Interpersonal Communication in the Context of Dementia: Examining Family Caregivers' Appraisals and Burden

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INTERPERSONAL COMMUNICATION IN THE CONTEXT OF DEMENTIA: EXAMINING FAMILY CAREGIVERS' APPRAISALS AND BURDEN

by

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ABSTRACT
INTERPERSONAL COMMUNICATION IN THE CONTEXT OF DEMENTIA: EXAMINING FAMILY CAREGIVERS' APPRAISALS AND BURDEN

Stacy L. Barnes, B.A., M.G.S.

Marquette University, 2014

Purpose and Objectives: The purpose of this study was to explore dementia family caregivers' appraisals of communication behaviors and strategies, and their relationships to caregiver burden. Study objectives were to investigate: 1) the relationship between frequency of dementia-related communication behaviors and caregivers' appraisals of frustration; 2) the relationship between caregivers' use of communication strategies and appraisals of helpfulness; 3) the structural relationships between communication behavior appraisal, communication strategy appraisal, problem behaviors, and caregiver burden; and 4) caregiver education level as a moderating variable of the final structural model.

Methods: A written, mailed questionnaire was developed to capture dementia family caregivers' perceptions of communication behaviors, communication strategies, problem behaviors, and caregiver burden ($N = 239$).

Results: Frequency and appraised frustration of the relatives' communication behaviors were significantly correlated ($r_s = 0.631$, $p < 0.001$). Pairwise comparisons of frequency and appraisal revealed significant differences for 18 of 32 communication behaviors. The two behaviors rated highest for both frequency and frustration were: failure to retain instructions and repeated questions/comments. Frequency of use and appraised helpfulness of the caregivers' communication strategies were also significantly correlated ($r_s = 0.631$, $p < 0.001$). Pairwise comparison of use and appraisal revealed strategy use was significantly greater than appraised helpfulness for 18 of 19 strategies. The two strategies rated highest for both use and helpfulness were: pay attention/actively listen and ask one question/give one instruction at a time. Results of structural equation modeling indicated that problem behaviors partially mediated the relationship between communication behavior appraisal and caregiver burden ($z = 2.98$, $SE = 0.065$, $p < 0.003$). Caregivers' education level did not moderate the mediated relationship. Caregivers' appraisals of communication strategies did not predict problem behaviors or caregiver burden.

Conclusions: Findings underscore the importance of understanding communication in the context of dementia family caregiving and dementia family caregivers' perceptions of it. This study expands upon previous empirical investigations of the relationships between communication, problem behaviors, and caregiver burden.

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TABLE OF CONTENTS

CHAPTERS

LIST OF TABLES

LIST OF FIGURES

Dementia is a general term referring to a group of symptoms associated with impaired memory and other cognitive deficits severe enough to interfere with a person's ability to perform everyday activities. These deficits denote significant deviations from a person’s previous level of performance in one or more of the following cognitive domains: complex attention, executive function, learning and memory, language, perceptual-motor, and social cognition (American Psychiatric Association, 2013). In May 2013, the American Psychiatric Association released the Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-5) and in doing so redefined dementia under the broad diagnostic category of major neurocognitive disorders (American Psychiatric Association, 2013). Differentiation between normal neurocognitive functioning, mild neurocognitive disorder (formerly referred to as mild cognitive impairment), and major neurocognitive disorder (formerly referred to as dementia) is now possible given the large and growing body of research detailing the neuropathology underlying dementing illnesses (Blazer, 2013; Fagan et al., 2006; Ganguli et al., 2011; Klunk et al., 2004; Petersen, 2011; Shaw et al., 2009).

Dementia is caused by any number of diseases and conditions. Some dementia-like symptoms have potentially reversible causes including delirium, depression, medication side effects, thyroid problems, vitamin deficiencies and substance abuse (Alzheimer's Association, 2013a; National Institutes of Health, 2013). In contrast, neurodegenerative disorders such as Alzheimer’s disease, frontotemporal disorders, vascular diseases, Parkinson’s disease, Huntington’s disease, and Creutzfeldt-Jakob disease also cause dementia, but these dementing illnesses cannot currently be reversed or cured (National Institutes of Health, 2013). The most common type of degenerative dementia in persons age 65 and older is Alzheimer’s disease, accounting for 60-80% of all dementia cases (Alzheimer's Association, 2013a). Despite its new clinical definition, the term dementia is still commonly used today (Ganguli et al., 2011) and it will be used throughout the current study in reference to all non-reversible neurocognitive disorders.

Dementia is a long-term degenerative condition that develops slowly over the course of many years. Health care professionals and researchers commonly refer to disease progression in terms of five overlapping clinical stages: 1) preclinical stage, in which no symptoms are apparent; 2) mild cognitive impairment, in which forgetfulness occurs and the person become self-aware of occasional, mild cognitive problems; 3) early-stage dementia, in which memory and cognitive problems become evident to family members, health care professionals, and others; 4) mid-stage dementia, in which major cognitive problems interfere with the person’s ability to perform daily activities and self-care; and 5) late-stage dementia, in which the person loses physical abilities, psychomotor skills, and speech (Albert et al., 2011; Hughes, Berg, Danziger, Coben, & Martin, 1982; Jack et al., 2011; McKhann et al., 2011; Reisberg, Ferris, de Leon, & Crook, 1982; Reisberg, 1988; Sperling et al., 2011). The rate of progression through these stages varies greatly and the symptoms exhibited in each stage differ by the type of dementia. Estimates of median survival following the onset of dementia symptoms range from three to eleven years, with younger age at onset and the female sex being consistently associated with longer life expectancy (Fitzpatrick, Kuller, Lopez, Kawas, & Jagust, 2005; Helzner et al., 2008; Rountree, Chan, Pavlik, Darby, & Doody, 2012; Xie, Brayne, & Matthews, 2008).

Current evidence indicates the prevalence and incidence of dementia has reached epidemic proportions. It has been estimated that 44.35 million people worldwide were living with some type of dementia in 2013 and this number is projected to increase, reaching 135.46 million by 2050 (Alzheimer's Disease International, 2013). In the United States alone, 13.9% of people age 71 and older in the United States are estimated to have dementia (Plassman et al., 2007). Even though dementia can occur in younger adults, the greatest risk factor is advanced age (Alzheimer's Association, 2013a; Prince et al., 2012). After the age of 65, the incidence of dementia doubles with every five-year increase in age (Jorm & Jolley, 1998), reaching an incidence rate of 40.7% per year in the 100+ age group (Corrada, Brookmeyer, Paganini-Hill, Berlau, & Kawas, 2010).

Family members provide the vast majority of care to persons with dementia who are living in the community (Institute of Medicine, 2008). Also referred to as informal caregivers, these individuals are the immediate family members (i.e., spouses, adult children) and other relatives who provide ongoing unpaid assistance with instrumental activities of daily living (e.g., transportation, shopping, bill paying) and activities of daily living (e.g., toileting, feeding, bathing). Sex and geographic proximity to the care recipient are two factors that strongly influence the choice of caregiver within a family. Persons living closest to the care recipient and women – most often wives, daughters, and daughters-in-law – typically assume the role of primary caregiver (Agency for Healthcare Research and Quality, 2001; Campbell & Martin-Matthews, 2003; Garner, 1999; Montgomery, 2007; National Alliance for Caregiving & AARP, 2009; National Alliance for Caregiving, 2010; M. Ory, Yee, Tennstedt, & Schulz, 2002). Findings from the 2010 Behavioral Risk Factor Surveillance System survey (Bouldin & Andresen, 2010) indicated that 62 percent of caregivers of people with dementia were women; 23 percent were 65 years of age and older; 50 percent had some college education or beyond; 59 percent were currently employed, a student, or homemaker; and 70 percent were married or in a long-term relationship. In 2012, it was estimated that more than 15 million informal caregivers provided 17.5 billion hours of unpaid care to persons living with dementia, valued at more than $216 billion (Alzheimer's Association, 2013a).

Family caregiving is a complex role capable of generating an array of different experiences for different types of caregivers (Kahana, Biegel, & Wykle, 1994; Montgomery, 2007). The consequences of caregiving vary widely, ranging from negative effects of stress, burden, depression, and strain to positive effects such as mastery, satisfaction, companionship, and personal fulfillment (Beach, Schulz, Yee, & Jackson, 2000; C. A. Cohen, Colantonio, & Vernich, 2002; Murray, Schneider, Banerjee, & Mann, 1999; Schulz, Visintainer, & Williamson, 1990; Wright, Clipp, & George, 1993). Many studies have explored the consequences of caregiving, hoping to explain why some family caregivers suffer profound adverse effects, while others are able to cope and mitigate any negative impact, and still others flourish in the role and experience positive effects (for reviews see: Barer & Johnson, 1990; Dunkin & Anderson-Hanley, 1998; Pinquart & Sorensen, 2003; Vitaliano, Zhang, & Scanlan, 2003; Yin, Zhou, & Bashford, 2002).

The vast majority of caregiving research documents negative consequences for family caregivers. The construct of caregiver burden has been used by researchers to describe the overall impact of the physical, psychological, social, and financial demands of caregiving (George & Gwyther, 1986). Greater levels of caregiver burden have been consistently shown leading to negative outcomes for both the caregiver and care recipient (Aneshensel, Botticello, & Yamamoto-Mitani, 2004; Beach et al., 2000; Cooney, Howard, & Lawlor, 2006; Damjanovic et al., 2007; Gainey & Payne, 2006; Gaugler, Kane, Kane, Clay, & Newcomer, 2003; Gaugler, Kane, Kane, Clay, & Newcomer, 2005; M. G. Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999; Schulz, O'Brien, Bookwala, & Fleissner, 1995; Schulz & Beach, 1999; Young & Newman, 2003). U.S. businesses also suffer the costs of caregiver burden in the form of lost productivity. Costs associated with absenteeism, workday interruptions, reduction in hours, and replacing employees was estimated to be as much as $33.6 billion in 2004 (AARP Public Policy Institute, 2007).

Family caregivers who provide care to a person with dementia report even greater levels of burden, depression, and stress than do caregivers to adults with other conditions (Bedard, Pedlar, Martin, Malott, & Stones, 2000; Bertrand, Fredman, & Saczynski, 2006; M. G. Ory et al., 1999; Pinquart & Sorensen, 2003). Studies have consistently shown that dementia caregivers, in comparison to non-dementia caregivers, provide more intensive and extensive care, experience greater stress and strain, and are more likely to indicate that caregiving had negatively impacted their own personal health and finances (MetLife Mature Market Institute, 2006; Baillie, Norbeck, & Barnes, 1988; Deimling & Bass, 1986; Moritz, Kasl, & Berkman, 1989; Bertrand, Fredman, & Saczynski, 2006; Bass, Tausig, & Noelker, 1989; Pinquart & Sorensen, 2003; Schulz, O’Brien, Bookwala, Fleissner, 1995). Because of the toll dementia has on families, informal caregivers are often referred to as the “hidden victims” of the disease (Zarit, Orr, & Zarit, 1985).

Of the many challenges faced by dementia family caregivers, the loss of meaningful communication with their loved one is reported to be one of the aspects caregivers find most difficult with which to cope (Murray et al., 1999; Richter, Roberto, & Bottenberg, 1995). A cross-national study of dementia caregivers revealed that "more caregivers were distressed by the loss of understanding and conversation than by having to take on responsibility for their partners' basic activities of daily living" such as feeding, toileting, and bathing (Murray et al., 1999). Persons with dementia commonly exhibit communication deficits related to word finding, naming, discourse management, comprehension, and verbalization, with overall communication becoming increasing difficult as the disease progresses (Macoir & Turgeon, 2006). Communication breakdowns between the caregiver and care recipient become commonplace, affecting task completion, everyday casual conversations, and family relationships (Purves & Phinney, 2012/2013). Family members with long-standing interaction patterns and habits often find their default communication style inadequate and are forced to develop new skills and strategies aimed at accommodating the person's declining abilities (Bourgeois, 2002; Murray et al., 1999). Maintaining meaningful and effective communication throughout the disease trajectory and up until the person's death is an unanticipated daily challenge faced by all dementia family caregivers. In a recent survey of 112 dementia caregivers, strategies for effective caregiver-to-patient communication were the most frequently expressed need of respondents – above and beyond all other medical, psychological, and educational types of support investigated in the study (Rosa et al., 2010).

In contrast to the abundance of research describing how dementia impairs a person's communication abilities, relatively little attention has been directed to family members' appraisals of the communication challenges they face. Few studies have employed family caregivers as sources of information on dementia-related communicative changes even though they are in a unique position to observe older adults with dementia over time. There is little empirical research investigating family caregivers' appraisals of their relative's communication problems or their appraisals of the interpersonal communication strategies they routinely use to facilitate interactions. Much of the existing evidence comes from clinicians' practical experience (e.g., Bourgeois, 2002; Clark, 1995; Mace & Rabins, 1981; Rau, 1993), qualitative studies using small samples (e.g., Brewer, 2005; Müller & Guendouzi, 2005; Purves & Phinney, 2012/2013; Richter et al., 1995) or experimental research which may not be representative of family communication generated in natural contexts (e.g., Bourgeois, Burgio, Schulz, Beach, & Palmer, 1997; Gentry & Fisher, 2007; Small, Kemper, & Lyons, 1997; Tomoeda, Bayles, Boone, Kaszniak, & Slauson, 1990). It is also uncertain whether caregivers' appraisals of communication problems and strategies have any effect on the outcome of caregiver burden.

This study is at the crossroads of five disciplines, building upon previous work in the fields of communication, psychology, nursing, speech-language pathology, and gerontology. The purpose of the study is to examine family caregivers' appraisals of communication within the context of dementia care. The first part of the study investigates the relationship between occurrence frequency of dementia-related communication behaviors and caregivers' appraisals of frustration. In the second part, the relationship between caregivers’ usage of communication strategies and their appraisals of helpfulness is explored. The third part of the study uses structural equation modeling to investigate the relationships between communication behavior appraisal, communication strategy appraisal, problem behaviors, and caregiver burden. In the fourth and final part of the study, caregivers’ education level is tested as a moderating variable of the final structural model.

Literature Review

Dementia and Communication

Over the past several decades, neurologists, clinical psychologists, and speech pathologists, in particular, have advanced significantly our understanding of how dementia impacts a person's ability to communicate. In general, the neurodegenerative diseases that cause dementia extensively damage the areas of the brain responsible for cognition, memory, and language, thereby impairing a person's ability to communicate (Appell, Kertesz, & Fishman, 1982; Hier, Hagenlocker, & Shindler, 1985; National Institute on Aging, 2008, September; Weiner & Lipton, 2009; Weintraub, Wicklund, & Salmon, 2012). Changes in communication abilities vary by the type and stage of the underlying disease(s) (Bourgeois & Hickey, 2009; Cummings, Darkins, Mendez, Hill, & Benson, 1988; Moorhouse, 2005; Shinagawa, Ikeda, Fukuhara, & Tanabe, 2006; Weiner & Lipton, 2009), but communication impairment to some degree is present in all forms of dementia as the disease progresses (Bourgeois & Hickey, 2009). Dementia-related communication impairments commonly manifest as cognitive deficits in memory, executive function, attention, concentration, perception, and visuospatial functions, as well as linguistic deficits in phonology, semantics, pragmatics, discourse, writing, and comprehension (Bayles & Kaszniak, 1987; Bayles & Tomoeda, 2007; Bourgeois, 2002; Bourgeois & Hickey, 2009; Kempler, 1995; Obler, DeSanti, & Goldberger, 1995; Powell, Hale, & Bayer, 1995; Ulatowska et al., 1988; Ulatowska & Chapman, 1995).

The slow degenerative course of dementing illnesses results in an ever-changing presentation of communicative symptoms to which the family caregiver must adapt. Initially, persons with dementia can communicate sufficiently, even though they commonly exhibit anomia (difficulty finding words), empty speech, paraphasia (using the wrong word), difficulty with divided attention, and/or difficulty comprehending abstract language or complex conversation (Bourgeois, 2002; Bourgeois & Hickey, 2009; Kemper, 2001; Macoir & Turgeon, 2006; Moorhouse, 2005; Rau, 1993; Shinagawa et al., 2006). As the disease progresses, impairments in semantics, pragmatics, memory, attention, language and comprehension become more pronounced. Empty vocabulary, overuse of pronouns, and less comprehensible circumlocutions increase in frequency (Appell et al., 1982; Dijkstra, Bourgeois, Allen, & Burgio, 2004). Persons with middle-stage dementia often have difficulty holding conversations, as sensitivity towards the listener's needs decreases and verbosity increases (Ripich & Terrell, 1988). Problems with topic maintenance, digression, and tangentiality are more common (Brewer, 2005; Mentis, Briggs-Whittaker, & Gramigna, 1995), but basic turn-taking patterns are often preserved (Ulatowska & Chapman, 1995). Language impairments in the middle stages of dementia have been associated significantly with reduced participation in social activities and increased social withdrawal (Hart & Wells, 1997; Potkins et al., 2003). In the late stages of dementing illnesses, the person may experience loss of language (i.e., incoherent babbling or muteness), severely limited auditory comprehension, repetitive vocal and physical behaviors, and/or increased delusions or hallucinations (Bayles & Tomoeda, 2007; Bourgeois, 2002; Minati, Edginton, Bruzzone, & Giaccone, 2009; Moorhouse, 2005; Potkins et al., 2003; Rau, 1993).

Given the many communication impairments that occur throughout the disease trajectory, it is not surprising that communication breakdowns frequently occur between the caregiver and care recipient. In addition to the care recipient's impaired expressive and receptive linguistic abilities, other factors potentially contribute to communication breakdowns, such as family caregivers' lack of knowledge regarding dementia-related communicative changes. The extent to which family caregivers are knowledgeable about common dementia-related language impairments prior to presentation of symptoms is unclear, as most studies focus on the caregivers' knowledge of the underlying disease rather than on the caregivers' knowledge of, or expectations for, dementia-related communicative declines (e.g., Ayalon & Arean, 2004; Dieckmann, Zarit, Zarit, & Gatz, 1988). A notable exception is the small study conducted by Williams (2011), in which the author tested 16 spousal dementia caregivers about their knowledge of communication declines related to Alzheimer's disease. Results revealed that subjects had limited knowledge of dementia-related communication changes, suggesting that dementia family caregivers may be unprepared for this particular caregiving challenge.

Not understanding the communication problems associated with dementia, family caregivers may have unrealistic communicative expectations based upon long-standing family communication patterns or may inadvertently adopt negative communication patterns with their family member (Müller & Guendouzi, 2005; Savundranayagam & Orange, 2014). Müller and Guendouzi (2005) conducted a qualitative analysis of conversations involving nursing home residents with dementia of the Alzheimer's type and examined the concept of order (i.e., perception of mutual understanding) within conversations. The authors concluded that dementia-related communication breakdowns emerge from the interplay of several factors including: the basic human need for social interaction; the care recipient's underlying neuropathology which severely disrupts the ability to meet this need; and, the assumption or expectation on the part of both interlocutors that order is achievable within the conversation. Together these factors create a frustrating tension in which both interlocutors experience increased difficulties monitoring the conversational dynamic. Both the caregiver and the relative with dementia continuously search for indicators of order, as defined by their own unique perspective.

Communication breakdowns have been consistently shown to trigger behavioral problems in the person with dementia such as agitation, aggression, swearing, or wandering (Bourgeois, 2002; Hart & Wells, 1997; Potkins et al., 2003; Rau, 1993; Ripich, 1994; Savundranayagam, Hummert, & Montgomery, 2005; Schneider, Murray, Banerjee, & Mann, 1999; Talerico, Evans, & Strumpf, 2002). Cohen-Mansfield (2000) developed a useful taxonomy of problem behaviors in dementia, classifying behaviors along two axes: a vertical axis of verbal/physical behaviors, and the horizontal axis of nonaggressive/aggressive behaviors. Examples of verbally nonaggressive problem behaviors include complaining, negativism, repetitive sentences or questions, and constant unwarranted requests for attention or help. Problem behaviors that are considered to be verbally aggressive include cursing, making strange noises, making verbal sexual advances, and screaming. Both family caregivers and professional caregivers report that problem behaviors not only become more prevalent with disease progression, but also are more difficult to manage given the person’s loss of verbal communication skills (Richter et al., 1995).

One school of thought is that problem behaviors are a direct result of impairments to the care recipient’s expressive and receptive language abilities (Algase, Beck, & Kolanowski, 1996; Beck et al., 1998; Bourgeois, 2002; Cohen-Mansfield, 2000; Hart &

Wells, 1997; Potkins et al., 2003; Rau, 1993). The care recipient's inability to verbally communicate his/her unmet needs may trigger problem behaviors, which in turn serve as a means of communication for the person with dementia. Bourgeois (2002) describes some examples:

> [W]hen a person cannot remember the words to tell a caregiver he or she wants something to do, that person may begin to vocalize disruptively or hit his or her hand repetitively on the nearest surface. When they need to be physically active, but cannot remember how to do that or express that need, they may exhibit physically agitated behavior such as pacing or exit seeking. (p. 137)

This relationship between dementia-related communication impairments and behavioral problems is captured in the Need-Driven Compromised Behavior Model (Algase et al., 1996; Beck et al., 1998). According to the model, persons with dementia have a range of personal, social, physical, emotional and environmental needs; behavioral problems result from the person being unable to communicate effectively these need(s). In other words, the person's maladaptive behaviors and disruptive vocalizations are communicative attempts, albeit unsuccessful ones.

Müller and Guendouzi (2005) remind us, however, that interpersonal communication is fundamentally collaborative and communication breakdowns do not stem solely from the care recipient's underlying brain pathology. Family caregivers may unknowingly trigger problem behaviors by misinterpreting the person's communicative intent (Bourgeois, 2002). Caregivers' misinterpretations may be more common in the early stages where the person's verbal fluency, semantics, and pragmatics are generally intact (Bourgeois, 2002) or in the late stages when language is severely limited and behavioral problems are more frequent (Bourgeois & Hickey, 2009). Caregivers' verbalizations may also trigger problem behaviors in the care recipient, underscoring the dynamic and interactive nature of interpersonal communication (R. B. Adler, Rosenfeld, & Proctor, 2013). Hart and Wells (1997) demonstrated through an experimental study that caregivers' use of language complexity at a level that is beyond a person's comprehension abilities can trigger greater levels of agitation. Vitaliano and colleagues (Vitaliano, Young, Russo, Romano, & Magana-Amoto, 1993) studied spousal caregiving dyads and found negatively expressed emotions (i.e., expressions of criticism and anger) from dementia caregivers to be significantly correlated with higher incidence of problem behaviors in the care recipient.

Once communication impairments begin to manifest, family caregivers are clearly aware of the nature and frequency of the problems (Orange, 1991; Powell et al., 1995). Rabins, Mace, and Lucas (1982) interviewed 55 family caregivers and found that nearly 70 percent reported communication disorders in their relative with dementia and almost 75 percent reported that the communication difficulties were a caregiving problem. Orange (1991) interviewed dementia family caregivers and non-dementia family caregivers and reported that all family members were able to detect and describe in detail the linguistic and communicative abilities and deficits of their relative. Dementia family members first observed communication problems in the semantic domain, but they also were aware of subtle declines in discourse, pragmatics, and comprehension as the disease progressed. Powell and colleagues (Powell et al., 1995) surveyed 79 dementia family caregivers and 76 non-dementia family caregivers about the presence/absence of 32 communication symptoms. All 32 communication symptoms occurred significantly more often in relatives with dementia, compared to relatives without dementia. More than half of the respondents reported eleven of the 32 communication impairments occurred fairly often, usually, or frequently.

In addition to the practical issue of impeding caregiving activities, dementia-related communication problems also change the very nature of the relationship between family members (Santulli, 2011). Relationships are ever-changing and dynamic, and communication is the means by which they are initiated, defined, maintained, and terminated (Dindia, 2003; VanderVoort & Duck, 2000). All families rely on discourse to some extent to construct their individual and familial identities (Stamp, 2004). As the dementing illness progresses and the person's communication abilities become increasingly impaired, family roles and relationships change (Purves & Phinney, 2012/2013). Expectations for social support and reciprocity, based upon established relational communication patterns, also change and so too may the caregiver's identity as he/she oscillates between the familial role (e.g., wife, daughter) and the caregiver role (Montgomery & Kosloski, 2013).

Purves and Phinney (2012/2013) recently conducted semi-structured interviews with two families, each of which included a relative with dementia. The authors took a family systems approach and explored how communicative changes impacted family roles and relationships. All individual members of both families described an interweaving of conversation and relationship, with each family member describing the development of their own unique relationship to the relative with dementia. The frequency and nature of conversations varied by each individual family member's perspective, yet feelings of loss were expressed by everyone, stemming from both communication breakdowns and changes to familiar, well-established patterns of talk. These findings are similar to other studies that used a family systems approach to describe family conversations in the context of dementia (Brewer, 2005). It is interesting to note that while communication was the primary issue of concern for one of the families in Purves and Phinney's study (2012/2013), the other family was primarily concerned with changes in roles and responsibilities which had to be realigned to accommodate the relative's declining abilities.

Previous research has reported that caregivers perceive communication problems as having a direct and negative impact on their relationship with the relative who has dementia (Clark & Witte, 1991; Orange, 1991; Orange, Lubinski, & Higginbotham, 1996; Orange, Van Gennep, Miller, & Johnson, 1998; Richter et al., 1995; Small, Geldart, & Gutman, 2000). Murray et al. (1999) conducted interviews with 280 spousal dementia caregivers from 14 different countries and found the most commonly expressed caregiving difficulty concerned communication; namely, "the loss of companionship through diminished quality of communication; loss of reciprocity as carers experienced their partners' growing dependency; and deterioration in their partners' social behavior" (p. 662). In fact, more family caregivers reported being distressed by the loss of understanding and conversation (24%) than by handling their partners' personal care needs (13%). Dindia (2003) captured the heart of the problem when she stated, "the quality of a relationship is primarily determined by the quality of the communication in the relationship. Thus, to maintain the quality of a relationship, one must maintain the quality of the communication" (p. 1). In the context of dementia and caregiving, quality communication that is mutually meaningful and satisfying is often not possible, particularly as the disease progresses.

Family caregivers' appraisals of communication problems offer researchers important insights as family members have in-depth knowledge of the person's communicative abilities prior to the onset of disease and are in a unique position of experiencing first-hand the communication challenges they face in the natural context of daily life (Orange, 1991). The perspective of family members will be – by its very nature – qualitatively different from that of a researcher or a health care professional.

Many dementia family caregivers describe communication with their relative as stressful (Clark & Witte, 1991; Purves & Phinney, 2012/2013; Rabins et al., 1982; Ward-Griffin, Oudshoorn, Clark, & Bol, 2007). Feelings of anger, depression, fatigue, fear, frustration, guilt, and embarrassment are commonly reported (Mace & Rabins, 1981; Orange, 1991; Rabins et al., 1982). Communication impairments are often reported to evoke feelings of loneliness and social isolation, particularly with spousal family caregivers who mourn the loss of conversation and the decline in the quality of their relationship. As one dementia caregiver described it:

> I feel lonely sometimes because it's not the same. There is nothing coming back in the way of conversation… but it's the talking I miss. I miss the conversation. I miss discussing the why's and wherefore's and trying to figure out why those people did that or what's going to happen down here. I miss that a whole lot. (Orange, 1991, p.184)

Family Caregivers' Communication Strategies

Given the communication impairments that stem from dementing illnesses, a significant challenge faced by family caregivers is how to accommodate the person's declining abilities and foster meaningful communication each day. The communication accommodation theory (Giles, 1973; Giles & Powesland, 1975; Giles & Smith, 1979; Giles, 1980) is useful in understanding family caregivers' adjustments in communication. Evolving from the Speech Accommodation Theory, the theory posits that speakers modify their speech, gestures, vocabulary, etc. to accommodate others (R. West & Turner, 2013). A person may use convergence to more closely resemble the communication patterns of the other interlocutor and/or divergence to accentuate differences between him/herself and the other person. Converging and diverging accommodations can be perceived as either good or bad, and can be beneficial or detrimental to interpersonal communication (R. West & Turner, 2013). Although convergent speech patterns used with older adults who have dementia are often intended to be a beneficial accommodation to the person's cognitive and memory impairments, it often results in under-accommodations (e.g., avoiding social interactions with the person) and over-accommodations (e.g., using simplified vocabulary, slower speech rate) based upon stereotypes of older adults and persons with dementia (J. Coupland, Coupland, Giles, & Henwood, 1991; N. Coupland, Coupland, Giles, & Henwood, 1988; Ryan, MacLean, & Orange, 1994).

