

Abstract

Alzheimer's disease and related dementias cause gradual cognitive and communicative decline over a period of several years creating a prolonged transitional period in the lives of people with the disease and their spouse. Relational turbulence theory served as a lens to examine 18 in-depth interviews with caregiving spouses regarding their experiences of relational uncertainty, and interference and facilitation from their partner throughout this prolonged relational transition. Counterintuitively, the experience of relational uncertainty was greatly influenced by the *certainties* of relational change and termination (death) that shifted the temporal focus of uncertainty to the future. Communicative symptoms and aggressive behavior were a main source of interference. Despite the impairment of the disease, caregiving spouses recognized their partners' expressions of gratitude, moments of recognition, and simple expressions of love as facilitation.

Keywords: Alzheimer's, dementia, relational turbulence theory, uncertainty, facilitation, interference, communication

Caregiving Spouses' Experiences of Relational Uncertainty and Partner Influence in the Prolonged Relational Transition of Alzheimer's Disease and Related Dementias

A diagnosis with Alzheimer's disease or related dementia (ARD) creates a prolonged relational transition for people with dementia (PWD) and their spouses. The term dementia refers to several medical conditions of the brain which cause detriments to memory, executive function, communication ability, and awareness (Henderson & Jorm, 2002). Alzheimer's disease is the most common form of dementia, accounting for 60-80% of all dementia cases and amounting to 5.8 million cases in the United States alone (Alzheimer's Association, 2019). The symptoms of cognitive decline in ARD create continuous relational change throughout the disease trajectory which lasts an average of four to eight years but can extend up to 20 years (Larson et al., 2004; Xie et al., 2008). Spouses often provide informal care across the disease trajectory (Cash et al., 2019) and must work to adapt to communicative and relational changes throughout the course of the disease (Ablitt et al., 2009; Hellström et al., 2007).

During this prolonged relational transition, caregiving spouses¹ might be particularly susceptible to relational turbulence, which is characterized by tumultuousness, chaos, and fragility (Solomon & Knobloch, 2004). However, relational turbulence may be uniquely experienced due to disease related changes in relational uncertainty and influence from their partner which are driving forces in relational turbulence (Solomon et al., 2010). Cognitive detriments caused by the disease may alter caregiving spouses' perceptions of their partner's behavior and influence, while the prolonged nature of the relational transition may alter the experience of relational uncertainty. Rooted in relational turbulence theory (RTT, Solomon et al., 2016), the goal of this study was to gain insight into caregiving spouses' experiences of

¹ The term "caregiving spouses" reflects participants' language in referring to themselves as caregivers to their partners who have ARD. This phrase will be used to refer to participants throughout the paper.

relational uncertainty and influence from their partner across the prolonged relational transition of ADRD. To this end, we used in-depth qualitative interviews to gain insight into caregiving spouses relational experiences. We begin by reviewing relevant ADRD and RTT literature, followed by a description of the methods and a presentation and discussion of the findings. These findings extend RTT literature by revealing a distinct interplay between certainty and relational uncertainty and provide insight into caregiving spouses' relational experiences throughout this prolonged transition.

Literature Review

Research on the relational aspects of caregiving highlights the distinct challenges experienced by caregiving spouses. The symptoms of ADRD create relational changes across the disease trajectory to which caregiving spouses must continually adapt. Relational turbulence theory provides insight into the relational processes experienced as caregiving spouses navigate this difficult relational transition.

Prolonged Relational Transition in ADRD

ADRD creates a prolonged relational transition which is characterized by increasing dependence, shifting roles and identity, and loss of companionship (Ablitt et al., 2009). Solomon et al. (2016) define a relational transition as a "period of discontinuity... during which individuals adapt to changing roles, identities, and circumstances" (p. 510). For caregiving spouses, this period of discontinuity extends across many years as the symptoms of ADRD gradually change the circumstances of the relationship until the relationship ends with the death of the partner. During this time, caregiving spouses must continually adapt as their relationships shift from interdependence to dependence. The transition from interdependence to dependence begins early in the disease trajectory when caregiving spouses take on additional household

responsibilities as their partner loses the ability to manage daily tasks and engage in shared decision-making (Boylstein & Hayes, 2012; Harris et al., 2011). This transition continues as the symptoms intensify and caregiving responsibilities gradually increase from reminding and supervising the partner to providing personal care such as dressing and bathing (McLaughlin et al., 2010). Many caregiving spouses experience identity changes as they shift from enacting the role of partner to caregiver (Quinn et al., 2009). Reflecting the gendered nature of caregiving, this identity disruption is particularly common for caregiving wives who describe experiencing an identity change from wife to mother as they took on the role of caregiver (Boylstein & Hayes, 2012). These changes in relational roles and identity, as the partner becomes more dependent, are at the heart of this relational transition.

