through Love (green).

### ***Relational Change 1: My Spouse has Alzheimer's Disease***

The recognition and diagnosis of the disease marked the beginning of this prolonged relational transition. Early symptoms of the disease strained the relationship as the behavior of partners with ADRD shifted. Before the diagnosis, many caregiving spouses reported that conversations about their partner's unusual behavior created tension and conflict, "early on we had terrible, terrible fights about it" (Tom). The diagnosis provided an explanation for the behavior and opened the door for conversation about the relationship and the disease. Jennifer explained, "I think it drew us closer only because we could talk about it openly because he had the diagnosis." These open conversations about Alzheimer's disease drew couples closer and helped them face the disease together. Thus, while the early symptoms shifted the relationship in a way that created strain, the diagnosis brought clarity and the greater relational closeness.

**Early Symptoms Shift the Relationship.** For couples affected by Alzheimer's disease and related dementias, changes in the relationship began with the appearance of early symptoms such as forgetfulness, getting lost or losing things, and difficulty managing routine tasks. These early symptoms were confusing to caregiving spouses who had no explanation for their partners' behavior. Bella explained, "when people start with their symptoms, the spouse or partner doesn't realize it's Alzheimer's or another dementia... it's just so bizarre." Recalling the time before his wife's diagnosis Garth said, "I was so confused. I didn't know what to make of all that, so for me it was total confusion." These inexplicable changes in functioning shifted the relationship. Garth continued, "So the relationship was a little different. It was questionable... There was some misreadings there for quite a while until I was finally convinced that there was something wrong." The relational shift caused by early symptoms was not necessarily a large one, but

caregiving spouses noticed that something was “a little different” or “questionable” in their relationships before the diagnosis.

For some couples, the “misreadings” caused by early symptoms strained the relationship. Several caregiving spouses recalled getting frustrated or angry with their partner during this time because they could not understand where their partner’s behavior was coming from. Tom said, “early on there was a lot of, you know, a lot of anger, like ‘what the hell are you doing?’” Similarly, Bella recalled, “I was mad at him because he didn’t tell me what was going on at work. I was very angry with him for hiding things from me.” Because she did not know her husband’s condition, she did not recognize that he was forgetting things rather than hiding things from her. Without an understanding of where the behavior was coming from, caregiving spouses reported losing their temper with their partners and engaging in conflict more frequently. This confusion and frustration about their partners’ changes in behavior strained the relationship.

Early symptoms also shifted the relationship because the strange behavior broke down the trust that caregiving spouses had in their partners. Emily recalled “feeling a little unconfident” in her relationship because of the changes she was noticing, “It breaks down confidence in your partner when they suddenly are behaving in a way that’s peculiar and not like their usual self.” Caregiving spouses who were accustomed to relying on their partners to fulfil specific relational and household functions lost trust in their partner when they struggled to perform routine tasks. Carol realized that her husband could no longer be trusted to cook on his own when she was awoken by the fire alarm because he had forgotten a pan of bacon on the stove, “that was like, wait a minute, you can’t leave him alone. You can’t trust him.” The confusion, frustration, and loss of trust caused by early symptoms strained the relationship because caregiving spouses did not understand the changes in their partners’ behavior.

**Spouse's Diagnosis.** Although the diagnosis “was devastating” (Bella) news, it was a positive turning point because it provided clarity and understanding that brought many couples closer together. Eleanor said that her wife’s behavior “started making more sense after [the diagnosis]. And I think that helped the relationship... it kind of brought us a little closer together.” For many caregiving spouses, receiving a diagnosis helped reduce the strain of initial symptoms because they understood where the changes in behavior were coming from. “I can at least try to be more patient because I know the cause and, you know, I know it’s not like a personality defect” (Robert). The understanding gained through the diagnosis helped reduce the strain of early symptoms because it took the blame off the partner with Alzheimer’s. Jane explained how this helped her relationship, “I know it’s something that happened to him. It is not something he’s doing to us.” Having a diagnosis helped caregiving spouses respond to their partners’ changing behavior with patience and understanding. “It gave me probably a better heart to just be super forgiving all the time” (Joni). Knowing the source of their partners’ behavior helped caregiving spouses adjust their expectations and behavior toward their partners. According to Michael, “You’ve got to calibrate differently, it’s a different calibration...you got to understand that you’re doing your best and they’re doing their best.” This ability to recalibrate their expectations helped couples adapt to life with Alzheimer’s disease and provided a positive turning point in their relationships.

### ***Relational Change 2: From Spouse to Caregiver***

The relational change from spouse to caregiver occurred through a series of four turning points: losing driving privileges, shifting household responsibilities, no more romance, and increasingly severe symptoms. These turning points shifted the relationship from one of equal partnership to that of caregiver and care recipient as spouses with ADRD became more reliant on

their partners. “It wasn’t like a light switch that everything just changed, it was gradual” (Robert). This gradual shift into caregiving occurred as each turning point moved the relationship a little closer toward caregiving.

**Losing Driving Privileges.** The turning point around driving ability and privileges marked the beginning of the shift from an equal partnership to a caregiving relationship. Almost every caregiving spouse identified their partner’s loss of driving privileges as a significant turning point. Those whose spouses had not yet lost their driving privileges all mentioned incidents with driving and concern about their partners’ ability to drive. Because driving is the “ultimate symbol of independence in our culture” (Emily), the loss of driving privileges was a manifestation of their partners’ decline and increasing dependence. The loss of driving privileges was often prompted by one or more accidents such as hitting stationary objects, “he actually backed into a tree that he was parked next to originally” (Jane); failing to perform the set procedure after a small accident, “you didn’t even call the insurance or the police, you have no right in driving” (Kevin); or making a driving mistake that could cause serious accident, “We could have caused a major, major disaster... So then there went the driver’s license” (Carol). These driving mishaps confirmed to caregiving spouses that their partners no longer had the ability to drive safely and responsibly.

Caregiving spouses felt a responsibility to monitor or potentially remove driving privileges. Frank recognized that if his wife had not stopped driving on her own, he would have had to stop her, “She gave up driving, which was a wonderful, wonderful thing for me. I didn’t have to take that away.” Similarly, Bella felt she had to step in to stop her husband from driving, “I had to take away his keys, his driving. He was very mad at me about that, didn’t talk to me for four days” (Bella). This sense of needing to monitor or control their spouses driving behavior put



caregiving spouses into a position of supervising their partner rather than equal partnership. Jane explained that she felt her relationship shift toward caregiving during conversations with her husband about driving, “I felt I was talking to a teenager... and that’s when I felt the shift was, I became his mother, and sometimes that punitive mother who was about ready to ground him.” As Jane explained, having to monitor or remove their partners’ driving privileges made caregiving spouses feel more like parents and less like equal partners in the relationship.

**Shifting Household Responsibilities.** As the symptoms of Alzheimer’s disease worsened, caregiving spouses realized that they could no longer rely on their partners to complete daily tasks and began to take on more responsibility. Caregiving spouses viewed reciprocity as central to the marital relationship, so when they were no longer able to rely on their partners, the marital relationship seemed to fade. For Emily, this shift in household tasks created the caregiving relationship:

It shifted quite drastically from a marital relationship to a caregiving relationship... with your spouse, you’ve been so reliant on them, there’s so much push-pull between the two of you... there’s all that push-pull and suddenly, it’s physics, the push or the pull just simply goes away, and there you are. You are simply thrown into caregiving... you just recognize the relationship is no longer a marital one, it’s one of caregiving.

For many couples, this occurred gradually with caregiving spouses gradually taking on more responsibility as their partners lost ability. William explained that things his wife “would normally have taken care of shifted. She was always the one that would get out our meds in the morning for both of us... got to the point where that was my job.” Because the division of household labor was central to a marital relationship, caregiving spouses began to see themselves as caregivers as they took on more household responsibilities. Tom said, “My wife really used to

run the show... I assumed all kinds of duties, decorated how I needed decorated, I buy the food, so our roles have switched completely. I'm a caregiver." In this way, the shifting of household roles moved the relationship away from partnership toward caregiving. "It's like less wife and more caretaker. That's the role" (Joni).

**No More Romance.** For many couples, romance decreased as the relationship became one of caregiving. Joni described this transition, "I am feeling less and less romantic as I'm being more and more of a caretaker." Several caregiving spouses said that there came a point when they no longer had the romantic side of their relationship. "We don't have romance no more and things like that. No romantic communication" (Annie). This occurred both because caregiving spouses felt less romantic toward their partners as they stepped into the role of caregiver and because their partners lost ability and interest in romance. Frank explained that his wife no longer showed interest in romance, "There were no more romantic moments. There weren't moments of affection. Even as far as an intimate kiss there was no more." Just as partnership was central to the marital relationship, romance and romantic communication were a core part of the marital relationship. With the romantic aspect of the marriage gone, the relationship shifted further from a marital relationship to a caregiving relationship.

**Increasingly Severe Symptoms.** The appearance of more severe symptoms solidified the shift from a marital partnership to a caregiving relationship. This turning point was specifically centered on symptoms that increased the requirements of providing care such as inability to attend to personal hygiene, incontinence, and hallucinations. These more severe symptoms made the spouses with ADRD more completely reliant on their partners.

The person can be chugging along functioning on a certain level and then suddenly an ability of some sort drops out... It's like hitting a floorboard that gives out on the floor, it's like, oh okay now we have to do this... now I'm truly caring for you. (Emily)

The appearance of these more severe symptoms increased the ADRD partners' dependence and solidified this change from spouse to caregiver. Tom told a story about realizing that his wife's ponytail had turned into a dreadlock because she was no longer capable of caring for her hair. Of this experience he said, "It was very, very upsetting because it gave a window on just how much more care was going to be required, whether it's in the bathroom, getting dressed, or helping with showering, all of that." These more severe symptoms increased caregiving spouses' load and reinforced the caregiving aspect of the relationship. This relational shift from spouse to caregiver was so complete that some caregiving spouses even used the word "patient" to refer to their partner. Garth described this change by saying, "There's no partnership in this now. It's strictly I take care of her and take care of everything around her and protect her."

### ***Relational Change 3: My Spouse is Gone***

This relational change was marked by a sense of one-sidedness because the disease had changed the ADRD spouse so completely that they were no longer present in the relationship. Many caregiving spouses conceptualized this with phrases like, "he's not the same person I married" (Wendy). Changes in personality and loss of function caused by the disease created a sense of loss for whom their spouse had been: "She is no longer the person she was. That's gone. She was a brilliant lady... now she sits there and counts buttons" (Garth). The loss of the partner with ADRD was so complete that caregiving spouses described their partners as being "gone" or having "disappeared." "It's very difficult to put in the fullest terms how someone disappears. It's like someone broke up with you and you still have to sit in the same class...your partner

disappears but is still visible” (Jane). Although their partners were still physically present, they had lost the sense of companionship and relationship. In some ways, the loss of the partner created a loss of the relationship itself. This relational change occurred through three key turning points: no more deep conversations, didn’t remember my name, and changes in living arrangements.