Kemper (1994) coined the term "elderspeak" to describe over-accommodations in speaking with older adults, characterized by simplified grammar and vocabulary, use of diminutives (e.g., sweetie, dearie), increased volume, slower speech rate, and exaggerated pitch or intonation. Elderspeak qualities have been shown to have both negative and positive effects on interpersonal communication (Kemper & Harden, 1999). Most of the research to date has demonstrated that elderspeak negatively impacts the older person and reduces communication success, with older adults typically perceiving this style as insulting and patronizing (Balsis & Carpenter, 2005; Kemper & Harden, 1999; O'Connor & Rigby, 1996; O'Connor & St. Pierre, 2004; Ryan, Hamilton, & See, 1994; Ryan et al., 1994; Whitbourne, Culgin, & Cassidy, 1995; K. N. Williams, Herman, Gajewski, & Wilson, 2009). However, other studies have demonstrated that elderspeak may be perceived positively, conveying affection and warmth, particularly when used by family members and others in close relationships (Hummert, Shaner, Garska, & Henry, 1998; O'Connor & Rigby, 1996; O'Connor & St. Pierre, 2004; Sachweh, 1998). Because elderspeak has both negative and positive qualities in the family care context, it is important that any communication strategies recommended to family caregivers be evaluated not only in terms of effectiveness in improving communication success but also in terms of caregivers' and care recipients' appraisals.

Communication strategies, broadly defined as any communicative modifications made by the caregiver intended to accommodate the communicative deficits of the relative with dementia, is the construct commonly referred to by health care professionals, researchers, and family caregivers alike (Savundranayagam, Ryan, Anas, & Orange, 2007; Savundranayagam & Orange, 2011; Small & Gutman, 2002; Vasse, Vernooij-Dassen, Spijker, Rikkert, & Koopmans, 2010; Watson, Aizawa, Savundranayagam, & Orange, 2012/2013; Wilson, Rochon, Mihailidis, & Leonard, 2012; Wilson, Rochon, Leonard, & Mihailidis, 2012; Wilson, Rochon, Mihailidis, & Leonard, 2013). When conversational disturbances arise, some dementia family caregivers are able to naturally and spontaneously repair the communication breakdown and achieve a successful resolution simply by using simple repair strategies of repeating, modifying, or ignoring information from the previous utterance (Orange et al., 1998). Other dementia family caregivers, however, seek suggestions of practical communication strategies to minimize the frequency of communication breakdowns and repair conversation when breakdowns do occur. Rosa and colleagues (2010) recently surveyed dementia family caregivers about their educational and social support needs and discovered the most frequently requested type of assistance was for strategies to facilitate effective caregiver-patient communication.

Health care professionals have responded to family caregivers' needs by offering them a variety of communication strategies (Bourgeois, 2002; Clark & Witte, 1991; Mace & Rabins, 1981; Rau, 1993) and by designing interventions to address care recipients' communication deficits (for reviews of interventions see Egan, Berube, Racine, Leonard, & Rochon, 2010; Vasse, Vernooij-Dassen, Spijker, Rikkert, & Koopmans, 2010). The Alzheimer's Association (Alzheimer's Association, 2011; Alzheimer's Association, 2013b) and other consumer-directed organizations such as WebMD (2014) also have produced guides for family caregivers which list strategies for facilitating interpersonal communication with a person who has dementia.

Small and Gutman (2002) reviewed consumer-directed publications of national associations and books targeted to dementia family caregivers. They identified the following ten communication strategies as those appearing most frequently in the consumer literature:

- use short simple sentences;
- speak slowly;
- ask one question or give one instruction at a time;
- establish & maintain eye contact;
- eliminate environmental distractions;
- avoid interrupting and allow time to respond;
- encourage circumlocution;
- use yes/no rather than open-ended questions;
- use verbatim repetition; and
- use paraphrased repetition.

The authors then surveyed 20 dementia family caregivers about the use and perceived efficacy of these ten strategies and discovered there was a significant effect of strategy type on reported use, but not on appraised efficacy. In other words, dementia family caregivers used some communication strategies significantly more often than others, but they did not perceive any of the strategies as being significantly more effective than others.

Even though many researchers continue to reference and use the ten communication strategies Small and Gutman (2002) identified in the consumer literature, empirical support for the strategies is currently lacking (Small, Gutman, Makela, & Hillhouse, 2003). Much of the evidence base for communication strategies comes from clinicians' experience working with dementia patients (Bourgeois, 2002; Clark & Witte, 1991; Clark, 1995; Mace & Rabins, 1981; Orange, 2001; Rau, 1993; Santulli, 2011) as well as case studies and other small qualitative studies (Brewer, 2005; Murray et al., 1999; Müller & Guendouzi, 2005; Purves & Phinney, 2012/2013; Richter et al., 1995). Conversation analysis, or discourse research, has also enriched the understanding of caregivers' use and appraisal of communication strategies (Gentry & Fisher, 2007; Purves & Phinney, 2012/2013; Small & Perry, 2005; Small, Perry, & Lewis, 2005; Small, Huxtable, & Walsh, 2009).

Communication strategies identified and/or recommended in these publications have had mixed results when tested in experimental research and in other quantitative studies with larger samples. For example, reducing one's speech rate is a commonly recommended strategy (e.g., Alzheimer's Association, 2013b; Santulli, 2011), intended to help reduce the care recipient's cognitive burden and compensate for his/her slower processing speed. Yet results from Kemper and Harden's (1999) study indicate older adults neither prefer, nor more easily comprehend, slower speech. Studies investigating speech rate modification have found persons with dementia show no improvements in comprehension with slower or faster than normal rates of speech (Pashek & DiVenere, 2006; Small et al., 1997; Tomoeda et al., 1990). Small, Andersen, and Kempler (1997) hypothesized the effect of speech rate on comprehension is determined by the extent of working memory capacity. The authors studied three Alzheimer's patients at varying stages and reported that slow speech rate was beneficial only for the one subject with early stage Alzheimer's disease who had the most preserved working memory. No benefit of a slower speech rate was observed in the moderately impaired subject, and a detrimental effect was observed for the subject who had late stage Alzheimer's disease and the most severely impaired working memory. This detrimental effect – observed as an increase in communication breakdowns following caregivers' use of slower than normal speech – has also been found in other studies (Small et al., 2003).

Another strategy frequently recommended to family caregivers is to avoid asking open-ended questions and instead use close-ended questions that require a yes/no or limited choice response from the relative with dementia (e.g., Alzheimer's Association, 2013b; Santulli, 2011). Again, support for this strategy is mixed. Most studies investigating question type have found the use of close-ended questions to elicit more appropriate responses from care recipients, while open-ended questions result in more communication breakdowns (Hamilton, 1994; Ripich, Ziol, Fritsch, & Durand, 1999; Small et al., 2003; Small & Perry, 2005). Some clinicians have taken this a step further and recommended that caregivers avoid yes/no questions altogether and instead use limited-choice questions like "Do you want a hamburger or pizza for dinner?" (Bourgeois, 2002). Tappen and colleagues (Tappen, Williams-Burgess, Edelstein, Touhy, & Fishman, 1997) investigated the effectiveness of open-ended, close-ended (i.e., requiring a yes/no or a one-word response) and mixed questions (i.e., using both open- and close-ended questions with no opportunity for a response in-between). They found no significant difference in the length or relevance of responses from persons with moderate and severe Alzheimer's disease based upon the type of question asked of them. Moreover, the authors found that care recipients were able to make positive, relevant, and meaningful responses to all types of questions. Based upon the authors' narrative analysis of recorded conversations, they suggest that different types of questions be used to elicit different types of information. Close-ended questions may be better suited to facilitate focused communication around task completion, while open-ended questions are preferred when discussing feelings and concerns. Support for this distinction comes from the findings of Tappen and colleagues (Tappen et al., 1997) who found that yes/no questions were more useful than open-ended questions in communication around planning a meal. However, Small and Perry (2005) contend it is not the type of question that leads to communication breakdowns, but rather the type of memory demands associated with the question type. Findings from their discourse analysis support this idea; questions requiring semantic memory (i.e., factual information, general knowledge) were found to be much more successful than questions requiring episodic memory (i.e., autobiographical information specific to time and place). When open-ended and yes/no questions were compared by type of memory demands, findings revealed that yes/no episodic questions actually resulted in *more* communication breakdowns than open-ended semantic questions.

Using simpler sentences is another commonly recommended strategy (e.g., Alzheimer's Association, 2013b; Santulli, 2011). Several researchers have found that reducing sentence complexity improves comprehension in persons with dementia (Hart & Wells, 1997; Kemper, Anagnopoulos, Lyons, & Heberlein, 1994; Small et al., 1997; Tomoeda et al., 1990). Reduction of semantic and syntax complexity has been demonstrated to aide persons with dementia in picture description tasks (Kemper et al., 1994). While a reduction in the number of clauses or propositions per sentence has also been shown to be effective in improving comprehension for people with dementia (Kemper et al., 1994; Kemper & Harden, 1999; Rochon, Waters, & Caplan, 1994), studies have also shown that a reduction in the number of words per sentence is an ineffective strategy which results in more communication breakdowns (Kemper & Harden, 1999; Rochon et al., 1994).

A few communication strategies have received relatively consistent support in the literature for their effectiveness in facilitating communicative exchanges. Eliminating environmental distractions such as television, radio or other external stimuli is helpful in achieving successful communication (Orange, 1991; Richter et al., 1995). Using verbatim and paraphrased repetition of messages (Bourgeois, 2002; Gentry & Fisher, 2007; Orange, 1991; Small et al., 1997; Tappen et al., 1997; Wilson, Rochon, Mihailidis, & Leonard, 2012) and verbalizing only one idea or one question at a time (Rochon et al., 1994; Wilson et al., 2012) help with comprehension. Using gestures to complement verbal messages can also help the person with dementia to better understand (Goldfarb & Santo Pietro, 2004; Orange, 1991; Richter et al., 1995; Small et al., 2003; Wilson et al., 2012; Wilson, Rochon, Leonard, & Mihailidis, 2012). Pretending to understand and going along with what the person with dementia is saying is better than reality orientation (Elvish, James, & Milne, 2010; Orange, 1991; Richter et al., 1995; Tuckett, 2012) and distracting the person by redirecting to a different topic or task is also helpful (Orange, 1991; Richter et al., 1995; Savundranayagam & Orange, 2014; Smith et al., 2011). Providing verbal or physical reassurance in the form of comforting words and/or calming touch are helpful in connecting with the person and minimizing problem behaviors (Orange, 1991; Richter et al., 1995).

A number of communication strategies have also been consistently found to have a negative effect on interpersonal communication. Using short sentences, a slow rate of speaking, and high pitch can decrease the comprehension abilities of the person with dementia (Kemper & Harden, 1999; O'Connor & St. Pierre, 2004; Rochon et al., 1994). Continuously pointing out errors and providing corrective feedback has been associated with less coherent speech from the person with dementia and a greater number of conversational breakdowns (Gentry & Fisher, 2007; Gentry, 2010; Hamilton, 1994; Orange, 1991; Richter et al., 1995). Using reality orientation (i.e., truth-telling) as well as showing frustration and being impatient with the person who has dementia may also trigger aggression from the person with dementia, leading to more unsuccessful communication (Orange, 1991; Tuckett, 2012). Direct repairs (i.e., corrective feedback) provided by the listener may serve to punish the person's verbal behaviors and has been suggested as a cause of premature reduction in the person's verbal abilities (Gentry & Fisher, 2007; Yury & Fisher, 2007).

Just as communication impairments may trigger problem behaviors, so too may the caregivers' communication style. Hart and Wells (1997) conducted a small experimental study testing whether caregivers' language complexity was connected to care recipients' display of problem behaviors. Results supported the authors' hypothesis, as persons with dementia displayed significantly greater agitation when exposed to language complexity beyond their comprehension, compared to language that was appropriate for their abilities. Previous studies have demonstrated that it is not only what caregivers say, but how they say it that contributes to communication success. Caregivers' use of critical emotional expression, harshness, or a negative tone has also been linked to increases in problem behaviors and reduced responsiveness in conversation (Edberg, Sandgren, & Hallberg, 1995; Hendryx-Bedalov, 1999; Small et al., 2005; Vitaliano et al., 1993). Caregivers' speech that is more respectful and caring, less controlling, and more supportive of the care recipient's competence has been significantly associated with fewer communication breakdowns (Small et al., 2005). Use of a softer, gentler tone has been demonstrated to facilitate responsiveness and reduce problem behaviors (Edberg et al., 1995; Hendryx-Bedalov, 1999). However once again, not all studies have found support for caregivers' adjustments to their communication style. Small, Huxtable and Walsh (2009) analyzed conversational segments obtained from 12 dementia spousal caregivers to determine whether increases in caregivers' prosody (i.e, pitch and loudness) had an impact on successful or unsuccessful communication. Results revealed that variation of caregivers' pitch and loudness made no significant difference in communication success. This finding contradicts earlier results. In a series of three experiments, Kemper and Harden (1999) demonstrated that providing semantic elaborations and reducing the use of subordinate and embedded clauses benefited older adults with dementia, whereas reducing sentence length, speaking slower, and using a high pitch resulted in more communication problems.

Relatively few studies have investigated dementia family caregivers' appraisals of communication strategies despite the fact that they confront their relative's communication impairments on a regular basis. Several studies have investigated caregivers' appraisals of strategy effectiveness (Orange, 1991; Richter et al., 1995; Savundranayagam & Orange, 2011; Savundranayagam & Orange, 2014; Small et al., 2003). Richter (1995) conducted a series of focus groups with family and professional caregivers who were caring for people with Alzheimer's disease and investigated caregivers' appraisals of successful strategies. While family and professional caregivers differed somewhat in their appraisals, all caregivers reported reducing environmental stimuli, providing verbal and nonverbal reassurances, and avoiding reality orientation as being effective strategies. Shifting from verbal to nonverbal communication as the disease progressed was perceived to be the most successful strategy.

Two studies have directly compared caregivers' appraisals of strategy effectiveness with other measures of effectiveness and have found differences between caregivers' perceptions and reality. Small, Gutman, Makela, and Hillhouse (2003) studied 18 dementia caregiver-care receiver dyads and investigated the use and effectiveness of ten communication strategies that frequently appear in the consumer literature. Caregivers' appraisals of strategy effectiveness were obtained through a survey, and objective measures of effectiveness were obtained through conversation analysis of audio-recorded interactions. Family caregivers reported using all ten strategies occasionally or frequently, but when compared to audio-recordings, it was discovered that family caregivers over-estimated usage of three strategies and under-estimated usage of three strategies. Caregivers also appraised all ten strategies as being somewhat or quite a bit helpful. When subjective and objective measures of effectiveness were compared, eliminating environmental distractions and using short simple sentences were the only two strategies appraised by family caregivers as helpful and also associated with a smaller number of communication breakdowns. A disconnect also existed for the strategy of speaking slowly, which was appraised by family caregivers as improving communication "quite a bit" but was associated with the greatest number of communication breakdowns, as identified in the analysis of audio-recorded interactions.

More recently, Savundranayagam and Orange (2014) conducted a similar study, examining whether dementia caregivers' appraisals of strategy effectiveness were consistent with evidence of effectiveness obtained from analysis of video-recorded conversations and the professional literature across stages of disease severity. Consistent with previous studies (Orange, 1991; Small et al., 2003), family caregivers in the study conducted by Savundranayagam and Orange reported using a wide variety of communication strategies, with caregivers of early stage Alzheimer's using the greatest number (early = 13 strategies; middle = 11 strategies; late = 8 strategies). Consistency between family caregivers' appraisals of communication strategies and more objective measures of effectiveness was high. Matches between appraised effectiveness and documented effectiveness ranged between 45% - 65%, with caregivers of persons with early stage Alzheimer's disease showing the greatest level of consistency in matches. Most mismatches were for communication strategies with documented effectiveness, which were judged as being ineffective by family caregivers. Results from this study highlight the difference between family caregivers' perception of interpersonal communication and the perceptions of health care professionals and researchers.

Only one study to date has empirically investigated the link between family caregivers' appraisals of communication strategies and the outcome of caregiver burden. Savundranayagam and Orange (2011) surveyed 84 dementia family caregivers and used hierarchical linear regression to test the relationships between strategy appraisal, problem behavior appraisal, and three types of caregiver burden (i.e., stress burden, relationship burden, and objective burden). Communication strategies were divided into two categories: effective and ineffective, which consisted of seven strategies and four strategies respectively. Results revealed that higher appraisals of effective strategies were linked with lower levels of stress burden ($\beta = -0.31$, $p < 0.01$) and with lower levels of relationship burden ($\beta = -0.24$, $p < 0.05$). No relationship was found between strategy appraisal and objective burden. These findings led the authors to conclude that caregivers' perceptions of "effective strategies have a greater impact on the interpersonal relationship between caregivers and their relatives with AD [Alzheimer's disease] than on perceptions of time infringement brought on by caregiving responsibilities" (p. 6). Caregivers' perceptions of ineffective strategies, however, were not correlated with caregiver burden or any other study variables and, consequently, were dropped from the regression analysis. Thus it remains unclear whether or not caregivers' appraisals of communication strategies – as a collective whole – is related to caregiver burden.

Caregiver Burden and Communication

The construct of caregiver burden has been used by researchers to describe the overall negative impact of the physical, psychological, social, and financial demands of caregiving (George & Gwyther, 1986). Montgomery and colleagues (Montgomery, Stull, & Borgatta, 1985; Montgomery, Borgatta, & Borgatta, 2000; Savundranayagam, Montgomery, & Kosloski, 2011) have further refined this concept, identifying three inter-related but distinct dimensions: relationship burden, stress burden, and objective burden. Relationship burden captures the extent to which the caregiver perceives the care recipient to be demanding, manipulative, or his/her requests to be excessive and unreasonable. Stress burden captures the affective component and refers to the caregiver's perceived level of emotional strain, stress, anxiety or tension. Objective burden captures the extent to which caregiving duties infringe upon the caregiver's time for self and others. It includes perceptions of imposition on observable aspects of one's life, such as time for personal activities, privacy, and other obligations.

Researchers from a wide variety of disciplines have found consistently that greater levels of burden can lead to negative outcomes for both the caregiver and care recipient. Greater levels of caregiver burden have been consistently shown leading to increased risk of mental and physical health problems (Adams & Sanders, 2004; Adams, McClendon, & Smyth, 2008; Aneshensel et al., 2004; Beach et al., 2000; Bourgeois, Schulz, & Burgio, 1996; Damjanovic et al., 2007; Frank, 2008; Kiecolt-Glaser, Marucha, Malarkey, Mercado, & Glaser, 1995; M. G. Ory et al., 1999; Sanders & Adams, 2005; Sansoni, Vellone, & Piras, 2004; Schulz et al., 1990; Schulz et al., 1995), social limitations (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Stephens, Franks, & Townsend, 1994; Stephens, Townsend, Martire, & Druley, 2001) and financial hardship (Johnson & LoSasso, 2006; MetLife Mature Market Institute, 1999; Young & Newman, 2003). If the burden of care becomes too great, it can also lead to premature death of the caregiver (Christakis & Allison, 2006; Schulz & Beach, 1999), premature or inappropriate institutional placement of the care receiver (Gaugler et al., 2000; Gaugler et al., 2003; Gaugler et al., 2005; Spillman & Long, 2007) and/or elder abuse or neglect (Cooney et al., 2006; Gainey & Payne, 2006; Paveza et al., 1992; Stone, Cafferata, & Sangl, 1987).

When the care receiver has dementia, the demands and stress associated with caregiving are even greater. Caring for a family member with dementia is often a more stressful experience because of the range and intensity of symptoms and associated care needs (Mace & Rabins, 1981; Rabins et al., 1982). Caregiving tasks often are made more difficult by the care recipient's confusion, disorientation, agitation, and poor communication abilities. Care recipients with dementia are less likely than other older adults to participate in their care and often resist care (Bass, Tausig, & Noelker, 1989). As the disease progresses and the care recipient’s behaviors become more difficult to manage, caregiving stress can become unbearable in a home setting (Corbin & Strauss, 1988). Studies have consistently shown that dementia caregivers, in comparison to caregivers of older adults with other conditions, provide care for a longer period of time, provide more intensive and extensive care, experience greater burden and strain, have higher rates of depression, and are more likely to indicate that caregiving had negatively impacted their own personal health and finances (Alzheimer's Association, 2013a; Baillie, Norbeck, & Barnes, 1988; Bass et al., 1989; Bertrand et al., 2006; Bouldin & Andresen, 2010; Deimling & Bass, 1986; Kahana et al., 1994; MetLife Mature Market Institute, 2006; Moritz, Kasl, & Berkman, 1989; Parks & Pilisuk, 1991; Pinquart & Sorensen, 2003; Russo, Vitaliano, Brewer, Katon, & Becker, 1995; Schulz et al., 1990; Schulz et al., 1995; Wright et al., 1993).

A large number of descriptive variables have been shown to correlate with caregiving burden. Characteristics of the caregiver (e.g., sex, race/ethnicity, education level, relationship to care recipient, presence of social supports, employment status, health status) have been investigated (Abel & Nelson, 1990; Albrecht & Adelman, 1987; Albrecht, Burleson, & Goldsmith, 1994; Barusch & Spaid, 1989; Brody, 1981; Deimling, Bass, Townsend, & Noelker, 1989; Horowitz, 1985; Neal, Chapman, Ingersoll-Dayton, & Emlen, 1993; B. Robinson & Thurnher, 1979; Schulz, Tompkins, & Rau, 1988; Schwartzer & Leppin, 1991; Tennstedt, Cafferata, & Sullivan, 1992; Wagner, 1987; Wright et al., 1993) as well as characteristics of the care recipient, such as the person’s sex, diagnosis, disease stage, living arrangement, and relationship to caregiver (Aneshensel et al., 1995; D. Cohen & Eisdorfer, 1988; George & Gwyther, 1986; Novak & Guest, 1989; Vitaliano, Russo, Young, Becker, & Maiuro, 1991; Zarit, Reever, & Bach-Peterson, 1980). Sex differences in the caregiving experience have received considerable research attention because women make-up the majority of family caregivers (Agency for Healthcare Research and Quality, 2001; Campbell & Martin-Matthews, 2003; Garner, 1999; Montgomery, 2007; National Alliance for Caregiving & AARP, 2009; National Alliance for Caregiving, 2010; M. Ory et al., 2002) and they report greater stress and burden in this role than their male counterparts (Barusch & Spaid, 1989; Bookwala, 2009; Kramer & Kipnis, 1995; Merrill, 1997; Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007; Pinquart & Sorensen, 2003; Thompson et al., 2004; Winslow, 1999; Yee & Schulz, 2000). However not all studies have found gender differences in the outcomes for dementia caregivers (Barusch & Spaid, 1996; Faison, Faria, & Frank, 1999; Fitting, Rabins, Lucas, & Eastham, 1986; Ford, Goode, Barrett, Harrell, & Haley, 1997; e.g., Schulz et al., 1995; Sparks, Farran, Donner, & Keane-Hagerty, 1998). Several meta-analyses have attempted to identify factors contributing to gender differences in the response to dementia caregiving stress, but the available evidence is inconclusive (Miller & Cafasso, 1992; Schulz et al., 1995). The meta-analysis conducted by Schulz and colleagues (1995) investigated the relationship between gender and depression of dementia caregivers and found no significant association, but Miller and Cafasso (1992) found a statistically significant relationship between gender and caregiver burden (n = 10). Gender differences only explained approximately 4% of the variance in caregiver burden, leading Miller and

Cafasso to question the practical significance of this difference. Small sample sizes of male dementia caregivers, inconsistency of results, and great variability in effect sizes have led some researchers to call for additional study of gender and family role differences in the caregiving experience (Houde, 2002; Miller & Cafasso, 1992).

One construct that has been reported consistently as not only a correlate of caregiver burden but also a predictor of it, is problem behaviors. Behavioral problems exhibited by care recipients with dementia have been consistently associated with higher levels of caregiver burden and increased risk of institutionalization for the care recipient (Acton, 1997; Baumgarden et al., 1992; Donaldson, Tarrier, & Burns, 1998; Faison et al., 1999; Gallicchio, Siddiqi, Langenberg, & Baumgarden, 2002; Hooker et al., 2002; Kosberg, Cairl, & Keller, 1990; Papastavrou et al., 2007; Pinquart & Sorensen, 2003; Richter et al., 1995; Ripich, 1994; K. Robinson, Adkisson, & Weinrich, 2001; Rymer, Salloway, & Norton, 2002; Sansoni et al., 2004; Savundranayagam et al., 2005; Savundranayagam et al., 2011; Schneider et al., 1999; Schulz et al., 1990; Schulz et al., 1995; Schulz et al., 2002).

Communication problems and difficulty with social interaction have also been linked to caregiver strain and burden (Deimling & Bass, 1986; George & Gwyther, 1986; Poulshock & Deimling, 1984; Rau, 1993). However, most studies have included dementia-related communication problems as part of a larger set of problem behaviors rather than examining them in isolation (e.g., Papastavrou et al., 2007; Vitaliano, Young, & Russo, 1991). This masks the precise relationship between communication problems and caregiver burden and also fails to address the full range of dementia-related communication issues (Watson, Aizawa, Savundranayagam, & Orange, 2012/2013). The

Revised Memory and Behavior Problems Checklist (RMBPC, Teri et al., 1992), for example, is frequently used to assess problem behaviors in dementia patients. This instrument includes several communication problems, such as repetitive questions, verbal aggression, and talking loudly and rapidly. While most studies have reported a three-factor solution for the RMBPC and have included the communication items in each of the factors, Papastavrou and colleagues (2007) reported a 7-factor solution and broke communication problems into its own factor. In this study, communication problems were significantly correlated with caregiver burden, but not with caregiver depression.

Although a small number of publications have discussed how dementia-related communication problems relate to problem behaviors and caregiver burden (Bourgeois, 2002; Orange, 1991; Schneider et al., 1999; Watson et al., 2012/2013), only one study has investigated this topic empirically with dementia caregiving dyads living in the community. Savundranayagam, Hummert, and Montgomery (2005) used a sample of 89 dementia family caregivers to examine the relationship between communication problem frequency, problem behaviors, and caregiver burden. Results of structural equation modeling revealed that problem behaviors partially mediated the relationship between communication problem frequency and all types of caregiver burden (i.e., relationship burden, stress burden, and objective burden). This finding confirms the conceptual arguments made by other authors that communication problems predict problem behaviors, which in turn predict caregiver burden.

Caregivers' Education Level

The association between education and health is documented extensively in the literature, spanning many different settings and countries (Cutler & Lleras-Muney, 2012;

Hurt, Rossmands, & Saha, 2004; Khang, Lynch, & Kaplan, 2004; Liang et al., 2000; Manor, Eisenbach, Friedlander, & Kark, 2004; Mustard, Derksen, Berthelot, Wolfson, & Roos, 1997; Shkolnikov, Leon, Adamets, Andreev, & Deev, 1998). Gradients in health by education have been documented for mortality (e.g., Christenson & Johnson, 1995; Elo & Preston, 1996; Montez, Hummer, & Hayward, 2012), health status (for a complete discussion see Cutler & Lleras-Muney, 2006), health behaviors (e.g., Kenkel, 1991; Leigh & Dhir, 1997; Sander, 1995), and perceived or self-reported health (e.g., Beach et al., 2000; Goesling, 2007). This body of literature collectively confirms that people with higher levels of education live longer, are healthier, engage in more preventative behaviors, and perceive their health more positively than their counterparts who have lower education. Cutler and Lleras-Muney (2006) report,

> An additional four years of education lowers five year mortality by 1.8 percentage points (relative to a base of 11 percent); it also reduces the risk of heart disease by 2.16 percentage points (relative to a base of 31 percent), and the risk of diabetes by 1.3 percentage points (relative to a base of 7 percent). Four more years of schooling lowers the probability of reporting in fair or poor health by 6 percentage points (the mean is 12 percent), and reduce[s] lost days of work [due] to sickness by 2.3 each year (relative to 5.15 on average). (p. 4)

Even though life expectancy has steadily increased (U.S. Census Bureau, 2011), the gap in health between those people with college degrees and those without continues to widen (Goesling, 2007; Mackenbach et al., 2003; Pappas, Queen, Hadden, & Fisher, 1993).