Relational transition also occurs as the symptoms of ADRD impact companionship and intimacy in the relationship. The symptoms of the disease, particularly those causing behavioral problems, have been shown to reduce emotional and physical intimacy and overall relational quality for caregiving spouses (de Vugt et al., 2003; Hayes et al., 2009). For example, symptoms limiting PWD's abilities to engage in conversation such as memory loss, challenges with word recall, and difficulty expressing themselves can lead to a loss of meaningful conversation between partners (Henry et al., 2004; Walters et al., 2010). These communicative limitations decrease the sense of reciprocity and companionship in the relationship (Evans & Lee, 2014), and many caregiving spouses report a sense of loss in their relationship (Conway et al., 2018). Caregiving spouses must continually adapt as the symptoms of the disease radically transform their relationships reducing companionship and altering their roles and identities as the partner becomes more dependent. These gradual but significant relational changes constitute a prolonged

transition the extends until the relationship ends with the death of the partner. This relational transition may be better understood through relational turbulence theory.

Relational Turbulence Theory

This study applies relational turbulence theory (RTT, Solomon et al., 2016) as a lens for understanding caregiving spouses' experiences throughout the prolonged relational transition of ADRD. Changes to the relational environment during transitions increase relational uncertainty and sensitivity to a partner's communication and behaviors (Knobloch et al., 2018), resulting in increased emotional reactivity and negative emotions (Knobloch et al., 2007; Knobloch & Solomon, 2002b). These conditions lead to relational turbulence (Solomon et al., 2016). For example, Theiss and Knobloch (2014) found that military spouses who reported higher levels of relational uncertainty and interference from their partner during the post-deployment transition perceived greater turmoil in their relationships as well as less responsiveness from their partner, less open communication, fewer relational assurances, and less constructive conflict. This increase in relational turbulence due to relational uncertainty and perceptions of partner influence is a well-documented part of relational transition (see Goodboy et al., 2020).

Relational turbulence is particularly likely to occur when one relational partner is experiencing health challenges (see Knobloch & Delaney, 2012; 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. Relationships in which one partner has ADRD may be especially turbulent because, unlike most relational transitions which eventually resolve into normalcy, ADRD is marked by continuous relational decline beginning with early symptoms and continuing through the final stages of the disease and death. Relational turbulence theory has been used to examine relational

transitions marked by discrete events (e.g., birth of a child, Theiss et al., 2013), reoccurring relational transitions (e.g., reentry after military deployment, Knobloch et al., 2016; Knobloch & Theiss, 2012), and distinct relational periods (e.g., long distance relationship, Ellis & Ledbetter, 2015). The current study extends this body of research by applying RTT as a sensitizing theoretical framework for understanding the experiences of relational uncertainty and influence from a partner throughout the prolonged transition of ADRD. We will begin by addressing relational uncertainty and then address partner influence.

Relational Uncertainty

Relational uncertainty occurs when individuals have questions about the nature of, and involvement in, their relationship (Knobloch & Solomon, 2002a; Solomon & Knobloch, 2004). Relational uncertainty takes 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 (Solomon et al., 2016). Relational uncertainty constrains talk between partners, increasing avoidance and indirect communication (Theiss, 2011; Theiss & Nagy, 2012; Theiss & Solomon, 2006). Individuals experiencing relational uncertainty are likely to view their partner 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). Caregiving spouses 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), but

further research is needed to understand how experiences of relational uncertainty shape the lived experiences of caregiving spouses. To this end, we pose the following research question:

RQ1: How do caregiving spouses experience relational uncertainty throughout the prolonged transition of Alzheimer's disease and related dementias?

Partner Influence: Interference and Facilitation

Influence from a partner is a natural part of relating in interdependent relationships. 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 through facilitation or interference (Solomon & Knobloch, 2004, p. 798). Facilitation from a partner occurs when an individual perceives that their partner's behavior makes it easier to pursue their goals. Whereas interference from a partner occurs when an individual perceives that their partner's behavior makes pursuing those goals more difficult (Solomon & Knobloch, 2004). 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).

