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# Belonging for Dementia Caregivers

BY

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THESIS

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## Introduction

For years, Marcy Sherman-Lewis went to a beauty salon in St. Joseph, Mo., every few weeks for a haircut and highlights. It had become something of an ordeal to prepare her husband, Gene Lewis, for this outing; he has Alzheimer's disease, at 79, and helping him shower and dress, insert hearing aids and climb into the car was a very slow process. But she could no longer leave him at home alone. And once at the salon, "he just sat, watched TV, slept — didn't bother anybody," said Ms. Sherman-Lewis, 62. Her stylist kindly trimmed his hair, too. Then last month, the salon owner took Ms. Sherman-Lewis aside. "Marcy, he makes my other patrons awfully uncomfortable," she said. "I was dumbfounded," Ms. Sherman-Lewis said. "It's O.K. for other people's little grandchildren to be running around sometimes. What am I supposed to do, keep him in a crate in the car? "Like so many caregivers, she has discovered that along with the abandoned career, the hands-on tasks, the medical scheduling, the insurance tussles and the disrupted sleep, she faces another trial: social isolation. "It's hurtful," she said. "You need friends more than ever."

(Span, 2017, D3)

## Rationale

The aforementioned excerpt is from a *New York Times* piece on how isolation can exacerbate the trials of caregiving on the caregiver. Caregiving is a difficult endeavor because the role is physically and mentally demanding on the caregiver. Caring for an individual with a neurocognitive illness such as dementia is more difficult because of the increased physical and emotional demands placed on the caregiver. Consequently, caregivers of individuals living with dementia suffer negative health effects because of caregiver demands.

The high rate of emotional distress and isolation among dementia caregivers makes it imperative to understand belonging and connectedness for this population. Studies have shown that caregiver stigma and burden are correlated, meaning that as stigma increases burdens increase. Researchers are proposing that strategies aimed at reducing the stigma could help to reduce burden. However, for these strategies to be effective, it is important to dig deeper into

factors that help to contribute to stigma. Specifically, living with dementia impacts the way caregivers view themselves and how they connect with others.

The rationale for this project is to understand the discursive construction processes of belonging. The hope is that by understanding these processes individuals in charge of dementia caregiver programs can better communicate with this population, better target health programming to this population, and reduce stigma around the illness.

## **Chapter 1: Literature Review**

### **Dementia**

#### *Medical Description*

Dementia is an umbrella term that is used to describe a group of symptoms that negatively impact cognitive functioning in a manner that reduces an individual's ability to perform activities in their daily life (Mayo Clinic, 2017; National Institute on Aging, 2017). For the purposes of this paper, dementia will be synonymous with Alzheimer's disease because Alzheimer's disease is the most common form of dementia that impacts individuals. The symptoms of dementia can vary from individual to individual, a minimum of two of the following mental functions need to be greatly impaired to be categorized as dementia: memory; communication and language; ability to focus and pay attention; reasoning and judgement; and visual perception (Alzheimer's Association, n.d.).

Dementia is caused when an individual has damage to their brain cells, and different types of dementia are linked with different types of brain cell damage in certain brain regions (Alzheimer's Association, n.d.). The causes of dementia are partially unknown at the moment, and while no treatment exists to cure the disease, therapies help manage the accompanying symptoms (Mayo Clinic, 2017). The World Health Organization (2017) estimates that 50 million

individuals are currently living with some form of dementia, and that number is expected to grow to 82 million by 2030. Dementia is becoming a global epidemic due to unprecedented population ageing, and it is predicted a large majority of the individuals that will be affected by the disease will be living in low and middle-income countries (World Health Organization, 2015). Within the United States, over 5 million individuals are living with Alzheimer's disease (Alzheimer's Association, 2020). The cost of caring for individuals living with dementia has an enormous impact on the United States health system with no cure for dementia and estimated direct costs in 2018 totaling \$277 billion (Alzheimer's Association, 2018).

While a variety of systems are used to assess the severity of dementia, a common type is the Global Deterioration Scale for Assessment for Primary Degenerative Dementia, otherwise known as GDS, which mainly focuses on cognitive abilities (Choi et al., 2016). The scale was developed by Dr. Barry Reisberg, and it consists of seven stages (Reisberg, Ferris, Leon, & Crook, 1982). Stages 1-3 are classified as pre-dementia stages that are associated with mild cognitive decline. Stages 4-5 are associated with mild to moderate dementia while stages 6-7 are associated with moderate severe to severe dementia (Reisberg et al., 1982). After stage 5, individuals living with dementia can no longer live without some type of assistance which impacts the lives of both the individual living with dementia and their loved ones, ultimately making the illness both a medical and social condition.

### *Social Condition*

Dementia is not only a medical condition, but it is also a social condition. Simply put, social factors impact the way the dementia is conceptualized among members of society. Today, the social construction around dementia focuses on personhood and humanity (Bosco, Schneider, Coleston-Shields, Higgs, & Orrell, 2019). The shift from conceptualizing dementia as

purely a medical issue grew out of Tom Kitwood's (1997) work who reasoned that a neurological impairment may become worse due to "malignant social psychology," which occurs when a relationship devalues the person living with dementia such as an objectification or infantilization of an individual living with dementia. Objectification treats individuals like an object rather than a human being, while infantilization treats adults as young children (Kitwood, 1990). An example of infantilization is when a person living with dementia is compared to a child because of their cognitive capabilities. This type of behavior implies that a person with dementia is not deserving of the rights of an adult. Consequently, Kitwood argued for a new definition of dementia care, highlighting the notion that by utilizing a positive care approach, the personhood of an individual living with dementia could be upheld (Kitwood, 1997). However, the changes in a person's social functioning challenges efforts in maintaining personhood, especially given the level of care needed for a person with dementia. Dementia is socially impactful because it changes not only the person with dementia, but also their caregivers.

### **Family Caregiving**

Family caregiving is a complex phenomenon because caregivers simultaneously experience positive and negative consequences in relation to their caregiving role. A family caregiver is defined as "any relative, partner, friend or neighbor who has a significant personal relationship with, and provides a broad range of assistance for, an older person or an adult with a chronic or disabling condition" (Family Caregiver Alliance, 2014). Currently, it is estimated that over 43 million adults in the United States have provided unpaid care to a family member within the last 12 months (National Alliance for Caregiving & AARP Public Policy Institute, 2015). The average age of a family caregiver is 49 years old, and at least 28% had children or grandchildren living with them (National Alliance for Caregiving & AARP Public Policy Institute, 2015).



The type of care that caregivers provide differs depending on the situation. Typically, caregivers are responsible for “activities of daily living” (ADL) which are tasks vital to basic functioning as helping their loved one get dressed or bathe. Additionally, caregivers assist with “instrumental activities of daily living” (IADL) which are tasks that allow any individual to live independently in a community such as managing money and cleaning their home (Bookman, Harrington, Pass, & Reisner, 2007; Williams, 2011). Caregiving activities are often delineated based on gender with men frequently helping with IADL responsibilities while women frequently handled ADL responsibilities (Hequembourg & Brallier, 2005; Laditka & Laditka, 2000; Mui, 1995). While there is no mold for a typical caregiver, it important to note that many caregivers experience a multitude of positive and negative emotions during their time as a caregiver.

Caregivers do experience positive benefits of being a caregiver. The National Opinion Research Center (2014) reported that 83% of caregivers perceived caregiving a positive experience. These benefits include spending time with the loved one, an augmented sense of purpose in their life, and general well-being (Grant et al., 1998; Marks et al., 2002; Raschick & Ingersoll-Dayton, 2004). The likelihood of whether the caregiver is going to experience these gains is based on the caregiver’s level of agreeableness, level of extroversion, socio-emotional support, and the quality of the relationship with the care recipient prior to the relationship (Koerner, Kenyon, & Shirai. 2009; Zarit, Reever, & Bach-Peterson, 1980).

Recent research has also found some hidden benefits associated with being a caregiver. In terms of physical health, female caregivers have been shown to have lower mortality rates than their non-caregiver counterparts (Fredman, Cauley, Hochberg, Ensrud, & Doros, 2010). This result occurs when caregivers exhibit lower levels of general stress or caregiving-connected

stress. In contrast, individuals with high stress levels had higher mortality rates regardless of whether they were a caregiver or not. The researchers have concluded that higher levels of stress rather than caregiving itself is the cause of higher rates of mortality among individuals.

Furthermore, dementia caregivers are nearly twice as likely to have declining health as a result of their caregiver role (National Alliance for Caregiving & Alzheimer's Association, 2017).