**No More Deep Conversations.** A major factor in this loss of the spouse with ADRD was their loss of ability to carry a conversation. “One thing that I missed was she was always able to have really good conversations and was a good sounding board...that’s probably the number one missing thing” (Michael). This loss of communication ability changed the relationship dramatically. Carol linked the loss in communication with the loss of her husband, “[he’s] not the same man I married in a way, no conversations. When you are living with somebody and you talk about everything, that is gone.” For Tom, the ability to confide in each other was a key part of marriage, and losing that ability shifted the very nature of the relationship. “The relationship is altered from one of a pair of equals, a marriage, co-counselors and co-planners of life... I miss the benefit of her counseling. You know, that’s what married people do.” Caregiving spouses greatly felt the loss of their partners’ ability to be a friend and confidant, an ability that was closely tied to the role of spouse. With their partners’ loss of communication abilities caregiving spouses felt a loss of the marriage relationship as well.

**Didn’t Remember My Name.** Although not all caregiving spouses experienced it, for the five who did, the moment when their partner forgot their name was a distinct turning point. Unlike some AD turning points, this turning point was linked to a discrete moment. Caregiving spouses could describe the exact moment when their partner first forgot their name. For Jane it happened when she and her husband were separated at the grocery store, “I could hear a

frightened man just yelling, ‘Hey you, Hey you.’ He didn’t even know my name. And that’s when it hit me how much it had progressed.” For caregiving spouses like Jane, this moment made them recognize just how much their spouse had changed and that the person they had been was gone. Michael characterized Alzheimer’s disease as “death a little at a time,” these moments created a sense of loss as if part of their partner or their relationship had died. Although many caregiving spouses anticipated that their partner might eventually forget their name it still came as a painful shock, “in 2018 was the first time that she forgot my name. I knew it was going to happen but you’re still, I still was not ready for it and it really devastated me at that moment” (Frank). The moment of forgetting was a devastating blow because it showed caregiving spouses how much they had lost.

**Changes in Living Arrangements.** Changes in living arrangements such as sleeping in different beds or moving to a care facility were physical manifestations of the loss of the partner that had already occurred. These changes came late in disease progression when greater care was required. For couples who had been together for a long time, changes in living arrangements were difficult. “The not sleeping in the same bed after 50 years, it was a major kind of a thing in our relationship” (Michael). Because physical distance was a reminder of the changes and loss in the relationship, many caregiving spouses did their best to maintain physical closeness despite changes in living arrangements. Once their partner was moved to a care facility, caregiving spouses spent large of amounts of time at the care facility with their partner. William said, “I’m there almost every day. I miss maybe a day, every two weeks or something.” Two participants even moved into assisted living with their spouses. These efforts to maintain physical closeness were one way the caregiving spouses tried to hold onto their relationships.

#### ***Relational Change 4: Transcending through Love***

Although caregiving spouses experienced difficult changes in their relationships that created distance between them and their partners, many described feeling an increase of love because of Alzheimer's disease. "I have felt more married and more in love with her than I did before the diagnosis... when something like this happens it can be in an agglomerator, it can be a glue" (Tom). Caregiving spouses found that the challenges of Alzheimer's disease reaffirmed their love and bonded them to their partners. For Kevin, seeing his wife's symptoms and knowing that their time together was limited, made him feel an increase of love, "I've been more in love with her and more concerned about her and more soulmate-ish with her." As the symptoms of Alzheimer's disease radically transformed their relationships, caregiving spouses found that they could love their partners in deeper and different ways than they had before the disease.

Caregiving spouses described this continued love in Alzheimer's disease as a different type of love than they had had earlier in their relationships. Joni explained this by describing three types of love, Eros (romantic love), Philos (friendship), and Agape (unconditional love). She said, "as Eros is fading away, Agape and Philos is increasing." Although romance was no longer present, other types of love such as friendships and commitment sustained the relationship. Speaking of the time she has spent with her husband since his diagnosis, Annie said, "In one sense, [Alzheimer's] has drawn us closer, not in a romantic way, it's just drawn us closer to be more friends and more caring for him to make sure that he's okay... we are true friends and soul mates." Love expressed through friendship and commitment sustained the relationship after romantic love had disappeared.

Many caregiving spouses reflected on their commitment to be there for their partner as a source of strength and love in providing care. “I made a promise to her for better for worse, sickness and health, until death do us part” (Frank). Reflecting on their marital commitment gave caregiving spouses determination to continue caring for their partner despite the challenges of AD. “I was here for the long haul when we got married. I’m still here for the long haul, whatever this takes” (Wendy). This commitment to be together through sickness and health gave caregiving spouses strength and satisfaction in providing care to their partners:

[Alzheimer’s disease] kind of shed a light on what marriage is... this was part of what we agreed to and I had to live up to my part of it. I’m quite proud of what I’ve done for her and I draw strength from it. (Tom)

Reflecting on their commitment to their partners helped caregiving spouses find love and satisfaction in providing care. The act of caregiving was a way that caregiving spouses demonstrated their commitment and love for their partners. Carol explained, “[caring for him] gives me satisfaction. It’s loving him.” Garth explained that providing care for his wife throughout the disease made him feel closer to her, “My relationship with my wife is probably as close now as it was at first, probably closer now than it was when we were first married.” In this way, caregiving became a form of love that drew spouses together and deepened their love despite the changes and loss of AD.

Many caregiving spouses also relied on the strength of their past relationship as a source of love in Alzheimer’s disease. “I mean, you live with somebody for 60 years, it’s different, but I don’t love her any less” (William). The strength and love that caregiving spouses developed throughout their lives together with their partners continued during the prolonged relation transition of AD. “I love my wife. I’ll always love this lady for all the years we’ve been

together” (Garth). Caregiving spouses loved their partners for who they were, and remembering their lives together increased their sense of love and affection for them. Particularly in the late stages of Alzheimer’s disease, caregiving spouses found strength and love in reflecting on their past relationship. Michael said, “The memory and love has to transcend because there’s really not the same relationship that you’ve had all your life.” Memories of the strength of the past relationship drew caregiving spouses closer to their partners and deepened their love in a tender way. “I say that that love wins because dementia will rob the brain, but I believe it doesn’t rob the heart” (Bella). Although the relationship had changed, caregiving spouses found they could love their partners in a deeper and different way.

### **Communication Strategies for Navigating the Relational Transition**

A core purpose of this study was to investigate the communication strategies caregiving spouses used to navigate the relational transition of Alzheimer’s disease and related dementias. In response to RQ2, caregiving spouses described six communication strategies that aided them in addressing the challenges of Alzheimer’s disease and maintaining companionship and closeness across the trajectory of AD. First, I will address the strategies/themes that aided participants in addressing the challenges of Alzheimer’s disease: direct and difficult conversations, avoiding confrontation, and avoiding talking about or bringing attention to Alzheimer’s disease. This will be followed by the strategies for maintaining companionship and closeness: daily activities and conversations, open and intimate conversations, and communicating love and affection.

### ***Addressing the Challenges of Alzheimer’s Disease***

An important goal of this investigation was to explore the communication strategies caregiving spouses used to manage the challenges of AD. Communication played a key role in



addressing the challenging behavioral symptoms and relational changes caused by the disease. In this respect, caregiving spouses' communication strategies ranged from open and direct (direct and difficult conversations), to indirect and avoidant (avoiding confrontation and avoiding talking about or bringing attention to Alzheimer's disease). Lack of communication was often as much a communication strategy as open conversation. I will address these different communication strategies beginning with the most direct and ending with the least.

**Direct and Difficult Conversations.** Early in the disease progression, caregiving spouses had direct and often difficult conversations with their partners to address the challenges of Alzheimer's disease. These conversations centered on sensitive topics such as the need to pursue memory testing, concerns about driving, and arranging long-term care. In describing these conversations Jennifer said, "I feel that communication, even uncomfortable, is important." For Tom, one of these conversations provided a "moment of reckoning" when he "put divorce on the table" after a year of confrontations over care with his wife's sister. Although this was a difficult conversation, it allowed his wife to decide who would care for her throughout AD and reaffirmed their commitment to facing the disease together.

In approaching these difficult conversations caregiving spouses strategically considered the best ways to address the problem at hand. Eleanor explained, "I have to stop and think how I'm gonna word things and bring it up because otherwise she feels like I'm attacking her." Emily addressed concerns about her husband's ability to drive in a way that would make sense to him, "[Safety] is kind of at the forefront of his personality, so when I put it in terms like, we don't want you to hit anyone, or get in a crash, or get disoriented, he accepted it." By adapting to the needs and concerns of their partners, these caregiving spouses were able to address the challenges of AD more successfully while reaffirming their love for their partners, "Honey, I

love you enough to make this decision that you're not comfortable with" (Jennifer). Direct and difficult conversations helped caregiving spouses resolve concerns, move forward with care, and reaffirm their love for their partners.

For a few caregiving spouses whose partners were more aggressive, direct conversations in the form of confrontation became a means of addressing the challenges of Alzheimer's disease. Wendy recalled addressing her frustration with her husband's behavior, "I said, 'this cannot continue,' I probably didn't say it in that [soft] tone of voice. I'm fully aware of the fact that I can be nasty." Although these confrontations did not serve to draw these couples closer, for caregiving spouses who described their partners as "belligerent," confrontation seemed the only way to address problems. Wendy explained that when her husband yelled, she would yell back, "I don't know that there's necessarily a way of communicating better." For Connie, engaging in confrontation served as strategy for slowing her husband's aggressive behavior:

Last week he went off about the pills and I said, "You know what? You can call the doctor... Because [doctor] will hire somebody else to come in once a day and help you take your pills. And you get to pay for it. If you want to do that, call [doctor]." He won't make any calls, but it did calm him down.

For these caregiving spouses, direct and difficult conversations in the form of confrontation were communication strategies for navigating the challenges of Alzheimer's disease.

**Avoiding Confrontation.** Although some participants turned to confrontation to address the challenges of Alzheimer's disease, all caregiving spouses mentioned the importance of avoiding confrontation with their partner. Tom explained that avoiding confrontation helped his wife function better, "The foremost thing is a healthy, at least neutral, if not happy environment... The last thing you want to do is get upset. For yourself, and for your patient, and

for anybody else in the house, stay calm.” Avoiding confrontation created an environment that helped caregiving spouses manage the challenges of AD. Eleanor described her approach to managing her wife’s aggressive behaviors, “I really try and keep things deescalated as much as possible... I just kind of shrug it off and say, forget this, I’m not going to engage.” Many caregiving spouses described using similar strategies, “I try to bite my tongue or, like I said, walk away.” (Cheryl). Avoiding confrontation helped caregiving spouses preserve a calm environment.

Avoiding confrontation meant putting up with some undesirable behaviors and symptoms of AD in order to keep the peace, “you gotta decide on the hill that you want to die on... you gotta pick the important battles” (Wendy). Annie explained that when it comes to changing clothes and showering, she takes what her husband is willing to do: “He don’t put his pajamas on no more. He sleeps in his clothes... I used to suggest ‘just put your pajamas on.’ ‘Hell no.’ So I let him do that. You know, it ain’t no big deal no more.” Avoiding confrontation over small things allowed Annie to maintain a peaceful relationship with her husband. To this end, Bella advised, “Pick your battles. You know they don’t want to shower at a certain time? Then wait and don’t fight over things that don’t need to be fought over. You just have to really be flexible.” The flexibility of avoiding confrontation helped maintain a peaceful environment, facilitated caregiving, and preserved goodwill in the relationship.