Influence from a partner may play a unique role within relationships affected by ADRD because of the shifts in interdependence caused by the disease. Gradually increasing dependence (McLaughlin et al., 2010) may reduce or amplify partner influence within the relationship. 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. Thus, to ascertain caregiving spouses' perceptions of interference and facilitation, we pose the following research question:

RQ2: What communication practices and behaviors do caregiving spouses report as (a) interference from their partner and (b) facilitation from their partner throughout the prolonged relational transition of Alzheimer's disease and related dementias?

Method

We applied qualitative methodology to gain insight into the experiences of caregiving spouses across the prolonged relational transition of ADRD. In-depth retrospective interviews provided space for participants to reflect upon and make sense of their experiences across the disease trajectory.

Participants and Procedures

Data for this study came from 18 in-depth interviews conducted as part of a larger study on the relational experiences of ADRD². To better understand participants' relational experiences across this prolonged transition, we collected data through in-depth interviews and the retrospective interview technique (RIT, Baxter & Bullis, 1986). Prior to the interview, participants were instructed to create a retrospective timeline of their relationships since the onset of ADRD. These timelines were used to elicit details about their experiences of relational uncertainty and influence from their partner at different points of the disease trajectory. Using RIT allowed participants time to recall and reflect on their relational experiences across this prolonged transition and yielded rich insight into their experiences. Applying the theoretically grounded interview guide in tandem with RIT provided a consistent line of inquiry in each

² This study was a part of the first author's master's thesis and has been presented in collaboration with her advisor, the second author. Both authors are white, married, females trained in qualitative methods with interest in relational and communicative processes at the end-of-life. As a portion of the first author's master's thesis, RIT served primarily as a data collection technique in this study. A second study is forthcoming which reports the relational turning points identified through the RIT technique.

interview with flexibility to seek additional detail and insight from individual participants when needed (see Appendix A for interview guide).

Participants were recruited between January and March 2020³ through gatekeepers (individuals with power to grant access to a group of interest; Lindlof & Taylor, 2011) at a local memory care center ($n = 1$) and local Alzheimer's caregiver support groups ($n = 11$), Alzheimer's caregiver Facebook groups ($n = 4$), and snowball sampling ($n = 2$). Most participants ($n = 14$) lived in the local community, but the participants recruited through Facebook lived in other regions of the United States. The sample consisted of 11 cisgender women (61.11%) and seven cisgender men (38.89%) ages 49-88 (mean = 69.39, median = 70.00, $SD = 10.17$) of which 72.22% identified as White, 11.11% as Black, 5.56% as Hispanic, and 11.11% as multiracial/other. One participant identified as lesbian (5.56%) while all others identified as heterosexual (94.44%). In order to participate, individuals must have self-identified as having been in a marital or romantic relationship with an individual who has ADRD. Three participants' spouses had died within three months prior to the interview. We included these participants because they continued to identify with the experience of providing care to their partners, and to gain perspective into the full relational transition of ADRD (see Table 1 for demographics). Nine interviews took place in person (in participants' homes or public places) and nine interviews took place over the phone or via Zoom. All participants were offered \$10.00 in compensation for completing the interview, however six participants declined payment. Interviews were recorded using a hand-held audio recording device and transcribed using Temi transcription software (see temi.com). We reviewed all transcripts for accuracy, removing major speech disfluencies and assigning pseudonyms to each participant. The interviews ranged from

³ The last two interviews were completed over the phone following local shut-down due to the COVID-19 pandemic.

47-90 minutes and yielded 284 pages of single-spaced text. Being able to offer both in-person and remote interviewing opportunities provided greater flexibility and environmental control for participants, and interviews did not differ in length or quality whether conducted in-person or over phone/Zoom.

[Insert Table 1 Here]

Data Analysis

Working in Nvivo12 to organize the transcripts, we used the iterative comparative process of thematic analysis to analyze the data (Braun & Clarke, 2006). In the first phase of analysis, we gained familiarity with the data by reading and rereading the transcripts and fieldnotes. In the second phase, we engaged in open coding which involves identifying portions of the text that provide insight into the research questions and assigning codes, or descriptive labels (Strauss & Corbin, 1998). When possible, we assigned in-vivo codes using participants' exact wording to label codes which kept coding grounded in participants' experiences (Creswell, 2013). During open coding we used RTT as a sensitizing framework (see Charmaz, 2014) to guide us in identifying relevant portions of the data with the flexibility to code data that did not align perfectly with RTT. For example, in open coding, we coded several instances of relational uncertainty but also coded instances of "no uncertainty" or not focusing on uncertainty, such as this in-vivo code: "I don't know what's going to change but I don't distress myself about it." This process of initial open coding yielded 333 unique codes.

