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Conversation Goals, Communication Satisfaction, and Relational Dynamics While Navigating Alzheimer's Disease: A Pre- and Post-Diagnosis Dyadic Examination of Family Communication

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CONVERSATION GOALS, COMMUNICATION SATISFACTION, AND
RELATIONAL DYNAMICS WHILE NAVIGATING ALZHEIMER'S DISEASE: A
PRE- AND POST-DIAGNOSIS DYADIC EXAMINATION OF FAMILY
COMMUNICATION

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DISSERTATION

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A dissertation submitted in partial fulfillment of the
requirements for the degree of Doctor of Philosophy in the
College of Communication and Information
at the University of Kentucky

By
Elizabeth A. Spencer
Lexington, Kentucky
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2020

ABSTRACT OF DISSERTATION

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Currently there are more than 16 million unpaid Alzheimer's disease and dementia caregivers in the United States. These caregivers are often family members of the person living with dementia, and as they navigate the process of giving care to the patient, they must also maintain relationships with each other. Families enter the dementia experience with a history of their relational experiences, and their relational experiences potentially change as they navigate family experiences after the dementia diagnosis. Much existing scholarship examining family communication in the context of progressive Alzheimer's disease and other related dementias has focused on the perspectives of one individual within a family, single communication encounters, and has operationalized communication in terms of frequency. This dissertation applied the multiple goals theory of interpersonal relationships (Caughlin, 2010) to address some of the gaps in extant scholarship by focusing on family dyads, collective past communication experiences, and measured the quality of family communication. Seven research questions were presented, which inquired about the associations between pre-diagnosis relational dynamics, post-diagnosis communication satisfaction, post-diagnosis interaction goals, and post-diagnosis relational dynamics.

Perspectives of adult family members of U.S. dementia patients were elicited through self-guided online questionnaires. Participants were recruited in dyadic pairs, and the total sample included 53 family dyads ($n = 106$ individuals). Data were analyzed using path analyses in actor-partner interdependence models to examine the relationships between variables. Statistically significant actor effects were observed between pre-diagnosis relational dynamics and post-diagnosis communication satisfaction, post-diagnosis interaction goals and communication satisfaction, and post-diagnosis communication satisfaction and relational dynamics. Statistically significant actor and partner effects were observed between pre-diagnosis relational dynamics and post-diagnosis interaction goals, pre- and post-diagnosis relational dynamics, and post-diagnosis interaction goals and relational dynamics.

The results of this dissertation provide compelling evidence that actual communication experiences are important to how family members evaluate their ability to attend to interaction goals in the context of dementia, and those perceptions in turn affect family relational dynamics after the dementia diagnosis. Findings of this research demonstrate that pre-diagnosis relational dynamics aggregate and influence post-diagnosis perceptions and evaluations of own and other's interaction goals and satisfaction with enacted communication. Additionally, results of this dissertation show family members' ratings of relational closeness increased and functioning decreased from pre- to post-diagnosis.

Results of this dissertation have several theoretical and practical implications. Theoretically speaking, these findings provide evidence supporting previous multiple goals research and extending this work into the family dementia context. Actual communication experiences are important to how family members evaluate their ability to attend to interaction goals in this context, and those perceptions in turn affect family relational dynamics after the patient's dementia diagnosis. The current research also provides some initial evidence that more global perceptions of interaction goals are related to more global relational concepts. Additionally, the findings from this dissertation can be used to inform the evidence-based evaluation of dementia caregiver interventions, education programs, and online social support resources. The interwoven experience of family members navigating the experience of dementia is complex. The practical insight gained from these results can be used to assist caregivers and families with their relational needs and to mitigate the negative implications associated with caregiving. These findings can be utilized to ultimately improve health outcomes for family members of dementia patients and patients themselves.

KEYWORDS: Family Communication, Family Relationships, Alzheimer's Disease, Dementia, Caregivers, Multiple Goals

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DEDICATION

It is because of her legacy that I was able to persevere. In honor of Georgia Ann, I dedicate this to Tristan Alton Spencer. Across generations, our interwoven family experiences collectively and individually influence and shape us. May you be encouraged and guided by what you have seen and by the ways in which your life course has forever been changed.

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CHAPTER ONE: INTRODUCTION AND RATIONALE

Alzheimer's disease is the sixth leading cause of death in the United States, affecting over five million people (Alzheimer's Association (AA), 2019). This number is expected to nearly triple by the year 2060 (Centers for Disease Control and Prevention (CDC), 2019). Due to medical advances, more people are advancing into later life years, and advanced age is the number one risk factor for developing Alzheimer's or dementia (AA, 2019; CDC, 2019; National Institute on Aging (NIA), 2019). Since there is currently no cure, one in three U.S. seniors will die with Alzheimer's or another dementia (AA, 2019). While the average prognosis is four to eight years, persons diagnosed with Alzheimer's can live up to 20 years with the disease (CDC, 2019; NIA, 2019). This prevalent disease creates complex situations and experiences for millions of people, compelling researchers to examine its impact upon individuals and their families.

In addition to impacting a significant number of people living in the United States, Alzheimer's disease also significantly impacts the families of these patients. There are 16.1 million unpaid Alzheimer's disease and dementia caregivers in the United States, most of whom are patients' family members (AA, 2019). Many of these familial caregivers are balancing the needs of not only the dementia patient, who is often an aging parent, but also the needs of their own immediate family unit. Although family caregivers note positive aspects of caregiving (i.e., emotional closeness, rewarding nature of helping), they also report higher levels of stress than non-caregivers (AA, 2019). Dementia caregivers report lower levels of mental and emotional health and greater levels of physical strain than non-caregivers (AA, 2019). Family caregivers face unique challenges with a dementia diagnosis (National Alliance for Caregiving (NAC) & AARP

Public Policy Institute, 2015). Compared to 17% of non-dementia diagnoses for persons of advanced age, 35% of dementia caregivers report that these responsibilities have negatively impacted their own health (AA, 2019). Caregivers of dementia patients report higher levels of burden and strain than caregivers of non-dementia patients (AA, 2019). The additional stress and demands of caregiving also can reduce an individual's support network or their perception of support. In short, the psychosocial impact of dementia caregiving on family members is great.

As family members navigate the process of giving care to the patient, they must also maintain relationships with each other. Research in various fields has examined the impact of caregiving on individual health, yet little scholarship has focused on the effects of caregiving on family relationships. In the context of families navigating caregiving for a family member living with Alzheimer's disease or another form of dementia, there are factors which make this situation especially challenging for family relationships. For instance, an Alzheimer's diagnosis is often a biographical disruption for individuals and their families (Bury, 1982). A biographical disruption occurs when serious illness, such as dementia, disrupts the normal rules of reciprocity and mutual support within families and it carries with it a reformulation of identity (Bury, 1982).

Families with an Alzheimer's patient have a unique set of needs, including demanding tasks and complex identity and relational concerns. Emotionally, families can experience an intense sense of loss and grief, even in the absence of death, as the patient slowly declines (Pearlin, 2010). Families must make clinical decisions and coordinate care for the patient while attending to their own and others' identities and the family relationship. The conversations in which these issues are raised can be difficult (Scott &

Caughlin, 2012) as multiple family members navigate their own and each other's goals within interactions (Caughlin, 2010). Additionally, families enter the situation of dementia care with the knowledge and influence of their family experiences before the patient's diagnosis. Yet, little research has examined the role of pre-diagnosis relational dynamics on current (i.e., post-diagnosis) family interactions. Likewise, few studies have examined the potential influence of current family interactions upon relational dynamics. There is a need for research to examine the influence of pre-diagnosis family relational dynamics upon post-diagnosis interactions and the ways in which families in this context must attend to their relationship quality while managing patient behaviors and making difficult care decisions.

In short, Alzheimer's disease is considered a public health epidemic (CDC, 2019), yet research has been slow to address perhaps the most salient issues associated with family members of persons living with Alzheimer's. The pervasiveness of this disease and its impact on individual caregivers and collective families provides researchers with an opportunity to translate their findings into practical recommendations that stand to benefit many individuals. Published scholarship to date has a lack of focus on the effect that Alzheimer's care has on family relationships. There is a need for research that focuses on the interwoven nature of family groups navigating this experience and to examine the impact of Alzheimer's upon family dynamics.

The Present Study

In this dissertation project, I used a multiple goals theoretical perspective to examine family dynamics as families navigate the progressive disease of Alzheimer's. Families do not face Alzheimer's having discarded all previous relational experiences.

Rather, the historical (i.e., pre-diagnosis) relational dynamics, communication patterns, perceived communication goals, and communication satisfaction are salient in current (i.e., post-diagnosis) family interactions (Caughlin, 2010), including those conversations specifically about dementia care. Therefore, this dissertation project examined what influence pre-diagnosis family relational dynamics (i.e., pre-diagnosis relational closeness and relational functioning) have on post-diagnosis perceptions of interaction goals (i.e., own and others') as well as on current communication satisfaction. Additionally, current interaction goal perceptions and communication satisfaction in this context of Alzheimer's or dementia were investigated with relation to their influence on post-diagnosis family relational dynamics (i.e., relational closeness, functioning, and distancing).

This dissertation contributes to theory development and offers practical recommendations. Most multiple goals research has focused on the relational impact of single communication encounters. Less work has utilized multiple goals theory to examine to the connection between relational dynamics and communication more globally (Caughlin, 2010). Thus, theoretically, by examining the association of goals with more global relational dynamics (rather than the relational impact of isolated conversations), the results of this research extend the multiple goals theory of interpersonal relationships from a micro to a more macro perspective (Caughlin, 2010). Practically speaking, most family caregivers report needing instrumental help and additional information on care topics (NAC & AARP Public Policy Institute, 2015). Findings of this dissertation could be used to inform the development and (re)evaluation of current and future caregiver interventions, education programs, and online social

support resources that can be used to assist caregivers and families with their

interpersonal needs, facilitate higher quality of life for patients as well as better family

relationships, and, ultimately, improve health outcomes for dementia patients and their

family members.

CHAPTER TWO: REVIEW OF LITERATURE

This chapter provides a review of literature relevant to the present investigation. Specifically, I provide background on the context of Alzheimer's disease and other related dementias and illustrate the impact of dementia on caregivers and families. Also, in this chapter, I discuss the theoretical frameworks in research on families navigating Alzheimer's. Finally, I address the conceptualization and operationalization of caregiver communication found in extant scholarship in this context.

The Context of Alzheimer's and Dementia Care

Research in various fields has examined the context of Alzheimer's disease and related dementias. Medical advances have increased projected life spans, allowing more people to advance in age; and advanced age is the leading risk factor for developing Alzheimer's or dementia (AA, 2019; CDC, 2019; NIA, 2019). As the prevalence of the disease grows, much research has focused on dementia patients and their experiences. In general, scholarship has also highlighted the crucial role that family members play in the disease and care experience as well as how dementia care can negatively impact caregivers (i.e., depression, anger, fatigue; Rabins, Mace, & Lucas, 1982). Extant research has recognized the public health epidemic and that it affects not only patients, but also family members.

Although research has recognized the prevalence of dementia and its impact upon caregivers, findings are often conceptualized as outcomes for patients while outcomes for caregivers are largely overlooked. Yet, there is some evidence that the health and wellbeing of family member caregivers can negatively impact the quality of care they provide to the patient (Kim, Chang, Rose, & Kim, 2012). Family caregivers of dementia

patients commonly experience burden, which can negatively affect the quality of care they provide and in turn the quality of life for dementia patients (Schulz & Martire, 2004). Caregiver burden can create negative effects on emotional health (e.g., depression, stress, fatigue), financial costs, and negative implications in the workplace (e.g. early retirement, reduction of hours, refusal of promotion; Black et al., 2010). These negative outcomes of caregiving can then have a negative impact on caregiving ability (Etters, Goodall, & Harrison, 2008).

Some scholarship has examined ways in which social support and coping can mitigate caregiver burden. Social support is generally assumed to include any behavior intended to be helpful (Goldsmith, 2004). For example, higher levels of emotional support can increase feelings of support and resilience (Wilks & Croom, 2008), and reduce feelings of isolation (Drentea, Clay, Roth, & Mittelman, 2006) and stress (Roth, Mittelman, Clay, Madan, & Haley, 2005). Yet the conceptualizations of social support vary greatly across research, which has led to mixed findings regarding the impact of social support. For example, social support can also have negative implications (Goldsmith, 2004). There is evidence in caregiving research that social support can actually be related to poor physical health outcomes for family members (Fuller-Jonap & Haley, 1995; Kiecolt-Glaser, Dura, Speicher, Trask, & Glaser, 1991), greater anxiety and depression (Harwood, Barker, Ownby, & Duara, 2000; Schrag, Morley, Quinn, & Jahanshahi, 2004). Hipper, Catona, and Nussbaum (2010) provide one possible explanation for these negative effects of support by suggesting that caregiving demands reduce support networks. Alzheimer's caregivers experience lost (i.e., actual or perceived) support due to the tremendous time and energy spent with the patient (and

thus not with members of their support network). In short, while social support can buffer against caregiver burden, it can also increase stress and tension, complicating the experiences of family members of dementia patients.

Likewise, family caregiver coping research has yielded mixed findings across and within various fields of study, likely due to varying conceptualizations of coping. For example, coping has been conceptualized in research as information seeking (Jeong, Kim, & Chon, 2018), uncertainty reduction (Lax & Stone, 2014), information forwarding (Jeong et al., 2018), humor (Sparks Bethea, Travis, & Pecchioni, 2000), and avoidance (Basnyat & Chang, 2017). Research on emotion-focused coping strategies versus problem-focused coping has varying implications for caregiver burden. For example, in one study, emotion-focused coping reduced caregiver anxiety, but problem-focused strategies did not (Cooper, Katona, Orrell, & Livingston, 2008). In other research, problem-focused coping appears to be more helpful than emotion-focused coping depending on the stage of disease (Jeong et al., 2018). Conflicting findings on effects of caregiver coping, as well as unclear conceptualizations of coping behaviors, emphasize the need for additional research that clearly conceptualizes issues facing dementia caregivers and the effect of caregiving on families.

In addition to inconsistent conceptualizations of caregiver issues, extant research also tends to examine family caregiver issues from the perspective of one single family member rather than on the family unit as a whole. Little family caregiver scholarship acknowledges the importance of the family relationship or recognizes the associated concepts of time, interdependence, and collective family experience (Schulz & Beach, 1999; Tremont, Davis, & Bishop, 2006). In one review of the literature, Hummert (2007)

called for family communication research to recognize the impact of Alzheimer's disease on the whole family and to focus on preserving the family network. This highlights the need for researchers to examine family caregiver issues by acknowledging the influence of collective family dynamics and conceptualizing family issues as an interdependence between members, rather than merely examining the effects of caregiving on one individual's wellbeing.

Theoretical Frameworks in Communication Scholarship on Families Navigating Alzheimer's

Within family communication research published in communication journals specifically, very little work has examined the actual context of Alzheimer's disease or another dementia and families. Most research on family communication in the context of Alzheimer's disease or another dementia has been conducted by scholars who are *outside* the field of communication (i.e., psychology, gerontology, nursing, speech and language, social work, the medical field) and published in journals that are not focused on communication. Some specific foci from that body of literature include family dynamics and caregiving in Latin America (i.e., Colombia; Trujillo et al., 2016), family resilience during caregiving in South Africa (Deist & Greefe, 2015), family members' experiences of guilt during caregiving (Paun et al., 2015), transitions to and through the caregiving role (Czekanski, 2017), the emotional impact of social support (Atienza, Collins, & King, 2001), and barriers to caregivers accessing services and support (Macleod, Tatangelo, McCabe, & You, 2017). Given that most communication research on caregiving for a patient with dementia has been conducted by scholars in other fields who are

understandably focusing on other processes, there has been a lack of coherent theorizing about communication in this context.

The small subset of research on dementia caregiving that *has* been published within the field of communication has typically incorporated a theory, although quite a few of these studies have used theories from outside the discipline of communication (i.e., nursing, social work, psychology). A few studies did not include a specific theory, but instead incorporated general theoretical concepts (i.e., narrative and coping). The communication theories which were most commonly utilized include relational dialectics, communication privacy management, problematic integration, uncertainty management, multiple goals theory of personal relationships, communication accommodation theory, and uses and gratifications.