A small number of studies have investigated the educational gradient as it relates to the health of family caregivers. Navaie-Waliser and colleagues conducted a nationally representative cross-sectional study of 1,002 informal caregivers in the United States and found vulnerable caregivers, defined as informal caregivers who report being in fair to poor health or who have a serious health condition, to be more likely than non-vulnerable caregivers to have low education (Navaie-Waliser et al., 2002). Beach et al. (2000) investigated the effect of caregivers' education level on caregivers' self-reported health by analyzing data from the first two waves of the Caregiver Health Effects Study. They found caregivers with higher levels of education tended to report improved health over time. This finding is consistent with other studies that have shown that persons with higher educational attainment are less likely to report negative emotions (N. E. Adler et al., 1994; Gallo & Matthews, 2003) and, when faced with negative life events, they are less emotionally responsive than their counterparts with lower education (McLeod & Kessler, 1990). Persons with higher education also report a higher sense of control and higher self-esteem (Ross & Dagley, 2009) and report having larger social networks that provide additional sources of support (Berkman, 1995).

More often than not, caregivers' education level is lumped together with other demographic and/or socioeconomic variables making it difficult to disentangle the relationship between caregivers' education and specific health outcomes. Nonetheless, dementia caregiver studies that have reported on this specific relationship have found results consistent with other populations. Sansoni, Vellone, and Piras (2004) investigated anxiety and depression in community-dwelling dementia family caregivers in three major Italian cities and found that the caregivers' level of education was negatively correlated with incidence of depression. Moreover, Gallagher et al. (2011) used multivariate regression analysis and found that caregiver depression was predicted in part by caregivers' education level ($\beta = -0.19$, $p < 0.02$), with lower caregiver education predicting higher levels of depression.

Similar to depression, caregivers' education level has been linked to caregivers' health status via the latent variable of caregiver burden. However, the findings in this area have been inconsistent. Papastavrou et al. (2007) found caregivers' level of education was negatively correlated with burden. Statistically significant differences existed in the study sample between the lowest and highest level of education, where elementary school graduates had significantly higher burden compared to caregivers with graduate degrees. While some studies could not confirm the negative correlation between caregivers' education level and burden (Gallagher et al., 2011), others found a predictive relationship between the two variables, with caregiver burden being predicted in part by caregiver education (Uei, Sung, & Yang, 2013).

Speculations about why education affects health are numerous. Higher educational attainment typically results in higher paying jobs, greater financial resources, improved access to health care and health insurance, higher societal rank, larger social networks, and greater risk aversion, among other things (for a complete discussion see Cutler & Lleras-Muney, 2006; 2012). While these factors also hold true for dementia family caregivers, the educational gradient for this population may be more directly related to the cognitive skills that come with education. Education improves critical thinking skills and decision-making skills, and helps one develop the cognitive skills necessary to access and understand health-related information (Cutler & Lleras-Muney, 2006). Previous studies have shown education is also positively related to self-efficacy and coping skills, which in turn are negatively related to caregiver burden (Almberg, Grafström, & Winblad, 1997; Gallagher et al., 2011; Garcia-Alberca et al., 2012; Huang et al., 2013; Romero-Moreno et al., 2011; Uei et al., 2013). It is possible that caregivers with higher educational attainment may have developed more effective skills for managing caregiving responsibilities and their own health.

Findings of a recent dementia caregiving study suggest that the educational gradient can be reduced by targeted interventions. Brown, Vassar, Connor, and Vickrey (2013) studied a group of 396 informal dementia caregivers in a cluster-randomized controlled trial of a dementia care management intervention program (for a description see Vickrey et al., 2006). Caregivers' education level was measured with four categories: 1) college graduate; 2) some college or 2-year college degree; 3) high school graduate or GED; and 4) did not graduate from high school. At baseline, an educational gradient was clearly present across educational groups for dementia care quality; dementia caregivers with higher education had significantly greater adherence to two of the four multifaceted care domains, compared to caregivers with lower education. At the 18-month follow-up, caregivers with lower education had improved significantly more than college graduates following intervention, thus narrowing gap between the educational groups.

Research Questions and Hypotheses

The purpose of this study is to examine dementia family caregivers' appraisals of communication behaviors and strategies, and their impact on caregiver burden. The first part of this study builds upon previous dementia family caregiving research by exploring caregivers’ appraisals of communication problems and strategies in the context of natural, everyday interactions. Specifically, it addresses the following research questions:

R1: What is the relationship between frequency of occurrence and caregivers’ appraisal of dementia-related communication behaviors?

R2: What is the relationship between family caregivers’ use and appraisal of communication strategies?

The present study also helps fill the need for empirical research by using structural equation modeling to investigate the relationships between communication behavior appraisal, communication strategy appraisal, problem behaviors, and caregiver burden. It is the first study to explore whether caregivers’ education level moderates these relationships. This portion of the study seeks to address two additional research questions:

R3: What is the relationship between communication behavior appraisal, communication strategy appraisal, problem behaviors, and caregiver burden?

  H1: Communication strategy appraisal will partially mediate the relationship between communication behavior appraisal and caregiver burden.

  H2: Problem behaviors will partially mediate the relationship between communication strategy appraisal and caregiver burden.

  H3: Problem behaviors will partially mediate the relationship between communication behavior appraisal and caregiver burden.

R4: Does caregiver education moderate the relationships between communication behavior appraisal, problem behaviors, and caregiver burden?

  H1: The structural path coefficient between problem behaviors and caregiver burden will be invariant across groups of caregiver education.

Methods

This study was conducted by the author in partnership with Interfaith Older Adult Program's Family Caregiver Support Network, Marquette University, and the Wisconsin Geriatric Education Center. Financial support was provided in part by a grant from the Health Resources and Services Administration (UB4HP19062) to the author. The study was approved by Marquette University's Institutional Review Board (HR-2455).

This chapter is divided into several sections. First, the variables and measures used within the present study are defined. Next, the methods and procedures used to carry out the study are described, including a summary of the results from pre-testing the questionnaire. Finally, this chapter concludes with a description of the analyses, including a brief discussion of the controversy surrounding the use of parcels in structural equation modeling.

Definitions and Measures

The variables under investigation in this study were operationalized using the following definitions and measures. Family caregivers were broadly defined in this study as adults (age 18+) living in the U.S. who provide any type of ongoing, unpaid assistance to a relative (age 60+) who has, or is suspected to have, dementia. Seventeen (17) different types of family members were provided as response options, plus an "other" category for write-in responses. Participants who indicated that "No one in my family has dementia," were excluded from the sample.

Dementia was defined as declines in the relative's memory and other cognitive abilities, severe enough to be noticeable by the family caregiver. The self-administered questionnaire used in this study included one question that asked caregivers to select the best categorization of their relative's dementia status. Response categories included: (1) no memory or cognitive problems exist; (2) memory or cognitive problems are suspected; (3) memory or cognitive problems are definite, but have not been medically diagnosed; and (4) dementia has been medically diagnosed. Participants who reported that "no memory or cognitive problems exist" were excluded from the study sample.

Communication behaviors were defined for the purpose of this study as communicative declines in language processing associated with dementia (Bayles & Kaszniak, 1987; Kempler, 1995). Thirty-two items measured this construct (see Table 1), adapted from the conversational abilities checklist included in Part A of the Conversation Analysis Profile for People with Cognitive Impairment (Perkins, Whitworth, & Lesser, 1997). Each item was measured along two scales: 1) frequency (i.e., how often the

Table 1: Communication behavior as concepts and operationalized items

Communication Behavior	Questionnaire Item
Ability to initiate conversation	1. Starts up a conversation with you
Failure to respond when selected as next speaker	2. Fails to respond when it is his/her turn to talk
Delay in responding when selected as next speaker	3. Pauses a long time before answering you
Production of long pauses in the middle of turns	4. Stops in the middle of his/her talking and leaves a long pause before continuing
Violation of conversational partner's turn	5. Interrupts you when you are speaking
Failure to hand over conversational floor	6. Talks on and on, without allowing you to participate in the conversation
Reliance on minimal acknowledgements	7. Restricts his/her responses to minimal acknowledgements like "yes" or "OK"
Ability to initiate new topics	8. Introduces new topics during a conversation
Ability to maintain topics	9. Able to maintain the same topic for awhile
Failure to orient conversational partner to new topics	10. Introduces new topics that do not really fit into what you are currently talking about
Presence of topics based on hallucinations and/or delusions	11. Talks about imaginary people/events as if they are real

Table 1 (continued)

Communication Behavior	Questionnaire Item
Repeated initiation of favorite topics	12. Brings up the same topic(s) in conversation
Ability to initiate repair on conversational partner's turn	13. Indicates when he/she has not followed or understood what you have said
Ability to initiate repairs on own errors	14. Notices mistakes he/she makes when talking and tries to correct them
Ability after self-initiation to repair own errors without help	15. Corrects mistakes in his/her speech without any help
Ability to repair own turn when initiated by conversation partner	16. Able to make his/her speech more specific if you do not understand him/her
Repeated questions and comments	17. Asks you the same question or makes the same remark over and over again
Fails to remember family, friends, events discussed in conversation	18. Fails to remember family, friends, or events being currently discussed
Failure to retain instructions	19. Forgets instructions you have given to him/her
Presence of abandoned turns	20. Stops speaking in the middle of a sentence
Failure in word retrieval	21. Struggles to find the right word when he/she is talking
Production of circumlocutions	22. Describes what he/she is talking about, even if he can’t think of the right word
Production of uncorrected semantic paraphasia	23. Uses the wrong word for something without correcting it
Overuse of pronouns and proforms	24. Uses words like “it” or “they” without making it clear what the word refers to
Failure in comprehension	25. Has difficulty understanding what you have said
Ability to make inferences	26. Able to “read between the lines” and understand what you really mean
Ability to interpret non-literal meaning	27. Takes things at the literal or surface meaning
Ability to use humor	28. Makes funny remarks on purpose, demonstrating that he/she has a sense of humor
Failure to understand humor	29. Misses the point of jokes
Impairment of articulation	30. Has difficulty speaking clearly
Impairment of volume control	31. Talks so softly it is difficult to hear him/her
Production of monotonous intonation	32. Uses flat, monotone speech

Note. Adapted from Part A of the Conversation Analysis Profile for People with Cognitive Impairment (Perkins et al., 1997).

relative with dementia displayed a particular communication behavior); and 2) frustration (i.e., caregivers' appraisal of how frustrating the behavior is when it occurs). Frequency of the communication behaviors was measured with a 5-point scale, ranging from 1 (*never*) to 5 (*always*). Caregivers' appraisal of frustration was measured along a 6-point scale, ranging from 1 (*does not apply*) to 6 (*extremely frustrating*). Cronbach's alpha was 0.804 for communication behavior frequency and 0.942 for communication behavior appraisal.

Communication strategies were defined as any behavior that involved the caregiver modifying his/her interpersonal communication patterns as a means of accommodating the communication needs of the person with dementia (Small & Gutman, 2002). A total of nineteen (19) items were used to measure caregivers' use and appraisal of communication strategies, including ten strategies tested by Small and Gutman (2002) and nine additional strategies identified consistently in the literature (see Smith et al., 2011, for a review). Examples include "use short simple sentences," "repeat your message using the same wording," "establish and maintain eye contact," and "point to objects and pictures." Each item was measured along two scales: 1) frequency (i.e., how often the caregiver used a particular strategy); and 2) helpfulness (i.e., caregivers' appraisal of how helpful the strategy was in improving communication when used during interactions with the relative who has dementia). Frequency was measured with a 5-point scale, ranging from 1 (*never*) to 5 (*always*). Caregivers' appraisal of the communication strategies was measured along a 6-point scale, ranging from 1 (*does not apply*) to 6 (*extremely helpful*). Cronbach's alpha was 0.864 for communication strategy frequency and 0.929 for communication strategy appraisal.

Problem behaviors were measured with a 14-item inventory originally published by Pearlin and colleagues (1990). Caregivers reported the number of days during the past week that the caregiver personally had to deal with the behavior. Responses were measured along a 4-point frequency scale (0 days, 1-2 days, 3-4 days, 5 or more days). Examples of the problem behaviors include: “became irritable or angry,” “kept you up at night,” and “had a bowel or bladder accident.” Cronbach’s alpha was 0.825, which is comparable to previously published studies (Pearlin et al., 1990; Savundranayagam et al., 2005; Savundranayagam et al., 2011).

Caregivers’ education was defined as the highest level of education completed. Response categories included: (1) 8th grade or lower; (2) high school degree (diplomas, GED); (3) Associate’s degree or some college; (4) Bachelor’s degree; and (5) Graduate degree or higher.

Caregiver burden was measured with the 16-item caregiver burden inventory developed by Montgomery and colleagues (Montgomery, Gonyea, & Hooyman, 1985; Montgomery et al., 1985; Montgomery et al., 2000). Caregivers responded to the question, “As a result of providing assistance to your relative who has memory problems, how have the following aspects of your life changed? Have your caregiving responsibilities…” Responses to each of the 16 items were measured along a 5-point scale, ranging from 1 (*not at all*) to 5 (*a great deal*). Previous studies have shown caregiver burden to be a multidimensional construct consisting of three domains: stress burden, objective burden, and relationship burden. Cronbach’s alpha for the three individual domains have previously ranged from 0.73 – 0.93 (Montgomery et al., 2000;

Savundranayagam et al., 2005; Savundranayagam et al., 2011; Savundranayagam & Orange, 2011). For this study, they ranged between 0.88 – 0.93.

- Stress Burden: A generalized form of negative affect that results from caregiving. It is not the result of any specific event, task, or interaction. Examples included feelings of hopelessness, anxiety, and worry. Five questions were used to measure this domain and internal consistency was 0.883.
- Objective Burden: A negative psychological state that results from the infringement of caregiving activities on the caregiver's free time. Examples included reduced time available for hobbies, entertainment, or relaxation. Six questions measured this domain and internal consistency was 0.930.
- Relationship Burden: The extent to which the relative with dementia makes demands for care and attention over and above the level that the caregiver perceives is warranted. Examples included appraisals of whether the relative manipulates the caregiver, makes unreasonable requests, and takes advantage of the caregiver. Five items measured this domain and internal consistency was 0.892.

Procedures

Data were collected through a self-administered, mailed questionnaire. Dillman's Tailored Design Method for mail surveys (Dillman, 1978; 1991; 2000; 2007; Dillman, Smyth, & Christian, 2008) guided the design of the study's printed pieces and administrative details. Dillman's method is considered to be the gold standard for survey research in the United States and is based upon social exchange theory, in which the researcher obtains information in exchange for information, monetary or nonmonetary incentives, and/or goodwill. Dillman recommends using a series of specific techniques to increase personalization and the respondent's desire to comply. Because the current study was conducted in partnership with three well-known and highly regarded organizations, company logos were used on all print pieces to increase respondents' trust and minimize nonresponse error. Additional techniques, recommended by Dillman (2000; 2007; 2008) and utilized in this study, included the use of a multiple contact sequence, nonmonetary incentive, letterhead stationery, first-class postage, a personalized salutation, a booklet style questionnaire, the researcher's real signature in contrasting ink, and a stamped return envelope rather than a business reply envelope.

Prior to mailing, the self-administered questionnaire was pre-tested for content validity and item clarity using informal methods and a focus group. Informal methods, recommended by Campanelli (2008) as the first step in any survey testing process, included reading the questionnaire aloud, role playing, and interviewing family and friends following survey completion. Once a complete draft of the questionnaire was ready, a focus group of dementia family caregivers was convened at Marquette University's Alumni Memorial Union. Eight family caregivers (50% female) participated, and each person was paid $25.00 cash as a token of appreciation. Participants were handed a copy of the self-administered questionnaire upon arrival and asked to complete it. Debriefing questions as well as planned and spontaneous probes were used to test question wording, directions and skip patterns, reactions to design variations, respondents' comprehension and judgment, and the overall flow of the questionnaire (Campanelli, 2008; Stewart, Shamdasani, & Rook, 2007). Following is a summary of the feedback obtained during the focus group; any changes made as a direct result of the pre-test are noted.

- **Completion Time.** Completion time ranged from 10 minutes (1 person) to 25 minutes (1 person). All other participants completed the questionnaire within this range, with most people completing it in 15-18 minutes. [*Action taken: The cover letter indicated that the questionnaire took approximately 20 minutes to complete.*]
- **Overall Impressions.** Reactions were very positive. Everyone found the questionnaire easy to understand and interesting to complete. Participants described the questionnaire and other print pieces as looking "professional."
- **Font.** No one had difficulty with the font style or size. Everyone described the questionnaire as being "easy to read."
- **Length.** Participants found the length of the questionnaire to be acceptable. Several commented that the instrument seemed "a little long, but not too bad" and one person noted that it seemed to cover the subject matter "very thoroughly." All participants liked the booklet format and question numbering scheme; several commented that these two elements made the questionnaire seem shorter.
- **Design.** Participants were given two design choices for consideration. One had blue waves on the front cover and the other had an image of shoes on the front cover. Unanimously, the group preferred the blue waves design. They described it as "more professional" and "easier to read." Conversely, they viewed the shoes design as a "rough draft" and most people did not find the color scheme visually appealing. Several reasons were offered for why the blue waves design was

preferable: 1) the year was more prominently displayed; 2) the front cover design was continued on the back cover; 3) the waves were perceived as soothing and calming to the reader; and 4) the blue color "popped" more and caught one's attention. [*Action taken: The blue waves design was selected as the final layout.*]

- **Internal Navigation.** All participants found it easy to follow the directions and skip patterns inside the questionnaire. One participant commented that he particularly liked the instructions at the beginning of the booklet about how to properly indicate a response to each question (e.g., check mark, x mark, circle). He noted that many questionnaires he had encountered had the respondent shade in a box or circle, so it was nice to have instructions indicating that he could use other types of marks in responding. While no one in the focus group had any difficulty with the question grids, they wondered whether people with lower IQ's or lower education levels would have difficulty following the format. One participant noted a flaw in the question grid formatting on page 4. [*Action taken: This flaw was corrected.*] A follow-up probe noted that no definition of "dementia" was provided before question number one. Participants were asked if they would prefer a definition be included in the general instructions and whether this might help them complete the questionnaire more accurately. Unanimously, the group thought this was unnecessary given that the respondents were all people who self-identified as having a family member with dementia. Everyone agreed that a definition would not help them complete the questionnaire more accurately.
- **Question Wording.** Everyone indicated that question wording throughout the survey was clear and understandable. Several probes were used with the focus

group to examine specific questions. One probe, for example, focused on language used in the questionnaire to describe interpersonal communication between the respondent and his/her relative with dementia. Many participants commented that the verbal utterances and nonsensical word substitutions that their relative uses were not “real communication.” Family caregivers did not view their relative’s verbal utterances to be communication between them, even though they were quick to acknowledge that the person with dementia always thinks they are making sense when in fact the caregiver often cannot understand the person. Participants objected to any directions or questions that used phrases such as “talk to,” “talk with,” or “conversation.” Participants preferred the phrase “interact with” to describe interpersonal communication in the context of dementia. [*Action taken: Whenever appropriate, changes were made throughout the questionnaire to emphasize interaction.*]

- **Most Difficult Question.** Most participants had difficulty answering a question about the primary method they use to communicate with their relative. Even though the question focused on the caregivers’ method of communicating, participants were confused about how to answer it because they automatically factored into their answer the relative’s comprehension skills. Most participants found this question so confusing that they skipped it. [*Action taken: This question was dropped.*]
- **Family Reference.** Participants strongly preferred the word “relative” to describe their family member with dementia. Participants unanimously viewed the phrase “your loved one” as being “too mushy” and the phrase “care recipient” as “too

cold and detached." [*Action taken: The term "relative" was used consistently throughout the questionnaire.*]

- **Additional Items.** One question was asked about the type of assistance provided to the relative with dementia and a list of activities of daily living (ADLs) and instrumental activities of daily living (IADLs) were provided as response options. Unanimously, participants felt that a key support that they provided to their relative with dementia was social interaction, which was not listed. Caregivers felt strongly that being with the person, verbally interacting with him/her, and providing non-verbal physical affection (e.g., hugs, kisses) was very important. [*Action taken: Social interaction was added as a response option, along with the ADLs and IADLs.*]
- **Question Grids.** Question grids pertaining to the relative's communication problems and the caregiver's communication strategies did not include a "not applicable" response option. Participants noted that this option is important in the case that a particular communication behavior is never used. [*Action taken: A response option of "does not apply" was added.*]

Following pre-testing, the questionnaire was revised and then administered using a three contact sequence. The first contact in the sequence was a tri-fold, direct mail piece with a detachable, self-addressed, postage-paid return postcard. This piece (see Appendix A) was designed to alert family caregivers to the study, pique their interest in the topic, and solicit qualified participants. It served as pre-notification and also specified the inclusion criteria for the study. A third-party mail house tabbed, printed the addresses, and mailed the piece via pre-sorted, first-class mail to all persons listed on the mailing list. Family caregivers opted-in to the study by writing their name and address on the detachable return postcard. Non-responses were considered to be persons who “opted-out” of the study. When an insufficient sample size was generated from the first mailing, the piece was reprinted and mailed to the entire mailing list four months later, excluding anyone who had already returned a postcard.

The second contact in the sequence consisted of the survey packet. Immediately upon receiving a returned postcard, the packet was assembled and mailed to the potential study participant. This mailing was packaged inside of a 9” x 12” envelope with the resource center’s logo on the outside and contained four items, paper clipped together: 1) a 1-page cover letter, printed on letterhead and signed in contrasting blue ink by the author; 2) the questionnaire, printed in two colors and assembled as an 8-page booklet with stapled binding (see Appendix B); 3) a 6” x 9” self-addressed, return envelope with a first-class stamp; and 4) a packet of colorful, pre-printed “Thank You” sticky notes, which served as a non-financial incentive. Return of a completed, anonymous questionnaire was construed as the respondent’s consent to participate in the study.

The final contact in the sequence was a follow-up postcard. One week following the survey mailing, a follow-up postcard was mailed with a first-class postage stamp to all persons who received the survey packet (see Appendix E). Upon receipt, each completed questionnaire was assigned an identification number and the data were entered directly into IBM SPSS Statistics (Version 19) [computer software].

The mailing list of a local caregiver resource center, consisting of 6,791 family caregivers, served as the sampling frame for this study. Although the center’s mailing list is a non-probability sample of family caregivers in the United States, it was suitable for the purposes of this study and the specific research questions under investigation because the focus is on examining multivariate relationships, not estimating univariate values (Basil, Brown, & Bocarnea, 2002; M. A. Shapiro, 2002). The mailing list is updated by staff each month, thus minimizing the amount of inaccurate or incomplete addresses. Following both waves of mailings, a total of 281 family caregivers indicated a willingness to participate in the study. Of these, a total of 249 (88.6%) questionnaires were completed and returned.

Analyses

Initially the dataset was examined to evaluate the characteristics of each variable, assess the extent and patterns of missing data, and test for assumptions underlying multivariate analyses. The processes outlined by Hair et al. (2010) guided data examination. Eight cases were dropped from the sample based upon responses to one of the three disqualifying questions (e.g., Q1 response: no one in my family has dementia). Two additional cases were dropped due to extremely high (i.e., > 86%) item non-response rates, which occurred outside of normal question skip patterns. Following individual case deletion, low levels of missing data remained (≤ 3.3% for any item, ≤ 8.0% for any individual case). Little’s MCAR test (R. J. A. Little, 1998) was used to diagnose the randomness of the missing data and results indicated the remaining data were missing completely at random, χ^2 (7684) = 7745.79, $p = 0.31$. Although any method of imputation may be applied because of the low levels of missing data and the completely random pattern of it, the expectation-maximization (EM) imputation technique was chosen for this study because it introduces the least amount of bias and generates the best representation of the original distribution of values (Hair et al., 2010). The final sample totaled 239 dementia family caregivers.

Assumptions underlying statistical tests and estimation techniques were tested. Univariate and multivariate normality were assessed for all measured items, and these results influenced the author's choice of non-parametric statistics and the choice of robust maximum likelihood estimation in structural equation modeling. Because univariate normality is a necessary, albeit insufficient, precondition for multivariate normality (Burdenski, 2000; Hair et al., 2010), it was assessed first, using histograms, normal probability plots, skewness and kurtosis values, and the Shapiro-Wilk's test (S. S. Shapiro & Wilk, 1965). Multivariate normality was assessed using the skewness and kurtosis test values generated by LISREL 9.1 and PRELIS software (Joreskog & Sorbom, 2013).

To address the first two research questions, the frequency and appraisal of dementia-related communication behaviors and the frequency and appraisal of caregivers' communication strategies were compared with descriptive statistics and rank ordered. Two non-parametric tests, Friedman's test (Friedman, 1937; Friedman, 1939; Friedman, 1940) and the Wilcoxon Signed Ranks test (Wilcoxon, 1945), were used to compare groups and rank orders. Spearman's correlation coefficient was used to measure the strength of association between frequency and appraisal ratings.

For latent variables used in the hypothesized structural models, the dimensionality of the items underlying each latent variable was determined, and measurement models were constructed prior to examination of the hypothesized structural models. Principal axis factoring was chosen specifically because it can be used with non-normal distributions (Fabrigar, Wegener, MacCallum, & Strahan, 1999). Prior to beginning the factor analysis, the suitability of the measured items was assessed using correlation coefficients (Tabachnick & Fidell, 2013), the Kaiser-Meyer-Olkin measure of sampling adequacy (Kaiser, 1970; Kaiser & Rice, 1974), and Bartlett’s test of sphericity (Bartlett, 1937). The number of factors to retain was determined by the Kaiser Criterion (Kaiser, 1960). Because Kaiser’s criterion has been criticized for retention of too many factors (Pallant, 2010), Horn’s parallel analysis was also used (Horn, 1965). The rationale underlying parallel analysis is that factors derived from observed data should have larger eigenvalues than those factors derived from random data having the same sample size and number of variables. Parallel analyses were conducted in this study using Monte Carlo PCA for Parallel Analysis software (Watkins, 2000).

Structural equation modeling was used to analyze the covariance matrix, using robust estimation because data violated the assumption of univariate and multivariate normality. Two measures of absolute fit and two measures of relative fit were used to judge each model: the root mean square error of approximation (RMSEA, Steiger & Lind, 1980); the standardized root mean square residual (SRMR, Hu & Bentler, 1998); the non-normed fit index (NNFI, Bentler & Bonett, 1980); and the comparative fit index (CFI, Bentler, 1990). In addition, the Satorra-Bentler scaled chi-square (Satorra & Bentler, 1994; 2001; 2010) was used in place of the maximum likelihood chi-square statistic. This scaled chi-square utilizes a scaling correction factor to adjust for bias due to non-normality and is commonly used in the structural equation modeling literature (Bryant & Satorra, 2012). When comparing nested models, a scaled difference chi-squared test (Bryant & Satorra, 2012; Satorra & Bentler, 2001) was computed using a software program developed by Bryant and Satorra (2013).

In constructing the measurement models, a decision was made to use the multivariate technique of item parceling. A parcel is “an aggregate level indicator comprised of the sum (or average) of two or more items, responses or behaviors” (T. D. Little, Cunningham, Shahar, & Widaman, 2002). Homogeneous parcels, also referred to as unidimensional or internally consistent parcels, are created by summing or averaging two or more items that load on the same first-order factor (Coffman & MacCallum, 2005; Kishton & Widaman, 1994; T. D. Little et al., 2002). This first approach maintains the unidimensional nature of each first-order factor and allows the higher-order latent construct to maintain its multidimensional nature. An alternative construction method is creating domain-representative parcels by randomly assigning an equal number of items into a set of parcels and then summing or averaging the items within each parcel (Coffman & MacCallum, 2005; Kishton & Widaman, 1994; T. D. Little et al., 2002). This second approach attempts to account for multidimensionality of the broader construct while allowing each parcel to equally represent all dimensions of it. Using either construction method results in summary variables which serve as composite indicators of the broader construct under investigation.

The utility and efficacy of parcels has been debated for more than 60 years, starting with the work of Cattell and colleagues (Cattell, 1956; Cattell & Burdsal, 1975). Although recent reviews of the parceling literature have concluded that the advantages of using parcels far outweigh the disadvantages (T. D. Little et al., 2002), careful consideration is nonetheless warranted before adopting this procedure.

