Aphasia and the identity of Alzheimer's family caregivers: The effect of communication ability on caregiver identity gaps

DISSERTATION

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By

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Abstract

Family caregivers for Alzheimer’s disease experience a unique communication climate. The diminishing communication associated with the progressive decline of cognitive ability in the person with Alzheimer’s disease can not only make meaningful communication difficult, but it can also have an impact on the family caregiver’s identity. The communication theory of identity, the identity interruption and stress model, and the caregiver identity theory all suggest that family caregivers will experience gaps in their identity because of the changes in enacted communication and behavior with their family member. Online surveys were completed by 179 caregivers recruited through multiple Midwest organizations and a professional sampling firm. Analysis of the data revealed that family caregivers experience identity gaps and that the enacted-relational identity gap is significantly related to the communication abilities of the person with Alzheimer’s disease. Identity gaps were also significantly related to decreased mental and physical health. This research adds to the growing body of knowledge for the communication theory of identity and the caregiver identity literature. This research also has practical implications for educating caregivers about identity changes over the course of their family member’s illness.
Dedication

For the Alzheimer’s family caregiver.
Acknowledgments

Graduate school is a difficult path to walk for anyone, and my personal path has been riddled with many obstacles. I am blessed to have had an incredible group of supporters helping me continue on this journey and clearing my path. To everyone named below, and those not named, I cannot begin to express my gratitude for the integral roles you have all played in aiding the achievement of this goal. My life would be infinitely worse without every single one of you.

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Fields of Study

Major Field: Communication
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Chapter 1: Introduction and Review of Literature

Family caregivers for persons with Alzheimer’s disease and related dementias (ADRD) are a unique population and continue to garner attention in the social sciences. A major factor for this increase in interest is due in part to the exponential growth of the number of people having to care for a family member with a dementing illness. Since 2000, there has been a ten percent increase in the number of diagnosed ADRD cases and over the next 40 years there is expected to be a 130 percent increase in the number of people afflicted with these illness types (Alzheimer’s Association, 2013). Current research and theoretical insight into this population has examined both identity issues and communication challenges. For example, caregivers experience role overload, when the number of roles an individual must satisfy exceeds the amount of time demanded of each (Skaff & Pearlin, 1992), and this in turn affects their identity (Noyes, Hill, Hicken, Luptak, Rupper, Dailey, & Bair, 2010).

ADRD family caregivers experience a distinctive communication climate that is a hallmark of progressive dementias. There is a gradual decline in their family member’s ability to meaningfully communicate with the world. This loss of ability to understand and produce language and meaningful communication over a period of time is called progressive aphasia. Family caregivers report that effectively communicating with their family member suffering from ADRD is one of the most
difficult parts of being a caregiver because of the gradual loss of a symbolically meaningful communication system (Murray, Schneider, Bannerjee, & Mann, 1999). The communication theory of identity and the identity interruption and stress framework suggest that this breakdown in communication will have a major impact on the identity processes of the caregiver. The impact of communication on the identity of the caregiver has the potential to also impact mental and physical health. Unfortunately, however, there is a lack of research examining the connection between communication and identity, specifically in the context of the ADRD family caregiver.

The communication theory of identity (CTI) suggests that communication and identity are inseparable; communication to and from the environment are portrayals and reflections of identity (Hecht, Warren, Jung, & Krieger, 2004). When there is a lack of communication to reinforce a person's identity or self-concept, they may begin to doubt or question who they are and their role(s) in relation to others. This results in an interruption, or ‘gap’, in identity. For example, when an adult child is caring for a parent, often referred to as 'adult-child' caregivers, with ADRD and worsening aphasia symptoms, the adult-child may no longer be receiving messages from their parent that reinforce their life-long held role as a ‘child’ to the parent. This can create identity turmoil, and as will be explained later, can cause adult-child caregivers to feel as if there has been a role reversal. The progressively declining communication ability of the person needing care has the potential to have a major impact on the caregiver’s identity.

The objective of this dissertation research is to test a unique model of identity and communication in the context of family caregivers for people with dementia and
Alzheimer’s disease. The model (Figure 1) illustrates the prediction of a curvilinear relationship between caregiver gaps in identity and the perceived communication abilities of family members with dementia. The model being advanced by this research synthesizes important components from different theories to explain this contextually distinctive phenomenon. The three theoretical perspectives that provide the impetus for this model and research are the communication theory of identity, identity interruption and stress, and the caregiver identity theory.

The first chapter of this dissertation will provide an overview of the dementia caregiver literature in addition to the history of the evolution of identity theories that ground the study. To begin, the section "Alzheimer's disease and related dementias" will provide a background on the manifestation of the disease, facts and figures of the prevalence of the disease in the US, and an overview of aphasia, the important outcome of ADRD in this study. The subheading in this section, "The dementia family caregiver", will cover issues such as the demographic make-up of the average family caregiver, the multiple roles that the caregiver maintains, the progression of care duties and responsibilities, and caregiver identity theory.

Following the account of family caregivers will be a theoretical explication to ground the research. This explication will begin by tracing the history of identity and identity research that will chronologically progress through Burke’s identity interruption and stress model, helping to explain the development of disruption and restoration to identity, and finally in to the communication theory of identity (CTI). Identity gaps, a major component of CTI, is one of the major variables of this research. Caregiver identity theory will help to bring Burke’s identity model as well
as CTI together into the context of the family caregiver. Each of the theories contribute important puzzle pieces to this dissertation. However, each of the theories by themselves are only able to provide a partial explanation for the proposed hypotheses in this research.

Chapter two will cover the methods used in conducting the proposed research including the specific population sampled, the measures used to collect data, the procedure for collecting data, and the statistical procedures used to analyze the data. Chapter three will explicate the data analysis. Chapter four will expand on the data analysis and explain how the results add to current identity theory and dementia caregiver literature as well as the practical relevance the findings have for aiding family caregivers in navigating the path of dementia care.

Through the dissertation, a uniform narrative will be used to illustrate the theoretical foundations being advanced and will provide a connection between the theory and the ADRD family caregiver. Our example caregiver is called Jane. Jane is a 52-year-old female. Her father passed away 3 years ago and her mother has moderate to severe Alzheimer’s disease. Jane is married and has 2 children. Her oldest son, Brice, is in college and has just turned 21. The youngest child, Joe, is 16 and a sophomore in high school. Jane’s husband, Larry, has become increasingly distant as Jane has been devoting more time and energy to take care of her ailing mother and has been spending less time with him and Joe. Jane is what is known as an 'adult-child caregiver'. This name derives from the fact that Jane is an adult but is the child of the person for whom she is providing care. She is also a prototype of the
'sandwich generation' – they are the generation who are providing care for both their children and parents, simultaneously.

Review of Literature

Alzheimer’s Disease and Related Dementias

Dr. Alzheimer, in the early 1900's, had been studying a woman in her early 50's who presented with symptoms of 'old age' (Shenk, 2003). Old age was a health condition marked by a significant loss of memory and cognition and was the accepted explanation for this kind of decline for thousands of years (Shenk, 2003). However, the woman that Dr. Alzheimer was monitoring was in her early fifties, and far from an acceptable 'old age' loss of mental faculties. Upon her death, Dr. Alzheimer studied her brain looking for a biological cause of her behaviors and symptoms:

Then, at magnification of several hundred times, he finally saw her disease. It looked like measles, or chicken pox, of the brain. The cortex was speckled with crusty brown clumps, plaques, too many to count. They varied in size, shape, and texture and seemed to be a hodgepodge of granules and short, crooked threads, as if they were sticky magnets for microscopic trash (Shenk, 2003, pg. 24).

Alzheimer's disease, the most prevalent type of dementia, is now the sixth leading cause of death in the United States. Of the top ten causes of mortality (ie: Heart disease, stroke, breast cancer), Alzheimer's disease is the only cause of death that has no form of treatment to prevent, cure, or slow it's progression (Alzheimer's Association, 2013). The number of deaths from Alzheimer's disease increased 68%
between the years 2000 and 2010. It is the only leading cause of death to have seen an increase in mortality rates, all other top causes of death declined over that same decade (Alzheimer's Association, 2013). Direct costs resulting from Alzheimer's disease in 2013 will total $203 billion. This includes $35 billion from Medicaid, $107 billion from Medicare, and $34 billion from personal out-of-pocket costs (Alzheimer's Association, 2013). As discussed later, these figures would be more than doubled if family members and friends were not providing unpaid care for these individuals.

There are several forms of dementia, the most common being Alzheimer’s disease, accounting for between 60-80 percent of dementia cases (Alzheimer’s Association, 2012). Alzheimer's disease is a progressive, degenerative disease that initially affects the areas of the brain responsible for short-term memory formation and storage (Alzheimer's Association, 2012). The etiology of the disease is still unknown. According to the Alzheimer’s Association (2013), age is the only known risk factor for the disease, even though Alzheimer’s is not a normal sign of aging. Additionally, five percent of people who have Alzheimer’s disease have a special form known as ‘early onset Alzheimer’s’, where people in their 40’s and 50’s start suffering from the disease (Alzheimer’s Association, 2013). The plaques and protein tangles that are the hallmark of the disease, in addition to the death of brain cells, exist in the brain well before symptoms are manifested (Alzheimer’s Association, 2012). As the disease progresses, however, the brain becomes increasingly cluttered with these plaques and tangles.
As the disease advances and the brain becomes increasingly littered with 'microscopic trash', the types and severity of symptoms increase as well. What begins as seemingly ordinary forgetfulness commonly associated with normal aging moves to memory loss that begins to disrupt daily life. People with the disease begin having problems performing normal daily functions like cooking meals, taking medications, remembering to bathe and perform other daily hygienic routines, balancing a checkbook, cleaning the house, and taking care of any yard work. These basic daily routines are referred to as instrumental activities of daily living (IADL). Family members, friends, and neighbors help with and ultimately take over the IADL’s that the person with dementia can no longer perform.

As the disease moves from mild to moderate and severe, individuals lose the ability to do basic, fundamental, activities for survival such as bathing, feeding, and toileting. In addition to these losses, people also begin to experience a decline in their ability to communicate. As the plaques and tangles multiply, the language centers of the brain are compromised. This results in aphasia, or the increasing difficulty, and complete loss in the case of Alzheimer's disease, to use and understand written and spoken language (Beers & Jones, 2004). Not only do individuals suffering from Alzheimer's disease and related dementias (ADRD) lose the ability to perform many tasks that were once second nature to daily life, but they also experience a loss in being able to effectively tell someone else their wants and needs, such as the person who is caring for them. In fact, one of the major issues that family caregivers report as being most problematic in their care duties is being able to understand and
communicate with their family member (Murray, Schneider, Bannerjee, & Mann, 1999).

Aphasia

In the early stages of ADRD, people have problems with word finding, repetition of words and phrases, and difficulty understanding complex language (Kempler, 1991; Orange, 2001). As the disease progresses, so do the communication difficulties (Orange, Lubinski, & Higginbotham, 1996). A person suffering from ADRD has problems with reading and writing, creating substantial sentences with context appropriate words, content, topics, verbal fluency, taking turns at speaking, and utterance production (Orange, 2001; Levine, 2006; Bayles, Tomoeda, & Trossett, 1992; Overman & Goeffrey, 1987). As the disease moves into its final stages, many patients will completely lose the ability to produce any meaningful verbal communication and some even become mute (Orange, 2001).

The onset of aphasia does not mean that sufferers do not try to communicate with those around them. In fact, many studies show that people with ADRD still actively attempt to engage their social environment (Hubbard, Cook, Tester, & Downs, 2002; Ward, Vass, Aggarwal, & Cybyk, 2008) but these attempts go unnoticed since they are not culturally appropriate symbols with readily apparent meaning. Unfortunately, these missed attempts at communication with the environment impede the care recipient's quality of life in addition to compromising the efficacy of the person(s) providing care for the ill individual.
The Dementia Family Caregiver

The loss of the ability to perform activities of daily living (ADL) requires constant provision of care by someone else. Placing a family member with ADRD in an institutionalized care facility is usually a last resort for many families for a number of reasons including things such as, but not limited to, smaller family sizes, increased need for women to participate in the workforce, strained family relationships, and relief from the physical and mental strain of caregiving (Chenier, 1997; Choi, 1996; Collins, Strommel, Wang, & Given, 1994; Dellasega & Mastrian, 1995; Rodgers, 1997; Park, Butcher, & Maas, 2004). Family and friends take on the majority of care responsibilities to meet the needs of their family member. Those within the family and extended family that take on care responsibilities can include, but are not limited to: spouses, siblings, adult children, adult grandchildren, friends and neighbors.

The impact of dementia and Alzheimer's disease on family caregivers is extensive, at the individual level and at the national level. In the United States alone, 15.4 million family members and friends are providing some level of care for a person with ADRD. These unpaid caregivers are providing a service worth $216.4 billion dollars, the total amount it would cost both personal funds and tax payers to provide the 17.5 billion hours of care needed by these individuals (Alzheimer's Association, 2013). Over one-third of caregivers report symptoms of depression in addition to the high emotional stress reported by almost two-thirds of caregivers. The physical and mental strain of providing care to a person with ADRD is so intense that caregivers spend an additional $9.1 billion annually on doctor's visits and other medical expenses (Alzheimer's Association, 2013).
The majority of caregivers are female, consistent with social norms of sex roles (Beers & Jones, 2004; Hooyman & Kiyak, 2011). In fact, the 2010 Behavioral Risk Factor Surveillance System (BRFSS) survey found that 62% of caregivers for Alzheimer’s disease were women (Bouldin & Andersen, 2010). Additionally, many caregivers, 59% in the BRFSS, continue to maintain a full time job (Beers & Jones, 2004; Hooyman & Kiyak, 2011) and those with young kids have to care for their own families in addition to their parent or other family member with dementia (Brody, 2004), 30% of all family caregivers according to The National Alliance for Caregiving (2009). This illustrates the multiple roles and identities informal caregivers are constantly juggling. Family and friends who are caregivers are referred to in research literature, policy, and the medical field as informal caregivers; they do not receive formal training for their responsibilities and are not formally compensated for performing their caregiving duties (Alzheimer’s Association, 2013).

Caregivers perform a multitude of tasks and take on a number of duties that have a vast range of intensity. Each care experience is different and the care needs shift and change as the illness evolves. Helping care for an older adult can involve aiding with instrumental activities both within the home and outside the home: driving the individual to a doctor's appointment or to the grocery store, mowing the lawn, moving heavy or large items, preparing meals, balancing a checkbook or paying bills, and cleaning the house (Beers & Jones, 2004; Hooyman & Kiyak, 2011). Older individuals who do not have as much independence may need help with more personal care activities, also known as activities of daily living (ADL): getting
dressed, bathing, toileting, and eating (Beers & Jones, 2004; Hooyman & Kiyak, 2011).

Help providing these instrumental activities becomes more complicated when only 42% of caregivers live within 20 minutes of the person needing care (Family Caregiver Alliance, 2009). Around fifteen percent of caregivers live an hour or more away from their family member. In addition to causing more barriers to care provision, these caregivers spend almost twice as much to provide care as those caregivers who live in close proximity to their family member (Alzheimer's Association, 2013). Long-distance caregivers spend their caregiving time trying to coordinate services for their family member, making sure those services are being provided, and managing their family member’s finances (Family Caregiver Alliance, 2009).

Caregiving is a complex and intensive role to undertake. There are a number of studies that have examined the amount of time care activities occupy. Results from these studies are variable and time ranges from all-consuming to a handful of hours each day. Some studies suggest that care takes up a vast majority of a caregiver's time. For example, caregivers spend an average of 25 hours a week performing caregiver tasks and spend more than four years caring for their family member (Hooyman & Kiyak, 2011). Wimo and colleagues directly observed the care activities and time-spent-caring of caregivers with a co-habitating family member with dementia. They found that care activities took up 16 hours of the day and half of that time was focused on supervising the care recipient (Wimo, Nordberg, Jansson, & Grafström, 2000). Other studies report that because there is usually more than one
person providing informal care for an individual, the amount of time caring for someone is not as drastic as previously mentioned. According to a study that assessed the amount of time spent per day caring for ADL's, IADL’s and supervising an individual, caregivers spent 1.5, 2.1, and 1.9 hours per day partaking in each of the above activities, respectively (Neubauer, Holle, Menn, Grossfeld-Schmitz, & Graesel, 2008) suggesting that care activities constitute about 5.5 hours of a caregiver’s average day.

Even though these studies show drastic differences in the amount of time spent caregiving, it is clear that a significant portion of the day is consumed by the caregiver role. Something that was not mentioned or accounted for in these studies was the differences in time spent caring based on ADRD severity; the differences in severity not only affect how much time is spent caregiving but it could also have a major impact on a caregiver’s identity. As care needs progress and caregivers have to devote more and more time to care activities, they necessarily devote less time to other roles and activities. The changes a caregiver must make in the allocation of their time affects all facets of their life including work, family relationships, family roles, and extracurricular activities (Hooyman & Kiyak, 2011).