Very few communication studies on dementia caregiving have recognized the most salient *family* communication issues in the context of Alzheimer's disease (i.e., family dynamics, collective perspectives), although there are some exceptions. For example, Polk (2005) noted that caregiving affects family dynamics because families communicate social support through verbal and nonverbal behaviors and suggested that researchers examining collective family dynamics (i.e., versus one family member's perspective) can best illustrate issues such as family involvement, disagreements regarding care decisions, negative support, relational tension, and how the dynamics of the family can aid or exacerbate caregiving. The anticipated relational futures of families include a collective family identity of disease and caregiving (Alemán & Helfrich, 2010). Overall, the lack of coherent theorizing about communication specifically in this context

indicates a need for continued research which examines the collective family dynamics of dementia caregivers.

Conceptualization and Operationalization of Caregiver Communication in Extant Work

Generally, extant research has lacked a recognition of communication or has utilized inconsistent conceptualizations of communication in examining the experience of family members of Alzheimer's patients. Even within literature published in the field of communication, there are incongruent conceptualizations of communication. Most communication research that examines the dementia context conceptualizes communication as one-on-one verbal interactions between caregivers and patients (e.g., Baxter, Braithwaite, Golish, & Olson, 2002; Bevan et al., 2012), caregivers and healthcare staff (e.g., Stone, 2013), or a caregiver and other caregivers within other families (e.g., Lax & Stone, 2014; Wenzel Egan & Hesse, 2018). A few studies conceptualize dementia caregiver communication as online communicative activity (i.e., posting or reading messages in online support groups; Jeong et al., 2018; Yoo, Jang, & Choi, 2010). A few scholars conceptualize dementia caregiver family communication as interactions between multiple family members (Alemán & Helfrich, 2010; Hummert, 2007; Nussbaum, 2008; Polk, 2005). However, most researchers define communication in terms of individual perspectives or one-on-one interactions in families.

Communication scholarship has also lacked consistent approaches to operationalizing communication. Typically, communication research has operationalized dementia caregiver communication in terms of frequency, implicitly suggesting that more communication is better. Some examples include: "How often do you avoid discussing

healthcare topics with your family member?" (Bevan et al., 2012); "How frequently do you avoid talking about issues with your family?" (Planalp & Trost, 2008); "How many times and for how long do you talk with your spouse?" (Baxter et al, 2002); "How often does the patient respond?" (Baxter et al, 2002). These scholars have noted that Alzheimer's disease and related dementias limit the patient's ability to verbally communicate (e.g., Baxter et al., 2002; Bevan et al., 2012; Hummert, 2007; Planalp & Trost, 2008), focusing on how *less* communication is worse than *more* communication. While Hummert (2007) noted that Alzheimer's disease attacks a patient's communicative ability, she also pointed out that communication scholarship should address the *quality* of family interactions. However, few studies on dementia caregiving have recognized the importance of measuring communication quality.

Furthermore, conceptualizations and operationalizations of family communication in extant research have focused on *individual* perspectives and have not accounted for family-level dynamics. Alemán and Helfrich (2010) have suggested that it is best to view families in the situation of Alzheimer's disease by considering that all family communication issues are a family's collective experience "as family aging with dementia" (p. 9). Similarly, little communication scholarship has considered families' past experiences or relational dynamics (i.e., pre-diagnosis family dynamics) when considering family communication while navigating Alzheimer's. Nussbaum (2008) noted that research on Alzheimer's disease has focused on caregivers communicating with patients and has conceptualized communication as a one-on-one exchange. However, in caregiving, there are relational changes that occur within the larger context

of the family, and Nussbaum argues that these issues should be examined from the level of the collective family relationship.

Specifically, past family relationship satisfaction affects how family members currently interact and communicate with one another. For instance, as I mentioned earlier, Polk (2005) noted how family history affects family relationships as well as communication and called for future scholarship to account for the whole family's role in the experience of dementia. In addition, Alemán and Helfrich (2010) present a powerful multiple family member narrative noting how family relational history is involved in the delivery of Alzheimer's care and decision making, while also noting the intergenerational, collective experience of Alzheimer's disease and care. However, there are limitations to the methodology of these studies (i.e., interpretive and ethnography); they offer rich descriptions of the experiences of few individuals, but the findings are not generalizable. There is a need for empirical research to more systematically address the impact of pre-diagnosis family relationship dynamics on post-diagnosis communication practices, communication satisfaction, and current relationship dynamics.

In short, the inconsistent conceptualization and operationalization of communication in dementia caregiving research is likely what has led to mixed findings in this context. Communication research has operationalized dementia caregiver communication in terms of frequency. A more appropriate way to operationalize and measure communication effectively is to examine the *quality* of family communication (Scott & Caughlin, 2014). Additionally, extant research has focused on individual perspectives rather than family-level dynamics. Similarly, little scholarship has considered families' past relational dynamics (i.e., pre-diagnosis). By conceptualizing the

dementia caregiving experience as one which impacts family dynamics, recognizing the potential impact of pre-diagnosis relational dynamics, and the collective nature of multiple family members comprising that dynamic, scholars can better examine family communication issues. Clearly, there is a need for research with more precise conceptualization and measurement of communication variables.

The Present Study

To summarize, extant research recognizes the difficult situation families experience when navigating Alzheimer's or dementia. This illness context creates unique demands and stresses for families. The Alzheimer's caregiving situation is ripe for family members to experience crippling uncertainty, overwhelming burden, and other negative health implications (e.g., emotional strain, physical and mental burnout, disruption to routine, financial strain, substance abuse, and elder abuse as a result of burden). In addition, family members' identities are greatly impacted with dementia caregiving (e.g., Alemán & Helfrich, 2010; Baxter et al., 2002; Hummert, 2007). Finally, families may experience relational tension while providing dementia care and struggling with past unresolved relational pain (e.g., Polk, 2005). This body of work acknowledges the importance of recognizing the role and needs of family members of dementia patients as well as the importance of family relationships and family communication. However, extant scholarship does not include communication theories or precise measures of communication. If communication is noted, it is often in a cursory observation that "good communication" is important, especially between healthcare staff and family members. The quality of communication is not consistently accounted for or measured.

There is a need for research grounded in communication theory that clearly conceptualizes and operationalizes family communication when studying families navigating dementia. The multiple goals theory of interpersonal relationships (Caughlin, 2010) represents a particularly fruitful way to conceptualize family communication in terms of communication goals. This theory allows for an examination of communication and interaction goal patterns as well as a macro view of relational constructs, instead of examinations of how relationships are impacted by single encounters. Additionally, this theory provides helpful guidance for how to operationalize communication in terms of the quality of interaction goal pursuit and communication satisfaction. Thus, I turn now to a detailed description of this theoretical framework for my dissertation.

CHAPTER THREE: THEORETICAL FRAMEWORK

In this chapter, the theoretical framework that guides this dissertation, a multiple goals perspective on communication (Caughlin, 2010), is described in detail. Also, I present a conceptual model identifying the variables examined in this research, and I present research questions which were shaped by that theoretical framework.

Multiple Goals Theory

The multiple goals theoretical framework is a collection of theories which all focus on how individuals pursue their goals in conversation. Caughlin (2010) has articulated several assumptions shared by this family of theories. First, the multiple goals perspective posits that communication is strategic (i.e., goal-oriented; Berger, 2004) and inherently automatic (Berger & diBattista, 1993; Kellermann, 1992; Wilson, 2002). In other words, goals influence how individuals create messages (Goldsmith, 2004; O'Keefe, 1988). Second, communication incorporates multiple goals at once, including primary goals (i.e., the principal objective in the interaction) and secondary goals (i.e., auxiliary goals that determine how/if primary goals are pursued; Berger, 2005; Brown & Levinson, 1987; Clark & Delia, 1979; Dillard, Segrin, & Harden, 1989; Wilson, 2002). There are three types of goals that are commonly pursued in communication encounters: instrumental or task goals (i.e., related to achieving specific objectives), identity goals (related to people's self-presentation), and relational goals (related to creating or maintaining relationships with others). Finally, an individual's many goals being pursued can conflict with each other (Dillard et al., 1989), and one's goals can conflict with their conversational partners' goals (Wilson, 2002). These assumptions illustrate how the multiple goals perspective provides a framework to account for the ways in which

individual members who make up a collective family group bring their own goals and expectations as well as the collective nature of a family, to conversations about making difficult health and care decisions for the dementia patient.

A multiple goals perspective can be applied at multiple levels of interaction, both at the level of single communicative encounters and at global relational levels (e.g., Caughlin & Scott, 2010; Goldsmith, Miller, & Caughlin, 2008). While much research has examined perceptions of multiple goal interactions, communication quality, and conversation satisfaction within single encounters, if researchers seek to examine the macro construct of relational dynamics, they must use the theory to examine perceptions of *patterns* in goal pursuit of conversational partners (Caughlin, 2010). Multiple goals research has found that goals often have a chronic or enduring nature, certain goals may be most relevant in particular situations and can become activated quicker and easier than other goals (e.g., Chartrand & Bargh, 1996; Meyer, 2007). This suggests that individuals' perceptions about their own and others' single-conversation goals likely aggregate into global perceptions of goal patterns or tendencies, and these in turn inform broader relational dynamics (Caughlin, 2010).

Caughlin's (2010) specific theoretical model is reproduced below in Figure 1, showing the aggregation of variables from single encounters to relational-level constructs. Smaller boxes on the outsides of the figure represent concepts relevant to single encounters, which accumulate to represent the larger, more global constructs (center in the figure). As Caughlin points out, this is not a simple matter of conversational frequency, meaning the mere occurrence of single encounters do not equate to communication satisfaction or quality (Scott & Caughlin, 2012; 2014). In fact, this is a

key point of examination in my dissertation: how past (i.e., pre-diagnosis) perceptions and evaluations aggregate and influence current (i.e., post-diagnosis) and more global constructs. The first small box in the upper left of Caughlin's model represents an individual's perception of goal tendencies during one encounter, labeled at time one (i.e., T_1). Perceptions at T_1 plus all subsequent encounters (i.e., T_2, etc.), including the most recent encounter (i.e., T_n), factor into the global perception of goal tendencies. Individuals' perceptions of their own goals and of other's goals are distinct and should be considered separately. Similarly, the other global constructs (i.e., perceptions of communication tendencies and satisfaction with relational communication) are comprised of aggregated single encounter-level constructs. An individual's perceived satisfaction with communication is influenced by interactions between perceived communication tendencies and the perceived goals underlying that communication.
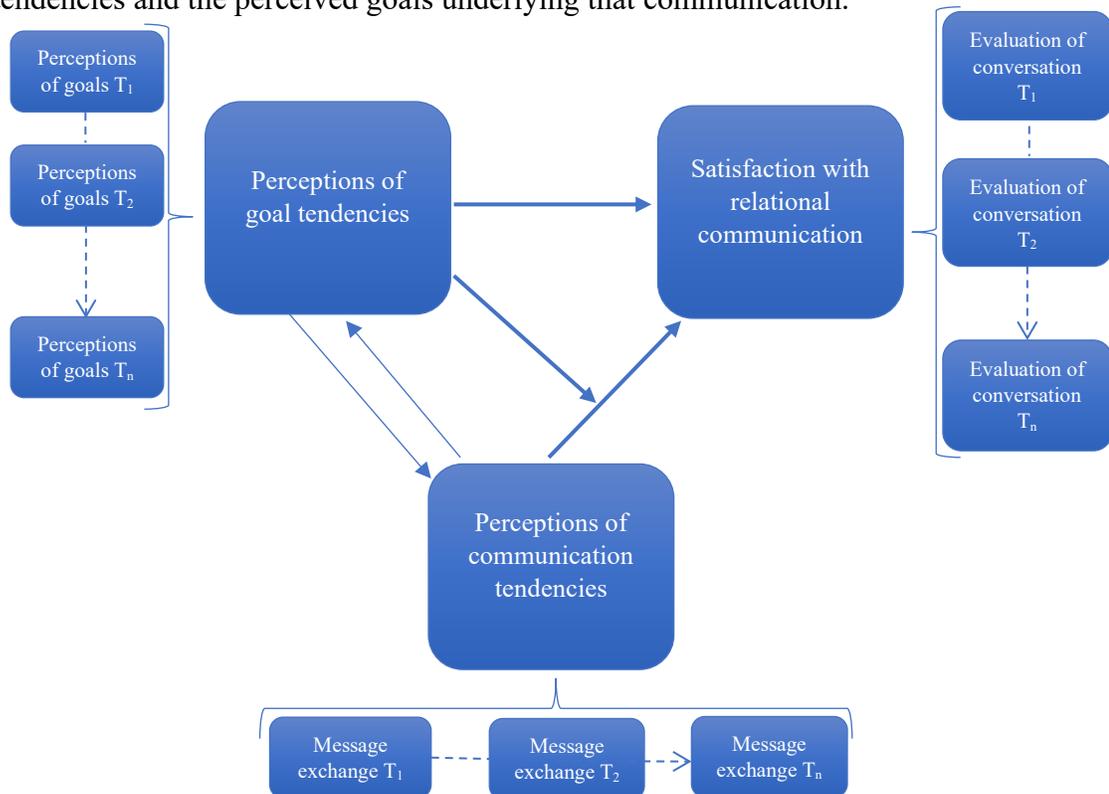
Figure 1. Aggregating from Particular Encounters to Relational-level Constructs (Caughlin, 2010, p. 837)

The Present Study

Caughlin's multiple goals theory of personal relationships has been applied in a myriad of communication contexts, including family in-law communication (Mikucki-Enyart & Caughlin, 2018; Mikucki-Enyart, 2018), examinations of divorce (Mikucki-Enyart, Petitte, & Wilder, 2018), long-distance caregiving (Bevan et al., 2012), end-of-life communication (Scott & Caughlin, 2012; 2014; Van Scoy, Reading, Scott, Green, & Levi 2016; Van Scoy et al., 2017), cancer contexts (Caughlin, Mikucki-Enyart, Middleton, Stone, & Brown, 2011; Donovan-Kicken & Caughlin, 2010; Iannarino, Scott, & Shaunfield, 2017), organ donation (Scott, Martin, Stone, & Brashers, 2011), mental illness (Scott, Caughlin, Donovan-Kicken, & Mikucki-Enyart, 2013), substance abuse (Wombacher, Waterson, Scott, Harrington, & Marin, 2018), intercultural communication (Guntzviller, 2017), risky health behavior (Minniear, Sillars, & Shuy, 2018; White & Malkowski, 2014), sexuality (McManus & Lucas, 2018), parolee and parole officer communication (Cornacchione & Smith, 2017), and vegetarianism (Romo & Donovan-Kicken, 2012). This wide range of contexts speaks to the broad applicability and utility of the theory. The present dissertation represents the first time Caughlin's theory has been explicitly applied in the context of families navigating Alzheimer's disease or dementia.

This dissertation addressed a number of the previously described gaps in extant research in theory, conceptualization, and measurement of communication for family members by applying Caughlin's multiple goals theory of personal relationships (2010) in the context of family members of persons living with Alzheimer's disease. Specifically this dissertation examines the relational history (i.e., pre-diagnosis relational dynamics) of families and its influence on current (i.e., post-diagnosis) goal pursuit and

conversational satisfaction as well as how current communication encounters (i.e., post-diagnosis goal pursuit and conversational satisfaction) influence current relational dynamics. Figure 2 depicts a conceptual model of the variables that were examined in the present study. This model builds on Caughlin's (2010) theoretical model and visually depicts the constructs in the current research context. Additionally, it visualizes the relationships between variables and the research questions which are examined in this research. The conceptualization of each variable is explained in greater detail below, and the operationalization of each variable is described in the method section.
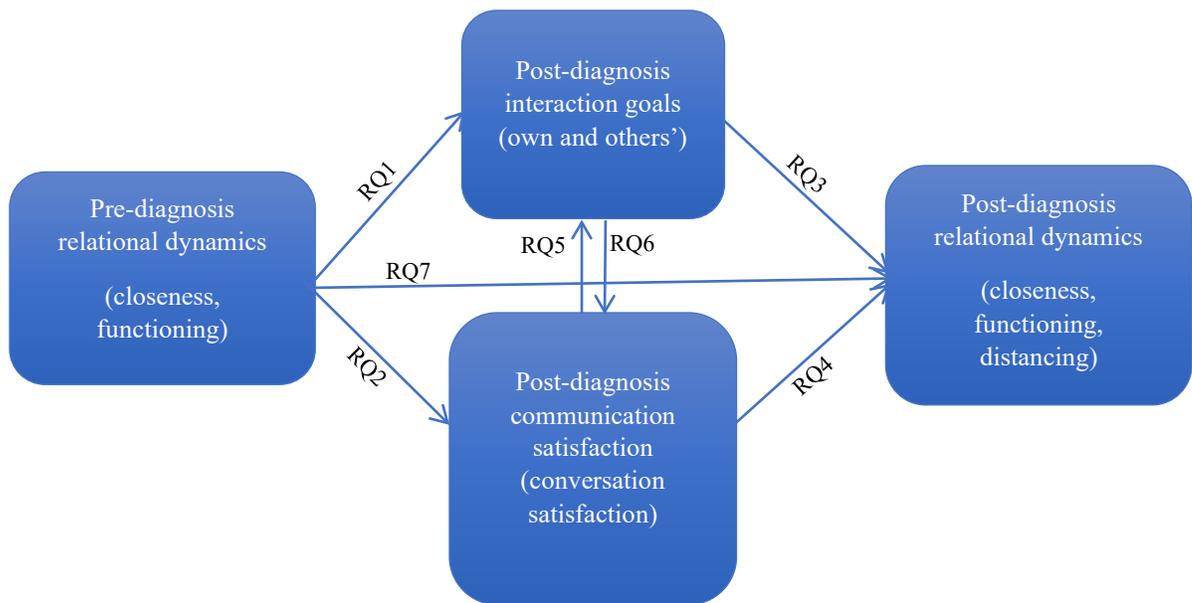
Figure 2. Model of Family Relational Dynamics, Interaction Goals, and Communication Satisfaction

Pre- and Post-Diagnosis Relational Dynamics

Relational dynamics are conceptualized in this study in terms of relational closeness, relational functioning, and relational distancing. Relational closeness is a measure of psychological feelings of closeness with a family member (Vangelisti & Caughlin, 1997). Family relational functioning is a complex variable to consider. In this

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study, it is examined by measuring how well families function and adapt to change (Stratton et al., 2014). Relational distancing is a measure of the relational effects of psychological change after an experience (Vangelisti & Young, 2000). By taking a more global perspective on relational dynamics, this dissertation addressed the gaps in previous research, which has not recognized the potential influence of families' past (i.e., pre-diagnosis) relational dynamics when considering how they communicate and maintain relationships when navigating the experience of Alzheimer's disease or another related dementia.