In addition, caregivers were able to sustain stronger physical performance than non-caregivers (Fredman, Doros, Ensrud, Hochberg, & Cauley, 2009). Finally, in terms of cognitive ability, caregivers in their early to mid-80s scored better on memory tests, typically at the level of individuals who were in their early to mid-70s (Bertrand, Saczynski, Mezzacappa, Hulse, Ensrud, & Fredman, 2011). It is important to note that there is a level of self-selection in these studies – an individual is only likely to be a caregiver if they are healthy enough to take on the tasks associated with the role (Span, 2011). On the whole, caregiving can provide some real benefits to the caregivers because, “Caregiving often requires complex thought. Caregivers monitor medications, they juggle schedules, they may take over financial responsibilities” (Span, 2011). These results should not be overgeneralized, but these studies demonstrate how complex and individualized the role of caregiving can be for caregivers.

The positive benefits of being a caregiver are more likely to be associated with African American caregivers than other ethnic groups (Dilworth-Anderson, Williams, & Gibson, 2002). Specifically, researchers have found that African American caregivers are more likely to view caregiving in a more positive light than their Caucasian peers (Freedman, Daly, & Lazur, 1995). It is important to note that even though some of the cultural factors such as emotion-focused coping strategies may be viewed as an asset for this population, it has the ability to equalize the positive effects of caregiving while increasing psychological distress (Knight, Silverstein,

McCallum, & Fox, 2000).

Caregivers also suffer negative consequences. These issues can vary from interpersonal issues such as problems in the workplace to mental health problems such as anxiety and depression (Atienza & Stephens, 2000; Cannuscio et al., 2002). The strain of being a caregiver is largely the result of the magnitude of work that goes into being a caregiver and the hardships associated with balancing a variety of roles such as caregiver, partner, and employee (Miller et al., 2008). Mental health issues among caregivers are highly dependent both on the health issues plaguing the care recipient as well as the demographics of the caregiver (Pinquart, 2001; Pinquart & Sorensen, 2003). Many caregivers go through both positive and negative experiences concurrently during their time as a caregiver (Beach et al., 2000; Harmell et al., 2012). Family caregiving is a complex phenomenon because of various layers to the job, but the experience of caregiving is greatly dependent on the illness being cared for by the caregiver. With some positive rewarding outcomes as well as clear negative outcomes, caregiving is complex as a social activity.

Communication scholars have started to unpack the phenomena of family caregiving (Halliwell, Wenzel Egan, & Howard, 2017; Miller, Shoemaker, Wilyard, & Addison, 2008; Wilyard, Miller, Shoemaker, & Addison, 2008). Much of the research on family caregiving from a communication perspective focuses on the relationships between adult children and their parents along with the sibling dynamics that ensue when caring for a parent. Miller et al (2008) found that caregivers draw on the meaning structure of family life and the meaning structure of work and competency. The structure of family life specifically refers to the parent-child structure where adult children feel as though they have to parent their elderly parent, and consequently rely on “memories of their own childhood and of their experiences in raising children.” The

structure of work and competence specifically refers to the idea that these caregivers feel they are the only one able to take on the multiple roles associated with being a caregiver. The structure of competency in particular maybe part of the reason why caregivers have an unequal distribution of work associated with caregiving. Overall, Miller et al (2008) argues there is little scholarship in the landscape of caregiving on the discursive ways caregivers identify themselves in relation to their caregiving duties and create meaning through these activities.

Despite the lack of research on the nuances of family caregiving from a communication perspective, scholars have been making an effort to understand how adult siblings make sense of their caregiving responsibilities through communication. When siblings are responsible for caring for an elderly parent, discussion is minimal about how to divide the responsibilities, and often caregiving falls on the shoulders of one sibling (Willyard et al., 2008). In terms of sense-making about caregiving responsibilities, caregivers conceptualize caregiving as an individualistic task and draw on values about family. However, some caregivers can forgive siblings who did not help with caregiving through an exclusionary framework. An exclusionary framework is when a caregiver excludes a sibling from their definition of “family” in order to reconcile their views on parental caregiving with the lack of caregiving responsibilities performed by a sibling (Willyard et al., 2008). When a caregiver is invoking an exclusionary framework, there is typically a characteristic about the no-participatory sibling such as being estranged from the family for many years. Those who cannot forgive their siblings engage in verbal backtracking when speaking about caregiving. Verbal backtracking is the sensemaking strategy in which a caregiver makes excuses for a non-participatory sibling when the caregiver does not have the structures of personality distinctions and exclusionary framework to draw upon in order to make sense of the situation (Willyard et al., 2008). This strategy is a way for

caregivers to resolve their strong family values with the fact their siblings do not share those same values.

Furthermore, recent research on communicative aspects of caregivers' narrative sense-making illustrates that caregivers with siblings are drawing on a narrative of inequity to establish their understanding of caregiving. Halliwell et al. (2017) found that siblings need to come together as a unit to support the work of parental caregiving. The team discovered that adult siblings draw from three types of stories to understand their role as a caregiver: the narrative of (in)equity, the narrative of ideal versus real, and the narrative of interconnectedness. The narrative of (in)equity refers to the struggle caregivers have in regard to the equal distribution of work among adult siblings in terms of task distribution and level of involvement. The narrative of ideal versus real refers to caregivers attempting to become an ideal caregiver in the face of real-world obstacles. The narrative of interconnectedness refers to the notion that caregiving unites adult siblings. At times, this connection is positive because it allows for reconnection among siblings. At other times, this connection is negative because of challenges among siblings to figure out their parent's care.

As life expectancy increases within the United States, the population of family caregivers will continue to rise. Oftentimes, family caregiving falls on adult children and women in regard to caring for a parent, but many individuals care for a spouse with a chronic health condition (Schultz et al., 2016; Pinquart & Sorensen, 2011). The experience of caregiving is highly dependent on the type of illness being cared for and the amount of support a caregiver receives. Caregiving is a role that does not happen independently of a caregiver's life. Rather, it is a role that impacts all of caregiver's relationships and their sense of belonging within each relationship. Communication scholars are starting to unpack the communicative processes and structures that

help to define a caregiver's relationships outside of the care recipient, but more research needs to be done on how various factors such as sense of belonging can impact a caregiver's relationship.

### **Caregiving & Dementia**

Oftentimes, family members help to take care of their loved ones with dementia because the quantity of available professional caregivers is not rising in line with the increased demand of those needing care (Zwaanswijk et al., 2013). Currently, it is estimated that 15.7 million adult family caregivers care for someone who has been diagnosed with Alzheimer's disease or another type of dementia (Alzheimer's Association, 2015). While informal caregiving can potentially have negative impacts on the caregivers' health, dementia caregivers are faced with unique challenges (Robinson et al., 2009; Schulz & Sherwood, 2008; Ory et al., 1999). In particular, the behavioral, cognitive, and affective losses in those living with dementia cause their caregivers to be more involved in their loved ones' caregiving tasks (Ory et al., 1999). Additionally, caregivers feel uncertainty when they are caring for patients because they have not experienced the disease and are unsure how to interpret communication interactions (Polk, 2005; Darcy, Brunsdon, & Hill, 2011)

Caregivers of those living with dementia are more likely to experience a wide range of both positive and negative emotions associated with caregiving such as enjoyment, grief, and sadness (Cohen et al., 2002; Family Caregiver Alliance, 2014). Stigma compounds the problems created by the illness because it can lead to patronization and discrimination to individuals living with Alzheimer's disease (Batsch & Mittleman, 2012; Corner & Bond, 2004; Werner & Giveon, 2008). In many instances, family members, who often become informal caregivers for their loved ones living the Alzheimer's, become subject to stigma themselves, and the feeling of stigma in connection to dementia is a significant and potentially changeable contributor in regard to

caregiver burden (Werner, Mittelman, Goldstein, & Heinik, 2012). Overall, the effects of this increased involvement mean that caregivers are more susceptible to chronic and emotional strains that can lead to emotional exhaustion and burnout (Takai et al., 2009). Specifically, Takai and colleagues found that higher levels of caregiver burnout are connected to greater levels of depressive symptoms and lower quality of life in home caregivers of individuals living with dementia (Takai et al., 2009).

Caregivers of those living with dementia are often considered invisible patients because of the health consequences of caregiving. Dementia caregivers are nearly twice as likely to state that their health has declined as a result of their caregiver duties (National Alliance for Caregiving & Alzheimer's Association, 2017). This decline in health is irrespective of age, but rather is a result of high rates of physical strain and emotional stress (National Alliance for Caregiving & Alzheimer's Association, 2017). In particular, in comparison to their non-caregiver counterparts, dementia carers have worse health outcomes such as higher levels of stress hormones in the body, weakened immune system, and more cognitive decline (Vitaliano, Young, & Zhang, 2004; Vitaliano, Echeverria, Yi, Young, & Siegler 2005). Oftentimes, physicians do not notice the caregiver's plight which partially explains why they become invisible patients (Adelman, Tmanova, & Delgado, 2014).