Family members provide an incredibly important service, not only to the family member who is suffering from Alzheimer’s disease and needs help with IADL’s and ADL’s, but also to the community and nation by saving billions of dollars every year in Federal expenditures. As Alzheimer’s disease progresses and the needs of the ill person increase, the family caregiver must spend more time and enact more intensive care behaviors than before. Not only does the family caregiver
have to suspend other activities and commitments to accommodate this increase in
needed care time, but also, the family caregiver must engage in behaviors to provide
care that are beyond established relationship appropriateness and expectations. For
example, Jane may have to begin helping her mother go to the toilet, including wiping
her clean. This is beyond normal relationship behavior for a daughter to be doing for
her mother. The increase in time commitment, the decrease in attention to other roles,
and the changing nature of the relationship between the caregiver and care recipient
can have an impact on the caregiver’s identity.

Identity

The following section will define how identity is being conceptualized in this
dissertation. The explication will begin with some of the foundational literature that
solidified and established identity research within the social sciences. Moving
chronologically through identity research, Burke's identity interruption and stress will
be covered and explained in terms of the importance to this research, followed by an
explication of the Communication Theory of Identity, and finally rounded out by the
most recent addition, the Caregiver Identity Theory, that helps tie the assumptions of
all three perspectives to the specific context of this research.

*Role and identity theory.* The self is conceived of as multiple components that
together create a whole (McCall & Simmons, 1966). Each of these components, or
roles, are distinct from one another but combine to produce a complete sense of self.
These roles have meaning to an individual based upon social interaction and
engagement (Mead, 1934; McCall & Simmons, 1966). Roles are an ongoing process
of socializing into positions of both organization and society (Blumer, 1969).
Through this socialization and positioning, one comes to have identity and self-understanding (Turner, 1979; McCall & Simmons, 1966; Mead, 1934; Blumer, 1969).

Identity is made up from the meanings given to a role both by the self and by others (Burke & Reitzes, 1981). Identity is thus the product of locating and labeling the self within society and through interaction with others (Stryker, 1968; Burke & Reitzes, 1981). Social interactions within differing environments help to define and organize the hierarchy of roles that make up identity. The hierarchy of identities is based on the shifting importance and context-specific salience of different role identities. The organization of the hierarchy is malleable and dependent upon each situation as determined by the demands and prospects that the situation includes.

Additionally, other identities that may be relevant to the situation and their competing importance for the situation also determine the positioning of the hierarchy (Turner, 1969). For example, Jane has roles of wife, mother, employee, caregiver, sister, and friend. Jane's roles of wife, mother, employee, and caregiver move up and down in her hierarchy of identity as she leaves her husband and child in the morning to go to work and shifts from wife and mother to employee, the wife and mother role move back up as she returns home again to make dinner, and then the caregiver role moves to the top of the hierarchy as she goes over to her mother's house to help her with daily routines in the evening. Her roles as sister and friend stay relatively low in the hierarchy since she has had limited contact with her brother and friends lately.

Based on the role identities most salient to that specific situation, an individual enacts behaviors through words, actions, and appearances (Mead, 1934) to convey the most appropriate role identity for the situation. Upon the enactment of the
identity, the audience responds to the individual's portrayal of identity and it is then that the individual can develop the meaning of the identity (Mead, 1934; Burke & Reitzes, 1981), a process showing that identity is reflexive in nature. Ultimately, identity is a significant symbol to the meaning of self (Burke & Reitzes, 1981). As Burke & Reitzes (1991) point out, "The meanings of the self (as object) are established and assessed in terms of the meanings of the performances generated by that self (as subject) within the culture of the interactional situation," (p. 85). For the ADRD family caregiver, the progression of the disease causes a slow and drawn out process of establishing the definition of the role of caregiver. The words, actions and appearances that enact the caregiver role change over the course of the disease, and so there is a continually evolving meaning and importance for that role in relation to overall identity.

Roles are distinct components that make up an individual's identity and are organized into a hierarchy with the most important role at the top. Roles are not fixed within that hierarchy; identity is context dependent and so the social environment dictates which role is most salient at that point in time. Interaction with the social environment is how identity comes into existence and acquires meaning for the individual. Social interaction, however, can also cause problems in providing an individual with a sense of coherence to their identity and can cause the individual distress.

Identity interruption and stress. Individuals continually strive to maintain cohesion of their identity but fragmentation is bound to occur when internal or external stressors arise (Wolf, 1988; Blustein & Palladino, 1991). Fragmentation is
marked by feelings of meaninglessness, depression, lethargy, anxiety, and uncertainty whereas coherent identity is marked by feelings of high self-esteem, stability, and wholeness (Robbins & Patton, 1985; Wolf, 1988). For example, a person who is providing care for a family member that does not embrace the caregiver role as part of their identity, even though that role is a significant part of their life, would feel a disconnect between the role they are playing and their identity. This would cause a person to feel uncertain about who they are and would provoke anxiety and distress. On the other hand, a person who embraces their role as a dementia caregiver and views the role as a strong part of their identity would exhibit higher self-esteem and find more meaning in their role.

To conceptualize identity and the idea of identity fragmentation, Burke (1991) produced an identity feedback model that shows identity as a loop of social processes. Burke operates under the assumption that identity is a process and not a state or trait of an individual. He also assumes identity as a reflexive process whereby identity is maintained through the constant negotiation of an identity standard (internal) and the inputs from the social environment (external) (Burke, 1991). Instead of fragmentation, though, Burke operates under a stress model whereby external forces exceed the internal resources available, resulting in stress. How an individual reacts to those stressors is distress (Burke, 1991).

Individuals have an identity standard, an internalized conception of the self. The individual enacts meaningful behaviors as an output to the social environment about their identity. The social environment provides input that is a reflected appraisal of that output and hopefully reflects the standard as well. These inputs help
the individual to regulate their behavior in their output to the social environment so that the input is a reflection of the standard (Burke, 1991). When the input does not reflect the standard, an interruption to the identity loop occurs and distress ensues (Burke, 1991). A majority of caregivers are juggling multiple roles in addition to their role as caregiver, and so they are constantly negotiating different identities dependent upon the situation. Our example caregiver, Jane, has tried to maintain her identity as a daughter, even though she provides seemingly intensive care for her mother. Jane continues to enact behaviors that are consistent with a normal mother-daughter relationship. However, as Jane's mother has continued to experience worsening symptoms from the Alzheimer's disease, her mother is rarely able to even recognize that Jane is in fact her daughter, and no matter how many times Jane reassures her mother of their familial relationship, it is usually in vain. Therefore, Jane experiences an interruption to her identity since the input from the environment does not match her standard, causing her to experience distress.

The level of experienced distress is dependent upon the degree of discrepancy between the input and the standard (Burke, 1991). In an attempt to return to a state of homeostasis, the distressed person will continue to change their behavior, or output, until the input from the social environment once again matches the standard. These changes in behavior tend to be more intense performances of the standard they are trying to convey (Swann & Hill, 1982). In addition, the level of distress is exacerbated when the identity in question is either high in salience and/or the person providing the discrepant input has a significant relationship to the individual (Burke, 1991). Relating back to the example above, to try and maintain the role of daughter,
an incredibly important relationship and role in her identity, Jane would continue to enact behaviors to try and get her mom to remember her as her daughter and not a stranger or person providing care for her. This could include things such as providing in-depth explanations about who she is, bringing pictures of when she was younger, a visual that her mother might recognize, and trying to explain that the picture is of her as a little girl, etc. Additionally, if the role of caregiver becomes too discrepant with her identity as a daughter, Jane might hire someone to help her provide care or even place her mother in a nursing home so as to maintain her identity standard and relieve the distress it is causing.

Distress results from two differing sources of the identity process. The first is a disruption to the identity loop and the second is when there are competing identities. The interruption to the identity loop can happen in one of two places. The first is at the point of the behavior output. The behavior will either be perceived to go unnoticed or will have no effect on the social environment (Burke, 1991). For example, although Jane is incredibly busy between working full time and providing 20 hours of care to her mother every week, she makes a concerted effort to make dinner for her husband and child every night. This seemingly small gesture has a major impact on Jane's identity as she tries to maintain her identity as a mother and wife. Even though she strains herself and stretches her time thin to prepare one meal every day for her family, her gesture goes unnoticed by both her husband and child, and Jane feels like her efforts are unappreciated.

The second point of interruption in the loop occurs during the reception of the input. Here, the behavior did have an impact on the social environment but for some
reason the individual is unable to understand or interpret the feedback (Burke, 1991). To illustrate, Jane is very affectionate, tender, and patient towards her mother. Jane's mother, however, has begun swearing and yelling at her when she tries to help her with tasks she can no longer perform on her own. Jane cannot understand why her patience and helpfulness is being met with verbal abusiveness. Jane is feeling distress about her identity as a caregiver since she is unable to understand the input she is receiving.

The second source of distress is when two or more identities are in competition. In other words, to maintain the cohesion of one identity, one or more other identities must be sacrificed (Burke, 1991). For example, Jane's mother's Alzheimer's disease is continuing to progress and the symptoms are getting worse. Jane now has to help her mother on the toilet and in the shower. These intense behaviors, necessary for proper care, are at odds with the behaviors that are consistent with a normal relationship between an aged mother and her adult daughter. Jane has to sacrifice some of the original meaning and definition of the relationship she has with her mother to continue providing the care her mother needs. In addition to this redefinition of her relationship with her mother, the intensity of the care needs has required that Jane spend more time with her mother. This has affected two major areas of her life: she has had to cut back to part time at her job and she is spending less time with her husband and her children. All of these changes in behaviors and the environments in which she is spending time have a major impact on her roles in life. The organization of the roles that usually reside at the top of the hierarchy of her
total identity are quickly changing and shifting in importance. This can be a major source of stress for Jane since her identity is being disrupted.

There are circumstances in which no change to the output or input will create congruence between the standard and input. When this occurs, the only way to alleviate the distress caused by the discrepancy is to shift, or change, the identity to restore congruence (Burke, 1991). One of the major components of an identity change is distress. A change in identity can be necessary for a number of reasons that include things like an exorbitant amount of effort to maintain congruence, multiple environmental sources of input that are incongruent, and incongruent input for an extended period of time (Burke, 1991).

Family caregivers for ADRD may be highly susceptible to identity shifts since they are in an environment of diminishing communication abilities as the ADRD progresses and aphasia worsens. Identity shift is integral to the proposed model (Figure 1) in hypothesis four. As will be discussed in further detail later, the downward slope of Figure 1 is hypothesized to represent a changed identity to alleviate gaps in identity.

This section discussed, at length, Burke's model of identity interruption and stress. To summarize, individuals have an internal standard of their perceived identity and they enact communicative behaviors to a social environment that reflect that internal standard. The social environment provides feedback to the individual about that identity, known as input, and ideally, those pieces of informational input match the standard the individual holds. If the input and the standard do not match, an interruption to identity occurs and distress ensues. An individual will change their
communicative behavior until the input matches the standard and congruence of identity is restored. Sometimes restoration of identity is unachievable and so an individual must change their identity. Another source of distress to identity is when two or more identities are in competition with each other. To alleviate the distress of these competing identities, one identity must be given up so that the other identity can continue to function. The idea of competition of identities and incongruence between the individual's concept of self and the social environment has clear links to the communication theory of identity.

*Communication theory of identity.* The communication theory of identity (CTI) is an important addition to the identity literature. Going back to Mead (1934), the identity process has, from the beginning, been located within social interaction, suggesting that identity is necessarily developed communicatively. The communication theory of identity, however, is the first time that identity has been conceptualized as communication, instead of two separate variables that affect one another (Hecht, Warren, Jung, & Krieger, 2004).

CTI draws upon both identity theory and social identity theory in building the base around which it is constructed. In line with identity theory, CTI assumes that identity is known through the symbolic interactions between the self and society and the meanings from those interactions are internalized as identity. Derived from social identity theory, CTI operates under the assumption that identity is also formed on the basis of categorization into identifiable social groups (Hecht et al., 2004). Pulling from the rich literature and these assumptions, CTI posits that identity is a layering of
four distinct but interdependent frames. Identity is located within the personal, the enacted, the relational, and the communal (Hecht et al., 2004).

The personal frame is located within the individual and includes the individual's self-perceptions of their identity. The enacted frame is located within the communicative behaviors that externalize the individual's identity. The relational frame is located within social relationships. There are three components to the relational frame: 1) identity work is shaped by feedback from others, 2) identity is shaped by the type of relationship between the individual and other, and 3) the relationship is itself an identity. Finally, the communal identity is based upon group membership and non-membership as ascribed by society (Hecht et al., 2004).

Each of these frames, while conceptualized as independent, can never operate in isolation from the others. At least two or more of these frames are operating at any one time. Additionally, the frames can work either together in concert and harmony or in competition and opposition to one another. The interpenetration of the frames, when working together, produces a coherent identity. When the frames are discordant, a rift in identity forms (Hecht et al., 2004). This means that the frames do not align to produce a single, steady identity, and as such, there is a disruption, or gap in identity. For example, Jane highly identifies with her roles as a mother and a wife, but the more she has to care for her mother, the less time she spends enacting those identities, and when she does enact them, it seems strained and half-hearted. In this example, Jane is experiencing an identity gap between her personal-enacted frames.

Discrepancy of identity, as shown in the literature reviewed previously, is something that has been a focus of research in multiple disciplines for a number of
years. CTI's conceptualization of identity gaps is similar to Burke's identity interruption and stress model. While Burke's model focuses on two major areas of disruption to identity, CTI provides more depth and precision in locating the areas where disruption to identity can occur. Gaps can occur between any of the frames when they are in competition with one another. Identity gaps can form in six locations when examined as dual competing frames (ex. personal-enacted, enacted-relational, personal-relational, enacted-communal, relational-communal, personal-communal) (Hecht et al, 2004). When more than three or four frames are working simultaneously, gaps can exist in five more locations, suggesting that identity gaps have potentially complex relationships.

Identity gaps are a major variable being measured in this dissertation research. This research only focuses on 3 out of the 4 frames: personal, enacted, and relational. The communal frame is being excluded for two reasons. Conceptually, the communal frame of identity is not as clearly relevant to the communication within the dyad of the caregiver and the care recipient. This research is focusing solely on the communication within this specific two-person relationship and how it affects the caregiver’s identity. Neither the communication environment outside of the care dyad nor group membership as ascribed by society is being considered because they are not the focus of this research. Second, there is no current statistical measure for the communal frame, and constructing a scale to measure it is a project for another research endeavor. The ADRD family caregiver is expected to experience identity gaps over the course of their tenure as a caregiver. The communication environment in which they are immersed becomes progressively more confusing and conflicted,
both in terms of enacted communication and the messages they receive from the social environment. Discrepant messages cause identity gaps to form. A gap between the personal-enacted frame is elaborated in the above example where Jane's identities as a mother and wife do not align with her communications to the environment. An identity gap between the personal-relational frames would be exemplified by a previous example as well. Jane's identity is still defined as being a daughter to her mother, however, her mother rarely ever behaves in a manner that reflects that identity, causing a gap between Jane's personal-relational frames. Finally, an example of a gap between the enacted-relational frame is when Jane communicates to her mother that she is ‘Jane’ and her daughter and her mother does not recognize her as having that identity. This lack of identity recognition could be in the form of calling Jane by a different name, sometimes seen in Alzheimer’s patients as other family members from earlier in life like a sibling or friend, by telling Jane that there is no way she could be her daughter (because her daughter is only a child or because she does not have any children), by proclaiming that she does not know Jane and that she is a stranger, or by lack of verbal and nonverbal recognition of identity.

In review, the communication theory of identity takes a symbolic interactionist approach to identity and frames identity and communication as inseparable. The four frames of identity (personal, enacted, relational, and communal) can work together to create a consistent identity or they can be discordant and cause gaps in identity to form. Identity gaps are hypothesized to be present in ADRD family caregivers due to their unique communication environment.
**Caregiver identity theory.** The amount of time spent caregiving has two important identity outcomes: the amount of time in a communication environment reflecting the care role and the salience of the caregiver role in the identity hierarchy. Although changes to identity are not unique to caregivers, the process by which identity changes occur is unique. Caregiver identity theory, explained below, defines some of the differences in identity processes experienced by caregivers, and how dementia, specifically, causes these changes.

Caregiver identity theory incorporates a number of established theoretical components about roles, identity, identity interruption and stress, and identity gaps. Although the authors do not cite any of the literature used here, the main ideas and even the terminology that are used to develop caregiver identity overlap. Concepts about identity such as incongruence, identity change, and distress are all integral components to this theory. The following provides an overview of the theory and highlights the intersections with role and identity theory, identity interruption and stress, and identity gaps.