**Avoiding Talking About or Bringing Attention to Alzheimer’s Disease.** Another communication strategy caregiving spouses used to address the challenges of AD was avoiding talking about or bringing attention Alzheimer’s disease. While avoiding confrontation was a means of keeping the peace in the relationship, avoiding bringing attention to AD was done in respect of their partners’ feelings. Bella said, “I had an ah ha moment... he knows that he can’t

do things. I don't need to remind him." These caregiving spouses tried to shield their partners from the pain of thinking about Alzheimer's by avoiding pointing out the symptoms of AD. Michael explained that his wife's symptoms "weren't a problem" because he "knew the workarounds" and could manage without pointing them out. Kevin described one of these interactions:

Every time she says, "Oh, I can't remember this," or "you didn't tell me that." I say, "yeah maybe you're right, maybe I forgot to tell ya." By saying that I feel much closer to her, much more love, that I don't want to create anything that's negative in her mind.

Avoiding pointing out AD protected their spouses from pain and helped maintain closeness in the relationship.

Beyond avoiding pointing out the symptoms of Alzheimer's disease, caregiving spouses did a lot of behind the scenes work to avoid bringing attention to complications arising from AD. Several of them explained that they give written reports to the doctor so that they do not have to talk about the symptoms in front of their spouses. Annie said, "I don't like to say too much in front of the doctor with him. I don't want to put him down or anything." Garth explained, "I'm not going to say these in front of her for fear that she might catch on and she might feel bad. So rather than make her feel bad, which is a possibility, I give it in writing." Other caregiving spouses described arranging household concerns to keep their partner from worrying about them. Connie had her husband's name removed from mailed bills and statements so that he would not see them and worry about them, "I spent an inordinate amount of time trying to get his name off of anything written so that he wouldn't see it." These avoidance strategies helped minimize the impact of symptoms and put the partner with ADRD more at ease.

Avoidant communication strategies also helped preserve their spouses' independence. Jennifer explained that she takes care of tasks her husband cannot manage, while encouraging him to work on things he can, "I want to keep his world as open as possible." By avoiding drawing attention to the symptoms of AD, these caregiving spouses allowed their partner to do things independently while removing challenges they would not be able to manage. Joni said, "Try not to be his mama. You can see him doing things not quite right, but just let him either resolve it or wait for him to ask for help." By avoiding pointing out his challenges, Joni helped her husband maintain some of his independence. Through these avoidant communication strategies, caregiving spouses helped protect their partners from hurt, minimized the effects of the symptoms, and preserved their partners' independence.

### ***Maintaining Companionship and Closeness***

Just as communication played a role in addressing the challenges of Alzheimer's disease, caregiving spouses employed several communication strategies to maintain companionship and closeness in their relationships. This was essential to preserving the relationship throughout the prolonged transition of Alzheimer's disease and related dementias. Communication strategies that aided caregiving spouses in maintaining a sense of companionship or closeness with their partners were: daily conversations and activities, open and intimate conversations, and communicating love and affection.

**Daily Conversations and Activities.** Couples affected by ADRD relied on daily conversations and activities for connection and closeness. Enjoying activities together gave these couples a sense of companionship. "We do have a lot of pleasant experiences like going to the movies... or social events, either with friends, family, or I mentioned going [out] with that one support group. Things like that are positive joint experiences" (Robert). These positive joint

experiences helped bring couples together, “he’ll challenge me to some dominoes and even Scrabble still. He still does pretty good with it. That’s fun” (Joni). Cheryl shared a daily routine that helped her feel closer to her husband, “we know the old songs of the 30s, 40s, and 50s... So usually every morning I play name that tune. I play the songs and he names them.” Even after the spouse with ADRD had been moved to memory care, spending time together helped preserve closeness in the relationship, “we could sit and hold hands, play Yahtzee, you know, just enjoy our alone time” (Jane). Engaging in these daily activities helped couples affected by Alzheimer’s and related dementias maintain closeness despite the changes and challenges of the disease.

Shared pleasant activities facilitated daily conversation which also helped these couples maintain a sense of companionship. Eleanor said, “I think one of the things that I see that changes us in our communication is when we do get out and go do something, I think that helps.” Couples affected by ADRD were able to have simple daily conversations about family and friends, daily activities, and faith. Several caregiving spouses turned to humor in their daily conversations. Garth explained, “a sense of humor always helps. If I can get her to laugh and goof around... She’ll laugh and I’ll laugh and maybe get something out of it that can be funny.” These moments of shared laughter brought couples affected by ADRD closer together. Carol also found ways to bring humor into her daily routines, “when I was dressing him, I’d be putting his socks on and I said, Oh my God, I’m so glad you’re not a centipede. And so that always made him laugh.” Jennifer referred to the positive shared moments with her husband as “the little victories, the little highlights” that she held onto to sustain them.

Later in the progression of the disease when conversations became more difficult, caregiving spouses still “went through the motions” of conversation with their partners. Frank explained his experience with communication after his wife had lost the ability to speak clearly,

“I would just pretend that I understood and had a communication and tried to communicate the best I could for her.” Although the regular flow of conversation had been disrupted by the symptoms of Alzheimer’s, these attempts at communication helped preserve a sense of continued connection. Michael explained, “My objective is simply to have happy moments. If I can get a happy moment, a smile... it’s probably the prime objective. So you try a lot of different things to communicate” (Michael). In this way, simple conversations helped maintain companionship and closeness across the prolonged relational transition of Alzheimer’s disease and related dementias.

**Open and Intimate Conversations.** The second way that caregiving spouses used communication to maintain companionship and closeness was through open and intimate conversations about Alzheimer’s disease. Not all participants had conversations like these with their spouses; in fact, some wished to have an open conversation about the disease but had little cooperation from their spouse. For those who did, open and intimate conversations about Alzheimer disease served to strengthen the relationship:

It was probably one of the most intimate conversations we’ve had because we were addressing deep emotions... it gave us time to cement that closeness we had when we were first together. It went to a deeper level that I could assure him that I would never abandon him. (Jane)

These open and intimate conversations occurred earlier in the disease progression when deep conversation was still possible and helped each spouse better understand the other. For Eleanor and her wife, open conversations about end of life care helped them face the future together. She said, “Our conversations just kind of brought us together. We’re all on the same page.” Through these open and intimate conversations about the disease, couples affected by ADRD could

reaffirm their love, address their fears and uncertainties, and strengthen their resolve to move forward together.

**Communicating Love and Affection.** Unlike the other communications strategies addressed in this section, communicating love and affection was both a communication strategy that caregiving spouses used to maintain closeness in their relationships, and a communication behavior they received from their partners that facilitated the goal of maintaining relationship in Alzheimer's disease. Expressing love and affection helped couples affected by ADRD to maintain closeness throughout the progression of the disease. "We exchange 'I love you' often... it brings us closer when we do that" (Carol). The knowledge that their partners loved them was a strengthening force for caregiving spouses. For some, expressions of love and affection became a tradition of communication throughout their Alzheimer's journey. Bella would hug her husband and ask, "who loves you baby?" while Carol and her husband would hold their arms wide and say, "I love you this much." By communicating love, caregiving spouses were able to reassure their partners. "I tell him, as long as I live, I'm not going to leave you" (Annie). Expressions of support and love such as these helped couples affected by ADRD to feel close.

Couples expressed affection in more ways than saying "I love you." Jennifer said, "in your tone, in your subject matter, in your facial expression, all of those levels of communication, you just express love." Expressions of love and affection came through being patient, apologizing, asking for forgiveness, forgiving, saying thank you, and being empathetic. "I made a conscientious effort to be not only cheerful but just be empathetic, being more sensitive to his needs" (Jane). These expressions of love helped caregiving spouses to bridge the gaps in their relationship and to maintain harmony despite the challenging symptoms of AD. Even when recalling some of the difficult times in their relationship Bella was comforted by remembering



her husband's love, "he was always loving, always forgiving." Describing his interactions with his wife, Michael said, "it was a communication, it was patience and understanding."

Caregiving spouses and their partner also communicated love and affection through non-verbal channels. Gentle and affectionate touch provided important expressions of love, "At nighttime, sometimes she'll reach over and pat my hand or my arm just to let me know that she's there and that she knows that I'm there and that's good" (Garth). Tom described the way he used "physical manifestations of care" to communicate love for his wife, "I brush her hair and cut her nails, and it's a way for me to love her and let her know that she's cared for." Nonverbal expressions of affection and love were even more important as the disease symptoms became more severe. Bella explained that when her husband was in the end stages of Alzheimer's they could communicate love without speaking, "we don't necessarily need words because our hearts are talking to each other." These nonverbal expressions of love and affection helped maintain a sense of closeness in the relationship despite the drastic changes caused by the disease. Frank explained that although his wife could no longer see him or speak, they still expressed their love in their own ways, "I said, I love you and she'd automatically smile because she knew my voice...She couldn't say anything, but that's okay. The smile was worth a thousand words." These sustained expressions of love, especially in the end stages of the disease, helped couples maintain a sense of closeness and relationship throughout the relational transition.

### **Interfering and Facilitative Communication of Partners with Alzheimer's Disease**

To gain a complete understanding of relational communication in Alzheimer's disease and related dementias, this investigation also addressed the facilitative and interfering role of the communication of the partners with ADRD across this prolonged relational transition (RQ4). In RTT, partner influence in the form of interference and facilitation are a core part of relating and

contribute to the experience of relational turbulence during transition (Solomon et al., 2016). Caregiving spouses perceived partner facilitation and interference on two levels, both in facilitating or interfering with daily task and goals and more broadly in facilitating or interfering with the goal of maintaining relationship throughout Alzheimer's disease. Daily facilitation/interference compounded to create a broader experience of relational closeness or strain. Because their partners were constantly being changed by the disease, caregiving spouses described their communication and behaviors within the context of the disease, acknowledging that although many of their partners' behaviors were shaped by the symptoms of the disease they could still be perceived as interference or facilitation. In addition to communicating love and affection (reported above), the facilitating and interfering communication behaviors of spouses with ADRD are presented as follows: symptoms create distance in the relationship, facilitating daily tasks, aggressive behaviors strain the relationship, and preserving the past.

### ***Symptoms Create Distance in the Relationship***

Symptomatic behaviors were a main source of interference for caregiving spouses. "She's not a neutral force in all of this, [she's] a negative force because she's being impacted by the illness all the time. She doesn't mean to, but she often brings us down" (Tom). Although caregiving spouses knew that their partners were not intentionally creating these behaviors, they still interfered with daily tasks and strained the relationship. Robert described the symptoms of AD as "a lot of annoyances." These included losing things or putting them in the wrong spot, losing sense of time, difficulty with driving, sleeping more than usual, wandering off, loss of sexual drive, obsessive behaviors, and becoming agitated or confused. Of these symptomatic behaviors Eleanor said, "they're little things, but they change how we interact." At the heart of it,

these symptomatic behaviors shifted the relationship because they changed the way couples interacted.

Many of the interfering symptoms related directly to communication and interaction. Most prominently, caregiving spouses described their frustration with the repetitive nature of conversation: “Our conversations are basically the same thing over, and over, and over, and over again” (Joni); “I just get tired of repeating and repeating” (Wendy); “Long term memory is there. It’s just the short-term stuff that drives me crazy” (Cheryl). This forgetfulness in conversation made daily interactions more frustrating, but also made it difficult to have longer more meaningful conversations. Robert described his wife’s confusion when he tried to share a piece of good news. He said, “it’s hard to have a long conversation about something that she can’t remember... even [positive experiences] we can’t always share.” Beyond the frustration of daily conversations, this forgetfulness in conversation hampered their ability to have meaningful conversations together.