### *Caregiver Burden*

While caregiver burden has no code in the *International Classification of Diseases, Ninth Revision (ICD-9)* or *ICD-10*, it is an issue that needs greater attention, even though it is largely overlooked by clinicians (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014). Caregiver burden can be defined as “the extent to which caregivers perceive that caregiving has had an adverse effect on their emotional, social, financial, physical, and spiritual well-being” (Zarit, Todd &

Zarit, 1986). While a variety of individuals are susceptible to caregiver burden, dementia caregivers are at a higher risk at developing medical and psychiatric issues (Alzheimer's Association, 2012). This fact is highlighted by the increased healthcare use and costs by caregivers (Zhu et al., 2015). Thus, with the growing rate of Alzheimer's disease and other forms of dementia, it is imperative to assess the factors leading to caregiver burden (Richardson, Lee, Berg-Weger & Grossberg, 2013).

Risk factors for caregiver burden include “female sex, low educational attainment, residence with the care recipient, higher number of hours spent caregiving, depression, social isolation, financial stress, and lack of choice in being a caregiver” (Adelman, Tmannova, Delgado, Dion, & Lachs, 2014). Present studies have shown that caregivers of those living with dementia have high perceived stress compared to caregivers of patients with other chronic illnesses (Anand, Dhikav, Sachdeva & Mishra, 2016). The impaired cognitive function of those living with dementia predicts caregiver burden, and interacts with caregiver-related and demographic factors, making dementia caregivers a vulnerable population (Kim, Chang, Rose & Kim, 2011).

Caregiver burden manifests both physically and emotionally for the caregiver. High perceived caregiving strain is associated with increased mortality which was not found to differ by sex, race, or the type of caregiving relationship (Perkins, Howard, Wadley, Crowe, Safford, Haley, Howard & Roth, 2013). It has been found that as stress levels and demands of care elevate, the risk for physical and mental problems increase for dementia caregivers (Hughes, Black, Albert, Gitlin, Johnson, Lyketsos & Samus, 2014). Caregiver burden can be spotted through the actions of caregivers such as through emotion-focused coping strategies that include avoidance and wishful thinking (Huang, Huang, Su, Hou, Chen, Yeh, & Chen, 2015).



The type of relationship the caregiver has with the individual living with dementia affects the degree of caregiver burden. Adult children reported having higher burden than spousal caregivers, even though they spent less time with the patient (Reed, Belger, Dell’Agnello, Wimo, Argimon, Bruno, Dodel, Haro, Jones & Vellas, 2014). However, caregivers’ relationship closeness with the person living with dementia predicts both negative and positive outcomes for the caregivers’ mental well-being and physical health, suggesting that the present closeness, after the onset of dementia, and the changes in closeness from the relationship before dementia, need to be analyzed to determine a positive or negative caregiver outcome (Fauth, Hess, Piercy, Norton, Corcoran, Rabins, Lyketsos, & Tschanz, 2013). A caregiver’s sense of belonging to their care recipient can influence the degree to which a caregiver is impacted by the stress of their caregiver duties.

While it may be helpful to say that caregivers need to engage in self-care, without the adequate support necessary to engage in such behavior, it leads to unrealistic expectations being set (Lily, Robinson, Holtzman & Bottorff, 2012). In many cases, family members become informal caregivers, indicating a need for additional professional support across all stages of dementia, (Zwaanswijk, Peeters, van Beek, Meerveld & Francke, 2013). Caregiver stigma increases caregiver burden in the case of Alzheimer’s disease, thus demonstrating that professional support ought to be provided during the entire progression of dementia to help reduce these feelings (Werner, Mittelman, Goldstein & Heinik, 2012). Consequently, it is important to understand the communicative processes that impact the way that dementia caregivers understand their role and conceptualize stigma surrounding the illness

The work that communication scholars have done in terms of dementia caregivers has mainly focused on feelings of stigma directed towards caregivers along with work about how

caregivers can better communicate with their loved ones with dementia (Baxter et al., 2002; Golden, 2015; Polk, 2015; Stites et al., 2018). Prior research has noted issues with dementia are oriented in communication and cognition (Ellis, 1996). Ellis (1996) looked at the discourse of individuals living with Alzheimer's disease to understand the linguistic characteristics and coherence patterns as the illness progresses. Dementia problems are based in cognition because as the illness advances, individuals are less able to use vital parts of a language system to effectively communicate. Specifically, the more advanced the illness, the more likely the language usage is vocabulary-driven, meaning that the individual will say a lot of words that are not necessarily connected by an underlying grammatical system. However, these dementia-created problems are grounded in communication because as the illness progresses, the weight of being able to communicate with dementia patients will rest on caregivers' shoulders. Past research has explored caregivers' communication through online mediums (Jeong, Kim, & Chon, 2018). Jeong and colleagues look at how communication behaviors impact coping outcomes. Specifically, the team found that information seeking and information forwarding positively affect coping processes and coping outcomes. Information seeking is getting information for uncertainty reduction. Information forwarding is a communication behavior focused on behavior directed on action in a social context such as sharing caregiving experiences in an online forum. Dementia caregiver communication is a complex phenomenon, so it is important to look at the variety of factors that can impact it such as stigma.

### *Caregiver Stigma*

Stigma can be conceptualized as an "attribute, behavior or reputation which is socially discrediting in a particular way: it causes an individual to be mentally classified by others in an undesirable, rejected stereotype rather than in an accepted, normal one" (Goffman, 1963). Family

members of individuals living with dementia may experience stigma and go through feelings of shame in regard to the disease (Kahn, Wishart, Randolph, & Santulli, 2016). The feeling of stigma is a potentially changeable contributor to caregiver burden (Werner, Mittelman, Goldstein, & Heinik, 2012). Stigma can be broken down into caregiver stigma, lay public stigma, and structural stigma (Werner, Mittelman, Goldstein, & Heinik, 2012). Within the dementia caregiver population, female and adult child caregivers are more susceptible to greater levels of stigma (Kahn, Wishart, Randolph, & Santulli, 2016). Caregiver stigma is a construct that can significantly influence a caregiver's overall experience with caregiving because it can snowball into larger issues such as social isolation.

### **Social Isolation among Dementia Caregivers**

Caregivers of individuals living with dementia are at risk for social isolation (Kovaleva, Spangler, Clevenger, & Hepburn, 2018; Pertl et al., 2015). Social isolation refers to “a state in which the individual lacks a sense of belonging socially, lacks engagement with others, has a minimal number of social contacts and they are deficient in fulfilling and quality relationships” (Nicholson Jr, 2009). The Alzheimer's Association (2017) found that 64% of caregivers feel isolated/alone which contribute to the stress of being a caregiver. This statistic makes sense since many caregivers give up their hobbies and reduce their employment in order to care for their loved one (Leong, Madjar, & Fiveash, 2001; Brodaty & Pavlovic, 1990). Furthermore, while caregivers think caregiving ought to be a group activity, half of all caregivers did not feel as though they could talk to anyone in work or social settings about their caregiving experiences (Alzheimer's Association, 2017). Caregivers are more likely to grow apart from family members because of caregiver duties (AARP, 2018).

Since dementia is an umbrella term, a variety of neuro-degenerative illnesses are placed

under the word “dementia.” Consequently, because dementia is not necessarily classified with the elderly, caregivers may be young, such as those who have care recipients with early onset dementia. Wawrziczny et al (2017) found that spousal caregivers of individuals living with early onset dementia experienced loneliness due to three factors: conversations with the care recipient are more restricted than before the illness, the increased rarity in out-of-town getaways, and the caregiver’s social network slowly distancing themselves.

Social isolation is shown to have negative impacts on caregivers. For example, loneliness among dementia caregivers is a strong predictor of perceived caregiver burden (Pertl et al., 2015). Dementia caregivers experience more hardships than the average caregiver due to the neurological effects of dementia on the care recipient (Schulz et al., 1995). These changes in the brain cause the caregiver to support more activities of daily living for the care recipient, and they create the need to reassess one’s identity in relationship to the individual living with dementia. This population experiences more detrimental health effects due to the nature of their caregiving and the associated stigma attached to dementia. Consequently, dementia caregivers withdraw and do not feel a sense of belonging to their networks because of the changing nature of their identity.

Despite the roadblocks in social interaction, it is important for caregivers to engage in respite and reduce their sense of isolation (Wawrziczny, Pasquier, Duchmarme, Kergoat, & Antoine, 2017). Several initiatives target caregiver socialization while involving the person living with dementia such as Memory Cafes and choruses (Abrahms, 2013; Mittelman & Papayannopoulou, 2018). These programs allow caregivers and their loved ones to socialize in a manner where they do not need to apologize for any mannerisms or issues caused by the neurological impairment. These types of initiatives may be helpful in reducing the psychological

impacts of caregiving. For instance, a psychosocial intervention (i.e., group therapy) targeted towards dementia caregivers greatly expanded the number of individuals supporting a caregiver, improved caregiver fulfillment with their support group, and the aid a caregiver offered in connection with caregiving (Serrano-Aguliar, Lopez-Bastida, & Yanes-Lopez, 2006). These types of initiatives allow caregivers to not feel forgotten by the wider community, and it is important to understand why these programs are effective with caregivers.