The third phase involved constant comparison to group codes with similar meanings into tentative categories. During this phase, codes about not focusing on uncertainty were grouped together into an initial category and codes about "no uncertainty" were grouped into an initial category. In the fourth phase, we continued the process of constant comparison of codes and

initial categories to refine themes until they accurately represented the data and the experiences of participants (Glaser & Strauss, 1967). During this phase the initial categories of “no uncertainty” and “avoiding uncertainty” were combined as part of a broader theme of (un)certainty in ADRD. Once the themes were satisfactorily refined, we completed the fifth and final phase which involved naming themes and selecting evocative exemplars from the data to illustrate participants’ experiences and define the conceptual boundaries of each theme.

We used Lincoln and Guba’s (1985) four criteria of qualitative trustworthiness (i.e., credibility, dependability, confirmability, and transferability) to establish excellence in qualitative inquiry. We enhanced our credibility by using in-vivo codes to ground the coding and analysis in participants’ language and experiences. To ensure dependability, we maintained a detailed audit trail of the analytical process, including descriptive field notes, analytic memos, decision-making regarding codes and coding, and notes about themes or patterns in the data (Rodgers & Cowles, 1993). For confirmability, we used member checking by inviting participants to review and reflect on preliminary findings to ascertain if the findings resonated with their experiences (Lincoln & Guba, 1985; Tracy et al., 2017). To do this, we sent a copy of the research questions and findings section to five participants requesting them to respond to these questions: (1) “Does this resonate with your experience?” and (2) “Are there parts you disagree with or would change?” The three participants who responded confirmed that the findings resonated with their experiences and no changes were suggested. Finally, to increase transferability we selected exemplars with thick description of participants’ experiences to give the reader a rich understanding of the experience (Geertz, 1973).

Findings

The goal of this study was to shed light on the experiences of caregiving spouses in the prolonged relational transition of ADRD. Data analysis yielded three themes about relational (un)certainty (RQ1): partner uncertainty: who will my partner become (25 codes), self uncertainty: will I be able to care (37 codes), and relationship (un)certainty: relationship change and loss are certain (47 codes); two themes about interference (RQ2a): frustrating symptoms (68 codes) and aggressive behaviors (64 codes); and three themes of facilitation (RQ2b): facilitating daily tasks (38 codes), reminders of the past (20 codes), and expressions of love and affection (31 codes).

The Experience of Relational Uncertainty

Caregiving spouses' experiences of relational uncertainty were shaped by the symptoms and terminal nature of ADRD. Because the effects of ADRD are well-documented, caregiving spouses had *certainty* that their partner and relationship would be greatly altered by the disease and that the disease would lead to the death of their partner. 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 experience of relational uncertainty. Across the trajectory of the disease, caregiving spouses' relational uncertainties reflected a tension between certainty and uncertainty with the certainties of the disease creating unique experiences of partner, self, and relationship (un)certainty (see Figure 1). Although the data were coded inductively, the themes of relational uncertainty coalesced around the three types of relational uncertainty described in RTT (self, partner, and relationship) and will be presented accordingly.

Partner Uncertainty: Who Will My Partner Become?

Caregiving spouses experienced partner uncertainty about who their partner would become and how they would engage in the relationship as the disease progressed. Knowing the symptoms of ADRD, caregiving spouses anticipated that their partners' personalities would shift due to the disease. This *certainty* created relational *uncertainty* about who their partner would be in the relationship and how willing/able their partner would be to engage in the relationship. Emily expressed uncertainty about "living with a different person" as her husband changed and how this altered version of her husband would behave toward her as a partner:

There's so much unknown... 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. Is that going to happen to him? He is very, very calm, but is that gonna come out in him? And is that going to come out in him in front of our daughter? or in front of me?

Knowing that their partners would change also generated uncertainty about how this new person would feel about the relationship. Jane recalled feeling this uncertainty shortly after her husband was diagnosed, "I had that question too, how long would he love me?" Partner uncertainty generally centers on questions about the partner's involvement in the relationship (Solomon et al., 2016). However, for caregiving spouses, partner uncertainty also included questions about who the partner would become and how their altered partner would feel about and behave in the relationship.