Proponents of parceling argue that parcels have psychometric and model specification advantages over measured items. With regard to the psychometric merits, parcels have higher reliability (Bandalos & Finney, 2001; Cattell & Burdsal, 1975; Kishton & Widaman, 1994) and have more continuous distributions (Bagozzi & Heatherton, 1994; Bandalos & Finney, 2001; Hau & Marsh, 2004; Kishton & Widaman, 1994) compared to measured items. Parceling can be used as an alternative to data transformations when working with non-normally distributed variables because parcels are also more normally distributed compared to individual items (Bandalos, 2002; Coffman & MacCallum, 2005; T. D. Little et al., 2002). Models with parcels have fewer chances for correlated residuals and cross-loadings (T. D. Little et al., 2002) and have reduced sources of sampling error (MacCallum, Widaman, Zhang, & Hong, 1999). With regard to model specification, parceling reduces the number of items in a model, thereby making the models more parsimonious and improving the variable to sample size ratio (Bagozzi & Heatherton, 1994; Bagozzi & Edwards, 1998; Coffman & MacCallum, 2005; T. D. Little et al., 2002). Parceling can also result in more stable parameter estimates and better model fit (Bandalos, 2002; Coffman & MacCallum, 2005; Kier, Melancon, & Thompson, 1998).

Opponents of parceling have cautioned that parcels can mask important model misspecification. The greatest threat to validity of parceling is multidimensionality, leading some researchers to conclude that parceling should only be considered when the set of items to be parceled is unidimensional (Bagozzi & Heatherton, 1994; Bandalos & Finney, 2001; Bandalos, 2002). In their review of parceling literature, Bandalos and Finney (2001) discovered this unidimensional assumption is rarely tested, with less than one-third of all reviewed articles describing dimensionality of the items prior to parceling. When dimensionality of the items is unknown, parcels may mask rather than illuminate the factor structure of the data (S. G. West, Finch, & Curran, 1995), resulting in biased parameter estimates and model misspecification (Hall, Snell, & Foust, 1999). In deciding whether or not to use item parceling, careful consideration of the research goals is essential. For example, parceling is not appropriate when one seeks to understand the precise relationships between measured items (e.g., developing a measurement instrument), but it might be appropriate if one seeks to understand the relationships between constructs (T. D. Little et al., 2002).

In the current study, the research questions, data distributions, sample size, and model specification drove the decision to use parcels as indicators of latent variables. First of all, the research questions under study focus on the relationships among constructs, not among the individual measured items, thereby affording an appropriate context for the use of parcels. Secondly, univariate and multivariate distributions had high skewness and/or kurtosis values, and item parcels improved upon these non-normal distributions. Third, the total number of parameters estimated in the hypothesized model needed to be substantially reduced in order to meet sample size guidelines for structural equation modeling. The informal rule of thumb concerning appropriate sample size in structural equation modeling is that the ratio of sample size to number of parameters being estimated should be no less than 5:1 and, ideally, 10:1 (Baumgartner & Homburg, 1996; Floyd & Widaman, 1995; Vieira, 2011). Freely estimating all parameters in the hypothesized model without the use of item parcels would have required a minimum sample size of 700 (140 estimated model parameters x 5 = 700). By using parcels, the total number of parameters being estimated was reduced to 40, thereby making the current sample size of 239 adequate for testing the hypothesized model. And lastly, to assess the appropriateness of using item parcels, the dimensionality of each set of items was examined and only under conditions of unidimensionality were parcels created. Both homogenous parcels and domain-representative parcels were used in the current study, depending on a given construct’s model specification either in the current study or as reported in the literature.

Results

Results of the study are organized into several sections. This chapter begins with a description of the study sample and then proceeds to address the first two research questions. The first research question investigates the relationship between the frequency of relatives' communication behaviors and the family caregivers' appraisals of these behaviors. The second research question investigates the relationship between the frequency and appraisal of family caregivers' communication strategies.

The remaining sections of this chapter pertain to the structural model that is explored in research questions three and four. First, measurement models for each of the four variables included in the hypothesized model are identified. Next, the hypothesized model is presented and tested to address research question number three, which explores the predictive and mediated relationships between appraised communication behaviors, appraised communication strategies, problem behaviors, and caregiver burden. Lastly, caregivers' education level is investigated as a moderating variable in the final structural model.

Study Sample

The typical respondent in this study sample was a White non-Hispanic female caregiver in her sixties who lives in Wisconsin (see Table 2). Even though the Family Caregiver Support Network serves any and all family caregivers regardless of location, most of the caregivers on its mailing list are from the state of Wisconsin because this is the program's primary place of business. In the study sample, only 5.4% of respondents were living in a state other than Wisconsin. The majority of respondents were White non-Hispanics (83.3%), with Black/African American and Hispanic/Latino family caregivers being the two largest minority groups. The sample's racial profile mirrors the state of Wisconsin (U.S. Census Bureau, 2013), except the sample had a slightly higher representation of Black/African Americans (sample = 10.9%, Wisconsin = 6.5%). Most respondents were female (87.9%), and their ages ranged from 27 – 98 years ($M = 63.7$, $SD = 12.3$). The sample was fairly evenly distributed among education levels, with a slight majority of family caregivers reporting an Associate's degree or some college (32.2%). According to the U.S. Census Bureau (2013), the study sample had a higher education level, overall, than the population for the state of Wisconsin (sample = 44.3% with Bachelor's or higher, Wisconsin = 26.0%).

Respondents were asked to identify the member(s) of their family who currently have dementia. Most commonly reported were parents (68.2%) and spouses (25.5%). Of those caregivers reporting a parent with dementia, more than three-quarters of respondents (75.5%) identified their mother as the afflicted parent. Other family members identified as having dementia included siblings, cousins, aunt/uncles, children, nieces/nephews, and grandparents.

Relatives with dementia closely mirrored the demographic make-up of the caregivers. Most relatives were female and White non-Hispanic. Not surprisingly, relatives with dementia were significantly older than the family caregivers ($z = -10.793$, $p < 0.001$), with the median age for relatives being 86 years and for caregivers 63 years. In most cases, the relative had been medically diagnosed as having dementia (85.4%); in all remaining cases, dementia was suspected by the family but had not been diagnosed. More than half of all relatives with dementia lived with family members (53.6%), with most of them living with the family caregiver who responded to the survey.

Table 2: Sample characteristics (*N* = 239)

Caregivers’ Characteristics		Relatives’ Characteristics	
Age in years		Age in years	
Age, range	27 – 98	Age, range	56 – 104
Age, *M*(*SD*)	63.7 (12.3)	Age, *M(SD)*	84.4 (9.3)
Age, *Mdn*	63.0	Age, *Mdn*	86.0
Gender		Gender	
Female	87.9%	Female	61.5%
Race/Ethnicity		Race/Ethnicity	
White non-Hispanic	83.3%	White non-Hispanic	82.4%
Black/African American	10.9%	Black/African American	12.1%
Hispanic/Latino	4.6%	Hispanic/Latino	5.0%
All Others	1.2%	All Others	0.4%
Education		Relationship to Caregiver*	
HS degree or less	23.4%	Parent	68.2%
Some college	32.2%	Spouse	25.5%
Bachelor’s degree	25.1%	Other family member	15.9%
Graduate degree	19.2%		
		Living arrangement	
Communication Frequency		Alone in own home	14.2%
Daily	62.8%	With caregiver	38.5%
Every 2-3 days	21.8%	With other family member(s)	15.1%
Weekly	15.5%	Group setting (not a NH)	15.9%
		Nursing home	16.3%
Support Provided			
Socialization	89.5%	Dementia medically diagnosed	85.4%
ADLs, *M(SD)*	1.4(1.7)		
IADLs, *M(SD)*	4.7(2.8)		

*Multiple responses possible (sum >100%)

Family caregivers provided a variety of assistance to their relative with dementia. The majority of caregivers reported socializing with their relative as one of the key types of support they provide. Almost two-thirds of the caregivers (62.8%) communicated with their relative daily, with an additional 21.8% communicating every 2-3 days. Family caregivers also provided an average of 4.7 instrumental activities of daily living (e.g., shopping, laundry, transportation) and 1.4 activities of daily living (e.g., eating, toileting).

Frequency and Appraisal of Relatives' Communication Behaviors

Dementia family caregivers rated thirty-two communication behaviors according to how frequently their relative with dementia displayed them. Visual inspection of histograms and normal probability plots as well as calculation of z-scores for skewness and kurtosis values helped assess univariate normality (see Table 3). All but one of the observed variables revealed significant skewness and/or kurtosis, and Shapiro-Wilk's test confirmed that all 32 items violated the assumption of normality. The tests of multivariate normality for skewness and kurtosis also showed significant departures from normality (skewness $z = 17.82$, $p < 0.0001$; kurtosis $z = 8.76$, $p < 0.0001$).

According to Friedman's test, there was a statistically significant difference in frequency of occurrence depending on the type of communication behavior, $\chi^2(31) = 1203.014$, $p < 0.001$. Examination of descriptive statistics revealed which communication behaviors were observed most and least frequently by dementia family caregivers. Means, standard deviations, medians, and mean rankings for frequency of the relative's communication behaviors are reported in Table 4. Median values of dementia family caregivers' ratings of frequency ranged between 1 (i.e., communication behaviors never occurring) and 4 (i.e., communication behaviors frequently occurring).

The five most frequently occurring communication behaviors, in rank order, were: failure to retain instructions (*Mdn* = 4, *IQR* 3-4); repeated questions and comments (*Mdn* = 4, *IQR* 3-4); failure to remember family, friends or events discussed in conversation (*Mdn* = 4, *IQR* 3-4); failure to respond when selected as next speaker (*Mdn* = 3, *IQR* 2-4); and repeated initiations of favorite topics (*Mdn* = 4, *IQR* 2-4). Four of these five most frequent behaviors had a median value of 4.0, which reflects the fact that more than half of all respondents (50.2% - 64.4%) indicated that these behaviors always or frequently occurred while interacting with the relative.

Table 3: Tests of univariate normality for 32 communication behavior frequency items (*N* = 239)

Item	Skewness		Kurtosis		Shapiro-Wilk	
	z	*p*-value	*z*	*p*-value	statistic	*p*-value
1	-0.770	0.441	-7.151	< .001***	.908	< .001***
2	-0.860	0.390	-5.017	< .001***	.907	< .001***
3	0.484	0.628	-4.395	< .001***	.918	< .001***
4	2.548	0.011*	-3.553	< .001***	.893	< .001***
5	4.464	< .001***	-0.898	0.369	.851	< .001***
6	6.186	< .001***	1.296	0.195	.770	< .001***
7	-0.014	0.989	-7.344	< .001***	.909	< .001***
8	2.265	0.024*	-3.404	0.001***	.876	< .001***
9	-0.062	0.950	-4.869	< .001***	.911	< .001***
10	1.753	0.080	-3.531	< .001***	.900	< .001***
11	5.280	< .001***	-1.924	0.054	.748	< .001***
12	-2.862	0.004**	-4.484	< .001***	.881	< .001***
13	0.882	0.378	-4.171	< .001***	.910	< .001***
14	0.737	0.461	-5.595	< .001***	.884	< .001***
15	2.898	0.004**	-3.055	0.002**	.860	< .001***
16	2.094	0.036*	-4.398	< .001***	.884	< .001***
17	-3.618	< .001***	-3.050	0.002**	.873	< .001***
18	-2.153	0.031*	-2.264	0.024*	.904	< .001***
19	-4.610	< .001***	1.543	0.123	.861	< .001***
20	2.549	0.011*	-4.469	< .001***	.880	< .001***
21	-1.248	0.212	-4.861	< .001***	.907	< .001***
22	0.512	0.609	-3.572	< .001***	.902	< .001***
23	1.783	0.075	-2.816	0.005**	.906	< .001***
24	1.274	0.203	-7.082	< .001***	.902	< .001***
25	-1.113	0.266	-0.556	0.578	.904	< .001***
26	3.462	0.001***	-2.566	0.010**	.863	< .001***
27	-0.404	0.686	-5.462	< .001***	.914	< .001***
28	-0.631	0.528	-4.881	< .001***	.908	< .001***
29	0.232	0.817	-4.036	< .001***	.917	< .001***
30	2.567	0.010**	-9.802	< .001***	.862	< .001***
31	4.658	< .001***	-2.552	0.011*	.813	< .001***
32	4.815	< .001***	-1.717	0.086	.815	< .001***

*p < .05   **p < .01   ***p < .001

Table 4: Mean ranking of 32 communication behavior frequency items (*N* = 239)

Communication Behavior	Frequency Rating		
	Mean Rank	*M* (SD)	*Mdn*
19. Failure to retain instructions	24.22	3.71 (1.01)	4.0
17. Repeated questions and comments	22.51	3.49 (1.28)	4.0
18. Failure to remember family, friends or events discussed in conversation	21.97	3.45 (1.09)	4.0
2. Failure to respond when selected as next speaker	20.84	3.34 (1.12)	3.0
12. Repeated initiations of favorite topics	20.83	3.24 (1.28)	4.0
1. Ability to initiate conversation	20.21	3.12 (1.25)	3.0
25. Failure in comprehension	20.04	3.18 (1.01)	3.0
21. Failure in word retrieval	18.95	3.00 (1.18)	3.0
27. Ability to interpret non-literal meaning	18.65	2.96 (1.24)	3.0
29. Ability to understand humor	18.36	3.00 (1.18)	3.0
28. Ability to use humor	18.32	2.89 (1.19)	3.0
7. Reliance on minimal acknowledgements	17.81	2.93 (1.27)	3.0
9. Ability to maintain topics	17.60	2.78 (1.13)	3.0
3. Delay in responding when selected as next speaker	17.54	2.85 (1.13)	3.0
13. Ability to initiate repair on conversational partner's turn	16.78	2.69 (1.12)	3.0
24. Overuse of pronouns and proforms	16.57	2.72 (1.29)	3.0
22. Production of circumlocutions	16.47	2.67 (1.14)	3.0
10. Failure to orient conversational partner to new topics	15.31	2.52 (1.13)	3.0
23. Production of uncorrected semantic paraphasia	15.25	2.56 (1.10)	3.0
30. Impairment of articulation	14.90	2.60 (1.43)	2.0
14. Ability to initiate repairs on own errors	14.88	2.41 (1.05)	2.0
4. Production of long pauses in the middle of turns	14.46	2.47 (1.19)	2.0
16. Ability to repair own turn when initiated by conversation partner	14.37	2.36 (1.12)	2.0
20. Presence of abandoned turns	13.51	2.33 (1.11)	2.0
8. Ability to initiate new topics	13.07	2.24 (1.02)	2.0
26. Ability to make inferences	12.65	2.17 (1.08)	2.0
15. After self-initiation repairs own errors without help	12.59	2.13 (1.03)	2.0
31. Impairment of volume control	12.55	2.20 (1.33)	2.0
5. Violation of conversational partner's turn	12.46	2.17 (1.14)	2.0
32. Production of monotonous intonation	12.41	2.17 (1.30)	2.0
11. Topics based on hallucinations and/or delusions	11.23	2.00 (1.31)	1.0
6. Failure to hand over conversational floor	10.26	1.95 (1.19)	2.0

Note. Frequency scale: 1=never, 2=rarely, 3=occasionally, 4=frequently, 5=always.
$*p < .05$ $**p < .01$ $***p < .001$

On the opposite end of the frequency spectrum, twelve of the communication behaviors had a median value of 2.0, indicating these behaviors occurred rarely during interpersonal communication. Only one behavior was reported by the majority of dementia family caregivers as never occurring; specifically, more than half of all respondents (56.1%) reported their relative never talked about topics based on hallucinations and/or delusions (*Mdn* = 1, *IQR* 1-3).

Dementia family caregivers also rated each of the 32 communication behaviors according to how frustrating the behavior is when it occurs during interactions with their relative. Histograms, normal probability plots, skewness values, kurtosis values, and Shapiro-Wilk's test were used to determine whether the data were normally distributed. A large number of significant *p*-values for skewness, kurtosis, and Shapiro-Wilk's test indicated that all 32 items violated the assumption of univariate normality (see Table 5). Multivariate normality was also violated (skewness $z = 27.73$, $p < 0.0001$; kurtosis $z = 14.42$, $p < 0.0001$).

Means, standard deviations, medians, and mean rankings for caregivers' frustration with the communication behaviors are reported in Table 6. Results of Friedman's test indicated there was a statistically significant difference in frustration depending on the type of communication behavior, $\chi^2(31) = 995.123$, $p < 0.001$. Only two of the communication behaviors assessed were rated by the majority of family caregivers as being somewhat frustrating (*Mdn* = 4). The two most frustrating communication behaviors, in rank order, were failure to retain instructions (*Mdn* = 4, *IQR* 3-5) and repeated questions and comments (*Mdn* = 4, *IQR* 3-5). Seven additional behaviors had a median value of 3.0, indicating they were a little frustrating to family

Table 5: Tests of univariate normality for 32 communication behavior appraisal items (N = 239)

Item	Skewness		Kurtosis		Shapiro-Wilk	
	z	p-value	z	p-value	statistic	p-value
1	5.055	< .001***	0.115	0.909	.849	< .001***
2	3.738	< .001***	-1.110	0.267	.902	< .001***
3	3.420	0.001***	-1.067	0.286	.911	< .001***
4	4.131	< .001***	0.098	0.922	.894	< .001***
5	4.119	< .001***	-1.217	0.224	.882	< .001***
6	5.202	< .001***	0.493	0.622	.844	< .001***
7	4.487	< .001***	-0.118	0.906	.885	< .001***
8	5.100	< .001***	0.991	0.322	.869	< .001***
9	3.766	< .001***	-1.218	0.223	.891	< .001***
10	3.451	0.001***	-0.349	0.727	.905	< .001***
11	5.401	< .001***	-0.671	0.502	.803	< .001***
12	0.885	0.376	-4.264	< .001***	.931	< .001***
13	2.101	0.036*	-4.232	< .001***	.915	< .001***
14	5.563	< .001***	2.020	0.043*	.851	< .001***
15	6.414	< .001***	3.508	< .001***	.826	< .001***
16	4.320	< .001***	0.089	0.929	.891	< .001***
17	-0.815	0.415	-3.474	0.001***	.937	< .001***
18	2.136	0.033*	-1.398	0.162	.925	< .001***
19	-0.340	0.734	-2.887	0.004**	.936	< .001***
20	4.383	< .001***	0.492	0.623	.883	< .001***
21	2.915	0.004**	-1.452	0.146	.912	< .001***
22	4.450	< .001***	0.523	0.601	.869	< .001***
23	4.846	< .001***	1.308	0.191	.871	< .001***
24	3.687	< .001***	-1.362	0.173	.902	< .001***
25	1.084	0.278	-3.618	< .001***	.933	< .001***
26	5.040	< .001***	1.329	0.184	.876	< .001***
27	4.698	< .001***	1.088	0.277	.885	< .001***
28	7.285	< .001***	3.992	< .001***	.765	< .001***
29	6.400	< .001***	2.884	0.004**	.805	< .001***
30	4.717	< .001***	-0.666	0.505	.871	< .001***
31	5.411	< .001***	0.182	0.856	.834	< .001***
32	6.472	< .001***	2.286	0.022*	.808	< .001***

*$p < .05$ **$p < .01$ ***$p < .001$

Table 6: Mean ranking of 32 communication behavior appraisal items (*N* = 239)

Communication Behavior	Appraised Frustration		
	Mean Rank	*M* (SD)	*Mdn*
19. Failure to retain instructions	23.90	3.68 (1.27)	4
17. Repeated questions and comments	23.39	3.59 (1.40)	4
25. Failure in comprehension	22.51	3.46 (1.30)	3
18. Failure to remember family, friends, events discussed in conversation	21.67	3.30 (1.21)	3
12. Repeated initiations of favorite topics	20.44	3.18 (1.42)	3
13. Ability to initiate repair on conversational partner's turn	19.49	3.10 (1.32)	3
7. Reliance on minimal acknowledgements	17.53	2.82 (1.35)	2
3. Delay in responding when selected as next speaker	17.52	2.82 (1.25)	3
21. Failure in word retrieval	17.33	2.76 (1.21)	3
1. Ability to initiate conversation	17.10	2.81 (1.31)	2
2. Failure to respond when selected as next speaker	16.96	2.78 (1.32)	2
10. Failure to orient conversational partner to new topics	16.81	2.72 (1.25)	3
24. Overuse of pronouns and proforms	16.66	2.72 (1.34)	2
27. Ability to interpret non-literal meaning	16.37	2.66 (1.22)	2
9. Ability to maintain topics	16.13	2.67 (1.28)	2
16. Ability to repair own turn when initiated by conversation partner	16.12	2.63 (1.27)	2
8. Ability to initiate new topics	15.32	2.52 (1.26)	2
4. Production of long pauses in the middle of turns	15.29	2.52 (1.24)	2
14. Ability to initiate repairs on own errors	15.10	2.49 (1.15)	2
5. Violation of conversational partner's turn	15.00	2.49 (1.33)	2
22. Production of circumlocutions	14.74	2.46 (1.10)	2
26. Ability to make inferences	14.61	2.48 (1.23)	2
23. Production of uncorrected semantic paraphasia	14.41	2.45 (1.11)	2
30. Impairment of articulation	14.41	2.60 (1.48)	2
31. Impairment of volume control	14.35	2.46 (1.51)	2
29. Ability to understand humor	14.30	2.43 (1.11)	2
20. Presence of abandoned turns	14.29	2.40 (1.19)	2
28. Ability to use humor	13.46	2.30 (1.09)	2
15. Ability after self-initiation to repair own errors without help	12.98	2.24 (1.09)	2
6. Failure to hand over conversational floor	12.95	2.29 (1.34)	2
11. Presence of topics based on hallucinations and/or delusions	12.93	2.26 (1.48)	2
32. Production of monotonous intonation	12.86	2.27 (1.36)	2

Note. Appraised helpfulness scale: 1=does not apply, 2=not at all, 3=a little, 4=somewhat, 5=very much, 6=extremely.

caregivers, but the vast majority of communication behaviors (23 of 32, or 72%) were viewed as not at all frustrating, with a median value of 2.0. The three lowest ranked communication behaviors, indicating family caregivers' found them least frustrating, were failure to hand over conversational floor (*Mdn* = 2, *IQR 1-3*); presence of topics based on hallucinations and/or delusions (*Mdn* = 2, *IQR 1-3*); and production of monotonous intonation (*Mdn* = 2, *IQR 1-3*).

When comparing mean rankings, concordance between frequency and appraisal existed for communication behaviors at both ends of the spectrum. The two behaviors occurring most frequently and ranked as most frustrating were: failure to retain instructions (frequency *Mdn* = 4, *IQR* 3-4; appraisal *Mdn* = 4, *IQR* 3-4) and repeated questions and comments (frequency *Mdn* = 4, *IQR* 3-5; appraisal *Mdn* = 4, *IQR* 3-5). Similarly, at the other end of the spectrum, the three least frequent communication behaviors were also the three lowest ranked in terms of frustration. The three behaviors which occurred least often and were least frustrating included: failure to hand over conversational floor (frequency *Mdn* = 2, *IQR* 1-3; appraisal *Mdn* = 2, *IQR* 1-3); presence of topics based on hallucinations and/or delusions (frequency *Mdn* = 1, *IQR* 1-3; appraisal *Mdn* = 2, *IQR* 1-3); and production of monotonous intonation (frequency *Mdn* = 2, *IQR* 1-3; appraisal *Mdn* = 2, *IQR* 1-3).

The Wilcoxon Signed Ranks test was used to examine pairwise comparisons of the frequency and appraisal of each communication behavior (see Table 7). Results indicated there was a statistically significant difference between frequency and appraisal for 18 of the 32 communication behaviors, with small and medium effect sizes (J. Cohen, 1988).

Table 7: Pairwise comparisons of communication behavior frequency and appraisal rankings (*N* = 239)

Communication Behavior	Wilcoxon Freq-Frus |*z*|	Effect size *r*
1. Ability to initiate conversation	2.85**	0.13
2. Failure to respond when selected as next speaker	3.77***	0.17
3. Delay in responding when selected as next speaker	0.46	--
4. Production of long pauses in the middle of turns	0.92	--
5. Violation of conversational partner's turn	5.58***	0.26
6. Failure to hand over conversational floor	5.54***	0.25
7. Reliance on minimal acknowledgements	1.51	--
8. Ability to initiate new topics	3.13**	0.14
9. Ability to maintain topics	1.09	--
10. Failure to orient conversational partner to new topics	2.93**	0.13
11. Topics based on hallucinations and/or delusions	3.76***	0.17
12. Repeated initiations of favorite topics	0.86	--
13. Ability to initiate repair on conversational partner's turn	3.83***	0.18
14. Ability to initiate repairs on own errors	0.32	--
15. Ability after self-initiation to repair own errors without help	1.03	--
16. Ability to repair own turn when initiated by conversation partner	2.18*	0.10
17. Repeated questions and comments	1.42	--
18. Failure to remember family, friends, events discussed in conversation	2.02*	0.09
19. Failure to retain instructions	0.34	--
20. Presence of abandoned turns	1.47	--
21. Failure in word retrieval	3.28***	0.15
22. Production of circumlocutions	2.80**	0.13
23. Production of uncorrected semantic paraphasias	1.77	--
24. Overuse of pronouns and proforms	0.25	--
25. Failure in comprehension	4.01***	0.18
26. Ability to make inferences	2.82**	0.13
27. Ability to interpret non-literal meaning	3.73***	0.17
28. Ability to use humor	5.81***	0.27
29. Ability to understand humor	6.74***	0.31
30. Impairment of articulation	0.34	--
31. Impairment of volume control	4.49***	0.21
32. Production of monotonous intonation	1.84	--

**p* < .05 ***p* < .01 ****p* < .001

Ten items had higher frequency ratings and significantly lower frustration levels, indicating these behaviors occurred frequently but were not very frustrating to the caregiver:

1. Violation of conversational partner’s turn;
2. Failure to hand over conversational floor;
3. Ability to initiate new topics;
4. Failure to orient conversational partner to new topics;
5. Presence of topics based on hallucinations and/or delusions;
6. Ability to initiate repair on conversational partner’s turn;
7. Ability to repair own turn when initiated by conversational partner;
8. Failure in comprehension;
9. Ability to make inferences; and
10. Impairment of volume control.

An additional eight communication behaviors had high frustration ratings and significantly lower frequency ratings, indicating these behaviors did not occur frequently but when they did, they were very frustrating to the caregiver:

1. Ability to initiate conversations;
2. Failure to respond when selected as next speaker;
3. Failure to remember family, friends, or events discussed in conversation;
4. Failure in word retrieval;
5. Production of circumlocutions;
6. Ability to interpret non-literal meaning;
7. Ability to use humor; and
8. Ability to understand humor.

Following reverse coding of all positively phrased behaviors, the correlation between mean frequency and appraisal (across all communication behaviors) was calculated and found to be significant, Spearman $r = 0.567$, $N = 239$, $p < 0.001$. In general, communication behaviors reported to occur more frequently also were appraised to be more frustrating by caregivers. Individual behaviors were also examined, and significant correlations were observed between frequency and appraisal for 30 individual behaviors (see Table 8). Two of the significant correlations were negative (i.e., failure to respond when selected as next speaker and failure to hand over conversational floor), indicating higher frequency of occurrence was associated with lower caregiver frustration.

Table 8: Spearman's correlations between communication behavior frequency and appraisal (*N* = 239)

Communication Behavior	Spearman *r*
1. Ability to initiate conversation	-0.12
2. Failure to respond when selected as next speaker	-0.66***
3. Delay in responding when selected as next speaker	0.69***
4. Production of long pauses in the middle of turns	0.65***
5. Violation of conversational partner's turn	0.80***
6. Failure to hand over conversational floor	-0.66***
7. Reliance on minimal acknowledgements	0.58***
8. Ability to initiate new topics	0.54***
9. Ability to maintain topics	-0.07
10. Failure to orient conversational partner to new topics	0.68***
11. Topics based on hallucinations and/or delusions	0.81***
12. Repeated initiations of favorite topics	0.62***
13. Ability to initiate repair on conversational partner's turn	0.25***
14. Ability to initiate repairs on own errors	0.29***
15. Ability after self-initiation to repair own errors without help	0.32***
16. Ability to repair own turn when initiated by conversation partner	0.21***
17. Repeated questions and comments	0.59***
18. Failure to remember family, friends, events discussed in conversation	0.38***
19. Failure to retain instructions	0.42***

Table 8 (continued)

Communication Behavior	Spearman *r*
20. Presence of abandoned turns	0.68***
21. Failure in word retrieval	0.55***
22. Production of circumlocutions	0.44***
23. Production of uncorrected semantic paraphasias	0.56***
24. Overuse of pronouns and proforms	0.70***
25. Failure in comprehension	0.57***
26. Ability to make inferences	0.24***
27. Ability to interpret non-literal meaning	0.41***
28. Ability to use humor	0.14*
29. Ability to understand humor	0.47***
30. Impairment of articulation	0.76***
31. Impairment of volume control	0.83***
32. Production of monotonous intonation	0.75***

$^{*}p < .05$ $^{**}p < .01$ $^{***}p < .001$

Frequency and Appraisal of Caregivers' Communication Strategies

Dementia family caregivers rated nineteen communication strategies according to how frequently they used each strategy during interactions with their relative. Frequency ratings were along a five-point scale, ranging from 1 (never) to 5 (always). Visual inspection of histograms and normal probability plots as well as calculation of skewness and kurtosis values helped assess univariate normality (see Table 9). Results of Shapiro-Wilk's test indicated that all items violated the assumption of univariate normality ($p < 0.001$). Multivariate normality, as expected, was also violated (skewness $z = 21.65$, $p < 0.0001$; kurtosis $z = 11.79$, $p < 0.0001$).