Overall, social isolation is a threat to a dementia caregiver's sense of well-being. Caregivers perceive obstacles to openly speaking about their experiences of caring for an individual living with dementia. To better understand how to reduce these obstacles, it is helpful to understand how caregivers experience social isolation as well as loneliness. By understanding social isolation and loneliness within dementia caregivers may be able to increase a sense of belonging within their various relationships.

### **Belonging for Dementia Caregivers**

Before defining belonging, it needs to be understood in relation to loneliness. Since caregivers for individuals living with dementia must spend more and more time providing for their care recipient's needs, caregivers' social networks diminish and can lead to isolation and loneliness. Despite the fact that social isolation and loneliness are closely related in the public's mind, a key distinction remains between the two concepts. Loneliness refers to "the unpleasant experience that occurs when a person's network of social relations is deficient in some important way" (Perlman & Peplau, 1981). In essence, loneliness is the emotional response to social isolation.

The aforementioned definition of loneliness is grounded in the idea of connectedness, but through its absence or the absence of meaningful connections. Connectedness focuses on engagement with social networks or social organizations (Crisp, 2010). Social connectedness can

be operationalized as feelings of caring for individuals and feeling cared about by individuals (O'Rourke & Sidani, 2017). Individuals assess their relationships to see the degree to which they feel socially connected (Ashida & Heaney, 2008). In contrast, the related construct of belonging is heavily tied to ideas of identity through discursive constructions (Ward, 2009). Belonging is an extension of connectedness and related in several, complex ways such as “connectedness as a precursor to belonging, connectedness reinforcing belonging, connectedness but not belonging, and belonging without connectedness” (Crisp, 2010). As such, connectedness is the counter to social isolation, but may not counter loneliness. For caregivers, to consider both isolation and loneliness, belonging goes beyond connectedness to consider the meaning of connections and the absence of connections. To understand caregivers better, it is useful to look at belonging and try to conceptualize how individuals situate themselves in accordance to their belonging.

Belonging is utilized in a variety of fields, but it is vaguely defined. For instance, sense of belonging is often used as the antithesis to loneliness in mental health research (Hagerty et al., 1992). Additionally, belonging has been framed in terms of citizenship (Yuval-Davis, 2011). In the broadest sense, there are two meanings for belonging. The first definition focuses on social connections (Gilmartin, 2017). In this sense, belonging focuses on the relationships around an individual and how they connect to a particular group (Gilmartin, 2017). The second definition focuses on the use of space (Gilmartin, 2017). In this instance, belonging is based on a connection to a particular place or location and the place can vary in terms of scale (Gilmartin, 2017).

Belonging can be conceptualized through the viewpoint of individuals, groups, or places. For instance, in terms of an individual perspective, it is possible to look at how belonging is experienced in people. In this case, words such as “belongingness” “sense of belonging” and

“place attachment” can be used to describe the experience. Another way that researchers attempt to measure belonging is through the quantification of the degree to which and the factors that influence individual belonging. Researchers are unsure whether it is the strength of social connections or the amount of connections that leads to a sense of belonging. However, by maintaining connections a sense of belonging is reinforced in an individual (Crisp, 2010).

While belonging is studied in many fields, it is useful to look at the concept from a communication perspective. Iverson (2010) extends the idea of belonging through a description of *basho* (ba), a Japanese notion of place. Iverson (2010) states that belonging is more than a set of actions and that “Belonging is about knowledge and repertoire, and also about the actions of others who are members of the group.” Specifically, *basho* examines the location of individuals as well as the identity that people draw on from place (Haugh, 2005; Nonaka & Konno, 1998; Nonaka & Nishigushi, 2001). Ba can be conceptualized “as a shared space for emerging relationships” and the space can take variety of forms such as physical, mental, virtual etc. (Nonaka & Konno, 1998; Nonaka & Nishigushi, 2001). Place in this case is grounded in connectivity and relations to others (Nonaka & Nishigushi, 2001). The word “*basho*” is comprised of two parts which are *tokoro*, inclusion, and *ichi*, distinction - one’s place in relation to others (Haugh, 2005). To better explain belonging as it relates to connectedness, it is helpful to use the story in the introduction.

Inclusion means “being a part of something else (such as a particular set or group)” (Haugh, 2005 p. 47). Inclusion can represent an insider/outsider status because belonging includes becoming a part of group with individuals who have similar beliefs (Crisp, 2010). Inclusion is generally marked by behavior at a group level (Anthony et al., 2020). For example, Marcy is a part of a group of patrons who regularly frequent a salon in Missouri. Marcy feels a

sense of connectedness to the beauty salon because there is a social network present within the salon. She is privy to the practices of this group and shares similar beliefs as the other women (i.e. understanding the necessity of a good haircut). In turn, the other members treat her with insider status such as talking with her while waiting for a hair stylist. Consequently, part of her identity is tied up in being a salon patron, and she feels part of the network. This inclusion ends because the owner tells Marcy to no longer come back with her husband. Marcy felt that to being part of the group meant that her husband was also considered a member, but the inclusion of both parties was no longer allowed once he developed dementia.

Distinction is grounded in knowledge of a group, meaning that how an individual stands out in a group gives an individual a feeling of belonging (Anthony et al., 2020). Furthermore, Iverson (2010) states that distinction “allows for a unique place within a group, just as a particular star in a constellation has a unique and important role relative to the others.” It is important to note that distinction is not the antithesis of inclusion, but it merely allows an individual a unique place in a group (Iverson, 2010). For example, Marcy distinguishes herself at her salon by being a dementia caregiver. That aspect of her identity makes her stand out because salon patrons recognize her as the woman who always comes with her husband due to his illness. When she is asked not to bring her husband, belonging to the social group puts her at odds with belonging as a spouse and caregiver. This distinguishing characteristic was not a part of Marcy’s identity before her husband’s diagnosis, but through her connection to him, her distinction within her group changes.

Caregiver stories such as the one in the introduction highlight that belonging is a complex construct with many different facets. It is imperative to start to deconstruct caregivers’ experiences of belonging. My framework for belonging is based on the idea that creating “a



sense of belonging is incredibly powerful when coping with illness” (Anthony et al., 2020).

*Basho* can be conceptualized as a collectively enacted group notion, it is useful for understanding how caregivers of individuals living with dementia enact relational-place (Haugh, 2005). While Iverson (2010, 2013) looks at belonging in terms of communities of practice, I explore how caregivers enact relational-place in the various communities that affect their daily lives. Caregivers’ sense of belonging may be fluid because the progression of their loved one’s dementia determines their position and understanding of the relationships around them. By analyzing *basho*, it is possible to understand how caregivers feel distinct in their communities and where they feel moments of inclusion and exclusion.

Overall, dementia can create difficulties for both the individual living with the illness and their loved ones because it is both a medical and social condition. Caring for an individual living with dementia is an act of love, but it is difficult role for anyone to fill no matter how good a caregiver’s intentions are towards the care recipient. In particular, loneliness is bound to creep into a caregiver’s life because the experiences of being a caregiver can make them different from those around them. Belonging and the absence of it is an approach to help unpack dementia caregivers’ experiences. Belonging is a complex phenomenon, but this approach allows for the inclusion vs exclusion as well as an individual’s position within a group to be understood within a caregiver’s experience. Since currently no clear characteristics have been developed to articulate belonging in general or for caregivers specifically, the project aims to build a more robust notion of belonging for caregivers. This concept allows researchers to bring together the variety of factors that may impact a caregiver’s experience such as loneliness, stigma, and burden. Consequently, belonging among dementia caregivers is worthy of study, and I hope to utilize this project as formative research in understanding belonging as it relates to dementia

caregivers.

While dementia caregivers have been studied by many disciplines such as psychology and sociology, a communication approach helps to provide a different perspective on how caregivers understand themselves in relation to individuals living with dementia. Specifically, it allows researchers to understand how caregivers of people living with dementia are crafting stories about their experiences. Human beings are the stories we tell ourselves because these stories help to define who we can potentially be in the world (Kapur, 2009, 7:06). I think by deconstructing these stories to understand how they are constructed through language; it is possible to understand the underlying values and beliefs of caregivers. Caregivers keep publishing their stories through alternative mechanisms like self-publishing as a way to tell their stories, so it is important not to dismiss their personal accounts. By understanding these communicative processes, it is possible to understand and offer insight to caregivers and provide support.

RQ#1: What are the communicative indicators of inclusion among dementia caregivers?