Self Uncertainty: Will I be Able to Care?

Self uncertainty in ADRD included questions about ability to fill the relational role of caregiver and to continue to feel love and care for the partner as they changed. *Certainty* that their partner would change generated relational *uncertainty* for caregiving spouses about their

ability to maintain involvement in the relationship as their partner changed. Some participants, like Kevin, felt uncertain about their ability to fill the role of caregiver, “I’m always questioning my ability. Can I do this?... she was always the stronger one.” Kevin’s questions about ability extend beyond the performance of daily caregiving tasks to uncertainty about his ability to take on the emotional and relational role of caregiver while losing the support of his wife. Eleanor expressed concerns about her ability to stay involved in the relationship as her wife continued to change, “The main concern I have is if she becomes more aggressive, what would I need to do? Would I leave or would I stay? ... I don’t know where that would lead.” Not being able to anticipate how their partner would change created uncertainty about how caregiving spouses would respond both tangibly and emotionally. 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?” Jane’s uncertainty was less about her ability to *provide* care, and more about her ability to *feel* care for her partner as he changed. Caregiving spouses’ experiences of self uncertainty centered on questions about their ability to be involved in the relationship by loving and caring for their partner as they changed.

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

Many caregiving spouses claimed that they did not experience relationship uncertainty, which centers on the nature and future of the relationship (Solomon & Knobloch, 2004). Further inquiry revealed that the absolute *certainty* of decline from ADRD eclipsed more abstract uncertainties about the relationship. When asked about her relationship, rather than address questions about *uncertainty*, Jennifer focused on the *certainty* that her relationship would be impacted by the disease, “I know at some point it’s going to become one-sided.” Similarly, Garth focused on his certainty about the future of his relationship, “The end result is death. That’s it.

Period. It's going to happen sooner or later." These bleak relational certainties of relational decline and death created a profound and prolonged experience of loss, "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" (Emily). Caught in this marathon of grief, caregiving spouses focused less on uncertainty about the relationship and more on their relationship certainties.

Faced with the grim reality of these relationship *certainties* caregiving spouses may have found it easier to focus attention away from about their uncertainties. This was reflected in their claims of "no uncertainty" during the interviews. Instead, caregiving spouses focused on the present moment and day-to-day aspects of care, "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). Bella's statement hints at the uncertainties she faced yet focuses attention away from the future and onto the present moment. Annie explained, "I don't want to worry about what may be down the pike right now... I can't do nothing about what's ahead... We're dealing with this thing a day at a time." Because they knew ADRD would eventually radically change their relationships, focusing on the present moment helped caregiving spouses avoid the certainties and uncertainties of future relational changes.

The Experience of Partner Influence

Interference and facilitation from a partner center on the ways the partner's behavior makes it easier or more difficult to accomplish goals (Solomon & Knobloch, 2004). Two main goals seemed to motivate caregiving spouses and were at the heart of interference and facilitation throughout the prolonged relational transition of ADRD: completing daily caregiving tasks and maintaining a sense of relationship with their partner. Although interference and facilitation do

not generally relate to relationship maintenance goals, sustaining a sense of relationship was an important goal in ADRD. Caregiving spouses described two sources of interference in ADRD, (1) frustrating symptoms and (2) aggressive behaviors; and three types of facilitation, (1) facilitating daily tasks, (2) preserving the past, and (3) expressing love and affection.

Frustrating Symptoms

Symptomatic behaviors such as misplacing belongings, losing track of time, wandering off, and general confusion interfered with goals for relational maintenance and providing care. Tom explained, “I’m trying to run an efficient household here, but you’re looking for something, like where’s the hammer, and you find the hammer where the makeup is, stuff like that. It’s very frustrating.” Tom’s example shows how the symptoms indirectly made daily household and caregiving tasks more difficult, but symptoms also caused direct interference. Several caregiving spouses described the daily interruptions required to redirect or re-explain things to their partner, “I just get tired of repeating and repeating” (Wendy). Caregiving spouses described these symptomatic behaviors as both interfering with the everyday tasks of caregiving and interfering with their goal to maintain relational connection. Eleanor explained, “they’re little things, but they change how we interact.” Because communicative interaction is at the heart of relational connection, communicative symptoms strongly interfered with the goal of maintaining relationship. Robert explained, “it’s hard to have a long conversation about something that she can’t remember... even [positive experiences] we can’t always share.” Caregiving spouses acknowledged that symptomatic behavior was caused by the disease, but they still perceived these behaviors as interference. Tom said, “she doesn’t mean to, but she often brings us down.” In this way, caregiving spouses perceived symptoms as interfering on both daily goals and their broader relational goals.