Perceptions of Interaction Goals

Individuals' perceptions of their own and others' communication goals are defined as the ways in which they perceive that they and their family member pursue particular goals in interactions. This study conceptualized family conversations as having seven potentially relevant types of goals that extant work suggests may be relevant in communication about Alzheimer's: affirming the positive face of the partner (i.e., embracing and accepting the other's self-image), affirming the negative face of the partner (i.e., respecting the other's independence and autonomy), maintaining the relationship (i.e., protecting and strengthening the relationship), avoidance (i.e., refraining or withdrawing from discussions or topics), giving support to the other (i.e., helpful actions and affirming messages), influencing the other (i.e., persuading or intervening in the other's thoughts, beliefs, or actions), and making clinical decisions (i.e., making care decisions on behalf of the patient and involving others in that process; e.g., Donovan-Kicken, 2008; Donovan-Kicken & Caughlin, 2010; Greenwell, 2019; Scott, 2010; Scott & Caughlin, 2012; 2014; Van Scoy et al., 2016; Van Scoy et al., 2017).

Communication Satisfaction

Evaluation of communication was conceptualized in terms of participants' perceived family conversation satisfaction. Individuals' perceived satisfaction with conversations is the degree to which they are glad they had the conversation (Hecht, 1978; Hecht, Sereno, & Spitzberg, 1984). In this study, I examined how participants' perceptions and evaluations of pre-diagnosis relational dynamics aggregate and influence current (i.e., post-diagnosis) and more global constructs of how they evaluate their family conversations in general.

Research Questions

To examine the interrelationships among these concepts in the context of families dealing with dementia, I present the following research questions (depicted in Figure 2):

RQ 1a: How are pre-diagnosis relational dynamics related to a family member's (i.e., actor's) perceptions of their other family member's (i.e., partner's) post-diagnosis interaction goals? Likewise, how are pre-diagnosis relational dynamics related to the partner's perceptions of the actor's post-diagnosis interaction goals?

RQ 1b: How are pre-diagnosis relational dynamics related to an actor's perceptions of their own post-diagnosis interaction goals? Likewise, how are pre-diagnosis relational dynamics related to the partner's perceptions of their own post-diagnosis interaction goals?

RQ 2: How are pre-diagnosis relational dynamics related to post-diagnosis communication satisfaction for actor and partner?

RQ 3a: How are an actor's perceptions of their partner's post-diagnosis interaction goals related to post-diagnosis relational dynamics? And how are the

partner's perceptions of the actor's post-diagnosis interaction goals related to post-diagnosis relational dynamics?

RQ 3b: How are an actor's perceptions of their own post-diagnosis interaction goals related to post-diagnosis relational dynamics? And how are the partner's perceptions of their own post-diagnosis interaction goals related to post-diagnosis relational dynamics?

RQ 4: How is communication satisfaction related to post-diagnosis relational dynamics for actor and partner?

RQ 5a: How is communication satisfaction related to an actor's perceptions of their partner's post-diagnosis interaction goals? Likewise, how is communication satisfaction related to the partner's perceptions of the actor's post-diagnosis interaction goals?

RQ 5a: How is communication satisfaction related to an actor's perceptions of their own post-diagnosis interaction goals? And how is communication satisfaction related to the partner's perceptions of their own post-diagnosis interaction goals?

RQ 6a: How are an actor's perceptions of their own post-diagnosis interaction goals related to communication satisfaction? Likewise, how are the partner's perceptions of their own post-diagnosis interaction goals related to communication satisfaction?

RQ 6b: How are an actor's perceptions of their partner's post-diagnosis interaction goals related to communication satisfaction? And how are the

partner's perceptions of the actor's post-diagnosis interaction goals related to communication satisfaction?

RQ 7: How are pre-diagnosis relational dynamics related to post-diagnosis relational dynamics for actor and partner?

CHAPTER FOUR: METHODS

In this chapter, I review the methods guiding this dissertation. First, I describe the characteristics of the participants involved in this study and how they were recruited. Second, I provide an explanation of the sampling and study procedure. Then I detail the participant demographics, control variables, and other measures I used to collect the data.

Participants

Participants in this study consisted of adult family members (age 18 years old or older) of persons living with, or who have died with, a medical diagnosis of Alzheimer's disease or another related dementia. Dementia is a term describing a set of symptoms (e.g., decline in memory and cognitive ability, impacting individuals' daily activities); it is not a specific disease (AA, 2020; NIA, 2019). Alzheimer's is the most common type of dementia (AA, 2020; CDC, 2019; NIA, 2019). Vascular dementia which occurs after a stroke is the second most common type (AA, 2020). Examples of other types include Lewy body dementia and frontotemporal disorders (NIA, 2019). Any of these diagnoses for a patient qualified a family member to participate in this study. In addition, the patient had to have been living in the United States; or, if already deceased, the patient had to have lived in the United States at the time of their death. A family member could be a blood or legal relative of the person with the dementia diagnosis. In addition to immediate family members, extended family members were also included in this study. For the purposes of this sample, a family member was conceptualized as a close relational other defined by the participant as a family member. This is consistent with previous research in which family is defined as persons having an emotional connection and shared closeness to the patient's dementia experience (Riedel, Ducharme, &

Geldmacher, 2013). Family members could have any type of role in the family or level of

care for the patient. A family caregiver relationship could be one in which someone is

closely involved in the activities of daily living (e.g., cooking, bathing) or instrumental

activities of daily living (e.g., shopping, housework, managing finances). Providing care

could also entail emotional support (e.g., sending messages of encouragement, calling).

Members of the family could be providing remote (i.e., long-distance) care. Family

members included in this study also did not need to have a strong or positive relationship,

nor did they need to be closely involved in the patient's care. Study inclusion was for any

member of the family.

The use of dyads represents a strength in examining family relational dynamics,

communication quality, and Alzheimer's care in families. Family systems theory

(Bowen, 1978; von Bertalanffy, 1955) highlights the interdependent nature of family

members, noting that the individual yet interconnected relationships in families create a

summative holistic experience of a family. Alzheimer's caregiving affects the dynamics

of the family as a whole, including all members and multiple generations (Hipper et al.,

2010; Polk, 2005). Thus, it was important in the present study to consider more than one

family member's perspective to accurately account for family processes and dynamics

(Cox & Paley, 1997).

The total sample included 53 dyads ($n = 106$ individuals). In addition, 36

individuals participated who did not have a participating family member. Only

participants with a participating family member (i.e., intact dyads) were included in the

present analyses. Descriptive statistics for the individuals excluded from the present

analyses ($n = 36$) are included in Appendix E. Ages of the participants ranged from 23 to

86 years old ($M = 54.63$, $SD = 14.87$). The majority of participants were females (72.64%, $n = 77$), 26.42% were males ($n = 28$), and 1 participant identified as demigirl/agender. Participants self-identified their race as Caucasian or white ($n = 88$; 83.81%), African American or black ($n = 4$; 3.81%), Hispanic or LatinX ($n = 3$; 2.86%), multiracial ($n = 9$, 8.57%), or other ($n = 1$; 0.95%). The majority of participants had college degrees, including 4-year ($n = 39$, 36.79%), master's ($n = 28$, 26.42%), professional/vocational ($n = 9$, 8.49%), doctorate ($n = 8$, 7.55%), and 2-year ($n = 5$, 4.72%) degrees; 9 participants (8.49%) had some college, and 8 respondents (7.55%) were high school graduates. Participants reported their marital status as married ($n = 83$, 79.81%), never married ($n = 8$, 7.69%), divorced ($n = 6$, 5.77%), widowed ($n = 5$, 4.81%), or separated ($n = 2$, 1.92%). Annual income was reported as under \$20,000 ($n = 8$, 7.54%), \$20,000-49,999 ($n = 23$, 21.70%), \$50,000-79,999 ($n = 28$, 26.42%), \$80,000-149,999 ($n = 30$, 28.30%), and over \$150,000 ($n = 17$, 16.04%). Participant demographics are shown in Table 1.

Participants were asked questions to describe their family (i.e., number of family members, number involved in care, patient living arrangement) and illness (i.e., year of diagnosis, year of symptom onset, year of patient death) situation. The patient was deceased in families of 62 of the participants represented in the sample (58.49%), and the patient was still living in 44 participants' families (41.51%). The average duration of disease (i.e., year of diagnosis to death) was 6.27 years ($SD = 3.87$). Duration of symptoms averaged 1.46 years ($SD = 1.49$). The majority of participants were not the primary caregiver for the patient ($n = 59$, 55.66%), however, 19 (17.92%) participants indicated they were the primary caregiver, and 28 (26.42%) share(d) caregiving

responsibilities with another family member. The mean number of members with each

patient's extended family was 13.94 (*SD* = 11.18) and the average number of family

members involved in the care or care decisions for the patient was 3.79 (*SD* = 2.12).

Table 1
Participant Demographics

Characteristic	*n*	%
Race		
Caucasian/White	88	83.8
African American/Black	4	3.8
Hispanic/LatinX	3	2.9
Multiracial	9	8.6
Education		
4-year degree	39	36.8
Master's degree	28	26.4
Professional/vocational	9	8.5
Some college	9	8.5
High school	8	7.6
Doctorate degree	8	7.6
2-year degree	5	4.7
Marital status		
Married	83	79.8
Never married	8	7.7
Divorced	6	5.8
Widowed	5	4.8
Separated	2	1.9
Income		
$80,000-149,999	30	28.3
$50,000-79,999	28	26.4
$20,000-49,999	23	21.7
Over $150,000	17	16.0
Under $20,000	8	7.5
Caregiving responsibilities		
Not primary caregiver	59	55.7
Primary caregiver	28	26.4
Shared primary caregiving	19	17.9

Family dyad relationship responses are shown in Table 2. Of the 53 dyads represented in the total sample, most participants reported a sibling ($n = 39$, 36.79%) relationship with their other family member who was also participating in the study. The other dyads included parent/child pairs ($n = 33$, 31.13%), spouses/romantic partners ($n = 23$, 21.70%), and other relatives or family friends ($n = 11$, 10.38%).

Table 2

Family Dyad Relationship Types

Survey Partner Relationship	*n*	%
Sibling	37	34.9
Legal spouse	20	18.9
Child	13	12.3
Other relative	6	5.7
Close friend	4	3.8
Romantic partner	3	2.8
Sibling-in-law	2	1.9
Parent-in-law	1	0.9
Grandparent	1	0.9

Note. Participants answered "They are my…".

The majority of participants were the child ($n = 56$, 52.83%) of a patient with dementia. Participants' relationships to patients are shown in Table 3.

Table 3

Patient Relationship Types

Patient Relationship	*n*	%
Parent	56	52.8
Grandparent	21	19.8
Parent-in-law	10	9.4
Legal spouse	6	5.7
Aunt	5	4.7
Grandparent-in-law	3	2.8
Close friend	2	1.9
Sibling-in-law	1	0.9
Uncle	1	0.9
Other relative	1	0.9

Note. Participants answered "They are/were my…".

Patient living arrangements are shown in Table 4. Most patients were living in a long-term care facility ($n = 50$, 47.17%) or their own primary residence ($n = 36$, 33.96%).

Table 4

Dementia Patient Living Arrangement

Patient Residence	n	%
In a long-term care facility	50	47.2
Patient's primary residence	36	34.0
Participant's primary residence	9	8.5
Another family member's primary residence	8	7.5
Other	3	2.8

Note. If deceased, this was the patient's living arrangement at the time of death.

Sampling

After receiving approval from the University of Kentucky Institutional Review Board, I engaged in purposive sampling techniques to recruit participants. Fliers were posted on public bulletin boards in the Lexington community and in dementia care facilities, senior centers, healthcare facilities, and caregiver organizations throughout the state of Kentucky as well as in central and southwest Missouri. Online notices were posted on my personal social network sites (i.e., Facebook, LinkedIn) and in electronic newsletters of dementia caregiver organizations and groups (e.g., Alzheimer's Association of Greater Kentucky and Southern Indiana, Alzheimer's support groups in religious organizations). The University of Kentucky human resources dementia care support network (i.e., UK Elder Care), which hosts multiple monthly caregiver education and resource events, also shared the study flier and information in their monthly electronic newsletter. Regional dementia care facilities and hospitals (e.g., Lexington Veterans Affairs Healthcare, University of Louisville Neurology, Baptist Health, Rockcastle Regional Hospital, Murray Calloway County Hospital, Pikeville Medical Center, Monroe County Medical Center, TJ Samson Community Hospital, and

Appalachian Regional Hospital locations) posted fliers in their facilities or distributed fliers to caregivers. Snowball network sampling was conducted to contact additional recruits by asking participants to extend the opportunity to participate with other eligible individuals in their social network who might be interested.

All disseminated recruitment materials contained a URL and QR code to the online survey. Recruitment materials also included my contact information, and individuals were encouraged to contact me with any questions and to learn more about the project. When participants contacted me, I described the purpose of the research (i.e., to learn about how individuals perceive their family relationships and talk with other family members), the activities entailed in participation (i.e., engaging in an online survey), and the remuneration for participation (i.e., each participant could elect to receive a $10 Amazon gift card). In addition, I screened the potential participants for eligibility based on their current age, relationship status to the patient, dementia diagnosis, and to verify that the patient is/was living in the United States.

In order to examine family dyads, at the start of the questionnaire, participants were asked to list their email address and the email address of their family member who was also participating (see Appendix F). This enabled me to identify dyads in the data. Prior to analysis, all identifying information (i.e., email addresses) was replaced with an alphanumeric code, which was linked to each participant's family member's code.

Procedure

This study used a self-report design with a self-guided online questionnaire. Self-report measures represent a systematic way to measure subjective phenomena and past (i.e., pre-diagnosis) relational dynamics, about which only the participants have access

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(Clark & Reis, 1988). Additionally, quantitative questionnaires permit data analysis to make more generalized claims about the target population, family members of dementia patients.

The questionnaire was administered online through a secure web survey service to maximize the possibility of recruiting a large and diverse sample. Research indicates that online recruitment and research designs may be advantageous because they result in higher response rates than traditional face-to-face methods; this could be due to a greater sense of anonymity (Donovan-Kicken, 2008; Hamilton & Bowers, 2006). Additionally, online questionnaires may increase the ability to access difficult-to-reach participants (Wright, 2005), such as dementia caregivers who often have limited time. The purposive sampling approach implemented (e.g., recruiting through dementia care organizations) reduced uncertainty over participant identity and validity of data, which can be a disadvantage in some online research designs (Wright, 2005). However, I experienced difficulty with malicious software applications (i.e., bots) completing the survey initially. This prompted me to incorporate a two-step verification process (which involved emailing participants to verify their demographic information) to ensure that the data collected were valid.