Caregiver identity theory revolves around the relationship between the caregiver and care recipient. It specifies that the care relationship evolves out of an already existing relationship (i.e., spouse, child-parent, grandchild-grandparent, etc.) where roles and identity are clearly defined. Over the tenure of the care relationship, the needs of the person needing care will change requiring the person providing care to alter their behaviors. These changes are the premise for caregiver identity theory and "views the caregiving career as a series of transitions that result from changes in the caregiving context," (Montgomery & Kosloski, 2009, p. 48).
The vast majority of time, the changes that occur in the needs of the person receiving care require more invasive and intensive attention from the caregiver. The behaviors required of the caregiver to accommodate the changing needs of the care recipient are usually outside of the behaviors consistent with the roles that once defined their relationship (Montgomery & Kosloski, 2009). In line with the identity interruption and stress perspective outlined by Burke (1991), the inconsistency between the previously defined relationship and the behaviors necessary for the current context results in an interruption of identity and ensuing distress. This disruption appears to produce a gap between three identity frames within CTI: enacted-relational, personal-enacted, and personal-relational.

The disruption in roles and identities that is generated by advancing care needs results in caregiver distress; the perception of self and the relationship are no longer compatible with the behaviors being performed (Montgomery & Kosloski, 2009; Burke, 1991). The level of distress experienced, however, is variable for all caregivers dependent upon a number of factors including the meaning placed on the new, enacted behaviors and an inevitable shifting identity (Montgomery & Kosloski, 2009). This inevitable shift in identity is where the caregiver identity theory breaks from previous models of identity interruption. Changes in behavior to make the input from the social environment match the identity standard are futile in the caregiver context. For example, if Jane's mother can no longer shower and toilet herself without assistance, Jane will find that her staunch refusal to partake in these care tasks for her mother will not restore her identity as a daughter; her care needs will not change, her behavior towards her will still be one of dependence and necessary
assistance. Therefore, Jane must redefine what her role as a daughter is, and ultimately her identity will shift from simply being a daughter to a caregiving daughter.

An additional contribution of the caregiver identity theory is the model provided by Montgomery and Kosloski (2009) illustrating the identity transitions as the care needs increase. The model of caregiver transition is divided into five phases. Each phase is a point at which a significant change in care need results in a shift of identity.

The first phase begins when the individual starts performing tasks that were not originally part of their role in the relationship. These tasks are usually somewhat mundane and may be seen as just helping out or picking up some slack, for example, providing rides to and from places like the doctor's office, the grocery store, etc and is only a sliver of overall relational identity is defined by the care role. The second phase is initiated when the needed assistance begins to feel uncomfortable and outside of the normal relationship identity. The tasks in the second phase begin to involve assistance with activities of daily living such as dressing and eating. Caregiver identity becomes a bit more pronounced in this stage, taking up about a quarter of the overall identity of the relationship. The third phase is marked by extreme discomfort on both ends of the caregiving relationship. The care needs at this phase have progressed well beyond the previously held relationship and half of the relational identity is based upon care. This phase can be too much for the identity of the relationship and may result in moving the care recipient to a care facility; the care transition skips the fourth phase and moves right to the fifth. The fourth phase is
when the dominant identity of the relationship is based upon care and only a fraction of the original relationship remains. The fifth and final phase is when the care recipient is moved to a facility and much of the original relational identity is restored between the caregiver and care recipient. An important point to note is that care tasks do not end with institutionalization. Therefore the amount of caregiver identity at the fifth phase is very similar to the amount during the first phase.

In summary, the caregiver identity theory incorporates a lot of already established identity principles into context specific theory for dementia caregivers. The important advancement that this theory makes for the purposes of this research is that in the specific population of the Alzheimer's caregiver, the role of caregiver gradually becomes a larger portion of the identity as care needs increase in intensity as the disease progresses. This theory rounds out the rationale for the major model advanced by the fourth hypothesis, as explained below.

Research Rationale

The objective of this dissertation research is to test a unique model of identity and communication in the context of family caregivers for people with dementia and Alzheimer’s disease. This model includes the synthesis of three theoretical perspectives that help explain a unique environment of progressively diminishing communication. The merging of the theoretical perspectives suggests that this progressive decline in communication will have an impact on the family caregiver’s identity. Essentially, the diminishing communication abilities in the person who has dementia or Alzheimer’s disease will have an impact on the identity of the family member providing care. The model being advanced by this research utilizes
important components from different theories to explain this contextually distinctive phenomenon. The model (Figure 1) is based upon a synthesis of theories that there is a curvilinear relationship between caregiver gaps in identity and the perceived communication abilities of family members with dementia. The three theoretical perspectives that provide the impetus for this model and research are the communication theory of identity, identity interruption and stress, and the caregiver identity theory.

There are a total of seven hypotheses and one research question for the proposed research. The first three hypotheses stem from the communication theory of identity (CTI). CTI assumes that communication and identity are inseparable. When communication to and from the environment is consistent with an already held identity, then identity is reinforced. When communication to and from the environment is inconsistent, identity is interrupted (Burke, 1991), and identity gaps form (Hecht, Warren, Jung, Krieger, 2004). The specific communication environment that family caregivers for ADRD are exposed to over the progression of the disease is prime for interruptions in identity to occur and identity gaps to form.

For example, an adult-child providing intensive care for their parent with ADRD may feel that the activities that they engage in to provide care for their parent are no longer consistent with how they defined their identity in relation to their parent; most adult-children do not have to help their parent bathe and toilet, and those activities are at odds with the common behaviors defined by the role of adult-child.

The proposed research will examine the personal, enacted, and relational frames of identity in the context of the communication environment of the family.
caregiver and the care recipient with ADRD. The progressive loss of communication ability over the course of ADRD creates a situation for the caregiver where meaningful and consistent interactions are increasingly few and far between.

Caregiving takes up a significant amount of time in a caregiver's life and as the disease progresses it increasingly consumes more resources, such as time and money (Wimo, Nordberg, Jansson, & Grafström, 2000; Neubauer, Holle, Menn, Grossfeld-Schmitz, & Graesel, 2008; Hooyman & Kiyak, 2011). As noted earlier, the roles that are at the core of a caregiver's personal identity, the individual's self-concept, come to be at odds with the behaviors in which they are engaging to provide care for their family member. Performing behaviors that are inconsistent with a person’s self-definition causes an interruption to identity, according to Burke or, under the lens of CTI, would cause a gap between two identity frames. The previous illustration concerning perceiving oneself to be patient and acting impatiently is an example of a gap between the personal frame and the enacted frames of identity. H1: Dementia caregivers will experience an identity gap between the personal-enacted frames.

The relationship between the caregiver and care recipient is an important one. Piiparinen and Whitlatch (2011) describe the dementia caregiver as an individual who must cope with the changes that are taking place in their family member and how the changes necessitate a redefinition of the relationship between the caregiver and care recipient. For example, Jane helping her mother bathe or toilet is a task or behavior uncommon to most family roles as traditionally defined. A gap between the enacted and relational frames of identity will grow as the behaviors the caregiver must
perform to care for their family member are no longer consistent or appropriate to the
original definition of the relationship.

H2: Dementia caregivers will experience an identity gap between the enacted-
relational frames.

An interruption to an individual’s personal identity and their relational identity
is likely to form. The caregiver’s self-concept will become discrepant with the
relational identity. The original relational role, such as adult-child and parent,
between the caregiver and care recipient will change, to a degree, due to the current
caregiving situation. This hypothesis is based upon information from an unpublished
qualitative pilot study conducted by the author in which adults who care for a parent
with ADRD reported feeling as though their roles had been reversed; they were now
the parent and their parent was now a child. This role reversal suggests a disconnect
between how the caregiver once conceived of their personal identity, such as that of
“son”, “daughter”, or “spouse” and their role in relation to the person they are now
caring for, “caregiver”.

H3: Alzheimer’s family caregivers will experience an identity gap between the
personal-relational frames.

For the following proposed hypotheses, the first three hypotheses need to be
supported. If the analysis of the first three hypotheses reveals that identity gaps do
not exist then H4, H5, and H5a become moot since these three hypotheses revolve
around the existence of identity gaps. The sixth hypothesis could still be tested since
it does not hinge on identity gaps, however, the results would be of little significance
to the rest of the study if it is no longer a competing hypothesis, or potential
alternative explanation, to H5 and H5a. Therefore, all of the following hypotheses assume the first three to be supported.

The hypothesized model of this research stems from the assumptions of CTI, identity interruption and stress, and the caregiver identity theory. The model (Figure 1) is encapsulated in the fourth hypothesis and proposes that the dependent variable, identity gaps of the caregiver, will have a curvilinear relationship with the independent variable, perceived communication ability of the person with ADRD. The model is continuous, but breaking it into three sections helps to illustrate the processes. The first stage (upslope) shows low identity gaps and normal perceived communication ability. The second stage (plateau) is marked by a moderate decline in perceived communication abilities of the person with ADRD and increased number and intensity of identity gaps for the caregiver. The third stage (downslope) shows low and few identity gaps for the caregiver, an indication of identity shift, and diminished perceived communication abilities of the person with ADRD. The following will provide a rationale for the model and a further explication of the areas of the curvilinear relationship proposed in the fourth hypothesis.

Identity gaps arise from communication from the social environment. Because of this, the identity gaps that caregivers experience will be the result of compromised communication abilities from the care recipient. In general, both the communication theory of identity and Burke's identity interruption and stress perspective posit that communication from the social environment, both the communication patterns of an individual and of those others around them, will begin causing interruptions to identity and gaps will form when the communication is
inconsistent with an individual’s assumed identity frames (personal, enacted, relational, and communal). More specifically related to ADRD caregivers, the caregiver identity theory indicates that there is a necessary shift in how much of the caregiver role makes up the overall definition of identity. The more intensive the responsibilities and time commitments become to provide care for a person with ADRD, the more that the role of ‘caregiver’ will consume of the individual’s overall identity (Montgomery & Kosloski, 2009). The basic assumptions of this theory, however, do not take into account the function that communication plays in this environment of changing identity. This shift in identity, to be consumed more by the caregiver role, is in line with Burke’s concept of identity shift, but Burke’s model accounts for the central role of communication in identity shift that the caregiver identity theory lacks.

Figure 1 is a visual representation of H4 and resembles an inverted-U pattern. At the very beginning stages of ADRD, communication abilities will seem relatively normal. There may be times when difficulty in finding the correct word to use in a sentence is apparent, but overall, communication ability is relatively undamaged. In this very early stage of the disease when communication is still mostly intact, caregivers will experience relatively few and transient identity gaps. At this early stage of ‘original identity’, communication ability is high and identity gaps are low.

As the communication ability of the person with ADRD progressively declines, identity gaps will become more pronounced; within the middles stages of the inverted U-curve (Figure 1), the gaps will be more numerous and there will be larger discrepancies between identity frames. The larger gaps between the frames of
identity (personal, enacted, relational) are indicative of each frame operating in a manner that is disconnected from the other frames (Hecht et al., 2005). This middle part of Figure 1 is where the level of identity gaps will be at their very highest. The underlying rationale for this climax of both the number and degree of identity gaps is based upon the perception that communication ability has reached a middle stage in the progression of aphasia symptoms. This middle stage is marked by communication ability that oscillates between normal, lucid speech and understanding and the unpredictability and inconsistency of the communication environment. The family member with ADRD may have completely lucid moments where their communication reflects the original identity to the caregiver and at other times dementia is the driving force behind communication ability and verbal and nonverbal communications are revealing of a singular role of caregiver. This constant shifting of roles within the identity hierarchy, which often happens very quickly and without notice, will cause discrepancies between the identity frames. At this middle stage of “discrepant identity”, identity gaps will be high and communication ability will be moderate.

Aphasia associated with Alzheimer's disease is progressive, therefore communication will continue to decline in the person with ADRD to a stage where meaningful communication is perceived by the caregiver to be completely dissolved. When communication ability is completely diminished, the caregiver will experience a communication environment that is reflective only of their role as caregiver. Even if verbal communication is nonexistent in the family member with ADRD, the nonverbal communication environment is consistent with needing care and reinforces
an identity of caregiver. Not only does the caregiver have no way of re-establishing their original, familial, identity through communication with the person for whom they provide care, but they are also now solely enacting a role as a caregiver. This final downslope, where identity gaps become fewer, is indicative of an identity shift outlined by Burke (1991) and Montgomery and Kosloski (2009). At this stage of advanced dementia, communication reflective of their original identity roles will be highly unlikely, resulting in very few identity gaps. This end stage of the inverted-U of Figure 1 represents low identity gaps and low perceived communication ability.

Progressive changes in communication patterns and the potential impact on identity has not been tested by research using either CTI or the caregiver identity theory, in fact, there is currently no known research that tests this relationship under any theoretical framework. As explained above, the fourth hypothesis is based upon the synthesis of the three theoretical frameworks. On their own, these frameworks are unable to provide the necessary explanations of the ADRD caregiver identity and communication process. The fourth hypothesis is an attempt to provide a parsimonious explanation for the identity process of the ADRD caregiver over the tenure of their care career.

H4: There will be a curvilinear relationship between the overall intensity and number of identity gaps and the perceived level of communication ability.

The last three hypotheses formulated for this research are competing hypotheses. Hypothesis 6 is a competing hypothesis with both H5 and H5a. The current literature and empirical evidence suggests that H5 and H5a or H6, about mental and physical health, could be supported in the current research. Empirical
support for one would negate support for the other, however, and so both hypotheses must necessarily be asserted and tested.

Research conducted under the communication theory of identity has found a relationship between two specific gaps in identity frames and psychological health; specifically identity gaps had a significant impact on self-reported depression (Jung & Hecht, 2008). Based upon this finding, the current research should also find that identity gaps are related to increased rates of depression and declines in overall mental well-being.

H5: Self-reports of diminishing mental health will resemble a curvilinear relationship similar to the model in Figure 1; mental health will rise and fall as identity gaps form and are relieved.

Figure 1. Level of identity gaps as influenced by communication abilities.
Effects on physical health have never been directly tested in relation to identity interruption or identity gaps, but a logical inference from the relevant literature suggests that identity interruption and identity gaps would have a detrimental impact on physical health similar to the effect it has on mental health. Burke’s identity interruption and stress (1991) asserts that having to continuously adapt and adjust behaviors to alleviate interruptions to identity causes the autonomic nervous system to begin working and as a result, the individual has heightened feelings of distress. Psychological distress can contribute to many physical ailments including problems such as heart disease, high blood pressure, chronic headaches, and back pain (Lemyre, Lalande-Markon, 2009). Since the literature shows that identity gaps are related to increased levels of depression (Jung & Hecht, 2008) and that identity interruptions cause distress, both psychological factors that can result in decreased physical health, it follows that:

H5a: Self-reports of diminishing physical health will resemble a similar curvilinear relationship as the model (Figure 1); physical health will rise and fall as identity gaps form and are relieved.

Stemming from the rationale outlined above concerning stress and identity interruption, it is important to assess what the relationship is, if one exists, between identity gaps and stress. The CTI literature has not, to date, empirically tested the relationship between identity gaps and stress. In addition to testing this relationship, it is important to control for perceived levels of social support. Research within the caregiver population continues to provide evidence that social support can help buffer
the negative effects of stress and strain, both with interpersonal social support (Wilks & Croom, 2008; Kaufman, Kosberg, Leeper, & Tang, 2010) and through support groups and online forums (Tanis, Das, Fortgens-Sillmann, 2011). Therefore, the following research question is proposed:

RQ1: What is the relationship between identity gaps and stress when controlling for social support?

Although the above relationship is likely to exist in general populations studied, the ADRD family caregiver is a unique population and may be experiencing symptoms of depression and decreased physical health due to their caregiving duties. The stressors that go along with caring for an individual with ADRD and the detrimental impact that these stressors have on a caregiver’s physical and psychological well-being in addition to their perceived quality of life have been well documented. Caregivers are at a higher risk for physical health problems (Vitaliano, Zhang, & Scanlan, 2003; Schulz & Beach, 1999; & Schulz & Sherwood, 2008) and psychological burden (Schulz, O'Brien, Bookwala, & Fleissner, 1995), the most significant being depression (Adams, 2008; Butler, Turner, Kaye, Ruffin, & Downey, 2005; Schulz & Sherwood, 2008; Schulz, O'Brien, Bookwala, & Fleissner, 1995; Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Kiecolt-Glaser, Dura, Speicher, Trask & Glaser, 1991). The caregiver literature suggests that the negative health outcomes may be the result of other well-documented stressors of being a family caregiver. Therefore, a competing hypothesis is necessary for this specific population under investigation and is visually represented in Figure 2.
H6: Self-reports of mental and physical health will become increasingly negative until they plateau and remain at a constant level.