RQ#2: What are the communicative indicators of distinction among dementia caregivers?

RQ#3: How do the communicative indicators of inclusion and distinction interact to create a sense of belonging for a dementia caregiver?

## **Chapter 2: Methods**

In this chapter, the qualitative methodology for the research on belonging among dementia caregivers is outlined. Specifically, a thematic analysis approach is utilized to synthesis the findings from 44 published narratives to explore insights on belonging for dementia caregivers.

### **Data Collection**

Caring for an individual living with dementia can be a full-time job depending on how far along the illness has progressed, making contact with caregivers and availability for interviews difficult (Leong, Madjar, & Fiveash 2001; Brodaty & Hadzi-Pavlovic, 1990). Fortunately, a variety of caregiver respite programs are in place to assist caregivers in managing their role. These programs include federal and state programs such as the National Family Caregivers Support Program, the Lifespan Respite Program, Willing Hearts Helpful Hands, and the Alzheimer's Disease Supportive Services Programs (ARCH National Respite Network and Resource Center, 2018). Respite for dementia caregivers can take a variety of forms such as assistance with household chores, assistance with caring for the care recipient, counseling services, and adult day center programming (Roberts & Struckmeyer, 2018). Despite the increase in respite care options, there are not enough programs to meet this population's need (Caregiver Action Network, 2015). This need for expansion will not come any time soon as states propose reducing funding for caregiver respite programs (Marcy, 2012).

Consequently, it is difficult for these caregivers to leave their loved ones to complete an interview discussing their experiences. However, this population is vocal about the challenges they face. Caregivers extensively utilize three platforms to tell their stories: online forums & blogs, self-publishing book services (i.e., CreateSpace), and podcasts. While the individuals giving these accounts are not speaking about direct experiences of inclusion or exclusion within

the context of dementia caregiving, the stories indirectly deal with belonging. Specifically, it is the “act of choosing—the stories we tell versus the stories we leave out— [that] reverberate across the rest of [an individual’s] life” because the stories individuals tell about their lives shape their perceptions about their world and their place in it (Miranda, 2016).

Therefore, I utilize the format suggested by Page and Keady (2009) and Noblit and Hare (1988) for finding data sources. This process involves deciding on a research question, defining the inclusion criteria for the search process, and engaging in a systematic review process. Below is a list of considered data sources after an extensive online search of recorded narratives. Each source met two criteria: (a) the person was or is a dementia caregiver and (b) their story is entirely their own, meaning that it is not a one sentence snippet in a caregiver guide or retold by someone other than the caregiver.

1. *Telling Tales About Dementia: Experiences of Caring* by Lucy Whitman
2. *Living with Alzheimer's & Other Dementias: 101 Stories of Caregiving, Coping, and Compassion* edited Amy Newmark and Angela Timashenka Geiger of the Alzheimer’s Association
3. *Alzheimer’s through My Mother’s Eyes* by Suzette Brown
4. *Living with Dementia: A Caregiver’s Journey* by Philip Edward Phlegar Weeks
5. *I Didn’t Sign Up for This: One Dementia Caregiver’s Story and How She Survived* by Mary Monroe
6. *Loving Gordon: A Dementia Caregiver’s Journey* by Ruth Baird Pollard
7. Posts from the Caregivers Forum of Alzconnected
8. Interviews from the podcast *Caregiver/Storyteller* which is produced by CaringKind

In order to limit the scope of the project, I analyze stories from options one and eight because these stories are meant to showcase the range of caregiver experiences rather than depicting it as a monolithic experience. Additionally, these sources allow for greater variety in terms caregiver demographics.

Option one, *Telling Tales about Dementia*, is an anthology of 30 caregivers of different backgrounds are sharing their experiences about caring for a loved one living with dementia.

This collection came into being after the editor wanted to write about her experience being a caregiver. Whitman notes in the introduction that when she was caring for her mother after her diagnosis, she did not have time to join a caregiver's support group. However, Whitman did read books about dementia, and when deciding how to present her caregiver story, she thought a collection of stories would help caregivers make sense of their caregiver situation. Whitman reached out to a variety of dementia-related organizations such as Uniting Carers for Dementia as well as reaching into her social network to friends, colleagues, and acquaintances. She acknowledges that the collection is not a scientific sample because it cannot be a comprehensive guide to the caregiver experience. However, this book is still an important source of data for this project. First, a variety of experiences are captured in this anthology, meaning that the data will be richer. Second, the editor simply wants to tell a variety of caregiver stories. Consequently, the editor is not trying to place a certain value or emotion, but rather depict the variation in the caregiver experience. In total, this book contained 183 pages that were analyzed.

Option eight is interviews from the podcast entitled Caregiver/Storyteller. Caregiver/Storyteller is a storytelling podcast about Alzheimer's disease and dementia caregiving. The podcast is produced by CaringKind, a non-profit organization that works to support those living with dementia as well as their caregivers. Specifically, I analyze 14 interviews from a variety of caregivers. Each interview ranges from 30 to 60 minutes in length. In total, there is an estimated 14 hours worth of dialogue in these interviews. I include these podcast episodes in the data for two reasons. First, the organization is not looking to tell a particular type of story about dementia caregivers. Caregiver/Storyteller argues every caregiver has a story to tell and states that the role of caregiving comes with a mix of positive and negative

emotions. Consequently, CaringKind, the producer of the podcast, argue that caregiving is a complex phenomenon, rather than trying to depict caregivers in a certain light.

### **Data Analysis**

To begin the data analysis, I transcribed the fourteen interviews using an electronic transcription service. The transcription process mirrors the methods outlined by Laditka et al (2009). The audio files are transcribed word for word by *Temí*, a professional transcription service. To ensure the correctness of the transcriptions, I compare the electronic transcriptions with the audio recordings word by word and made necessary corrections to the transcriptions. The anthology is already transcribed, so no electronic transcription is necessary for the data analysis.

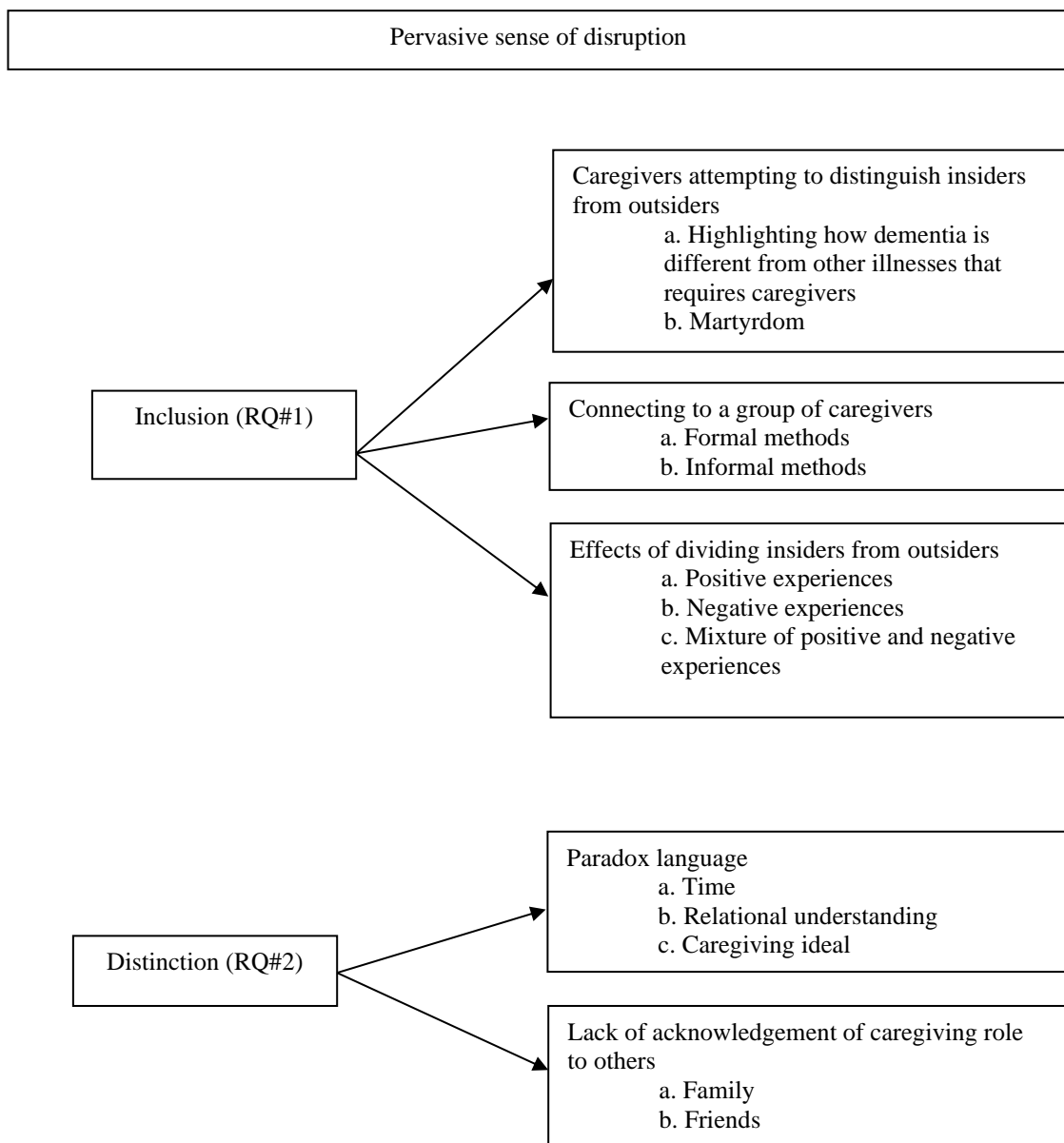
I utilize a thematic analysis approach during the coding process. The data is organized by naturally occurring themes utilizing a constant comparison method (Glaser & Strauss, 1967). Once the data is coded the first time, the researcher engages in a second axial coding process (Charmaz, 2006). Axial coding is when the researcher finds relationships between the open codes (Tracy, 2010). This step is crucial because it allows the researcher to reconstruct the data along with examine category relationships and association to the theory. Additionally, axial coding presents the researcher with an opportunity to finesse out the distinct differences and similarities between categories, ensuring the placement of data in certain categories during the open coding process (Tracy, 2013). Furthermore, this method allows the researcher to take advantage of the strengths of qualitative analysis by organizing the data through themes and valuing the experiences of research participants (Tracy, 2013).