Making the questionnaire easy to access (e.g., providing a hyperlink in online recruitment materials and a QR code in printed recruitment materials; Daley, McDermott, McCormack Brown, & Kittleson, 2003) ensured greater response and completion rates. Purposive sampling of Kentucky healthcare facilities (i.e., Rockcastle Regional Hospital, Murray Calloway County Hospital, Pikeville Medical Center, Monroe County Medical Center, TJ Samson Community Hospital, and Appalachian Regional Hospital locations),

cooperative extension offices, dementia care organizations, and senior centers serving rural areas of Kentucky as well as a hospital system and long-term care facility serving rural regions of Missouri (e.g., Mercy Hospital, Carthage Health and Rehab) targeted rural participants. Participants living in suburban areas were recruited through Lexington and Louisville regional healthcare facilities (e.g., University of Louisville Neurology, Baptist Health; Lexington Veterans Affairs Healthcare) and area dementia care and caregiver organizations (e.g., Lexington dementia care facilities, Bluegrass Area Agency on Aging, Greater Kentucky and Southern Indiana Alzheimer's Association, UK Eldercare).

After completing the questionnaire, participants were provided with information from the Alzheimer's Association on caregiving services, resources, connecting with other caregivers, and support groups. Additionally, participants were provided with links to locate a licensed therapist and to access other dementia caregiver information and resources (i.e., AARP, Family Caregiver Alliance, Caregiver Action Network, National Alliance for Caregiving, National Institute on Aging, National Family Caregiver Support Program).

Measures

The following section describes each of the measures in the questionnaire. The complete measurement instruments and scoring procedures are provided in the appendices of this manuscript. Some measures assess family dynamics as a whole; others called for having one specific family member in mind (i.e., the family member who was also participating). For each measure that called for a family member referent, the participant was directed to think about his or her participating family member when

responding to the measures. The measures for relational closeness and relational functioning were assessed for both pre- and post-diagnosis. All other measures were assessed post-diagnosis.

Relational Dynamics

Pre-diagnosis relational dynamics were measured by examining relational closeness and relational functioning, and participants were asked to think back to the time before the patient was diagnosed and to refer to that time period when answering the questions for each relational dynamics measure. Post-diagnosis relational dynamics were measured by examining relational closeness, relational functioning, and relational distancing. In measuring post-diagnosis relational dynamics, participants were asked to respond to all relational dynamics measures, but instead of reflecting on the time before diagnosis, they were asked to consider their current relationship (post-diagnosis) with their family member. Additionally, a measure of relational distancing was included to examine post-diagnosis relational dynamics. This allowed participants to reflect on the ways in which the experience of dementia or Alzheimer's care has affected their family relationship. The relational dynamics measures can be found in Appendix A.

Relational closeness. To assess relational closeness, six items from Vangelisti and Caughlin's (1997) measure of psychological closeness were used. Participants were asked to respond to questions about the closeness of their relationship (e.g., "How close are you to this person?," "How important is your relationship with this person to you?") using 7-point Likert-type responses (1 = *not at all*, 7 = *extremely*). The reliability of this instrument was excellent in this study both in the pre-diagnosis measurement (α = .93;

item $M = 6.24$; scale $M = 37.43$, $SD = 6.37$) and when assessing post-diagnosis relational closeness ($\alpha = .93$; item $M = 6.36$; scale $M = 38.18$, $SD = 5.81$).

Relational functioning. The SCORE-15 index of family functioning and change (Stratton et al., 2014) assessed the health of relationships by asking participants to rate their family relationship in a series of 15 statements (e.g., "In my family we talk to each other about things which matter to us," "We are good at finding new ways to deal with things that are difficult"). Each item was rated on a 5-point scale used to describe the relationship. Participants rated how well each statement described their relationship with their family member (1 = *very well*, 5 = *not at all*). SCORE-15 is a proven measure of family functioning and of therapeutic change in the functioning of families (Stratton et al., 2014). The pre-diagnosis measure of relational functioning had strong reliability in this study ($\alpha = .89$; item $M = 4.00$; scale $M = 59.99$, $SD = 9.42$). Likewise, the post-diagnosis measure also had strong reliability ($\alpha = .93$; item $M = 4.00$; scale $M = 60.00$, $SD = 11.35$).

Comparing pre- and post-diagnosis scores of relational closeness and relational functioning allowed me to note the impact of Alzheimer's using a discrepancy score (the difference between pre- and post-diagnosis scores). During data analysis, a new change variable was created to examine differences between pre- and post-diagnosis relational closeness, as well as pre- and post-diagnosis relational functioning.

Relational distancing. Post-diagnosis relational distancing was assessed with an adaptation of the measure developed by Vangelisti and Young (2000). This dissertation asked respondents to complete five 7-point semantic differential items to indicate the extent to which Alzheimer's or another related dementia has impacted their relationship

(e.g., "This experience [has] made the relationship more…"). They answered by selecting

a point on each line that best describes what they think (e.g., "distant/close,"

"hostile/friendly"). The reliability of this instrument was strong in this study ($\alpha = .86$;

item $M = 2.66$; scale $M = 13.30$, $SD = 6.64$).

Perception of Interaction Goals

To assess perceptions of interaction goals, participants were asked to report on

their perceptions of their own goals as well as the goals their family member pursued in

conversations. The measure was adapted from Scott (2010), whose measurement was

based on instruments developed by Dillard et al. (1989) and Samp and Solomon (1998).

The measure contained 23 items that assessed seven goals relevant in family

conversations: affirming the positive face of the partner, affirming the negative face of

the partner, maintaining the relationship, avoidance, giving support to the other,

influencing the other, and making clinical decisions.

Communication research has noted the complex nature of particular types of goals

(e.g., influence, avoidance). Goals research has noted that communication is strategic

(e.g., Berger, 2004; Kellerman, 1992). Individuals try to persuade or influence others to

start or stop behaviors or thoughts (e.g., bystander intervention, White & Malkowski,

2014; healthcare provider communication, Brashers, Hsieh, Neidig, & Reynolds, 2006;

Scott, Harrington, & Spencer, 2020; etc.). Avoidance can have both positive and negative

relational impacts (Guerrero, Andersen, & Afifi, 2018). Avoidance can be unproductive

and negative for relationships, for example during relational conflict (e.g., Canary,

Cupach, & Messman, 1995; Meeks, Hendrick, & Hendrick, 1998; Roloff & Ifert, 1998).

However, avoidance can also be positive. For example, avoidance can be considered an

empathetic action of perspective-taking (Davis, 1994) and can be beneficial to relationships (Donovan-Kicken & Caughlin, 2010; Roloff & Ifert, 2000). Topic avoidance and indirectness can serve as a protective buffer in relationships (Goldsmith, 2004). Avoidance can be utilized as a tactic to prioritize relational goals over instrumental goals (Caughlin & Afifi, 2004; Hocker & Wilmot, 2013). The goals measure in this study was considered as a whole (i.e., all goals collapsed into one variable) for participants' own goal attention and another variable for their perceptions of their partner's goal attention.

The items used a 7-point Likert-type response (1 = *strongly disagree*, 7 = *strongly disagree*). Participants were asked to complete the measure twice, once for their perceptions of their own goals and again for perceptions of their family member's goals. The reliability in this study was .84 (perceptions of partner goals; item *M* = 5.00; scale *M* = 114.19, *SD* 17.17) and .81 (perceptions of own goals; item *M* = 5.18; scale *M* = 119.16, *SD* = 16.65). The measure can be found in Appendix B.

Communication Satisfaction

One effective way to evaluate communication is to examine participants' satisfaction with conversations (e.g., Scott & Caughlin, 2014). Conversation satisfaction was assessed using items based on measures of interpersonal communication satisfaction (Hecht, 1978; Hecht et al., 1984). Participants were asked to respond to eight statements about conversations with their family member (e.g., "I am generally satisfied with our conversations," "Our conversations are productive," etc.) using 7-point Likert-type items (1 = *strongly disagree*, 7 = *strongly agree*). The measure had strong reliability in this

study ($\alpha = 88$, item $M = 5.88$; scale $M = 47.07$, $SD = 8.26$). The measure described in this section can be found in Appendix C.

Demographics and Control Variables

In addition to the main measurement instruments, the questionnaire asked participants to report on their age, gender, and demographic information (e.g., ethnicity and geographic location), and to characterize their family situation by noting the relationship to the patient, the number of other adults in the family, and the number of others involved in the care. Participants were asked if the patient was deceased, and if so, the year of death. They were also asked to report their relationship with their family member who was also participating. Additionally, they were asked about the nature of the disease (e.g., when symptoms started, year of diagnosis, and living arrangements for the patient). These demographic and control questions are listed in Appendix D.

CHAPTER FIVE: RESULTS

In this chapter, I describe the analyses used to answer the research questions presented in this dissertation. I also present the results of those analyses. Results of descriptive statistics, correlations between variables, and scale reliability calculations are also included in this chapter.

Data Analysis

Data analysis first involved cleaning the quantitative data file, identifying missing data points, calculating descriptive statistics and scale reliability statistics, testing the influence of interdependent variables (i.e., the actor and partner effects), and testing the dyad-level phenomena. A significance level of .05 was used for all tests of significance. To analyze associations between the variables used in this dissertation, the zero-order correlations were calculated between independent and dependent variables. These correlations are presented in Table 5.

To answer the research questions addressed in this study, path analyses were used to model relationships between variables. Specifically, the scores from the variables were modeled in actor-partner interdependence models (APIM) using IBM AMOS version 25. APIM estimates unique intrapersonal effects (actor effects) and interpersonal effects (partner effects) of each dyad member (Kenny, Kashy, & Cook, 2006). Each APIM was assessed for fit to the data and considered a good fit if it met the following criteria: non-significant χ^2, CFI >.95, RMSEA <.05 (Hu & Bentler, 1998; 1999). The magnitude and direction of the associations were examined in each model. Additionally, IBM SPSS version 25 was used to examine descriptive statistics, create a Pearson's correlation matrix, and calculate scale reliabilities.

Table 5

Correlation Matrix

Variables	1	2	3	4	5	6	7	8	9	10
1 Post-Diagnosis Relational Distancing	**.21***	-.54**	-0.25	-0.23	-.44**	-.59**	-.34*	-.41**	-.62**	-0.23
2 Post-Diagnosis Conversation Satisfaction	-.56**	**.38***	.34*	0.25	.49**	.65**	.36*	.53**	.65**	0.08
3 Post-Diagnosis Perceptions of Others' Goals	-0.25	0.10	**.34***	.69**	.32*	0.23	-0.07	.30*	.32*	-0.03
4 Post-Diagnosis Perceptions of Own Goals	-0.21	0.26	.75**	**.51***	0.24	0.16	-0.06	.37**	.35*	-0.10
5 Pre-Diagnosis Relational Functioning	-.43**	.57**	.28*	.35*	**.54***	.77**	-0.15	0.26	.38**	0.13
6 Post-Diagnosis Relational Functioning	-.47**	.69**	0.14	0.23	.80**	**.44***	.53**	.45**	.60**	0.13
7 Change in Relational Functioning	-0.19	.39**	-0.15	-0.1	0.001	.60**	**.33***	.36**	.43**	0.03
8 Pre-Diagnosis Relational Closeness	-.37**	.33*	0.07	0.26	.43**	0.28	0.01	**.36***	.82**	-.48**
9 Post-Diagnosis Relational Closeness	-.54**	.55**	0.2	.36**	.48**	.55**	0.28	.80**	**.38***	0.11
10 Change in Relational Closeness	-0.26	.29*	0.19	0.12	0.07	.38**	.47**	-.42**	0.22	**.34***

Note. Correlations for actors (partner #1) are presented in the upper triangle; correlations for partners (i.e., partner #2) are presented in the lower triangle. Correlations between actors and partners are presented along the diagonal in bold text. Dyadic pairs were assumed to be indistinguishable. Individuals within dyads were randomly assigned as partner 1 or partner 2.

* $p < .05$, ** $p < .01$

Overviews of the main analyses are provided in the following pages, organized by research question. Each of the main analyses in response to the research questions examined the data dyadically. Due to the varied nature of the dyads in this study (e.g., parents and adult children, same gendered siblings, different gendered siblings, romantic partners, etc.), dyadic pairs were assumed to not be distinguishable (Kenny et al., 2006), therefore individuals within the dyads were randomly assigned to be partner 1 or partner 2.

RQ1. Pre-Diagnosis Relational Dynamics and Post-Diagnosis Interaction Goals

To answer RQ1, an APIM was created to examine the relationship between pre-diagnosis relational dynamics (i.e., relational closeness and functioning) and participants' perceptions of their own (*RQ 1a*) and other family members' (*RQ 1b*) post-diagnosis interaction goals. The model showed an excellent fit ($\chi^2 = 11.828$, $p = .297$, CFI = .993, RMSEA = .042) and is depicted in Figure 3. Significant actor effects were observed, indicating that pre-diagnosis relational closeness was positively associated with participants' perceptions of their own post-diagnosis goal attention, and pre-diagnosis relational functioning was positively associated with participants' perceptions of their partner's post-diagnosis goal attention. Significant partner effects were also observed in participants' pre-diagnosis relational functioning's positive association with their partners' perceptions of own post-diagnosis goal attention.
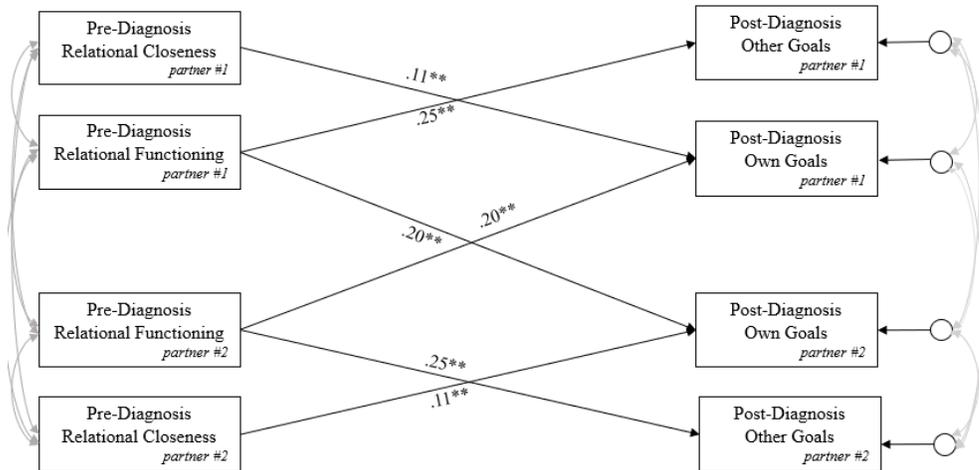
Figure 3. RQ1 APIM. * *p* <.05, ** *p* < .01, *** *p* < .001

RQ2. Pre-Diagnosis Relational Dynamics and Post-Diagnosis Communication

Satisfaction

The APIM created to answer RQ2 showed an excellent fit (χ^2 = .502, *p* = .973, CFI = 1.00, RMSEA = .000). The model is shown in Figure 4. Several significant actor effects were observed, indicating that pre-diagnosis relational dynamics (i.e., both relational closeness and functioning) were positively associated with post-diagnosis communication satisfaction (i.e., conversational satisfaction). No significant partner effects were observed.
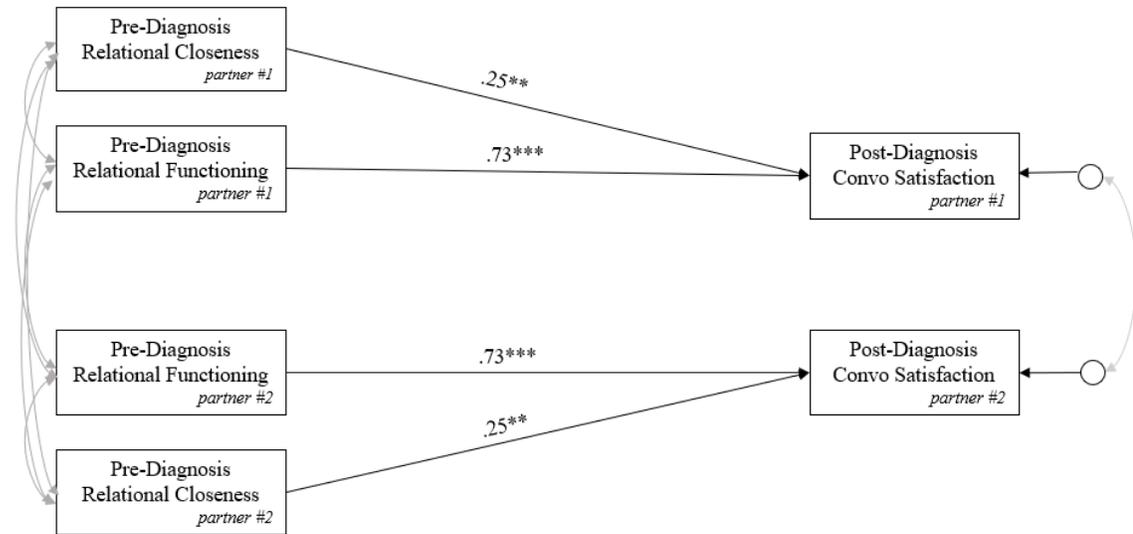
Figure 4. RQ2 APIM. * *p* <.05, ** *p* < .01, *** *p* < .001

RQ3. Post-Diagnosis Interaction Goals and Post-Diagnosis Relational Dynamics

To answer RQ3, an APIM was created to examine the relationship between participants' perceptions of their own (*RQ 3a*) and other family members' (*RQ 3b*) post-diagnosis interaction goals and post-diagnosis relational dynamics (i.e., relational closeness, functioning, and distancing). The model showed an excellent fit (χ^2 = 10.266, *p* = .742, CFI = 1.000, RMSEA = .000) and is depicted in Figure 5. Significant actor effects were observed in participants' perceptions of their own and of their partners' post-diagnosis goal attention. Specifically, participants' perceptions of their own post-diagnosis goal attention were positively associated with post-diagnosis relational closeness. Perceptions of others' post-diagnosis goal attention were negatively associated with post-diagnosis relational distancing. Significant partner effects were observed in participants' perceptions of their own and others' post-diagnosis goal attention such that participant perceptions of their own and others' post-diagnosis goal attention were negatively associated with post-diagnosis relational closeness.