The final prediction is a contingent hypothesis. The seventh hypothesis will help to explain the curvilinear pattern of Figure 1 if H4 is in fact supported. The seventh hypothesis stems from both Burke’s identity interruption and stress framework (1991) and the Caregiver Identity Theory (Montgomery & Kosloski, 2009). At a crucial point in the caregiving career, an identity shift is bound to occur. In line with Burke’s interruption model, when the social environment no longer provides communication inputs that are consistent with the original identity, or when too much effort is required to try and maintain the original identity, an identity shift occurs. In the caregiver identity theory, the progression of the dementing illness over time requires more time and effort on the part of the caregiver to provide care. As the family member progressively spends more time enacting the role of caregiver, that role moves higher in the identity hierarchy and consumes more of the overall identity definition (for pie chart visual, see Montgomery & Kosloski, 2009). This supports the model in Figure 1 and H4; when the communication abilities of the care recipient become largely aphasic, the caregiver will no longer receive communication inputs that are consistent with their original identity (personal or relational), this will initially cause identity gaps to exist (Figure 1 – upslope and peak) and eventually there will be a shift in identity so that identity gaps are relieved (Figure 1 – downslope). The caregiver role will come to hold a position at the top of the identity hierarchy and will consume the identity of the person providing care.
H7: There will be a negative correlation between role salience and perceived communication ability: The role of caregiver will become increasingly salient as communication ability diminishes in the person needing care.

Figure 2. Hypothesis 6 – Declines in Mental and Physical Health as represented in caregiver literature.
Chapter 2: Methods

Sample

Participants were family members who provide care for a relative suffering from Alzheimer’s disease or a related dementia. A convenience sample of caregivers was obtained through multiple organizations that provide help and resources to dementia caregivers in the Midwest. The original recruitment plan included four organizations that had agreed to help with recruitment efforts. After recruitment began, additional organizations to recruit through were necessary. The changes will be elaborated at the beginning of the results section. The organizations originally included National Church Residences, Willow Brook Christian Homes, Central Ohio Area Agency on Aging, and the Alzheimer's Association: Central Ohio Chapter. The recruitment efforts were expanded during data collection and the other organizations that participated were: The United Way of the Eastern Upper Peninsula, The Alzheimer’s Association: UP Region, Sault Ste. Marie Area Public Schools – Employee Listserv, The Ingham County Medical Care Facility, Community Action Partnership, and War Memorial Hospital. An estimate based on information provided by contacts at each one of these organizations suggested that around 2,000 caregivers were part of the clientele and could potentially be contacted to participate in this research.
In order to test the hypotheses asserted in this research, and specifically the major model of H4, the sample contained people providing care for individuals at all stages of ADRD. Discussed in more detail later, a power analysis revealed that a minimum of around 180 participants would be needed for this research. However, testing the model advanced in this dissertation required that multiple people participate from each of the stages of Alzheimer’s disease and related dementias, and to achieve that kind of a spread, the researcher aimed to recruit 250 participants. This was to ensure that enough people from each stage of the disease were included in the sample.

The researcher funded compensation for participation in this study. Participants were entered into a random drawing for one of fifteen, $20 gift cards to a retailer of their personal preference, as indicated on the survey (Kroger, Walgreens, CVS, Walmart, Giant Eagle). Participant entry into the drawing was not based upon completion of the study. If a participant had been drawn as a winner but they had not completed the entire survey, the award was pro-rated for the percentage that was completed.

Procedure

Each organization was provided with an e-mail that included an invitation for caregivers to participate in an online study in addition to the link to fill out the survey. Not all organizations were able to use this option based upon policies within their organization, but the e-mail to distribute to a member listserv was available for the organizations that could use this method.
Caregivers were recruited through all specified organizations through posters, handouts, and announcements in organization newsletters. The researcher documented the number of fliers and handouts distributed to each organization. This helped to calculate the response rate overall.

The online survey was the primary mode of participation for caregivers, however, a paper and pencil survey was available upon request. Additionally, for those caregivers who have difficulty reading and writing, an option to participate by answering the survey questions over the phone or in person was also available upon request. Should a potential participant request a phone or in-person survey, the researcher would have personally read the participant each component of the survey and marked the verbal responses on the survey for the participant. The single alternative mode survey was completed by paper and pencil and was denoted in SPSS during data entry.

Informed consent was obtained prior to the participant beginning the survey. The online survey took an average of 30 minutes to complete. Upon completion of the survey, the participant had the opportunity to provide their mailing information and select one gift card option, from a select group of stores, to be entered into the gift-card drawing for their participation. The survey was available online for 3 months.

Measures

*Identity Gaps.* Three different scales were used to measure identity gaps. These scales were integral to Hypotheses 1-4. They were also the measurement for the dependent variable, identity gaps, of the fourth hypothesis. Jung and Hecht
(2004) developed the first two scales for measuring identity gaps. The personal-relational identity gap scale contains eleven items that address the degree to which a person’s self-perceptions are in-line with how they think other people view their character. This scale was factor analyzed with the Principal Component extraction method, resulting in two factors and the removal of one item (Jung & Hecht, 2004). Cronbach’s alpha for the eleven items was initially reported by the authors was good at .86 (Jung & Hecht, 2004). One item was removed from this scale, for this study, because the subject of the item was not related to this specific population of family caregivers. The reliability of the remaining ten items used in this research was acceptable at .791.

The personal-enacted identity gap scale measures the degree to which an individual perceives that his or her self-concept aligns with his or her outward actions. This scale was also factor analyzed using the Principal Component extraction method. The factor analysis and Direct Oblimin rotation revealed two factors (Jung & Hecht, 2004). Reliability for the personal-enacted identity gap scale was initially reported as good with Cronbach’s alpha at .89 (Jung & Hecht, 2004), and was acceptable in this study with a Cronbach’s alpha of .718.

The third scale, assessing the enacted-relational identity gap, consists of six items measuring the way in which an individual expresses his or her identity and how that coincides with how others perceive that individual. This scale was constructed assuming a single construct and as such was tested with a CFA single-factor model, establishing construct validity (Jung, 2011). Jung (2011) reported reliability for this scale at .82. The Cronbach’s alpha for this research was higher at .868.
Communication and dementia. The Montreal Evaluation of Communication Questionnaire for use in Long-term Care (MECQ-LC) is a measure that evaluates the communication abilities of both the caregiver and the care recipient (Le Dorze, Julien, Genereux, Larfeuil, Navennec, Laporte, & Champagne, 2000). The MECQ-LC measured the independent variable, perceived communication ability, which was used to test the fourth hypothesis that there would be a curvilinear relationship between caregiver identity gaps and the perceived communication abilities of the person with ADRD. Although constructed to be used in long-term care facilities and to assess professional caregivers’ experiences, this measure was useful for the informal caregiver context as well. Items that are clearly institutionally specific were left out of the final version of the survey for the purposes of this study since they were not relevant. The MECQ-LC is comprised of a total of eight subscales; six subscales for communication ability of the person with dementia and two subscales for caregiver communication behaviors. The six dementia communication subscales were combined to form a variable for ‘perceived communication ability’ and a Cronbach’s alpha for this aggregate variable was highly reliable at .937.

Role Salience. The salience of the caregiver role, as seen in H7, was measured using two different modes, thought listing of roles and a thirteen-item scale. At the very beginning of the survey, participants were asked to thought-list the top five roles that they assume on a daily basis, and then asked to rank order them by importance to their identity by placing a number, one through five, next to each role. Placement of thought listing at the beginning of the survey was to combat priming the
participant to write down the caregiver role, since that was the focus of the majority of the survey.

A thirteen-item scale measured role-identity salience. The thirteen items are broken into two subscales, ‘salience’ and ‘other’s expectations’. Salience consists of five items with a reported reliability of .81 (Callero, 1985). This scale measured the extent to which the caregiver internalizes the role of caring for an individual with ADRD as part of their self-definition. Others’ expectation of role has eight items and was reported to be reliable at .82 (Callero, 1985). This scale measured the extent to which the individual perceives other people’s expectations of their role as a family dementia caregiver. The original scale was produced to measure the salience of blood donation identity; for the purposes of this study, “blood donor/donation” was replaced with “caregiver/caregiving”. Role-identity salience was included in this survey to assess whether or not the role of caregiver did actually move higher in the hierarchy of identity over the tenure of care provision as communication abilities diminish, in addition to whether or not outside expectations to continue the role of caregiver have any effect on role identification. Reliability was analyzed in this research and was low for the salience scale (.523), acceptable for others’ expectations (.712), and acceptable for both scales combined in a role total variable (.764).

Health Status. To assess the path of mental and physical health status as it relates to the model in Figure 1, the study employed the 36-item Short-Form (SF-36) health survey (Ware & Sherbourne, 1992). The SF-36 was used to test the competing hypotheses, H5, H5a, and H6, about whether mental and physical health move in a curvilinear pattern similar to Figure 1 or if it resembles a roughly linear pattern of
decreasing health where it climaxes and plateaus, as seen in Figure 2. The SF-36 measures eight health related concepts with one scale. Multiple items on the scale measure the following: "1) physical functioning; 2) role limitations because of physical health problems; 3) bodily pain; 4) social functioning; 5) general mental health (psychological distress and psychological well-being); 6) role limitations because of emotional problems; 7) vitality (energy/fatigue); and 8) general health perceptions" (Ware & Sherbourne, 1992, p. 474). Multiple projects have tested the properties of this scale, but within specific populations (Parkinson’s disease, multiple sclerosis, halitosis therapy recipients, Crohn’s disease, etc). Reliability was computed for all of the subscales and for the combined scales making up a total physical health variable and a total mental health variable. The total physical health variable was reliable at .909 and total mental health variable was reliable at .819.

Depression. In addition to measuring psychological distress and well-being with the SF-36 for H5 and H6, depression was also measured as an additional gauge of mental health status since it is a specific outcome established in the literature for both the ADRD caregiver population and identity gaps. Rimon’s brief depression scale (Keltikangas-Harvinen & Rimon, 1987) is made up of seven different items on a 4-point Likert-type scale. Reliability and construct validity of the scale were assessed in relation to Beck’s depression inventory (Beck, Ward, Menelson, Mock, & Erbaugh, 1961) and both were reported as high, but no specific scores were reported. Rimon’s seven item scale was chosen for its succinctness compared to Beck’s 21-item inventory. A longer measure, like Beck’s depression inventory, was less than ideal considering that the inclusion of a depression scale was a second measure for mental
health status in caregivers. Reliability assessed for this study established a Cronbach’s alpha of .859.

**Social Support.** The empirical evidence is ample and strong in the caregiver literature on the positive outcomes of social support. Perceived social support was measured as the control variable between identity gaps and stress, proposed in RQ1. The Multidimensional Scale of Perceived Social Support is a 12-item scale with three subscales. The entire scale has a reliability of .88 (Zimet, Dahlem, Zimet, & Farley, 1988), and the subscales have adequate reliability as well: the Significant Other subscale was reliable at .72, the Family subscale was reliable at .85, and the Friends subscale was reliable at .75 (Zimet, Dahlem, Zimet, & Farley, 1988). The reliability for the entire scale in this research is high at .93.

**Stress.** Stress is another well-documented outcome of being an ADRD caregiver. Additionally, the identity literature, specifically identity interruption, suggests that lapses in identity are stress inducing. Stress, in RQ1, was analyzed for its relationship to identity gaps. The Psychological Stress Measure (PSM-9) is a short, 9-item, unifactorial scale used to assess levels of self-rated stress (Lemyre, Lalande-Markon, 2009). Although validity and reliability were reported for longer versions of this stress measure, both at highly acceptable numbers, the reliability of the condensed scale was not reported. The nine-item PSM had a good reliability in this study with a Cronbach’s alpha at .868.

**Caregiving Demographics.** Information regarding the context of each caregiving situation was important to understanding how caregiving affects identity. As such, items in the demographic portion of the survey asked for information about
the number of hours per week an individual spends caring for their family member, the types of tasks they perform on a daily basis to provide care for their family member, the status/severity of their family member’s ADRD, their relationship to the person they provide care for, and how long they have been providing care. Some of these items, like time spent providing care and the length of the caregiving tenure, were tested as possible covariates in this research.

This research required that the sample include an equal number of participants from early to late stages of Alzheimer’s disease. The delineation of stages for this research was taken from the Alzheimer’s Association. The Alzheimer’s Association website explains that the seven stages of Alzheimer’s and their descriptions are based on the framework developed by Dr. Barry Reisberg, the clinical director of the Silberstein Aging and Dementia Research Center (Alzheimer’s Association, 2013). Stage 1 is ‘no impairment’, Stage 2 is ‘very mild decline’, Stage 3 is ‘mild decline’, Stage 4 is ‘moderate decline’, Stage 5 is ‘moderately severe decline’, Stage 6 is ‘severe decline’, and Stage 7 is ‘very severe decline’. A more detailed account of each of these stages can be found in Appendix J.

Demographics. Other demographic information usually found in social science research was included on the survey such as age, gender, occupation, level of education, income level, marital status, and race and ethnicity.
Analysis

A power analysis revealed that a minimum of 182 participants was needed to obtain a power of .95 with an alpha level of .01 and an effect size of .1. The researcher intended to recruit 250 participants to offset potential missing data or incomplete surveys. Upon completion of data collection, all data were entered into SPSS to conduct analyses. Identity gaps were summed into four different variables for testing: personal-enacted, enacted-relational, personal-relational, and total identity gap.

Hypotheses 1-3

The first, second, and third hypotheses predicted the existence of gaps between three identity frames. To test these hypotheses, one-sample $t$-tests were conducted (for an example of such an analysis see Ramirez, Dimmick, Feaster, Lin, 2008). The $t$-test analyzed the mean of each scale in relation to the null hypothesis that no identity gaps exist. Since the scale ranges from 5-1, one denotes no gap, the number one was entered into the SPSS one-sample $t$-test analysis. A significant finding would suggest that identity gaps do exist and the null hypothesis could be rejected. In addition to the $t$-test, all means and standard deviations were included in the report (Hayes, 2005).

Hypothesis 4

The model depicted in Figure 1 shows the curvilinear relationship proposed by H4 between the independent variable, perceived communication ability, and the dependent variable, identity gaps. Curvilinear regression (SPSS curve estimation) was used to analyze the relationship between the IV and the DV. The curves
hypothesized as most likely to fit was a quadratic or cubic equation but the ten most common curves were tested for a best fit with the data. The best fit of a curve was determined by two criteria: 1) level of statistical significance achieved, and 2) the largest R squared. The linear model in the curve estimation procedure was compared to the curvilinear sequences to determine which was a better fit (Hayes, 2005).

Hypothesis 5, 5a, and 6

Both H5 and H5a suggested that mental and physical health would also demonstrate an inverted U-shaped pattern, the same as H4 shown in Figure 1. Therefore, the data for mental and physical health were also tested for a best fitting curve as outlined above. The competing hypothesis, H6 was tested using a linear regression. This hypothesis suggested that the decreased mental and physical health may not be as closely related to identity gaps in this population and may resemble a more linear form, where mental and physical health get worse and then plateau, instead of rising and falling as identity gaps are formed and relieved (See Figure 2). This hypothesis would have been supported if the linear model were a better fit to the data than the curvilinear models.

Research Question 1

A partial correlation was used to assess RQ1, which asked if there was a relationship between identity gaps and stress and controlling for social support. By partialing out social support as a covariate, the relationship between identity gaps and stress was evaluated (Hayes, 2005).

Hypothesis 7
Hypothesis 7, the contingent hypothesis predicting increased salience of the caregiver role as related to perceived diminishing communication abilities, was analyzed using a Pearson’s correlation coefficient. The 5-item role salience scale was correlated with the MECQ-LC. Support for H4 would have predicted, for H7, a negative correlation between role salience and perceived communication ability; as perceived communication abilities continued to decline, the salience of the caregiver role should have increased.
Chapter 3: Results

Participants were recruited through two approaches. The first method of recruitment was through the distribution of flyers and handouts in multiple organizations in two Midwestern states. Recruitment began with four large central Ohio agencies (The Alzheimer’s Association Central Ohio Branch, The Ohio Area Agency on Aging, The National Church Residences, and Willowbrook at Delaware Run) that deal with family caregivers as clients. After a month of very low response rates, and after having visited organizations to increase contact and visibility for the research, recruitment efforts very clearly needed to be expanded. The researcher contacted organizations in Michigan and received approval to recruit through them as well (The United Way of the Eastern Upper Peninsula and The Alzheimer’s Association – UP Region). Again, after another month and still incredibly low response rates, recruitment efforts were again expanded to an additional four organizations (Sault Ste. Marie Area Public Schools – Employee Listserv, The Ingham County Medical Care Facility, Community Action Partnership, and War Memorial Hospital).