Aggressive Behaviors

Some caregiving spouses experienced aggressive behaviors from their partners which were a severe interference to their goals of providing care and maintaining the relationship. They described these behaviors with phrases like “verbally belligerent,” “blows up,” “got nasty,” “angry attack,” and “adult temper tantrum.” Although not always the cause of the aggression, forgetfulness often created situations in which the partner with ADRD acted aggressively. Joni explained that one of the greatest sources of interference she experienced was that her husband became “more aggressive with sex” because he could not remember the last time they were intimate. She explained that this often led to a disagreement, and then once the disagreement was resolved, “he would be better and want to make love.” Joni concluded, “I felt like this was just wrong. This isn’t love. I don’t know what this is.” This painful cycle was exacerbated by her husband’s forgetfulness and interfered with both her daily tasks and relational goals.

For some, aggressive behaviors seemed to be tied to an inability to recognize or accept dementia, “in his mind he has no problems... he can’t accept anything” (Connie). Both Connie’s and Wendy’s partners refused to cooperate with memory testing because they did not believe they had a problem. This lack of acceptance led them to blame their problems and symptoms on others. Wendy said that her husband believed that she had “manufactured this whole thing and it was [her] fault” which 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... 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.

This aggressive behavior from the partner with ADRD made it difficult to complete daily caregiving tasks and interfered with relational goals by creating tension and resentment.

Facilitating Daily Tasks

Despite the impairments of ADRD, caregiving spouses perceived facilitation from their partners throughout the disease trajectory. Early in the disease progression, partners with ADRD facilitated daily tasks by expressing appreciation and helping 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’re workin’... at least I can do this” (Joni).

For Joni, her partner’s contribution to daily household tasks enabled her to focus on other responsibilities, such as working to provide an income, that her partner could no longer engage in. Caregiving spouses also viewed their partner’s expressions of appreciation as facilitative, “He tells me every night whenever I cook, ‘thank you so much’... he appreciates those things that he probably wouldn’t have before” (Jennifer). These expressions of appreciation helped caregiving spouses feel more positive about the work they do to provide care and facilitated their relational goals by increasing goodwill in the relationship.

Many caregiving spouses mentioned the importance of their partner’s easy cooperation in facilitating daily tasks, especially once the symptoms became more severe. “She just rolls along with whatever’s going on, whatever the program is, she’s with it” (Garth). Cooperation from the partner made providing care much easier. Caregiving spouses’ appreciation for their partner’s cooperation seemed to be derived from comparison to others with ADRD, “From listening to other people and reading other information, I know it could be worse, but it’s pretty good for the most part” (Annie). Caregiving spouses often emphasized their partner’s amiable qualities in contrast to what they *could* be. Jane compared her husband to 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 on their partner’s good behavior and qualities in contrast to what they could be, caregiving spouses came to appreciate their partners’ cooperative behaviors as facilitation.

Reminders of the Past

Caregiving spouses viewed moments when their partners communicated in ways that were reminiscent of the past as facilitation because it helped accomplish their goal of preserving the relationship. Jane appreciated moments when her partner remembered important relational moments from the past, “he would try to make me happy too, in his limited way, by remembering.” Reminders of their early relationship helped strengthen their connection and preserve a sense of relationship. Caregiving spouses also perceived facilitation when their partners behaved in ways that were characteristic of them before ADRD. Emily explained, “It’s sort of like getting the old person back... it just makes me pause and remember that part of him that I love so much.” These moments were powerful because they reminded caregiving spouses of the strength of their relationships prior to the disease. Later in the disease progression, continued recognition from their partners helped preserve relational connection. Garth explained, “She looks up with a big smile on her face because here I am... that’s a great feeling to see her like that, that she knows who I am.” Although their partners were often not in control of these moments of preserving the past, caregiving spouses viewed these moments as facilitative.

