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Toward a Theory of Rhythmic Synergy in Caregiving for Older Adults Living with  
Dementia

A Thesis submitted in partial satisfaction of the  
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in Communication

by

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Lastly, to my mom. Mom, here's to creating and savoring more moments of love, joy, and presence with you.

## ABSTRACT

### Toward a Theory of Rhythmic Synergy in Caregiving for Older Adults Living with Dementia

by

Chloe Elizabeth Gonzales

As family members and their loved one living with Alzheimer’s disease and other related dementias (ADRD) navigate their new reality as a family, understanding how they communicatively manage challenging interactions while also foster moments of joy and emotional co-presence is a pivotal concern for all stakeholders. Caregiving informally has been associated with poor physical and mental health outcomes, and the unique challenges inherent to an ADRD diagnosis present significant complexities. Given that the trajectory and symptomology associated with ADRD are highly unpredictable, this can create an overwhelming number of uncertainties for families. A hallmark of these conditions is the impact that cognitive changes have on communication ability, which can make fostering meaningful interactions and feeling confident about care-related decisions even more uncertainty-inducing. Previous research examining how family members and their loved ones living with ADRD communicate tend to focus on limited recommendations rather than the process that led to these strategies. In addition, previous research investigating the needs of family caregivers of loved ones living with ADRD suggest a deeper analysis on how

exactly family members can better support each other that ultimately help them to work together to compassionately care for their loved one.

The construct of rhythmic synergy emerged from the narratives of 31 adult family caregivers who were currently providing care (or had previously provided care) for a loved living with ADRD. The interviews were analyzed to understand how informal family caregivers navigate their experiences with regards to how they make sense of their caregiving experience, learn to communicate specifically with their loved one, and how the family navigates trying to come together to coordinate care. By focusing on the process of communication at both the dyadic level and family level, a more nuanced picture of communication in the family caregiving context became clearer. Rhythmic synergy conceptualizes the way people develop and continually evolve their communication patterns by being sensitively attuned to the abilities of someone who has differing communication abilities related to a cognitive condition. The goal of creating rhythmic synergy is that it not only eases certain aspects of caregiving but also becomes a way to promote social and emotional presence. Overall, the construct of rhythmic synergy bridges together multiple bodies of literature and offers several theoretical contributions, namely focusing specifically on the role of communication as a temporal process. As for practical contributions, rhythmic synergy helps conceptualize how family members and care partners can better perceive their communication patterns to ultimately nurture moments of connection and co-presence with the loved one and work together as an entire family to coordinate care.

## **Toward a Theory of Rhythmic Synergy in Caregiving for Older Adults Living with Dementia**

Every three seconds, someone in the world develops dementia (Alzheimer's Disease International, 2018). Dementia is not a single disease but encompasses a host of dementia-related diseases, with Alzheimer's disease as the most common type (National Institute on Aging, 2021). In the United States, there are an estimated 6.5 million people age 65 and older living with Alzheimer's disease and other related dementias (ADRD; Alzheimer's Association, 2022). Most of the care comes from family members, who in 2021 provided an estimated 16 billion hours' worth of informal (i.e., unpaid) care, amounting to an average 27.1 hours per week (Alzheimer's Association, 2022). The total lifetime cost of care for someone living with ADRD in 2021 was \$377,621, of which 70% was borne by family caregivers, making it one of the costliest group of diseases (Alzheimer's Association, 2022; El-Hayek et al., 2019). While the socioeconomic impact is alarming, what is perhaps more pressing is the impact ADRD has for the family caregivers, especially given the additional stress created by the COVID-19 pandemic (Cohen et al., 2020).

Even though there are positive effects of being a family caregiver, such as growing in love and companionship (Lloyd et al., 2016; Yu et al., 2018), the research overwhelmingly suggests it is a stressful and uncertainty-producing experience (Gilsenan et al., 2022). Family members, especially those that provide aid with tasks like activities of daily life (e.g., bathing, feeding, incontinence), often experience psychological, physical, emotional, and social stressors that contribute to their distress (Lindeza et al., 2020; McCabe et al., 2016). Being a caregiver also involves managing the shifting uncertainties associated with the psychological and cognitive declines of ADRD that ultimately impact their communication

with their loved one and the other care providers with whom they are coordinating the care (Banovic et al, 2018; Kim et al., 2017).

Communicating with a loved one living with ADRD is difficult because of the unpredictable nature of the behaviors associated with ADRD progression (Cerejeira et al., 2012). Perhaps one of the most important challenges when communicating with a loved one living with ADRD is how to adapt one's communication to that person in order to reduce the likelihood that they will become agitated and distressed (Nickbakht et al., 2023; van Manen et al., 2021). Consequently, drawing upon literature across multiple disciplines and interviews with caregivers of older adults living with ADRD, the purpose of this thesis is to set forth a new construct of *rhythmic synergy* and its underlying theoretical properties in order to address this issue. Specifically, this study examines how family caregivers use communication to establish rhythms with a family member living with ADRD in order to manage stress and uncertainty, as well as promote moments of joy and presence. This study also explores how family members and other care partners enhance or disrupt that rhythm and the potential consequences.

This project has numerous theoretical and practical contributions. Theoretically, the construct of rhythmic synergy extends the extant research by highlighting the temporal and processual nature of communication in the caregiving experience (Werner & Baxter, 1994). In addition, rhythmic synergy builds on the research on social entrainment (McGrath & Kelly, 1986) and interpersonal synchrony (Bernieri et al., 1988; Cacioppo et al., 2014; Koban et al., 2019) by focusing on how rhythms are established and maintained through verbal and nonverbal communication patterns and actions with someone with a cognitive impairment. Practically, rhythmic synergy offers care partners a way to understand and identify how they



can engage and adapt their communication in a personalized way to someone living with ADRD in an effort to better manage uncertainty, reduce stress and moments of chaos, and promote co-presence and connection (Candlin & Candlin, 2016; Finfgeld-Connett, 2006).

### **Uncertainties and Family Caregiving**

In order to articulate how and why family caregivers establish a rhythmic synergy with their loved one living with ADRD and the role that family members play in this process, it is important to first understand what uncertainty is and the types of uncertainties these caregivers experience. In an effort to understand how people navigate initial interactions between strangers, uncertainty reduction theory (URT) conceptualized uncertainty as undesired and something that people always wanted to reduce (Berger & Calabrese, 1975). However, other scholars have since questioned this assumption. For example, Sunnafrank (1986) proposed an alternative approach to URT with an emphasis of one's perception of a predicted outcome with another person as the motivating force. This model challenged the notion that reducing uncertainty inherently leads to positive relational outcomes (Sunnafrank, 2015).

Other scholars (see Babrow & Kline, 2000; Fowler & Afifi, 2011; Mishel, 1990) have examined uncertainty with illness, aging, and other contexts and argued that uncertainty is something that people do not always want to reduce. People with chronic illnesses cannot reduce their uncertainty in the traditional ways people with short-term illnesses can and they subsequently learn how to manage it. Ultimately, uncertainty management theory (UMT; Brashers, 2001) was a response to the assumptions of uncertainty reduction theory (URT; Berger & Calabrese, 1975). In this way, uncertainty was conceptualized as something people seek to manage by keeping their uncertainty the same, reducing it, or even increasing it, and

not necessarily always reducing it. Therefore, Brashers (2001) defines uncertainty as existing when “details of situations are ambiguous, complex, unpredictable, or probabilistic; when information is unavailable or inconsistent; and when people feel insecure in their own state of knowledge” (p. 478). Research has supported ADRD family caregivers as finding uncertainty, as conceptualized by Brashers (2001), as salient to their experiences (Cooper & Pitts, 2022; Stone, 2013; Stone & Jones, 2009). While understanding what uncertainty is and how people respond to it is necessary and important, what requires additional examination is how family caregivers use specific communication patterns with their loved one living with ADRD and fellow care partners (i.e., family members, friends, professionals) to manage the unique dementia-related uncertainties they experience.

The uncertainties family caregivers experience are two-fold, with the first being uncertainties related directly to caring for the loved one living with ADRD and the other being coordinating care with family members. The uncertainties caring for someone living with ADRD stem largely from the effects of the condition itself and its progression. First, ADRD are typically organized into early/mild, middle/moderate, and late/severe stages that give way to providing some insights into how there are particular caregiving demands and uncertainties that are likely to emerge at each stage (World Health Organization, 2021). In fact, Brashers (2001) pointed out that different kinds and degrees of uncertainty can be salient during certain stages of an event like an illness. As a result, uncertainties specific to each stage of the ADRD trajectory speak to the desire caregivers likely have to create predictability. This predictability is created through their awareness of their loved one’s communication and subsequently adapting their own communication and the communication of other care providers in their family system accordingly.

There is also a great deal of individual variability with ADRD diagnoses (National Institute on Aging, 2021). Even though each type of dementia has distinguishing behavioral and cognitive markers, it can reveal itself very differently depending upon the individual. In addition, it is hardly ever the case that any one specific type of symptom marks a discernable and permanent progression to the next stage (Alzheimer's Society, 2021). In fact, the Mayo Clinic (2021) asserts that Alzheimer's disease is a continuous process and that the stages are only rough generalizations. Consequently, this further adds support to the idea that family caregivers of someone living with ADRD might be utilizing specialized ways to communicate with their loved one to create predictability and keep their loved one calm. While this unpredictability of symptoms and progression through the stages would indicate that having a routinized communication would eventually become ineffective, it would make sense that caregivers would still try to create strategies and adapt as the symptoms change (Braithwaite-Stuart et al., 2022).

Another aspect of how the symptoms related to the condition of ADRD can create uncertainties for caregivers are related to the cognitive deficits (i.e., losses in brain function related to memory and learning) and behavioral and psychiatric symptoms (e.g., aggression, delusions, depression; Gulli et al., 2020). For instance, caregiving spouses have expressed uncertainty about being able to care for their partners as their partners undergo psychological changes, such as becoming more aggressive, caused by the dementia (Cooper & Pitts, 2022). Similarly, Jones (2015) analyzed 70 phone calls over a two and a half year period between a mother living with dementia and her daughter and son-in-law. They sought to better understand how dementia changes a person's capacity to communicate with others and found striking instances of co-constructed communicative problems. The family illustrated the

challenges of maintaining a collaborative interaction by identifying some of the pitfalls of the adult children (e.g., asking questions that make the loved one engage with an episodic memory) and choices made by the loved one (e.g., repetitive questions, skillfully eliciting further information so a more definitive response can be made).

Making these conversations even more challenging are the nature of the topics themselves. Deciphering out how to communicate with the loved one about sensitive topics, such as them no longer being able to drive due to safety concerns, is an uncertainty for many caregivers (Hoang et al., 2022). In fact, in a study exploring how to improve the anticipatory guidance given by clinicians, Shafir et al. (2022) interviewed people living with ADRD and ADRD family caregivers on their retrospective attitudes of guidance from their physicians after receiving the diagnosis. Of note, they found that people had an array of uncertainties that were ultimately insufficiently addressed, including behavioral, safety, and communication issues. Other caregivers have cited a lack of communication efficacy, and subsequent uncertainty, regarding even more complex topics like when and how to tell the truth regarding their loved one's dementia or related illness (Merl et al., 2022).

These concerns about the 'what' and 'how' of communicating with a loved one with dementia can be further complicated by family roles and relational meanings (Quinn et al., 2015). For instance, research has found that adult children caring for their parent living with ADRD are stressed about having to adopt the seeming reverse role of being a caregiver to their parent (Dupuis, 2002; Sanders & Corley, 2003; Stone & Jones, 2009). Moreover, interviewing primarily spouses, van Wijngaarden et al. (2018) found that their participants struggled with losses of equality and reciprocity as well as a kind of exhaustion in feeling "imprisoned" in their own home with their spouse. Determining how to communicate with

their loved one, as well as simultaneously conversing about complex topics like mortality, are likely prime uncertainties for many families.

The second primary domain of uncertainties related to ADRD involves coordinating care with other family members. Adding other family members into an already highly uncertain caregiving experience contributes to the complexity involved. From deciding who will accompany doctor visits to establishing who gets legal privileges like power of attorney, it is likely intensive and straining for family members to divide as well as share tasks (Halliwell et al., 2017; Lin & Wolf, 2020). In a study involving focus groups of family caregivers, Unson et al. (2015) described family conflicts and lack of social support as a major uncertainty. For their participants, conflict occurred not just between them and their ill loved one but also between them and their spouse, siblings, children, and other relatives as tensions about unequal involvement with caregiving became salient. The authors also found that the stress of caregiving exacerbated long standing family tensions. This exacerbation created uncertainty because it made it difficult to know what caregiving role each sibling would adopt, whether it would get enacted effectively or at all, and the extent to which the caregiving would be disrupted.

Similarly, Stone and Jones (2009) found that their adult children participants shared how caregiving put a strain on their relationships with their siblings concerning issues ranging from the equity of caregiving, particularly with regard to some siblings living closer than others, to the acceptance of the diagnosis itself. In the case of distance, the more proximal caregivers could find themselves taking more of the share of caregiving responsibilities and thus draining more of their resources. This issue of inequity could create a situation where the overloaded and distressed caregiver finds themselves trying to

communicate with their other family members to be more involved. However, any kind of upheaval or disagreement these conversations could create would end up absorbing their already precious spare time and become an additional unnecessary stressor altogether. Aside from siblings, Stone and Jones (2009) also found that the adult children experienced uncertainty and conflict with their parent who did not have Alzheimer's over the kind of care the parent who was ill should receive. Overall, conflicts concerning who is involved in caregiving and to what extent it is a major point of uncertainty for families and care partners. As the uncertainties likely change as the loved one progresses through the stages of their dementia, so do the uncertainties with the other family members as the roles and capabilities of each person evolve.

Recognizing how families are embedded with prior histories and relationships that likely impact caregiving related uncertainties is important. Better understanding the family unit and their own specialized communication patterns can potentially help ease caregiving. For example, Esandi et al. (2021) investigated the full range of experiences of a family navigating caring for their loved one diagnosed with Alzheimer's disease. By interviewing seven family units, they were able to develop four different typologies of family dynamics. Their theory of family dynamics in Alzheimer's disease incorporated not just present interactions and values but also recognized the influence of past interactions and histories that shaped the ways in which families reacted to the diagnosis. These factors included prior family relationships and history, motivation to care, family roles and organization, communication patterns within the family, and the family vision for the future. In this way, there is increasing interest on examining how the ADRD caregiving experience impacts an

entire family system and how to better understand the specialized communication patterns within families.

One way that caregivers might navigate the uncertainties they experience with their loved one living with ADRD is by using communication to create a “rhythmic synergy” with them. Then they can share these techniques with the other family members and care partners to facilitate better cohesion and support. Thus, a rhythmic synergy can be created at the family level as well. In the sections that follow, multiple related bodies of literature are discussed in an effort to lay a foundation for this new theoretical construct. Its underlying theoretical properties are then set forth in the findings from interviews with family caregivers.

### **Rhythmic Synergy**

Thinking about the specialized communication processes among family members caring for a loved one living with ADRD calls into question the notion of temporality. Because of the inherently unpredictable nature of ADRD symptomology, families are ideally situated to speak to the ways in which their communication evolves over time. More importantly, the implications the communication has on the interpersonal relationships can be conceptualized as a dynamic process of iterative changes (Werner & Baxter, 1994). As the loved one begins to experience increasingly demanding physical and psychological challenges, family members and other care partners may become especially sensitive in recognizing and adapting their communication to accommodate their loved one. Learning those cues and strategies along with sharing them with others remains unexplored in the communication literature and beyond. Of the studies that attempt to understand the communicative needs and patterns of ADRD caregivers, the conclusions provide extremely

broad generalities about communication, such as classifying communication strategies as helpful and unhelpful (Polenick et al., 2020; Braithwaite-Stuart et al., 2022), which might not be particularly useful for theory or practice.

Some scholars like Eggenberger et al. (2013) have identified and organized specific skills and strategies used by caregivers. However, how and why these skills and strategies were created in the first place and subsequently refined by the caregivers while communicating with their loved one living with ADRD is unknown. Relatedly, other scholars like Polenick et al. (2020) have noticed larger patterns of how caregivers view approaching communication with their loved one like making analogies of “going with the flow.” Similar to specific communication tactics family members use to establish a rhythm or “flow” with their loved one, it is important to understand what that sensemaking process is like for families as they create their caregiving approaches. Unlike previous research, the current study adopts more of a nuanced approach to the communication process of creating a rhythmic synergy with a loved one living with ADRD and how the process operates in the caregiver-care recipient relationship as a sensemaking tool. What is the essence of the way people communicate caring for someone who lives with a condition that differentially impacts their cognitive, emotional, and psychological presence? Moreover, how does this greater understanding become a way that caregivers make sense of the process of their experience?