During this research project, the categories are based on comprehensive themes appearing in the data which allowed for a variety of themes to develop. This process allows the researcher to become keenly familiar with the data. During this process, I choose not to assign pseudonyms to participants because the stories were part of the public record. After the preliminary data

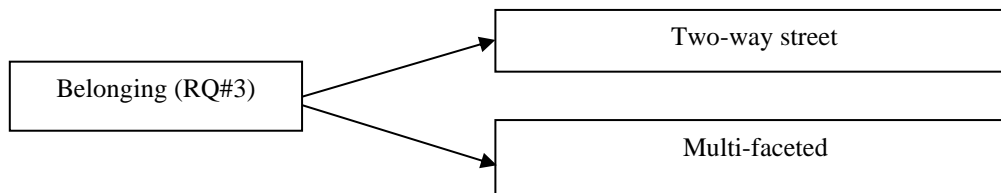
analysis, I engaged in a second round of analysis, axial coding (Charmaz, 2006). During this process, the researcher is able to deepen the analysis based on the data that may be left out during open coding (Tracy, 2013). After beginning to engage in the data coding process, I used literature on belonging (Iverson, 2003) and *basho* (Haugh, 2005; Iverson, 2010) as a guide for my analysis. Specifically, I wanted to use the concepts of inclusion and distinction to better understand specific places where caregivers felt a sense of belonging. From the concepts of inclusion and distinction, it is possible to see the common themes in terms of belonging. These concepts serve a basis to be able to dig deeper into my research questions about belonging. This dual-coding process allows the researcher to tease out recurring experiences and themes, which stray away from preliminary themes in order to best use the data.

## Chapter 3: Results

For this study, I analyze 44 published dementia caregiver narratives to understand how caregivers construct a sense of belonging in various social settings. Fourteen narratives are part of the Caregiver/Storyteller podcast and thirty narratives are part of the anthology *Telling Tales about Dementia*. The results are broken down by the three research questions that guided the thematic analysis of the narratives.







The 44 narratives vary widely. In terms of demographics, the caregivers come from a variety of backgrounds. Out of the 44 caregivers, 13 are male and 31 are female. The caregivers were well into adulthood when they became a primary caregiver for someone living with dementia. However, one theme that emerges out of all the stories is a theme of disruption. The results indicate that a loved one’s diagnosis of dementia prove to be a point of disruption in caregivers’ lives. All caregivers describe their own lives and the person living with dementia in terms of life before dementia and life after dementia, signaling the point of disruption in their lives.

**Communicative Indictors of Inclusion for Dementia Caregivers (RQ#1)**

Throughout this study, I seek to better understand how dementia caregivers construct belonging through communication. Belonging can be broken down into inclusion and distinction. Inclusion can be defined as “being a part of something else (such as a particular set or group)” (Haugh, 2005 p. 47). Built into the definition of inclusion is exclusion as its antithesis. It is important to be aware of the specific communication markers used to construct inclusion to understand if there are inclusion communication signs that are specific to dementia caregivers. Forty caregivers experienced some type of inclusion based on their narratives. The two emergent themes in terms of communicative indicators of inclusion are distinguishing insiders from outsiders and connecting to a group of caregivers.

### *Theme #1: Distinguishing Insiders from Outsiders*

This theme encapsulates participants' struggle to make sense of their new place in social situations in light of their caregiving responsibilities, and it appears in 40 out of the 44 caregiver narratives. As a result of their experiences with caring for someone with dementia, a caregiver sees the world differently than they did before this change in their life. This notion of distinguishing relates back to the disruption that occurs as a result of becoming a dementia caregiver. Becoming a caregiver for someone living with dementia drastically alters a caregiver's life because it causes an upheaval in terms of how they understand their world. There are several ways that caregivers distinguish their role.

#### Sub-theme #1: Distinguishing dementia from other disease

This distinguishing happens in a few different ways such as highlighting how dementia differs from other chronic illnesses and framing dementia caregivers in a heroic light. Due to this demarcation, caregivers have positive and negative experiences in the world. Out of the 40 caregivers that employ distinguishing, 30 caregivers have a mixture of positive and negative experiences and 10 have merely negative experiences.

Caregivers make sense of their new place by employing language to separate themselves from individuals who did not identify as dementia caregivers. The first way dementia caregivers distinguish insiders from outsiders was to focus on the neurological impact of dementia on an individual. Specifically, dementia caregivers utilize this tactic to emphasize the differences in caregiving that occur when caring for someone with a neuro-cognitive illness.

One main difference for dementia caregivers is that caregiving demands can become all-consuming for caregivers, and they may have little reprieve over the course of caring for their loved one. Dementia is a neurodegenerative disease, a condition that leads to progressive degeneration of nerve cells, and it is most commonly associated with memory loss. However,

dementia can have physical implications such as changing the way an individual walk and their ability to speak. Consequently, as dementia progresses, the individual living with the illness requires more help from their caregiver in all aspects of their lives which can take a physical and mental toll on a caregiver. Caregivers often remark that there was “such a steep learning curve” because the disease would constantly change what was required of them to take care of their loved one. Other caregivers note that their lives are so closely intertwined with being a caregiver they would develop a sense of paranoia regarding their loved one’s care, and some caregivers would use phrases such as “worried for hours” and “not coping well.”

#### Sub-theme #2: Balancing self-care with caring for the patient

Another difference between dementia caregivers and non-dementia caregivers is that caregivers are trying to uphold a delicate balance between respecting their loved one’s autonomy and doing what it is in their loved one’s best interest. Dementia patients fall into a complicated category because prior to their dementia diagnosis, these individuals lived independent lives and had been able to clearly express their desires to others. After the diagnosis, an individual living with dementia slowly starts to lose their autonomy as the disease progresses and increasingly debilitates their ability to make choices. Consequently, caregivers are constantly negotiating how much autonomy to give their loved one while maintaining their loved one’s well-being because dementia is constantly changing how a caregiver relates to their loved one living with dementia.

It is important to note that many dementia caregivers are trying to strike a balance between their loved one’s autonomy and beneficence while attempting to live their own lives. Dementia caregivers are not making these decisions simply with their loved one in mind. Rather, these caregivers are making these decisions about their loved one with both parties’ well-being in mind because being a caregiver is only one of many roles that caregivers inhabit.

### Sub-theme #3: Martyrdom

The second way dementia caregivers set themselves apart from non-caregivers is through martyrdom when describing themselves in relation to their loved one with dementia, and fifteen caregivers fall into this category. Dementia is an illness that causes the individual living with the disease to forget their memories and by extension who they were in the past. For caregivers, this deterioration of the person they once knew is a jarring experience because they are losing the essence of their loved one. Compounded with the physical impacts of dementia on the person living with the illness, the role of being a caregiver can be draining at times. As a result, caregivers place themselves as the hero who deserves praise for their role as a caregiver because their life circumstances have unfairly robbed them of their loved one.