The partner effects between participant perceptions of their own post-diagnosis goal attention and relational functioning and closeness approached significance (i.e., partner 1's own goals to partner 2's relational closeness $p = .052$; partner 1's own goals to partner 2's relational functioning $p = 0.51$). Additionally, the actor effect of participants' perceptions of their own post-diagnosis goal attention and relational distancing approached statistical significance ($p = .077$).
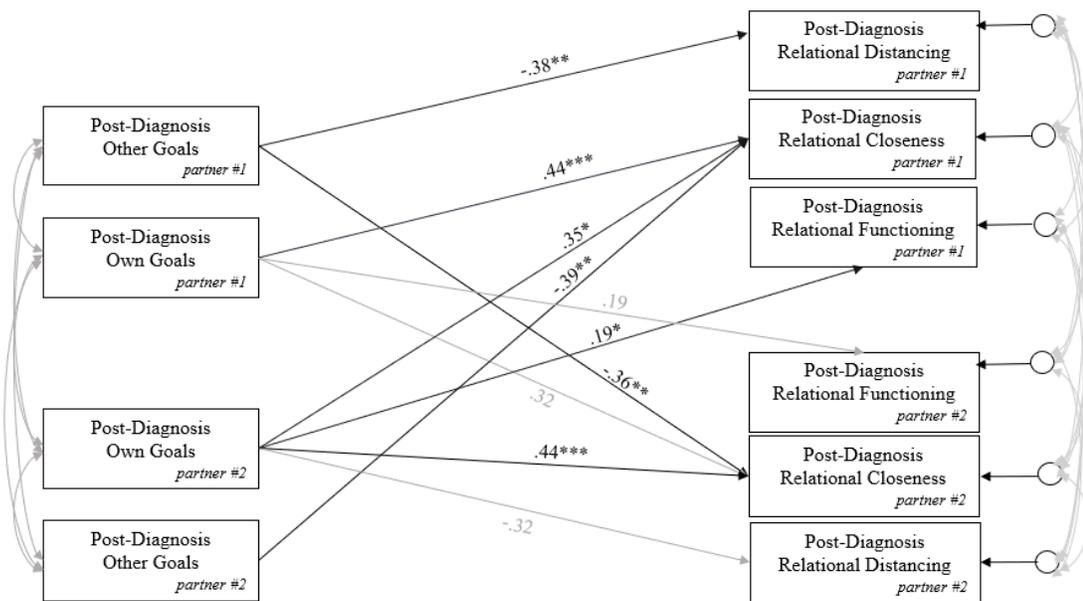
Figure 5. RQ3 APIM. *Note.* The nature of APIM would assume this figure is probably not using indistinguishable dyads. * $p < .05$, ** $p < .01$, *** $p < .001$

RQ4. Post-Diagnosis Communication Satisfaction and Post-Diagnosis Relational Dynamics

To answer RQ4, an APIM was created to examine the relationship between communication satisfaction (i.e., conversation satisfaction) and post-diagnosis relational dynamics (i.e., relational closeness, functioning, and distancing). The model showed a moderate fit ($\chi^2 = 12.776$, $p = .047$, CFI $= .980$, RMSEA $= .104$) and is depicted in Figure 6. Several significant actor effects were observed: Conversation satisfaction was

positively associated with relational closeness and functioning, and conversation

satisfaction was also positively associated with relational distancing. No significant

partner effects were observed.
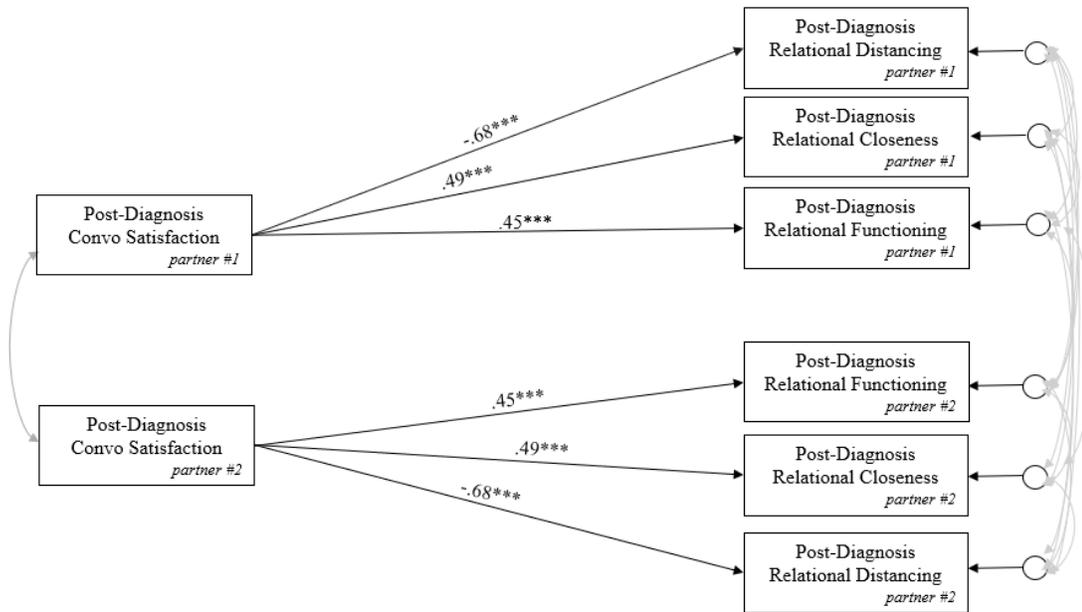
Figure 6. RQ4 APIM. * *p* <.05, ** *p* < .01, *** *p* < .001

RQ5. Post-Diagnosis Communication Satisfaction and Post-Diagnosis Interaction Goals

To answer RQ5, an APIM was created to examine the relationship between post-

diagnosis communication satisfaction (i.e., conversation satisfaction) and own (RQ5a)

and others' (RQ5b) post-diagnosis interaction goals. The model showed an excellent fit

($\chi^2 = 1.356$, *p* = .852, CFI = 1.000, RMSEA = .000) and is displayed in Figure 7.

Significant actor effects included that post-diagnosis communication satisfaction (i.e.,

conversation satisfaction) was positively associated with perceptions of own post-

diagnosis interaction goals. The positive association between post-diagnosis conversation

satisfaction and others' post-diagnosis interaction goals approached statistical

significance (p = .055). No significant partner effects were observed.
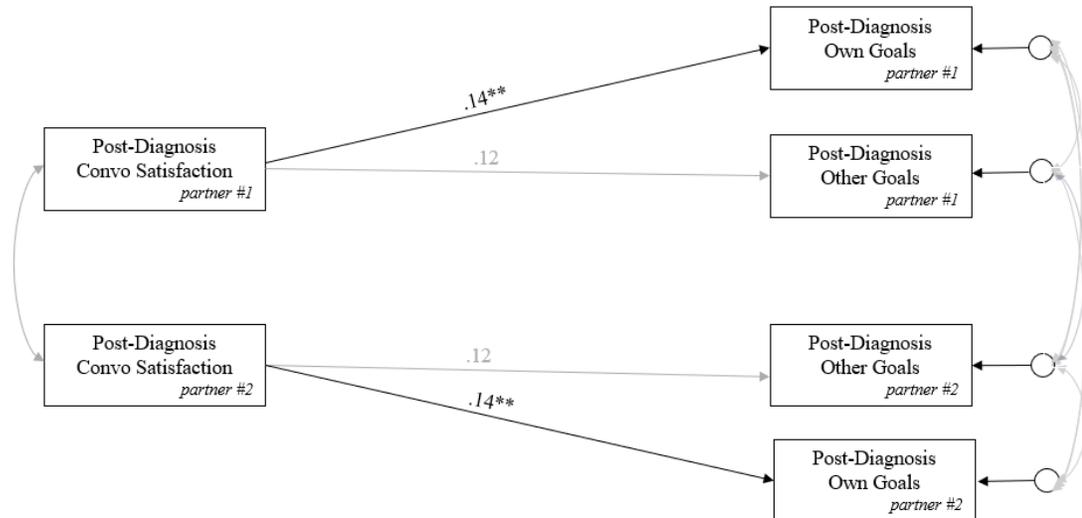
Figure 7. RQ5 APIM. * p <.05, ** p < .01, *** p < .001

RQ6. Post-Diagnosis Interaction Goals and Post-Diagnosis Communication

Satisfaction

To answer RQ6, an APIM was created to examine the relationship between own

(RQ6a) and others' (RQ6b) post-diagnosis interaction goals and post-diagnosis

communication satisfaction (i.e., conversation satisfaction). The model showed an

excellent fit (χ^2 = .006, p = .997, CFI = 1.000, RMSEA = .000) and is depicted in Figure

8. Significant actor effects were observed: Perceptions of own and others' post-diagnosis

interaction goals were positively associated with post-diagnosis communication

satisfaction (i.e., conversation satisfaction). No significant partner effects were observed.
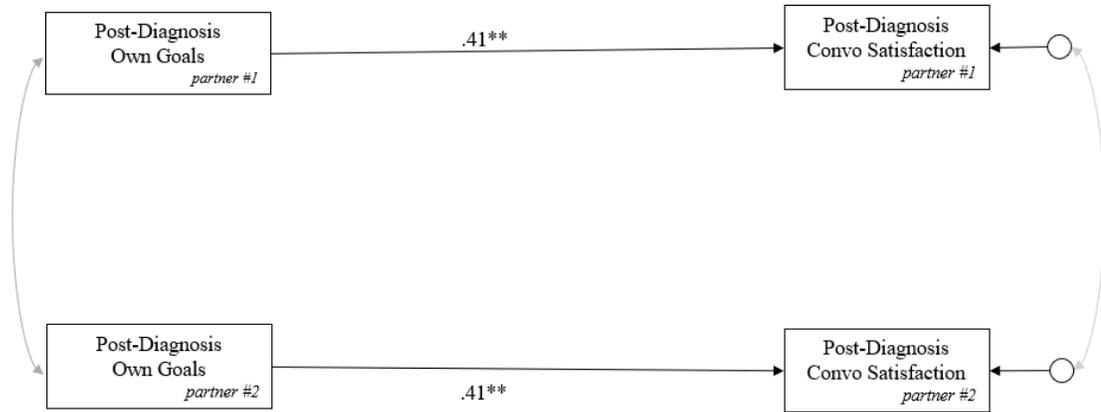
Figure 8. RQ6 APIM. * *p* <.05, ** *p* < .01, *** *p* < .001

RQ7. Pre-Diagnosis Relational Dynamics and Post-Diagnosis Relational Dynamics

To answer RQ7, an APIM was created to examine the relationship between pre-diagnosis relational dynamics (i.e., relational closeness and functioning) and post-diagnosis relational dynamics (i.e., relational closeness, functioning, and distancing). The model showed an excellent fit ($\chi^2 = 8.141$, *p* = .774, CFI = 1.000, RMSEA = .000) and is depicted in Figure 9. Significant actor effects included: Pre-diagnosis relational dynamics (i.e., relational closeness and functioning) were positively associated with post-diagnosis relational functioning and closeness and negatively associated with relational distancing. Significant partner effects included that pre-diagnosis relational closeness was positively associated with post-diagnosis relational functioning.
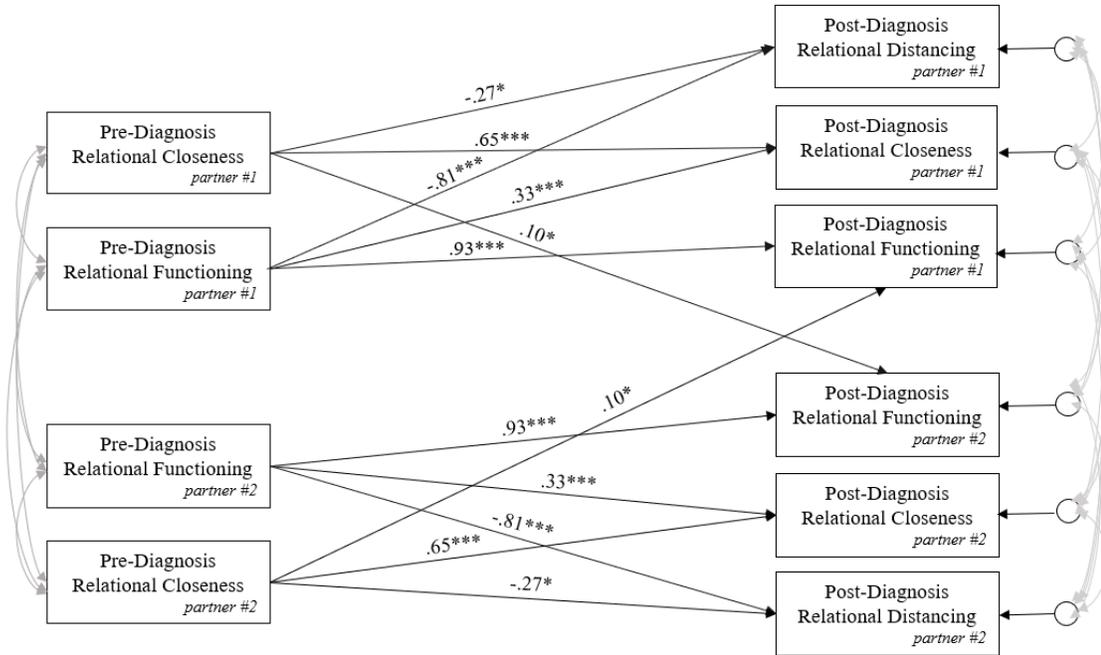
Figure 9. RQ7 APIM. * *p* <.05, ** *p* < .01, *** *p* < .001

Change in Relational Closeness and Relational Functioning

To examine the impact of Alzheimer's disease upon family dynamics, two discrepancy scores were calculated to compare pre- and post-diagnosis relational closeness, as well as pre- and post-diagnosis relational functioning. Descriptive statistics, shown in Table 6, indicated an overall increase in relational closeness (*M* = .1217) and decrease in relational functioning (*M* = -.0054).