These communication symptoms also made it difficult for the ADRD partners to express themselves. Emily described this challenge, “it’s like trying to talk through honey or cobwebs.” These difficulties with communicating made conversations less common and less in depth. This was a difficult change for caregiving spouses, “I wanted him to communicate with me, but he didn’t” (Bella). This made caregiving spouses feel more distant because they wanted to be able to discuss the challenges of the disease. Joni said, “I wish he would be able to talk more about his feelings and concerns and fears.” Beyond the frustration of repetitive questions and conversations, the communication-related symptoms of Alzheimer’s interfered with relationships because they made it difficult to maintain closeness through conversation. Emily summed up these challenges in this way, “it’s just increasingly sad, and increasingly frustrating.”

### ***Facilitating Daily Tasks***

While the symptoms of the disease were a source of daily interference to caregiving spouses, the partners with ADRD also communicated and behaved in ways that facilitated daily tasks. These daily aspects of facilitation helped preserve the relationship by making the work of providing care easier and increasing reciprocity and appreciation in the relationship. Early in the disease progression this was done through expressing appreciation and helping out and later in disease progression this was through being cooperative (not combative).

**Expressing Appreciation and Helping Out.** Spouses with ADRD facilitated the relationship by expressing appreciation and helping out around the house. This was particularly impactful for caregiving spouses who were taking on greater responsibilities with the progression of symptoms. Jennifer described her husband's appreciation and willingness to help out around the house shortly following his diagnosis:

I think he's become more appreciative...He tells me every night whenever I cook, "thank you so much"... he appreciates those things that he probably wouldn't have before...

And before if I was the unloading the dishwasher, *I* was unloading the dishwasher. Now when he hears me open the door, he comes to help me.

Her husband's expressions of appreciation and willingness to help with daily chores created a sense of cooperation and goodwill in their relationship. Partners with ADRD were able to lighten the load for caregiving spouses through their willingness to help out, even in small ways such as making the morning coffee, taking out the trash, and cleaning. Joni was very appreciative of the help her husband gave around the house:

He is excellent about washing the dishes, making up the bed, vacuuming, cleaning the bathroom. ... he says, "you know, it would be just so wrong of me to just sit here all day

while you workin' and then you've got to cook and clean too." He said, "at least I can do this." It's like, "Thank you. Bless you. I can sit down and relax for a minute. Thank you!"

These expressions of appreciation and effort to help out around the house preserved some of the reciprocity of the relationship, lightened the load of caregiving spouses, and increased goodwill within the relationship.

**Cooperative (Not Combative).** Later in the disease progression, many spouses with ADRD were no longer able to help out around the house, but they still facilitated daily tasks by being cooperative. Many caregiving spouses mentioned the importance of their partners' easy cooperation in facilitating the day to day functioning. "She just rolls along with whatever's going on, whatever the program is, she's with it" (Garth). ADRD spouses' easy cooperation made it much easier to manage the symptoms and changes of the disease. William described how his wife's agreeable nature made the transition to not driving much easier, "I don't feel there ever was any friction or any, 'you won't let me drive because you don't trust me.'" Caregiving spouses were very appreciative of their spouses' willingness to cooperate without confrontation. Michael explained, "she didn't get antagonistic or anything... she was a princess in every way." The lack of confrontation in the relationship helped preserve harmony despite the challenging symptoms and changes of Alzheimer's disease.

This appreciation for the easy cooperation of their partners seemed to be derived from comparison to other couples affected by ADRD. Annie said, "From listening to other people and reading other information, I know it could be worse, but it's pretty good for the most part." Caregiving spouses often emphasized their partner's amiable qualities in contrast to what they *could* be: "She is, you know, a delightful person. She was sweet and kind, and she's more sweet and kind. Sometimes they can get a little loopy and they hit people and get crabby. She's not like

that” (Tom). Similarly, Jane contrasted her husband with a hypothetical dementia patient, “He was never that combative dementia patient that we hear about; he was not that unruly one. He was a sweet guy.” By focusing not only on their partner’s good behavior and qualities but also on how bad they could be, caregiving spouses came to appreciate their partners’ cooperative behaviors as facilitating the daily functioning of the relationship.

### ***Aggressive Behaviors Strain the Relationship***

While cooperative behaviors facilitated daily functioning and maintenance of the relationship, aggressive behaviors were a severe interference to daily functioning and to maintaining relationship in Alzheimer’s disease. Caregiving spouses described these behaviors with phrases like “verbally belligerent,” “blows up,” “got nasty,” “angry attack,” “goes crazy,” and “adult temper tantrum.” The aggressive behavior of spouses with ADRD made it difficult to provide care and to complete daily tasks. The repeated interference with daily tasks from their partners’ aggressive behavior compounded to create frustration and strain in the relationship. Connie described her husband’s aggressive behavior when he forgot that he had opened his mail: “He just kind of goes crazy... He said, ‘Do you have any other mail that you opened for me that should have gone to me?’ Screaming and yelling, ‘You opened some of my mail!’” Although not the cause of the aggression, as seen in this interaction, forgetfulness created situations in which the partner with ADRD acted aggressively. Joni explained that one of the greatest challenges in her relationship was that her husband has become “more aggressive with sex” because he could not remember the last time they had it. For Joni and other caregiving spouses, aggressive behavior was made more difficult because their partners were unwilling or unable to address the behavior. Joni explained, “I can’t talk to him about [his behavior] unless he’s real upset and blows up and then I have to defend myself.” Eleanor described her partners aggressive behavior

by saying, “it’s almost like the cycle of abuse.” These aggressive behaviors were hurtful to caregiving spouses and strained the relationship.

Their partners’ aggressive behavior often seemed to be tied to an inability to recognize or accept the fact that they had Alzheimer’s disease. This made it quite difficult to address problems related to AD, “anytime I mentioned memory she would be very defensive” (Garth). Both Connie’s and Wendy’s husbands became so belligerent and uncooperative with memory testing that they were unable to get a clear diagnosis beyond knowing that it was dementia. Connie explained, “In his mind he has no problems... he can’t accept anything.” This lack of acceptance led their husbands to blame their problems and symptoms on others, usually on the caregiving spouse. Wendy said that her husband believed that she had “manufactured this whole thing and it was [her] fault.” Denial and blame led to increased aggressive behavior:

His attitude has become so argumentative and so belligerent, not physically but verbally.

And he would be screaming at the dogs because they were in his way or because they were making dog noises... it was either their fault or my fault. And the only relief was that when he was yelling at the dogs, it wasn’t my fault.

Although these were two extreme cases of denial and belligerence, aggressive behavior was a difficulty for many caregiving spouses and was often exacerbated by denial of Alzheimer’s disease. Denial and aggression limited opportunities for meaningful conversation about the disease and cause hurt that damaged the relationship.

### ***Preserving the Past***

Caregiving spouses found that it facilitated their relationships when their partners behaved and communicated in ways that preserved their past relationship. For some, this was just about remembering the past. Jane said, “he would try to make me happy too in his limited way

by remembering.” Others appreciated moments when their partners behaved in ways that were characteristic of them before the symptoms of Alzheimer’s set in, “it’s like, ah, it’s my husband back” (Joni). These moments were powerful because they reminded caregiving spouses of the strength of their relationships prior to the disease. Emily described it this way, “it’s sort of like getting the old person back when they can sort of suddenly kick into awareness or that wisdom shows up... it just makes me pause and remember that part of him that I love so much.” These moments when “the old person is back” helped preserve the love and strength of the past relationship.

Later in the disease progression, spouses with ADRD preserved the past by continuing to recognize their loved ones. This continued recognition was very important for caregiving spouses. Bella said, “I feel blessed that he did know us right to the end.” Similarly, Frank took comfort in knowing that his wife knew his voice till the end of her life. Seeing his wife’s recognition gave Garth a lot of satisfaction, “She looks up with a big smile on her face because here I am coming through the door. So that’s a great feeling to see her like that, that she knows who I am. That’s a great feeling.” Being recognized by their spouse seemed to preserve the relationship in a way. Jane, whose husband did not recognize her said that the disconnect from him forgetting was the hardest part of Alzheimer’s disease. Although spouses with ADRD were not in control of these moments of preserving the relationship, they were valuable to caregiving spouses and facilitated a continued sense of relationship.

### **Discussion**

A growing body of literature addresses the relational changes caused by Alzheimer’s disease and related dementias. This literature broadly frames Alzheimer’s as a time of loss and decline in relationships, yet scholars have identified both positive and negative aspects of this relational transition (see Ablitt et al., 2009; Conway et al., 2018). This study sheds light on the



complex relational changes caused by Alzheimer's disease and related dementias by providing a closer look at the relational turning points and the communication that shape this transition (see Table 6). The use of relational turbulence theory as a guiding framework provides insight into the facilitative and interfering role of communication in maintaining relational connection and addressing relational challenges and uncertainties across the trajectory of the disease. In this section, I will situate these findings in the broader theoretical discussion beginning with findings about relational turning points, followed by a discussion of relational uncertainty, and concluding with the communicative findings.

### **Relational Turning Points and Relationship Transformation in Alzheimer's Disease**

The relational transition caused by Alzheimer's disease and related dementias is unique because the symptoms continually change the relationship across the trajectory of the disease and because it ends with death. Previous work with RTT has investigated discrete events that create a relational transition such as the birth of a child (Theiss et al., 2013) or a partners return from deployment (Knobloch et al., 2018). While adjusting to these events may take time, it is expected that the relationship settles into a sense of normalcy after a period of adjustment. Contrastingly, as an end of life transition, there is no return to normal in the relationships of couples affected by Alzheimer's disease and related dementias. The prolonged relational transition of AD requires continued adjustment as the symptoms intensify throughout the disease trajectory. Solomon et al., (2016) have explained, "A relational transition ends not when the emergent conditions subside, but when partners establish patterns of relating that are adapted to their new circumstances" (p. 510). Unlike many relational transitions, the goal of relational adaptation in Alzheimer's disease is not to bring the relationship back into a state of normalcy but to maintain a sense of connection, despite the ever-changing symptoms, until the relationship ends with death.

**Table 6***Overlapping and Interrelated Findings*

Turning Points	Relational Uncertainty			Caregiving Spouses' Communication Strategies					Partner's Facilitative & Interfering Communication					
	Partner-Uncertain.	Self-Uncertain.	Relation-Certain.	Direct & Difficult Convos	Avoiding Confront.	Avoid Talking about AD	Daily Convo & Activities	Open & Intimate Convos	Love & Affection	Distance from Symptoms	Appreciate & Helping	Aggressive Behavior	Cooperate	Preserve the Past
Early Symptoms Strain	X			X						X		X		
Spouses' Diagnosis	X	X	X	X				X	X					
Loss of Driving Privileges				X		X		X		X		X	X	
Shifting Household Roles		X			X	X				X	X			
No More Romance			X				X			X	X	X		
Increasingly Severe Symptoms	X	X	X		X	X			X	X		X	X	X
No More Deep Convos.			X				X		X	X				
Didn't Remember my Name	X	X	X							X				X
Changes in Living		X								X			X	
Transcend through Love							X		X					X

*Note.* This table shows the uncertainty and communication strategies that play a role in shaping or navigating each relational turning point.