Response rates were very low considering that the combined reach of all participating organizations had the potential to recruit around 2,000 caregivers. After continually expanding recruitment efforts over the course of three months and only resulting in a total of 36 completed surveys, 35 of those being usable, a second
method for finishing the sample was necessary. The researcher contracted with a private sampling firm, EMI – Online Research Solutions, to collect an additional 150 surveys from family caregivers. The final sample size for this research was 214, 179 from EMI and 35 from the researcher’s recruitment efforts.

The participants in this research were 79 percent female, 90 percent Caucasian, and ranging in age from 23 to 86 with a median age of 58 years. With the exception of two participants, everyone in this sample had a high school diploma or GED and about 58 percent had completed a degree in higher education (associates, bachelors, and graduate).

The familial relationships most frequently reported for this sample of caregivers were ‘adult daughter’ (46.8%), ‘wife’ (24.1%), ‘adult son’ (13.4%), and ‘husband’ and ‘adult granddaughter’ (each at 5.1%). The average tenure of care provision, in years, for this sample of family caregivers is 5.5 years and they provide, on average, 46.5 hours of care per week, ranging from zero hours in the past week (“they are in rehab for aspirational pneumonia since July 4th”, “recently put my grandmother in a nursing facility”) to 168 per week (“Live with my mother, so even when I'm out for errands, etc., I am her only caregiver”, “I am with him 24/7 I get 2 hours to myself a week”, “it is a full time job”, “24/7 job”).

Finally, participants were providing care for family members with stages of Alzheimer’s disease ranging from stage 2 (‘very mild decline’) through stage 7 (‘very severe decline’) (see Appendix J for a detailed description of each stage). Before data collection began, an assessment was made about the stages of Alzheimer’s disease that would be most integral to this research. The symptoms in stages 1 and 2 are very
mild and may either go unnoticed or unusual behaviors are explained away as normal byproducts of aging, like forgetfulness. People experiencing these stages may not even have a diagnosis of dementia or Alzheimer’s disease yet because the behaviors are not out of place or alarming. In light of this, the researcher decided that it was most important to focus on stages 3 through 7 since the communication abilities described in these stages very closely resembled the communication described by the major model of hypothesis 4 and Figure 1. The lack of participants in stage 1 and the small sample of those in stage 2 have been deemed acceptable for the purposes of this research. Table 1 shows the number of participants from each of the stages. Considering the difficulty of recruiting this population in general, the number of participants that represent each stage of the disease is distributed quite well.

**Table 1. Distribution of Participants by Stage of Alzheimer’s Disease.**

<table>
<thead>
<tr>
<th>Stages of Alzheimer’s</th>
<th>Total participants</th>
<th>Percentage of sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stage 2</td>
<td>12</td>
<td>5.6%</td>
</tr>
<tr>
<td>Stage 3</td>
<td>24</td>
<td>11.3%</td>
</tr>
<tr>
<td>Stage 4</td>
<td>42</td>
<td>19.7%</td>
</tr>
<tr>
<td>Stage 5</td>
<td>49</td>
<td>23%</td>
</tr>
<tr>
<td>Stage 6</td>
<td>55</td>
<td>25.8%</td>
</tr>
<tr>
<td>Stage 7</td>
<td>31</td>
<td>14.6%</td>
</tr>
</tbody>
</table>
The first three hypotheses were conducted with a Bonferroni adjusted alpha level of .0166 (.05/3). The skewness and kurtosis of these three hypotheses is presented in Table 2. Hypothesis 1 predicted that family caregivers would experience a gap in their identity in the personal-enacted frame. This hypothesis was supported using a one-sample \( t \) test evaluating that the mean, \( M = 2.53 \) (\( SD = .80 \)), of this identity gap was statistically different from 1 (1 would indicate no identity gap), \( t(213) = 27.89, p < .001 \), with a 95% confidence interval ranging from 1.42 to 1.63. The results of this test show that Alzheimer’s and dementia family caregivers do experience an identity gap in the personal-enacted frame.

A one-sample \( t \) test was used to test hypothesis 2, predicting that family caregivers would experience an identity gap in the enacted-relational frame. The \( t \) test revealed a sample mean of 2.72 (\( SD = .815 \)), and was statistically significant from 1, \( t(213) = 30.84, p < .001 \). The 95% confidence interval for the enacted-relational identity gap ranged from 1.6 to 1.8. Alzheimer’s and dementia family caregivers also experience a gap in their identity at the enacted-relational frame.

Hypothesis 3 predicted an identity gap would be present between the personal and relational frames of identity and was supported by a one-sample \( t \) test. The sample mean, the largest of all of the identity gaps, was 3.2 (\( SD = .73 \)) and was significantly different from 1, \( t(213) = 43.94, p < .001 \), with a 95% confidence interval between 2.09 and 2.29. Family caregivers for people with Alzheimer’s disease and related dementias experience a gap in their identity between the personal-relational frames.
An aggregate variable was formed by summing all three identity gaps to assess a ‘total identity gap’ score. The total identity gap was analyzed with a one-sample t test. The mean score for total identity gap was 2.8 (SD = .62), \( t(213) = 42.07, p < .001 \), with a 95% confidence interval ranging from 1.71 to 1.89. Family caregivers for Alzheimer’s disease and related dementias experience a gap in their identity overall.

Table 2. Skewness and Kurtosis for Identity Gap Hypotheses 1-3.

<table>
<thead>
<tr>
<th></th>
<th>Skewness</th>
<th>Kurtosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal-Enacted</td>
<td>-.001</td>
<td>-.654</td>
</tr>
<tr>
<td>Enacted-Relational</td>
<td>-.205</td>
<td>.133</td>
</tr>
<tr>
<td>Personal-Relational</td>
<td>-.192</td>
<td>.170</td>
</tr>
<tr>
<td>Total ID Gap</td>
<td>-.417</td>
<td>-.017</td>
</tr>
</tbody>
</table>

Hypothesis 4 advances the major model of this research (Figure 1) and predicts that there will be a curvilinear relationship between identity gaps and the perceived communication abilities of the person with Alzheimer’s disease or dementia for whom they provide care. The model was tested with curvilinear regression to find the best fitting curve to the model. The ‘total identity gap’ score was entered into the model and the curve estimation revealed none of the 10 common curves to be a good fit.
To explore this model further and to see if there was any relationship between caregiver identity gaps and perceived communication ability, each of the three identity gap frames surveyed were analyzed using the same curve fitting technique. The personal-enacted frame was not significantly related to perceived communication ability under any of the curves. A graph of the quadratic curve, although not significant, interestingly resembles the curve that was initially predicted in the model of H4 (See Figure 3).

Figure 3. Quadratic relationship between personal-enacted identity gap and perceived communication ability.
The personal-relational identity gap was also not significant under any of the curves. The enacted-relational frame was significant with all of the curves. The curve estimation that explained the most variance was the cubic model, $R^2 = .099$, $F(3, 210) = 7.703, p < .001$. Although the graph for this curve (see Figure 4) does not coincide with the original hypothesized model of H4, the relationship found between this identity gap and perceived communication ability has interesting and important outcomes and will be elaborated upon further in the discussion section. Overall, the

**Figure 4.** Cubic relationship between enacted-relational identity gap and communication ability.

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curvilinear model (see Figure 1) predicted for this research was not supported and only one significant relationship was found between identity gaps and perceived communication ability.

Hypothesis 5 predicted that mental health’s relationship with perceived communication ability would resemble the same curvilinear pattern predicted by H4 where declining mental health would increase and then decrease as perceived communication ability declined (See Figure 1). Curve fitting analyses revealed no significant relationship between mental health and perceived communication ability, thus H5 was not supported.

Physical health was also hypothesized, in H5a, to resemble the same curvilinear pattern depicted in Figure 1; over the course of communication decline in the person with ADRD, declining physical health was expected to rise and fall for the family caregiver. H5a was not supported; curve fitting analyses revealed that physical health was not significantly related to perceived communication ability.

The sixth hypothesis was an alternative hypothesis to H5 and H5a. H6 predicted that both mental and physical health would decline to a critical point and then plateau and remain at that heightened level as communication ability declined. Neither mental health nor physical health was significantly related to perceived communication ability. Linear depictions of the relationships between mental health and perceived communication ability and physical health and perceived communication ability show that both health variables decline as communication ability worsens, but neither to a significant extent.
RQ1 asked if there was a relationship between identity gaps and stress while controlling for social support. A Pearson’s correlation coefficient was conducted initially to determine the relationship between the total identity gap score and stress. The bivariate correlation showed a significant relationship, $r(214) = .362, p < .01$. Next, a partial correlation was conducted to control for social support, which is known to buffer the effects of stress. The partial correlation was $r(211) = .316, p < .01$. The three individual identity gaps were also tested and the partial correlations revealed that stress and the personal-enacted ($r(211) = .266, p < .001$), the personal-relational ($r(211) = .248, p < .001$), and the enacted-relational ($r(211) = .235, p = .001$) identity gaps are all significantly associated, controlling for social support. Overall, stress is significantly associated with identity gaps, even after controlling for social support.

Finally, hypothesis 7 was a contingent prediction that hinged on the support of the model advanced in H4. This final hypothesis predicted that the salience of the caregiver role would increase as perceived communication abilities continued to decline. Hypothesis 4, predicting a curvilinear relationship between identity gaps and perceived communication ability, was not supported and thus it is not surprising that hypothesis 7 was also not supported. Pearson’s correlation coefficient revealed no significant relationship between the role salience and perceived communication abilities.

The hypotheses and the research question advanced by this study received mixed support. Although some of the hypotheses were not supported in the predicted direction or to the expected level, the data contained interesting and useful
information for moving forward with further studies examining the relationship between caregiver identity and the impact of changing communication abilities related to ADRD. Family caregivers do experience identity gaps, declining communication significantly affects the enacted-relational frames of identity gaps, and identity gaps do play a role in declining mental and physical health as well as levels of stress. To further understand the data, follow-up analyses were conducted and are explained in the next section of the results chapter.

Follow Up Analyses

Further analyses were necessary to understand what these data held since the major model proposed in this research (H4, Figure 1) was not supported. Each follow-up analysis reported below was performed based on the outcomes of the initial hypothesis testing. The basic conjectures of three major theoretical frameworks that informed this study were not completely supported in the research: 1) communication abilities of the person with dementia was not an overall predictor of the high identity gaps seen in this sample of family caregivers, 2) family caregivers reported high identification with the role of caregiver from Alzheimer’s disease stages 2-7 instead of a gradual heightening of identification across the advancement of the illness, and 3) there is nothing to suggest that family caregivers experience a change in identity when the communication no longer reinforces their old identity. The results of this research do not clearly align with the theoretical assumptions and ultimately required further probing.

An important relationship that needed to be tested was between stages of Alzheimer’s disease and perceived communication ability. Decreasing verbal
communication is one of the main symptoms of advancing stages of Alzheimer’s disease making it important that these two variables measured were correlated. A Pearson’s correlation revealed that the two variables were significantly related, $r(214) = .540, p < .01$. In addition to the Pearson’s correlation coefficient, curve fitting was also performed and revealed that a cubic model was significant and explained 40 percent of the variance, $R^2 = .406$, $F(3, 209) = 47.573, p < .001$. As the disease progresses, caregivers report perceptions of communication decline around stage 5 (moderately severe decline) and continues to decline severely through stages 6 and 7. Figure 5 illustrates the sharp upslope in caregiver perceptions of decreasing communication abilities in their family member with ADRD.

Hypothesis testing for H1, H2, and H3 revealed that family caregivers experience identity gaps between the personal-enacted, enacted-relational and personal-relational frames of identity, in addition to a significant ‘total identity gap’ score. In an attempt to understand if any of the identity gaps were significantly larger than the others, each identity gap measured was compared to the other two using a paired samples $t$ test. There were significant differences found between all of the identity gaps. The personal-relational ($M= 3.2, SD= .73$) and enacted-relational ($M= 2.7, SD= .815$) identity gaps were significantly different, $t(213) = -9.216, p < .001$. The personal-relational frame ($M= 3.2, SD= .73$) and the personal-enacted frame ($M= 2.52, SD= .8$) were significantly different, $t(213) = 11.998, p < .001$. Finally, the enacted-relational frame ($M= 2.7, SD= .815$) and the personal-enacted frame ($M= 2.52, SD= .8$) were significantly different, $t(213) = 3.173, p = .002$. 

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Hypothesis 4 revealed that only one of the identity gaps (enacted-relational) was significantly related to perceived communication ability. Since communication was not a significant predictor of two out of the three identity gaps tested, as well as the ‘total identity gap’ score, the next step was to analyze the relationship between identity gaps and the stages of Alzheimer’s disease. In line with the analysis for H4, curve fitting was used to estimate the best model fit for each identity gap across the stages of Alzheimer’s disease. The personal-enacted identity gap was best explained
by a quadratic model, $R^2 = .038$, $F(2, 210) = 4.124$, $p = .018$. Interestingly, the quadratic model, when graphed (Figure 6) shows a curve very similar to the one predicted to exist in H4 (Figure 1). This similar curve may suggest the occurrence of an identity shift. The enacted-relational identity gap, the only identity gap to be significantly related to communication ability, was also tested for a curve of best fit. The analysis revealed a linear relationship between the enacted-relational frame and the stages of Alzheimer’s disease, $R^2 = .052$, $F(1, 211) = 11.482$, $p = .001$. The enacted-relational identity gap increased as the stages of Alzheimer’s progressed. Curve fitting for the personal-relational identity gap also revealed a significant relationship that resembled the curve predicted in H4 (Figure 1). Again, this inverted-u pattern may suggest a shift in identity over the stages of Alzheimer’s disease. The quadratic model, $R^2 = .044$, $F(2, 210) = 4.872$, $p = .009$, shows a rise and fall pattern in the personal-relational identity gap across the stages of Alzheimer’s disease (Figure 7).
Figure 6. Quadratic model of the personal-enacted identity gap across the stages of Alzheimer’s disease.
Figure 7. Quadratic model for the personal-relational identity gap across the stages of Alzheimer’s disease.

Hypothesis testing for H5, H5a, and H6 showed no relationship, neither linear nor curvilinear, between perceived communication ability and mental and physical health. The dementia caregiver literature is filled with empirical evidence that family caregivers are at higher risk for detrimental effects to their mental and physical health (see Kiecolt-Glaser, et al., 1991; Vitaliano, Zhang, & Scanlan, 2003; Schulz & Beach, 1999; & Schulz & Sherwood, 2008; Schulz, O'Brien, Bookwala, & Fleissner, 1995). Because caregivers are at increased risk for declines in mental and physical health
and because the CTI literature has also established that identity gaps are related to increased levels of depression (Jung & Hecht, 2008), mental and physical health were analyzed in relation to identity gaps.

Curvilinear regression analyses revealed that the relationship between mental health and total identity gaps was significant. Curve fitting suggested that a cubic model is most appropriate for the mental health equation, $R^2 = .139$, $F(3, 204) = 11.021$, $p < .001$. Figure 8 shows this relationship, and although the line of best fit on the graph appears to be almost linear, the linear model did not explain as much of the variance as did the cubic model, 12.8% as compared to 13.9%, respectively. Mental health was higher (a high score indicates good mental health) when identity gaps were non-existent or low. As identity gaps increase, mental health gradually declines.

Physical health was significant at the .05 level when fitted to a linear model. The linear regression of physical health predicting total identity gaps, $R^2 = .023$, $F(1, 196)$, $p = .034$, shows a negative relationship where physical health decreases as identity gaps increase.
Figure 8. Cubic model of H5 relationship between mental health and identity gaps.

The only hypothesis to examine role salience was contingent hypothesis 7. H7 found no significant relationship between role salience and perceived communication ability. Role identity was a major theoretical component of this research and thus, role salience was explored further to determine its potential importance to this research. Seen in Figure 9, the salience of the caregiver role was very high for family caregivers across all stages of Alzheimer’s disease.
Exploratory regression analysis revealed that role salience was significantly related to total identity gaps and two out of the three identity gap frames. Total identity gap was significant with role salience at the .05 level, $R^2 = .029$, $F(1, 212) = 6.269$, $p = .013$. The personal-enacted identity gap was significant with role salience, $R^2 = .023$, $F(1, 212) = 4.957$, $p = .027$. The personal-relational frame was not significantly related to role salience, $R^2 = .011$, $F(1, 212) = 2.313$, $p = .13$. And finally, the enacted-relational identity gap was significantly related to role salience,
$R^2 = .02, F(1, 212) = 4.304, p = .039$. With the exception of the personal-relational frame, the salience of the caregiver role was significantly related to identity gaps.
Chapter 4: Discussion & Conclusion

The research presented in the previous chapter illustrates a number of issues that persons caring for a family member suffering from Alzheimer’s disease or related dementias experience during their care tenure. The results suggest that caregivers experience identity gaps, that family caregivers highly identify with their role as caregiver, and that identity gaps are significantly related to declines in mental and physical health. In this chapter, the major findings from this research are explicated in light of theory, implications for practical application, and plans for future research.