Through interviews with caregivers of older adults living with ADRD, the construct of *rhythmic synergy* and its related theoretical properties was inductively generated.

*Rhythmic synergy* is defined here as *the result of the process by which a person strategically enacts reoccurring and patterned prosocial behaviors and other communicative actions that*



*develops into a communication-based repertoire of person-centered knowledge, known as macro- and micro-rhythms, with another person who has differing cognitive abilities that impact their ability to communicate. By developing more specialized and effective ways to communicate with the other person, rhythmic synergy becomes a way to navigate experiences with more ease that ultimately creates a higher order social connection and sense of co-presence between the individuals.*

The interpersonal communication between two or more people is what creates and sustains the construct of rhythmic synergy. When interacting and caring for someone who lives with differing cognitive abilities that impacts their communication, people often need to adopt new ways to communicate effectively (i.e., macro- and micro-rhythms). Rhythmic synergy attempts to capture the dynamic, interactive element of this unique process of trial and error. The communication behaviors and cues enacted are central to how rhythms are co-constructed. This iterative co-constructed, communication process is not a simplistic series of back-and-forth actions and reactions. Because of the continually changing nature of AD/HD, the iterative process of creating rhythmic synergy is ongoing and the rhythms created are continually and simultaneously evolving as the loved one's behaviors change. In this way, the construct conceptualizes the trial and error of the creation of these rhythms as a series of feedback loops as the caregiver simultaneously adapts to their loved one's behavior over time.

In the case of caregiving, the caregiver does not simply respond to their loved one's behavior devoid of the prior behaviors and responses. Responding is a process that continues to build on itself. Consequently, synergy becomes an integral part of the rhythm. The synergy also assumes that this process is an interpersonal interaction with at least two people. When

an identifiable kind of rhythm is established where the caregiver can sense that the desired outcome is being achieved consistently (e.g., the loved one is less agitated), the communication, while still effortful, becomes less intensive for the caregiver to enact. The caregiver can lean on the rhythm as the communication of the caregiver and corresponding communication of the care recipient become more routinized and predictable. The problem, of course, is that ADRD behaviors are often unpredictable and can change at any moment if something triggers the loved one (Cerejeira et al., 2012). As it will be illustrated in the findings, however, those unpredictable behaviors become predictable and can still be used to establish rhythmic synergy.

A higher order result from creating rhythmic synergy would be the new meanings of connection, insight, and understanding of and with the loved one (Candlin & Candlin, 2016; Finfgeld-Connett, 2006). For example, when a caregiver notices their loved one's anxious behaviors, they likely attempt to make sense of the changes by enacting different strategies to calm them down (van Manen et al., 2021). Ultimately, the caregiver would hopefully determine what communication strategies are most effective at calming their loved one when this specific behavior occurs. In this situation, the rhythm of a touch of a hand can take on a whole new level of meaning beyond utility (Fredricksson, 1999). Therefore, constantly being sensitive to and refining the communication patterns between care partners and their loved ones can not only help create meaningful communication but also be an important way to maintain the relationship (Alsawy et al., 2019; Ward et al., 2008).

Relatedly, this notion of rhythmic synergy can also speak to the ways in which some caregivers may be leading the charge to get other family members to adopt the same or similar rhythm with the loved one. The family members and care partners could

communicate with each other so that everyone can find their own rhythmic “grooves” with the loved one to help make the caregiving experience easier. If a caregiver and a loved one are in a kind of rhythmic synergy, how might that caregiver attempt to have others become “in sync” with their loved one as well? Just as some people can learn and acquiesce to an established pattern of doing things (i.e., rhythmic synergy) that creates a positive change (i.e., enhancing the rhythm), others can intentionally or unintentionally interrupt an established rhythmic synergy that would create a negative change (i.e., disrupting the rhythm). Communicating to get members on the “same page” and appropriately adjust when someone gets “out of step” is another element of rhythmic synergy.

Rhythmic synergy can be a relational mechanism used by caregivers, who often need assistance understanding the impact of a health stressor like a family member’s ADRD diagnosis on the family system (Morris et al., 2020). Taking 1) the notion rhythmic synergy created with the loved one living with ADRD alongside 2) the idea of everyone’s rhythms with the loved one and each other getting in lockstep with each other can be a way of helping families better understand their experience and work together to successfully caregive as a collective. Embedded within the construct of rhythmic synergy is how these communication efforts are occurring throughout time. Therefore, a detailed analysis of the temporal qualities of communication is necessary.

### ***Temporality in Rhythmic Synergy***

As caregivers create rhythmic synergy by continually adapting their communication with their loved one as symptoms increasingly change their loved one’s cognitive and psychological abilities, the function of time cannot be overlooked. Rather than thinking about

the communication patterns as momentary fixes, rhythmic synergy requires recognizing and understanding the relationship between communication and time as evolving.

Werner and Baxter (1994) offered a framework outlining the temporal qualities of communication. Their goal was to articulate underlying assumptions about the dynamic nature of relationships by identifying five temporal aspects of communication. As such, they sought to understand how temporal qualities contribute to relationship viability or “the extent to which the individual or group can function to stay alive psychologically and socially, to flourish, to grow and change, and to achieve short- and long-term goals” (Werner & Baxter, 1994, p. 324). Organized into two overarching dimensions, a linear perspective views relationships as always changing, never to repeat or be able to “go back” to a particular stage or way of being. Events themselves may have continuity for a relationship, such as with repeated wedding anniversaries, but the relationship itself is never the same again. On the other hand, a cyclical/spiraling perspective emphasizes relationships as characterized by recurring events. However, they recognize that no interaction is exactly replicated each time. Consequently, a cyclical/spiraling perspective does assume some development. The cyclical/spiraling time dimension supports rhythmic synergy’s underlying assumption of how relationships operate as patterned and ever evolving in a recursive way, which also allows for flexibility in some irregularity.

Looking specifically at cyclical/spiraling time, Werner and Baxter (1994) provide five temporal qualities: amplitude (height of curves represent the intensity or degree of change in affect, behavior, or biological variables), salience (whether the time orientation of a recurrent activity emphasizes the relationship’s past, present, and/or future), scale (duration of the reoccurring events and duration of the interval between these events), sequencing (the

order and repetitions of the same or similar series of behaviors), and pace or rhythm (defined by all the previous qualities; the pace of any recurrent activities remains fairly constant or regular). A spiraling rhythm can be portrayed as smooth sine waves where there is consistency in the time between the onset and offset of the activity (i.e., pace), height of the curves (i.e., amplitude), and the cycle lengths themselves (i.e., scale).

Importantly, rhythm is exclusive to the cyclical/spiraling time dimension, not the linear time dimension. Subsumed within the idea of cyclical rhythm, Werner and Baxter (1994) discuss the concepts of entrainment and synchrony, which they define as the “willingness and ability of two partners to effectively coordinate their individual cycles into an overall rhythm” (p. 333). They go on to discuss the notion of mutual social entrainment or how people coordinate their interactions with their partners over time. Werner and Baxter (1994) were building their idea on McGrath and Kelly (1986), who first borrowed the idea of entrainment from the biological sciences as the basis for their social entrainment model. McGrath and Kelly (1986) describe entrainment as when “one cyclic process becomes captured by, and set to oscillate in rhythm with, another process” (p. 80). While strongly researched at the physiological level, the authors propose that entrainment can occur at psychological and social levels. At the physiological level, human circadian rhythms like body temperature and heart rate are entrained or coupled biological rhythms (Bente & Novotny, 2020; McGrath & Kelly, 1986).

In McGrath and Kelly’s (1986) social entrainment model (see Figure 1), the *rhythm* component describes endogenous temporal processes (e.g., biological and behavioral processes), the *mesh* component entails a system or regulating device as establishing and maintaining mutual entrainment of those multiple endogenous rhythms, the *tempo*

component consists of the temporal patterns expressed as behaviors, and *pace* illustrates the external factors and other cycles that can impact any of the three temporal patterns. The authors offer an example that incorporates all of these elements with two individuals having a conversation. Each person enters the conversation having their own idiosyncratic temporal patterns (i.e., rhythms) that influence their personal preferences for conversational patterns. In order to have an understandable and substantive conversation, both individuals must coordinate their individual conversation patterns with one another (i.e., mesh). The result of their coordination is a kind of temporal pattern of conversation behavior specific to these two individuals (i.e., tempo). Lastly, an example of an external event that would “disrupt” their established tempo (i.e., pace) would be if one of the individuals learned the other is actually an expert on the topic of their conversation. Alterations to the speaking and listening choices would be the resulting impact of the external factor of expertise differences as a kind of *pace* would change the overall *tempo*.

Rhythmic synergy contributes to the work of both McGrath and Kelly (1986) and Werner and Baxter (1994) in two key ways. First, McGrath and Kelly’s (1986) social entrainment model outlines the steps and factors of what people entraining to each other could potentially look like. In this way, their work supports the general idea within rhythmic synergy of rhythms as something that can be created and influenced as an entity itself. In addition, the components of the authors’ model offer a way to visually represent the underlying pathways that are proposed in rhythmic synergy (see Figure 2). However, the way rhythmic synergy builds off the social entrainment model is by bringing in the communication element that is assumed and thus lost within the model. It is unclear how exactly people communicate to entrain to one another over time, in particular. This is where

rhythmic synergy redefines the process of social entrainment. The relationship between the model's concepts of *mesh* and *rhythm* as well as the role of *pace* on the other three concepts all assume communication, but it is never acknowledged nor has research further refined this conceptualization with a lens of interpersonal communication until now. By foregrounding communication's role, rhythmic synergy extends what is known regarding how people become interpersonally entrained or "in sync" with one another.

Second, Werner and Baxter (1994) offer the first touchpoint of the concept of entrainment within the field of interpersonal communication outside the topic of nonverbal mimicry and synchrony behaviors. In their conceptualization of cyclical/spiraling time dimensions and temporal qualities, the authors explore the idea of how one way of explaining how people create a cyclical/spiraling rhythm together in the first place may be because they are coordinating their individual cycles (i.e., mutual entrainment). Ultimately, the authors pose that the extent to which individuals' rhythms can be coordinated or coupled with others determines relationship viability. In this way, they are making an argument for the importance of successful coordination of peoples' rhythms. However, one could argue that the stakes for relationship viability are profoundly high in the case a relationship with someone living with ADRD. Therefore, importantly, rhythmic synergy challenges an underlying assumption within what is known about social entrainment and interpersonal communication. What happens when one person out of the dyad has cognitive challenges due to a condition and sometimes is unable to regulate their own communication and emotions? It centers on situations where one person (i.e., care partner) is attempting to establish a rhythm with someone whose cognitive abilities inhibit their communication processes.

In all other previous research, the assumption is that both communicators are freely and equitably able contribute to the establishment and maintenance of a rhythm (see also Baxter et al., 2002). When the caregiver does not willingly engage in creating a rhythmic synergy with their loved one, the relationship viability is likely to suffer with consequences for the loved one and potentially one's self (e.g., more erratic behaviors and crises on the part of the loved one with cognitive impairments because of the lack of an established rhythm, which creates uncertainty and stress for the care provider). Since research demonstrates how social engagement and quality relationships are two of the most significant factors related to quality of life and subjective wellbeing in older adults living with ADRD, a lack of communication would likely result in a loss of social presence as well as increased distress and loneliness (Martyr et al., 2018). In addition to extending interpersonal communication and entrainment theorizing, rhythmic synergy importantly makes inroads regarding interpersonal synchrony.

### ***Interpersonal Synchrony and Rhythmic Synergy***

Scholars in many disciplines have taken entrainment and given it life in the area of interpersonal synchrony. The concept of interpersonal synchrony can be defined as the “mutual attunement of biological and behavioral rhythms between interactants” (Novotny & Bente, 2022, p. 487). The concepts of interpersonal synchrony and behavior matching (i.e., mimicry) are subcategories of the larger category of interpersonal coordination (Bernieri & Rosenthal, 1991). Whereas mimicry involves the imitation of another's actions with a time lag of a few seconds, interpersonal synchrony occurs when two or more people exhibit a kind of repetitive motion, can perceive each other, and are prone to engage in a shared pattern by synchronizing (Bente & Novotny, 2020; Stupacher et al., 2017). Rhythmic synergy



contributes to the scholarship on interpersonal synchrony in two distinct ways. The first is combining two sub-concepts to further support the notion of differing communication abilities when it comes to interactions. The second is providing support for the area of perceived synchrony.

To address the first contribution, there are two sub-concepts within interpersonal synchrony related to entrainment that have not been combined before. Doing so offers support for one of the underlying assumptions of rhythmic synergy. Koban et al. (2019) contend that interpersonal synchrony be divided into two types where one involves synchrony that is unintentional or spontaneous whereas the other is intentional. The role of intentionality helps further support the need for the concept of rhythmic synergy because the efforts of the caregiver are intentional and effortful whereas the behaviors by the loved one fluctuate depending on their cognitive state or abilities. Because the loved one could be doing less of the entraining, this creates another question of whether a concept has been created to account for this.

Speaking to this exact question, Cacioppo et al. (2014) explained three types of entrainment processes within motor level interpersonal synchrony. The focus of their study was on unilateral entrainment, which pertains to one person entraining their behavior to another person. In their study, they used an experimental task where the participant was the referent and was told they had a partner who was trying to synchronize with them. The participant would click a key on a keyboard at the designated frequency of one click every second to create a series of beats or pulses. They were instructed to focus on this beat frequency regardless of their partner's beat frequency. The participant was also told their partner was tasked with responding to their beat with no time constraint. Thus, the participant

was supposed to think that their partner was trying to match nearly exactly the same tempo of their beat frequency as a kind of synchronization. Unknown to the participant, their partner's beats were actually generated by a computer program. In this way, the researchers could manipulate the frequency of the partner's beats and thus alter the perception the participant had on how much their partner was entraining or synchronizing to their beat frequency. This study and others offer valuable support in the kind of accommodative entraining and rhythm creation the caregiver likely does in comparison to their loved one with dementia. What remains unknown is how this kind of unilateral entrainment operates within an interpersonal interaction where features like walking strides and brain activity scans are not the focal points of the interaction (Gordon et al., 2014; Miles et al., 2009). There has yet to be a concept that touches on the notion of unilateral, intentional entrainment at an interpersonal communication level within interpersonal synchrony. Instead, scholars in this area examining communication within interpersonal synchrony are either in the realm of conversation analysis or nonverbal behaviors (Bente & Novotny, 2020).

Addressing the second contribution, rhythmic synergy offers another example of a subjective type of synchrony. Bernieri et al. (1988) articulate that the essence of synchrony is “the sustained non-random co-occurrence of two behavioral phenomena” and that when the two behavioral elements are unified, they describe a whole “perceptual unit” (p. 244). They go on to categorize synchrony into three broad categories: biological rhythms, simultaneous behavior, and perceived synchrony. Various studies have explored notions of perceived synchrony, and scholars have started to go toward a direction of “sharing of emotional experience” as a dimension of perceived synchrony (Scheidt et al., 2021, p. 2). For example, Mühlhoff's (2015) concept of affective resonance describes the experience of moving with

and by others that constitutes a quality of “being-in-relation” that does not focus on individual voluntary behaviors with a specific target state but rather being in an experience of relatedness (p. 1011). A similar notion of this emotion sharing is also evident with Stern’s (1985) concept of affect attunement which refers to coordination in vocal utterances, facial expressions, and body movements among infant-caregiver dyads that create an immediate “experience of feeling-connectedness” (pp. 156-157). In this way, rhythmic synergy contributes to the category of perceived synchrony, given that it is a form of creating moments of shared connection through being attuned to another’s physical and emotional states. This contribution also is inextricably a factor to support why rhythmic synergy is used in the first place and why it matters, which is detailed below.