Table 9: Tests of univariate normality for 19 communication strategy frequency items ($N = 239$)

Item	Skewness		Kurtosis		Shapiro-Wilk	
	z	*p*-value	*z*	*p*-value	statistic	*p*-value
1	2.666	0.008**	-19.236	< .001***	.819	< .001***
2	-1.252	0.211	-9.485	< .001***	.892	< .001***
3	-6.128	< .001***	0.831	0.406	.771	< .001***
4	-6.203	< .001***	3.002	0.003**	.804	< .001***
5	-4.954	< .001***	1.365	0.172	.840	< .001***
6	-4.599	< .001***	0.023	0.981	.851	< .001***
7	-6.193	< .001***	2.444	0.015*	.802	< .001***
8	-3.193	0.001***	-0.317	0.751	.888	< .001***
9	-2.972	0.003**	1.118	0.263	.867	< .001***
10	1.988	0.047*	-8.314	< .001***	.870	< .001***
11	-4.542	< .001***	0.875	0.382	.863	< .001***
12	-1.611	0.107	-2.775	0.006**	.911	< .001***
13	-4.887	< .001***	1.458	0.145	.851	< .001***
14	-5.785	< .001***	3.59	< .001***	.805	< .001***
15	-1.995	0.046*	-2.987	0.003**	.906	< .001***
16	0.113	0.910	-3.732	< .001***	.911	< .001***
17	-1.02	0.308	-5.775	< .001***	.911	< .001***
18	-3.647	< .001***	-1.026	0.305	.884	< .001***
19	-7.869	< .001***	4.951	< .001***	.713	< .001***

*$p < .05$ **$p < .01$ ***$p < .001$

Descriptive statistics revealed that all of the nineteen communication strategies measured in this study were used by dementia family caregivers to some extent. Table 10 includes the means, standard deviations, medians, and rankings of strategy frequency. Friedman's test revealed there was a statistically significant difference in frequency depending on the type of communication strategy, $\chi^2(18) = 1097.23$, $p < 0.001$. Noteworthy was the strategy of "paying attention, actively listening to your relative" which had a median of 5.0 for usage, indicating family caregivers reported always using it. Ten additional strategies were frequently used by family caregivers (*Mdn* = 4). These strategies, listed in rank order, were ask one question/give one instruction at a time

Table 10: Mean ranking of 19 communication strategy frequency items (*N* = 239)

Communication Strategy	Frequency Rating		
	Mean Rank	*M* (SD)	*Mdn*
19. Pay attention, actively listen	14.45	4.38 (0.85)	5.0
4. Ask one question or give one instruction at a time	12.92	4.07 (0.95)	4.0
14. Use relaxed, calm tone	12.70	4.10 (0.84)	4.0
7. Allow plenty of time for a response	12.46	4.01 (1.08)	4.0
5. Use short, simple sentences	12.30	3.98 (0.97)	4.0
3. Call your relative by name	12.27	3.95 (1.29)	4.0
6. Speak slowly and clearly	11.83	3.88 (1.08)	4.0
13. Establish and maintain eye contact	11.40	3.82 (1.06)	4.0
18. Watch for nonverbal cues	10.31	3.56 (1.14)	4.0
8. Repeat message using same wording	10.19	3.58 (1.01)	4.0
11. Use closed-ended questions (yes/no, choice)	9.97	3.51 (1.06)	4.0
2. Attract relative's attention before speaking	8.49	3.15 (1.37)	3.0
15. Suggest word(s) or help complete a sentence	8.38	3.18 (1.13)	3.0
12. Eliminate distractions & noise (TV, radio)	8.30	3.21 (1.13)	3.0
9. Repeat message using different wording	7.97	3.15 (0.89)	3.0
17. Point to objects, pictures	7.78	3.07 (1.22)	3.0
16. Use gestures & body language	6.44	2.79 (1.14)	3.0
1. Identify yourself as you approach	6.44	2.54 (1.54)	2.0
10. Encourage "talking around" a missing word	5.42	2.40 (1.22)	2.0

Note. Frequency scale: 1=never, 2=rarely, 3=occasionally, 4=frequently, 5=always.

(*IQR 4-5)*; use a relaxed, calm tone of voice (*IQR 4-5)*; allow plenty of time for a response (*IQR 3-5)*; use short simple sentences (*IQR 3-5)*; call your relative by name (*IQR 3-5)*; speak slowly and clearly (*IQR 3-5)*; establish and maintain eye contact (*IQR 3-5)*; watch for nonverbal cues (*IQR 3-4)*; repeat your message using the same words (*IQR 3-4)*; and use close-ended questions (*IQR 3-4).* On the opposite end of the frequency spectrum, two strategies were rarely used by family caregivers: identify yourself as you approach (*Mdn* = 2, *IQR* 1-4), and encourage your relative to talk around a missing word (*Mdn* = 2, *IQR* 1-3).

Communication strategies also were rated by dementia family caregivers according to how helpful they were in facilitating communication with their relative who has dementia. Ratings were made along a 6-point scale ranging from 1 (does not apply) to 6 (extremely helpful). Histograms, normal Q-Q plots, skewness values, and Shapiro-Wilk's test were used to determine whether the data were normally distributed (see Table 11). Shapiro- Wilk's test results indicated that all nineteen items violated the assumption of univariate normality ($p < 0.001$). As expected, multivariate normality was also violated (skewness $z = 27.73$, $p < 0.0001$; kurtosis $z = 14.42$, $p < 0.0001$).

Table 11: Tests of univariate normality for 19 communication strategy appraisal items (*N* = 239)

Item	Skewness		Kurtosis		Shapiro-Wilk	
	z	*p*-value	z	*p*-value	statistic	*p*-value
1	1.728	0.084	57.548	< .001***	.828	< .001***
2	-2.385	0.017*	-5.744	< .001***	.908	< .001***
3	-2.924	0.003**	-5.716	< .001***	.895	< .001***
4	-4.993	< .001***	0.061	0.951	.855	< .001***
5	-4.648	< .001***	0.069	0.945	.878	< .001***
6	-4.132	< .001***	-1.076	0.282	.889	< .001***
7	-4.248	< .001***	-1.011	0.312	.885	< .001***
8	-3.250	0.001***	-1.411	0.158	.908	< .001***
9	-3.214	0.001***	-0.456	0.648	.912	< .001***
10	1.220	0.222	-13.955	< .001***	.879	< .001***
11	-3.672	< .001***	-0.875	0.382	.907	< .001***
12	-2.173	0.030*	-4.526	< .001***	.921	< .001***
13	-3.582	< .001***	-1.857	0.063	.905	< .001***
14	-4.040	< .001***	-1.131	0.258	.889	< .001***
15	-2.309	0.021*	-3.640	< .001***	.920	< .001***
16	0.316	0.752	-5.233	< .001***	.925	< .001***
17	-2.103	0.036*	-5.291	< .001***	.916	< .001***
18	-2.946	0.003**	-2.803	0.005**	.912	< .001***
19	-5.149	< .001***	0.489	0.625	.859	< .001***

**p* < .05 ***p* < .01 ****p* < .001

Means, standard deviations, medians, and rankings of communication strategy appraisal are reported in Table 12. Median values for strategy appraisal ranged between 3 and 5, indicating most family members found each of the strategies to be at least a little helpful in facilitating communication. Friedman's test revealed there was a statistically significant difference in appraised helpfulness depending on the type of communication strategy, $\chi^2(18) = 656.38$, $p < 0.001$. Most noteworthy were the six strategies reported as being very helpful (*Mdn* = 5). These six strategies, listed in rank order, were paying attention, actively listening (*IQR 4-6)*; ask one question/give one instruction at a time

Table 12: Mean ranking of 19 communication strategy appraisal items (*N* = 239)

Communication Strategy	Appraised Helpfulness		
	Mean Rank	*M* (SD)	*Mdn*
19. Pay attention, actively listen	12.88	4.58 (1.33)	5
4. Ask one question or give one instruction at a time	12.37	4.48 (1.29)	5
5. Use short, simple sentences	12.08	4.40 (1.29)	5
14. Use relaxed, calm tone	11.99	4.42 (1.32)	5
6. Speak slowly and clearly	11.83	4.35 (1.38)	5
7. Allow plenty of time for a response	11.39	4.25 (1.37)	5
13. Establish and maintain eye contact	10.75	4.15 (1.41)	4
3. Call your relative by name	10.28	3.98 (1.57)	4
11. Use closed-ended questions (yes/no, choice)	10.19	4.02 (1.34)	4
18. Watch for nonverbal cues	10.17	3.98 (1.44)	4
8. Repeat message using same wording	10.12	4.05 (1.25)	4
12. Eliminate distractions & noise (TV, radio)	9.45	3.84 (1.49)	4
2. Attract relative's attention before speaking	9.34	3.74 (1.53)	4
9. Repeat message, using different wording	9.27	3.84 (1.22)	4
17. Point to objects, pictures	9.08	3.69 (1.50)	4
15. Suggest word(s) or help complete a sentence	9.06	3.77 (1.43)	4
1. Identify yourself as you approach	7.14	2.95 (1.86)	3
16. Use gestures & body language	6.96	3.21 (1.46)	3
10. Encourage "talking around" a missing word	5.66	2.81 (1.51)	3

Note. Appraised helpfulness scale: 1=does not apply, 2=not at all, 3=a little, 4=somewhat, 5=very much, 6=extremely

(*IQR 4-5)*; use short simple sentences (*IQR 4-5)*; use relaxed calm tone (*IQR 4-5)*; speak slowly and clearly (*IQR 4-5)*; and allow plenty of time for a response (*IQR 4-5)*. The three lowest ranked strategies, reported as being only a little helpful, were use gestures and other body language (*Mdn* = 3, *IQR* 2-4), identify yourself as you approach (*Mdn* = 3, *IQR* 1-5), and encourage your relative to talk around a missing word (*Mdn* = 3, *IQR* 1-4).

Comparison of the mean rankings for communication strategy frequency and appraisal indicates concordance at both ends of the spectrum. The two communication strategies used most frequently by dementia family caregivers were also the strategies they felt were most helpful. Namely, these were pay attention/actively listen (frequency *Mdn* = 5, *IQR* 4-5; appraisal *Mdn* = 5, *IQR* 4-6) and ask one question/give one instruction at a time (frequency *Mdn* = 4, *IQR* 4-5; appraisal *Mdn* = 5, *IQR* 4-5).

Pairwise comparisons of the frequency and appraisal of each communication strategy were examined using the Wilcoxon Signed Ranks test (see Table 13). Results indicated there were statistically significant differences between frequency and appraisal for all but one of the nineteen strategies, with small and medium effect sizes according to Cohen's guidelines (1988). All of the statistically significant differences were based upon negative ranks wherein the caregivers' use of the communication strategy was greater than the appraised degree of helpfulness.

The correlation between mean strategy use and appraisal (across all strategies) was significant, Spearman $r = 0.631$, $N = 239$, $p < 0.001$. Significant correlations were observed between use and appraisal for all individual strategies (see Table 13).

Table 13: Pairwise comparisons of and Spearman correlations between communication strategy use and appraisal (*N* = 239)

Communication Strategy	Wilcoxon Use-Appraisal *z*	Wilcoxon Effect Size *r*	Spearman *r*
1. Identify yourself as you approach	-4.95***	0.23	0.78***
2. Attract relative's attention before speaking	-7.16***	0.33	0.67***
3. Call your relative by name	-0.63	--	0.45***
4. Ask one question or give one instruction at a time	-5.07***	0.23	0.37***
5. Use short, simple sentences	-5.34***	0.24	0.42***
6. Speak slowly and clearly	-5.60***	0.26	0.47***
7. Allow plenty of time for a response	-3.47***	0.16	0.43***
8. Repeat message using same wording	-6.04***	0.28	0.49***
9. Repeat message, using different wording	-8.44***	0.38	0.45***
10. Encourage "talking around" a missing word	-6.75***	0.31	0.85***
11. Use closed-ended questions (yes/no or choice)	-6.91***	0.32	0.57***
12. Eliminate distractions & noise (TV, radio)	-7.58***	0.35	0.62***
13. Establish and maintain eye contact	-4.68***	0.21	0.57***
14. Use relaxed, calm tone	-3.88***	0.18	0.37***
15. Suggest word(s) or help complete a sentence	-8.18***	0.37	0.69***
16. Use gestures & body language	-6.45***	0.29	0.75***
17. Point to objects, pictures	-8.24***	0.38	0.72***
18. Watch for nonverbal cues	-6.17***	0.28	0.68***
19. Pay attention, actively listen	-3.10**	0.14	0.41***

*$p < .05$ **$p < .01$ ***$p < .001$ (two-tailed)

Measurement Models

Prior to assessing the hypothesized structural models, measurement models were constructed for each of the latent variables. Measurement models for communication behavior appraisal, communication strategy appraisal, problem behaviors, and caregiver burden are each discussed separately.

Measurement model for communication behavior appraisal. Exploratory factor analysis was performed on the 32 communication behavior appraisal items to identify the underlying factor structure. Prior to beginning the factor analysis, the suitability of the items was assessed. The correlation matrixes for communication behavior appraisal revealed 55% (272 of 496) of the correlation coefficients were greater than $r = 0.3$. The Kaiser-Meyer-Olkin measure of sampling adequacy was 0.904 for communication behavior appraisal; this value is categorized as "meritorious" in Kaiser's classification of values and exceeds the recommended value of 0.6 (Hair et al., 2010; Tabachnick & Fidell, 2013). Bartlett's test of sphericity was also significant for communication behavior appraisal, χ^2 (496) = 4453.25, $p < 0.0001$. Taken together, these test results confirm the inter-correlations among the variables and provide a clear indication that exploratory factor analysis was appropriate for this set of items.

Principal axis factoring with an oblimin (correlated factors) rotation was performed on the 32 items of communication behavior appraisal. The initial solution revealed seven components with eigenvalues exceeding the Kaiser Criterion value of 1.0, which explained 35.4%, 7.5%, 4.4%, 3.6%, 2.5%, 2.3%, and 2.0% of the total variance, respectively. Horn's parallel analysis revealed that only the first four factors should be retained, as they had eigenvalues exceeding the corresponding criterion values for a randomly generated data matrix of the same size (see Table 14). A four-factor solution was then imposed upon the data and the rotated solution exhibited simple structure, explaining 49.9% of the total variance. Factor loadings and communalities of the rotated solution are presented in Table 15.

Table 14: Comparison of actual and random eigenvalues for communication behavior appraisal ($N = 239$)

Factor	Actual Eigenvalue	Random Eigenvalue
1	11.761	1.756
2	2.757	1.647
3	1.826	1.572
4	1.570	1.505
5	1.173	1.446
6	1.121	1.394
7	1.045	1.343

Table 15: Loadings and communalities for 32 communication behavior appraisal items (*N* = 239)

Item	Rotated Solution				
	Factor 1	Factor 2	Factor 3	Factor 4	Communalities
21	**.749**	.140	-.061	-.036	.574
20	**.727**	.084	-.004	-.023	.560
23	**.696**	.117	-.019	.122	.584
4	**.674**	.023	.079	-.025	.527
24	**.634**	.150	.023	.060	.522
22	**.631**	.141	.005	.145	.542
11	**.529**	.018	-.038	.187	.335
30	**.509**	-.303	.349	-.102	.541
16	**.501**	-.044	.153	.264	.487
19	.143	**.667**	.272	-.130	.664
17	.164	**.654**	-.014	.122	.574
12	.065	**.528**	.063	.360	.580
18	.324	**.465**	.103	-.021	.470
25	.300	**.390**	.332	-.134	.546
26	-.241	.159	**.699**	.280	.565
1	.082	.066	**.676**	-.083	.532
27	-.088	.104	**.662**	.204	.523
28	-.072	-.012	**.607**	.160	.384
2	.265	.125	**.549**	-.333	.576
29	.167	-.007	**.522**	.092	.439
32	.323	-.348	**.508**	.093	.564
7	.201	.042	**.496**	-.231	.397
3	.390	.034	**.464**	-.309	.573
31	.409	-.299	**.453**	-.007	.553
13	.110	.303	**.438**	.064	.460
9	.129	.218	**.310**	.287	.427
8	.052	.122	.176	**.549**	.467
14	.297	-.027	.217	**.453**	.505
15	.257	-.122	.119	**.437**	.338
6	.165	.182	.082	**.428**	.378
10	.203	.290	.038	**.371**	.407
5	.157	.288	.067	**.351**	.370

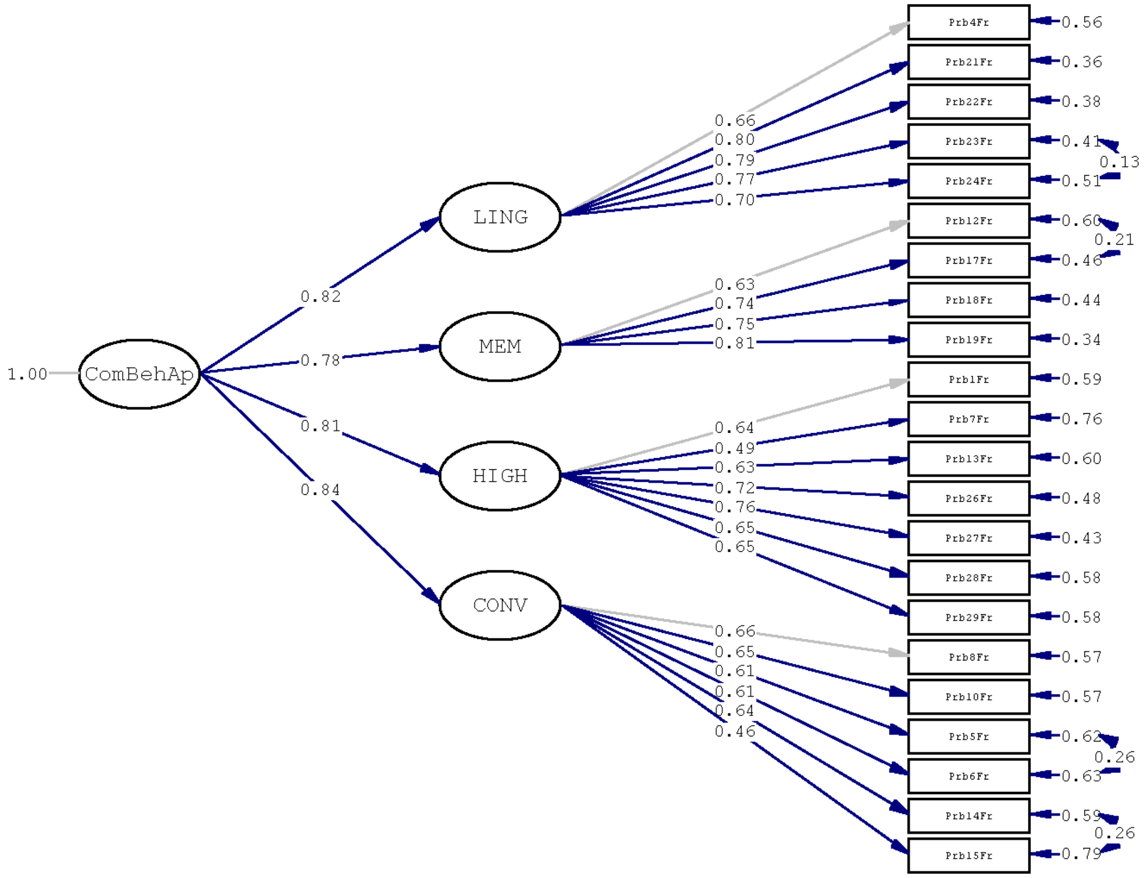
Note. Principal axis factoring with an oblimin rotation. Major loadings for each item are bolded.

Interpretation of the factors was consistent with the communication behavior classifications identified by Perkins, Whitworth and Lesser (Perkins et al., 1997), with strong loadings of linguistics items on factor 1, memory/attention items on factor 2, high-level linguistics items on factor 3, and conversation skills on factor 4. Correlations among the four factors was relatively strong, ranging from 0.62 – 0.77.

Using LISREL software, an oblique four-factor measurement model was imposed upon the data. Goodness-of-fit indices revealed a poor fit [scaled χ^2 (458, N = 239) = 1195.26, $p < 0.0001$, RMSEA = 0.130, SRMR = 0.0999, CFI = 0.954, NNFI = 0.951]. A higher-order model, with one second-order factor and four first-order factors, was imposed upon the data, and a scaled difference chi-square test was run to compare models. The second-order model produced a smaller chi-square value than the oblique first-order model with two fewer estimated model parameters, and therefore was preferred. Although the second-order model nearly attained acceptable goodness-of-fit, it was still not considered acceptable [scaled χ^2 (460, N = 239) = 1108.80, $p < 0.0001$, RMSEA = 0.103, SRMR = 0.0882, CFI = 0.956, NNFI = 0.953]. Subsequently, each factor in the four-factor measurement model was examined individually to ascertain how to improve upon model fit. Items were deleted one-by-one based upon strong cross-loadings, low multiple squared correlations, and/or high modification indices (Bentler, 1990; Hooper, Coughlan, & Mullen, 2008) and analyses were then rerun one at a time. Modification indices suggested that one pair of unique error terms be allowed to correlate within the memory/attention factor between items assessing “repeated questions and comments” and “repeated initiation of favorite topics” (MI = 67.05) and within the linguistics factor between items assessing “production of uncorrected semantic paraphasia” and “overuse of pronouns and preforms” (MI = 92.62). In addition, two pairs of correlated errors were also added to the conversation skills factor, between items assessing “violation of conversational partner’s turn” and “failure to hand over the conversational floor” (MI = 111.27) and between items assessing “ability to initiate repairs on own errors” and “ability after self-initiation to repair own errors without help” (MI = 52.53). These correlated errors seemed reasonable based upon the content of the measured items and because each correlated pair occurred within a factor. Figure 1 illustrates the full measurement model for communication behavior appraisal, which had acceptable fit across all goodness-of-fit indices [scaled χ^2 (201, N = 239) = 309.30, $p < 0.0001$, RMSEA = 0.071, SRMR = 0.065, CFI = 0.984, NNFI = 0.982] and strong internal consistency ($\alpha = 0.919$). All parameter estimates were completely standardized with the variances of items and factors fixed to 1.0.

To reduce the number of parameters being estimated in the subsequent structural models, homogeneous parcels were constructed for each of the factors underlying the broader construct of communication behavior appraisal. Using parcels as indicators of the latent variable was determined to be appropriate because the second-order model consisted of four unidimensional first-order domains, as indicated by the goodness-of-fit indices (see Table 16). Homogeneous parcels were constructed by averaging the scores of all items loading onto the same first-order factor. The resulting model (see Figure 2) had equally good fit [scaled χ^2 (2, N = 239) = 2.22, $p = 0.330$, RMSEA = 0.022, SRMR = 0.014, CFI = 0.999, NNFI = 0.998] and equally strong loadings compared to the hierarchical model which included all 22 measured items.

Figure 1: Full measurement model for 22-item communication behavior appraisal



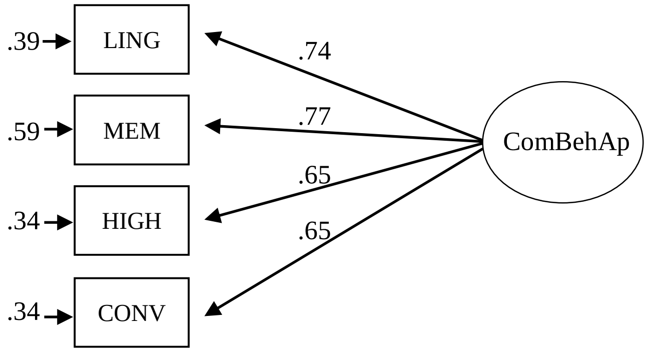
Note. ComBehAp = communication behavior appraisals; LING = linguistics; MEM = memory/attention; HIGH = high level linguistics; CONV = conversation skills. All parameter estimates were completely standardized. *N* = 239. Scaled χ^2 (201) = 309.30, *p* < 0.0001, RMSEA = 0.071, SRMR = 0.065, CFI = 0.984, NNFI = 0.982.

Table 16: Goodness-of-fit indices for communication behavior appraisal (*N* = 239)

Model	Number of Items	Scaled χ^2	*df*	RMSEA	SRMR	CFI	NNFI	α
Communication behavior appraisal 2nd order model	22	309.30	201	.071	.065	.984	.982	.919
Linguistics	5	4.96	4	.079	.020	.999	.997	.863
Higher-level linguistics	7	28.72	14	.089	.047	.984	.975	.831
Memory/attention	4	0.48	1	.000	.006	1.00	1.00	.838
Conversation skills	6	11.61	7	.078	.037	.992	.983	.797
Communication behavior appraisal model w/ parcels	4	2.22	2	.022	.014	.999	.998	.825

Note. RMSEA = root mean square error of approximation; SRMR = standardized root mean square residual; NNFI = non-normed fit index; CFI = comparative fit index.

Figure 2: Measurement model for communication behavior appraisal with 4 homogeneous parcels



Note. ComBehAp = communication behavior appraisals; LING = linguistics; MEM = memory/attention; HIGH = high level linguistics; CONV = conversation skills. All parameter estimates are completely standardized. *N* = 239. Scaled χ^2 (2) = 2.22, *p* = 0.330, RMSEA = 0.022, SRMR = 0.014, CFI = 0.999, NNFI = 0.998.

Measurement model for communication strategy appraisal. Exploratory factor analysis also was performed on the 19 communication strategy appraisal items to identify the underlying factor structure. Suitability of the items was assessed prior to beginning the factor analysis. The correlation matrixes for communication behavior appraisal revealed 82% (141 of 171) of the correlation coefficients were greater than *r* = 0.3. The Kaiser-Meyer-Olkin measure of sampling adequacy was 0.916 for communication behavior appraisal, which is categorized as "meritorious" in Kaiser's classification of values. Bartlett's test of sphericity was also significant for communication behavior appraisal, χ^2 (171) = 2624.48, *p* < 0.0001. Taken together, these test results confirm the inter-correlations among the variables and provide a clear indication that exploratory factor analysis was appropriate for this set of items.

Principal axis factoring with an oblimin rotation was performed on the 19 items of communication strategy appraisal. The initial solution revealed four components with eigenvalues exceeding the Kaiser Criterion value of 1.0, which explained 44.0%, 4.6%, 4.4%, and 2.8% of the total variance, respectively. Horn's parallel analysis revealed that only the first factor should be retained, as it was the only factor with an eigenvalue exceeding the corresponding value for a randomly generated data matrix (see Table 17). A one-factor solution was then imposed upon the data and the rotated solution exhibited simple structure, explaining 43.4% of the total variance. Factor loadings and communalities of the rotated solution are presented in Table 18.