Theoretical Implications

The theoretical frameworks that informed the major crux of this dissertation research were stress and identity interruption (Burke, 1991), the Communication Theory of Identity (Hecht, Warren, Jung, & Krieger, 2005), and Caregiver Identity Theory (Montgomery & Kosloski, 2009). The combination of these three theories clearly suggested that dementia family caregivers were in a very unique situation where the progressively diminishing communication abilities of the person for whom they provide care had the potential to make a significant and, most likely, a detrimental impact on their identity. The unpredictable communication and decline in cognitive abilities, the major symptoms of dementing illnesses, cause a communication climate where an inconsistent identity would be reflected back to the family member providing care. This interruption to identity would cause the caregiver distress and identity gaps would form. For example,
Jane’s mother requires very intensive care as her illness has progressed to stage 6 and her limited ability to communicate with those around her is focused on care needs. Jane is no longer having her identity as an adult daughter, or even a family member, reflected back to her from her mother, and this causes an interruption to identity.

Due to the nature of a progressively degenerative disease, there would be no way for the family caregiver to change their communicative behaviors with the care recipient to facilitate a reflection of identity consistent with the caregiver’s self-concept. The resulting stress that the caregiver would experience from this interrupted identity could only be alleviated through an identity change (Burke, 1991) because the communication environment could not alleviate the disparity. The resulting identity shift, where the role of caregiver would become the salient role in the overall identity is consistent with the Caregiver Identity Theory (Montgomery & Kosloski, 2009). The responsibilities of a family caregiver intensify over the course of Alzheimer’s disease, and this increase in time and the number of duties causes the role of ‘caregiver’ to gradually consume more of the overall identity, also explained as a shift in identity. This shift in identity would, in turn, cause the identity gaps and the resulting stress to be relieved.

The combination of the three theories described above in relation to the family Alzheimer’s caregiver was the underlying rationale for this research and inspired the major model of Hypothesis 4 (see page 35). Although caregivers did report experiencing identity gaps between the personal-enacted, the enacted-relational, and the personal-relational frames of identity, the caregiver’s perception of communication ability of the person with ADRD was only significantly related to one identity gap, the enacted-relational frame.
A gap in the enacted and relational identity frames means that there are discrepancies between how an individual conveys their self-concept in their communication and the identity ascribed by another person (Jung, 2011). In this case the person ascribing identity is the family member with ADRD. This identity gap, shown in the data, increased sharply as communication ability was perceived by the caregiver to be severely compromised. When communication ability is severely compromised in persons suffering from ADRD, they are often in advanced stages of the illness. The definition of the stages of Alzheimer’s disease (see Appendix J) support communication problems in the end stages and so do the data in this research. Cognitive abilities are severely compromised in the final stages of Alzheimer’s disease and often this results in a lack of recognition of the family member providing care. When the family caregiver tries to enact their identity, even in an attempt to get recognition of their face, their name, or their relation to the person, this attempt is met with non-recognition in these later stages, stages 6 and 7. Therefore, the caregiver’s enactment of their identity and the ascribed identity from their ill family member are at odds with each other, because the person with Alzheimer’s disease either cannot utter the words to confirm that identity or they do not recognize their family member and call them by a different name or treat them like a stranger.

Karner and Bobbitt-Zeher (2005) studied identity issues with family caregivers in qualitative interviews. Non-recognition was evident in a number of the interviews the authors conducted. A narrative taken from their interviews that clearly demonstrates the gap between the enacted-relational frames and how communication affects the identity is from a wife caring for her husband with Alzheimer’s disease, “He doesn’t know me
most of the time. [He has] called me by other names. One time he even told me I had better leave because his wife was coming home,’”(Karner & Bobbitt-Zeher, 2005, pg. 559).

In light of the unique context of the family caregiver, however, the lack of connection between communication ability and identity gaps may not be as anomalous as communication literature might suggest. The original role that makes up the family caregiver’s identity in relation to the person they provide care for is most likely a role that is deeply established and has been held for a very long time, often for decades, whether it is ‘daughter’ or ‘spouse’ or any of the other familial roles. Although the role of caregiver may take precedence over that original role at certain times, the family member may still view their identity as that of a daughter or a spouse, even if the role of caregiver is higher in the identity hierarchy. Again, Karner and Babbitt-Zaher’s (2005) qualitative interviews with family caregivers illustrates how family members continue to remember that original, lasting identity and how the current role is only momentary,

‘A long time ago, I faced the fact that there was a definite role reversal . . . now all the responsibility is on myself and my husband. [I’m] still his daughter and so I remember what he used to be like and I have emotional feelings that are tied up with my relationship with him’, (pg. 559).

The language used by the caregiver above demonstrates that caregiver is only a role (“a definite role reversal”) while “daughter” is a deeply felt and long-term identity (“I’m still his daughter”). The family caregiver’s self-concept may still be tied mostly to the original relationship instead of the new role they are internalizing, enacting, and that is being ascribed (or not ascribed) by the person for whom they provide care. This helps
explain why there are identity gaps present in family caregivers and why the perceived communication ability is not related to these frames of identity. It is not the decline in communication that is interrupting the caregiver’s identity, but may instead be the disease. Family caregivers may attribute the cause of the interruption to their identity as arising from the illness their family member is afflicted with instead of anything the family member is doing purposefully.

The above quote from Karner and Bobbitt-Zeher (2005) also suggests that there may be a method to how these family caregivers deal with identity interruption and identity gaps that is not completely consistent with Burke’s underlying assumption of re-establishing balance and resolution of the interruption. The way to alleviate the interruption, as described below, may also help explain why the model in H4 was not supported. As explained in Chapter 1, Burke’s identity interruption and stress model suggests that when an individual experiences a disruption to their identity standard at one of two different communication points (output or input), that individual will change their communication behaviors so that the input from the social environment matches their identity standard. If no change in communication results in an input that matches the identity standard, an identity change is necessary to alleviate the distress experienced from the disruption.

Burke’s model along with other well-known theories such as Heider’s Balance theory (1946) and Festinger’s Cognitive Dissonance theory (1957) make similar assumptions of consistency and balance in human behavior. They all assume that people behave in a rational manner, to differing degrees, and that these behaviors provide the individual with organized meaning (Harari, 1967). When there is inconsistency between
any cognitions, behaviors, attitudes, or beliefs, the discord will motivate the individual to eliminate the inconsistency and restore balance or equilibrium (Harari, 1967; Heider, 1946; Festinger, 1957). The major difference between Burke’s identity interruption and stress model and the other theories is that Burke only outlines two possibilities to restore balance: change behaviors or change identity. Cognitive dissonance, however, suggests that there are multiple routes for an individual to reestablish consonant cognitions and bring their thoughts, attitudes, beliefs, and behaviors back into harmony (Harmon-Jones, Amodio, & Harmon-Jones, 2009).

One way that a consonant identity may be restored in the case of the family Alzheimer’s caregiver is evinced in the second half of the quote from Karner and Bobbitt-Zeher (2005) fully cited above, “…I faced the fact that there was a definite role reversal...[I’m] still his daughter and so I remember what he used to be like and I have emotional feelings that are tied up with my relationship with him”, (pg. 559). This daughter acknowledges that her current relationship with her father, for whom she provides care, is more consistent with her being the parent to him, as opposed to the way it has been her entire life, he is her parent. The mention of a role reversal is evidence of an identity interruption and gap that this caregiver is experiencing, but there is not even the slightest indication that she has had to change her identity to be once again balanced. She instead asserts that she is holding on to her original identity and her original relationship with her father, in addition to his original identity as well – his pre-dementia identity.

The quote above illustrates that the model for H4 may not have been supported because of the limitations of Burke’s model and that there may be other ways that family
caregivers are creating consonant cognitions about their identity and roles. These methods for maintaining identity and dealing with identity interruption and identity gaps merits further investigation. The author of this dissertation suggests that qualitative interviews with family caregivers would be an appropriate way to further understand identity interruption, identity gaps, identity management methods, and creating consonant cognitions about identity.

In the current study, identity gaps are related to increased rates of depression, decreased mental health status, and decreased physical health status. The relationship between identity gaps and depression is consistent with current CTI literature (Jung & Hecht, 2008). In addition to increased rates of depression, as reported in the results chapter, identity gaps were also related to decreases in mental health, which is not surprising since depression signifies compromised mental health. The literature has established that family caregivers for Alzheimer’s disease are at increased risk of developing depression (Adams, 2008; Butler, Turner, Kaye, Ruffin, & Downey, 2005; Schulz & Sherwood, 2008; Schulz, O'Brien, Bookwala, & Fleissner, 1995; Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Kiecolt-Glaser, Dura, Speicher, Trask & Glaser, 1991) and psychological burden (Schulz, O'Brien, Bookwala, & Fleissner, 1995) and the current study suggests that identity gaps may be adding to the overall accumulation of these mental health issues. Identity gaps in this study were also related to declines in physical health, even after controlling for age. This is the first empirical evidence linking identity gaps to physical health. Similar to mental health, family caregivers are also at an increased risk for diminished physical functioning (Vitaliano, Zhang, & Scanlan, 2003; Schulz & Beach, 1999; & Schulz & Sherwood, 2008). The
implications of identity gaps in relation to mental and physical health potentially have practical associations for family caregivers and will be discussed further in the section below called ‘practical implications’.

The caregiver identity was highly salient to this sample of family caregivers. Although they reported feeling high levels of identity gaps, they also felt highly connected, internally, to their role as a caregiver. As shown in the results chapter (see Figure 9), role salience is, on average, high for stages 2-7 of Alzheimer’s disease. There is a spike in role salience around Stage 3. A logical explanation for this spike is based on the definition of stages 2 and 3. Stage 2 is defined by symptoms of memory lapses or forgetting familiar words, but that no symptoms of dementia would probably be detected by a medical examination. Stage 3 is the first stage where the Alzheimer’s Association suggests that a medical professional would finally be able to detect problems with memory and concentration and is also the stage where family and friends would finally begin to notice changes in the individual (Alzheimer’s Association, 2013). This peak of role salience more than likely coincides with the initial Alzheimer’s disease diagnosis. After some time has passed, role salience is still high, but it comes down from that peak at stage 3 and plateaus through to stage 5. In the final stages of Alzheimer’s disease, stages 6 and 7, role salience begins to increase again. This is consistent with caregiver identity theory since stages 6 and 7 necessitate increased intensity and time spent providing care to the individual as they have lost the ability to do most activities of daily living (Montgomery & Kosloski, 2009). The role of caregiver is more salient at these stages because that role is being activated more often by the increase in care activities. This is also consistent with results of the thought-listing of roles in the current study. The
rank of the caregiver role was significantly related to the stages of Alzheimer’s; as the
disease continued to progress, the higher the role of caregiver moved in the identity
hierarchy. Although family caregivers experience heightened levels of identity gaps,
they have also internalized their role as a caregiver.

The research presented in this dissertation supports current identity literature and
Alzheimer’s family caregiver literature. This study shows that identity gaps are
experienced by Alzheimer’s family caregivers and that identity gaps are significantly
related to increased rates of depression and decreased mental health status. This study
also provides the first evidence that identity gaps are linked with decreased physical
health status. The current research also indicates that the communication ability of a
person with Alzheimer’s disease or related dementia has any effect on identity gaps. This
research does show, however, that identity gaps are significantly related to the stage of
Alzheimer’s disease. Finally, caregivers highly identify with the role of caregiver in all
stages of the disease; the caregiver role becomes increasingly salient and moves higher in
the identity hierarchy as the disease progresses and as time spent caregiving increases,
consistent with the caregiver identity theory.

Practical Implications

The major practical outcome of this research is caregiver education. Identity gaps
were high for this sample of family caregivers and other theory and literature suggests
that, overall, family caregivers experience issues with identity (Hagedoorn, Sanderman,
Buunk, & Wobbes, 2002; Hayes, Boylstein, & Zimmerman, 2009; Karner & Bobbitt-
Zeher, 2005; Miller, Shoemaker, Willyard, & Addison, 2008; Montgomery & Kosloski,
2009; O’Connor, 2007; Skaff & Pearlin, 1992). The concept of identity gaps
differentiates and targets components of identity and can help caregivers pinpoint where they are feeling interruptions to a coherent identity. Informing caregivers that identity gaps exist and providing an understanding of the way in which each of these frames work in conjunction with the others would first and foremost, bring to light the existence of multiple layers of identity. Emphasis should be placed on the personal-relational frames of identity since this identity gap was rated highest in the current research. Another identity gap that educational materials should focus on is the enacted-relational identity gap and how the changing communication abilities of their family member with Alzheimer’s disease can play a major role in these two frames working together or against each other.

Second, the inextricable link between communication and identity would need to be explained and illustrated so that caregivers are aware of how all of their actions and interactions were enacting and reflecting identity. Finally, caregivers need to be informed of the detrimental outcomes these identity gaps can have on their mental and physical health, placing more emphasis on the mental health outcomes since the relationship to identity gaps is so strong. Providing caregivers with information about what to expect in terms of their identity and identity interruption over the tenure of care can help better prepare them to thwart some of the adverse effects that may intensify and worsen because of these identity gaps.

This information about caregiver identity and identity gaps can and should be built into already existing interventions, educational workshops and documents, and support group materials. There are many organizations around the nation that provide resources for caregivers and could easily include this new, helpful information. Materials
could be readily distributed by most of the organizations that were used to recruit caregivers in this current study: The Alzheimer’s Association, The Central Ohio Area Agency on Aging, The National Church Residences, The United Way. The same is true for any other organization or care facility that works with people with Alzheimer’s disease and their family members. This information would be most useful, however, to family members very early on in the illness so that they have time to prepare for the changes that will take place in their self and in their family member. The optimal place to locate family members dealing with early stages of Alzheimer’s disease would be when the dementia is initially diagnosed. Physicians are the first and primary source of information for the person diagnosed as well as their family members. Distribution of available information and available resources at this point of contact would be the farthest reaching for the person with Alzheimer’s disease and their family members.

Future Research

One of the first areas that should be explored based on the outcomes of this research is the lack of relationship between perceived communication ability and the personal-relational and personal-enacted frames of identity. One potential reason for this finding is that the family relationship was already causing gaps; the caregiver may have always felt as though they could not express an accurate reflection of their self-concept around their family member. For example, an adult child may not feel like they can express themselves freely around their parents because they know that certain behaviors they engage in are deemed unacceptable by the parents or that certain beliefs and attitudes are not shared between the adult child and the parent. In an attempt to keep interactions and visits as smooth and pleasant as possible, the adult child is forced to
conceal certain parts of their identity while interacting with their parent. Therefore, identity gaps pre-dementia should be assessed to determine if these identity gaps are the result of the caregiver role or if family relationships generally cause identity gaps to exist. In addition to the identity-gap status pre-dementia, the value that the caregiver places on the familial relationship would also be important to measure. A strong or a weak connection between the dyad in terms of the familial relationship could make a difference in the number and intensity of identity gaps the caregiver feels.

Another topic to explore in future studies is the way in which family caregivers speak about the communication changes they see taking places in their family member and how they attribute and characterize those changes and the associated decline in communication. Changes in communication and how that communication reflects the caregiver’s identity could potentially be attributed as a result of the person enacting that communication or it could be attributed as a result of the disease. In a study by Karner and Bobbitt-Zeher, a number of the caregiver’s they interviewed highlighted that their family member was no longer a person with a clear and distinct ‘self’, but was a person with an illness. They perceived the ‘self’ of the ill person to have vanished with Alzheimer’s disease and attributed behavioral and identity changes to the result of the progression of the disease. One caregiver points to the changes in relational identity and says that the “…illness has changed our relationship,” (Karner & Bobbitt-Zeher, 2005, p. 561). The attribution of communication and behavioral changes may have an impact on how much of an interruption to their identity they experience. If they perceive that behaviors and communication were in the control of the person with ADRD, they may experience more identity gaps than someone who perceives any behaviors or
communication that are inconsistent with any frame of identity as the result of an illness and unintentional. Ultimately, attributions of locus of control, whether external or internal, could also improve understanding of how identity gaps between frames are formed and alleviated.

Finally, the relational identity measured in this research was limited to an ‘ascribed identity’. The CTI literature explicitly outlines four components to the relational frame of identity: the relational identity as ascribed by another person, the identity of the individual in relation to another person (spouse, friend, daughter), the relationship of different roles as they exist and affect the total identity of an individual (police officer and mother), and the identity of actual relationship between two people (Jung & Hecht, 2004). So much of the family care dyad revolves around the changing relationship between the caregiver and the care recipient that the other facets of relational identity should be examined more completely. Based on evidence from this sample of caregivers, the ascribed relational identity is working against the enactment of identity by the caregiver and this identity gap is related to perceived communication abilities in the person with Alzheimer’s disease. What is unknown, however, is whether or not the other types of relational identity would also be affected by communication ability in the same manner.