### ***Why Rhythmic Synergy is Used and Why it Matters***

One of the reasons why rhythmic synergy is being established here is that it could be connected to the reasons why people engage in interpersonal synchrony. Scholars have found empirical evidence for many positive social consequences of interpersonal synchrony, including rapport, social cohesion, cooperation, and compassion (Bernieri, 1994; Launay et al., 2016; Reddish et al., 2013). In fact, synchrony in autonomic physiology (e.g., heart rates) has been associated with constructs like higher-quality relationships and behavioral indicators of positivity resonance (Helm et al., 2014; Wells et al., 2022). As such, rhythmic synergy could be associated with similar positive outcomes like with interpersonal synchrony. Another equally viable explanation is that having a more organized way of communicating with a loved one living with ADRD or other cognitive impairments, as well as with others in the family system to cope communally, could speak to caregivers’ desires for control and predictability. In addition, caregivers could be trying to improve the quality of

life of their loved one. By trying to proactively anticipate their loved one's behaviors and emotional well-being, the caregiver could be effectively curbing, or preventing altogether, some of the negative consequences of some ADRD symptoms like agitation or anxious thoughts.

Advancing these considerations, identifying the positive and negative consequences of creating rhythms or routines is necessary. Clark (2000) makes a strong argument for the benefit of having habits and routines on quality of life. The author offers five key hypotheses that outline functions of habits and routines from the perspective of the person enacting the habits and routines for themselves: 1) habits as allowing creativity and innovation because relying on routines can free up the brain's limited cognitive effort capacity, 2) habit and routine as enriching lived experience because they enable people to predict and plan which are essential to survival, 3) habit and routine as important to the quality of life for older people and people living with disabilities for creating outcomes like less distress, having a sense of purpose, and greater coping efficacy, 4) habits and routines having negative outcomes, such others disrupting established routines and those being distressing, routines becoming boring, and impeding spontaneity and creativity, and finally 5) habit and routine constructing identity where they can have symbolic meaning like autonomy. These hypotheses for the benefits of routines support the underlying creation of rhythms for the loved one. The caregiver could intentionally and unintentionally be promoting these positive outcomes for their loved one.

An applied example of this argument comes from the related context of people who provide care for those with other communication differences like autism. Schaaf et al. (2011) investigated the role and benefits parents of children with autism discovered when employing

individual and family routines to facilitate functioning for their child, as well as the whole family. Similarly, just as parents of children with autism can find benefit in creating and instilling routines, a goal of this study is to explore the extent to which family members caring for a loved one living with ADRD also find a similar utility instilling routines conceptualized as rhythms. Schaaf et al. (2011) describe wanting to address how families “choreograph their routines” to account for the needs of their child, which aligns with the current study as well (p. 375).

The reason why rhythmic synergy matters is because it can help family members feel like they are meaningfully communicating with their loved one, effectively coordinating care with other members of their family, and finding ways to enhance (or prevent the deterioration of) everyone’s mental, physical and relational health. Being a caregiver of someone living with ADRD can be especially challenging for many reasons. Whether it is caregiving after an already long work day or trying to lift someone without help from others or machinery, being an ADRD caregiver is often detrimental to one’s health (Brodaty & Donkin, 2009; Riffin et al., 2019). Care partners of people living with ADRD have been found to be at an increased risk of cardiovascular disease (Xu et al., 2020), depressive disorders (Cuijpers, 2005), and stress as a result of providing care (Srivastava et al., 2016). Using communication patterns to establish a rhythm will likely not only provide meaningful moments of lucidity and emotional connection where true “presence” of the loved one living with ADRD emerges (see Baxter et al., 2002), but it could also help manage uncertainty and stress and subsequently improve everyone’s mental and physical health. In fact, research, including interventions, has started to indicate that addressing improving communication is correlated

with beneficial outcomes like improved quality of life for the loved ones and care partners (Swan et al., 2018; Warren, 2021).

Moreover, the unpredictable nature of the progression of the condition and the onset of different symptoms are also major concerns for family caregivers (Hiyoshi-Taniguchi et al., 2018), which could be partially managed by caregivers learning to establish rhythmic synergy. As caregivers experience their loved one's psychological, emotional, and behavioral changes, their uncertainties, and correspondingly their rhythms, also likely change. Given all of the uncertainties related to the condition itself and how the family navigates these uncertainties over time, caregivers are likely in states of chronic stress (Allen et al., 2017), emotional overload (Ma et al., 2018), and depleted executive functioning (Pertl et al., 2017). In fact, Cheng (2017) found that neuropsychiatric symptoms were most predictive of caregiver burden and depression, especially behaviors such as agitation, aggression, and disinhibition. Therefore, helping caregivers identify to adapt their ways of understanding and communicating with their loved one to manage these uncertainties and stress as their behaviors change over the course of their condition is paramount (Nickbakht et al., 2023; O'Rourke et al., 2022).

Establishing rhythms could also help caregivers make sense of their experience, which could also contribute to reducing their stress (see also Brijnath et al., 2021; Weick, 1995). For instance, experiencing moments of fluctuating psychological presence and lucidity can be upsetting and emotionally heavy for caregivers (Boss, 1999). Being able to rely on established rhythms to create moments of emotional and social presence that are not tied to temporal factors (e.g., the loved one is functioning in a previous time period) could be a helpful way for caregivers and their loved ones to feel connected and feel each other's

meaning outside of verbal communication (Hughes et al., 2013). Drawing on the research conducted in the field of nursing, the concept of *presencing* or *presence* supports this element of rhythmic synergy. According to Finfgeld-Connett (2008), presence is an interpersonal process characterized by sensitivity and adaptation to unique circumstances that result in improved mental well-being for both nurses and patients as well as improved physical well-being for patients. Further, Candling and Candlin (2016) state that presencing oneself means that “one is available to understand and be with someone, where each person can at times share in the ‘being’ of the other” (p. 440). Within this context of nursing, the authors emphasize how there is an element of being together while the nurse imparts to the patient a feeling of the patient’s centrality. Just as “the nurse enters the patient’s world,” so would the care partner with their loved one in creating rhythmic synergy (Fredriksson, 1999, p. 1171).

In addition to the role of presence within rhythmic synergy, the way scholars have discussed presence also gives credence to examining the temporality and communication elements assumed in presence, which is accounted for with rhythmic synergy. Finfgeld-Connett (2006, p. 710) states,

Presence consists of a process that is enacted in moments or over days, weeks and years. Given extended periods of time, a rhythmic pattern of presencing develops between the nurse and patient. This process is characterized by interpersonal sensitivity and is holistically focused on each individual’s physical, psychological, and spiritual well-being.

Rhythmic synergy speaks perfectly to this conceptualization by highlighting how repeated prosocial communicative actions create patterns over time. Like with interpersonal synchrony and social entrainment, rhythmic synergy elucidates the role of communication

operating in this creation of presence. Extending this concept, rhythmic synergy also encompasses all care partners, not just professional care partners like nurses.

Therefore, similar to the notion of “co-presence” where people who experience virtual reality together can “sense” each other’s presence even though they are in an altered reality (Biocca et al., 2003), care givers could experience a type of co-presence with their loved one living with ADRD where they are psychologically and emotionally in tune with one another. Coming with a mindset of sensitivity, awareness, and continuous attunement to the loved one that creates repeated moments of presence can eventually result in a kind of ‘grand presence’ or synergy. By having this notion of presence at the forefront, a care partner having a perspective of seeking connection and joy with their loved one can help to buffer against a more pessimistic view of seeing their loved one as someone that requires needing strategies to cope with (Lin & Lewis, 2015; Sideman et al., 2023). In fact, in their study on communication with people living with dementia, Ward and colleagues (2008) advocate for the importance of maintaining a social presence for the person living with dementia as a profound element of meaningful relationship maintenance. This attunement is created and sustained through communication patterns on the part of the caregiver. Therefore, focusing on communication, as rhythmic synergy does, can help families and care partners more practically grasp creating these moments of connection and presence.

Finally, on top of a dyadic relationship, rhythmic synergy may be a helpful construct for families and other care partners to think about how they operate within a larger network together in the caregiving experience. Each person has their own rhythms and patterns in the way they function and interact with other members, including the loved one living with ADRD. Thus, rhythmic synergy becomes a useful mechanism to think about the multilayered



rhythms occurring at the same time for everyone else and how they see themselves fitting within the larger family caregiving system. Using rhythmic synergy as a mechanism could prove helpful for caregivers to actively step out of their narrow point of reference to gain a greater perspective on the caregiving experience. All care partners could mentally visualize all of the rhythms occurring at once and how some people could be helping or impeding others' rhythms. Additionally, caregivers could find utility in thinking about some of the strains and differences in their caregiving efforts as a product of the rhythms established. In this way, tensions are not individual shortcomings or failures but rather an unideal rhythm. In addition, caregivers could come to understand that the ways other family members create rhythms with the loved one may look different than their own. As a result, rhythmic synergy can help answer concerns related to communal coping (Afifi et al., 2020; Lyons et al., 1998) and family system functioning. Families could find it helpful to determine how and why some members struggle to learn and/or adhere to the strategies that have become rhythms for other members. With this information in mind, the following research questions are posed:

**RQ1:** What are the ways in which the notion of rhythm gets communicatively revealed in the caregiving experience?

**RQ2:** What are the factors that create these rhythms?

**RQ3:** What are the potential positive and negative consequences of the rhythms for the caregivers and loved one living with ADRD?

## **Method**

### **Participants**

Thirty-one adult caregivers for a family member living with ADRD participated in this study. The mean age of the participants was 57 years old (range = 20–81), with the

majority identifying as females ( $n = 27$  or 87.1%) than males ( $n = 4$  or 12.9%). Participants identified as 77.4% ( $n = 24$ ) White, 9.7% ( $n = 3$ ) Hispanic, 6.5% ( $n = 2$ ) as Asian, and 6.5% ( $n = 2$ ) as two or more races and ethnicities (Hispanic and Indigenous and White and Hispanic). Twenty-nine of the participants answered a question about their current personal annual income question. Participants ranged in financial status with six (20.7%) making less than \$25,000 a year, two (6.9%) making between \$25,000 and \$49,999 a year, seven (24.1%) making between \$50,000 and \$74,999 a year, one (3.4%) making between \$75,000 and \$99,999 a year, two (6.9%) making between \$100,000 and \$124,000 a year, three (10.3%) making between \$125,000 and \$149,999 a year, three (10.3%) making between \$150,000 and \$174,999 a year, one (3.4%) making between \$175,000 and \$199,999 a year, and four (13.8%) making more than \$200,000 a year. Data for this study were collected from October of 2022 through February of 2023.

At the time of the interviews, a little over half ( $n = 16$  or 51.6%) of the participants were giving their retrospective accounts of what their caregiving experience was like for their now deceased loved one. The rest of the participants ( $n = 13$  or 41.9%) were in the midst of currently caring for their loved one who was still alive. Only two participants (6.5%) identified as caring for their loved one in the past but now the loved one lives in a senior living community (e.g., continuing care retirement community, assisted living community, group home, nursing home, memory care unit, etc.). Therefore, they were giving their retrospective accounts but their loved one was still living. The average amount of time participants said they provided significant caregiving for their loved one was 8.1 years (range = 0–30 years). Participants were also asked how many hours per week they provided help and care. Of the 29 participants that responded to the question, 15 answered with an average

of 42 hours per week (range = 8–168). There were seven participants who offered ranges of time: 4–10, 5–10, 8–56, 10–12, 10–48, 12–16, and 72–96 hours per week. A few participants ( $n = 4$ ) mentioned how this time would depend on when they would be traveling to see their loved one and thus be in person to provide care. Therefore, as long distance caregivers, these participants did not provide a specific number to this question. Lastly, the three remaining participants answered that within the context of how their time commitment changed due to their loved one's progression into the later stages.

In terms of relationship to their loved one, most participants identified caring for their mother ( $n = 18$  or 58.1%) or father ( $n = 6$  or 19.4%). The remaining cited caring for their husband ( $n = 4$  or 12.9%), mother-in-law ( $n = 1$  or 3.2%), grandfather ( $n = 1$  or 3.2%), and grandmother ( $n = 1$  or 3.2%). Importantly, two participants were related to each other as a mother-daughter dyad. Together, both the mother and her daughter cared for the same loved one. For the mother participant, she discussed in her interview caring for her mother. For the daughter participant, she discussed in her interview caring for her grandmother. In calculating the following demographic data, the loved one of the dyad was only counted once. Of the loved ones being cared for who were still alive at the time of the interviews, the mean age was 82.1 years old (range = 73–90). Of the loved ones that were not alive, the mean age when they passed away was 83.5 years old (range = 74–97). The majority of the loved ones were identified by their family member as being female ( $n = 19$  or 63.3%) and the rest as male ( $n = 11$  or 36.7%). In addition, participants identified their loved one's racial and ethnic identities as 76.7% ( $n = 23$ ) White, 10% ( $n = 3$ ) Hispanic, 6.9% ( $n = 2$ ) two or more races and ethnicities (Hispanic and Indigenous and White and Hispanic), 3.2% ( $n = 1$ ) Asian, and 3.2% ( $n = 1$ ) Middle Eastern or North African. Regarding the type of dementia the loved

ones had, 14 (46.7%) had Alzheimer's disease, seven (23.3%) had unspecified dementia, three (10%) had mixed dementia, two (6.7%) had fronto-temporal dementia, two (6.7%) had vascular dementia, one (3.3%) had Lewy body dementia, and one (3.3%) had Parkinson's disease dementia.

If their loved one was alive, participants identified the current stage of the dementia their loved one was in. Loved ones that were still alive comprised of seven (46.7%) in the late stage, six (40%) in the middle stage, one (6.7%) in the early stage, and one (6.7%) in the early-middle stage. If their loved one was no longer alive, participants identified the stage or stages their loved one was in when they were present for providing care. Of those giving their retrospective accounts, five (31.3%) provided care through all three stages from early to the late stage dementia, five (31.3%) provided care during the late stage only, three (18.8%) provided care during the middle stage only, two (12.5%) provided care from the middle through the late stage, and one (6.3%) did not answer the question. In the mother-daughter dyad, the mother participant identified caring from the early through the late stage of her mother whereas the daughter participant only identified caring for her grandmother during the middle stage.

## **Procedures**

After gaining Institutional Review Board approval, participants were recruited through convenience and snowball sampling. The recruitment flyer included brief information about the study, the eligibility criteria, the author's contact information, and a prompt to access a Qualtrics link via a web address and QR code. To participate, respondents had to be at least 18 years old and self-identify as someone who helps take care of a family member (i.e., loved one) living with Alzheimer's disease or another related dementia (e.g.,

Fronto-temporal dementia, Lewy body dementia, mixed dementia, vascular dementia, etc.). They could have currently been providing care or providing care in the past either due to changing circumstances or the loved one passing away. By care, the recruitment flyer specified that responsibilities could include (but were not limited to) eating, assisting with personal hygiene, transferring, managing finances or legal affairs, monitoring medications, providing transportation, shopping, and doing chores (Alzheimer's Association, 2022; Johns Hopkins Medicine, n.d.). There were no restrictions regarding the distance the participant lived from their loved one, the stage of the disease the loved one was in, or the type of family relationship the participant had with their loved one. A conscious choice was made to deliberately avoid using the term "caregiver" in recruitment materials, consent forms, and interview questions to respect the perspectives of family members and their own sense of personal and relational identities (Purves & Phinney, 2012).

To recruit, the author and their undergraduate research assistants shared the recruitment flyer with people in their personal networks and digitally shared the document on their personal social media accounts such as Facebook, Instagram, and LinkedIn. The research assistants were also instructed to contact an exhaustive list of the departments on the campus of a public university on the West Coast of the United States regarding whether they would be willing to share the flyer with those on their e-mail listservs. The author contacted the organization the Family Caregiver Alliance and was able to make an online post about the study under the graduate student research section of the website. The recruitment flyer was also printed and posted around the university campus and in community spaces of the city the university is located in.

Once an individual accessed the Qualtrics link, they were able to read the full consent form and provide their consent, answer a brief demographics sheet, and provide their personal information to be contacted for a private, individual interview. The author trained their research assistants on how they were to conduct the semi-structured interviews. The author explained over several group meetings the purpose of the study, the rationale behind each interview question, proper ways to conduct themselves in the interview (e.g., if the participant gets emotional), and how to ask probing questions. In asking probing questions, the author and research assistants were able to gather more insight and detail in specific topics that were not covered in the interview schedule, allowing for more depth to emerge from the data that reflects the complexity of the participants' experiences. In individual meetings, the author practiced with the research assistants being the interviewer and being the participant as a way to demonstrate and apply their knowledge. Following the first couple of interviews, the author reviewed with the research assistants the audio and critiqued the delivery of the questions, probing questions, and overall demeanor of the interviewer as a way to improve and ensure ethical protocol.