Table 17: Comparison of actual and random eigenvalues for strategy appraisal (*N* = 239)

Factor	Actual Eigenvalue	Random Eigenvalue
1	8.762	1.538
2	1.370	1.425
3	1.221	1.352
4	1.012	1.284

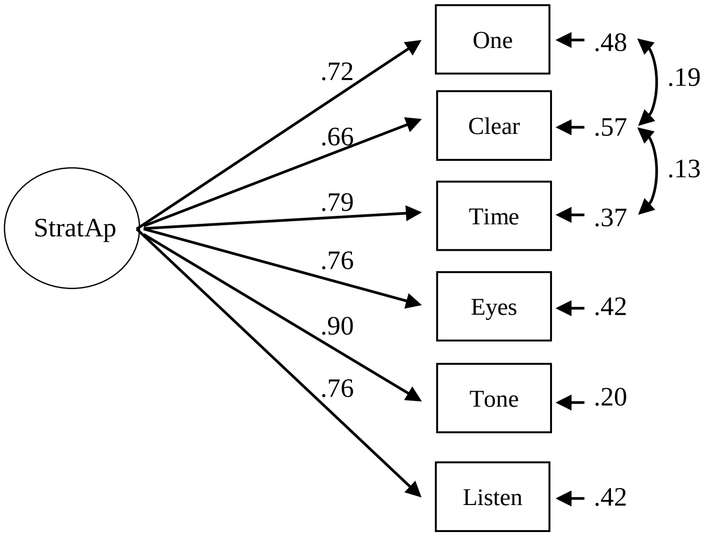
A one-factor measurement model for communication strategy appraisal was imposed upon the data using LISREL software. Goodness-of-fit indices revealed poor fit when all 19 items were included [scaled χ^2 (152, *n* = 239) = 507.36, *p* < 0.0001, RMSEA = 0.121, SRMR = 0.071, CFI = 0.954, NNFI = 0.948]. Items were deleted one-by-one based on strong cross-loadings, low multiple squared correlations, and/or high modification indices, and analyses were rerun one at a time. Modification indices suggested that two pairs of error terms be allowed to correlate: (a) between item 4, "ask one question or give one instruction at a time" and item 6, "speak slowly and clearly" (MI = 26.64); and (b) between item 6, "speak slowly and clearly" and item 7, "allow plenty of time for your relative to respond" (MI = 19.78). These correlated errors seemed reasonable based upon the content of the measured items and because each correlated pair occurred within the same factor. Figure 3 illustrates the full measurement model for communication strategy appraisal, which had acceptable fit across all indices [scaled χ^2 (7, *n* = 239) = 6.26, *p* = 0.509, RMSEA = 0.054, SRMR = 0.021, CFI = 1.00, NNFI = 1.00] and strong internal consistency (α = 0.901). All parameter estimates are completely standardized with the variances of items and factors fixed to 1.0.

Table 18: Loadings and communalities for communication strategy appraisal (*N* = 239)

Item	Rotated Solution	
	Factor 1	Communalities
14. Use relaxed, calm tone of voice	0.800	0.640
7. Allow plenty of time for a response	0.772	0.595
4. Ask one question or give one instruction at a time	0.766	0.587
6. Speak slowly and clearly	0.752	0.565
5. Use short, simple sentences	0.734	0.538
19. Pay attention, actively listen	0.728	0.530
15. Suggest word(s) or help complete a sentence	0.727	0.528
8. Repeat message using the same wording	0.711	0.505
13. Establish and maintain eye contact	0.710	0.504
3. Call your relative by name	0.694	0.481
17. Point to objects and pictures	0.610	0.372
11. Use closed-ended questions (yes/no or choices)	0.607	0.369
9. Repeat message using different wording	0.604	0.364
16. Use gestures & body language	0.603	0.363
18. Watch for nonverbal or behavior messages	0.597	0.357
2. Attract relative’s attention before speaking	0.578	0.334
12. Eliminate distractions & noise (TV, radio)	0.521	0.272
10. Encourage “talking around” a missing word	0.428	0.184
1. Identify yourself as you approach	0.385	0.148

Note. Principal axis factoring with an oblimin rotation.

Figure 3: Full measurement model for 6-item communication strategy appraisal



Note. StratAp = communication strategy appraisal; One = ask one question or give one instruction at a time; Clear = speak slowly and clearly; Time = Allow plenty of time for a response; Eyes = establish and maintain eye contact; Tone = Use relaxed, calm tone of voice; Listen = Pay attention, actively listen. All parameter estimates were completely standardized. *N* = 239. Scaled χ^2 (7) = 6.26, *p* = 0.509, RMSEA = 0.054, SRMR = 0.021, CFI = 1.00, NNFI = 1.00.

Measurement model for caregiver burden. Univariate and multivariate normality were assessed for 16 caregiver burden items and results are reported in Table 19. All but one of the items had distributions with significant skewness and/or kurtosis. Results of the Shapiro-Wilk's test confirmed all caregiver burden items had non-normal distributions.

Montgomery's 16-item caregiver burden scale has been demonstrated previously to be multidimensional with a 3-factor structure consisting of objective burden (i.e., strain on the caregiver's time), stress burden (i.e., psychological strain on the caregiver), and relationship burden (i.e., strain on the relationship between the caregiver and relative with dementia) (Savundranayagam et al., 2005; Savundranayagam et al., 2011). Six measured items load onto the factor of objective burden (e.g., decreased time for self, changed your routine, left you with no time to relax). Five additional items load onto the factor of

Table 19: Tests of univariate normality for 16 caregiver burden items ($N = 239$)

Item	Skewness		Kurtosis		Shapiro-Wilk	
	z	*p*-value	z	*p*-value	statistic	*p*-value
1	-3.386	0.001***	-0.213	0.831	.876	< .001***
2	3.935	< .001***	-2.969	0.003**	.836	< .001***
3	0.113	0.910	-2.852	0.004**	.909	< .001***
4	-1.138	0.255	-2.111	0.035*	.911	< .001***
5	2.668	0.008**	-2.705	0.007**	.882	< .001***
6	-0.376	0.707	-4.133	< .001***	.905	< .001***
7	-0.222	0.824	-6.269	< .001***	.909	< .001***
8	4.887	< .001***	-0.006	0.996	.830	< .001***
9	-0.831	0.406	-1.53	0.126	.901	< .001***
10	-3.718	< .001***	0.025	0.980	.878	< .001***
11	6.052	< .001***	1.171	0.242	.776	< .001***
12	-0.621	0.534	-2.93	0.003**	.904	< .001***
13	-0.036	0.971	-4.512	< .001***	.914	< .001***
14	3.432	0.001***	-2.7	0.007**	.866	< .001***
15	-3.196	0.001***	-0.609	0.543	.886	< .001***
16	-0.232	0.817	-5.481	< .001***	.908	< .001***

*$p < .05$ **$p < .01$ ***$p < .001$

relationship burden (e.g., caused conflicts with your relative, made you feel like you were being taken advantage of, increased the number of unreasonable requests made by your relative), and five other items load onto the factor of stress burden (e.g., created a feeling of hopelessness, made you nervous, caused you to worry). Because the presence and the exact configuration of correlated error terms have varied across studies, correlated error terms were initially omitted from the measurement model. An oblique three-factor model was imposed on the data and determined to have reasonably close fit [scaled χ^2 (101, N = 239) = 213.79, $p < 0.0001$, RMSEA = 0.080, SRMR = 0.059, CFI = 0.982, NNFI = 0.978] and strong internal consistency ($\alpha = 0.928$).

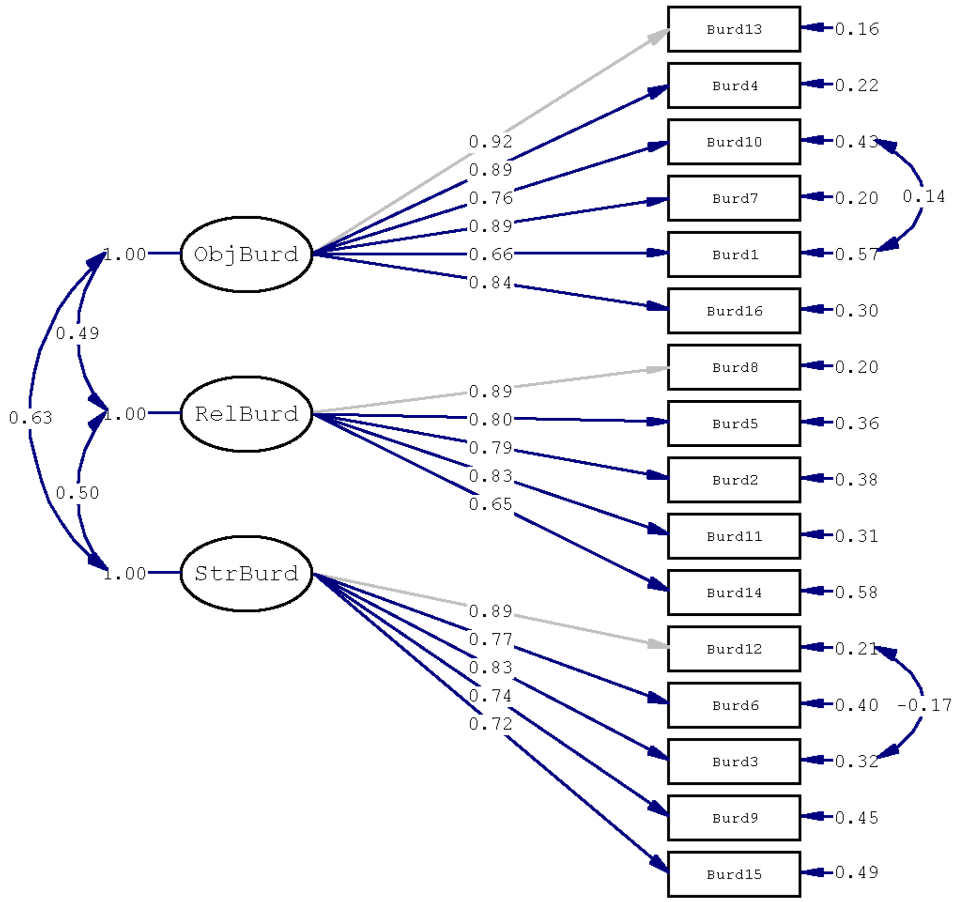
Each of the three factors was examined individually to confirm its dimensionality and appropriateness for parceling. The one-factor measurement model for relationship burden was found to have good fit without any modifications (see Table 20). Objective burden and stress burden, however, only achieved acceptable fit after allowing one pair of error terms to correlate within each factor. For objective burden, modification indices suggested a correlation between the error terms for item 1, “decreased time for self” and item 10, “changed your routine” (MI = 17.70). For stress burden, modification indices suggested a correlation between the error terms for item 3, “created a feeling of hopelessness” and item 12, “made you anxious” (MI = 28.14). These correlated errors seemed reasonable, particularly since they occurred within a factor. A scaled difference chi-squared test was performed and results indicated the model with the two correlated error terms fit the data significantly better [scaled $\Delta\chi^2(2) = 40.803$, $p < 0.0001$] and therefore it was preferred. The full measurement model for caregiver burden appears in Figure 4. All parameter estimates were completely standardized with the variances of items and factors fixed to 1.0. Three homogeneous parcels were created by averaging the scores of all items loading onto a particular factor. The resulting model, with three parcels, is illustrated in Figure 5.

Table 20: Goodness-of-fit indices for caregiver burden (*N* = 239)

Model	Number of Items	Scaled χ^2	*df*	RMSEA	SRMR	CFI	NNFI	α
Caregiver burden oblique 3-factor model with 2 correlated error terms	16	173.30	99	.068	.058	.988	.985	.928
Objective burden	6	10.23	8	.053	.0143	.999	.998	.930
Relationship burden	5	4.64	5	.045	.0156	1.00	1.00	.892
Stress burden	5	7.32	4	.070	.022	.996	.990	.883

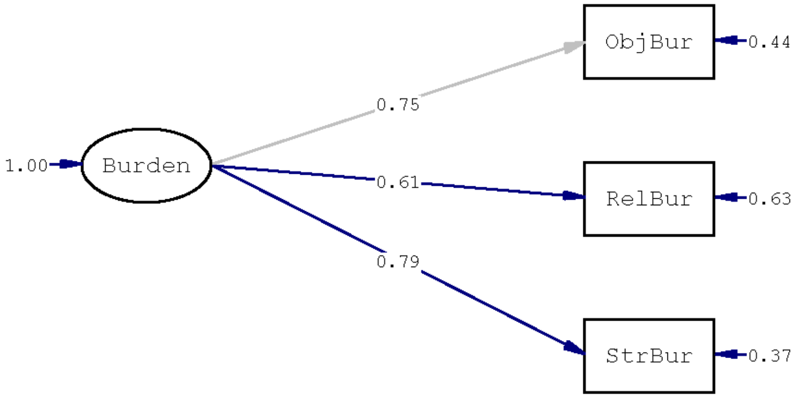
Note. RMSEA = root mean square error of approximation; SRMR = standardized root mean square residual; NNFI = non-normed fit index; CFI = comparative fit index.

Figure 4: Full measurement model for caregiver burden



Note. ObjBurd = objective burden; RelBurd = relationship burden; StrBurd = stress burden. All parameter estimates were completely standardized. *N* = 239. Scaled χ^2 (99) = 173.30, *p* < 0.0001, RMSEA = 0.068, SRMR = 0.058, CFI = 0.988, NNFI = 0.985.

Figure 5: Measurement model for caregiver burden with 3 homogeneous parcels



Note. ObjBurd = objective burden; RelBurd = relationship burden; ObjBurd = objective burden. All parameter estimates were completely standardized. *N* = 239. Model is saturated; fit is perfect. Scaled χ^2 (0) = 0, *p* = 1.0.

Measurement model for problem behaviors. Fourteen items, originally published by Pearlin and colleagues (1990), were used to measure the latent construct of problem behaviors. Univariate and multivariate normality were assessed, and distributions were found to vary significantly from the normal distribution (see Table 21).

Table 21: Tests of univariate normality for 14 problem behavior items (*N* = 239)

Item	Skewness		Kurtosis		Shapiro-Wilk	
	z	*p*-value	*z*	*p*-value	statistic	*p*-value
1	8.148	< .001***	3.644	< .001***	.597	< .001***
2	-1.55	0.121	-38.326	< .001***	.819	< .001***
3	7.728	< .001***	3.107	0.002**	.631	< .001***
4	4.43	< .001***	-3.571	< .001***	.793	< .001***
5	6.846	< .001***	2.012	0.044*	.702	< .001***
6	9.641	< .001***	5.73	< .001***	.513	< .001***
7	4.861	< .001***	-0.879	0.379	.803	< .001***
8	7.323	< .001***	2.409	0.016*	.651	< .001***
9	4.8	< .001***	-0.815	0.415	.806	< .001***
10	5.633	< .001***	0.703	0.482	.778	< .001***
11	8.9	< .001***	4.679	< .001***	.544	< .001***
12	7.081	< .001***	2.272	0.023*	.678	< .001***
13	11.822	< .001***	7.862	< .001***	.362	< .001***
14	12.768	< .001***	8.646	< .001***	.293	< .001***

**p* < .05 ***p* < .01 ****p* < .001

The set of problem behavior items was determined to be appropriate for factor analysis, as indicated by the Kaiser-Meyer-Olkin measure of sampling adequacy (0.814) and Barlett's test of sphericity, χ^2 (91) = 1015.324, $p < 0.0001$. Principal axis factoring with an oblimin (correlated factors) rotation was used. According to the Kaiser criteria, four factors should be retained as they each had eigenvalues exceeding 1.0, explaining 29.5%, 5.6%, 5.3%, and 4.0% of the total variance, respectively. However Horn's parallel analysis indicated only the first three of these factors differed from the eigenvalues generated by a random sample with the same sample size and same number of variables

Table 22: Comparison of actual and random eigenvalues for problem behaviors (*N* = 239)

Factor	Actual Eigenvalue	Random Eigenvalue
1	4.62	1.43
2	1.35	1.33
3	1.28	1.25
4	1.16	1.18

(see Table 22). Communalities and loadings for the problem behavior items are reported in Table 23. Six items loaded onto the first factor and six additional items onto the second. Only two items loaded onto the third factor. An oblique three-factor model was imposed upon the data using LISREL software (see Figure 6) and determined to have reasonably close fit [scaled χ^2 (74) = 173.03, $p < 0.0001$, RMSEA = 0.098, SRMR = 0.072, CFI = 0.944, NNFI = 0.932] and a high level of internal consistency ($\alpha = 0.825$). Domain representative parceling was used for this latent variable to maintain consistency with previous studies (e.g., Savundranayagam et al., 2005) and because the distribution of items was so unequal. Domain representative parcels have been demonstrated previously to result in stable and acceptable estimates of parameters (Kishton & Widaman, 1994).

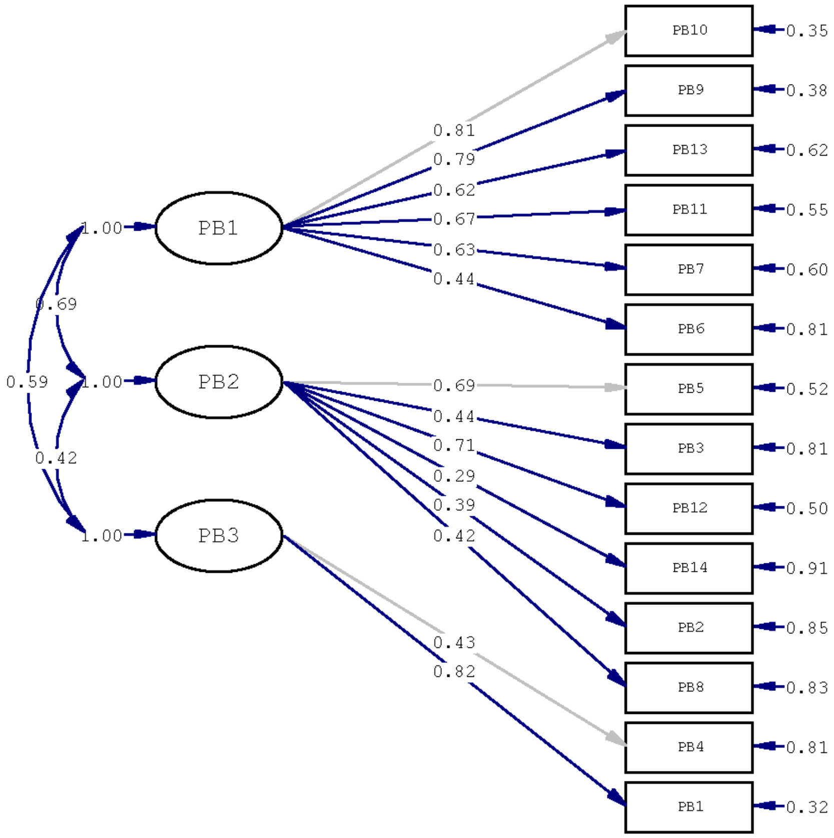
Table 23: Loadings and communalities for problem behaviors (*N* = 239)

Item	Rotated Solution			
	Factor 1	Factor 2	Factor 3	Communalities
10. Became irritable or angry	**.870**	-.118	-.013	.666
9. Became restless or agitated	**.790**	-.094	.235	.667
13. Threatened people	**.642**	.021	-.064	.417
11. Swore or used foul language	**.622**	.084	-.030	.440
7. Acted depressed or downhearted	**.603**	.069	-.001	.409
6. Cried easily	**.306**	.203	.087	.221
5. Hid belongings and forgot about them	.095	**.701**	-.139	.542
3. Tried to dress the wrong way	-.002	**.485**	.292	.377
12. Became suspicious of others	.417	**.472**	-.383	.614
14. Showed sexual behavior at wrong place/time	-.083	**.376**	.100	.139
2. Repeated questions or stories	.075	**.346**	-.070	.144
8. Clung to you or followed you around	.237	**.248**	.151	.226
4. Had a bowel or bladder accident	.095	.080	**.518**	.324
1. Kept you up at night	.371	.063	**.398**	.382

Note. Principal axis factoring with an oblimin rotation. Major loadings for each item are bolded.

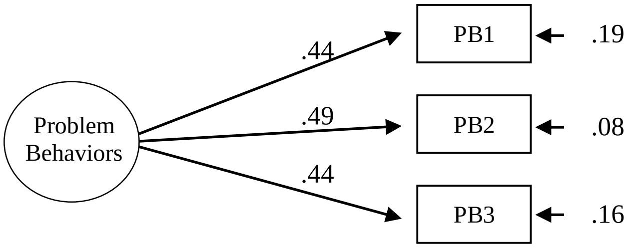
Three parcels were created by averaging the scores from random sets of items. The final measurement model for problem behaviors appears in Figure 7.

Figure 6: Full measurement model for problem behaviors



Note. All parameter estimates were completely standardized. *N* = 239. Scaled χ^2 (74) = 173.03, $p <$ 0.0001, RMSEA = 0.098, SRMR = 0.072, CFI = 0.944, NNFI = 0.932.

Figure 7: Measurement model for problem behaviors with 3 domain representative parcels



Note. All parameter estimates were completely standardized. *N* = 239. Model is saturated; fit is perfect. Scaled χ^2 (0) = 0, *p* = 1.0.

Hypothesized Model

The third research question of this study focused on the relationships among communication behavior appraisal, communication strategy appraisal, problem behaviors, and caregiver burden. Based on *a priori* conceptualization, it was hypothesized that: 1) strategy appraisal would partially mediate the relationship between communication behavior appraisal and caregiver burden; 2) problem behaviors would partially mediate the relationship between communication strategy appraisal and caregiver burden; and 3) problem behaviors would partially mediate the relationship between communication behavior appraisal and caregiver burden. Correlations, means, and standard deviations for all observed variables are reported in Table 24. The hypothesized model is illustrated in Figure 8.

The hypothesized model was imposed upon the data. Goodness-of-fit indices revealed excellent fit [scaled χ^2 (96, *n* = 239) = 142.94, *p* = 0.001, RMSEA = 0.053, SRMR = 0.061, CFI = 0.983, NNFI = 0.978]. Procedures outlined by Baron, Kenny, and Kelber (1986) were used to test for mediation. According to Baron and Kenny, there are three necessary conditions that must exist to establish mediation: 1) the initial variable (A) must be significantly related to the outcome variable (C); 2) the initial variable (A)

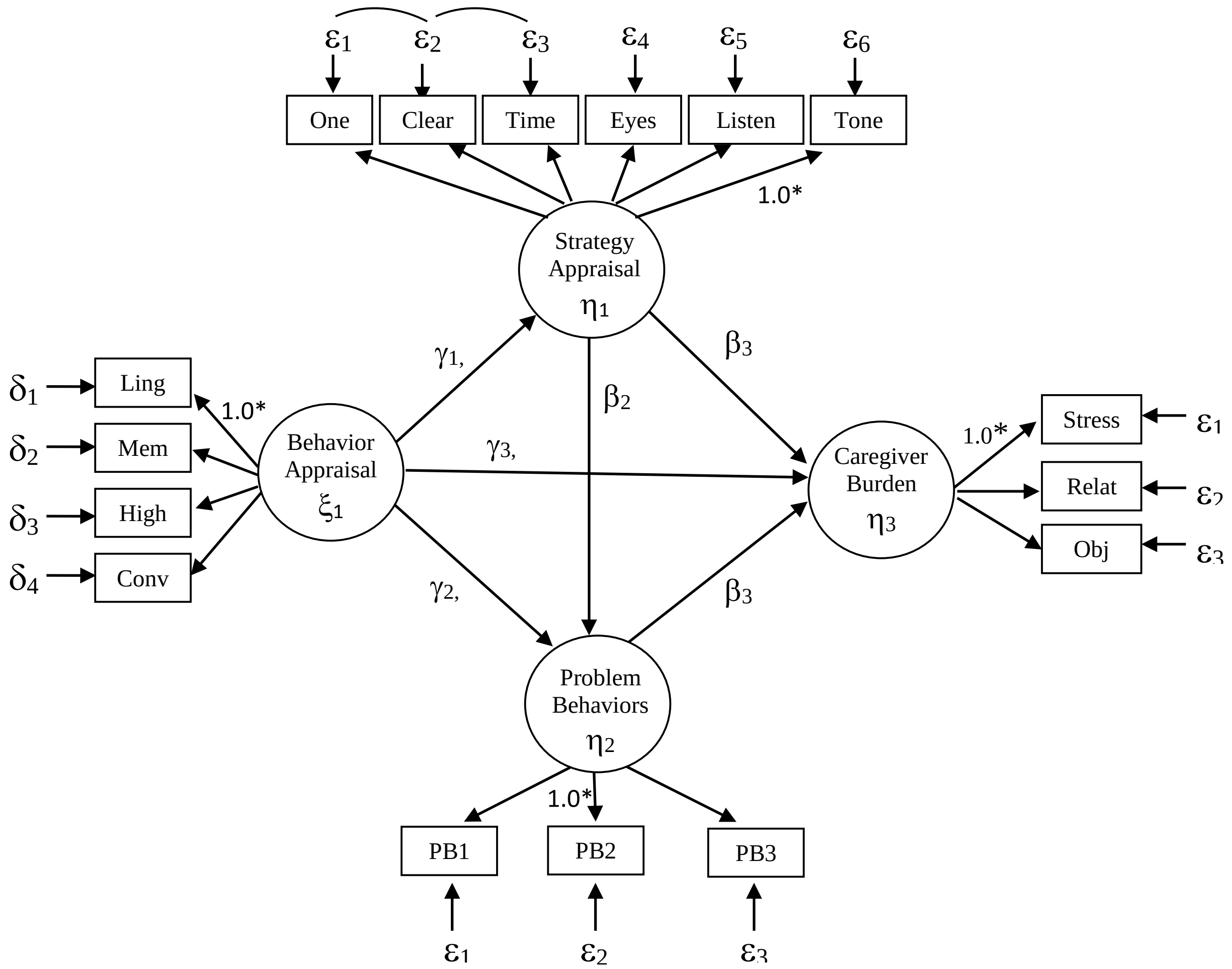
Table 24: Correlations, means, and standard deviations for observed variables (*N* = 239)

	Observed Variables															
	Ling	Mem	High	Conv	PB1	PB2	PB3	One	Clear	Time	Eyes	Tone	Listen	Obj	Relat	Stress
Ling	1.00															
Mem	.51***	1.00														
High	.55***	.52***	1.00													
Conv	.50***	.50***	.51***	1.00												
PB1	.15*	.14*	.18**	.19**	1.00											
PB2	.22**	.14*	.23***	.21***	.55***	1.00										
PB3	.21***	.22***	.18**	.20***	.43***	.62***	1.00									
One	.07	.02	-.03	.02	.07	.05	-.08	1.00								
Clear	.07	.00	-.01	-.02	.12	.03	-.05	.68***	1.00							
Time	.00	-.11	.00	-.03	.12	.06	-.06	.60***	.69***	1.00						
Eyes	.00	-.05	-.05	-.11	.06	-.03	-.10	.53***	.51***	.59***	1.00					
Tone	.01	-.07	-.08	-.02	.09	-.02	-.10	.61***	.61***	.68***	.71***	1.00				
Listen	-.13*	-.16*	-.14*	-.03	.04	-.04	-.11	.55***	.55***	.64***	.55***	.68***	1.00			
Obj	.15*	.10	.21***	.10	.40***	.38***	.34***	.06	.07	.09	.05	.01	.00	1.00		
Relat	.17**	.37***	.31***	.32***	.27***	.32***	.38***	-.07	-.05	-.08	-.11	-.16*	-.14*	.43***	1.00	
Stress	.23***	.33***	.35***	.25***	.39***	.28***	.27***	.04	.05	.02	-.06	-.09	-.03	.57***	.44***	1.00
M	2.58	3.44	2.66	2.46	1.71	1.60	1.49	4.48	4.35	4.25	4.15	4.42	4.58	3.24	2.15	3.00
SD	0.97	1.09	0.87	0.87	0.62	0.57	0.59	1.29	1.38	1.37	1.41	1.32	1.33	1.00	0.96	0.92

Note. Ling = linguistics parcel; Mem = memory/attention parcel; High = high level linguistics parcel; Conv = conversation skills parcel; PB1, PB2, PB3 = problem behaviors parcels; One = ask one question/give one instruction at a time; Clear = speak slowly and clearly; Time = allow plenty of time for a response; Eyes = establish and maintain eye contact; Tone = use a relaxed calm tone; Listen = pay attention, actively listen; Stress = stress burden parcel; Relat = relationship burden parcel; Obj = objective burden parcel.

$*p < .05$ $**p < .01$ $***p < .001$

Figure 8: Hypothesized model



Note. Ling = linguistics; Mem = memory/attention; High = high level linguistics; Conv = conversation skills; One = ask one question or give one instruction at a time; Clear = speak slowly and clearly; Time = Allow plenty of time for a response; Eyes = establish and maintain eye contact; Listen = Pay attention, actively listen; Tone = Use relaxed, calm tone of voice; Stress = stress burden; Relat = relationship burden; Obj = objective burden; PB1, PB2, PB3 = problem behaviors. Asterisks denote parameters fixed to 1.0.

must be significantly related to the potential mediating variable (B); and 3) the potential mediating variable (B) must be significantly related to the outcome variable (C), when also controlling for the effect of the initial variable (A) on the outcome variable (C). To examine the hypothesized mediated effects, two different path models were constructed. In the first path model, the A-C and A-B relationships were examined, while B-C was constrained to zero. This tested the first two preconditions. If these preconditions were met, then a second path model was constructed to examine the A-C, A-B, and B-C relationships simultaneously. If all preconditions were met, then the Sobel test (Sobel, 1982) was conducted to test the hypothesis that the intervening variable significantly mediates the influence of the initial variable on the outcome variable.