Limitations

In order to move forward with the suggestions outlined previously in this section, a few limitations of the current research need to be highlighted. The first limitation is that this sample was a convenience sample. The first recruitment method was through organizations that work with family caregivers. The participants from this method may
not be representative of all family caregivers as those caregivers who are utilizing available resources may be much different than those family caregivers who do not utilize community and organizational resources. The second method of recruitment to complete the sample of caregivers was through a professional sampling firm. These participants may also be fundamentally different than other caregivers since they are enrolled in a pool of participants to fill out surveys through online forums.

The mode of survey completion was mostly online, with only 1 survey filled out in paper and pencil format. This, again, suggests that there may be fundamental differences between this sample and caregivers in general. Caregivers who use a computer and the Internet may potentially have more access to information and support than family caregivers who do not use such technology. Since only one person filled the survey out in paper and pencil format, this research may only be representative of a certain kind of caregiver.

This research was cross-sectional and because data were collected at only one point in time, it is impossible to determine any causal relationships between communication, identity gaps, and physical and mental health. This cross-sectional study is especially problematic for Alzheimer’s disease caregivers because behaviors and cognitive functioning can change drastically in a short period of time. The time period that the participants were asked to respond in relation to may not have been an accurate reflection of a more normal profile of the care recipient’s behaviors, or even a normal week of caregiving duty. A few people mentioned in their responses that the previous week for which they were responding was not a normal week; they had been gone on vacation for the week prior to the study and so they did not provide any care for their
family member in the past week or that the person was in a rehab facility currently for aspirational pneumonia. A longitudinal study would be beneficial to actually capture the progression of identity gaps over the course of Alzheimer’s disease and how the decline in communication and cognitive functioning affects identity issues.

Another limitation was the length of the survey. Out of a total of 63 people who began the survey in the sample recruited through aging and Alzheimer’s disease organizations, only 35 completed usable surveys. In the sample recruited through the professional sampling firm, 179 people completed usable surveys out of 305 who began the survey. Although the survey may have been too long to complete for some people, it is worth mentioning that the majority of the surveys that were began and not completed were abandoned after only answering one or two items.

Finally, some of the demographic characteristics of this sample need to be taken into account. The majority of this sample, almost 80%, was female. Although women are noted as the most likely to take on care responsibilities within families (Beers & Jones, 2004; Hooyman & Kiyak, 2011), this is not necessarily an accurate representation of the amount of male to female caregivers in the general population. The 2010 Behavioral Risk Factor Surveillance System reported that 62% of caregivers for Alzheimer’s and related dementias were women, meaning that the sample for the current research is not representative of male caregivers. Another area of disproportional representation in this sample as compared to the general population is that over 90% of the respondents were of Caucasian descent. The National Alliance for Caregiving and the AARP (2009) found that although more Caucasian people (54%) are providing care for a person with Alzheimer’s disease than other racial/ethnic groups (38%) (Alzheimer’s
Association, 2013). This also limits the ability of this research to be generalized to Alzheimer’s family caregivers in the rest of the population since it cannot account for the differences between cultures of the Alzheimer’s caregiving experience. Another limitation of this sample is that it is highly educated, of a total of 214 respondents, only two of them had not finished high school, 18% had at least completed some college, 14% had an associates degree, 25% had a bachelors degree, and almost 20% of the sample had a graduate or advanced degree. This is not consistent with the general population. The education of this sample may not be as far removed from other caregivers in the general population; the BRFFS (2010) reports that 50% of caregivers had at least some college education or higher. Some of the demographic characteristics of this sample limit the ability to generalize the results of this research to a broader population and future studies should seek funding sources to obtain a more representative sample of Alzheimer’s family caregivers.

Conclusion

The research presented in this dissertation provides further support that family caregivers for Alzheimer’s disease and related dementias experience changes and that this specific population experiences gaps to the personal, enacted, and relational frames of their identity as outlined by the communication theory of identity. The results of this research provide evidence that caregivers are susceptible to identity gaps and that these gaps are related to decreased mental and physical health, but this research raises further lines of questioning about the major sources of these identity gaps. The failure to support the major model in this research requires that future research continue to build theory between communication and identity processes. Research needs to examine how family
Alzheimer’s caregivers make sense of and create consonant cognitions about their identity when they experience identity gaps. Although more research needs to be conducted to better understand changes in caregiver identity and what influences identity gap formation and relief, the results of this research are useful to inform caregiver education and early intervention.
References


Behavioral Risk Factor Surveillance System. Seattle, WA; University of Washington Department of Epidemiology.


Appendix A
The Montreal Evaluation of Communication Questionnaire for use in Long-Term Care
(MECQ-LTC)

Instructions: Here is a list of means of communication that may be employed by your loved one to express him/herself. Please indicate on a scale from 1 to 5, where 1 is never and 5 is frequently, if he/she uses each of the following:

<table>
<thead>
<tr>
<th>Never</th>
<th>2</th>
<th>Sometime</th>
<th>4</th>
<th>Frequently</th>
</tr>
</thead>
<tbody>
<tr>
<td>'Yes' and 'No' indicated by a head movement</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Facial expressions</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Speech</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Body movements</td>
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<td></td>
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<tr>
<td>'Yes' and 'No' verbally</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attitudes/behaviors that carry particular meaning</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Vocalizations or variations in intonation</td>
<td></td>
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<tr>
<td>Pointing</td>
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<tr>
<td>Gestures</td>
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<tr>
<td>A code that needs to be interpreted</td>
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<td></td>
</tr>
<tr>
<td>Writing or drawing</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gesticulations</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>'Yes' and 'No' indicated by pointing to the written words or pictures</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other:</td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

Instructions: Here is a list of means of communication that you may be employing in order to understand your loved one when he/she tries to transmit you a message. Please indicate on a scale from 1 to 5, where 1 is never and 5 is frequently, if you are using each of the following:

<table>
<thead>
<tr>
<th>Never</th>
<th>2</th>
<th>Sometimes</th>
<th>4</th>
<th>Frequently</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asking yes/no questions</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Verifying</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Waiting</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Giving a choice of responses</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Interrupting
Guessing
Knowing your loved one's routine
Being very attentive
Calming your loved one
Other:

Instructions: Here is a list of means of communication that you may be employing in order to transmit messages to your loved one. On a scale of 1 to 5, with 1 being never and 5 being frequently, indicate how often you use each of the following:

<table>
<thead>
<tr>
<th>Method</th>
<th>Never 1</th>
<th>2</th>
<th>Sometimes 3</th>
<th>4</th>
<th>Frequently 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Speech</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Simplifying your sentences</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Checking if your loved one has understood</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gesturing</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reformulating</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Repeating</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Demonstrating</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asking your loved one to read your lips</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Using writing or drawing</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Obtaining your loved one's attention</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Asking your loved one to repeat</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asking help from a familiar person</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Speaking very slowly</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Speaking loudly</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Other:</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

Instructions: In situations related to personal care, does your loved one:

<table>
<thead>
<tr>
<th>Need</th>
<th>Never 1</th>
<th>2</th>
<th>Sometimes 3</th>
<th>4</th>
<th>Frequently 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Express the need to go to the toilet?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Express the need to rest?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Express needs related to changing position?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Express needs and preferences related to personal hygiene?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Express preferences related to clothing</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Understand instructions related to changing positions</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Understand instructions related to</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>
**Instructions: In situations related to nutrition, does your loved one:**

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>1</th>
<th>2</th>
<th>Sometimes 3</th>
<th>4</th>
<th>Frequently 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Express the need to eat or drink?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Express preferences related to nutrition?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Express a choice of menu?</td>
<td></td>
<td></td>
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<tr>
<td>Express a refusal to eat?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Understand the menu?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Understand information related to nutrition?</td>
<td></td>
<td></td>
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<td></td>
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<td></td>
</tr>
</tbody>
</table>

**Instructions: In situations related to moving about and orientation, does your loved one:**

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>1</th>
<th>2</th>
<th>Sometimes 3</th>
<th>4</th>
<th>Frequently 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Express the need to be oriented in time and place?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ask for help to move about?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Understand information related to time and place?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Understand information related to moving about?</td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

**Instructions: In situations related to recreation, does your loved one:**

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>1</th>
<th>2</th>
<th>Sometimes 3</th>
<th>4</th>
<th>Frequently 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Express pleasure when participating in an activity?</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Express a preference for activities?</td>
<td></td>
<td></td>
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<tr>
<td>Understand information related to an activity?</td>
<td></td>
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</tr>
</tbody>
</table>
Instructions: Until now, we considered communication situations closely related to specific daily care plans. We will not consider general communication situations. Some questions resemble questions already asked; try to answer in general, to elaborate beyond care routines. Once again, you are invited to answer to the best of your knowledge.

In general, does your loved one:

<table>
<thead>
<tr>
<th>Question</th>
<th>Never 1</th>
<th>2</th>
<th>Sometimes 3</th>
<th>4</th>
<th>Frequently 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Express feelings in general like anger, grief, anxiety, joy, etc?</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Express why he/she feels the way he/she does?</td>
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<td></td>
<td></td>
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<tr>
<td>Express disagreement?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Explain why he/she disagrees?</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Express preferences in general?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ask for precise objects?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Express him/herself about family and life?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Express needs to socialize?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Understand simple instructions?</td>
<td></td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>Understand general explanations?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Understand complicated information?</td>
<td></td>
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</tr>
</tbody>
</table>
Appendix B:  
Identity Gap Scales

Instructions: The following items ask you to rate your agreement with each statement about your feelings and interactions with the person for whom you provide care. Each statement is rated on a scale from 1 to 5 (1 meaning strongly agree and 5 meaning strongly disagree).

<table>
<thead>
<tr>
<th>Personal-Relational Gap</th>
<th>Strongly agree</th>
<th>Somewhat agree</th>
<th>Neither agree nor disagree</th>
<th>Somewhat disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel that my loved one sees me as I see myself</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am different from the way my loved one sees me</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I agree with how my loved one describes me</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel my loved one has wrong images of me</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel that my loved one has correct information about me</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel that my loved one portrays me based not on information provided by myself but information from other sources</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel that my loved one stereotypes me</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel that my loved one does not realized that I have been</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
changing and still portray me based on my past images

I feel that my loved one knows who I used to be when they portray me

When my loved one talks about me, I often wonder if they talk about me or someone else

I feel that there is no difference between who I think I am and who my loved one thinks I am

<table>
<thead>
<tr>
<th>Personal-Enacted Gap</th>
<th>Strongly agree</th>
<th>Somewhat agree</th>
<th>Neither agree nor disagree</th>
<th>Somewhat disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I usually communicate with my loved one in a way that is consistent with who I really am</td>
<td>1</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel I can be myself when communicating with my loved one</td>
<td>1</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I often hide some aspects of myself in communication with my loved one</td>
<td>1</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel there are differences between the &quot;real me&quot; and the impressions I give my loved one</td>
<td>1</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I speak truthfully to my loved one</td>
<td>1</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I freely express the &quot;real me&quot; in communication with my loved one</td>
<td>1</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
I do not reveal important aspects of myself in communication with my loved one

When communicating with my loved one, I often lose sense of who I am

I do not express the real me when I think it is different from my loved one's expectation

I sometimes mislead my loved one about who I really am

<table>
<thead>
<tr>
<th>Enacted-Relational Gap</th>
<th>Strongly agree</th>
<th>Somewhat agree</th>
<th>Neither agree nor disagree</th>
<th>Somewhat disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel my loved one portrays me not based on the information I provide, but instead, on information from other sources</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>When I communicate with my loved one, I am usually successful in making him/her know me</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am usually successful in conveying my intended image to my loved one</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I often wonder why my loved one has a different image of me from what I try to give him/her</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Although I try to show my loved one what kind of person I am, they seem not to see me as I show</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
I feel there are differences between how I express myself in communication with my loved one and how they picture me.
Appendix C
Rimon's Brief Depression Scale

Instructions: The following questions ask you to indicate whether or not you experience any of the following feelings, behaviors, and changes in yourself. Please answer each question to the best of your ability based upon the last six months.

<table>
<thead>
<tr>
<th>Question</th>
<th>No</th>
<th>A little</th>
<th>Moderate</th>
<th>Severe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have you noticed a recent decrease in your interest in your work and/or your hobbies?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Has your ability to make decisions and/or concentrate been impaired lately?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have you recently observed any change in your appetite and/or general physical well-being (for example, abnormal tiredness or headache), or have you experienced any unusual pains and/or diminished sexual interest?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have you recently observed any change in your general appearance?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have you recently consumed alcohol more than usual, and/or taken drugs that have affected your nerves, for example, painkillers, sleeping pills, or drugs to decrease anxiety?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have you recently blamed yourself for your thoughts or reactions, or had thoughts of not wanting to live?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have you recently been unusually irritable, tense, sensitive or had crying spells?</td>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>
Appendix D
Role Salience and Expectation of Others Scale (Callero, 1985)
(Revised from "Blood Donor" to "Caregiver")

Instructions: Please indicate your agreement with the following items on a scale from 1 to 5 where 1 means strongly disagree and 5 means strongly agree.

<table>
<thead>
<tr>
<th>Strongly Disagree 1</th>
<th>Disagree 2</th>
<th>Neither agree nor disagree 3</th>
<th>Agree 4</th>
<th>Strongly Agree 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiving is something I rarely even think about</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I would feel a loss if I were forced to give up providing care to my loved one</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I really don't have any clear feelings about being a caregiver</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>For me, being a caregiver means more than just providing care</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregiving is an important part of who I am</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Instructions: Please indicate your agreement with the following items on a scale from 1 to 5 where 1 means strongly disagree and 5 means strongly agree.

<table>
<thead>
<tr>
<th>Strongly Disagree 1</th>
<th>Disagree 2</th>
<th>Neither agree nor disagree 3</th>
<th>Agree 4</th>
<th>Strongly Agree 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Many people think of me in terms of being a caregiver</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other people think that caregiving is important to me</td>
<td></td>
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<tr>
<td>------------------------------------------------------------------</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>It is important to my friends and relatives that I continue as</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a caregiver</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>It really wouldn't matter to most people I know if I decided</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>to give up providing care for my loved one</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Many of the people that I know are not aware that I am a</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>caregiver</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Many of the people that I know expect me to continue to</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>provide care to my loved one</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No one would really be surprised if I just stopped providing</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>care to my loved one</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Many people would probably be disappointed in me if I just</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>decided to stop providing care to my loved one</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix E
Thought-Listing

Instructions:
We all have a number of different roles that we play in our daily lives. Some examples of roles people play are: "employee", "sister", "student", "friend", "mentor", "spouse".
Think about the roles you play in your life and list the top 5 roles you play the most. Please rank them in order of how often you are in that role.

1 = the role I play the most, 5 = the role I play less than the other roles listed.

1.

2.

3.

4.

5.
Appendix F
Psychological Stress Measure (PSM-9)

Instructions:
Mark the number that best indicates the degree to which each statement applies to you over the past week.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Not at all 1</th>
<th>Very Little 2</th>
<th>A Moderate Amount 3</th>
<th>Quite a bit 4</th>
<th>All the time 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel calm</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel rushed; I do not seem to have enough time</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I suffer from physical aches and pains; sore back, headaches, stiff neck, stomach aches, etc.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel preoccupied, tormented or worried</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel confused; my thoughts are muddled, I lack concentration and I cannot focus my attention</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel full of energy and keen</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel a great weight on my shoulders</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have difficulty controlling my reactions, emotions, moods or gestures</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel stressed</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix G
Multidimensional Scale of Perceived Social Support

Instructions:
Please indicate your level of agreement by circling the number that best applies

<table>
<thead>
<tr>
<th>Strongly Disagree (SD)</th>
<th>Neutral (N)</th>
<th>Strongly Agree (SA)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>7</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Statement</th>
<th>SD</th>
<th>N</th>
<th>SA</th>
</tr>
</thead>
<tbody>
<tr>
<td>There is a special person who is around when I am in need.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>There is a special person with whom I can share my joys and sorrows.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>My family really tries to help me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I get the emotional help and support I need from my family.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I have a special person who is a real source of comfort to me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>My friends really try to help me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I can count on my friends when things go wrong.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I can talk about my problems with my family.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I have friends with whom I can share my joys and sorrows with.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>There is a special person in my life who cares about my feelings.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>My family is willing to help me make decisions.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>I can talk about my problems with my friends.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
Instructions:
The following questions are about your overall health. Please check the line next to the answer that best reflects yourself and your health.