All but one of the interviews was conducted over Zoom ( $n = 25$  or 80.6%) or over the phone ( $n = 5$  or 16.1%). One participant was interviewed in person, and the author ensured that the participant would be comfortable with where the participant chose to have their interview. Ultimately, the first part of the interview was conducted in a private room in a university building. The second part of the interview was conducted in the participant's home. Participants were asked predetermined questions regarding their overall experiences, uncertainties, communicative patterns and routines, and family dynamics of caring for their loved one living with dementia (see Appendix C for the interview schedule).

The interviews were transcribed for clarity, such as in deleting disfluencies like filler words (e.g., “uh” and “like”) and repeated words. In addition, all identifying information was replaced with randomized information and pseudonyms. Interviews lasted an average of 105 minutes in length ( $SD = 53$ , range = 52 – 284 minutes). The interviews were audiotaped and transcribed, resulting in 709 pages of single-spaced text. At the end of the interview, participants were asked to give themselves a pseudonym and asked if they would be willing to be contacted again to review and discuss the results. Of the 31 participants, all agreed to be contacted again. Within a few days after the interview, the interviewer emailed the participant with a document of various resources including information about dementia in general, support groups, and mental health services should they want or need to talk to a professional about their experiences.

### **Data Analysis**

The data were analyzed using a phronetic iterative approach (Tracy, 2018; Tracy & Hinrichs, 2017). This interpretive method was used to better unpack peoples’ uncertainties, patterns of communication, and coping strategies during times of stress when they care for their family member living with dementia. Utilizing this analysis process allowed for the study’s core phenomenon to be investigated as both grounded in the data as well as drawing on literature iteratively to allow for both sources to shape the emerging analysis (Tracy, 2018; Tracy & Hinrichs, 2017). By alternating between emergent readings of the data and existing theories and explanations, a detailed understanding of how communication functions as a tool to create and enforce order and predictability in one’s day, as well as functioning as a process whereby communication itself becomes patterned, was developed (Tracy, 2018; Tracy & Hinrichs, 2017).

The data analysis consisted of five phases: Organizing and preparing the data, data immersion and the primary coding cycle where first-level descriptive codes were created, focusing and displaying activities, the secondary coding cycle where second level analytic codes were created, and synthesizing activities. In the first phase, the data were organized and prepared where each participant's interview was represented in a single document file to be analyzed on its own. There was a choice made to not organize the data by a specific demographic. Moreover, the choice to use Atlas.ti as the software to aid in analysis was chosen during this phase. Due to scheduling constraints of participants, interviews were still being conducted by the time data analysis began. During the open coding process, interviews and transcriptions of those interviews were happening concurrently. By the time the secondary coding cycle began, all interviews were completed, transcribed, and ready to be analyzed.

First, the author and four research assistants who were involved with the interviewing process submerged themselves in the data. The research assistants read the first 15 transcripts as those were the only ones fully transcribed at that point in time, and they were instructed to make codes that refer to anything they found salient to one of the research questions or particular to a specific idea they thought would be important to discuss. Since they all had been trained in conducting interviews, they all had at least been a part of one interaction with a participant and heard their responses. All but one of them had also been a part of the transcription process where they had some exposure to at least another participant's experiences by the time they immersed themselves in the data. The remaining research assistant was delegated as the primary point of contact for participants and responsible for scheduling the other research assistants for their interviews. There were discussions



informing the research assistants about the analysis method chosen and the goals of primary coding. The prior experience enabled them to have a sufficient starting point in terms of general direction but were encouraged to code widely in terms of breadth of ideas. They coded short phrases or single words in Atlas.ti as well as had a document they were instructed to use as a place to make notes about a participant's experience and the family members involved, pose questions, and any comments or thoughts had while reading the transcript. During this phase, the author and the research assistants had discussions regarding common patterns or themes across codes or notes that everyone had noticed, answered questions, and the author posed ideas to get feedback from the research assistants. The first-level codes focused on the basic content of the data (e.g., *early signs, denial, advice, humor, fears, family system, rhythm*) and were often descriptive in nature of activities or processes (e.g., *communicating, reframing, reminiscing, storytelling*).

Then the author and research assistants started to focus their analysis by discussing the first-level codes created in Atlas.ti with an aim of creating a codebook. The research team reviewed all of the first-level codes and determined which codes were relevant to answering the research questions. Codes that had low frequency were discussed for their relevancy and either deleted or subsumed under another code due to similarity. Some codes had high frequencies but were ultimately not found relevant to the research questions and could not be subsumed under any other codes. Codes salient to the research questions included *relationship, roles, positive change, negative change, language, knowledge, conflict, communication, and adapting*. Discussions were made regarding how the codes could be broken up into more discrete codes as well as the relationships between them that reflected the participants' experiences. Around this same time, the author chose to go back into the

literature. Possessing a greater understanding of the data, the author went to do another dedicated search to get more insight regarding the concept of rhythms. Meanwhile, they provided their research assistants three research articles relevant to the study and the research questions to read. This process for both the author and the research assistants facilitated discussions that prompted a breakdown of the codes with larger frequencies to analyze more deeply within each code and incorporate the new knowledge created in reworking the codes and the greater understanding of the meaning coming from the data.

Finally, once the conceptualization of the codes and their names was decided, a codebook was created with definitions of each code and one or two corresponding exemplar quotes. Exemplars were taken from the first set of 15 transcripts that were open coded because those were the only ones fully transcribed at that time. After having discussions about the codebook and the codes, the author made an activity that prompted the research assistants to practice coding some pre-selected quotes to ensure a consensus of understanding and serve as a trial of secondary-level coding. During this process, discrepancies amongst the research assistant about what constituted each code were resolved. Necessary changes were made to the definitions such as adding clarifying statements. After the author and research assistants reached a strong understanding and consensus, each research assistant was assigned to secondary-level code approximately seven to eight transcripts. The research assistants were given an equal amount of transcripts that had been part of the open coding process (i.e., the first 15 transcripts that were fully transcribed at the start of the open coding cycle) and the newly transcribed transcripts (the remaining 16 transcripts). As the research assistants were coding, weekly meetings consisted of answering questions and clarifying the understanding of the codes. These discussions started to transition to also discussing the

nature of the codes in relationship to each other. As the author went back and forth between the data of the quotes and the literature, themes and a model started to coalesce.

### **Findings**

In this study, the construct of rhythmic synergy emerged. Rhythmic synergy describes the result of the process by which a person strategically enacts reoccurring prosocial behaviors and other communicative behaviors and actions that develop into a communication-based repertoire of person-centered knowledge, known as macro- and micro-rhythms, with another individual who has differing cognitive abilities that impact their communication abilities. Rhythmic synergy becomes a way to better communicate, navigate experiences with more ease, and ultimately create a higher order connection and co-presence between individuals. Beyond this dyadic interaction, rhythmic synergy also conceptualizes the ways in which members of a family or other network operate at a group level. These findings will detail how caregivers co-created their rhythms with their loved one living with ADRD, which is illustrated in Figure 3. Then the findings will explore how these rhythms operated as other family members and care partners were incorporated into the system of caregiving.

The rhythm creation process between a caregiver and their loved one has multiple steps (see Figure 3). Creating rhythms and rhythmic synergy is founded upon caregivers being attuned to their loved one's behaviors. This sensitivity was prevalent in large part due to the context of uncertainties that caregivers experienced. This general sense of unease stemming from a desire to take care of their loved one properly helped to foster an environment where the caregiver was primed to be sensitive to their loved one. Thus, caregivers were quick to take note of and appraise both the loved one's behaviors that were

anxiety related or upsetting, as well as the behaviors that were related to calm or joyous states. After appraising the loved one's behavior, typically the anxious behaviors created uncertainty and stress for the caregiver. This unease led caregivers to make a decision about a change they wanted to make regarding their own behavior to assess how their loved one would respond. With this, participants cited various reasons for their decision making. After witnessing their loved one's responses, the participant would adjust their reasoning and/or behaviors and continue this process indefinitely of noticing their loved one's reactions and making adaptations.

The back-and-forth communication to approximate the best ways to connect with and not agitate the loved one created a kind of feedback loop. This communicative feedback loop between the participant and their loved one is what creates and sustains rhythms. The spiral is meant to depict how the series of interactions and decisions build on each other rather than repeat each other in a cyclical way. Ultimately, participants identified what worked and did not work (i.e., multiple rhythms) for their loved one to create a sense of calm and predictability for both parties. This is how rhythmic synergy was created. The findings also illustrate what happens when the rhythm gets disrupted, such as by other family members. The following sections go into the process of rhythmic synergy in-depth, with excerpts from participants to illustrate this phenomenon. The associations among all of the themes are depicted in Figure 4.

### ***Uncertainties***

Many participants shared feeling uncertain about how they could best provide care and make decisions that would honor their loved one's wishes yet also be realistically achievable. These uncertainties provide valuable insight to the context of the kinds of stress

participants were experiencing. Each of the following uncertainties illustrate how caregiving for someone living with ADRD would set the stage for a caregiver to be in a position of wanting to instill ways of effectively and meaningfully communicating with their loved one.

### ***Knowledge***

Prior to a loved one's particular behavior that would be the typical starting point for a rhythm, participants were worried about their family's understanding of the diagnosis and what having ADRD entailed as well as best practices for care and communication. Not feeling sufficiently knowledgeable and supported on how to best take care of their loved one was a considerable point of difficulty for participants. Several mentioned disparaging experiences with members of their loved one's medical care team, like in the case of Olivia who shared the memorable experience she had during the visit when her mother was diagnosed with Alzheimer's. Olivia's family did not receive any information about the condition from the physicians nor did the physicians inquire about the family's understanding of the condition. She explained, "I just learned about this disease as I just was witnessing it in [my mother] versus than [...] in that visit" (Participant 37AK, p. 5). In an unfortunately similar case, Alice shared that she was most uncertain about the unknown and continued saying that,

I think it's not having any insight of what the best thing is to do for him at this stage. And even when we ask his neurologist, he just kind of gives very generic responses, like very textbook replies. Like, "Seek out a home caregiver. Chat and go walking."  
(Participant 9I, p. 32)

Feeling left in the dark too, Barbara shared, "I think one of the biggest pieces of uncertainty for me in this entire thing has been making sense of the medical establishment in terms of

who does what, and how I get help?” Not having any formal medical support or feeling lost in terms of navigating how to get help leaves care partners and their loved ones to fend for themselves to navigate the caregiving journey ahead.

Unsurprisingly, many participants also discussed the ways in which they felt uncertain about how to communicate with their loved one. Feeling underequipped about how to respond to her father when he was not acting like himself, Terri remarked, “How much do I kind of deny his reality? [...] To what extent do you just kind of say, "That's all in your head? It's not true." And how do you say that?” (Participant 21U, p. 14). For Katia, it was her mother’s anxiety that proved to be the most challenging and created uncertainty because her and her siblings “didn’t know how to calm her” (Participant 5E, p. 5). She implored, “I just wish I would have had somebody who could advise us on what we could do that would calm her down” (Participant 5E, p. 23). Similarly, Zak articulated, “There was so much uncertainty on like, [...] how do we communicate with her when she's going through these episodes?” (Participant 16P, p. 66). These accounts likely reflect some of the impact of what a lack of guidance from medical professionals creates. With poor, and sometimes even nonexistent, support from formal systems, participants found themselves feeling underprepared to take care of and communicate with their loved one effectively. This finding supports how these family caregivers were put in positions where they would be especially invested in crafting ways of communicating with their loved one.

### ***Timing***

The uncertainty surrounding the timing related to caring for someone living with ADRD contributes to the context of pressure family caregivers are under. *Timing* refers to participants being worried and stressed about when symptoms would occur and when

transitions like moving the loved one to a care community would need to happen.

Highlighting his concerns of his mother's rate of decline, Shay stated, "In the early stages, it can progress quickly, or it can progress slowly, you don't know how fast it's going to work or how fast the cognitive decline is going to be" and that is what "makes it difficult to plan certain stages of care" (Participant 18R, p. 8). Similarly, when thinking about her uncertainties when she first found out her mother had Alzheimer's, Marie explained, "At the time, I think it was just like, how fast is this going to go? Is this going to be really rapid deterioration? Or is this going to be kind of longer?" Then when she reflected on her uncertainties during the middle stage, she shared, "I got real nervous, and I'm like, "How bad is this gonna get? And what do we need to do?"" (Participant 10J, p. 7). For many participants, they recognized the inherent difficulty in an ADRD diagnosis and how it makes being sufficiently prepared for each stage nearly impossible.

Alongside these concerns were worries about loved ones' living situations. Participants were concerned about when they should be making significant decisions about their loved one's care to ensure that they were being taken care of appropriately. For instance, when Elizabeth first learned her mother had dementia, she explained she was uncertain about how long her mother "was going to be able to stay in [her] independent apartment in [a] retirement community" and how long she had before her mother had "to get more advanced help." She went on to detail how these uncertainties made her "scared about the future" because she did not "have any idea how long it's going to last" and "how bad it's going to get and how quickly" (Participant 1A, p. 7). Relatedly, Alice and her mother take care of Alice's father (her mother's husband) together. Due to the "physical, mental, and emotional toll" it had been taking on them, Alice stated, "At some point, we are going to

have to ask for additional support, we just don't know when the appropriate time is. So, I feel like we're kind of like in no man's land right now” (Participant 9I, p. 6). This deep uncertainty about the future concerning the loved one’s symptoms as well as timing the transition of care appropriately provides context for the kind of world these family caregivers are in. This would likely make them be especially hyperaware of their loved one’s progression through their condition so that they can be as prepared as possible. Therefore, this finding supports how family caregivers would be in a position to be “locked in” with their loved one and create rhythms to care for them better.

### ***Capabilities***

One other type of uncertainty that seemed to characterize these family caregivers’ experiences was their concern regarding their capabilities. In caregiving long-distance for her mother, Nancy described feeling worried about her mother’s capability in providing for her father. She shared, “[My mother] said to me what the biggest uncertainty is when do we know it's time [...] like when it's too hard for her to take care of him by herself?” (Participant 7G, p. 30). Barbara also shared,

When we started with this diagnosis, I thought there would be markers that Dad would give, where we would know that this was the time to move him into the next level of care. But I'm coming to realize that it's actually markers my Mom is gonna give in terms of her caregiving capacity. [...] And I think we will come to a place where she physically cannot do what needs to happen. [...] All of my uncertainty is around care, getting care, what will that look like. (Participant 35AI, p. 20)

In this situation, Barbara recognized that every decision regarding her father’s care is more likely going to stem from her mother as the primary caregiver. The emphasis and attention to



the caregiver's bandwidth is paramount, and the participants seem to recognize it in themselves and others. To this end, caregivers expressed uncertainty about their own or others' capabilities in providing the necessary kind of care such as being able to lift the loved one or even the endurance both mentally and emotionally. They also expressed a great deal of financial uncertainty. In fact, Val stated, "You're uncertain about how much it's going to cost, and it costs a lot [...] So I'd say money was definitely an uncertainty as well" (Participant 4D, p. 4). She represents many others who wanted to impart transparent advice on the financial difficulties related to caregiving. This is not without those that also expressed gratitude for being financially secure either from their own means or from health care, savings, and/or retirement. For Gail, she even explicitly said, "I never sat and worried about finances and my decision [unlike] where I think that is a huge uncertainty in people's lives" (Participant 34AH, p. 49).

For other people, the uncertainty of their capabilities stemmed from not having input from their loved one. As Regina expressed, "I could not depend on any input from him to advocate for him within the medical care system for the non-dementia-related stuff. [...] So there was a lot of uncertainty about his medical care" (Participant 23W, p. 5). Her husband was unable or potentially unwilling to share with her any bouts of pain or symptoms related to his urinary tract infections, so Regina felt a lot of uncertainty regarding her decision making capabilities in his medical care. With Val and her grandfather, she said, "The biggest uncertainty would be the level of pain and distress that he was in because he couldn't really articulate" (Participant 4D, p. 5). Without the valuable input from their loved one, participants were uncertain about what they could discern from their loved one's health and well-being and ultimately make decisions based on those conjectures. Along with *knowledge*

and *timing* uncertainties, feeling highly uncertain about being able to conduct proper care as well as trusting their own decisions fostered a situation that is ripe for a caregiver to establish rhythms with the loved one in order to create stability and a reliable way of maintaining their relationship.

### **Rhythms with the Loved One**

With uncertainty acting as a powerful backdrop to the family caregiving experience, the findings look next to how macro- and micro-rhythms were created along with the reasons given. The reasons identified were connection and social presence, emotional affect, predictability and control, and stress and anxiety.