The first hypothesis of this study suggested communication strategy appraisal mediated the relationship between communication behavior appraisal and caregiver burden. Results of the first path model revealed that the initial variable of communication behavior appraisal had a statistically significant relationship with the outcome variable of caregiver burden [unstandardized $\gamma = 0.215$, $SE = 0.108$, $p < 0.05$, standardized $\gamma = 0.218$]. However, communication behavior appraisal had no significant relationship with the mediating variable of communication strategy appraisal [unstandardized $\gamma = -0.065$, $SE = 0.132$, $p = 0.624$, standardized $\gamma = -0.040$]. Thus the data failed to satisfy Baron and Kenny’s second precondition for mediation, and the hypothesis was rejected.

The second hypothesis suggested problem behaviors mediated the relationship between communication strategy appraisal and caregiver burden. The initial variable of communication strategy appraisal showed no significant relationship with problem behaviors [unstandardized $\beta = -0.001$, $SE = 0.033$, $p = 0.977$, standardized $\beta = -0.002$] or caregiver burden [unstandardized $\beta = -0.031$, $SE = 0.042$, $p = 0.467$, standardized $\beta = -0.051$]. The second hypothesis was thus rejected also. Moreover, the absence of significant correlations and path coefficients between communication strategy appraisal and any other variable in the model indicates that strategy appraisal should be entirely removed.

The third hypothesis suggested that problem behaviors mediated the relationship between communication behavior appraisal and caregiver burden. After constraining the beta coefficients to zero in the first path model, the initial variable of communication behavior appraisal showed a significant relationship with the outcome variable of caregiver burden [unstandardized $\gamma = 0.427$, $SE = 0.128$, $p < 0.001$, standardized $\gamma = 0.44$] and also with the mediating variable of problem behaviors [unstandardized $\gamma = 0.228$, $SE = 0.062$, $p < 0.001$, standardized $\gamma = 0.38$]. These results satisfied the first two necessary preconditions for mediation. In the second path model, problem behaviors showed a significant relationship to caregiver burden [unstandardized $\beta = 0.855$, $SE = 0.168$, $p < 0.001$, standardized $\beta = 0.52$]. Thus, the data also satisfied the third and final necessary precondition for establishing mediation.

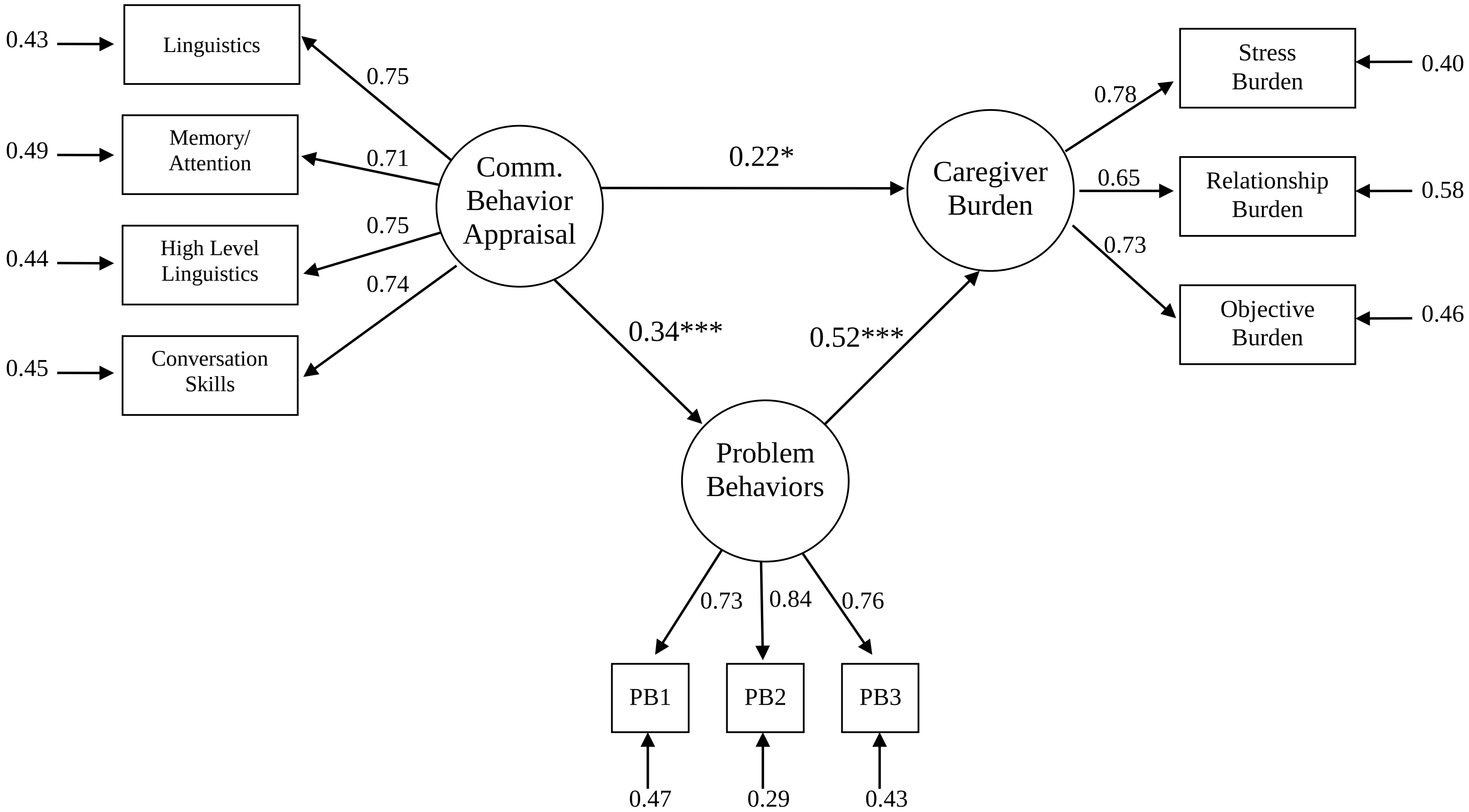
Communication behavior appraisal explained 19.2% of the variance of caregiver burden in the first path model. In the second path model, communication behavior appraisal and problem behaviors explained 39.9% of the variance in caregiver burden ($\Delta R^2 = 20.7\%$). Thus, including the latent variable of problem behaviors as a predictor more than doubled the proportion of variance explained in caregiver burden (scaled $\chi^2(1) = 18.082$, $p < 0.0001$). Because the standardized path coefficient between communication behavior appraisal and caregiver burden was smaller in magnitude after adding the mediating variable of problem behaviors and because it remained statistically significant [unstandardized $\gamma = 0.219$, *SE* = 0.108, $p < 0.05$, standardized $\gamma = 0.22$], the results support the conclusion of partial mediation. The standardized indirect effect of communication behavior appraisal on caregiver burden was 0.180 (unstandardized 0.178, *SE* = 0.052, $p < 0.001$). Confirming the *a priori* hypothesis, results of the Sobel test indicated that problem behaviors was a statistically significant mediator between communication behavior appraisal and caregiver burden ($z = 2.98$, *SE* = 0.065, $p < 0.003$). Problem behaviors explained 45.25% of the total effect of communication behavior appraisal on the outcome variable of caregiver burden. The final model, with completely standardized parameter estimates, is illustrated in Figure 9.

Testing Structural Invariance Across Caregivers' Education

The last research question of this study investigated whether caregivers' education level moderated the mediated relationship between communication behavior appraisal, problem behaviors and caregiver burden. Based on *a priori* conceptualization, it was hypothesized that the structural path coefficient between problem behaviors and caregiver burden, $\beta(2,1)$, would be weaker among caregivers with higher education, compared to those caregivers with lower education.

Structural invariance across groups was tested based upon the full structural equation model illustrated in Figure 9. To create two groups for structural comparison, the study sample was divided according to their responses to the caregiver education item. This variable was collapsed into two groups: caregivers with low education (some

Figure 9: Final model



Note. All parameter estimates were standardized. *N* = 239. Scaled χ^2 (32) = 73.33, *p* < 0.0001, RMSEA = 0.079, SRMR = 0.057, CFI = 0.970, NNFI = 0.957. **p* < .05 ****p* < .001

college or lower; $n = 133$) and caregivers with high education (Bachelor's degree or higher; $n = 106$).

Initially, the latent variable model was imposed upon the two groups separately to gain a better sense of the path coefficients in both groups. Goodness-of-fit indices revealed acceptable fit for the low education group [scaled χ^2 (32, $n = 133$) = 68.07, $p <$ 0.001, RMSEA = 0.099, SRMR = 0.060, CFI = 0.957, NNFI = 0.940] and for the high education group [scaled χ^2 (32, $n = 106$) = 46.65, $p = 0.046$, RMSEA = 0.067, SRMR = 0.078, CFI = 0.969, NNFI = 0.957]. In accordance with the hypothesis of moderated mediation, the path coefficient between problem behaviors and caregiver burden was weaker for the high education group (standardized $\beta = 0.44$, unstandardized $\beta = 0.62$), compared to the low education group (standardized $\beta = 0.58$, unstandardized $\beta = 1.07$).

Next, a baseline multi-group model with no cross-group equality constraints was generated. Goodness-of-fit indices suggested acceptable fit [scaled χ^2 (64) = 104.19, $p <$ 0.001, RMSEA = 0.073, CFI = 0.970, NNFI = 0.957]. Two additional models were imposed upon the data using equality constraints to test for invariance across groups in the magnitude of the unstandardized path coefficient linking communication behavior appraisal and problem behaviors, GA(1,1), and in the structural path between problem behaviors and caregiver burden, BE(2,1). Results of the Satorra-Bentler scaled difference chi-square test indicated that GA(1,1) was invariant across caregiver education level (ΔSB $\chi 2 = 0.025$, $\Delta df = 1$, $n = 239$, $p = 0.874$), and BE(2,1) was invariant across groups also (ΔSB $\chi 2 = 1.332$, $\Delta df = 1$, $n = 239$, $p = 0.248$). A third model tested for moderated mediation by using an algebraic constraint to set the indirect effect for Group 1 equal to the indirect effect of Group 2 (see Conley, Rudolph, & Bryant, 2012, p. 696). The

Satorra-Bentler scaled difference chi-square test was used to compare the baseline multi-group model to the nested model constraining the indirect effects to be equal. Contrary to the *a priori* hypothesis, results indicate failure to reject the null hypothesis of invariance across groups (scaled $\Delta\chi^2 = 0.308$, $\Delta df = 1$, $n = 239$, $p = 0.579$) and thus support the conclusion that there is no statistically significant moderated mediation.

Discussion

This study used survey research methods to address four objectives concerning family caregivers' appraisals of communication within the context of dementia care. It investigated: 1) the relationship between frequency of dementia-related communication behaviors and caregivers' appraisals of frustration; 2) the relationship between caregivers' use of communication strategies and their appraisals of helpfulness; 3) causal, or structural, relationships between communication behavior appraisal, communication strategy appraisal, problem behaviors, and caregiver burden; and 4) caregiver education level as a moderating variable of the final structural model. Results from each study component will be discussed separately and placed within the context of other available literature, including implications for research, teaching, and practice.

Frequency and Appraisal of Communication Behaviors

Family caregivers' reports of communication behavior frequency varied significantly by type of behavior, indicating that dementia family caregivers perceived some of their relative's communication behaviors occurred significantly more than others. The five communication behaviors that occurred most frequently were: failure to retain instructions; repeated questions and comments; failure to remember family, friends, or events discussed in conversation; failure to respond when selected as next speaker; and repeated initiations of favorite topics. These behaviors clearly reflect the care recipient's episodic memory impairments, which are known to be one of the earliest hallmarks of dementing illnesses (Small et al., 2000; Weintraub et al., 2012). Previous studies have described in detail the communication problems that are commonly exhibited by dementia patients (e.g., Bayles & Kaszniak, 1987; Bourgeois, 2002;

Kempler, 1995; Powell et al., 1995). Surprisingly, a substantial number of the communication behaviors measured in this study were reported by family caregivers as occurring rarely, which could be a reflection of the study sample and care recipients' disease type and/or stage of disease severity (Bourgeois & Hickey, 2009; Cummings et al., 1988). For example, the one communication behavior caregivers reported as never occurring (i.e., talking about topics based on hallucinations and/or delusions) is more commonly found in dementia with Lewy bodies and Parkinson's disease dementia (Alzheimer's Society, 2013) as well as patients in the late stages of most other dementing illnesses (Bayles & Tomoeda, 2007; Minati et al., 2009). Neither the type dementing illness nor the disease severity stage were assessed in the present study.

Family caregivers' appraisals of communication behaviors also varied significantly by type of behavior, indicating caregivers' perceived some of their relative's communication behaviors as being much more frustrating than others. However, in general, most communication behaviors were not frustrating to the caregiver. Twenty-three of the 32 behaviors measured in the study were appraised as not at all frustrating, while an additional seven behaviors were appraised as being a little frustrating. Failure to retain instructions and repeated questions/comments were the most frustrating communication behaviors to family caregivers, which is consistent with previous studies that have shown repeated vocalizations to be one of the most stressful problem behaviors for caregivers (Bourgeois et al., 1997).

Frequency and appraisal of communication behaviors were significantly correlated indicating that, in general, greater behavior frequency was associated with greater appraised frustration. When examined on the item level, significant correlations between frequency and appraisal were observed for 30 of the 32 communication behaviors measured. Concordance between rankings of frequency and appraisal existed at both ends of the spectrum. Failure to retain instructions and repeated questions/comments were the communication behaviors that occurred most frequently and were the most frustrating to dementia family caregivers, while failure to hand over conversational floor, presence of topics based on hallucinations and/or delusions, and production of monotonous intonation occurred least often and were least frustrating. The present study also identified ten communication behaviors with high frequency and low frustration ratings, plus an additional eight communication behaviors with low frequency and high frustration ratings. Additional study is needed to disentangle whether it is frequency of dementia-related communication behaviors (Savundranayagam et al., 2005), caregivers' appraised frustration with these behaviors, or the combined effect of the two factors that is contributing to caregiver burden.

Taken together, findings from the first part of the study support the conclusion of Orange (1991) that family caregivers are not only aware of the communication problems displayed by the person who has dementia, but they are able to report the relative frequency in which specific communicative behaviors occur. The two communication behaviors that were reported in the current study to occur most frequently and appraised as most frustrating (i.e., failure to retain instructions; repeated questions/comments) warrant special attention in any interventions designed to support family caregivers. While a small number of post-intervention studies have demonstrated success at reducing patients' repetitive vocalizations (Bourgeois et al., 1997; Dijkstra, Bourgeois, Burgio, & Allen, 2002), additional research is needed to identify best practices for family caregivers. Findings from the study also suggest that dementia family caregivers are able to maintain their emotional distance from their relative's communication problems, but when the frequency of any given communication problem becomes too great, frustration sets in. Future studies could advance our understanding of the relationship between frequency and appraisal of communication behaviors by exploring the precise "tipping point" in which the frequency of a particular behavior begins triggering greater frustration in the family caregiver.

Quality of life and quality of care for the person with dementia can best be supported when family caregivers and direct care workers are cognizant of the communication deficits caused by dementing illnesses. It is important that educational interventions not only include information on disease progression and symptomology, but they should also set forth realistic expectations for how interaction patterns with the person will change over time. Faculty can support family caregivers by educating current and future health care professionals about the types of communication problems that are observed most frequently in persons with dementia and are perceived as most frustrating by family caregivers. Faculty and health practitioners with professional seniority can also help students to adopt a practice paradigm that views family caregivers as partners in the dementia care process and as informants of the care recipient's symptoms throughout the disease trajectory.

Frequency and Appraisal of Communication Strategies

Usage frequency of caregivers' communication strategies varied significantly by strategy type, suggesting that some communication strategies are used more than others. While all nineteen communication strategies measured in the present study were used to some extent by family caregivers, eleven of the strategies were identified as being used frequently or always. Of these eleven, four strategies overlap with the most frequently used strategies identified by Small and colleagues: ask one question, give one instruction at a time; use short simple sentences; allow plenty of time for the person with dementia to respond; and repeat your message using the same words. While some previously published reports of dementia caregiver surveys (Small & Gutman, 2002; Small et al., 2003) have not found strategy appraisal to vary significantly by strategy type as the current study did, basic principles of psychometric theory (Nunnally & Bernstein, 1994) suggest that these difference may stem from the combination of several factors. In comparison to the studies conducted by Small and colleagues (Small & Gutman, 2002; Small et al., 2003), the current study used of a slightly different definition of caregiver appraisal (i.e., appraised helpfulness vs. appraised effectiveness), used a more discerning measurement scale for assessing caregivers' appraisals (i.e., 6-point vs. 4-point), and had a much larger sample size (i.e., N = 239 vs. N = 18, 20). Additional studies exploring dementia caregivers' appraisals could help illuminate whether there is any meaningful distinction between appraised helpfulness and appraised effectiveness in the eyes of the family caregiver.

Caregivers' appraisals of communication strategies also differed significantly by strategy type, suggesting some strategies are more helpful than others. Six communication strategies were identified as being very helpful to dementia family caregivers: pay attention, actively listen; ask one question or give one instruction at a time; use short, simple sentences; use a relaxed, calm tone of voice; speak slowly and clearly; and allow plenty of time for the person with dementia to respond. Of these six, two strategies overlap with the strategies appraised highest by the sample of family caregivers used by Small and colleagues (Small & Gutman, 2002; Small et al., 2003): ask one question, give one instruction at a time; and use short simple sentences.

Significant differences between frequency and appraisal ratings were found for 18 of the 19 communication strategies measured, with all significant differences indicating the caregivers' use of the strategy was greater than the appraised helpfulness of it. Caregivers' use and appraisal of communication strategies were also significantly correlated, which is consistent with earlier findings (Small & Gutman, 2002; Small et al., 2003). In general, strategies used most frequently by dementia family caregivers and appraised to be the most helpful were: pay attention/actively listen, and ask one question/give one instruction at a time.

Results pertaining to dementia family caregiver's communication strategies are best understood in the context of the communication accommodation theory conceptualized by Giles and colleagues (Giles, 1973; Giles & Powesland, 1975; Giles & Smith, 1979; Giles, 1980). Most of the research in this area related to older adults has described the type of accommodations made by various social groups, as well as the impact of over- and under-accommodation (Caporeal, 1981; J. Coupland et al., 1991; N. Coupland et al., 1988; Harwood, Soliz, & Lin, 2006; Harwood, 2007; Kemper, 1994; Kemper et al., 1994; Kemper, 2001; Ryan et al., 1994). While over-accommodations have been shown to be patronizing and insulting to older adults in some contexts (Balsis & Carpenter, 2005; Kemper & Harden, 1999; O'Connor & Rigby, 1996; O'Connor & St. Pierre, 2004; Ryan et al., 1994; Ryan et al., 1994; Whitbourne et al., 1995; K. N. Williams et al., 2009), they have also been shown to convey affection and warmth in other contexts, particularly when used by family members and others in close relationships (Hummert et al., 1998; O'Connor & Rigby, 1996; O'Connor & St. Pierre, 2004; Sachweh, 1998). The present study extends this research by exploring family caregivers' communication strategies, or in other words accommodations, in terms of both usage frequency and appraised helpfulness. In contrast to many previous studies, the focus of the current study was on the family caregivers' perceptions and appraisals of the accommodations made, not on the perceptions of the older adult with dementia. Family caregivers' reported that some of the accommodations they made to their speech style were significantly more helpful than others in facilitating effective communication with their relative, which is consistent with previous studies that demonstrated accommodations can be perceived as having both positive and negative effects on communication success (Hummert, Garstka, Ryan, & Bonnesen, 2004; Kemper & Harden, 1999).

The extent to which stereotypes of the elderly influenced dementia family caregivers' perception of their relative's communication behaviors and of their own communication strategies is open to speculation because no information about respondents' age stereotypes or attitudes was collected in the present study. Previous studies have repeatedly demonstrated that stereotypes of older adults, especially those with cognitive impairments, are known to affect communication practices (N. Coupland et al., 1988; N. Coupland & Coupland, 2001; Forgas, Vincze, & Laszlo, 2013; Harwood, 2007; Hummert, 1994; Hummert et al., 2004; McCann & Keaton, 2013). The age stereotypes in interaction model developed by Mary Lee Hummert (1994) suggests that negative stereotypes are more likely to result in the use of an age-adapted speech style (i.e., over-accommodation and under-accommodation), and positive stereotypes are more likely to result in the use of normal adult speech. Family members, compared to paid caregivers or health professionals, may be more likely to hold positive stereotypes based upon relational history with the care recipient and it is possible that they used fewer accommodations and/or appraised their strategies more positively. Future studies could investigate which of the relative's communication behaviors are related to family caregivers' positive and negative stereotypes, as well as how ageist stereotypes and attitudes affect caregivers' usage and appraisal of communication strategies.

A large number of intervention studies have investigated various methods of enhancing caregivers' communication between caregivers and persons with dementia. To date there have been three systematic reviews of communication intervention programs (McCann & Keaton, 2013; McGilton et al., 2009; Zientz et al., 2007) but only one of these has reviewed quantitative studies of interventions targeted at family caregivers. Egan and colleagues (Egan et al., 2010) conducted a systematic review of the literature pertaining to quantitative experimental studies of interventions designed to enhance verbal communication between caregivers and care recipients with Alzheimer's disease. The authors concluded that memory aides combined with specific caregiver training programs are the most promising method available at this time for improving dementia discourse. Memory aides generally include basic biographical information about the care recipient (e.g., name, address), pictures of family members, and short simple phrases about significant life events. However, the authors noted that memory aides have received only limited testing with family caregivers, as most intervention studies have been carried out with nursing assistants and other paid caregivers.

Interventions aimed at changing nursing assistants’ communication strategies have been shown to increase positive verbal interactions between the caregiver and care recipient with dementia (Burgio et al., 2001; Dijkstra et al., 2002) and more research is needed to test whether these interventions are equally successful when used by family caregivers in a community-based setting.

Structural Model

Two new measurement models for communication behavior appraisal and communication strategy appraisal were developed as part of this study and additional research is necessary to investigate reliability across populations. Both measurement models had strong loadings and high internal consistency, thereby providing students and other researchers with practical means of measuring these constructs in future studies.

Empirical support for the hypothesized structural model was mixed. Contrary to expectations, caregivers’ appraisals of communication strategies did not predict problem behaviors or caregiver burden. Hypothesis number one, which posited that communication strategy appraisal would partially mediate the relationship between communication behavior appraisal and caregiver burden, was rejected. Hypothesis number two, which posited that problem behaviors would partially mediate the relationship between communication strategy appraisal and caregiver burden, was also rejected. While no causal relationship was found between the appraised helpfulness of caregivers’ strategies and the outcome of caregiver burden, it is unknown whether usage frequency of caregivers’ strategies might have an impact on burden. Further analysis is necessary to address this question.

Only one other published study to date has explored the structural relationship between family caregivers' appraisals of strategies and caregiver burden. Results from Savundranayagam and Orange (2011) contradict findings of the present study, but the authors used a different set of measured items than the one in the current study, which thereby precludes direct comparison. Savundranayagam and Orange measured caregivers' appraisals of 22 communication strategies and divided them a priori into effective and ineffective strategies. Seven effective strategies were used in the regression model; all other items were either dropped or deemed to have internal consistency that was too low. The authors calculated an appraisal score using the means from the seven effective strategies, and this variable was found to be a significant predictor variable of stress burden and relationship burden, but not objective burden. While a similar number of items were used to represent the construct of strategy appraisal in the present study (i.e., six items), there was no overlap in the individual items measured. Furthermore, no attempt was made in the present study to categorize communication strategies as either effective or ineffective, but post-hoc examination suggests that the six items used in the current study's measurement model would be considered effective strategies. Clearly, further investigation is needed to identify a reliable measurement model for caregivers' appraisals of communication strategies and to clarify whether it is a predictive variable of caregiver burden or not.

Empirical support was found for hypothesis number three, which posited that problem behaviors partially mediate the relationship between communication behavior appraisal and caregiver burden. This is a valuable contribution to previous work in this area, underscoring the important role that communication plays in the family caregiving relationship and ultimately the amount of burden experienced by the caregiver. Findings expand upon the work of Savundranayagam, Hummert, and Montgomery (2005) who previously demonstrated that the frequency of communication problems predicts problem behaviors, which in turn predict caregiver burden. The present study demonstrates that it is not only the frequency of these problems, but also the caregivers' appraisal of the problems that is significant to the dementia caregiving experience. Many dementia family caregivers describe communication with their relative as stressful and frustrating (Clark & Witte, 1991; Purves & Phinney, 2012/2013; Rabins et al., 1982; Ward-Griffin et al., 2007), and this study underscores the importance of recognizing these feelings and helping family caregivers adopt effective communication practices.

Caregivers' Education Level

Caregivers' education level did not moderate the mediated relationship between communication behavior appraisal and caregiver burden in the final structural model. However, statistically significant moderated mediation is a relatively rare occurrence in structural equation modeling, primarily because the conditional indirect effect is very small, as are the samples typically used to test it (F. Bryant, personal communication, March 1, 2014). While the current study's sample size was sufficient for invariance testing of the hypothesized model, it is unknown whether a larger sample would have led to a detectable effect.

Another potential explanation for the absence of moderated mediation pertains to how the caregiver education groups were defined in the current study. It is possible that the cut-off point used to form the groups (i.e., Bachelor's degree or higher) was simply set too high to detect differences in the highest and lowest levels of caregiver education.

In the current study, the variable to sample size ratio, model specification, and sample characteristics dictated the cut-off point for defining the caregiver education groups, and a greater number of groups was not possible. Previous dementia caregiving studies have collapsed years of education into a nominal level variable, but the exact cut-off point for these groups has been much lower than the current study. For example, Navaie-Waliser et al. (2002) used completion of a high-school degree as the cut-off point and found caregivers' education was a significant predictor of caregiver vulnerability; whereas Uei, Sung, & Lang (2013) used nine years of education as the cut off, and found caregivers' education was a significant predictor of caregiver burden. Other dementia caregiving studies have used ordinal scales (3 – 5 point scales) for measuring caregiver education and found significant relationships between caregiver education and the outcome variable under investigation (Beach et al., 2000; Brown et al., 2013; Gallagher et al., 2011; Papastavrou et al., 2007; Sansoni et al., 2004). Future studies could help identify the precise level of caregiver education in which caregiver health is negatively impacted. Such insight would help educators and healthcare practitioners better design and target interventions aimed at preventing declines in dementia caregivers' health.

The lack of any significant correlation between caregiver education and caregiver burden in the present study is consistent with the findings of Gallagher and colleagues (2011), but inconsistent with other studies that found a significant negative correlation (Papastavrou et al., 2007; Uei et al., 2013). This adds to the uncertainty of whether an educational gradient exists for the specific outcome measure of caregiver burden. Future studies could investigate further whether an educational gradient exists for dementia caregiver burden and could explore the precise mechanisms by which education may be associated with caregiver health.

Study Limitations

A few study limitations may have influenced the results and constrain generalizability of the findings. The cross-sectional research design used in this study is a threat to internal validity because it results in an ambiguous temporal precedence of the variables under investigation. Also, use of a self-administered, mail survey restricted the dataset to self-report data, which is subject to recall bias and requires a heightened level of self-awareness and literacy on the part of the respondent. Additionally, the relatively small sample size used in this study limited statistical power and did not permit the inclusion of other potentially important variables in the causal model (e.g., length of caregiving, caregiver gender, and family relationship). Moreover, no objective measures of the underlying dementing illness or stage of disease severity were included and it is possible that results may vary when these variables are taken into consideration. Also, coverage error is also a potential source of bias because the sampling frame contained a limited number of dementia caregivers and may not be representative of the entire population. Non-responses from eligible study participants may have stemmed from any number of reasons including: failure to make contact (e.g., address errors, absence), refusal to participate (self-selection bias), accidental loss of the questionnaire, and/or inability to respond (e.g., health problems, language barrier, low literacy).

Our understanding of how caregivers perceive communication in the dementia caregiving context could be enhanced by future studies examining whether the observed patterns of behavior and strategy appraisal, as well as this study's final structural model are invariant across caregiver sex, family relationships, types of dementing illnesses, and disease severity stages. It is possible, for example, that male and female caregivers may perceive communication behaviors and strategies differently. Considerable research has been conducted exploring gender differences in listening skills, perception, and language are well other interpersonal communication skills (R. B. Adler & Proctor, 2014; DeVito, 2013; R. West & Turner, 2009). This study's sample consisted mostly of female caregivers and their appraisals of communication behaviors and strategies could differ substantially from appraisals made by their male counterparts.