It is important to note that caregivers' martyr language lies on a spectrum. Most caregivers do not heavily employ martyrdom, and they eventually move on in order to focus on their loved one's care. However, a minority of caregivers will strongly employ martyr language, bemoaning their caregiving experience and wishing for a life before the disruption in their life. The factors influencing how the caregiver falls on the spectrum are the impacts of dementia on their loved one (i.e., the appearance of aggression, the inability to articulate words) and the life circumstances of the caregiver over the course of caring for their loved one with dementia.

The experience of caring for someone with dementia changes a caregiver and separating themselves from others who do not have similar experiences allows them to understand their place in the world. Dementia caregivers can represent a group that have their own set of knowledge (i.e., how to speak to someone with dementia, how to pick an assisted living facility for someone with memory loss, etc.). Caregivers may not choose for their loved one to be diagnosed with dementia, but they make the choice to be involved in their loved one's care once they know about the diagnosis (as opposed to abandoning them – choosing not to be involved).

That choice to get involved in all the nitty-gritty details of caring for someone with a neuro-cognitive illness does help include someone as part of a group of dementia caregivers, and with the status of “group” comes the ability to decide who is an insider and who is an outsider. In this case, a dementia caregiver sees someone who does not have experience of directly caring for an individual with dementia as an outsider.

For instance, Cynthia states that due to caring for her mother: “There is simply no way that a person can go through an experience like that and not be completely changed forever. If you can maintain some sort of perspective, you look at life differently and I am enriched for it.” Cynthia acknowledges that her mother’s dementia diagnosis and subsequently becoming a dementia caregiver altered her life. These events allow her to have a viewpoint than non-dementia caregivers who have not had the same experiences as her.

Sub-theme #4: Caregiver experiences are both positive and negative

It is important to note that this is not a change that happened all at once. Rather, it is a gradual process that occurs as a caregiver negotiates their place in relation to the person with dementia. Going back to the case of Cynthia, she describes the knowledge of seeing her friend Kitty decline from dementia as a “sort of despair” that needed to be kept at bay. Caring for a loved one with dementia is not simply a cross for caregivers to bear – while they may gain some perspective from the experience, it is important to highlight that caregivers are human and will feel positive and negative emotions about their caregiving responsibilities.

This creation of a group leads to two types of experiences: positive or negative. Positive experiences resulting from the creation of the group means caregivers feel closer to other caregivers. One way caregivers reach out to other caregivers is through the use of technology such as email. For instance, Jim notes that “I am corresponding by email with a man whose wife also has Alzheimer’s and I find this long-range sharing of experience really cathartic. Although

family and friends tell me to feel free to talk to them about Jan, I am reluctant to do so as I feel they must be bored to death listening to my outpourings.” While Jim and others like himself are able to find solace in the company of others caring for a loved one with dementia, caregivers do not necessarily have to reach out to individuals outside their social network to connect with other dementia caregivers. Rather, they were able to connect to family members who are helping to care for the loved with the dementia diagnosis. Jordana notes that her relationship with her father is stronger because of dementia caregiving. The two view caring for Jordana’s mother as a shared activity that they can do together. Furthermore, Cynthia notes that while it is difficult to watch her mother Lucille deteriorate as a result of her illness, she is able to reconnect with her sister Val because they both help to care for their mother. Cynthia hints at the fact that being a caregiver leads to a mixture of positive and negative experiences when she states:

Ironically, my mother's illness was precisely the thing that [ended the estrangement with Val], and one afternoon my sister and I were sitting, we were both exhausted by this time. She had moved mother in with her in West Beth. My sister put her coffee down and looked at me and said, “Well, I'll tell you one good thing. I got my sister back.” So yes, in a very strange way, in a tragic way, but still heartwarming as it turned out.

While watching her mother decline is a negative experience for Cynthia, she notes that without her mother’s dementia diagnosis, mending her fractured relationship with her sister would be difficult. Similar to Jordana’s case, the activities associated with caring for a loved one with dementia become activities that Cynthia and Val both engage in during the last years of their mother’s life. Consequently, the sisters are closer with one another because of their similar experiences as dementia caregivers, and they feel connected to other caregivers who had similar experiences while inhabiting the caregiver role.

It is important to note that these positive experiences are happening alongside negative experiences throughout one’s time as a dementia caregiver. The life of a dementia caregiver is

filled with nuance, meaning that being a caregiver is not simply a death sentence for the caregiver nor is it simply a role that an individual is eager to fill. Caregivers can and do experience positive and negative emotions (often both in the same day) while they care for a loved one with dementia, and many caregivers accept that their experience as a caregiver cannot be simply placed into one category. These caregivers are still living their lives which are being formed through the intersection of good and bad moments. Debbie echoes this sentiment when she states: “The life of carer for someone with dementia is many-faceted. It brings stress and great sadness, but it can also include many moments of deep-felt happiness and shared love.”

Negative experiences typically occur because a caregiver thinks that non-caregivers cannot understand their world. It is important to note that many of these negative experiences result from caregivers perceiving a lack of understanding from others rather than an actual misunderstanding. For instance, U Hla Htay states that at the start of caring for Minnie, his wife, “Getting our sons involved from the beginning was my first dilemma: as a father I wanted to protect my sons from feelings which could be distressing, but they did have the right to know their mother’s diagnosis. U Hla Htay believes that his sons are not be able to handle the immense emotional toll that accompanies a dementia diagnosis. This perception leads to U Hla Htay isolating himself from his family and causes him to carry the caregiving load by himself. However, U Hla Htay is ultimately wrong about his sons’ reactions to their mother’s dementia diagnosis, and they are willing to support their father. They have been supportive and helpful to Minnie and me ever since. This reduces my burden of caring and stress.” The perception of the situation rather than the facts of the situation drive U Hla Htay to hide the dementia diagnosis, and this type of pre-determined judgment about the situation almost cut this caregiver off from the support he needs from his family.

This type of pre-determined boundary setting can happen in a variety of situations. For some caregivers like U Hla Htay, this pre-determined judgment of the situation can be with family members who either do not handle the day to day caregiving responsibilities or family members who may not be aware of the dementia diagnosis. For other caregivers, this pre-determined judgment can happen when they need to interact with strangers when managing their loved one's care. For instance, Keith has to handle his mother's financial affairs as her illness progressed, and he is nervous with having to interact with a bank official who would not be able to understand his situation as a dementia caregiver. He notes:

Um, so I make an appointment with the Merrill Lynch Rep and I go to see Margo. And I'd had a conversation with her on the phone, a couple of them before that and explain the situation, blah, blah, blah. But this woman didn't know me, and I didn't know her. She knew I existed, but that's about all she knew. And uh, we sat down to have the conversation and Margo was, uh, an older woman, so she was well-heeled. And a boy, that was another massive piece of luck for me. We had the conversation and she explained that to just recently. Uh, she had given her power of attorney to her brother because she realized she was aging, etc. Etc. Etc. And um, you know, my mother being in a situation where she was aging, and she was very careful in the way that she approached my mother. And this is, I, this is very hard for my mother and I'm watching her and I'm thinking, oh my God, what am I going to do? She says, no, because this means all the legal work just goes right down the drain. And Margo talked to her and she responded and Margo talked to her and finally she said, "Well, I suppose if I were to give this to anyone, I guess I'd give it to my son." And I took a deep breath and I said to her directly, "Could you have possibly constructed a more conditional sentence?" And she just didn't respond. And that was the end of that.

Keith prejudices Margo before engaging in a conversation with her because he thinks a non-dementia caregiver is unable to understand his mother's situation and his perspective on the situation because she had not had experience with caring for someone for dementia. After engaging with a conversation with Margo, Keith realizes his perception of non-dementia caregivers is preemptively setting the tone for a negative experience with individuals who did not have the experience of being a caregiver to a loved one with dementia. Ultimately, Keith's perception of the situation is wrong because even Margo did not have his particular experience



(caring for someone with dementia), she is able to sympathize with his situation due to giving her power of attorney to her brother.

Not all negative experiences are the result of the caregiver's perception of the situation. Caregivers note that negative experiences can result when people are not willing to take the time to understand the effects of dementia on an individual. U Hla Htay states that when he is caring for his wife Minnie, strangers unfamiliar with the impacts of dementia on an individual can be rude to his wife when her behavior appears erratic.

Our three sons and I agreed after the diagnosis that from now on we must understand that Minnie's actions and behavior are driven by the disease, not her intention to hurt us in any way, or anyone around us. Thus, although there were initial embarrassments and some difficulties, we accepted her behaviour. We then began to realise that we do not need to excuse her behaviour to the public. At times, members of the public are shocked to witness Minnie's occasional outbursts and assume such behavior and assume such behaviour is directed at them personally. They can be unsympathetic, rude, and abusive in response. At first I used to try to explain Minnie's condition to those people – some are ready to listen and to understand, others not so.

Some people who are not dementia caregivers do not understand what these caregivers go through because they do not have access to the same knowledge as this group.