#### ***Macro-Rhythms***

Part of the way people developed rhythmic synergy with their loved one was how they created macro-rhythms which involved noticing behaviors and mental states of their loved one that ultimately led the participant structuring their days differently. The implications for creating macro-rhythms made caregiving often easier because the participant could optimize certain aspects of the day such as where they would take their loved one, the time of the day they scheduled activities, and with whom their loved one would be most receptive to being around. In this way, the participant was adjusting their rhythm with their loved one so that they could have a flow together that would make their days go by more smoothly. Three participants serve as exemplars demonstrating how a macro-rhythm was created. In the case of Ruth, who takes care of her mother living with Alzheimer's disease, she shared,

I always knew that we didn't do anything like after three o'clock. If I was going to take her somewhere, I was taking her somewhere in the morning. No way would I go

to the store with her after three o'clock. [...] It'd be a nightmare because who knows what's going to happen. (Participant 31AE, p. 18)

The macro-rhythm that Ruth created involved her mother's timing of outings. Ruth realized that her mother tended to get anxious often and that this anxiety was exacerbated during the late afternoon. She also recognized this caused her mother and herself immense stress and negative emotional affect. In order to reduce that stress and keep her mother in a calmer state, Ruth decided to try and change when she would take her mother out in public. After implementing this change, Ruth must have realized that this change had beneficial outcomes for the both of them. Over time, Ruth established and maintained a macro-rhythm of only taking her mother for outings in the mornings and early afternoon.

In a similar situation but with different reasonings, Shay described how he knew that there were optimal times to visit his mother. He disclosed,

A lot of people with dementia, they're not functional at a certain point and so kind of knowing that my mom around four o'clock- [...] I've learned because of those rhythms when I was living with her that it's going to be a much more productive companionship if I take her to lunch than if I take her to dinner. Right? Because, you know, she starts to fade as the sun goes down. And then, you know, she's really not present. (Participant 18R, p. 15)

The macro-rhythm that Shay had with his mother concerned his visitation times. He noticed that she becomes less present when the sun goes down which hampers their ability to have meaningful interactions together. Therefore, his reasoning for changing his visitations stems from wanting to foster a sense of co-presence together. He would come to visit earlier in the day and realized that was a positive change because she would be more present with him due

to being less tired and cognitively exhausted. Realizing this positive change, Shay maintained this macro-rhythm of visiting earlier. Building off on that rhythm, Shay also became cognizant of other conditions that worsened his mother's functioning. Shay shared how he would notice that his mother would often get tired quickly and her ability to walk would deteriorate with long visits. To work with her physical capabilities, he learned that activities could not be more than two hours long. In the end, Shay created an optimal macro-rhythm of how he would structure his visitations with his mother to ensure her comfortability and presence. In sum, many participants described instances that would be categorized as macro-rhythms because they were noticing their loved one's stressors and proceeded to make decisions with various reasonings that would have implications for the way the day was structured. To that end, participants and their loved ones being in sync at a functional or macro level created some ease in caregiving because the caregiver was more tuned into their loved one. Having macro-rhythms of being aware of a loved one's anxieties and functionality could help care partners be more readily able to notice other factors influencing their loved one.

### ***Micro-Rhythms***

The other class of rhythms evident among these participants concern what are called micro-rhythms. *Micro-rhythms* describe how participants established strategies to communicate more effectively with their loved one which ultimately enabled the participant to better anticipate their loved one's general mental and emotional states. By getting in this communicative flow, the participant often felt more presence from their loved one and feeling that they were supporting their loved one given their changing capabilities.

Communication was a salient point for nearly all participants. There were five micro-rhythms that characterized these participants' experiences.

**Affirming.** The *affirming* micro-rhythm typically involved the following pattern. First, the participant would notice that their loved one would say things that they knew were not factually true or that their loved one appeared to be in a different reality. Then the participant would appraise this negatively and would try to correct their loved one. These corrections usually went poorly because it made the loved one agitated, stressed, and confused which would in turn cause the participant frustration and stress as well. Ultimately, the participant would re-evaluate their approach by realizing that the benefit of their loved one being momentarily brought to the participant's reality was not worth the stress and anxiety it caused for both parties. Many participants shared how they switched from correcting and arguing with their loved one to affirming language and agreeing. In this way, the participant was entering the reality of their loved one as a way to give them peace and comfort in their reality. Having this micro-rhythm of affirming was important because it allowed the participant and their loved one to find a way to have more positive interactions with each other as well as help re-frame the participant's priorities to that of presence and connection rather than truth and objectivity.

Several participants exemplified creating affirming micro-rhythms. For example, Val's grandfather would share elaborate stories that included details Val knew never happened. She admitted, "I used to get quite irritated and angry and really fight it and [say], "No, this didn't happen." But then you realize that you're actually causing more distress to the person by denying what they think is their reality." Recalling a previous story her grandfather told about how a family member supposedly stole his ketchup bottle, she stated how her and

her family responded in a new way by saying, “Oh, okay, [...] I'm sorry that happened to you, but we'll go to the shop and get you some more.” In doing so, Val expressed that “instead of fighting the things that [our grandfather] would say we knew were incorrect, we'd accept it, say they were right, unless it was something that was going to harm them” (Participant 4D, p. 8). She found that the benefit to having a rhythm of affirming him was that the rhythm “definitely meant minimizing their distress and like maximizing your sanity” (Participant 4D, p. 9). With Val and her family, they found a rhythm that allowed them to foster more positivity and less distress for everyone involved. By being able to rely on this micro-rhythm, they would be more likely to feel assured and confident in how to navigate future interactions which gets at the positivity of having this sense of flow.

Like Val, Beth and her family originally tried correcting their loved one when her mother's coherence of speech was becoming nonsensical. Beth revealed, “At the early stages, we were all so stupid, we would be like “Well mom, that doesn't make sense” or “That's not what it is.”” However, after a while, they learned that was not a productive way to communicate with her. Admonishing her past self, she expressed, ““What the heck are you doing?” Like what?! She's incapable of being corrected. So what the hell are you doing that to her for?” (Participant 3C, p. 13). Ultimately, Beth learned to repeat the same statements her mother would use as a way to speak her mother's language. She shared that if her mother asked her if she had a spider toaster that she would reply, “Spider toaster. I don't have a spider toaster, do you?” (Participant 3C, p.20). Rather than argue about the meaning of spider toaster, Beth opted to affirm her mother's language use and continue the conversation as if her mother asked a typical question. The resulting reaction of her mother giggling and

smiling acted as a feedback loop for Beth indicating to her that this action of using her mother's language was a beneficial choice.

Similarly, Leslie and her family created an affirming micro-rhythm of letting the loved one tell them every story over and over and not say, "We've heard this before." Instead, Leslie said they always replied, "Oh that's really interesting!" or "Oh, you're kidding?!" She imparted the message, "Enjoy that, you know, the telling of the story. There was no reason to tell her that she had dementia. There was no reason to tell her, you know, anything" (Participant 14N, p. 16). Cognitively reframing the situation from repetitive storytelling to an act that brought her mother happiness likely helped the family view other potentially challenging situations as an opportunity for joy with the loved one rather than annoyance. Echoing this, Shay said, "I validate whatever reality that she's in. Because it makes her happy, right? I don't deny her truth in the moment. I mean, I just think that's the best way to approach it" (Participant 18R, p. 24). Here Shay cited that it brings his mother joy when he accepts the world she finds herself in instead of telling her she is wrong or make her feel like she is not making sense. Finally, Alice, who cares for her father, asserted that "you don't correct someone with dementia" and that you "just have to find a way to go into their world" (Participant 9I, p. 11). Across these participants and others, coming to the conclusion of using affirmative language was a learning processes that initially started with correcting or disagreeing with the loved one in an attempt to use logic and reasoning for the sake of the truth and reality the participant themselves was in. However, whether it was through noticing the negative impact it was having on their loved one and/or themselves, the participants changed their approach by entering the world of their loved one to make them feel validated, happy, and understood.

**Compassionate Deception.** The *compassionate deception* micro-rhythm typically involved a situation where the loved one started to need more advanced care, and the caregiver recognized that they needed outside help. With the intention to help their loved one receive better care and ease the caregiving stress on themselves, the participant would try and introduce this change to their loved one with complete honesty and transparency. Using this approach made the loved one upset and not receptive to these changes which would impede the care. For other participants, it was clear that some other indicators like personal history let the participant know that introducing a new care environment would not go well. Whether the participant went through the trial and error directly or experienced it in another way, ultimately their loved one's negative reactions indicated to them that a different approach was needed. For this micro-rhythm, the participants withheld certain information or lied to their loved one in order to make them comply with these requests and stay calm. Having this rhythm allowed the participants to help their loved one more easily adapt to changes. As with all of the micro-rhythms, this rhythm is built on intimately knowing the loved one's tendencies and ways of being that consequently further generate a synergy of greater connection and understanding.

Participants detailed a variety of situations of types of care transitions that necessitated a kind of compassionate deception micro-rhythm. For example, Regina, who cared for her husband, explained that her husband was in daycare program for a significant part of the week because she was working and needed him to be supervised and safe. So she said, "I had to lie to him and tell him he was a volunteer there" (Participant 23W, p. 11) because otherwise he would have resisted going. When Regina's husband could no longer attend the daycare, she had to bring in an in-home caregiver which her husband resented at



first. However, to combat this, she remarked, “I explained to him that for my comfort and in order for me to go out to work, I needed somebody there to manage his diabetes, so I lied” (Participant 23W, p. 6). Similarly, Zoe was trying to ease her mother’s acceptance of an in-home care professional. Zoe explained that she, her sister, and her mother’s husband “had to make up a story” that the care professional “was coming to take art lessons” (Participant 6F, p. 4). By utilizing the mother’s previous history of being an artist and having a studio, the family was able to leverage this to allow the mother being comfortable letting the professional caregiver into the house. Another participant took a similar approach when her original plan of having a professional caregiver visit failed. Ida Mae shared that her mother initially reacted by saying, “No, you’re not gonna get anybody for me!” and “I’m perfectly capable still!” In a new approach, Ida Mae said that she told her mom, “Oh mom, these are some new friends of ours, and they're gonna stay with you a little bit during the day.” She explained, “[My mom] kind of accepted that better than me saying they’re caregivers” (Participant 15O, p. 9). In this way, omitting the truth of the reason why they were there seemed to be the right approach for Ida Mae’s mother to allow the caregivers into the home. In the end, her mother even came to enjoy the presence of the caregivers.

Another way the compassionate deception micro-rhythm emerged was regarding the loved one’s agitation about the whereabouts of another person or making unknowingly dangerous requests like trying to drive a car. In these cases, if the complete truth was told, then the loved one would have likely become very upset, and it would send both themselves and their caregivers into a tailspin. Therefore, being able to face these situations by relying on a micro-rhythm of compassionate deception helped to mitigate the probability of their loved one feeling displaced. With Barbara, sometimes her father would forget that he could

not drive or would become restless inside the house and express interest in leaving. In a specific memory when her father stated he would drive himself to a particular location, she recalled, "I was like, "Oh, I'm so sorry, daddy, the car is not working today." And he was like, "Oh, it isn't?" I was like, "Yeah, I'm so sorry. I don't know why, but it's not working today." Her father would then accept this and let the subject go. Barbara later explained that they "tried redirection first, and it didn't work" and "now we tell him that the car is broken today" (Participant 35AI, p. 16). While this did not eliminate his repetitive questions entirely, lying to him in this way did help avoid more confrontational conversations. Aside from safety, the person living with ADRD would also request seeing loved ones. For Katia, her main reasoning in this rhythm was to keep her mother calm. When her mother would ask why her husband was not coming to pick her up, Katia said that she and the rest of her family would not say the truth of "Daddy's been gone for six years." Instead, they would say, "I think he is probably on his way. Let us just sit and talk for a little bit" (Participant 5E, p. 7). Margaret more explicitly laid out this tension regarding telling the truth. She and her family used to always be truthful to her father, but when he started to insistently ask about the whereabouts of his wife, Margaret had a dilemma. She outlined,

What I asked myself at a certain point and what started to become the approach was, "What was more important? Was it more important to be truthful? Or was it more important to be kind to him and deal with his immediate anxiety and be able to have a nice conversation with him and put his mind at rest?" So, at first, I was trying very hard to be accurate with my conversations. And as time went by, I made a pretty affirmative decision that it was more compassionate to bend the truth in ways that

kept him engaged and relieved his anxiety than it was to be accurate. So that was a sort of a pattern that develops through time. (Participant 36AJ, p. 21-22).

Drawing on a desire for her father to feel peace and have decreased anxiety, she decided that ultimately telling him that his wife would be coming the next day and say that they were waiting on some tests before he could get discharged was the best course of action. These participants created the micro-rhythm of altering their statements so the truth was concealed in such a way so that their loved one's reality would not be disturbed.

**Censoring.** The *censoring* micro-rhythm refers to when the participants noticed their loved one's negative reaction to a phrase or topic. The participant realized that this created agitation and confusion and sought to reduce this negative emotional affect and stress for their loved one. They learned to avoid triggering words and noticed how their loved one maintained a sense of calm. Different from lying, the micro-rhythm of censoring captures how caregivers might be aware of how certain words and topics can be triggering and would avoid them. The need of reducing the propensity for agitation caused the creation of this micro-rhythm.

As Bennett expressed, she learned that the word Tylenol would cause her mother, who used to be a doctor, to start to ask for Tylenol and ultimately never believe that Bennett actually gave it to her. Bennett said, "So we were careful not to use that word" (Participant 26Z, p. 11). Not only would mentioning Tylenol trigger the mother to demand the medicine repeatedly, but it also prompted her memories of being a doctor. Another way this family maintained this censoring micro-rhythm was when they noticed how mentioning Tylenol also made her think she needed to be at her hospital working. Bennett explained that they were careful not to use words they thought would remind her mother of practicing medicine

“because then she would think she’s a doctor again, and then she thought she had to go see patients” (Participant 26Z, p. 12). As the daughter to Bennett and granddaughter to the loved one, Zak explained that when they triggered her grandmother, she “would get so erratic about going to the hospital going to see her patients” (Participant 16P, p. 18). To combat this, Zak often drove her grandmother to her old place of work, the hospital, to help calm her down. But unfortunately this would create more confusion for the grandmother because the hospital building was redesigned and unrecognizable. The grandmother was confused as to why her hospital was not how she remembered it which put Bennett and Zak in a precarious situation where they struggled with how to rectify this confusion. Ultimately, trying to avoid the topic altogether so the loved one would not get upset was how they navigated the situation. Doing so also inadvertently avoided creating more confusion because now they also did not take her to her old hospital. This example demonstrates how the family continually refined their rhythm by utilizing the knowledge of Tylenol and its connection to the loved one’s career to ultimately learn to avoid discussing anything related to medicine and health care.

Aside from specific words, others noticed that certain topics should likely be avoided. When recounting how she had a friend who was visiting and using her family’s house back home, Nancy realized her father would get particularly agitated with the thought that someone was inside his home. She stated, “I just tried not to talk about the house back home because it seemed to make him anxious to know that someone was in his house” (Participant 7G, p. 40). Nancy even made the connection that he seemed most comfortable with the immediate present and what he could perceive with his senses. Therefore, she tried to not mention objects or ideas that he could not readily see with his eyes or discern immediately. Like with Bennett and Zak, Nancy was continually refining her micro-rhythm with her father

by being aware of these idiosyncrasies. In another example of censoring an entire topic, Jeannette shared how she learned to avoid talking about her mother's parents to her mother. Jeannette revealed, "I usually avoided anything to do with her parents because of just the history there" since she "had a rocky relationship with her mom" (Participant 8H, p. 20). Already knowing that that topic was a "sore spot" for her mother before her dementia, Jeanette recognized that it became an even bigger issue with the onset of her dementia and was able to adjust by creating this micro-rhythm. Along with already being sensitive to their loved one, participants demonstrated efforts to determine what was causing the trigger. This micro-rhythm communication strategy was helpful in reducing potential flares in anxiety for loved ones as caregivers began to make some underlying connections regarding their loved one's history.