Conclusion

Findings from this study highlight the importance of understanding interpersonal communication in the dementia caregiving context. A key reason for pursuing this line of inquiry was identified by focus group participants during the pre-testing phase of this study; specifically, socialization is an essential function of caregiving. Nine out of every ten survey respondents in this study (89.5%) reported socialization as a type of assistance they provided to their relative with dementia. While the importance of communication is widely recognized by faculty, researchers, health care professionals and family caregivers alike, interpersonal communication remains under-valued and under-reported within the dementia family caregiving literature. Descriptive studies of caregiving typically do not include socialization as a caregiving task despite the fact that communication and connection to others meets a basic human need (R. B. Adler & Proctor, 2014). More often, caregivers' assistance is measured in terms of activities of daily living (Katz, Downs, Cash, & Grotz, 1970) or instrumental activities of daily living (Lawton & Brody, 1969). Interpersonal communication is rarely treated as central to understanding the caregiving experience even though it shapes all aspects of familial, caregiver-care receiver, and patient-provider relationships. Empirical studies of interpersonal communication in the context dementia caregiving are particularly lacking and are necessary to better understanding interaction patterns occurring between caregivers and care recipients in natural, community-based settings.

The present study also underscores the importance of family caregivers' subjective appraisals of communication. Relatively little research attention has been directed to exploring dementia family caregivers' appraisals of the communication challenges they routinely face, or of the strategies they commonly use. In contrast to the voluminous literature documenting how dementia affects a person's memory, cognition, and linguistic abilities, only a small number of empirical studies have investigated family caregivers' appraisals of communication behaviors and strategies, and the relationship of these appraisals to outcomes such as caregiver burden. Most of the existing evidence in this area comes from clinicians' experiences with dementia patients and studies using small samples of dementia family caregivers ($n < 20$). Future studies might investigate the perception process used by dementia family caregivers, illuminating how they attend to, select, organize, interpret, and retrieve verbal and nonverbal stimuli. In addition, studies could build upon recent work (Savundranayagam & Orange, 2014) investigating how family caregivers' perceptions of communication behaviors and strategies differ from those of paid caregivers, health care professionals, and researchers. Being mindful of the messages from, observations of, and perceptions of family caregivers will undoubtedly enrich our understanding of how best to support quality of life for both the caregiver and care receiver.

Some authors have cautioned against the reliance upon self-reports for measuring caregivers' use of communication strategies (Orange, 2001; Small et al., 2003). Small, Gutman, Makela, and Hillhouse (2003) compared reported and actual use of communication strategies and discovered significant differences in six of the ten strategies under investigation, with dementia caregivers over-estimating their usage of half of those strategies and under-estimating the other half. Discrepancies in perceived and actual communication behavior patterns has led some investigators to conclude that studies should use a combination of objective and self-reported measures to obtain the most accurate record of strategy usage. While this may be a good recommendation for verifying strategy usage patterns, objective measures should in no way mitigate caregivers' appraisals. Perceptions are based upon a number of different variables, including but not limited to relational context and history (R. West & Turner, 2009). Family caregivers may perceive some communication problems as more frustrating or some strategies as more useful than an external observer, and, as this study demonstrates, it is caregivers' appraisals of communication behaviors that contribute to the outcome of caregiver burden. As dementia family caregivers' appraisals of frustration increased in the current study, so did the relative's problem behaviors and the caregivers' level of burden. This finding is consistent with previous studies that have found caregivers' use of critical emotional expression, harshness, or a negative tone to be linked to increases in problem behaviors and reduced responsiveness in conversation (Edberg et al., 1995; Hendryx-Bedalov, 1999; Small et al., 2005; Vitaliano et al., 1993).

In conclusion, dementia family caregivers face a myriad of challenges in caring for a relative with dementia and the loss of meaningful communication is reported to be one of the most difficult and stressful aspects. This study provides empirical evidence that caregivers' appraisals of their relative's communication behaviors affect caregiver burden, and that this relationship is partially mediated by problem behaviors. Helping family caregivers to cope with communication difficulties and adopt effective communication strategies will help caregivers maintain positive meaningful communication with their loved one and promote emotional well-being and quality of life. Supporting family caregivers in their role also helps persons with dementia to maintain social connections to others throughout the disease trajectory and avoid premature institutionalization.

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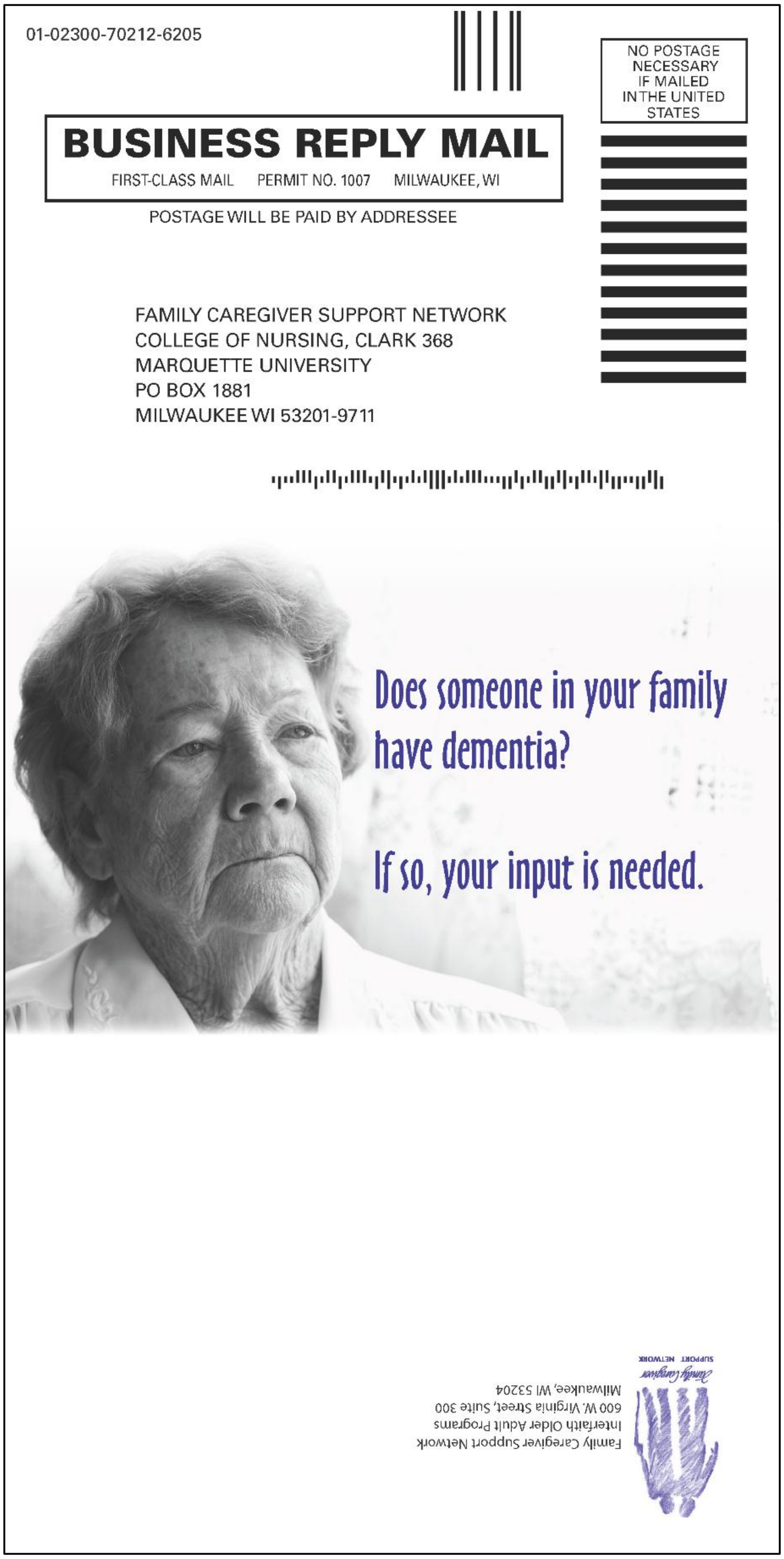
APPENDIX A
Tri-Fold Postcard Invitation



01-02300-70212-6205

NO POSTAGE
NECESSARY
IF MAILED
IN THE UNITED
STATES

BUSINESS REPLY MAIL

FIRST-CLASS MAIL PERMIT NO. 1007 MILWAUKEE, WI

POSTAGE WILL BE PAID BY ADDRESSEE

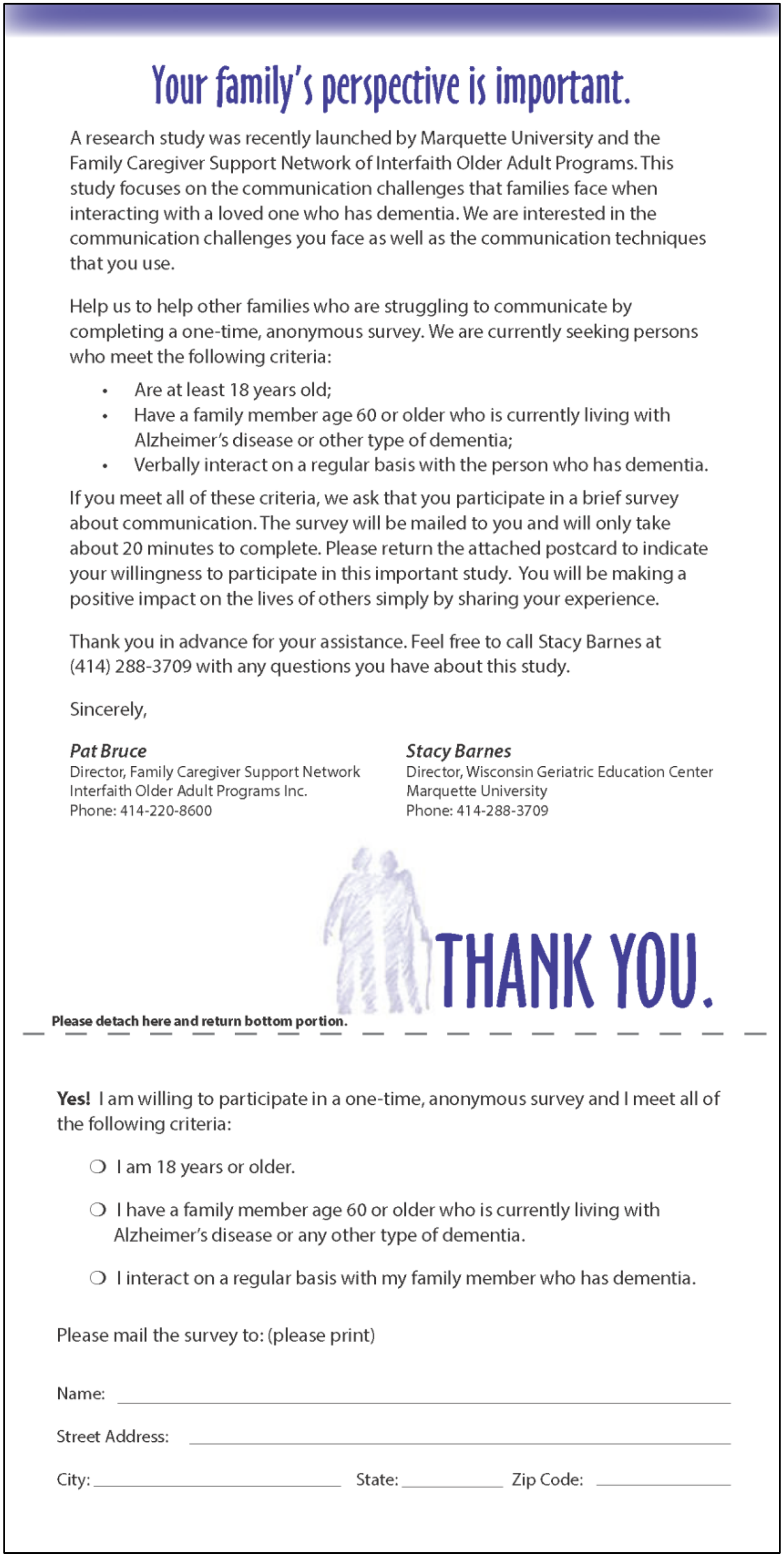
FAMILY CAREGIVER SUPPORT NETWORK
COLLEGE OF NURSING, CLARK 368
MARQUETTE UNIVERSITY
PO BOX 1881
MILWAUKEE WI 53201-9711

Does someone in your family have dementia?

If so, your input is needed.

Family Caregiver Support Network
Interfaith Older Adult Programs
600 W. Virginia Street, Suite 300
Milwaukee, WI 53204

APPENDIX A (continued)



Your family's perspective is important.

A research study was recently launched by Marquette University and the Family Caregiver Support Network of Interfaith Older Adult Programs. This study focuses on the communication challenges that families face when interacting with a loved one who has dementia. We are interested in the communication challenges you face as well as the communication techniques that you use.

Help us to help other families who are struggling to communicate by completing a one-time, anonymous survey. We are currently seeking persons who meet the following criteria:

- Are at least 18 years old;
- Have a family member age 60 or older who is currently living with Alzheimer's disease or other type of dementia;
- Verbally interact on a regular basis with the person who has dementia.

If you meet all of these criteria, we ask that you participate in a brief survey about communication. The survey will be mailed to you and will only take about 20 minutes to complete. Please return the attached postcard to indicate your willingness to participate in this important study. You will be making a positive impact on the lives of others simply by sharing your experience.

Thank you in advance for your assistance. Feel free to call Stacy Barnes at (414) 288-3709 with any questions you have about this study.

Sincerely,

Pat Bruce
Director, Family Caregiver Support Network
Interfaith Older Adult Programs Inc.
Phone: 414-220-8600

Stacy Barnes
Director, Wisconsin Geriatric Education Center
Marquette University
Phone: 414-288-3709

THANK YOU.

Please detach here and return bottom portion.

Yes! I am willing to participate in a one-time, anonymous survey and I meet all of the following criteria:

○ I am 18 years or older.

○ I have a family member age 60 or older who is currently living with Alzheimer's disease or any other type of dementia.

○ I interact on a regular basis with my family member who has dementia.

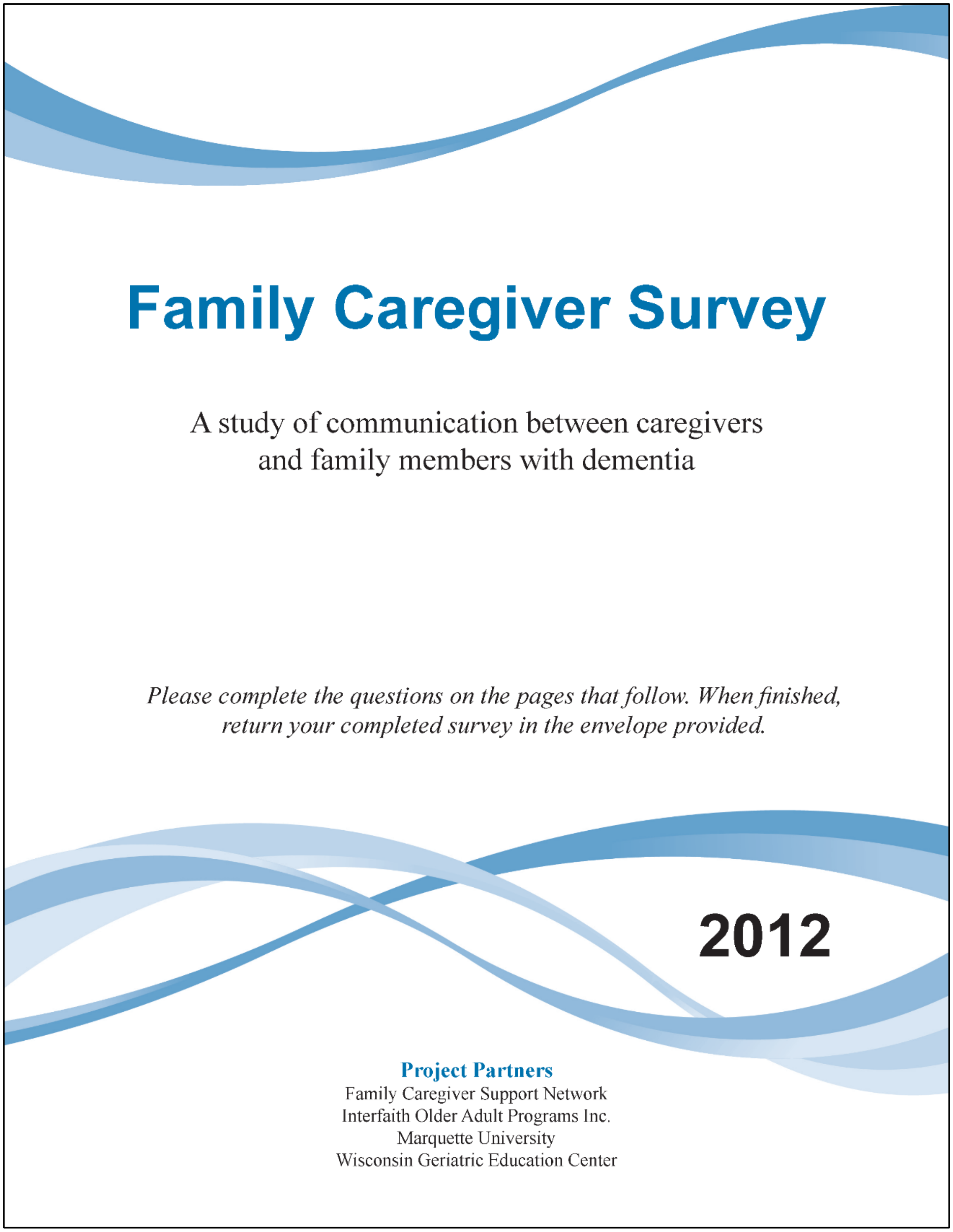
Please mail the survey to: (please print)

Name: ______________________________

Street Address: ______________________________

City: ______________ State: ________ Zip Code: __________

APPENDIX B
Questionnaire



Family Caregiver Survey

A study of communication between caregivers
and family members with dementia

*Please complete the questions on the pages that follow. When finished,
return your completed survey in the envelope provided.*

2012

Project Partners
Family Caregiver Support Network
Interfaith Older Adult Programs Inc.
Marquette University
Wisconsin Geriatric Education Center

Care Recipient's Characteristics

Please mark your response with either ☒ or ☑.

1. Who in your family has dementia? (Check all that apply)

☐ My mother
☐ My mother-in-law
☐ My father
☐ My father-in-law
☐ My grandmother
☐ My grandmother-in-law
☐ My grandfather
☐ My grandfather-in-law
☐ My wife
☐ My husband
☐ My partner
☐ My aunt
☐ My uncle
☐ My sister
☐ My brother
☐ My daughter
☐ My son
☐ Other ___________________

☐ No one in my family has dementia

If you checked this box, please proceed to Question 16 on back cover

If more than one family member has dementia, please select the relative who you interact with most frequently and answer all remaining questions with this individual in mind.

2. Which of the following best describes your relative?
☐ Dementia has been medically diagnosed
☐ Memory or cognitive problems are definite, but have <u>not</u> been medically diagnosed
☐ Memory or cognitive problems are suspected
☐ No memory or cognitive problems exist (please go to Question 16 on back cover)

3. Where does your relative live?
☐ Lives alone in his/her own home
☐ Lives with me
☐ Lives with another family member
☐ Lives in an assisted, group setting (but not a nursing home)
☐ Lives in a nursing home

4. On average, how often do you verbally communicate with your relative?
☐ One or more times a day
☐ Once every 2-3 days
☐ Once a week
☐ Once every 2 weeks (please go to Question 16 on back cover)
☐ Once a month or less (please go to Question 16 on back cover)

5. What type(s) of assistance do you provide to your relative? (Check all that apply)

- ☐ Social interaction
- ☐ Transportation
- ☐ Housekeeping
- ☐ Food preparation/cooking
- ☐ Shopping
- ☐ Taking/managing medications
- ☐ Laundry
- ☐ Managing money
- ☐ Using the telephone
- ☐ Bathing
- ☐ Dressing
- ☐ Getting in/out of bed
- ☐ Using the toilet
- ☐ Eating
- ☐ I do not provide any assistance

6. Think about recent interactions you've had with your relative. Please indicate below how many days during the last week you personally observed the following behaviors.

	0 Days (did not observe)	**1-2 Days**	**3-4 Days**	**5 or more Days**
Kept you up at night	☐	☐	☐	☐
Repeated questions or stories	☐	☐	☐	☐
Tried to dress the wrong way	☐	☐	☐	☐
Had a bowel or bladder "accident"	☐	☐	☐	☐
Hid belongings and forgot about them	☐	☐	☐	☐
Cried easily	☐	☐	☐	☐
Acted depressed or downhearted	☐	☐	☐	☐
Clung to you or followed you around	☐	☐	☐	☐
Became restless or agitated	☐	☐	☐	☐
Became irritable or angry	☐	☐	☐	☐
Swore or used foul language	☐	☐	☐	☐
Became suspicious of others	☐	☐	☐	☐
Threatened people	☐	☐	☐	☐
Showed sexual behavior or interests at wrong time/place	☐	☐	☐	☐

7. In what year was your relative born? (YYYY) ___________

8. What gender is your relative? ☐ Female ☐ Male

9. What is your relative's race?

- ☐ White or Caucasian
- ☐ Black or African American
- ☐ Hispanic or Latino
- ☐ Asian
- ☐ American Indian or Alaska Native
- ☐ Native Hawaiian or Other Pacific Islander
- ☐ More than one race

Please continue survey on following pages >>>

10. Please indicate how difficult it is for your relative to do the following things.

	Cannot do at all	**Very difficult (needs a lot of help)**	**A little difficult (needs some help)**	**Not difficult (needs no help)**
Remembering recent events	☐	☐	☐	☐
Knowing what day of the week it is	☐	☐	☐	☐
Remembering his/her home address	☐	☐	☐	☐
Remembering words	☐	☐	☐	☐
Understanding simple instructions	☐	☐	☐	☐
Finding his/her way around the house	☐	☐	☐	☐
Speaking sentences	☐	☐	☐	☐
Recognizing people that he/she knows	☐	☐	☐	☐

11. Next, we would like to get a better understanding of your relative's communication abilities. For each item below, please indicate: 1) how often your relative displays this communication behavior; and 2) how frustrating the behavior is to you, when it occurs.

	How often?					**How frustrating?**					
	Always	**Frequently**	**Occasionally**	**Rarely**	**Never**	**Extremely**	**Very much**	**Somewhat**	**A little**	**Not at all**	**Does not apply**
Starts-up a conversation with you	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Fails to respond whenever it's his/her turn to talk	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Pauses a long time before answering you	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Stops in the middle of his/her talking and leaves a long pause before continuing	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Interrupts you when you are speaking	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Talks on and on, without allowing you to participate in the conversation	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Restricts his/her responses to minimal acknowledgements like "yes" or "OK"	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Introduces new topics during a conversation	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Able to maintain the same topic for awhile	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Introduces new topics that don't really fit into what you are currently talking about	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Talks about imaginary people/events as if they are real	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Brings up the same topic(s) in conversations	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

	How often?					How frustrating?					
	Always	Frequently	Occasionally	Rarely	Never	Extremely	Very much	Somewhat	A little	Not at all	Does not apply
Indicates when she/he has not followed or understood what you have said	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Notices mistakes he/she makes when talking and tries to correct them	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Corrects mistakes in his/her speech without any help	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Able to make his/her speech more specific if you don't understand him/her	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Asks you the same question over and over again	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Fails to remember the family, friends, or events being currently discussed	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Forgets instructions you have given him/her	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Stops speaking in the middle of a sentence	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Struggles to find the right word when he/she is talking	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Describes what he/she is talking about, even if he/she can't think of the right word	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

	How often?					How frustrating?					
	Always	Frequently	Occasionally	Rarely	Never	Extremely	Very much	Somewhat	A little	Not at all	Does not apply
Uses the wrong word for something without correcting it	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Uses words like "it" or "they" without making it clear what the word refers to	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Has difficulty understanding what you have said	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Able to "read between the lines" and understand what people really mean	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Takes things at the literal or surface meaning	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Makes funny remarks on purpose, demonstrating that he/she has a sense of humor	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Misses the point of jokes	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Has difficulty speaking clearly	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Talks so softly it's difficult for you to hear him/her	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Uses flat, monotone speech	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Please continue survey on following pages >>>

12. Below is a list of techniques that people sometimes use when communicating with a person who has dementia. For each item below, please indicate: 1) how often you use the technique in communicating with your relative; and 2) how helpful it is in facilitating communication.

	How often?					How helpful?					
	Always	**Frequently**	**Occasionally**	**Rarely**	**Never**	**Extremely**	**Very much**	**Somewhat**	**A little**	**Not at all**	**Does not apply**
Identify yourself as you approach your relative	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Attract your relative's attention before speaking	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Call your relative by name	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Ask one question or give one instruction at a time	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Use short simple sentences	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Speak slowly and clearly	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Allow plenty of time for your relative to respond	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Repeat your message using the same wording	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Repeat your message using different wording	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

	How often?					How helpful?					
	Always	**Frequently**	**Occasionally**	**Rarely**	**Never**	**Extremely**	**Very much**	**Somewhat**	**A little**	**Not at all**	**Does not apply**
Encourage him/her to "talk around" a missing word	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
When asking for information, give choices or use "yes/no" questions	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Eliminate distractions and noise (TV, radio)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Establish and maintain eye contact	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Use a relaxed and calm tone of voices	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Suggest a word or help complete a sentence	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Use gestures or other body language	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Point to objects and pictures	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Watch for nonverbal or behavior messages	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Pay attention; actively listen to your relative	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Caregiver's Characteristics

13. In what year were you born? (YYYY) ___ ___ ___ ___

14. When you think about how you interact with your relative who has dementia, would you say that you personally…
    - ☐ Act as a relative (daughter, son, spouse, etc.) almost all of the time
    - ☐ Act most often as a relative, but sometimes you are a caregiver
    - ☐ Act equally as a relative and as a caregiver
    - ☐ Act most often as a caregiver, but sometimes you are still a relative
    - ☐ Act as a caregiver almost all of the time

15. As a result of providing assistance to your relative who has memory problems, how have the following aspects of your life changed? Have your caregiving responsibilities…

	Never	Rarely	Sometimes	Often	Almost Always
Decreased time you have for yourself?	☐	☐	☐	☐	☐
Increased attempts by your relative to manipulate you?	☐	☐	☐	☐	☐
Created a feeling of hopelessness?	☐	☐	☐	☐	☐
Kept you from recreational activities?	☐	☐	☐	☐	☐
Increased the number of unreasonable requests made by your relative?	☐	☐	☐	☐	☐
Made you nervous?	☐	☐	☐	☐	☐
Caused your social life to suffer?	☐	☐	☐	☐	☐
Caused you to feel that your relative makes demands beyond his/her needs?	☐	☐	☐	☐	☐
Depressed you?	☐	☐	☐	☐	☐
Changed your routine?	☐	☐	☐	☐	☐
Made you feel you were being taken advantage of by your relative?	☐	☐	☐	☐	☐
Made you anxious?	☐	☐	☐	☐	☐
Given you little time for friends and other relatives?	☐	☐	☐	☐	☐
Caused conflicts with your relative?	☐	☐	☐	☐	☐
Caused you to worry?	☐	☐	☐	☐	☐
Left you with almost no time to relax?	☐	☐	☐	☐	☐

Please continue survey on following page >>>

16. What is your gender? ☐ Female ☐ Male

17. What is the highest level of education you completed?

- ☐ 8th grade or lower
- ☐ High school degree (diploma, GED)
- ☐ Associate's degree or some college
- ☐ Bachelor's degree
- ☐ Graduate degree or higher

18. What is your race?

- ☐ White or Caucasian
- ☐ Black or African American
- ☐ Hispanic or Latino
- ☐ American Indian or Alaska Native
- ☐ Native Hawaiian or Other Pacific Islander
- ☐ More than one race

Thank you for taking time to complete and return this survey.
Results from this study will be shared in an upcoming
issue of the Family Caregiver Support Network's newsletter.

Please return your completed survey in the envelope provided and mail it to:

Wisconsin Geriatric Education Center
Marquette University
Clark Hall 368
P.O. Box 1881
Milwaukee, WI 53201-1881

Should you have questions about this survey, please contact
Stacy Barnes at 414-288-3709 or stacy.barnes@marquette.edu