Relational turning points detail the numerous ways relationships shift across the disease trajectory and provide necessary insight into couples' experiences of turbulence and efforts to maintain connection throughout this unique relational transition. Relational turning point research has demonstrated that individuals can identify discrete communicative and relational moments that shifted their relationships either increasing or decreasing their commitment and closeness (Baxter & Bullis, 1986). This body of research often centers on the relational changes that occur in developing relationships (see Docan-Morgan & Manusov, 2009; Huston et al., 1981) but this investigation of relational turning points in AD sheds light on the relational transformation that can occur in well-established relationships. The four relational changes identified here, my spouse has Alzheimer's disease, from spouse to caregiver, my spouse is gone, and transcending through love were shaped by several distinct relational turning points and provide insight into the relational experiences and relational management across the prolonged transition.

The relational turning points caused by early symptoms and the diagnosis of AD created the first relational change, my spouse has Alzheimer's disease. This period of the relational transition coincided with a period of pronounced relational uncertainty. Caregiving spouses reported that early symptoms strained the relationship because they could not understand their partners' behavior. During this time couples experienced "misreadings," tension, and loss of trust. RTT proposes that a global sense of relational uncertainty limits individuals' ability to interpret specific communication episodes and leads to biased appraisals of their partners' communication and behavior (Solomon et al., 2016). The relational turning point caused by early symptoms created turbulence and strained the relationship because caregiving spouses had difficulty interpreting and understanding their partner's behavior. Relational uncertainty

increases topic avoidance and constrains communication, especially on sensitive issues (Knobloch et al., 2016). The diagnosis with Alzheimer's or a related dementia provided an explanation for the partner's behavior and reduced relational uncertainty. Although this turning point introduced new uncertainties about the disease, the diagnosis also opened the way for couples to engage in open and intimate conversations. Leustek and Theiss (2018) found that relational uncertainty was a stronger predictor of topic avoidance than disease uncertainty, thus the transfer from relational uncertainty about their partner's behavior to disease uncertainty at the diagnosis may have opened the door for intimate and vulnerable conversations. These conversations enabled couples to reaffirm their commitment and draw closer in the face of the disease. Knowledge of the realities of Alzheimer's disease created new unique relational uncertainties that will be discussed in further detail in the relational uncertainty section.

The relational change from spouse to caregiver represents the change from a partnership to a more one-sided relationship. This change is common in Alzheimer's literature (Evans & Lee, 2014), but understanding the distinct relational turning points that shape this change provides insight into how it occurs and the role of communication in shaping and navigating this period of transition. This relational change occurred through a series of relational turning points (loss of driving privileges, shifting household responsibilities, no more romance, and increasingly severe symptoms) as the partner with ADRD lost the ability to function independently. This occurred both physically as PWD lost functionality and communicatively as conversation became less representative of an equal partnership. Relational communication, such as consulting and counseling with the partner or communicating romantically, became less common as couples progressed through these turning points and communication such as monitoring and instructing became more common. For example, discussions about their partners'

driving ability put the caregiving spouses in a position of supervising their partners and diminished the sense of equal partnership in the relationship. The loss of independence throughout these turning points also resulted in the loss of interdependence because the partner with ADRD was no longer capable of acting or communicating as an equal partner in the relationship. Interdependence is a core aspect of relating in close relationships (Solomon & Knobloch, 2004; Solomon et al., 2016) and these changes in interdependence created a sense of turbulence. This loss of interdependence drove the change from a marriage to a caregiving relationship.

The third relational change, my spouse is gone, provided insight into the experience of relational loss in Alzheimer's disease and related dementias. One participant conceptualized this by describing Alzheimer's as two deaths; the first death occurs when the partner is transformed by the symptoms of AD, and the second occurs when they die. This first death was shaped by the loss of communication (no more deep conversations), memory (didn't remember my name), and physical proximity (changes in living arrangements). Meaningful, mutually disclosive, conversations promote relational satisfaction and closeness (Lippert & Prager, 2001), and lack of meaningful communication in AD has been shown to disrupt marital closeness (Boylstein & Hayes, 2012). This study extended this research, connecting the loss of deep reciprocal conversations to loss of the partner. Participants described their partners as "co-planners of life" (Tom) and "fox-hole buddies" (Michael) they could rely on and confide in. The loss of deep reciprocal conversations amounted to the loss of this aspect partnership. The turning point when the ADRD spouse forgot their partner's name amplified the sense of loss in the relationship because, beyond losing the ability to be a confidant and friend, the partner with ADRD could no longer remember or fulfil their place as a partner. Finally, the turning point caused by changes in

living arrangements solidified the sense of losing the partner by inserting physical distance between the couple. In contrast to research on relational dissolution dissolution turning points which focus on the eventual separation of partners and termination of relationship (see Johnson et al., 2004; Lloyd & Cate, 1985), these turning points represent the disappearance of partnership within ongoing relationships.

The fourth and final relational change, transcending through love, sheds light on the ability to adapt and maintain closeness despite the difficult relational changes of Alzheimer's disease. Relational turning points research demonstrates that relational development is not linear but reflects a process of negotiating tension between both development and deterioration (Baxter & Erbert, 1999; Johnson et al., 2003). Caregiving spouses described both the sense that their partners had disappeared and a continued and even growing sense of love throughout the transition. This demonstrates the tension between relational development and deterioration in this period of relational change and caregiving spouses' ability to hold together both growth and decline in maintaining a sense of closeness in their relationships. Caregiving spouses were able to reconstruct a sense of couplehood (Boylstein & Hayes, 2012) by thinking of love in Alzheimer's as a "different type of love," drawing strength from their commitment, and remembering the goodness of the pre-Alzheimer's relationship. In this way, caregiving spouses were able to transcend the change and loss of Alzheimer's disease through love and maintain a sense of love and connection throughout the prolonged relational transition.

### **Relational Uncertainty and Certainty in Alzheimer's Disease**

The experience of relational uncertainty in Alzheimer's disease was shaped by the certainty of cognitive decline and eventual death from AD. Relational uncertainty encompasses individuals' concerns about the nature and future of their relationships and is derived from three sources, partner-uncertainty, self-uncertainty, and relationship-uncertainty (Solomon et al.,

2016). Although the timing of decline in Alzheimer's disease and related dementias varies, the knowledge that their partners would experience cognitive decline and eventually die created a unique interplay of certainty and uncertainty for caregiving spouses. Amidst the certainty of decline and death, caregiving spouses faced uncertainty about how their partners and relationships would be changed by the disease. This interplay of certainty and uncertainty created a unique experience of relational uncertainty. In this section, I will situate the experience of relational uncertainty in AD within relational turbulence theory. I will then address the implications of relational uncertainty for communicative and relational management in Alzheimer's disease and related dementias.

The certainty of cognitive decline and eventual relational change in Alzheimer's disease created a shift in the temporal focus of relational uncertainty which distinguished the experience of relational uncertainty in AD from traditional conceptualizations of this construct. Relational uncertainty is generally centered on individuals' concerns about the qualities of their current relationship and whether the current relationship will last (Solomon et al., 2016).

Operationalizations of self- and partner-uncertainty focus on individuals' questions about their own and their partner's current feelings about, and involvement in, the relationship (Knobloch & Solomon, 1999; Solomon & Brisini, 2017). Contrastingly, caregiving spouses' partner-uncertainty (I don't know who my partner will become) and self-uncertainty (I don't know if I can make it through this) were not about current involvement in the relationship, but focused instead on relational involvement in a future relational period effected by the symptoms of Alzheimer's disease. The certainty of decline focused participants' uncertainty on concerns about who their partner would become in the relationship when affected by ADRD and how they, personally, would respond to these changes. Similarly, while relationship-uncertainty generally

focuses on the nature of the current relationship and its likelihood of continuing (Solomon & Brisini, 2017), relationship-(un)certainty in AD (relationship change and loss are certain) focused on the certainty that the nature of the relationship would be drastically changed and that the relationship would end with death. Interestingly, even participants whose partners had already died described their experience of relational uncertainty in AD with this future focus.

The certainty that the PWD would be changed by the symptoms of the disease was at the heart of partner-uncertainty in Alzheimer's disease. Although the symptoms and irregularities of the disease are a main source of uncertainty in Alzheimer's disease (Stone & Jones, 2009), using the lens of RTT made it clear that these uncertainties are at once relational and about the disease. Participants' experience of partner-uncertainty, I don't know who my partner will become, was centered in uncertainty about how the disease would change their partners physically, cognitively, and emotionally (disease uncertainty), but also how these changes would affect their partners interest in and ability to be involved in the relationship. Thus, the heart of relational uncertainty was how the partner's relational involvement might be affected when they eventually became a "completely different person" (Emily) through the symptoms of AD.

The future focus of relational uncertainty in AD was particularly noticeable in the experience of self-uncertainty, I don't know if I can make it through this. Traditionally, self-uncertainty encompasses individuals' questions about their own commitment to and feelings about their partner and relationship (Knobloch & Solomon, 1999; Solomon & Brisini, 2017). Yet, in anticipating the cognitive decline of their partners, caregiving spouses experienced uncertainty not only about their future commitment and feelings toward their relationship, but also about their *ability* to provide care, to feel love for their partner, and to endure the challenge of watching their partner change. This additional aspect of self-uncertainty about one's ability to



manage a difficult relational transition may be unique to end of life relational transitions that shift the relationship so dramatically toward caregiving. Certainty of a difficult relational future introduces concern that regardless of how they felt about their partner and their relationship they might not be able to make it through the transition.

The interplay between certainty and uncertainty and the temporal aspect of relational uncertainty in AD shaped caregiving spouses' responses to relationship uncertainty. Rather than expressing concerns about the nature and future of the relationship (Knobloch & Solomon, 1999; Solomon & Brisini, 2017), caregiving spouses described their expectation that future relationship change and loss are certain. While in some relational contexts maintaining relational uncertainty is preferable to reducing uncertainty (see Mikucki-Enyart & Caughlin, 2018), caregiving spouses neither tried to reduce nor maintain relational uncertainty. Rather, they focused attention away from the future certainties and uncertainties of Alzheimer's disease and focused instead on the good of the present moment. Considering the future-focus nature of self- and partner-uncertainty, this focus on the present moment makes a lot of sense. Although caregiving spouses acknowledged the reality of death and relational decline, focusing their attention away from their uncertainties about the future enabled them to enjoy the current relational moment and manage their uncertainties about the future. This is similar to Scharp et al.'s (2020) finding that taking a break from focusing on uncertainty can help individuals manage their uncertainties. Rather than focusing on future uncertainty, caregiving spouses focused their attention on the good of their everyday interactions and current relationship with their partners.

These efforts to focus attention on the present were reflected in caregiving spouses' use of communication across the disease trajectory. Research with RTT has found that relational uncertainty spurs topic avoidance (Knobloch & Carpenter-Theune, 2004; Knobloch et al., 2016;

Theiss & Nagy, 2012). Rather than discussing the changes they expected to eventually see in their relationships, caregiving spouses focused their conversations and their interactions with their partners on the present moment. Several caregiving spouses explained that they focused on the positive activities and daily conversations that they could still share with their partner, regardless of what the future of the relationship would look like. Using humor, finding the positive moments, and sharing activities helped couples maintain the sense of relationship. Prior research has established shared activities as a resource for maintaining relational closeness in AD (Boylstein & Hayes, 2012; Wadham et al., 2016), and this was reaffirmed here. Focusing on shared activities and daily conversations helped couples affected by AD maintain a sense of companionship and focus on the present state of their relationships. Even in the late stages of Alzheimer's disease, going through the motions of conversation and spending time together strengthened the relationship.