Table 6
Change in Relational Closeness and Functioning

Variable	*n*	Min	Max	*M(SD)*
Change in Relational Closeness	106	-1.83	3.17	.1217(.6347)
Change in Relational Functioning	101	-1.52	0.87	-.0054(.4688)

CHAPTER SIX: DISCUSSION AND CONCLUSION

The objective of this dissertation was to address some of the gaps in current literature on family communication during dementia care. Much existing scholarship has focused on the perspectives of one individual within a family and has assessed communication in terms of frequency, assuming that more communication is better. Also, little scholarship has considered the impact of the dynamics of families before the dementia diagnosis. By contrast, the present dissertation focused on family dyads, communication quality, and examined the influence of families' past experiences on post-diagnosis experiences. This dissertation applied the multiple goals theoretical perspective (Caughlin, 2010), which allowed for an examination of communication quality (i.e., interaction goal patterns, conversation satisfaction) instead of communication frequency, and it allowed for a macro view of relational dynamics instead of examinations of single encounters. In this chapter, the theoretical and practical contributions of the results are considered, and the limitations and future opportunities for research are addressed. A visual summary of the research questions and the significant partner and actor effects in this study is reproduced in Figure 10.
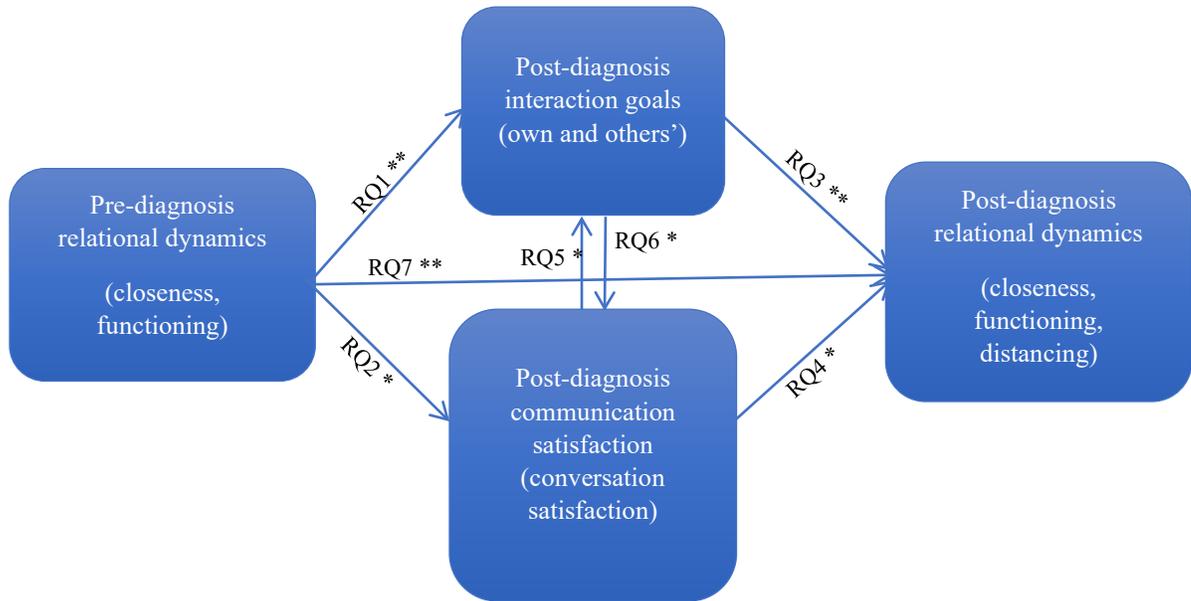
Figure 10. Conceptual Model. Visual summary of research questions and variables examined in this study. * actor effects, ** actor and partner effects.

Theoretical Implications

This dissertation was designed to address the gaps in existing scholarship on conceptualizations and operationalizations of family communication during dementia care and to apply Caughlin's multiple goals theory of personal relationships (2010) in the context of family member caregivers living with Alzheimer's and other related dementias. The findings have a number of theoretical implications.

To begin, Caughlin (2010) has called for scholarship to move beyond examining single conversation encounters to examine how more global perceptions of interaction goals are related to more global relational concepts. The results of this dissertation answer this call by examining the ways in which the relational history (i.e., pre-diagnosis relational dynamics) of families influences current (i.e., post-diagnosis) goal pursuit and conversational satisfaction, as well as how current communication encounters (i.e., post-diagnosis goal pursuit and conversational satisfaction) influence current relational

50

dynamics. For example, the results for RQ1 demonstrate that past (i.e., pre-diagnosis) relational dynamics aggregate and influence post-diagnosis perceptions and evaluations of own and other's interaction goals. The collective actor and partner effects observed in this finding show the interwoven nature of how families' experiences (i.e., closeness and functioning) before a dementia diagnosis aggregate and influence their perceptions of how well they attend to goals in post-diagnosis discussions. That is, the better a family functioned and how close they were before facing the patient's diagnosis, the better they will be able to effectively attend to multiple interaction goals during the family experience of dementia. More specifically, this dissertation research examined seven goals, and the better families perceived their pre-diagnosis relational dynamics, the better they could affirm each other's (1) positive and (2) negative face, (3) maintain their relationships, (4) support each other, (5) use avoidance, (6) influence each other, and (7) make better clinical decisions during caregiving. The goals measures were examined as one collective score (i.e., types of goals were not examined individually) for participants' perceptions of their own and others' goal attention. Collectively, these findings provide some initial evidence that more global perceptions of interaction goals are related to more global relational concepts and thus bolsters the utility of the multiple goals theoretical perspective to explain macro level interaction patterns.

In addition, an individual's perceived satisfaction with enacted family communication influenced their evaluation of interaction goal tendencies. There were no partner effects (*RQ 5b*) in the model for RQ5, but a significant relationship was observed between participants' post-diagnosis communication satisfaction and their own post-diagnosis interaction goals (*RQ 5a*). This positive association indicates that the higher a

participant ranks satisfaction with communication with their family member partner, the higher they perceive their own ability to attend to interaction goals. Similarly, the lower their satisfaction with conversations, the lower their rankings of their own goal attention. And while it was not a significant relationship, there was an association ($p = .055$) between individuals' post-diagnosis conversation satisfaction and their evaluation of their family member's post-diagnosis interaction goals. Again, these findings demonstrate that more global perceptions of interaction goals are related to more global patterns of communication, which extends the multiple goals perspective to apply beyond single encounters (which is primarily how the theory has been historically applied).

In response to RQ3, this dissertation's findings revealed that families' perceptions of interaction goal tendencies influenced post-diagnosis relational dynamics in both expected and surprising ways. The actor effects observed in RQ3 demonstrated the associations between participants' perceptions of their own post-diagnosis goal attention and their own post-diagnosis relational closeness (*RQ 3a*). The higher participants ranked their own interaction goal attention, the higher they rated relational closeness and the lower they rated relational distancing. Also, as participants highly ranked others' post-diagnosis goal attention, the lower they scored their own perceptions of relational distancing (*RQ 3b*). This finding carries the expected implication that if family members can successfully attend to identity, task, and relational goals, they will in turn have better family relationships, consistent with previous scholarship (e.g., Scott & Caughlin, 2012; 2014).

However, surprising partner effects were observed in both participants' perceptions of their own (*RQ 3a*) and others' (*RQ 3b*) post-diagnosis goal attention. The

higher participants rated perceptions of their own post-diagnosis goal attention, the higher

their partners rated relational functioning and closeness (*RQ 3a*); however, participant

perceptions of others' post-diagnosis goal attention were *negatively* associated with their

partner's perception of post-diagnosis relational closeness (*RQ 3b*). In other words, as

families navigated dementia, the higher that participants ranked their partner's ability to

attend to interaction goals, the lower their partner ranked relational closeness. One

potential explanation for this finding is offered by multiple goals research: Individuals

have multiple goals in their conversations, and sometimes one goal can conflict with

other goals (e.g., Dillard et al., 1989). Additionally, individuals within a family might

have goals that compete with other family members' goals (e.g., Wilson, 2002). For

example, in the context of families navigating dementia care, one family member might

want to keep the patient home as long as possible, while other family members may see

that a professional care setting would better meet the needs of the patient (e.g., Miller,

Whitlatch, Lee, & Lyons, 2018). This clash of goals between family members creates

tension and conflict and potentially has negative effects on their relational closeness. This

explanation is consistent with findings in other extant work that as families navigate

dementia, caregiving demands and the overwhelming nature of loss and grief (Pearlin,

2010), as in the case of other family health crises (Segev, Levinger, & Hochman, 2018),

the experience of dementia can negatively impact their feelings of closeness.

Overall, the current pattern of findings is consistent with previous family science

work demonstrating that past family experiences influence current individual and

relational factors (e.g., Crosnoe & Elder, 2004; David, Demo, & Acock, 1996;

Hetherington, 1989). This pattern of findings is also consistent with previous multiple

goals research, which has shown that individuals' ability to purposefully attend to goals is developed over time (Caughlin & Scott, 2010; Clark & Delia, 1979; Jacobs, 2002) and that goal attention is primarily automatic (Kellermann, 1992). The current study builds on this work by extending multiple goals research into the dementia caregiving context—a high-stakes communication context—and by examining how historical family relational dynamics and communication satisfaction influence the way goal attention is perceived during the dementia experience on a global (rather than single interaction) level. In short, these results provide compelling evidence that actual communication experiences are important to how family members evaluate their ability to attend to interaction goals in the family context of dementia, and those perceptions in turn affect family relational dynamics after the dementia diagnosis. These results also demonstrate that multiple goals operate at a macro, not just a micro, level in communication.

Practical Implications

The findings from this dissertation can be used to inform the development of evidence-based caregiver interventions, education programs, and online social support resources and ultimately to improve health outcomes for family members of dementia patients and patients themselves. Families in this context of navigating dementia care must attend to their relationship quality while managing patient behaviors, making difficult care decisions, and balancing other family responsibilities and demands. As previous research has indicated, conversations in which families discuss the issues addressed in this dissertation can be difficult (Scott & Caughlin, 2012) as multiple family members navigate their own and each other's goals within family discussions (Caughlin, 2010). The current findings lay a foundation for a number of concrete recommendations

for improving communication practice to benefit family members of persons living with dementia.

First, the present study provides evidence that an individual's perceived satisfaction with communication is influenced by perceived communication tendencies and the perceived goals underlying that communication. As individuals have family discussions during a health crisis, they can be drawn together simply because they have common goals (Segev et al., 2018) such as making clinical decisions on behalf of the patient, and satisfaction with this communication can be bolstered by ensuring that family members attend to task, identity, and relational goals in conversations. For example, there were no associations to partner responses (*RQ 6b*) in the model for RQ6. However, relationships were observed between participants' own post-diagnosis interaction goals and post-diagnosis communication satisfaction (*RQ 6a*). The positive association indicates that as they face the experience of dementia in the family, the higher a participant perceives their own ability to attend to interaction goals, the higher they rank satisfaction with discussions with their family member partner. Likewise, the lower their own goal rankings, the lower their satisfaction with conversations. This finding suggests that family communication is higher quality if family members can attend to identity, task, and relational goals (e.g., Scott & Caughlin, 2012; 2014) and implies that if families having low quality discussions can improve their enacted communication, they will better be able to purposefully attend to goals such as affirming each other's positive and negative face, protecting their family relationship, supporting each other, and making better clinical decisions for the dementia patient.

The findings of this dissertation also revealed that enacted family communication after the patient's diagnosis influenced individuals' perceptions of family relational dynamics, which underscores the importance of promoting good communication in families dealing with dementia given its relational impact. For instance, the actor effects observed in the results of RQ4 demonstrate the higher participants rated their satisfaction with discussions with their family member after the patient was diagnosed, the higher they also rated their relational dynamics post-diagnosis. This finding implies that higher quality enacted family communication post-diagnosis facilitates better relational dynamics. Family members who engage in better family discussions in the midst of a serious illness have better family relationships (Lim & Shon, 2018). While there were no associations to partner responses in the model for RQ4, the actor effects support the multiple goals of interpersonal relationships (Caughlin, 2010). Actual communication experiences are important to how family members evaluated their family's ability to function, their perceived relational closeness, as well as their feelings of relational distancing post-diagnosis. This means that in families with a person living with dementia, they would do well to concentrate on improving the quality of their communication as a means of improving their family functioning.

Practical insight can also be gained from the results related to RQ2. Specifically, significant actor effects demonstrated that an individual's perceived level of closeness to their family member and how they perceived their family functioned before the dementia experience influenced their satisfaction with enacted communication after diagnosis. This implies that the preexisting relational climate appears to play out in enacted communication and that within families with positive pre-diagnosis dynamics,

individuals will be more satisfied by their family conversations as they navigate the experience of dementia. This finding lays the foundation for making practical recommendations for improving family communication in this context because it identifies how past relational dynamics can be leveraged to support satisfying communication through the enactment of high-quality communication post-diagnosis. For example, evidence-based caregiver social support and family resources can mitigate the negative implications associated with caregiving by helping individuals to find ways to maintain healthy family functioning (Drentea et al., 2006; Roth et al., 2005; Wilks & Croom, 2008).

Although the findings from this dissertation suggest ways to improve family communication and functioning, it is important to recognize that the association between participant and partner responses in the results related to RQ7 depicting family dynamics before and after the dementia diagnosis. The results suggest that the onset of dementia and ensuing experience of the family might not change the course of relational dynamics in families. This implies that it can be difficult for families to turn around negative dynamics amid dementia, and families with positive relational dynamics might be better prepared to maintain their positive interaction patterns. This pattern of findings is consistent with extant work demonstrating that families often grow closer during the experience of a family health crisis (Gage, 2013; Segev et al., 2018) and that unresolved relational issues often resurface during the experience of dementia and further hinder a family's relational functioning (Carr & Wang, 2012; Polk, 2005). These findings provide evidence that individuals' evaluations of their family relationships unfold over time through many conversations within the family, and thus it is critical for family

communication researchers to examine relational dynamics over time rather than within a single interaction when considering ways to improve how a family responds to a chronic health crisis.

One final observation is warranted about the increase in relational closeness and decrease in relational functioning that was observed in this study. This study revealed that the experience of dementia had a slight negative impact to family functioning. However, family members' ratings of relational closeness increased from pre-diagnosis to post-diagnosis. This indicates that as families face the demands of dementia, their perceived ability to function together as a family unit might decrease, but they can feel closer through this experience (Segev et al., 2018). While the discrepancy scores indicate an overall negative change in relational functioning, it does not mean the change is meaningful since this score was calculated as an examination of the differences in means. The interwoven experience of family members navigating dementia is complex. What is clear is that enacted communication experiences of families and goal tendencies of family members have an influence on larger family relational constructs as they navigate the experience of dementia. With statistical significance observed in the results of each research question, the conceptual model in this research design demonstrated an effective way to examine variables and research questions in this study.

Overall, the present findings confirm that there is a historical nature to the influence of family relational dynamics and suggest that while pre-diagnosis relational dynamics can influence how families communicate (i.e., interaction goals, communication satisfaction) and how families evaluate their post-diagnosis relational dynamics, practitioners can use the pre-diagnosis measures to establish a baseline for

families navigating dementia. For example, it might be particularly fruitful for dementia caregiver organizations (i.e., Alzheimer's Association, National Alliance for Caregiving, AARP, etc.) to develop interventions for families who screen with lower perceived pre-diagnosis relational dynamics. The focus of these initiatives could be to help families improve their goal attention in conversations about dementia care, which would in turn improve family members' communication satisfaction and relational functioning. Ultimately, caregiver organizations, family therapists, and healthcare practitioners could better meet the needs of families facing dementia care. One example is developing caregiver trainings and online social support resources aimed at improving interaction goal attention. Other interventions could include guided family conversational practice (e.g., see Scott & Caughlin, 2012; 2014; Van Scoy et al., 2016). In turn, these interventions and resources could help improve the quality of life for family members of dementia patients. Ultimately, with better family relationships and higher caregiver quality of life, health outcomes for patients themselves can improve.

<center>**Limitations and Opportunities for Future Research**</center>

As with any scholarly pursuit, the choices made in this study design provided the opportunity to contribute to scholarship, but they also created parameters which constrained what contributions could be made. The current dissertation had limitations, which arose from the conceptual definitions, sample, design, and methodological approaches in this study. These limitations suggest opportunities for future research on family communication during dementia care.

Conceptualizations in this study were limited by the sampling inclusions and measurement variables. Family was conceptualized in this study as a close relational

other. In addition to an immediate or extended biological or legal connection to the dementia patient, family was defined as persons having an emotional connection and shared closeness to the patient (Riedel et al., 2013). This created a wide variety of possibilities for family members to pair together and thus allowed for multiple relational possibilities for dyads. While most were sibling pairs, the variation of dyad types created indistinguishable dyads. While this may be a confounding factor in some of the results, this is also a strength of the findings. Since this study allowed for multiple relational constellations in the dyadic pairs, this strengthens the generalizability of the results.

The conceptualizations of variables were also a constraint of this study design. The quality of family relationships or family relational satisfaction was conceptualized in this study as relational dynamics. Specifically, pre-diagnosis relational dynamics was conceptualized as relational closeness and relational functioning. Post-diagnosis was conceptualized as relational closeness, relational distancing, and relational functioning. This limited the measure of family relationship dynamics to those variables. Perceptions of interaction goal pursuit were conceptualized as participants' own and others' goal attention. Each goal measure contained 23 items that assess seven goals which were conceptually determined as relevant in family conversations: affirming the positive face of the partner, affirming the negative face of the partner, maintaining the relationship, avoidance, giving support to the other, influencing the other, and making clinical decisions. However, different goals (not assessed) may have been important to some participants.