**(Re)phrasing.** The *(re)phrasing* micro-rhythm involved participants trying to facilitate more meaningful and productive conversations with their loved one. They would first notice that the communication with their loved one was too short, not substantive in content, or that the loved one did not seem to follow the conversation. The participants were unhappy with this kind of communication and sought to change this dynamic because they wanted to foster a sense of presence for their loved one. In reflecting upon why this was happening, most participants realized that it was because of the way they were prompting the conversations such as questions that required using one's short term memory. Creatively, participants were able to alter their phrasing of their questions. They maintained these strategies if it seemed the loved one was responding well and able to be more fully engaged in the conversation. By creating this micro-rhythm, the participants and their loved ones were

able to create moments of meaningful conversations where the loved one was more present, able to contribute, and feel the efforts of the participant to connect with them.

Prominent examples of this micro-rhythm include Barbara's accounts of how she learned to communicate with her father. When Barbara compared her and her mother's communication with her father, she described how mother actually picked up more quickly on the kinds of questions that did not work. Barbara explained that she learned not to ask questions like, "How are you doing? Or how was your day?" or "anything that remotely involves him having to remember anything." She would ask her father how his day was, and he would not be able to answer and would just say he did not know. This created uncertainty for Barbara since this was not a response she continually wanted from him. She then reflected and realized, "I thought, "Oh, right. I'm setting you up for failure (Participant 35AI, p. 19). She realized asking questions that are foundationally grounded upon being able to recall the day's events were essentially impossible questions she was giving her father. Relatedly, with her father, Margaret realized that she had to accommodate the conversation topics as it relates to time. She learned that she had to have conversations about "what was happening right now because [of] his short term memory" and that "conversations about what happened yesterday or even [that] morning were no longer really fruitful" (Participant 36AJ, p. 20). She adjusted strategically to only ask questions about the present or the distant past because she knew his long term memory was still fairly good.

Additionally, some participants made the simple switch to open ended questions. In trying to keep her father communicating with her, Lisa found that providing open ended questions that prompted storytelling from his past, thus drawing on his long term memory,

was a more successful method. Given that she knew that “his conversations [were] always very short and mostly just answering questions” she explained,

I try to create the question so that it's not just a yes or no. Then I'd say, "Tell me a story or tell me about a time when we did this." [...] He's pretty good at remembering some stuff from time periods and describing certain situations of what his family did. If I say, [...] "Tell me how grandma and grandpa used to do this" and then he can reply right and share a story about that. (Participant 12L, p. 24-25)

Lisa utilized the knowledge that her father’s long term memory could be channeled to foster their communication. Rather than having the issue of her questions being unanswerable, Lisa’s concern was how to make sure her father could not answer it with a simple yes or no response, thus ending their conversation prematurely. For these participants, they were able to establish a rhythm with their loved one where conversations could be more meaningful. Participants recognized the abilities of their loved one and matched their rhythm.

**Nonverbally Communicating.** Finally, the micro-rhythm of utilizing *nonverbal cues* was utilized by numerous participants. With the verbal capacities of their loved ones becoming a less reliable channel, participants shifted to creating a way to be in touch with their loved one’s well-being. The behavior that participants seemed to notice were not necessarily stressor related. Instead, they took notice of their loved one’s positive response to touch, certain foods, and improved engagement with people and animals. The participants often appraised the situation as positive and sought to harness this positivity. The reasoning linked to this micro-rhythm usually involved improving social presence as well as positive emotional affect. The result was that participants would take a more active note and role in their loved one’s body language and facial expressions and selectively make decisions such

as choose their loved one's favorite foods and hobbies. With noticing these responses, many realized this made their loved one more present and happier. Thus, creating a micro-rhythm of being aware of the ways a loved one is communicating nonverbally could help caregivers more readily understand and thus aid their loved one when they cannot verbally communicate their wishes. Family caregivers could even share these insights if professional caregivers become involved and sought to meaningfully connect with the loved one.

In terms of the objects and experiences, participants described the various types of activities, foods, and animals that their loved one enjoyed. Regarding her mother-in-law, Heather shared, "I think just physically patting her and, you know, touching her, being close physically, is really, really important. [...] We would see what made her smile (Participant 11K, p. 9) She also took note of how her mother-in-law loves to eat, has "delight in the dog and different things like music" (Participant 11K, p. 11). Here, Heather's reasoning for creating this micro-rhythm stems from the positive emotional affect that she wanted to foster in her mother-in-law. Ruth shared the same reasoning when she explained how her mother loved to eat sweets. Ruth exclaimed her reasoning and action, "We knew that sweets made her happy. We used sweets a lot because she enjoyed them" (Participant 37AK, p. 19).

Other participants like Marie explained how nonverbal communication sometimes signaled changes she needed to be aware of. In Marie's case, her mother's pacing throughout the house would signal that to her that her mother's anxiety was increasing and sundowning was starting. In those moments, she was likely able to use this knowledge as a factor of her mother's overall mood and make more informed decisions. Likewise, Alice explained that she could see it in her father's body language when he would get negatively affected by loud people. She said her and her family learned from those experiences and know that he needs



to be in exclusively calm and peaceful environments. Contributing to the creation of this micro-rhythm, Alice also shared that she was able to sense nonverbally when her father was being negatively impacted by her mother's energy if her mother was feeling irritable. Being aware of his nonverbals allowed Alice to not only notice when he would get agitated in chaotic environments but also recognize his sensitivity and awareness of other people's states. Ultimately, having this rhythm helped her to be able to make appropriate suggestions like going on a walk or a trip to the library in order to get his mood back to a calm state. Discussing her micro-rhythm, Alice described how her strategy was to "go based off the facial expression or body language." She suggested to "change the subject or continue on the same trajectory that you're on and just see how they join [or] if they do at all" (Participant 9I, p. 11). In this way, the participant aligning their communication with their loved one helped them to be in sync with one another and make keeping their connection alive and subsequently caregiving easier. This is advantage of having rhythms is evident with Dale who said, "So pretty much before she would need something like to drink or go to the bathroom, I can pretty much tell that just by the movements that she was making in the chair (Participant 27AA, p. 26). By utilizing her body movements, Dale was able to attend to his mother's needs effectively by perceptively determining that she wanted gum on movement alone.

## **Rhythms with Others**

### ***Enhancing***

**Communal Coping.** When thinking about how rhythms function at a broader level, other peoples' actions can serve as enhancing or disrupting a particular micro-rhythm or macro-rhythm. Attempting to coordinate care for a loved one illustrates this notion of

enhancement and disruption well. When someone engages in a behavior that the participant views as being helpful in influencing and maintaining their rhythm, that person's involvement would be considered an enhancement. Just like how it is important to merge easily and successfully with oncoming traffic, it could be helpful to think about rhythms in the same way. From the perspective of a primary caregiver, other people getting involved need to try and merge as seamlessly as possible to match the already established rhythms. Any changes to the rhythm need to be communicated as clearly as possible, like one would use a blinker. That way everyone can be aware and adjust their speeds accordingly. The communal coping label is meant to highlight the focus on instances of enhancement that are more centered on familial coordinated effort rather than isolated instances of support given and received. This would look like families who appear to have appraised the stressor of the loved one's ADRD as co-owned together as a family and tackling care together (see Afifi et al., 2006; Lyons et al., 1998).

Numerous participants described what it was like coming together as a family and establishing a consensus about the situation, desired outcomes, and everyone's level of resources and effort. For example, Val shared a time where her family came together to discuss a concern about her grandfather. When he would say incorrect statements, the family tried to correct him with the truth. However, they soon learned that doing that was an ineffective method. In order to make sure everyone was on the same page or rhythm, they had a family discussion to communicate that everyone needed to "stop getting irritated or stop arguing with him if he says something that is clearly not true" and instead "just [be] patient, just accepting whatever he says" (Participant 4D, p. 11) as long as it did not harm him. This example demonstrates rhythmic synergy because multiple members synchronized

their micro-rhythms of communicating individually with the loved one. Care partners who are same page together more by informing one another when decisions like avoiding new words (i.e., micro-rhythms) or changes to the loved one's schedule (i.e., macro-rhythms) happen are likely to have positive outcomes. This is because they probably would run into fewer instances of someone making a mistake regarding care. When one or more people are not informed when changes are made, this can create friction amongst care partners. By actively ensuring that no one is falling behind in receiving recent updates *and* that no one is making executive decisions without informing others, families that exhibit strong rhythmic synergy together are able to weather the challenges of caregiving more robustly.

In another exemplar demonstrating the utility of rhythmic synergy at a group level, Marie and her family of four sisters cared for their mother. They managed to coordinate efficiently through orderly, planned, and consistent communication to prepare as best as possible for certain tasks and events. When they first learned about their mother's diagnosis, they investigated their mother's Medicare coverage, priced memory care options and home health care services, and delegated one sister to be the power of attorney. After seeking support from their cousins who used to be Alzheimer's caregivers, Marie explained how her and her sisters became prepared regarding hospice, transferred the bank account information, and moved the house under one of the sister's names. Adding further support to the evidence that this family demonstrated effective communal coping, Marie said,

Oh, we definitely are a team. I mean, we established routines, we established open conversations about our availability, when we were available, and when we're not. Also, like for our mental health, like how much we can take and how much we can't. You know, we always talk about that. [...] Sharing information. That's part of the

team is just being open about everything, and letting people be frustrated about stuff.

We would just let people be frustrated, too, you know. And be sad and be sad about things. So that was something that we had to establish. (Participant 10J, p. 23).

This family would also constantly share stories and insights about their mother by sharing “some things that would happen that we thought were going to be effective” (Participant 10J, p. 15). Whether it was coordinating all of the preparations or sharing these insights, this family demonstrates what having a high level of rhythmic synergy and communal coping looks like. The benefits of having this rhythmic synergy not only helped as a form of efficient problem solving but also a way to bond and reaffirm their relationships with each other.

### ***Disrupting***

Whereas enhancements contribute to strong rhythmic synergy, disruptions hinder it. From the perspective of a primary caregiver, disruptions concern instances where others’ behaviors act as an interruption of the pre-existing rhythmic synergy between the primary caregiver and the loved one. Just as an accidental clattering cymbal or intentional wrong note would throw a musician off the beat, the same goes for people who disrupted the macro- and micro-rhythms the participant established with the loved one. These disruptions can be both positive and negative, however in this study, negative disruptions were most prominent. There were many factors such as distance, relationship history, and more that hindered other peoples’ ability to be aware of the extent of the loved one’s level of care that the participant would be satisfied with. These discrepancies in awareness, knowledge, and skill level created a lot of frustration for participants. With others not being aware of the existence of the participant’s rhythms, this led to the other person unintentionally disturbing the grooves and

rhythms that the participant had established for making their caregiving experience as stress-free as possible.

For some participants, these disruptions were characterized by infrequent and/or short visits that created intense moments of demand. Barbara's experience with her sister illustrates this point perfectly. She explained how her sister was unable to garner an accurate understanding and impression of the father's well-being through short Zoom calls. Consequently, when her sister would visit, Barbara exclaimed that she felt that for her sister it was "an overwhelmingly sad experience [...] because she sees the way in which her dad has changed." She explained further, "[My sister] parachutes in and leaves again, and so she comes in and is disruptive." The disruption would often be so great that their parents would be tired for a week after the sister's visits. Because of this, Barbara said, "And sometimes actually that's frustrating because like she's here and disruptive, and then she leaves and it's still disrupted. It takes a while for the patterns to kind of, like, come back" (Participant 35AI, p. 37). In this prime example, the sister's lack of frequent visits combined with living far away created a disconnect in the synergy between the sister and the rest of the family. While she did provide Barbara some respite, overall her franticness in trying to achieve multiple tasks during her short visits to make up the lost time was exhausting for the rest of the family. Because the family's rhythmic synergy was at a much slower pace, the sister's faster pace because of her urgency to get tasks done while she was there in-person created tension. This sentiment of "parachuting" echoes a similar metaphor used by Zoe who expressed that she felt like her siblings were "seagulling" and that "seagull siblings are where they would come into town, and they would like do a bunch of stuff and then they leave again" (Participant 6F, p. 8). For Zoe, her siblings' arrivals provided temporary help, though not that

helpful due to their swift and messy departures. She later described seagulling as “It’s because they come into town. They shit on your plans. And then they leave” (Participant 6F, p. 32). For these participants and others, macro-rhythm disruptions were an often jarring experience that created stress. However, it is important to note that not all long distance caregivers were considered disruptive during their visits as they seemed to take steps to mitigate their knowledge gaps.

In addition, there were several examples of people disrupting specifically micro-rhythms. For example, Max explained a time in which her daughter was visiting and recalled, “I found her quizzing my husband, asking him questions like, “Oh, do you remember this? And do you remember that?”” Max said that she talked to her daughter later and explained to her, “You can’t quiz him because he doesn’t know the answer” and even “sent her documents from the Alzheimer’s Association about how to talk to him in a more pleasant way, where it’s not quizzing him and putting him on the spot” (Participant 17Q, p. 5). This situation depicts the more common example participants gave regarding disruptions where it involved an accidental type of disruption. Despite the disruption, participants were willing to help the family member adjust by informing them of their mistakes, and the family member was receptive to these corrections. In this example, Max’s daughter was unaware of the micro-rhythm that her mother had with her father concerning a particular way she needed to speak to him. Because Max’s daughter was never informed of this micro-rhythm of communication, she accidentally disrupted that rhythm. Ultimately, Max helping her daughter promoted greater rhythmic synergy as a family because they were more strongly moving at the same caregiving pace together.

In another example of a family member disrupting a micro-rhythm but regarding compassionate deception, Shay mentioned how he was trying to move this mother to a care community without her being fully aware because otherwise she would become frightened and unsettled. To do so, he needed his cousin Brooke's help. He said, "I kept telling Brooke, "Do not say that this is for [my mother's] own good. Do not say this is about her health. Do not say this is about dementia. You have to say this is about money." He knew this was the best strategy because he learned this was a positive trigger for his mother where she would accept an explanation related to money since she had a career in payroll. This is a strong example for how having these rhythms and set of knowledge can be helpful to make caregiving easier. With this micro-rhythm established, he instructed his three other family members to answer that "[they] can't afford to keep her in the house, that there's not enough money" if she asks why she is moving. He was trying to get his other family member's to adapt to his micro-rhythm. However, when his mother inquired about what was happening and making distressing threats, Brooke said, "Well [Shay's mother], this is for your own good." Shay recounted that his response to that statement was, "Ugh, I told you not to say that. That just made her more upset" (Participant 18R, p. 18). For this family, Shay was trying to invoke what he knew to have beneficial outcomes related to the compassionate deception micro-rhythm he had with his mother. He did this by informing his other family members about this rhythm, but ultimately his family member, Brooke, failed to adapt and chose to reveal the truth of the situation to Shay's mother. In this way, she disrupted the rhythmic synergy Shay had with his mother and the rhythmic synergy he was trying to create amongst them. The ramifications of this disruption were two fold. First, it created stress for Shay and anxiety for his mother because they ended up in the situation that Shay was trying

to avoid in the first place where his mother would be agitated about the idea of moving. Secondly, it made Shay's caregiving process more difficult because his mother refused to be moved to a new care environment now that she knew the reason was not about money.

Lastly, these disruptions did not just happen between family members. A few participants mentioned how they felt disrupted by non-family members like professional caregivers. With Val, she shared how she got irritated when the professional caregivers would be aggressive with her grandfather. She continued, "That sort of disrupts the flow because you think they're treating him so nicely and doing all of this, and then someone that we're paying a lot of money isn't treating him to the same high standard as we are" (Participant 4D, p. 13). These professional caregivers were unaware that Val and her family have particular ways they interact (i.e., macro- and micro-rhythms) with their loved one. Because they were not aware of these rhythms, they unintentionally disrupted them. Taken together, disruptions strongly characterize the complexity of a family navigating a stressor together. Rhythms create synergy and momentum whereby caregiving becomes more streamlined and thus easier. However, when people are unwilling or unable to adapt to these pre-existing rhythms, they disrupt the synergy and thus cause a loss in momentum and ease in caregiving. The implications of these disruptions likely have downstream effects not just for the primary caregiver and the loved one but also the whole family and care partner system.

## **Discussion**

Given the unique reality of ADRD as an inherently ever changing experience, this study explored the role of timing and adaptive communication efforts for family members who care or have cared for a loved one living with ADRD. The participants seemed to not



only find a way to expect the unexpected, but also manage the unexpected. They were creative in their thinking, flexible in their approaches, and willing to share their insights. This study resulted in detailing and conceptualizing this phenomenon of how family members established their processes of learning, adapting, and implementing strategies to determine what communication strategies worked and did not work for their loved one and families. Drawing on multiple bodies of literature, the findings resulted in the proposal of the construct of rhythmic synergy, the communicative and dynamic process where people generate patterned ways of interacting with each other to navigate a stressor more easily and instill a sense of co-presence. Rhythmic synergy is not only a matter of the caregiver and the loved one living with ADRD but also for all care partners involved and how they interact with each other to be in sync with one another. The theoretical and practical utilities of this construct and its underlying properties are outlined in the following sections.