### **Communication Shapes the Relational Transition**

Investigating communication in Alzheimer's disease through the lens of relational turbulence theory provided insight into how couples' daily interactions and behavior shape the relational turning points and changes that occurred across this prolonged transition. Grounded in the RTT concepts of facilitation and interference, this section will address the communication of both caregiving spouses and their partners. The communication and behavior of partners with ADRD facilitated and interfered with daily activities and the relationship as a whole. Caregiving spouses employed several communication strategies to address the challenges of AD and maintain companionship and closeness. These aspects of communication played a role in forming and adapting to the relational turning points across the disease trajectory.

Daily experiences of facilitation and interference were impactful in shifting the relationship from spouse to caregiver. RTT proposes that interruptions of daily activities in the form of interference and facilitation lead to a state of heightened emotional arousal that makes individuals more sensitive to their partner's behavior (Solomon et al., 2016). Repeated instances of interference/facilitation of daily activities likely compounded to make caregiving spouses more sensitive to their partners' behavior, amplifying their awareness of the changes occurring in their relationships. Caregiving spouses reported that their partners facilitated daily tasks through expressing appreciation and helping out, and they interfered with daily tasks through aggressive and symptomatic behaviors. The experience of the interference/facilitation of daily tasks was intricately tied to the turning points, shifting roles and responsibilities and increasingly severe symptoms, that drove the change from spouses to caregiver. For example, spouses with ADRD facilitated daily tasks by helping with household chores like taking out the trash or making the bed. This behavior was helpful but also drew attention to the many other responsibilities caregiving spouses had already taken on with the shift of household responsibilities. Similarly, daily interference caused by symptomatic behaviors were repeated reminders of their partners' increasingly severe symptoms and the changes occurring within the relationship. Thus, it was through these daily instances of interference/facilitation that caregiving spouses experienced the shift from spouse to caregiver.

Interfering communication also played a role in the loss of deep conversation which contributed to the relational change, my spouse is gone. Interference through communication-related symptoms reduced PWD's ability to engage in deep conversation, and interference through aggressive behavior diminished caregiving spouses' willingness to engage in conversation with their partners. Partner interference is associated with reduced openness in

communication and increased aggressiveness (Theiss & Knobloch, 2013). Avoiding confrontation with their partners was a common way that caregiving spouses managed challenging relational moments. They chose to ignore, leave the room, or suppress irritated responses when their partners exhibited frustrating symptoms or behaved aggressively. Interference also increases the perceived hurtfulness of the partner's communication (Theiss et al., 2009). For caregiving spouses, repeated instances of partner interference likely amplified the hurtfulness of their partner's aggressive behavior. Under these conditions, a few caregiving spouses reported turning to direct confrontation to address their partner's aggressive behavior. Together, interference through PWD's communication-related symptoms and aggressive behavior, paired with caregiving spouses' avoidant and confrontational management of these behaviors, led to the loss of deep conversation that contributed to the loss of the partner in AD.

Increased arousal and reactivity from partner interference and facilitation also provides insight into a unique finding regarding facilitation. Facilitative behaviors are often normalized in relationships and therefore become less arousing or noticeable to relational partners (Solomon et al., 2016). Yet, caregiving spouses identified seemingly small, almost unnoticeable, aspects of their partners' communication such as smiling, saying thank you, and being cooperative as facilitation. Caregiving spouses viewed their partners' cooperative (not combative) behavior as facilitation, but only in contrast to the combative behavior they had heard of other PWD exhibiting. While this may be rooted in participants' engagement with local support groups, it is still notable that caregiving spouses considered the absence of aggressive behavior as facilitating daily tasks and the relationship. This propensity to view small behaviors, and even the lack of behavior, as facilitative may reflect the tendency for individuals to become more vigilant about their relationships during times of heightened relational turbulence (Knobloch et al., 2018).

Solomon and Priem, (2016) found that relational turbulence increased perceptions of partner supportiveness directly following a high-stress experience. It is possible that due to the highly turbulent nature of relationships in Alzheimer's disease, caregiving spouses might have been extra sensitive to the supportive and facilitative behaviors of their partners.

Communication that facilitated the goal of maintaining relationship in AD contributed to the relational change, transcending through love. These aspects of communication, daily conversations and activities, preserving the past, and communicating love and affection, moved beyond facilitating daily goals to facilitate the goal of sustaining relational connection in AD. Sharing daily conversations and activities helped caregiving spouses maintain friendship with their partners. These friendships constituted the "different type of love" caregiving spouses developed in Alzheimer's disease which helped them maintain connection in AD. Within these daily conversations, caregiving spouses found it particularly facilitative when their partners preserved the past by reminiscing about their life together. Reminiscing and relying on the strength of the past relationship were core parts of transcending through love, and moments when their partners remembered the past helped caregiving spouses recall the goodness of their relationships before the disease. For caregiving spouses, both communicating love and affection to their partners and receiving love and affection from their partners facilitated the goal of maintaining relationship. Both giving and receiving affection have been shown to increase relational satisfaction (Floyd et al., 2005), and both help caregiving spouses cultivate a sense of love in their relationships. These types of facilitative communication help caregiving spouses transcend the relational change and loss and maintain relationship throughout the prolonged relational transition of Alzheimer's disease and related dementias.

Although avoidant communication is often found to be a negative effect of relational uncertainty and interference (see Knobloch et al., 2013; Theiss & Nagy, 2012), avoidant communication also facilitated the goal of preserving the relationship in Alzheimer's disease. Caregiving spouses avoided talking about or bringing attention to AD to maintain harmony in the relationship, shield their partner from the reality of the disease, and keep their partner's world open by finding ways for them to contribute and be independent. One strategy for maintaining relationship was adjusting behavior to the needs and abilities of the PWD (Wadham et al., 2016). Avoidant communication strategies were a key part of this. Both in topic avoidance and in working behind the scenes to create opportunities and mitigate the challenges their partner might face. These efforts to shield their partner from Alzheimer's disease and to keep their world open also served to protect the identity of the spouse with ADRD and promote their wellbeing and functioning (Conway et al., 2018; Kitwood, 1997).

### **Extending Theory to an End of Life Context**

This study provides a potentially fruitful extension of relational turbulence theory and relational turning points research by applying these frameworks as a means of understanding the relational experiences of an end of life transition. Communication and relationships are central to the end of life transition (Prince-Paul & Exline, 2010), yet few communication theories take a lifespan perspective to include the end of life experience. The lifespan perspective asserts that growth and development occur throughout the life course and that development is "best viewed as a gain/loss dynamic" (Nussbaum et al., 2002, p. 359). Approaching RTT and relational turning points research with a lifespan perspective requires anticipating both relational growth and decline in this end of life transition. By extending these frameworks to an end of life context,

this study clarifies areas for consideration in adding a lifespan perspective to these bodies of research.

With regard to relational turning points, this study provides insight into the unique relational trajectory of romantic relationships in an end of life context. Relational turning points research has provided insight into the early development of romantic relationships (Baxter & Bullis, 1986) and the decline of romantic relationships (Lloyd & Cate, 1985). However, in many romantic relationships, particularly marriage, the goal is long-term relational commitment with the relationship lasting to the death of one of the partners. Applying a lifespan perspective to relational turning points research extends the scope of this body of research to include the growth and decline that occur in the final, end of life, period of relationship development. Although Alzheimer's disease and related dementias create a unique relational transition, this study provides a first step in understanding the relational development and deterioration that occur in relationships that end with the death of a partner.

Applying a lifespan perspective to relational turbulence theory extends the theory by showing how relational uncertainty and partner influence are experienced in an end of life transition. The certainty of death in this end of life relational transition shifted relational uncertainty in ways that were distinct from those in other relational periods. End of life transitions provide a unique space to investigate the interplay between certainty and uncertainty and should be further investigated to better understand the relational experience at the end of life. The extension of relational turbulence theory into an end of life context also sheds light on the experience of partner influence. One key tenet of RTT is that partner influence occurs because of the interdependence between relational partners (Solomon et al., 2016). Much of the work with relational turbulence theory has been centered on relationships that are likely to maintain or

increase in interdependence such as marital or dating relationship (see Ellis & Ledbetter, 2015; King & Theiss, 2016). The relational transition of Alzheimer's provided a unique look into partner influence because relationships affected by AD shifted to greater dependence as the PWD experienced physical and cognitive decline. Despite the eventual shift to complete dependence, interference and facilitation are still a part of caregiving spouses experience with the prolonged relational transition of AD. This suggests that partner influence may be less about interdependence and more about partner interaction or interconnection. Thus, it may be through couples' continued commitment and interactions that interference and facilitation were present in the relationship. Further research is needed to investigate the role of relational uncertainty and partner influence in shaping relational transitions at the end of life.

### **Practical Recommendations, Limitations, and Directions for Future Research**

This study provides a rich picture of the relational experience of Alzheimer's disease and related dementias for married couples affected by ADRD. To conclude the discussion of this research, I have included a brief discussion of the practical applications of the findings, a few limitations, and directions for future research. I will first address some practical applications of these findings for practitioners serving the Alzheimer's community. This will be followed by an acknowledgement of the limitations of this study and recommendations for future research related to relational management in Alzheimer's disease and related dementias.

### **Practical Recommendations**

Understanding the relational uncertainties caregiving spouses face, and the relational turning points and communication experienced across the relational transition can aid practitioners who serve couples affected by ADRD in supporting caregiving spouses in their difficult role. Here I make two practical suggestions for professionals serving the Alzheimer's



community. First, recognize the temporal focus of relational uncertainty in Alzheimer's disease and help caregiving spouses manage that uncertainty. This may be particularly helpful around the time of the diagnosis when couples experience high levels of uncertainty about the future of their relationships. Helping couples shift their focus to the present and encouraging them to take full advantage of the quality of their current relationships may help them reduce their relational uncertainty and increase relational closeness directly following the diagnosis. This may be particularly beneficial because relational satisfaction has been linked to reduced caregiver burden and depressive symptoms, and greater overall wellbeing for caregiving spouses (Quinn et al., 2009; Watson et al., 2019; Williams, 2011). Relational quality also has implications for the overall care and wellbeing of the spouse with AD (Conway et al., 2018).

The second practical recommendation is to anticipate the relational turning points couples will experience throughout the disease trajectory and the communication that facilitates or interferes with the relationship during those periods. The commonly used division of the disease into three stages based on the severity of symptoms (i.e., mild, moderate, severe) provides little insight into the relational changes that occur in Alzheimer's disease. The relational turning points identified here provide a more detailed guide of when and how relational changes occur in AD. Using this guide to relational turning points, practitioners may be able to identify the relational changes occurring for the couples they work with and make recommendations to aid them in managing these changes. For example, for couples going through the turning point "no more deep conversations," practitioners may recommend they engage in more shared activities and communicate love and affection to maintain a sense of companionship and closeness despite the relational change. Further, knowledge of the ways communication shapes relational transitions may aid practitioners in mitigating the effect of these relational changes. For example, knowing

that couples' early conversations about driving ability begin the shift from spouse to caregiver, practitioners may help delay this relational shift by taking it upon themselves to initiate conversations about driving ability and to dictate and enforce changes to driving privileges. By anticipating and guiding couples through these relational turning points, practitioners may be able to aid couples in maintaining a sense of relationship throughout the course of the disease.