Expressions of Love and Affection

Caregiving spouses viewed their partners’ expressions of love and affection as relational facilitation. These often came in the form of an affectionate touch or word, “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” (Garth). These expressions of affection brought a sense of continued love, making

it easier for caregiving spouses to achieve the goal of preserving a sense of relational connection with their partners. Because of the degenerative symptoms, expressions of love shifted throughout the disease trajectory. Carol explained, “Before he would say, just out of the clear blue skies, I need a hug, or I need a kiss. This was a routine that stopped.” Once the symptoms became more severe, expressions of love and affection became more simplistic. 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 nonverbal expressions of love and affection helped maintain a sense of closeness in the relationship despite the drastic changes caused by the disease.

Discussion

Using relational turbulence theory (RTT), this study investigated caregiving spouses’ experiences of uncertainty and partner influence throughout the prolonged relational transition of ADRD. As an end-of-life transition, ADRD stands in contrast to the many discrete transitions that occur across the lifespan. While most relational transitions settle into a sense of normalcy after a period of adjustment (Solomon et al., 2016), ADRD requires continuous adjustment to symptoms until the relationship ends with the death of the partner. Further, in most transitions, both partners are expected to be able to uphold their relational roles and facilitate a positive transition, but in ADRD, the partner’s capacity diminishes as the transition progresses. The results of this analysis center caregiving spouses’ experiences of relational uncertainty and perceptions of partner influence during this prolonged relational transition.

The Interplay of Relational Certainty/Uncertainty

Applying RTT to this prolonged relational transition revealed a distinct interplay between *certainty* and relational *uncertainty*. Research has established that ADRD caregiving is fraught with uncertainty, including uncertainty about roles within the relationship (O'Donnell, 2000; Stone & Jones, 2009), but this study extends this literature by providing insight into the process and experience of relational uncertainty in ADRD. Changes in personality and behavior in PWD are well-documented ADRD symptoms that lead to changes in the marital relationship, decreased conversation and intimacy, and a sense of loss (Evans & Lee, 2014). Using RTT as a theoretical lens revealed how certainty about these disease-related changes drives the experience of relational uncertainty in ADRD. As seen in Figure 1, certainty of cognitive decline and personality change in ADRD shape the experiences of self and partner uncertainty. Much scholarship centers on the reduction or management of uncertainty (i.e., uncertainty reduction theory; Berger & Calabrese, 1975); however, this approach to uncertainty research falls short without considering the role of certainty in driving relational uncertainty in ADRD. This interplay between certainty and relational uncertainty provides a more nuanced view of the changes in relational dynamics experienced in ADRD.

[Insert Figure 1 Here]

The certainty-uncertainty interplay also creates a shift in the temporal focus of relational uncertainty which distinguishes the experience of relational uncertainty in ADRD from traditional conceptualizations of this construct. For example, 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' experiences of partner and self uncertainty were not about current involvement in the relationship but focused instead on involvement in a

future relational period affected by the symptoms of the disease. 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 ADRD focused on the certainty of future relational change and termination through death. Interestingly, even participants whose partners had already died described their experience of relational uncertainty in ADRD with this future focus, indicating that future focused uncertainty derived from anticipated symptoms and decline was central to the experience of relational uncertainty in ADRD.

This temporal aspect of the interplay between certainty and uncertainty was particularly apparent in caregiving spouses' tendency to describe only their *certainties* when asked about relational *uncertainty*. While scholars have recognized that maintaining relational uncertainty can be an uncertainty management strategy (see Mikucki-Enyart & Caughlin, 2018), caregiving spouses neither tried to reduce nor maintain relational uncertainty. Rather, they directed attention away from the future certainties and uncertainties of ADRD and focused instead on the good of the present moment. This orientation toward the present has been documented in other chronic illness (e.g., HIV/AIDs, Brashers et al., 2000) and may be an important strategy for managing the difficult certainties and uncertainties that accompany chronic illness. Mishel (1990) argues that reorientation to uncertainty prompts individuals to "reevaluate what is important in life" and to "appreciate the fragility and impermanence of life" (p. 260). Thus, although the interplay between the certainties and uncertainties of ADRD is challenging, it may serve as a catalyst for appreciation and growth of the relationship even in this difficult relational transition.

The Experience of Partner Influence in ADRD

The extension of RTT into this end-of-life transition sheds new 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 relationships (see King & Theiss, 2016; Knobloch & Carpenter-Theune, 2004). However, ADRD relationships are marked by increasing dependence rather than interdependence. Despite the eventual shift to complete dependence, caregiving spouses continued to perceive interference and facilitation from their partner across the prolonged relational transition of ADRD. This suggests that perceptions of partner influence may be derived less from interdependence and more from partner interaction or interconnection. Knobloch et al. (2020) suggest that changes in a partner's autonomy may create sources of partner influence in caregiving relationships, but further research is needed to investigate the effects of shifting interdependence on partner influence, particularly in end-of-life relational transitions.