### **Theoretical Contributions**

Rhythmic synergy was built upon bridging the temporal qualities of communication, notion of presence from nursing, multidisciplinary concept of interpersonal synchrony, social psychological lens of entrainment together. The current study contributes to these four existing bodies of literature. This study extends Werner and Baxter's (1994) notion of the spiraling time dimension where rhythmic synergy portrays relationships as characterized by recurring, yet also evolving events. The authors offer a few examples such as talking cycles to demonstrate rhythmic activities, but the illustration for cyclical/spiraling time remains sparse. The research expanding upon their theoretical underpinnings is also extremely limited (see Merolla, 2010). The relationship between a care partner and their loved one is organized by the series of rhythms that are established. In this way, their relationship itself can be

characterized as repetitive but also possessing an element of change and growth. The visual depiction of the rhythmic synergy created between the caregiver and the loved one as a spiral in Figure 3 is illustrative of this fact. The constant adjustments a care partner may make over time with their loved one build on each other as they approximate to temporary conclusions until new changes arise which would prompt more communication changes. A care partner who does not take notice of their loved one's behaviors or responses is also bound to make the same communicative actions over and over, thus creating a cyclical relationship. Therefore, if the care partner does not adjust their communication patterns based upon the cues from the loved one, a rhythm may be difficult to establish or could get disrupted more easily.

Alongside the contribution of furthering conceptualizations of temporality within interpersonal communication, rhythmic synergy also adds to the research on presence within nursing. At the forefront of rhythmic synergy is the outcome that enacting this kind of sensitized communication can foster moments of greater connection and presence together. Therefore, rhythmic synergy and its communication orientation represents a means whereby people can transcend their verbals and nonverbals to feel a higher order sense of social and emotional connection (Candlin & Candlin, 2016; Finfgeld-Connett, 2006). While research on presence or presencing acknowledges communication, they do not offer a more detailed understanding on how to create presence. For example, Finfgeld-Connett (2006) suggest behaviors such as affectionate touching, increased eye contact, listening, and "sensitive verbal communication" (pp. 710-711). However, no further research has focused on the communication element of creating this notion of presence until now. Moreover, presence is discussed being inextricably related to time. As Finfgeld-Connett (2006) stated, a "rhythmic

pattern of presencing” develops over extended periods of time and “occurs in a context of dynamic adaptation to unique circumstances” (pp. 710-711). Rhythmic synergy extends the concept of presence by providing specific and detailed insight on how exactly care partners can practically create patterns of presencing over time within the dynamic context of ADRD caregiving. Thus attaching a processual communication lens to presence strengthens the utility of the concept beyond that of vague communication suggestions. The contribution is not one-sided because presence adds credence to the profound power of communication and articulates perhaps *the* primary reason why we communicate in the first place—to feel truly ‘with’ someone (Fredricksson, 1999).

Rhythmic synergy also demonstrates support for their argument that two partners can coordinate their individual rhythms together to create a new rhythm via mutual social entrainment. However, rhythmic synergy addresses an important and overlooked factor of ability where social entrainment may not always be mutual. One of the parties may have differing cognitive abilities that influence their capacity to communicate in ways that are considered normative. It requires effort on the part of the care partner to learn the communication patterns of the person living with ADRD (which could be erratic due to the cognitive impairment) and adjust to them, especially in the early phases of caregiving or during different stages of the disease. While maintaining the recognition of personhood and agency for the person living with ADRD, rhythmic synergy is specifically illustrating how one person (i.e., the care partner) adjusts their rhythm to complement the other person (i.e., the loved one living with ADRD).

The support for the intentional accommodation made by one party in rhythmic synergy was created by combining two sub-concepts within entrainment and interpersonal

synchrony. Koban et al. (2019) argue that interpersonal synchrony can be distinguished in terms of intentionality. This notion of intentionality provides support that the care partner can be deliberate in their creation of rhythmic synergy with their loved one. In this way, rhythmic synergy is not just a spontaneous, coincidental, or unconscious oscillation of cycles like with mimicry (see Chartrand & Bargh, 1999). This intention speaks to the reasons that participants gave regarding why they chose to implement or change their strategies and thus their rhythm with their loved one. Alongside this, Cacioppo et al. (2014) explored and defined the sub-concept of unilateral entrainment as a type of entrainment process where one person is adjusting or entraining their behavior to another. Therefore, unilateral entrainment ultimately serves to support how the family member could be adjusting their actions to accommodate their loved one.

However, it is important to note that this does not mean that rhythmic synergy is an entirely one-sided process where it is always unilateral toward the care partner. Both individuals are active agents that retain personhood no matter the conditions involved. Instead, rhythmic synergy represents a constant flux of efforts by both parties of being sensitive to and making communicative changes. That is, the loved one may be making active efforts to adjust their communication with their care partner, especially in the earlier stages. And as the loved one's symptoms progress, the level and intensity with which the two individuals work together may change where the care partner becomes more attuned. Therefore, within the context of rhythmic synergy, the sub-concept of unilateral entrainment refers to the degree of involvement for both parties as a unit together rather than one party's gain is the other party's losses. Taken together, this study offers a strong illustration of how

unilateral, intentional entrainment can operate together outside of the context of motor level interpersonal synchrony.

In terms of social entrainment specifically, this study further refines the conceptualization by McGrath and Kelly (1986). While McGrath and Kelly (1986) focus on extending entrainment to be social, what is lost in their conceptualization is what is happening at a communicative level. No further research has explored this process of social entrainment in an interpersonal way other than with music (see also Kim et al., 2019; Phillips-Silver et al., 2010). However, within music, that research does not adopt a communicative, relational perspective on the implications for social entrainment. Rhythmic synergy builds on the social entrainment model by focusing on the specific role of communication in this process, especially regarding what McGrath and Kelly (1986) call *rhythm* and *mesh*. In Figure 2, *rhythm* and *mesh* are essentially how the loved one and their care partner co-create their rhythm together through communication. Following that, the macro- and micro-rhythms from the findings constitute the rhythms themselves that are created. Finally, those rhythms as well as the co-creation process can be enhanced or disrupted by others. In this way, the model of rhythmic synergy, Figure 3, offers a more nuanced and detailed illustration of how communication is operating to uphold the social part of social entrainment. Rhythmic synergy brings the social entrainment model to life by depicting how people come together, communicatively manage their rhythms, and how they handle outside influences within the context of family caregiving.

### **Practical Contributions**

For every person living with ADRD, there are family members, friends, and medical care professionals that are impacted. While the world's leading geneticists, epidemiologists,

and other scientists race to find ways of tackling these conditions (National Health Service, 2021), millions of people all of the world will continue to develop ADRD and millions more care partners will need guidance and support. Understanding how people living with ADRD and their care partners communicate to not only manage their stress but also facilitate moments of joy and connection is vital, and this study is trying to bring this to light by highlighting the nature and depth of the communication patterns involved. There are several key areas that rhythmic synergy offers practical insights.

By articulating the construct of rhythmic synergy, this study attempts to contribute to the perspective shift of highlighting the positive aspects of caregiving (Quinn & Toms, 2019) and the greater movement toward fostering dementia positivity (Lin & Lewis, 2015).

Therefore, rhythmic synergy should be not just be viewed as a helpful construct that can reduce stress and uncertainty. Instead, it should be viewed also as a mechanism to optimize positive experiences as a way to better support caregivers and their loved one's well-being (Sideman et al., 2023). This is achieved through one of the key outcomes of rhythmic synergy—its ability to create higher order social and emotional connection beyond that of physical means and a feeling of co-presence. Drawing from the ways in which nurses have theorized about how to effectively care professionally with their patients (Candlin & Candlin, 2016; Finfgeld-Connett, 2006), rhythmic synergy incorporates presence as a way to keep positivity at the forefront and ultimately be a driving force for people.

In support, van Corven and colleagues (2022) explored the strategies family caregivers employed to promote connecting with their loved one living with ADRD, such as the contextual strategy of visiting at 'the right time' of the day. The study confirms the importance of what creating those meaningful connections does for both parties, including

improved mood for the person living with ADRD and feelings of fulfilment for the family caregivers. In addition, care partners and loved ones living with ADRD could find it motivating to think about their interactions as opportunities for creating presence with one another. For instance, Duggleby et al. (2013) emphasized the importance of connecting with the loved one living with ADRD as a key element in the family caregiver's hope experience. Embracing rhythmic synergy as a way to foster connection could improve the mental well-being of those involved, but especially the care partners. It could also empower them to enact these types of interactions in the future (see van Corven et al., 2021). As a result, rhythmic synergy is a useful starting point for helping these families recognize and make sense of their communication patterns, as well as maintain meaningful interactions in order to enhance or grow the relationship.

Another way that rhythmic synergy can be useful for families is that it offers them a way to better understand and articulate the web of people often involved in caregiving. Recent research has started to focus on the nature of family dynamics in the caregiving experience and noted the competing interests and complications involved (see Smith et al., 2022; Tatangelo et al., 2018). Rhythmic synergy does not focus on one person or even just the dyad of one caregiver and the loved one, but rather a system of care partners that can help enable each other to achieve a collaborative caregiving goal or impede it. In articulating this construct, the goal is that families and care partners can begin to see themselves as intricately and vitally connected together as an orchestral system. Beyond each person fulfilling their own separate roles, everyone mutually influences each other. Moreover, family members and care partners could find it helpful to think about their rhythms as valuable knowledge they can harness and ultimately share as a way to communally cope together. For instance, if a

family member notices that the loved one is starting to get disoriented when topics about his childhood get mentioned, then it would prove crucial to share that information with others to ensure that everyone is on the same page. By being “in rhythm” together as care partners, this could reduce instances of accidentally triggering the loved one or accidentally disrupting another person’s rhythm. If that family member kept that information to themselves or was not even conceptualizing that change in behavior as resulting in a kind of shift in their own responses, then that could create situations where other people interrupt the flow the family member was maintaining for the loved one. By creating the concept and theoretical underpinnings of rhythmic synergy, family members can now be provided with language and tools necessary to help them be more reflective and proactive in their caregiving.

In addition to family and friends, professional caregivers and staff are likely to establish rhythms with people living with ADRD, particularly when transitions to in-home care or senior living communities occur. Therefore, nurses and other professionals may find the construct of rhythmic synergy inherently beneficial to their own rhythm creation with their patient. They may also find it helpful to facilitate communication with their patient’s family as both parties try to navigate the caregiving process together. In the current study, many family members expressed their uncertainties transitioning their loved ones to new care environments or introducing professional caregivers into their lives. Some even divulged frustrations concerning how the care their loved one was receiving was not the same level of care they provided. Thus, the professional was disrupting the rhythmic synergy the family member created with their loved one.

The finding of professional care partners disrupting the rhythm of the family members is consistent with previous studies that have examined the role of hospital staff and



professional caregivers, especially as they try to cultivate meaningful interactions with their patients (see Haunch et al., 2023). Gathering ethnographic data including interviews with people living with ADRD, their families, and staff in hospital wards, Kelley et al. (2019) explained how families' intimate role in care routines and personal knowledge proved crucial for their loved one's transition to the hospital and the staff's ability to provide individualized care. The staff found it helpful to be aware of information like certain phrases and topics that tended to prolong conversations, as well as be informed about personalization of the loved one's care routine in order to provide comfort and reduce confusion for the loved one. Both the personal knowledge and the routines were valuable means of facilitating and maintaining meaningful connections between staff and the person living with dementia. Similarly, in a study by Ryan and McKenna (2014), family caregivers who had loved ones recently move into a nursing home shared that their loved one had well-established routines prior to moving and considered it important that their previous routine was respected and maintained as much as possible. Rhythmic synergy is exemplified in both of these studies and demonstrates how care can be re-imagined under this idea of rhythms as a helpful way to make sense of the experience.

Finally, the applicability to rhythmic synergy could extend beyond that of just ADRD caregiving. Those who have a loved one in their life with differing cognitive and communication abilities like individuals with Down syndrome or individuals with autism spectrum disorders might be interested in learning about rhythmic synergy. These families and care partners could find it helpful in facilitating the way they communicate with their loved one as well as understand how they communicate with each other as caregivers. In fact, recent research has pointed toward the desire to more deeply explore how care partners can

be aided in better communicating with their loved one with an autism spectrum disorder or other 'complex communication needs' (Denney et al., 2022) as well as Down syndrome (Melvin et al., 2019). Future research should explore the ways in which rhythmic synergy is and is not salient to other caregiving contexts.

### **Concluding Remarks**

This study laid the foundation for a new theory of rhythmic synergy as a way to conceptualize the communication patterns of families and care partners as they care for a loved one living with ADRD. Rhythmic synergy captures the process of how care partners create macro- and micro-rhythms with the loved one by engaging in co-constructing the rhythms together. Embedded within this spiraling process are evolving uncertainties and reasons care partners have as time progresses. Moving beyond the dyadic interaction, rhythmic synergy also characterizes how a family system interacts and illustrates how multiple family members and care partners can ultimately enhance or disrupt each other's rhythms. By understanding the scale at which everyone is operating, the care partners could become invested in facilitating or enhancing each other's rhythms and keeping one another informed as new behaviors and subsequent rhythms change. With an entire care partner network working together to keep everyone moving at the same pace, the cascading impacts this could have for all parties involved likely would be beneficial. The construct of rhythmic synergy challenges prevailing notions of communication in which the other person may have differing communication capabilities. Transcending traditional ways scholars think about communication, rhythmic synergy attends to the ways in which people vulnerably, sensitively, and creatively try to connect and be present with these loved ones.

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## Appendix A

Table

**Table 1**

*Participant Information*

ID No.	Pseudonym	Age	Race and ethnicity	Gender	Family member they care for	Years caregiving	Family member living?	Family member's age	Family member's race and ethnicity?	Family member's gender	Family member's diagnosis	Current stage of diagnosis or when participant helped
1A	Elizabeth	59	White	Woman	Mother	8 years	Yes	86	White	Woman	Alzheimer's	Middle
2B	Bob	80	White	Man	Mother	1 year	No	85	White	Woman	Mixed dementia	Late
3C	Beth	55	White	Woman	Mother	7 years	Yes	81	White	Woman	Alzheimer's	Late
4D	Val	28	White	Woman	Grandfather	3 years	No	82	White	Man	Vascular dementia	Early-Late
5E	Katia	81	White	Woman	Mother	3 years	No	97	White	Woman	Dementia	Middle-Late
6F	Zoe	56	White	Woman	Mother	5 years	No	83	White	Woman	Dementia	Late
7G	Nancy	50	White	Woman	Father	1.5 years	Yes	80	White	Man	Fronto-temporal dementia	Middle
8H	Jeanette	57	White	Woman	Mother	10 years	No	88	White	Woman	Dementia	Early-Late
9I	Alice	37	White	Woman	Father	2.5 years	Yes	73	White	Man	Lewy body dementia	Late
10J	Marie	44	Hispanic	Woman	Mother	4 years	No	79	Hispanic	Woman	Vascular dementia	Late
11K	Heather	62	White	Woman	Mother in-law	10 years	Yes	88	White	Woman	Alzheimer's disease	Late
12L	Lisa	57	White	Woman	Father	5 years	Yes	80	White	Man	Dementia	Middle