The sample in this study also had limitations. Only family members of patients who were living or had lived in the United States were included in this sample. This

limited the sample to families navigating the dementia experience within the U.S. healthcare system. The total sample was a relatively small sample (Anderson & Johnson, 2010) of 53 dyads which limits the generalizability of results. Future research could include continuation of this project, collecting responses from additional dyads to grow the sample. The sample was also a purposive sample of convenience, not a random sample, and thus would not be representative of the general U.S. population (Keyton, 2001). The sample was limited to the willing members (i.e., dyads) from the represented families. Family members who had a very poor relationship or who did not want to share their perspectives on their family experiences likely did not participate. Family member caregivers of dementia patients often have limited time due to the nature of the demands of providing care. Several potential participants, who initially expressed interest in participating, stated that they could not participate because the dementia patient had to be hospitalized and they had to devote their time and attention to caregiving.

The self-report design of the study introduced the potential for participant and measurement errors. First, participants may have perceived questions differently than were intended in the study design. For example, participant responses within dyads differed on family questions in some instances (e.g., How many family members are/were involved in the care and/or care decisions for the patient?; In approximately what year did you first notice symptoms of the disease?). Additionally, participants may have perceived certain communication behaviors as acceptable while others would not. This could have differed by family expectations as well as goal differences. For example, some families might prioritize involving all family members in making clinical decisions for the dementia patient, while others would not. Second, self-report bias is another

potential participant error. People tend to assess their own communication more positively than others' communication (e.g., Canary, 2003; Sillars, Roberts, Leonard, & Dun, 2000). Measurement error is another limitation of a self-report design. These measures which require researchers to create standardized questions for consistent measurement which are general enough for a variety of participants, but this may create a gap which misses what is most important to some participants.

Other design limitations include the survey format. The length of survey was overestimated (i.e., due to IRB requirement) to be 30-45 minutes in duration, and this was stated in the recruiting materials and the survey cover page, which may have limited the willingness of some individuals to participate. In fact, one participant reported to me that their initially selected family member declined to participate based on the time estimate for the survey. Since this design asked for participants to share their pre- and post-diagnosis evaluations of relational dynamics variables plus perceptions of their own and their family member's interaction goals, they may have experienced survey fatigue. The online format of the survey offered benefits and limitations to this research design. While it offered relative ease to administer, convenience for researchers and participants, and lower costs than many other research methods (Charania & Ickes, 2006; Harvey, Hendrick, & Tucker, 1988; Wright, 2005), it also allowed for uncertainty over participant identity and validity of data and created need for validation of the data and enhanced screening measures in early data collection stages.

Future Research

The constraints of the current dissertation suggest opportunities for future research on family communication during the experience of dementia. Future research

designs could focus on particular types of family dyads (e.g., siblings, parents/children, etc.). This would create distinguishable dyads and allow for more detailed analysis. Additionally, more than dyads (i.e., more members of one family, such as triads) could be sampled to examine an even more holistic view of a family's experience of communication and relational dynamics during dementia. Future research could take a longitudinal approach to examining the experiences of families across the entire course of the disease. Future projects could also take a specific cross-cultural comparison approach to examine cultural differences and specifically examine families of patients living in different countries under different healthcare systems. Finally, future studies could take a qualitative approach to elicit richer descriptions of experiences of families navigating dementia to examine the contradictory findings in this research.

Conclusion

There is no cure for dementia. An estimated 5.8 million people in the United States are currently living with Alzheimer's disease (AA, 2019). As the number of families facing this experience continues to grow, caregiver interventions and family resources can be improved to better meet the needs of family members of dementia patients. In turn, families can experience improved relational outcomes and better quality of life.

By addressing some of the gaps in current literature, this research offers new insight into ways that families can improve their post-diagnosis family discussions and thereby improve their family dynamics. These findings provide evidence that after the patient's diagnosis, communication satisfaction is influenced by family members' communication tendencies and their perceived goals in family discussions. There is an

enduring nature to the influence of family relational dynamics. It is important to consider the history of family relationships before the diagnosis of dementia in order to anticipate families' ability to communicate after diagnosis.

Additionally, these findings build on multiple goals research, extending this scholarship into the context of families navigating dementia. This research also extends the multiple goals perspective to apply beyond single encounters by demonstrating that more global perceptions of interaction goals are related to more global communication patterns. This dissertation's findings thereby bolster the utility of the multiple goals theoretical perspective to explain macro level interaction phenomena. Dementia care organizations, family therapists, and healthcare practitioners can utilize this research for evidence-based evaluation of interventions, therapies, and support resources. Families facing the experience of dementia can improve their enacted communication and family relationships can be improved. Finally, future scholarship can also use these findings to continue examining ways to help families navigating this experience.

APPENDICES

APPENDIX A. RELATIONAL DYNAMICS MEASURES

Relational Closeness Measures

For the following questions, think about your family member who will also be taking a survey. Enter their first name here. Or if you prefer not to list their first name, please enter a nickname: _____ *text fills in place of "{your family member}" in all measures

Pre-Diagnosis Relational Closeness

*Think back to the time **before the patient was diagnosed** with dementia. Refer to that time period when answering the following questions. Please tell us how you would describe your **past** relationship with {your family member} by selecting a number from 1 (not at all) to 7 (a lot).*

	not at all		somewhat				a lot
1. How close were you to {your family member}?	1	2	3	4	5	6	7
2. How much did you like {your family member}?	1	2	3	4	5	6	7
3. How often did you talk about personal things with {your family member}?	1	2	3	4	5	6	7
4. How important was {your family member}'s opinion to you?	1	2	3	4	5	6	7
5. How much did you enjoy spending time with {your family member}?	1	2	3	4	5	6	7
6. How important was your relationship with {your family member} to you?	1	2	3	4	5	6	7

Scoring
The mean scores were calculated. Higher scores indicate higher levels of relational closeness.

Post-Diagnosis Relational Closeness

*Please tell us how you would describe your relationship with {your family member} **after the patient was diagnosed** with dementia. Refer to that time period when answering the following questions. For each question, please answer by selecting a number from 1 (not at all) to 7 (a lot).*

	not at all		somewhat				a lot
1. How close are you to {your family member}?	1	2	3	4	5	6	7
2. How much do you like {your family member}?	1	2	3	4	5	6	7
3. How often do you talk about personal things with {your family member}?	1	2	3	4	5	6	7
4. How important is {your family member}'s opinion to you?	1	2	3	4	5	6	7
5. How much do you enjoy spending time with {your family member}?	1	2	3	4	5	6	7
6. How important is your relationship with {your family member} to you?	1	2	3	4	5	6	7

Scoring

The mean scores were calculated. Higher scores indicate higher levels of relational closeness.

Relational Functioning Measures

Pre-Diagnosis Relational Functioning

*Think back to the time **before the patient was diagnosed** with dementia. Refer to that time period when answering the following questions.*

For each line, **how much would you say that *"this described our family"*** in the time **before** the patient was diagnosed with dementia?

Very well	Well	Partly	Not well	Not at all
1	2	3	4	5

1. In my family we talked to each other about things which mattered to us.

2. People often didn't tell each other the truth in my family.

3. Each of us got listened to in our family.

4. It felt risky to disagree in our family.

5. We found it hard to deal with everyday problems.

6. We trusted each other.

7. It felt miserable in our family.

8. When people in my family got angry they ignored each other.

9. We seemed to go from one crisis to another in my family.

10. When one of us was upset they got looked after within the family.

11. Things always seemed to go wrong for my family.

12. People in the family were nasty to each other.

13. People in my family interfered too much in each other's lives.

14. In my family we blamed each other when things went wrong.

15. We were good at finding new ways to deal with things that were difficult.

Scoring
Items number 1, 3, 6, 10, and 15 were reverse coded. Mean scores were calculated. Higher scores indicate higher family functioning.

Post-Diagnosis Family Functioning

*For each of the following questions, think about the time **after the patient was diagnosed**. Refer to that time period when answering the following question*

For each line, **how would you say that *"this describes our family"*** in the time **after** the patient was diagnosed with dementia?

Very well	Well	Partly	Not well	Not at all
1	2	3	4	5

1. In my family we talk to each other about things which matter to us.

2. People often don't tell each other the truth in my family.

3. Each of us gets listened to in our family.

4. It feels risky to disagree in our family.

5. We find it hard to deal with everyday problems.

6. We trust each other.

7. It feels miserable in our family.

8. When people in my family get angry they ignore each other.

9. We seem to go from one crisis to another in my family.

10. When one of us is upset they get looked after within the family.

11. Things always seem to go wrong for my family.

12. People in the family are nasty to each other.

13. People in my family interfere too much in each other's lives.

14. In my family we blame each other when things go wrong.

15. We are good at finding new ways to deal with things that are difficult.

Scoring
Items number 1, 3, 6, 10, and 15 were reverse coded. Mean scores were calculated. Higher scores indicate higher family functioning.

Relational Distancing Measure

Post-Diagnosis Relational Distancing

*Please use these words to describe your relationship with {your family member} in the time **after the patient was diagnosed** with dementia.*

Consider the following question:

How has Alzheimer's or another related dementia impacted your relationship with {your family member}? Answer by selecting a point on each line that best describes what you think.

Has this experience made your relationship more:

distant : ____ ____ ____ ____ ____ ____ ____ : close

relaxed : ____ ____ ____ ____ ____ ____ ____ : tense

hostile : ____ ____ ____ ____ ____ ____ ____ : friendly

intimate : ____ ____ ____ ____ ____ ____ ____ : remote

closed : ____ ____ ____ ____ ____ ____ ____ : open

Scoring

The spaces were converted to numbers, beginning with "1" for the most left-hand space and ending with "7" for the most right-hand space. Items 1, 3, and 5 were reverse coded. The mean scores were calculated. Higher scores indicate greater relational distancing.

APPENDIX B. PERCEPTION OF CURRENT INTERACTION GOALS MEASURES

Perception of Own Interaction Goals

Whenever people have a conversation, they are not just talking—they are also trying to do things, like informing, persuading, or sharing feelings. On the next two pages we ask you about some things people might try to do in family conversations.

*For the questions on this page, please select the appropriate number to let us know how important you think the following items have been __to you__ in your conversations with {your family member} **in the time since the patient was diagnosed with dementia**.*

Please select the appropriate number to let us know how important you think the following items are __to you__ in your conversations. For example, if you think it is very important, select 7. If you think it's not important at all, select 1. If you think it is somewhat important, select 4.

	not at all important	somewhat important	very important
	1 2	3 4 5	6 7

Affirming the positive face of the other
1. How important is it to you to let {your family member} know that you appreciate him/her?
2. How important is it to you to try to let {your family member} know that you value him/her?
3. How important is it to you to let {your family member} to know that you accept him/her?

Affirming the negative face of the other
4. How important is it to you to respect {your family member}'s independence?
5. How important is it to you to respect {your family member}'s choices?
6. How important is it to you to respect {your family member}'s beliefs and attitudes?

Maintaining the relationship
7. How important is it to you to protect your relationship?
8. How important is it to you to try not to damage your relationship?
9. How important is it to you to try to make your relationship stronger by talking about these issues?

Avoidance
10. How important is it to you to avoid talking about caregiving issues?
11. How important is it to you to change the subject away from the topic of caregiving?
12. How important is it to you to say very little about caregiving and related topics?

Support
13. How important is it to you to try to reassure {your family member}?
14. How important is it to you to try to let {your family member} know that you support him/her?
15. How important is it to you to try to show {your family member} that you are there for him/her?

Influence
16. How important is it to you to try to influence {your family member}?
17. How important is it to you to try to change {your family member}'s mind?
18. How important is it to you to try to persuade {your family member}?

Making clinical decisions
19. How important is it to you to involve {your family member} in care decisions?
20. How important is it to you to be involved with {your family member} in care decisions?
21. How important is it to you to involve others in clinical decisions?
22. How important is it to you to make a quick clinical decision?
23. How important is it to you to make a careful and well-thought-out decision?

Scoring
The mean score for each perceived goal was calculated. Higher scores indicate greater goal importance.

Perception of Partner Interaction Goals

*Now we would like to ask about what you think is important **to {your family member}** in conversations.*

*Please select the appropriate number to let us know how important you think the following items have been **to {your family member}** in your conversations **in the time since the patient was diagnosed with dementia**. For example, if you think it is very important to {your family member}, select 7. If you think it's not important to {your family member} at all, select 1. If you think it is somewhat important, select 4.*

not at all important	somewhat important	very important
1 2	3 4 5	6 7

Affirming the positive face of the other
1. How important is it to {your family member} to let you know that he/she appreciates you?
2. How important is it to {your family member} to let you know that he/she values you?
3. How important is it to {your family member} to let you know that he/she accepts you?

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Affirming the negative face of the other
4.   How important is it to {your family member} to respect your independence?
5.   How important is it to {your family member} to respect your choices?
6.   How important is it to {your family member} to respect your beliefs and attitudes?

Maintaining the relationship
7.   How important is it to {your family member} to protect your relationship?
8.   How important is it to {your family member} to not damage your relationship?
9.   How important is it to {your family member} to try to make your relationship stronger by talking about these issues?

Avoidance
10.   How important is it to {your family member} to avoid talking about caregiving issues?
11.   How important is it to {your family member} to change the subject away from the topic of caregiving?
12.   How important is it to {your family member} to say very little about caregiving and related topics?

Support
13.   How important is it to {your family member} to reassure you?
14.   How important is it to {your family member} to let you know that he/she supports you?
15.   How important is it to {your family member} to show that they are there for you?

Influence
16.   How important is it to {your family member} to try to influence you?
17.   How important is it to {your family member} to try to change your mind?
18.   How important is it to {your family member} to try to persuade you?

Making clinical decisions
19.   How important is it to {your family member} to involve you in making care decisions for the Alzheimer's patient?
20.   How important is it to {your family member} to be involved with you in making care decisions for the Alzheimer's patient?
21.   How important is it to {your family member} to involve others in clinical decisions?
22.   How important is it to {your family member} to make a quick clinical decision?
23.   How important is it to {your family member} to make a careful and well-thought-out decision?

Scoring
The mean score for each perceived goal was calculated. Higher scores indicate greater goal importance.

APPENDIX C. POST-DIAGNOSIS COMMUNICATION SATISFACTION MEASURE

Perception of Conversation Satisfaction

*Now we'd like to ask you about your general thoughts on conversations with {your family member} **after the patient was diagnosed** with dementia.*

Please tell us how much you agree or disagree with these statements about discussions you have with {your family member}.

	strongly disagree						strongly agree
1. I am generally dissatisfied with our conversations.	1	2	3	4	5	6	7
2. Our conversations tend to go well.	1	2	3	4	5	6	7
3. I'm glad we have these conversations.	1	2	3	4	5	6	7
4. It feels like nothing is accomplished by our conversations.	1	2	3	4	5	6	7
5. I am pleased with our conversations.	1	2	3	4	5	6	7
6. I wish we did not have our conversations.	1	2	3	4	5	6	7
7. Our conversations are productive.	1	2	3	4	5	6	7
8. I am generally satisfied with our conversations.	1	2	3	4	5	6	7

Scoring
The mean scores were calculated. Items number 1, 4, and 6 will be reverse coded. Higher scores indicate higher levels of conversational satisfaction.

APPENDIX D. DEMOGRAPHICS AND CONTROL VARIABLES

Family and Illness Questions

Please answer the following questions to describe your family:

1. What is your relationship to your family member who is also participating in this study? They are my …
   - ☐ parent
   - ☐ parent-in-law
   - ☐ child
   - ☐ child-in-law
   - ☐ grandchild
   - ☐ grandchild-in-law
   - ☐ grandparent
   - ☐ grandparent-in-law
   - ☐ sibling
   - ☐ sibling-in-law
   - ☐ legal spouse
   - ☐ romantic partner
   - ☐ close friend
   - ☐ other relative (please list): _____

2. What is/was your relationship to the patient (the person diagnosed with dementia)? They are/were my…
   - ☐ parent
   - ☐ parent-in-law
   - ☐ grandparent
   - ☐ grandparent-in-law
   - ☐ sibling
   - ☐ sibling-in-law
   - ☐ aunt
   - ☐ uncle
   - ☐ cousin
   - ☐ legal spouse
   - ☐ romantic partner
   - ☐ close friend
   - ☐ other relative (please list): _____

3. Is the person who was diagnosed with dementia still living or deceased?
   - ☐ still living
   - ☐ deceased

4. If the patient is deceased, what year did she/he die?

5. Approximately what year was the patient diagnosed with dementia?

6. In approximately what year did you first notice symptoms of the disease?

7. Where does the patient currently reside? If the patient is deceased, where did they reside at the time of their death?
   - ☐ in their own primary residence
   - ☐ with you in your primary residence
   - ☐ with another family member in their primary residence
   - ☐ in a long-term care facility
   - ☐ other (please list): _____

8. Are/were you the primary caregiver?
   - ☐ yes
   - ☐ no
   - ☐ I share(d) primary caregiving responsibilities with another family member.