This study also sheds light on the RTT construct facilitation. Facilitation is investigated less frequently because facilitative behaviors are often normalized in relationships and may become less noticeable to relational partners (Solomon et al., 2016). Yet, caregiving spouses perceived seemingly small, almost unnoticeable, aspects of their partners' communication as facilitation. 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). Caregiving spouses attributed meaning and positive intention to their partner's behaviors,

allowing them to experience facilitation from their partner even in the late stages of ADRD. Solomon and Priem (2016) found that relational turbulence increased perceptions of partner supportiveness directly following a high-stress experience. The highly turbulent nature of ADRD, might have made caregiving spouses extra sensitive to their partner's potentially facilitative behaviors enabling them to experience facilitation whether the behavior was intentional or not.

Taken together, these findings about the interplay between relational certainty and uncertainty and participants' tendency to perceive interference and facilitation despite their partner's cognitive decline, shed light on caregiving spouses' experiences of managing and sustaining relationship throughout this prolonged relational transition. Although relational challenges such as increasing dependence, role changes, and loss of intimacy have been well documented in ADRD (Evans & Lee, 2014; Harris et al. 2011), the literature suggests that caregiving spouses also maintain a sense of closeness and love for their partner (Ablitt et al., 2009; Wadham et al., 2016). Boylstein and Hayes (2012) found that both disruption and reconstruction of the marital relationship are ongoing parts of ADRD. Interference and facilitation from the partner provide one means of explaining these paradoxical findings. Even though all participants experienced interference from their partners, their propensity to perceive continued instances of facilitation enabled them to maintain a sense of connection and relationship with their partners despite relational decline. Further, faced with the intractable interplay between certainty and uncertainty, caregiving spouses focused their attention on the good of the present moment enabling them to sustain a sense of connection despite the relational challenges of ADRD.

Limitations and Directions for Future Research

The limitations of this study point toward opportunities for future research. First, this relatively small sample could not capture the wide diversity of marital relationships and was limited to individuals willing to share their experiences. As such, this study provides rich insight into the experiences of these participants but may not fit the experiences of all caregiving spouses. We failed to collect information about participants' disability status and relationships quality which may have influence individuals' willingness to participate in the study. Caregiving spouses with more positive relationships with their partners may have been more likely to volunteer to participate, resulting in limited insight into discordant ADRD relationships. Future work should seek samples that are diverse in terms of race, gender, sexuality, disability status, and relationship quality. Second, factors outside the scope of this study may have affected participant's appraisals of their relationship such as the quality of the relationship prior to the onset of ADRD, the partner's age when diagnosed, the health of the caregiving spouse, and length of time providing care. These factors should be considered in future research.

Third, the nature of ADRD prohibited us from collecting data from partners with dementia and although most relational ADRD research has focused solely on the caregiving spouse's perspective, this leaves the relational experiences of PWD relatively unknown (see Wadham et al., 2016). Future research should investigate the relational experiences of PWD including their experiences of relational uncertainty and interference and facilitation. Fourth, although this dataset includes perspectives from caregiving spouses at different stages of the disease trajectory, the retrospective and cross-sectional nature limits insight into the ways the relational experience might shift across the disease trajectory. A fruitful next step would be a longitudinal approach using diaries and interviews with both partners to fully capture their relational experiences across the disease trajectory. Future translational research encouraging

caregiving spouses to look for facilitation from their partner and focus on the present moment might also be beneficial in gaining further insight into this relational transition and supporting couples affected by ADRD.

Conclusion

This study extends relational turbulence theory by identifying the interplay between relational uncertainty and the certainties of decline and death in ADRD and highlights the ways in which this interplay alters the experience of prolonged relational transitions. This study also sheds light on the experiences of interference and facilitation in relationships that are shifting from interdependence to dependence, and showed that even in cases of severe dependence, facilitative communication may help maintain a sense of relational connection. Caregiving spouses' ability to center the positive experiences in their relationships enabled them to sustain a sense of relational closeness despite the challenges of ADRD. To put it in the words of one of our participants, "love wins because dementia will rob the brain, but I believe it doesn't rob the heart" (Bella).

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Appendix A: 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 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 achieve your goals and 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 achieve your goals and 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!