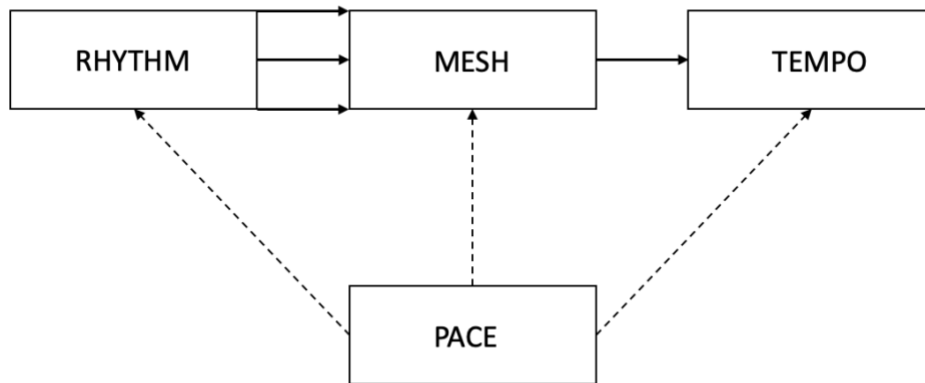
13M	Carlos	71	Hispanic & Indigenous White	Man	Mother	7 years	Yes	90	Hispanic & Indigenous White	Woman	Dementia	Middle
14N	Leslie	66	Indigenous White	Woman	Mother	4 years	No	88	White	Woman	Dementia	Middle
15O	Ida Mae	66	White & Hispanic	Woman	Mother	6 years	No	85	White & Hispanic	Woman	Alzheimer's	Middle - Late
16P	Zak	20	Asian	Woman	Grandmother	4 years	No	78	Asian	Woman	Alzheimer's	Middle
17Q	Max	78	White	Woman	Husband	11 years	No	80	White	Man	Alzheimer's	Late
18R	Shay	49	White	Man	Mother	4 years	Yes	76	White	Woman	Dementia	Late
19S	Sarah	46	Hispanic	Woman	Mother	7 years	Yes	78	Hispanic	Woman	Fronto-temporal dementia	Late
21U	Terri	54	White	Woman	Father	0 years	Yes	88	White	Man	Alzheimer's	Middle
23W	Regina	76	White	Woman	Husband	23 years	No	74	Middle Eastern or North African	Man	Mixed dementia	Early - Late
24X	Cheryl	58	White	Woman	Mother	30 years	No	75	White	Woman	Alzheimer's	Middle
26Z	Bennett	49	Asian	Woman	Mother	8 years	No	78	Asian	Woman	Alzheimer's	Early - Late
27AA	Dale	54	White	Man	Mother	23 years	No	97	White	Woman	Mixed dementia	Late
31AE	Ruth	49	White	Woman	Mother	15 years	Yes	83	White	Woman	Alzheimer's	Late
33AG	Donna	76	White	Woman	Husband	20 years	Yes	78	White	Man	Alzheimer's	Early - Middle
34AH	Gail	77	White	Woman	Husband	4 years	No	77	White	Man	Parkinson's	Early - Late
35AI	Barbara	48	White	Woman	Father	3 years	Yes	75	White	Man	Alzheimer's	Middle
36AJ	Margaret	61	White	Woman	Father	3 years	No	85	White	Man	Alzheimer's	N/A
37AK	Olivia	50	Hispanic	Woman	Mother	13 years	Yes	88	Hispanic	Woman	Alzheimer's	Late
39AM	Gwendolyn	60	White	Woman	Mother	6 years	Yes	88	White	Woman	Alzheimer's	Early

## Appendix B

### Figures

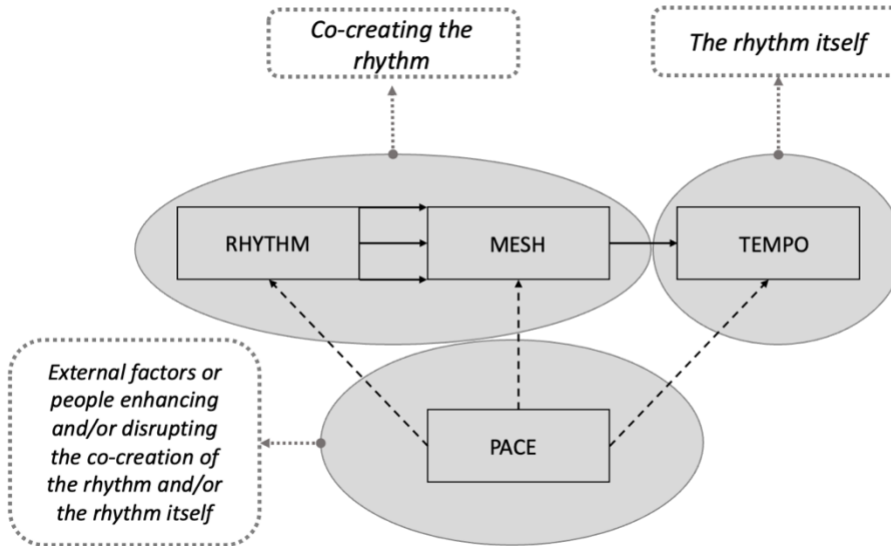
**Figure 1**

*McGrath and Kelly's (1986) Social Entrainment Model*



**Figure 2**

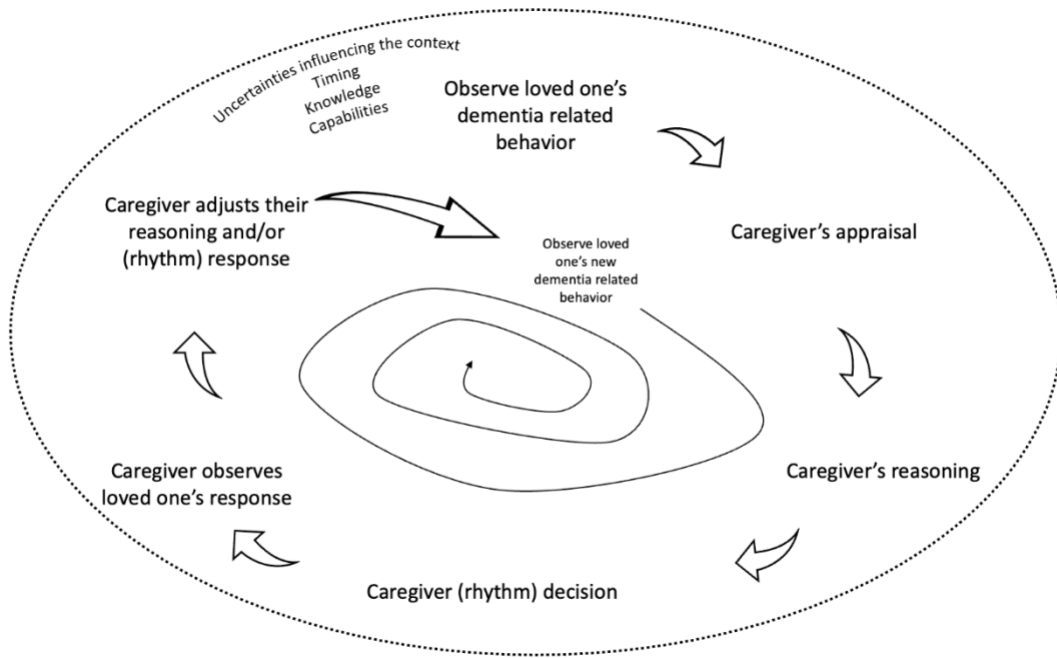
*Rhythmic synergy mapped onto McGrath and Kelly's (1986) Social Entrainment Model*





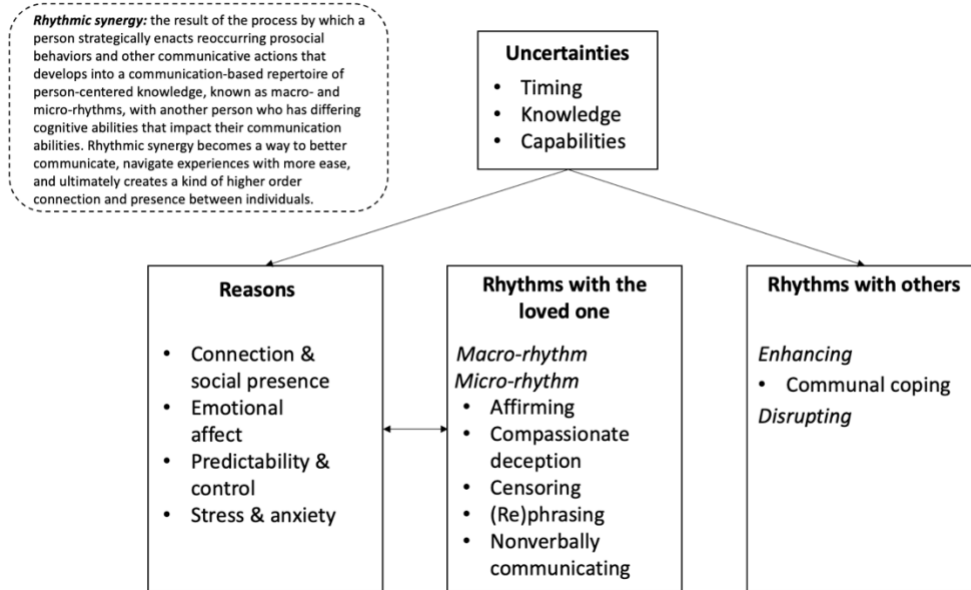
**Figure 3**

*Model of the rhythm creation with the loved one*



**Figure 4**

*Summary of themes*



## Appendix C

### Semi-Structured Interview Schedule

Hello, it's nice to meet you. My name is \_\_\_\_\_, and I will be conducting your interview. As a reminder, we will be audiotaping this interview so that we can transcribe it later. The file will remain on a protected cloud service that will only be accessible by people on the research team. Once we transcribe the audio, we will delete the file so that the transcript will only remain. Lastly, your participation in this study is completely voluntary, your information will be kept confidential, you can refuse to answer any questions, and you can remove yourself from the study at any time.

Are you okay with all of this?

Do you have any other questions before we get started?

START RECORDING, SAY "ZOOM/IN PERSON INTERVIEW [PARTICIPANT ID]"

#### **Getting to know the participant and their family**

- To start, tell me about yourself and your family by walking me through all of your relationships.
  - What is the quality of these relationships?
- *\*Note to interviewer\* Make sure you know:*
  - Name of loved one with dementia
  - The participants' relationship to their loved one with dementia

Now I would like to know more about your loved one and their dementia.

- When did you realize your loved one had dementia?
- What was that process like realizing that?
- How did people in your family react?
- What was the communication like in your family during that time?
- How did this affect the relationships in your family?

#### **Defining uncertainty and the participant's uncertainties**

Next, I would like to hear more about what exactly this experience has been like for you. There may be many uncertainties you have. Uncertainty means the inability to predict what will happen or the unknown. For example, you might worry about your loved one's well-being because their dementia makes their behavior unpredictable. It is also possible that your uncertainties have changed over time. You may already be aware, but if not, physicians tend to organize dementia into three stages: early/mild, middle/moderate, and late/severe.

- So when you first learned your loved one had dementia, what were you uncertain about at that time?
  - What were you uncertain about during the time they were in the **early stage** when there were mild symptoms?
    - i. *If applicable*, what were you uncertain about during the time they were in the **middle stage** when there were moderate symptoms?
    - ii. *If applicable*, what were you uncertain about during the time they were in the **late stage** when there were severe symptoms?
  - Do you like being uncertain about some of these things? Why or why not?
  - Is there anything that you think you are uncertain about specifically as a spouse as opposed to say a sibling or child?
- Have you ever been uncertain about the equity of responsibility in caring for your loved one? Why or why not?
  - If so, did you have conversations with anyone about it? What happened?
  - Speaking on your role as the spouse, did you feel a particular obligation to be a part of those conversations? Why or why not?
- From what you've said, there are a lot of uncertainties involved with caring for someone living with dementia. In what ways would you say that these uncertainties themselves became expected?

### **The rhythm of uncertainties, communication, and the family dynamics**

*With the family member living with dementia*

- Take me through a typical day when you are caring for your family member. What does that look like?
- Describe to me the **patterns or rhythms** in the way that you communicate with your family member that have become established over time.
  - And how did you come to establish those patterns?
- When thinking about this kind of **pattern or rhythm** you end up learning...
  - What would you say have been some benefits to establishing this rhythm?
  - What have been some downsides to this rhythm or pattern?
  - How, if at all, do you think being the spouse plays into how much you feel like you are able to speak to a kind of pattern or rhythm?
- Are there ways that your loved one communicates (including through their body language) that, because of the dementia, becomes predictable? For example, you may know that mentioning a specific topic or person makes them anxious. Explain these instances to me.
  - And how have these ways of communicating and expectations changed over time?

- Do you ever discuss those techniques with other family members? If so, what has been said in those conversations?

*With other family members*

- Sometimes when families try and care for one another, but especially in the case of someone living with dementia, it can bring out the best and worst in family relationships like with siblings, parents, children, and extended family. Can you think of times when caring for your loved one brought out the best and worst for you and your sibling(s), parent(s), partner(s), child(ren), extended family?
  - Can you give me an example of when it brought out the **best**?
  - Can you give me an example of when it brought out the **worst**?
  - Under what circumstances were good and bad conversations happening?
- What about your experience taking care of your loved one makes your flow similar or different than another family member's?
- What roles would you say your other family members play in **creating** your rhythm?
  - Specifically, what is it about their communication that enhances this flow?
  - What are some *positives* of this?
  - What are some *negatives* of this?
- What roles would you say that your other family members play in **disrupting** your rhythm?
  - Specifically, what is it about their communication that disrupts this flow?
  - What are some *positives* of this?
  - What are some *negatives* of this?
- *If applicable*: Who would you say in your family is the least involved (this could but not always include those in your family who live the furthest away) with providing care to your loved one?
  - Describe to me what would typically happen when they would come visit you.
  - ***\*If the participant is the family member who lives at a distance away\**** → Describe to me what would typically happen when you visited your family member who provided most of the care?

*Miscellaneous*

- In addition to family members, are there other people in caregiving roles (e.g., in home care providers, staff in the senior living communities) who help establish or disrupt your rhythms and/or your loved one's rhythms?
- Are there other factors (e.g., distance, gender, finances, severity of the dementia) that enhance or disrupt the flow or rhythm of your communication with your loved one? If so, how?

- Have there ever been instances where your loved one is not acting like themselves, making false statements, or imagining various scenarios?
  - If so, what is communicating with them during those moments like?
    - Do you ever find yourself trying to explain to them that what they were explaining is not real or accurate? If so, what is that like?
  - How much would you say adapting or not adapting to these instances has become a part of your rhythm?
  - As their spouse, what makes navigating these interactions more challenging (or easier) than other kinds of relationships?

### **Communication in the family**

Thank you again for all of your insights. I'm interested to get more detail about what your conversations have been like, so I'm going to ask some follow up questions.

#### ***Communal coping***

- Sometimes families feel like they are a team and can work together to tackle life's challenges. In what ways would you all say that your family is like this?
  - What about your family's communication do you think is reflective of being a team?
  - Can you provide specific examples of this?
- And in what ways would you say your family is **not** like a team?
  - What about your family's communication do you think is reflective of this?
  - Can you provide specific examples of this?

#### ***Communicated narrative sensemaking***

- How much would you say that you and your family are the kind of family that talks about and share stories together? Why do you think that is?
- How much would you say that you and your family reminisce and tell stories about events from the past with each other ever since your loved one's diagnosis? Why do you think that is?

#### ***General***

- Have you ever had a conversation with a stranger or situation in public concerning your loved one that comes to mind? If so, what happened?
  - Were you able to rely on other family members to help you in the moment?
  - Did you end up talking about that event with other family members later after it happened? If so, what was that like?
- Some families struggle with the way dementia can make a loved one **not** act like themselves and be psychologically present some moments and other times not.

- Is this something you and/or your family would say that you are uncertain about? Why or why not?
  - Have you ever discussed this with another family member? If so, what did you discuss?
  - Have you ever discussed this with your family member with dementia? If so, what was that like?

### ***Practical***

I would like to hear what you have to say about practical solutions that you think could ultimately help other families in your community and beyond.

- If you had to choose one, what would you say has been your biggest challenge in caring for your family member?
- What is something you wished you had that you think could be crucial in alleviating this challenge?
- What practical tips would you give to someone whose family member was recently diagnosed with dementia? What would you want them to know?

### **Final question and concluding remarks**

Lastly, I'm sure there are things that have come to mind during this conversation that I didn't ask about.

- What else would you like to share that you want me and others studying families impacted by dementia to know before we wrap up?

Thank you very much for participating in this study. This has truly been a pleasure and honor to have this discussion with you. We appreciate you taking the time to share your experiences and opinions with us. Your insights will help us learn more about these types of conversations so that researchers can help educate and provide guidance to other families who have been impacted by dementia.

Would you be willing to be contacted to share your thoughts with us on the study's findings? This would involve an hour or so of your time within the next 6 months (until the end of March).

- Yes
- No

In order to protect your privacy and confidentiality, we will use a pseudonym to name your audio, transcript, and demographics sheet files. We plan to present and publish the results of this study which may include direct quotations from your interview but we would use the pseudonym you pick. During the transcription process, we will also remove any

personally identifying information from the interview itself. What pseudonym would you like us to use?

Pseudonym: \_\_\_\_\_