### **Limitations and Directions for Future Research**

Although this study had many strengths, a few limitations must be addressed here. There are three limitations regarding the sample. First, this sample could not fully represent the incredible diversity that is found in married couples from same sex marriages, to diverse racial and ethnic backgrounds, to compounding variables such as the caregiving spouses' health and wellness. A wider sample including more same-sex couples, broader racial diversity, and non-marital romantic partnerships would have provided a broader look into the effects of AD on romantic relationships. Second, this study did not capture the perspectives of the spouses with dementia. Although a majority of relational AD research has focused solely on the caregiving spouse's perspective, this leaves the relational experiences of PWD relatively unknown (Braun et al., 2009). As the marital relationship is inherently dyadic, failing to capture the perspectives of the PWD can give only a one-sided picture of this relational transition. Future research should incorporate the perspectives of the PWD including their experiences of relational uncertainty and partner interference and facilitation. Third, this sample predominantly included caregiving spouse in positive, satisfying relationships and provided less insight into relationships that were unsatisfying or problematic. The recruitment flier featured an image of a loving older couple and may have inadvertently attracted participants who were in positive, satisfying relationships. Moreover, recruiting through support groups may have resulted in a greater number of

participants who were well supported and managing the challenges of Alzheimer's disease. Future research should investigate alternative, more negative, relational experiences to give a more nuanced representative picture of the lived experience of AD.

Regarding methodology, one strength of this study was that it included caregiving spouses at every stage of the disease trajectory. Additional insight into the relational changes that occur in AD may have been gained through a longitudinal design. Future research should interview caregiving spouses at various points throughout the relational transition to investigate their experiences of relational change and their use of communication in managing changes. Second, while rich insight was gained through in-depth interviews and the turning points graph, additional insight might have been gained through observational data. Future research should utilize interviews and observations in concert to better ascertain couples' use of communication in managing their relationships on a daily basis. Additionally, observations of caregiver support groups and support materials such as Alzheimer's Association brochures and website, would provide insight into the ways these conversations and materials shape caregiving spouses' perceptions of relational change in AD and their communicative strategies for managing the transition. Third, it was beyond the scope of this study to investigate the prior relational patterns of these couples, yet the communication strategies employed in AD were likely greatly affected by their relational history. Further research should investigate couple's relational patterns prior to the diagnosis and the ways these patterns affect their adjustment to Alzheimer's disease.

Finally, there are three directions for future research regarding theory. In relational turbulence theory, the cumulative effects of relational uncertainty and partner influence lead to a sense of relational turbulence (Knobloch et al., 2018). Future research should measure caregiving spouses' levels of relational turbulence at various stages of this prolonged transition to ascertain

how relational turbulence might be related to the various relational turning points experienced across the disease trajectory. This would illuminate the most trying relational turning points and those through which caregiving spouses may require additional support. Second, RTT proposes that relational turbulence affects couples' levels of supportiveness and disclosure to social network members about the relationship (Solomon et al., 2016). Future research should investigate the effects of relational turbulence on caregiving spouses' level of supportiveness at various stages of the disease, and their willingness to disclose concerns about their relationship to members of their social networks. This line of research might have implications for couples' ability to support one another and to seek support from outside the relationship when needed. Third, this study revealed a unique interplay of relational certainty and uncertainty in AD. Future research should investigate the ways caregiving spouses manage relational uncertainty across the trajectory of Alzheimer's disease and related dementias.

### **Conclusion**

Approaching the prolonged relational transition of Alzheimer's disease and related dementias through the lens of relational turbulence theory provided necessary insight into caregiving spouses' experiences of managing their relationships across the trajectory of AD. This relational period was marked by a difficult interplay between relational uncertainty and the certainties of decline and death. The facilitative and interfering communication of caregiving spouses and their partners played an important role in shaping and navigating this relational transition. Investigating the relational turning points experienced across the trajectory of AD provided insight into the many relational changes that make up this prolonged relational transition. This also shed light on the role of everyday interaction and communication in shifting and maintaining the relationship despite the challenges of cognitive decline in Alzheimer's

disease. Perhaps most notably, this study explicates several facilitative communication strategies that aid caregiving spouses in maintaining a sense of relational connection across the various relational changes and turning point of AD. This study demonstrates the possibility for caregiving spouses to experience relational growth in the midst incredible personal and relational difficulty in Alzheimer's disease and related dementias.

## Appendix A: Recruitment Flier



Does your spouse/romantic partner  
have Alzheimer's disease ?

**I want to hear your story.**

- Participate in a 60-90 minute interview
- Interview in person or via Skype/FaceTime/Zoom
- Receive \$10 after completing your interview
- Study approved by the University of Arizona

**SHARE • YOUR • STORY**

*Contact Amanda Cooper for an interview 208-221-9293  
ramandacooper@email.arizona.edu*

## Appendix B: Interview Packet

### 1. Interview Packet Instructions

**Hello and thank you for your interest in participating in an interview!**

This packet contains three important documents for you to fill out and bring to our interview:

1. The research consent form approved by the University of Arizona institutional review board
2. A brief questionnaire to give me a little background information about you
3. A blank timeline

#### **Instructions for the timeline**

I would like you to build a timeline of your relationship with your spouse/partner since you first noticed Alzheimer's symptoms. Please place all the events or experiences that you feel have changed your relationship in some way on the timeline. Did this event make you feel closer to your spouse/partner or more distant from your spouse/partner? Place events that made you feel closer above the line, and events that made you feel more distant below the line.

I have also included an example of what a timeline might look like. You may have different experiences that have impacted your relationship. Please place all the events you can think of on the timeline.

**Please bring this packet with you to our interview. Thank you!**

### 2. Interview Reminder Card

<p style="margin: 0;">INTERVIEW REMINDER</p> <p style="margin: 0;">With Amanda Cooper</p> <p style="margin: 0;">DATE: _____</p> <p style="margin: 0;">TIME: _____</p> <p style="margin: 0;">LOCATION: _____</p> <p style="margin: 0;">Questions? Call Amanda at 208-221-9293</p>
--

### 3. IRB Consent Form



Consent Version: 10/08/19  
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## University of Arizona Consent to Participate in Research

**Study Title:** Alzheimer's Disease and Romantic Relationships

**Principal Investigator:** R. Amanda Cooper, Department of Communication at the University of Arizona, [ramandacooper@email.arizona.edu](mailto:ramandacooper@email.arizona.edu).

### Summary of the research

This is a consent form for participation in a research project. Your participation in this research study is voluntary. It contains important information about this study and what to expect if you decide to participate. Please consider the information carefully. Feel free to ask questions before making your decision whether or not to participate.

### Why is this study being done?

This is an interview study aimed at understanding the communication practices of couples who are coping with Alzheimer's disease or probable Alzheimer's disease. This study will shed light on how communication might play a role in managing and maintaining relationships while adapting to life with Alzheimer's disease. Specifically, this study will provide insight into the ways that daily communication might facilitate or interfere with relational maintenance at different times over the course of Alzheimer's disease.

### Eligibility

You are eligible to participate if you are:

1. Over the age of 18
2. Fluent in English
3. The spouse or romantic partner of a person who has been diagnosed with Alzheimer's disease or probable Alzheimer's disease.

### What will happen if I take part in this study?

If you consent to participate in this study, you will be asked to participate in a 60-90 minute conversational interview with the researcher. Before the interview you will be asked to complete a brief questionnaire and timeline of your relationship that will help guide the conversation. With your permission, the interview will be audio recorded. This interview may take place anywhere that you feel comfortable which may include a space on the University of Arizona campus, a library, park or other public place, or in your home. You may also choose to participate in the interview via communication technology such as Skype, FaceTime, Zoom, or a simple telephone call.

Once the interview is complete, once the interview conversation has been transcribed, the recording will be deleted. Your interview will be kept fully confidential. Your name and contact information will not appear in the transcript, nor will the names of your family or friends.

HSPP Use Only: Consent Form  
Fed non-medical vJan 2018





**How long will I be in the study?**

Interviews for this study will range from 60 to 90 minutes. However, your participation is voluntary, and you may end the interview at any time if you so choose. You will also be given the opportunity to indicate whether you would like to receive a copy of the results of the study.

**How many people will take part in this study?**

It is estimated that 20 people whose spouses/romantic partners have Alzheimer's disease will participate in this study.

**Can I stop being in the study?**

**Your participation is voluntary.** You do not have to participate in this study. If you decide to take part in the study, you may leave the study at any time. Your decision will not affect your future relationship with The University of Arizona. Compensation will be paid at the completion of the interview.

**What risks or benefits can I expect from being in the study?**

There are no risks inherent to participating in this study. However, talking about your experience with Alzheimer's disease may bring up strong emotions. The interviewer will be sensitive to your experience and your comfort, and you may take a break or discontinue your participation in the interview at any time. Many interview participants express relief and a sense of being heard after participating in an interview.

The findings from this study may inform training and resources to enhance communication and relationship quality for individuals with Alzheimer's disease and their romantic partners.

**Will I be paid for participating in the study or experience any costs?**

Each interview participant will receive \$10 at the completion of the interview. There are no costs to participating in this study beyond the investment of 60-90 minutes of time.

**Will my study-related information be kept confidential?**

Your name will not be used in any report, nor will the names of your family members. Pseudonyms will be used for all publication and presentations. Identifiable research data will be encrypted and password protected. Only the research team will have access to the data.

With your permission, interview will be audio recorded. The recording will be erased once the interview is transcribed. Your name will not be included in the transcript.

The information that you provide in the study will be handled confidentially. However, there may be circumstances where this information must be released or shared as required by law. The University of Arizona Institutional Review Board; other federal, state, or international



Consent Version: 10/08/19

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regulatory agencies; or the sponsor of the study, if any, may review the research records for monitoring purposes.

#### Who can answer my questions about the study?

For questions, concerns, or complaints about the study you may contact Amanda Cooper, Department of Communication at the University of Arizona, at [ramandacooper@email.arizona.edu](mailto:ramandacooper@email.arizona.edu).

For questions about your rights as a participant in this study or to discuss other study-related concerns or complaints with someone who is not part of the research team, you may contact the Human Subjects Protection Program at 520-626-6721 or online at <http://rgw.arizona.edu/compliance/human-subjects-protection-program>.

#### Agreeing to the consent form

I have read (or someone has read to me) this form, and I am aware that I am being asked to participate in a research study. I have had the opportunity to ask questions and have had them answered to my satisfaction. I voluntarily agree to participate in this study.

I am not giving up any legal rights by signing this form.

\_\_\_\_\_  
Printed name of subject

\_\_\_\_\_  
Signature of subject

\_\_\_\_\_  
Date

Researcher's signature:

\_\_\_\_\_  
Printed name of principle investigator

\_\_\_\_\_  
Signature of principle investigator

\_\_\_\_\_  
Date

HSPB Use Only: Consent Form  
Feb non-medical star 2018

#### 4. Demographic Questionnaire

What is your age? \_\_\_\_\_

What is your gender? (Please circle one)

Male

Female

Prefer not to answer

What is your Race/Ethnicity? (Please circle one)

European American ("White")

African American ("Black")

Hispanic American (or Latino/a)

Native American

Asian American

Please circle the option that best represents your highest level of education.