9. If you are/were not the primary caregiver, what is your relationship to the primary caregiver? They are my…
   - ☐ parent
   - ☐ parent-in-law
   - ☐ child
   - ☐ child-in-law
   - ☐ grandchild
   - ☐ grandchild-in-law
   - ☐ grandparent
   - ☐ grandparent-in-law
   - ☐ sibling
   - ☐ sibling-in-law
   - ☐ legal spouse
   - ☐ romantic partner
   - ☐ close friend
   - ☐ other relative (please list): _____

10. Within the patient's family, how many adult family members are there? Please count the total number of living adults in the family of the person with dementia. Include ALL members of the patient's immediate and extended family who are age 18 and over (For example: spouse, life partner, siblings, adult children, spouses of adult children, adult grandchildren, spouses of adult grandchildren.). If the patient is deceased, count the total number of adults in the patient's family at the time of the patient's death.

11. How many family members are/were involved in the care and/or care decisions for the patient?

Demographic Questions

Please answer the following questions so that we can describe the group of people who have taken this survey:

1. In what year were you born?

2. What is the zip code of your primary residence?

3. What is your gender?
   - ☐ Male
   - ☐ Female
   - ☐ Other (please specify):

4. What is your race/ethnicity?
   - ☐ White
   - ☐ Black or African American
   - ☐ American Indian or Alaska Native
   - ☐ Asian
   - ☐ Native Hawaiian or Pacific Islander
   - ☐ Hispanic or LatinX
   - ☐ Other (please specify):

5. What is the highest level of education you have completed?
   - ☐ Less than high school
   - ☐ High school graduate
   - ☐ Some college
   - ☐ 2-year degree
   - ☐ 4-year degree
   - ☐ Professional or vocational degree
   - ☐ Master's degree
   - ☐ Doctorate

6. What is your annual household income level?
   - ☐ Less than $10,000
   - ☐ $10,000 - $19,999
   - ☐ $20,000 - $29,999
   - ☐ $30,000 - $39,999
   - ☐ $40,000 - $49,999
   - ☐ $50,000 - $59,999
   - ☐ $60,000 - $69,999
   - ☐ $70,000 - $79,999
   - ☐ $80,000 - $89,999
   - ☐ $90,000 - $99,999
   - ☐ $100,000 - $149,999
   - ☐ More than $150,000

7. What is your marital status?
   - ☐ Married
   - ☐ Separated
   - ☐ Widowed, single
   - ☐ Divorced, single
   - ☐ Never married

APPENDIX E. DESCRIPTIVE STATISTICS FOR INDIVIDUALS

In addition to the total sample included in this dissertation's analyses, 36 individuals participated who did not have a participating family member. Descriptive statistics for the individuals excluded from analyses ($n = 36$) are included in this appendix. Ages of the individuals in this subsample ($n = 36$) ranged from 25 to 78 ($M = 49.63$, $SD = 13.15$). The majority of participants were females (66.67%, $n = 24$), 33.33% were males ($n = 12$). Participants self-identified their race as Caucasian or white ($n = 32$; 88.89%), Asian ($n = 1$; 2.78%), multiracial ($n = 2$, 5.56%), or other ($n = 1$; 2.78%). The majority of participants had college degrees, including 4-year ($n = 12$, 33.33%), master's ($n = 10$, 27.78%), professional/vocational ($n = 8$, 22.22%), doctorate ($n = 1$, 2.78%), and 2-year ($n = 2$, 5.56%) degrees; 2 participants (5.56%) had some college, and 1 respondent (2.78%) was a high school graduate. Participants reported their marital status as married ($n = 30$, 83.33%), never married ($n = 4$, 11.11%), divorced ($n = 1$, 2.78%), or separated ($n = 1$, 2.78%). Annual income was reported as under $20,000 ($n = 1$, 2.94%), $20,000-49,999 ($n = 13$, 38.24%), $50,000-79,999 ($n = 13$, 38.24%), and $80,000-149,999 ($n = 7$, 20.59%).

Participants were asked questions to describe their family and illness situation. The patient was deceased in families of 7 of the participants represented in this subsample (19.44%), and the patient was still living in 29 participants' families (80.56%). The average duration of disease (i.e., year of diagnosis to death) was 4.71 years ($SD = 2.36$). Duration of symptoms averaged 0.88 years ($SD = 1.27$). Of the individuals in this subsample, 15 (41.67%) participants indicated they were the primary caregiver for the patient, 5 were not the primary caregiver (13.89%), and 16 (44.44%) share(d) caregiving

responsibilities with another family member. The mean number of members with each patient's extended family was 9.48 (*SD* = 6.95) and the average number of family members involved in the care or care decisions for the patient was 3.24 (*SD* = 1.79). The majority of participants in this subsample were the child (*n* = 23, 65.71%) of the patient with dementia. Participants' relationships to patients are shown in Table 7.

Table 7
Patient Relationship Types for Individuals

Patient Relationship	*n*	%
Parent	23	65.7
Parent-in-law	4	11.4
Grandparent	3	8.6
Legal spouse	3	8.6
Aunt	1	2.9
Other relative	1	2.9

Note. Participants answered "They are my…".

Patient living arrangements are shown in Table 8. Most patients were living their own primary residence in (*n* = 19, 52.78%) or in a long-term care facility (*n* = 10, 27.78%).

Table 8
Dementia Patient Living Arrangement for Individuals

Patient Residence	*n*	%
Patient's primary residence	19	52.8
In a long-term care facility	10	27.8
Participant's primary residence	4	11.1
Another family member's primary residence	2	5.6
Other	1	2.8

Note. If deceased, this was the patient's living arrangement at the time of death.

APPENDIX F. SURVEY COVER LETTER

Thank you for your interest in this research. Before you begin, please review the following instructions.

Researchers at the University of Kentucky are inviting you and your family member to take part in an online survey about **family members of persons with Alzheimer's disease or another related dementia**. This study is inviting **pairs of family members** to each take an online survey to better understand the nature of family communication and relationships during dementia care.

Step 1: Pick a family member
This study is inviting you and a family member to each take an online survey. Please be sure you have found a family member who is also willing to participate. Both family members should be age 18 or over.

For this study, we are defining "family members" as individuals who may be blood or legal relatives of the person who is/was living with dementia (for example: a spouse, life partner, siblings, adult children, spouses of adult children, adult grandchildren, spouses of adult grandchildren, etc.). However, a family member need not have a biological or legal connection to the patient. In addition to a biological or legal connection, family can also be defined as persons having an emotional connection and shared closeness to the patient's dementia experience or "family of choice".

Step 2: Confirm email addresses
In order to pair up your responses, you will each be asked to enter your own and your family member's email address. Please note: This is requested in order to pair up your responses as a family pair when the survey data is analyzed. We will retain your email address only long enough to ensure that gift card compensation has been successfully delivered. Then the email addresses will not be linked with data.

We know that most people have more than one email address. Before you start, please confirm with your family member which email address each of you should enter.

Step 3: Each person takes the survey individually
Each person should take the survey individually, at different times, and not in the presence of one another.

As you begin the survey, if you are the first member of your family pair, please, as described above, enter both your email address and your family member's email address to pair up your responses.

If you are the second member of your family pair to take the survey, you do **<u>not</u>** need to find a NEW family member, please enter your <u>first</u> family member's email (who has already taken the survey) and your own email address. This will allow researchers to pair you up as the second member of the family pair.

If you have any questions at any time, please contact Elizabeth Spencer at liz.spencer@uky.edu or **859-359-2081 (call/text).**

For this study, we are defining "family members" as individuals who may be blood or legal relatives of the person who is/was living with dementia (for example: a spouse, life partner, siblings, adult children, spouses of adult children, adult grandchildren, spouses of adult grandchildren, etc.). However, a family member need not have a biological or legal connection to the patient. In addition to a biological or legal connection, family can also be defined as persons having an emotional connection and shared closeness to the patient's dementia experience or "family of choice".

Although you may not get personal benefit from taking part in this research study, your responses may help us understand more about the nature of family communication and family relational dynamics before and after a dementia diagnosis. Some volunteers experience satisfaction from knowing they have contributed to research that may possibly benefit others in the future.

You will be paid a $10 Amazon gift card for taking part in this study. Each member of the family pair who participates will receive a $10 Amazon gift card.

The survey will take about 30-45 minutes to complete.

Although we have tried to minimize this, some questions could make you upset or feel uncomfortable and you may choose not to answer them. If you choose not to answer some questions, you will still be eligible for the gift card at the end of the survey. If some questions do upset you, we can tell you about some people who may be able to help you with these feelings. Please see the information at the bottom of this page.

Your responses to the survey will be kept confidential to the extent allowed by law. When we write about the study you will not be identified.

Identifiable information such as your email address will only be retained long enough to ensure that gift card compensation has been successfully delivered. Then the email addresses will be removed from the information collected in this study. After removal, your questionnaire responses may be used for future research or shared with other researchers without your additional informed consent.

We hope to receive completed questionnaires from about 240 people (120 pairs), so your answers are important to us. Of course, you have a choice about whether or not to complete the questionnaire, but if you do participate, you are free to skip any questions or discontinue at any time.

Please be aware, while we make every effort to safeguard your data once received from the online survey company, given the nature of online surveys, as with anything involving the Internet, we can never guarantee the confidentiality of the data while still on the survey company's servers, or while en route to either them or us. It is also possible

the raw data collected for research purposes will be used for marketing or reporting purposes by the survey company after the research is concluded, depending on the company's Terms of Service and Privacy policies.

The person in charge of this study is Elizabeth Spencer, a doctoral student in the University of Kentucky's College of Communication and Information. If you have questions, suggestions, or concerns regarding this study; or once you begin, if you want to withdraw from the study, her contact information is: **859-359-2081 (call/text)** or email **liz.spencer@uky.edu**. You may also contact the faculty advisor for this study, Allison Gordon, Ph.D., an Associate Professor in the Department of Communication, at a.gordon@uky.edu. If you have complaints, suggestions, or questions about your rights as a research volunteer, contact the staff in the University of Kentucky Office of Research Integrity at 859-257-9428 or toll-free at 1-866-400-9428.

Thank you in advance for your assistance with this important project.

Elizabeth Spencer
College of Communication and Information
University of Kentucky
PHONE: 859-359-2081
E-MAIL: liz.spencer@uky.edu

If you become distressed while taking this survey, a therapist may be able to help. Please go to psychologytoday.com/us/therapists to locate a therapist in your area.

By clicking the arrow below to continue, you are indicating that the research study has been explained to you, and that any questions and concerns have been addressed. You are also indicated that you are at least 18 years old, you have read and understand this consent form, and you voluntarily agree to participate in this study.

Do you voluntarily agree to participate in the study?

☐ Yes
☐ No

Are you at least 18 years old?
☐ Yes
☐ No

Are you a family member (immediate, extended, or family of choice) of a person who is/was diagnosed with dementia who is/was living in the United States? For this study, we are defining "family members" as individuals who may be blood or legal relatives of the person who is/was living with dementia (for example: a spouse, life partner, siblings, adult children, spouses of adult children, adult grandchildren, spouses of adult grandchildren, etc.). However, a family member need not have a biological or legal connection to the patient. In addition to a biological or legal connection, family can also

be defined as persons having an emotional connection and shared closeness to the patient's dementia experience or "family of choice".

- ☐ Yes
- ☐ No

Please note: Your email address is requested ONLY in order to pair up your responses to your family member's when the survey data is analyzed. When you enter email addresses, they will be transformed into non-identifying numerical codes. Your email addresses will be kept confidential and you will NOT be contacted. Your responses to the survey questions will not be associated with your email address.

We know that most people have more than one email address. Please be sure to confirm with your family member which email address each of you should enter.

If you are the first member of your family pair, please enter both your email address and your family member's (the person who will also be taking a survey) email address to pair up your responses. If you are the second member of your family pair to take the survey, you do not need to find a NEW family member, please enter your own email address and your first family member's email (who has already taken the survey). This will allow researchers to pair you up as the second member of the family pair.

Please enter your email address:

_____

Please enter the email address of your family member who will also be taking a survey (or who already has taken the survey):

_____

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VITA

EDUCATION

M.A.   Pittsburg State University (2015)
Communication
Thesis Project: *Unraveling: A caregiver's journey of discovery*

B.S.   Missouri Southern State University (2014)
Communication, Public Relations emphasis; Mass Communication minor

A.A.   Hawkeye Community College (2003)
Professional Photography

ACADEMIC APPOINTMENTS

2016-2019   Instructor of Record
Department of Communication, University of Kentucky

2016   Instructor
Department of Communication, Pittsburg State University

2016   Instructor
Department of Communication, Missouri Southern State University

2014-2016   Instructor
Department of Communication, Crowder College

2014-2015   Graduate Teaching Assistant
Department of Communication, Pittsburg State University

HONORS AND AWARDS

2019   Dissertation Year Fellowship, College of Communication and
Information, University of Kentucky

2019   Competitively selected for inclusion in the National Communication
Association (NCA) Doctoral Honors Seminar

2018   Emeriti Faculty Doctoral Fellowship, University of Kentucky

2017   Tall Grass Farm Foundation Fellowship, Institute for Rural Journalism and
Community Issues, University of Kentucky

2016	NCA Ethnography Division Best Aural/Visual Project Award
2016	Kansas Association of Broadcasters, graduate TV documentary award
2015	Top Paper Award, Pittsburg State University (PSU) graduate research colloquium
2015	Excellence in Research Award, Department of Communication, PSU
2015	Feature Writing Award, second place, Missouri College Media Association
2014	Photojournalist of the Year, Missouri College Media Association
2014	Pinnacle Award, best multimedia feature story, third place national ranking, College Media Association
2014	Gold Awards, magazine photography and writing and design, MarCom International Competition for Marketing and Communication Professionals
2014	First place award, newswriting; second place editorial writing, Missouri College Media Association
2003	Top Portrait Portfolio Award, Professional Photography department, Hawkeye Community College

ACADEMIC PUBLICATIONS

Refereed Journal Publications

Scott, A. M., Harrington, N. G., & **Spencer, E. A.** (2020). Primary care physicians' strategic pursuit of multiple goals in cost-of-care conversations with patients. *Health Communication.* doi: 10.1080/10410236.2020.1723051

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Mason, A. M., **Spencer, E. A.**, Macek, K., Clarke, E., & Potter, S. (2019). Using the theory of Emotional Stakeholders to experimentally test the influence of proxy communicators about organizational crises in digital news reports. *International Journal of Business and Social Science, 10,* 25-38.

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Spencer, E. A., & Limperos, A. M. (2018). ESPN's coverage of intimate partner violence in the National Football League. *Communication & Sport*. doi:10.1177/2167479518817759

Spencer, E. A. (2017). The use of deception in interpersonal communication with Alzheimer's disease patients. *The Midwest Quarterly, 58,* 176-194.

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Edited Chapters

Mason, A.M., Bhati, S., Jiang, R., & **Spencer, E. A.** (in press). Medical tourism patient mortality: Considerations from a 10-year review of global news media representations. Accepted for publication in M. Merviö (Ed.), *Global issues and innovative solutions in healthcare, culture, and the environment.*

Spencer, E. A. (2019). Narrative legacy of family caregiving. In P. M. Kellett & J. M. Hawkins (Eds.), *Women's narratives of health disruption and illness: Within and across their life stories* (pp. 201-213). Lanham, MD: Lexington Books.

Mason, A. M., & **Spencer, E. A.** (2016). Health communication: Insights for quality H2H delivery in medical tourism. In DeMicco, F. J. (Ed.), *Medical tourism: Hospitality bridging healthcare (H2H) and wellness* (pp. 127-146). Waretown, NJ: Apple Academic Press.

Manuscripts Under Review

Harrington, N. G., Scott, A. M., & **Spencer, E. A.** (2019). Working toward evidence-based guidelines for cost-of-care conversations between patients and physicians: A systematic review of the literature. Manuscript submitted for publication (revise and resubmit, under second review).

Elizabeth A. Spencer

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