1. In general, would you say your health is:
   Excellent ________
   Very Good _________
   Good ______
   Fair ______
   Poor ______

2. Compared to 1 year ago, how would you rate your health in general now? (please check the line next to your answer)
   Much better than 1 year ago ______
   Somewhat better now than 1 year ago _________
   About the same as it was 1 year ago ________
   Somewhat worse now than 1 year ago ________
   Much worse than 1 year ago _______

3. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?
   a. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports
      Yes, Limited a lot ______
      Yes, Limited a little ______
      No, not limited at all ______

   b. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf
      Yes, Limited a lot ______
      Yes, Limited a little ______
      No, not limited at all ______

   c. Lifting or carrying groceries
      Yes, Limited a lot ______
      Yes, Limited a little ______
      No, not limited at all ______
d. Climbing several flights of stairs
Yes, Limited a lot ______
Yes, Limited a little ______
No, not limited at all ______
Not Applicable ______

e. Climbing one flight of stairs
Yes, Limited a lot ______
Yes, Limited a little ______
No, not limited at all ______

f. Bending, kneeling, or stooping
Yes, Limited a lot ______
Yes, Limited a little ______
No, not limited at all ______

4. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health? (please check the line next to your answer)
a. Cut down on the amount of time you spent on work or other activities?
Yes ______
No ______

b. Accomplished less than you would like?
Yes ______
No ______

c. Were limited to the kind of work or other activities?
Yes ______
No ______

d. Had difficulty performing the work or other activities (for example, it took extra effort)?
Yes ______
No ______

5. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

a. Cut down on the amount of time you spent on work or other activities?
Yes ______
No ______

b. Accomplished less than you would like?
Yes ______
No ______

c. Didn't do work or other activities as carefully as usual?
Yes ______
No ______

6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?
Not at all ______
Slightly ______
Moderately ______
Quite a bit ______
Extremely ______

7. How much bodily pain have you had during the past 4 weeks?
None ______
Mild ______
Moderate ______
Severe ______
Very severe ______

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?
Not at all ______
A little bit ______
Moderately ______
Quite a bit ______
Extremely ______

9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks:

a. Did you feel full of energy?
All of the time_______
Most of the time ______
Some of the time ______
A little of the time ______
None of the time ______

b. Have you been a very nervous person?
All of the time_______
Most of the time ______
Some of the time ______
A little of the time ______
None of the time ______

c. Have you felt so down in the dumps that nothing could cheer you up?
All of the time_______
Most of the time ______
Some of the time ______
A little of the time ______
None of the time ______

d. Have you felt calm and peaceful?
All of the time_______
Most of the time ______
Some of the time ______
A little of the time ______
None of the time ______

e. Have you felt downhearted and blue?
   All of the time_______
   Most of the time ______
   Some of the time ______
   A little of the time ______
   None of the time ______

f. Did you feel worn out?
   All of the time_______
   Most of the time ______
   Some of the time ______
   A little of the time ______
   None of the time ______

g. Have you been a happy person?
   All of the time_______
   Most of the time ______
   Some of the time ______
   A little of the time ______
   None of the time ______

h. Did you feel tired?
   All of the time_______
   Most of the time ______
   Some of the time ______
   A little of the time ______
   None of the time ______

10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?
   All of the time ______
   Most of the time ______
   Some of the time ______
   A little of the time ______
   None of the time ______

11. How TRUE or FALSE is each of the following statements for you?

a. I seem to get sick a little easier than other people
   Definitely true ______
   Mostly true ______
   Don't know ______
Mostly false ______
Definitely false ______

b. I am as healthy as anybody I know
Definitely true ______
Mostly true ______
Don't know ______
Mostly false ______
Definitely false ______

c. I expect my health to get worse
Definitely true ______
Mostly true ______
Don't know ______
Mostly false ______
Definitely false ______

d. My health is excellent
Definitely true ______
Mostly true ______
Don't know ______
Mostly false ______
Definitely false ______
Appendix I
Demographic Information

What is your age in years?

What is your sex?
   Male _____
   Female _____

What is your occupation? __________________________

Do you consider yourself Latino/a or Hispanic?
   Yes ____
   No ____

Which category best describes your race?
   White ______
   Black or African American _____
   Asian ______
   Native Hawaiian/Pacific Islander _____
   American Indian/Alaska Native _____
   Other ______________________

What is your marital status?
   Single, never married _____
   Married ______
   Separated ______
   Divorced _____
   Widowed ______
   Other __________________

How long have you been a caregiver to your loved one? ________________ (In years)

How many hours per week, on average, do you spend caring for your loved one? ______

Additional comments about care hours:

What are the most common activities you perform as a caregiver? Please list:
Appendix J
Stages of Alzheimer's disease

The following are the stages of Alzheimer's disease as outlined by the Alzheimer's Association. Please carefully read each description and identify, to the best of your ability, the stage that most accurately describes your family member's current state of functioning by checking the line next to the most appropriate stage.

_____ Stage 1 - No impairment (normal function) - The person does not experience any memory problems. An interview with a medical professional does not show any evidence of symptoms of dementia.

_____ Stage 2 - Very mild cognitive decline (may be normal age-related changes or earliest signs of Alzheimer's disease) The person may feel as if he or she is having memory lapses — forgetting familiar words or the location of everyday objects. But no symptoms of dementia can be detected during a medical examination or by friends, family or co-workers.

_____ Stage 3 - Mild cognitive decline (early-stage Alzheimer's can be diagnosed in some, but not all, individuals with these symptoms) Friends, family or co-workers begin to notice difficulties. During a detailed medical interview, doctors may be able to detect problems in memory or concentration. Common stage 3 difficulties include:
- Noticeable problems coming up with the right word or name
- Trouble remembering names when introduced to new people
- Having noticeably greater difficulty performing tasks in social or work settings,
- Forgetting material that one has just read
- Losing or misplacing a valuable object
- Increasing trouble with planning or organizing.

_____ Stage 4 - Moderate cognitive decline (Mild or early-stage Alzheimer's disease) At this point, a careful medical interview should be able to detect clear-cut symptoms in several areas:
- Forgetfulness of recent events
- Impaired ability to perform challenging mental arithmetic — for example, counting backward from 100 by 7s
- Greater difficulty performing complex tasks, such as planning dinner for guests, paying bills or managing finances
- Forgetfulness about one's own personal history
- Becoming moody or withdrawn, especially in socially or mentally challenging situations

Stage 5 - Moderately severe cognitive decline (Moderate or mid-stage Alzheimer's disease) Gaps in memory and thinking are noticeable, and individuals begin to need help with day-to-day activities. At this stage, those with Alzheimer's may:
- Be unable to recall their own address or telephone number or the high school or college from which they graduated
- Become confused about where they are or what day it is
- Have trouble with less challenging mental arithmetic; such as counting backward from 40 by subtracting 4s or from 20 by 2s
- Need help choosing proper clothing for the season or the occasion
- Still remember significant details about themselves and their family
- Still require no assistance with eating or using the toilet

Stage 6 - Severe cognitive decline (Moderately severe or mid-stage Alzheimer's disease) Memory continues to worsen, personality changes may take place and individuals need extensive help with daily activities. At this stage, individuals may:
- Lose awareness of recent experiences as well as of their surroundings
- Remember their own name but have difficulty with their personal history
- Distinguish familiar and unfamiliar faces but have trouble remembering the name of a spouse or caregiver
- Need help dressing properly and may, without supervision, make mistakes such as putting pajamas over daytime clothes or shoes on the wrong feet
- Experience major changes in sleep patterns — sleeping during the day and becoming restless at night
- Need help handling details of toileting (for example, flushing the toilet, wiping or disposing of tissue properly)
- Have increasingly frequent trouble controlling their bladder or bowels
- Experience major personality and behavioral changes, including suspiciousness and delusions (such as believing that their caregiver is an impostor) or compulsive, repetitive behavior like hand-wringing or tissue shredding
- Tend to wander or become lost

Stage 7 - Very severe cognitive decline (Severe or late-stage Alzheimer's disease) In the final stage of this disease, individuals lose the ability to respond to their environment, to carry on a conversation and, eventually, to control movement. They may still say words or phrases. At this stage, individuals need help with much of their daily personal care, including eating or using the toilet. They may also lose the ability to smile, to sit without support and to hold their
Appendix K
Informed Consent – Paper and Pencil Version

Consent to Participate in a Study

Name of Study: Aphasia and the identity of Alzheimer’s family caregivers: The effect of communication ability on caregiver identity gaps and identity shift.

Name of Investigator: Katey Price, John Dimmick

Contact Information for Investigators:

Katey Price                      Dr. John Dimmick
School of Communication          School of Communication
The Ohio State University        The Ohio State University
Columbus, OH 43210               Columbus, OH 43210
(616) 540-0697                   (614) 292-3400
dr.jprice.739@osu.edu            dimmick.1@osu.edu

Invitation to Participate: You are invited to participate in a research study about the communication challenges experienced by family caregivers of dementia and Alzheimer’s disease. The following information should help you make an informed decision whether or not to participate. If you have any questions, please feel free to contact Katey Price or Dr. John Dimmick.

What is the purpose of this study? The purpose of this study is to understand the communication challenges caregivers face with their loved one and how these challenges impact a number of different areas of life.

What will I do in this study? If you decide to participate in this research project, you will be asked to complete a survey by paper and pencil.

How long will it take? The survey will take between 25 and 40 minutes to complete. Overall, your participation in this study should take no more than 45 minutes.

Are there any risks of participating in the study? The risks associated with participating in this study are only slightly more than might occur in normal, everyday activities. However, there is the possibility that feelings of guilt, anxiety, sadness or depression may be evoked due to the subject of this study. If you experience any psychological distress or discomfort, you are free to withdraw from the study without penalty. If you do feel psychological distress or discomfort from
participation in this study, please contact one of the following counseling services in the Central Ohio area.
Northwest Counseling Services - (614) 457-7876
Dublin Counseling Services - (614) 889-5722
Concord Counseling Services - Franklin County (614) 276 - 2273, or Delaware County (800) 684-2324

No one besides the researcher will have access to these surveys. Any identifying information provided will be separate from the survey and therefore unmatchable to the survey, so there is no possibility of legal risk.

What are the benefits of participating in the study? This research will give you an idea of how we collect data in the field of communication and you can feel some satisfaction knowing that you have contributed to scientific knowledge. It may also help us to implement programs in the community to help ease the burdens associated with caring for someone with dementia and Alzheimer's disease.

Will anyone know what I do or say in this study (Confidentiality/Anonymity)? You will be asked to provide your name and mailing address if you would like to be entered into a random drawing for a gift card. This information will be immediately separated from the survey once it has been submitted to the researcher and be kept in a secure, locked location. This will ensure your confidentiality and make it impossible to match you with your survey. As soon as the winners for the gift cards have been drawn and compensation sent to the winners, all identifying information will be destroyed.

Will I receive any compensation for participation? There will be a drawing once all of the research has been completed for ten $25 gift cards to a store of your preference as you indicate at the end of the survey. You have a 1 in 25 chance of winning one of these gift cards.

Right to Refuse or Withdraw: You may refuse to participate in this study. You may stop participating at any time once you have started if you feel uncomfortable or for any reason wish to discontinue. Your cooperation is completely voluntary. Withdrawing from the study does not affect your chances of receiving compensation, you will still be entered into the drawing.

Who can I contact for information about this study? If you have any questions, concerns, complaints, or if you feel you were harmed as a result of study participation, you may contact Katey Price at (616) 540-0697 or Dr. John Dimmick at (614) 292-3400. You will be provided with a copy of this consent form so that you may contact either of the researchers should you have any concerns or questions in the future.

You are free to refuse to participate in this research project or to withdraw your consent and discontinue participation in the project at any time without penalty or
loss of benefits to which you are otherwise entitled or effect on your relationship to
the institution(s) involved in this research project.

For questions about your rights as a research participant, or to talk to someone who
is not a member of the research team, please contact Ms. Sandra Meadows in the

Signing your name in the space provided below indicates that all of your questions
have been answered and you have voluntarily decided to participate in the research
project as described above.

________________________________________  __________________________
Participant’s signature                          Date
Appendix L
Informed Consent form – Online

Consent to Participate in a Study

Name of Study: Aphasia and the identity of Alzheimer’s family caregivers: The effect of communication ability on caregiver identity gaps and identity shift.

Name of Investigator: Katey Price, John Dimmick

Contact Information for Investigators:

Katey Price
School of Communication
The Ohio State University
Columbus, OH 43210
(616) 540-0697
price.739@osu.edu

Dr. John Dimmick
School of Communication
The Ohio State University
Columbus, OH 43210
(614) 292-3400
dimmick.1@osu.edu

Invitation to Participate: You are invited to participate in a research study about the communication challenges experienced by family caregivers of dementia and Alzheimer’s disease. The following information should help you make an informed decision whether or not to participate. If you have any questions, please feel free to contact Katey Price or Dr. John Dimmick.

What is the purpose of this study? The purpose of this study is to understand the communication challenges caregivers face with their loved one and how these challenges impact a number of different areas of life.

What will I do in this study? If you decide to participate in this research project, you will be asked to complete a survey online.

How long will it take? The survey will take between 25 and 40 minutes to complete. Overall, your participation in this study should take no more than 45 minutes.

Are there any risks of participating in the study? The risks associated with participating in this study are only slightly more than might occur in normal, everyday activities. However, there is the possibility that feelings of guilt, anxiety, sadness or depression may be evoked due to the subject of this study. If you experience any psychological distress or discomfort, you are free to withdraw from the study without penalty. Listed below are agencies who provide counseling
services for those living in the central Ohio area if you feel the need to speak with someone about any feelings of guilt, anxiety, or depression:
Northwest Counseling Services - (614) 457-7876
Dublin Counseling Services - (614) 889-5722
Concord Counseling Services - Franklin County (614) 276-2273, or Delaware County (800) 684-2324

No one besides the researcher will have access to these surveys. Any identifying information provided will be separate from the survey and therefore unmatchable to the survey, so there is no possibility of legal risk.

**What are the benefits of participating in the study?** This research will give you an idea of how we collect data in the field of communication and you can feel some satisfaction knowing that you have contributed to scientific knowledge. It may also help us to implement programs in the community to help ease the burdens associated with caring for someone with dementia and Alzheimer's disease.

**Will anyone know what I do or say in this study (Confidentiality/Anonymity)?** We will work to make sure that no one sees your survey responses without approval. But, because we are using the Internet, there is a chance that someone could access your online responses without permission. In some cases, this information could be used to identify you. Additionally, you will be asked to provide your name and mailing address if you would like to be entered into a random drawing for a gift card. This information will be immediately separated from the survey once it has been submitted to the researcher and be kept in a secure, locked location. This will ensure your confidentiality and make it impossible to match you with your survey. As soon as the winners for the gift cards have been drawn and compensation sent to the winners, all identifying information will be destroyed.

**Will I receive any compensation for participation?** There will be a drawing once all of the research has been completed for ten $25 gift cards to a store of your preference as you indicate at the end of the survey. You have a 1 in 25 chance of winning one of these gift cards.

**Right to Refuse or Withdraw:** You may refuse to participate in this study. You may stop participating at any time once you have started if you feel uncomfortable or for any reason wish to discontinue. Your cooperation is completely voluntary. Withdrawing from the study does not affect your chances of receiving compensation, you will still be entered into the drawing.

**Who can I contact for information about this study?** If you have any questions, concerns, complaints, or if you feel you were harmed as a result of study participation, you may contact Katey Price at (616) 540-0697 or Dr. John Dimmick at (614) 292-3400. You will be provided with a copy of this consent form so that you may contact either of the researchers should you have any concerns or questions in the future.
You are free to refuse to participate in this research project or to withdraw your consent and discontinue participation in the project at any time without penalty or loss of benefits to which you are otherwise entitled or effect on your relationship to the institution(s) involved in this research project.

For questions about your rights as a research participant, or to talk to someone who is not a member of the research team, please contact Ms. Sandra Meadows in the Office of Responsible Research Practices at 1-614-688-4792.

Typing your name in the space provided below and checking the "I agree to voluntarily participate in this research" indicates that all of your questions have been answered and you have voluntarily decided to participate in the research project as described above.

_________________________________________________   ___________________________
Participant's signature                                  Date
ATTENTION: DEMENTIA AND ALZHEIMER'S FAMILY CAREGIVERS
Complete a 30-minute online survey and be entered to win a $20 gift card.

My name is Katey and I am a graduate student at The Ohio State University. I am conducting my dissertation research that could result in better ways to help caregivers process the changes they face in their family member with dementia. I am interested in learning more about your caregiving experiences; specifically how you communicate with your loved one and how it affects you. If you would like to know more about this study, please feel free to contact me at the phone number or email address below. To participate, please go online and type in this web address:
https://osucomms.qualtrics.com/SE/?SID=SV_5AzWr29tX33mY7j

*Survey is also available in paper format, please contact researcher to obtain a copy. If it would be more convenient, phone interviews are also available.

**Please note, contacting me does not mean you have to participate, I would be more than happy to answer any further questions or concerns you may have.

Thank you,

616-540-0697
kateyaprice@gmail.com