Some high school

High school diploma

Some college

Bachelor's degree

Vocational training

Graduate or professional degree

Please circle the option that best represents your annual household income.

Less than \$20,000

\$90,000-\$100,000

\$20,000-\$30,000

\$100,000-\$110,000

\$30,000-\$40,000

\$110,000-\$120,000

\$40,000-\$50,000

\$120,000-\$130,000

\$50,000-\$60,000

\$130,000-\$140,000

\$60,000-\$70,000

\$140,000-\$150,000

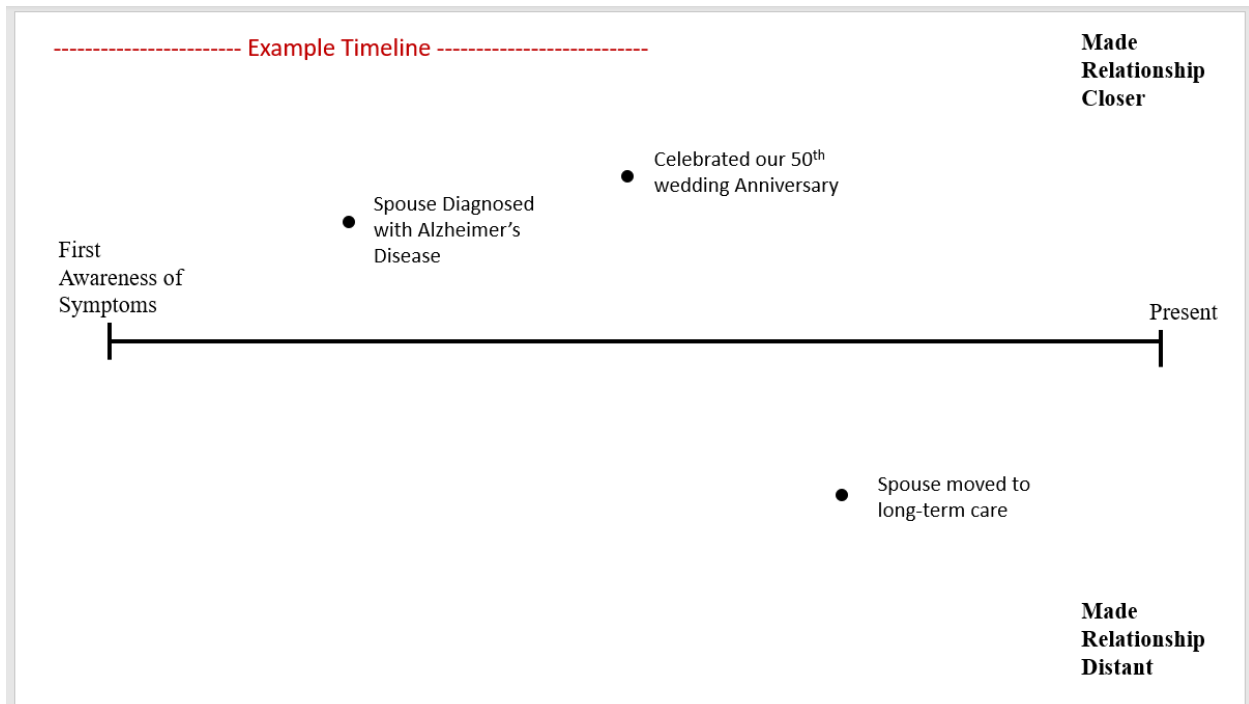
\$70,000-\$80,000

\$80,000-\$90,000

### 5. Blank Retrospective Interviewing Timeline



### 6. Example Retrospective Interviewing Timeline



### **Appendix C: Recruitment Schedule**

#### February 3, 2020

I received approval from the university's institutional review board and began recruitment procedures including distributing fliers to the Alzheimer's Association support groups and Banner Alzheimer's institute, contacting managers of local memory care facilities, and reaching out to gatekeepers of Alzheimer's focused Facebook groups.

#### February 12, 2020

I completed the first interview.

#### March 11-13, 2020

The Coronavirus pandemic hit Arizona and all support groups and Alzheimer's events were cancelled.

#### March 20, 2020

I completed the 18th interview over the phone. Because the data the data that I had collected to that point was rich and evocative and the pandemic made it difficult to recruit participants, I chose to conclude data collection.

## Appendix D: Interview Guide

### Introduction and Purpose of Interview

Thank you for being willing to talk with me today. I am interested in hearing about some of the ways that Alzheimer's disease has affected your relationship with your partner, and how you and your partner have adapted to life with Alzheimer's disease.

Before we can begin the interview, I need to review the IRB consent form with you. [Here have collect the consent packet from them.] Did you have any questions about the consent form or other documents?

Now I would like to tell you a little bit about the process of the interview. I want you to feel as comfortable as possible during this interview. Remember that you do not have to answer any question(s) that you are not comfortable answering and you can stop this interview at any time if you choose to. Feel free to take your time in answering the questions. Would you mind if I audio recorded this interview and took brief notes?

Once our interview is recorded it will be transcribed, and your information will not be attached to the recording or the transcript in any way. Your name will not appear in the transcript, nor will the names of your family members. Pseudonyms will be used in any papers written for publication or presentations.

Do you have any questions before we begin?

### Interview Questions & Probes

First, can you tell me a little bit about your relationship with your partner since you and your partner became aware that they might have Alzheimer's disease?

- How long have you been in a relationship with your partner?
- When/how did you find out that your partner has Alzheimer's disease?
- How does Alzheimer's disease influence your relationship on a day to day basis?

Now let's look at your timeline. Can you walk me through the events you placed on your timeline?

- Can you tell me about how this event impacted your relationship?
- Tell me what the communication was like with your partner in the time surrounding this event.
- What conversations influenced your relationship during this time? Can you give me an example of a conversation you had at that time?
  - What did you say to your partner?
  - What did they say to you?

- How do you think this conversation impacted your relationship with your partner?

### **Uncertainty**

Looking back at your timeline, can you point out any moments when you had questions or uncertainties about how Alzheimer's disease would impact your relationship?

- Can you talk to me about the questions or concerns might have had about **your role** in the relationship after you found out that your partner has Alzheimer's?
- Can you talk to me about the questions or concerns might have had about **your partner's** role in the relationship after you found out that he/she has Alzheimer's?
- Can you talk to me about the questions or uncertainties you felt about the nature of your relationship once you found out that your partner has Alzheimer's disease?

How did communication with your partner influence how you felt about your relationship?

- Can you tell me about a conversation with your partner that made you feel more concerned or uncertain about your relationship?
- Can you tell me about a conversation with your partner that made you feel more confident about your relationship?

### **Facilitation/Interference**

Now I want to hear a little bit more about how you and your partner interact on a daily basis. How does your partner communicate in ways that make it easier for you to maintain your relationship?

- Can you tell me more about what those interactions look like?
- Please give me an example of one of these conversations.

How does your partner communicate in ways that make it more difficult for you to maintain your relationship?

- Can you tell me more about what those interactions look like?
- Please give me an example of one of these conversations.

### **Wrap-up**

Thank you for sharing some of your story with me today. As a communication scholar, I am interested in learning more about the ways that communication influences our lives. What else would you like to share with me, that perhaps I didn't ask about, about the role of communication in your relationship with your partner as you manage Alzheimer's disease.

What do you wish that you had known about communication and relationships when your partner was first diagnosed? Thank you!





## Appendix E: Audit Trail Excerpt

**4/8/2020 3:12 PM**

### **Coding note:**

My coding process involves reading each interview and coding it chunk by chunk. I won't say that I'm coding line by line because most caregivers take more than one line to make a point. In my coding I highlight the section and label it with a descriptor that kind of defines it or labels the meaning of that section. So sections get coded with multiple codes because participants will often be making two points together in the same section. At other times they circle back and reiterate the same point in a later section of the interview, in that case I take that chunk of data and drop it into the original code. I am trying to be as nuanced as possible so sometimes micro differences are highlighted as two codes, even if they end up in the same place eventually.

It is also important to note that I have been coding with my research questions on the desk right in front of me. My goal is to code specifically the chunks of data that answer the research questions. Sometimes I may code something that does not relate directly to the RQs because they are so interesting.

**4/20/2020 4:20 PM**

Coding timelines right now

Process Memo - I decided to code the timelines into Nvivo - I'm doing this by copying in each turning point on the timelines as an individual node in Nvivo. I have been pulling up the coordinating interview and just referencing the header giving the interview number so that when I click into a timeline memo I can go back and see which timeline it came from. I also decided to do it this way because I want to be able to sort references to the turning points in the interviews along with references from the timelines. I also decided to include a note about whether the event made the relationship closer or more distant by adding 'closer' or 'distant' at the end of each node label to demonstrate which side of the line each on fell on.

There are definitely certain events that are common turning points - one thing that's sticking out as interesting right now - one man put 'lonely nights' on his timeline in the made it closer area - another mentioned feeling closer to his wife because he was afraid of losing her - I wonder if to some degree people feel closer to their spouse because of the loss they are experiencing at the time - does loss make us feel closer to our loved ones?

To some degree, it seems that the people write stuff on the closer side not because it brought the relationship closer but because it was still close at the time.

**4/21/2020 4:33 PM**

### **Sorting Timeline Nodes**

In coding I find that I move codes from one part to the other a lot - one code might go first into relational transition com, then get moved to turning points, and then end up in the facilitation section. This is a pretty fluid process and that's part of the constant comparison process.

It's all a bit messy still, but I sorted the turning points nodes! Go me!! Some big events that are featured on most timelines are - the diagnosis; a big first event that showed that something was wrong or a buildup of many smaller odd events that signaled something was wrong; a move having to do with care - either moving together to an area, house, or facility or just moving the partner to a memory care unit;

certain symptoms featured as turning points - becoming incontinent and having hallucinations especially; losing driving privileges was another big turning point for a lot of people - loss of independence; another big turning point that not everyone faces is when the spouse forgets their name, or in one case the relationship all together.

There was a lot of talk about this idea of closeness and distance. Some people talk about the relationship changing but not changing how they feel about the person. I need to dig in a bit more to see what's going on there.

**4/25/2020 1:08 PM**

**Sorting Communication Node**

I started today by sorting free codes into the categories they fit with that moved the list of codes from 5 pages down to two.

I finally made the decision to move all the relationship codes to the relational turning points section and did that - that moved the list down to barely over one page.

As I've been coding these I've been thinking about how I'm going to write up my findings - Some of these communication codes explain why the relationship shifted in the way it did. Many (not all) people said that the diagnosis made the relationship closer, and some of that is explained by communication codes - talking openly about fears and the future seemed to bring couples closer right after the diagnosis. Many caregivers also expressed that knowing what was going on helped them understand their spouse better and be more patient and understanding with the behavior - this cut down on arguments, and for some seems to have been a bit of a relational repairing for them. EX: the spouse was acting odd and that was creating tension in the relationship, once they understood what was going on the tension was released because they realized that the spouse wasn't behaving in those ways maliciously. That understanding brought some repair. Even for one caregiver contemplating divorce, even though it didn't make her feel closer to her partner, knowing that his behavior was the result of a disease made her decide to stay in the relationship. A few other caregivers felt closer to their partners after the diagnosis because they could see that time was limited and their partner was beginning their end of life journey.

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