Going back to Jim's story: "My elder daughter finds it especially difficult to hear how her mum has deteriorated and so I find myself keeping my thoughts to myself." These caregiver experiences mirrors Marcy's story from the introduction because the salon owner judges her for being a dementia caregiver. These individuals make the choice to be dementia caregivers – other people did not and so may not want anything to do with this group. It is important to note that positive and negative experiences are not mutually exclusive. For a majority of caregivers, they experience both positive and negative caregiver experiences over the course of their caregiving journey.

Overall, distinguishing between insiders and outsiders is highly prevalent in the data. Caregivers use language to separate themselves from non-dementia caregivers in two ways. First, dementia caregivers focus on how dementia's impact on the brain makes caring for individual living with dementia different than caring for individuals with other types of illnesses. Second, caregivers would use martyr language, meaning caregivers place themselves as an individual who deserves praise for their role as a caregiver because their life circumstances have unfairly robbed them of their loved one. This demarcation between dementia caregivers and others leads caregivers to evaluate subsequent experiences as positive, negative, or a mixture of positive and negative experiences. Beyond making a clear distinction between insiders and outsiders, caregivers also creates a sense of group among dementia caregivers.

*Theme #2: Connecting to a Group of Caregivers*

This theme captures participants' methods of creating a "group" of dementia caregivers. Forty-one out of the forty-four caregivers employ this tactic to feel part of a group. Dementia caregivers feel inclusion from other caregivers through intentional or unintentional means. Some caregivers are blatant about asking for help from other caregivers over the course of their caregiving journey, and thirty-one caregivers seek out other caregivers. Others are able to connect with caregivers by chance because they interact with individuals who by happenstance are also caring for a loved with dementia, and ten caregivers discover other individuals dealing with similar circumstances by chance. Caregivers feel included by discussing their experiences of being a caregiver and being able to sympathize with other caregivers' experiences. Dementia caregivers appear to feel more comfortable around other dementia caregivers. They do not have to spend time catching someone up to speed, but rather they can just commiserate in their caregiving efforts which is why caregivers may explicitly seek out people that are going through

a similar situation. For example, Ellen feels a sense of inclusion when she went to an event for dementia caregivers.

Yes, and I have to say, you know, I got there, got in line, the line went around the building and I burst into tears because I thought, oh my God, all these people are here for the same reason I am. I stopped feeling alone. I felt I had felt so incredibly alone because I was confused. And there was no one to, you know, there was no one to ---

Ellen feels a sense of inclusion just seeing the physical presence of other individuals who have similar experiences.

Sub-theme #1: Intentional connection with other caregivers

The most prevalent place caregivers explicitly meet other caregivers is at support groups.

In these groups, caregivers can be comforted by the physical presence of other caregivers while also being able to connect with other caregivers about their similar experiences. For example,

Rob highlights the multiple benefits of support groups when he states:

Well, I do go to a, um, a dementia support group and I found that to be helpful. Um, it's good to be around other people who are going through the same things because a lot of times your thoughts, your feelings, you're not sure what to make of them. It's good to know that other people are having these same thoughts and these same feelings. So there is a, um, camaraderie there that is helpful. It's good to be able to go and just get things off your chest when you need to. They can provide other resources, you know, if you need it. Like they were the ones who helped me find an individual therapist to go to, um, to deal with this. So, um, that's been very helpful. I don't know, 90 minutes a week is, is not enough. You know, and an hour's worth of therapy a week is not enough and I still struggle with, I still struggle with the things, um, that I have to do for myself to take care of myself. They talk a lot about self care, you know, you can't take care of someone else if you're not taking care of yourself first. I've never really excelled at the self care bed. I'm good at taking care of other people but I'm not very good at taking care of myself. So, uh, that's, um, after, you know, all this time that's still kind of a work in progress.

Caregivers have a sense of inclusion when conversing with other dementia caregivers because their feelings are validated. This sentiment is echoed by Debbie who stated

As a carer, I was catered for by Jewish Care in an invaluable support group meeting once a month. This group continues, and it gives carers who wish to attend the support of mutual understanding and enables us to express our feelings and reactions to sometimes traumatic events, in a safe and confidential setting.

For caregivers, the act of being able to hear that their experiences are not unique to their situation helps to create a sense of group because the caregivers feel that they are all in the same boat (being caregivers to a loved one with dementia) even though their individual situations are in fact highly unique due to the nature of dementia.

Sub-theme #2: Connecting with other caregivers by chance

Caregivers do not have to blatantly seek out other dementia caregivers to feel a sense of inclusion with others who are going through a similar circumstance. At times, caregivers center a conversation on dementia, and over the course of a conversation a caregiver would discover that the other person was going through a similar situation. For instance, Cynthia notes that individuals should “Reach out to others. Don’t be shy. There are into the millions now with people caring for an elder beloved with either Alzheimer’s or some kind of dementia. Talk about it. You may be very surprised to know that someone on your block, it happened to me, um, or in your building has a similar concern.” While the caregiver may not intend to find another dementia caregiver, the intentional communication act of discussing can open a caregiver up to a feeling of being included because there is a chance that they can connect to someone who is going through a similar situation.

Dementia caregivers employ specific communication strategies to enact inclusion. First, caregivers attempt to separate themselves from non-caregivers. Specifically, caregivers will discuss the unique impacts of dementia on the individual living with illness and why they deserve praise for inhabiting the caregiver role. Second, caregivers will populate the conversations with talk of dementia and dementia caregiving to feel included with other caregivers. These conversations can happen on purpose (i.e., attending a support group) or by happenstance. The act of intentionally discussing the trials and tribulations of being a caregiver

allows caregivers to feel a sense of community because dementia caregivers only allow individuals who have had similar experiences to be part of this group.

### **Communicative Indicators of Distinction for Dementia Caregivers (RQ#2)**

Distinction is the other subcomponent of belonging. Distinction is defined as knowledge of a group, meaning that how an individual stands out in a group gives an individual a feeling of belonging (Anthony et al., 2020). The opposite of distinction that is inherent within the definition is conformity, blending into a group. The two emerging themes in terms of communication strategies are caregivers using language that conveyed the uncertainty, daily-changing reality of caring for an individual living with dementia and not acknowledging the role of being a caregiver among non-caregivers. Thirty-nine caregivers experience some type of distinction based on their narratives. One way caregivers convey their uncertain reality to others is through the language of paradox which emerges in three ways: the paradox of time, the paradox of relational understanding, and the paradox of caregiving.

#### *Theme #3: Language of Paradox*

On some level, being a caregiver appears to be a limbo for those caring for a loved one with dementia. The person living with dementia is present physically but is not the same person mentally that they were before dementia. This presents itself in the notion of a paradox. A paradox can be thought of as convergence of opposite types of behavior appearing to be mutually exclusive (MacQuarrie, 2005). Again, the notion of disruption marks this finding because the paradoxes occur as a consequence of the jarring nature of dementia. Thirty-nine caregivers experience some type of paradox. More specifically, three paradoxes emerge from the data: time, relational understanding, and caregiving. A majority of the caregiver narratives exhibit more than one type of paradox.

### Sub-theme #1: Paradox of time

Thirty-nine caregivers highlight this paradox. This paradox concerns relationships caregivers have with both the carer and non-caregivers. Dementia caregivers are distinct from other types of caregivers because they are seeing their loved ones physically and psychologically deteriorate. For instance, Jennifer notes that “I find myself writing in the past tense, although Mom is still living. I suppose I do so because of Mom’s condition now and how different she is. But although very different, mentally and physically, from what I describe above, she is still Mom. This is simply another phase of her life. However, I do miss her and it does tend to feel a little like bereavement.” It is hard for dementia caregivers to situate themselves in relation to their loved one with dementia, and as a result uncertainty is the distinct factor that marks this relationship.

### Sub-theme #2: Relational Understanding

Twenty-five caregivers are impacted by this paradox. This paradox affects how a caregiver interacts with others. For instance, Debbie notes that “one acquaintance (a man) said to me after we’d met on several occasions, ‘Now, why did I think you were a widow?’ Why indeed? In common with many people in similar situations, one feels ‘neither here nor there’ in this respect.” It is hard to clearly delineate categories for the events and feelings in one’s life as the signpost (the people around) are constantly changing.

### Sub-theme #3: Paradox of caregiving

Seventeen caregivers experience this paradox. Dementia caregivers can have a pre-convinced notion of what an ideal caregiver looks like based on the opinions of non-dementia caregivers. However, the aspects that make up this idealized caregiver are grounded in different values, and as a result, they are often at odds with each other. Rachel best illustrates this notion when she states:

“Caring for a loved one who has dementia means nothing is ever quite right – you know you need a break but you also feel you need to be there caring. If you want company and go out, you wonder what you’re doing there, and want to get away from everyone. If you’re on your own, you wish you had company. Nothing is right, simply because nothing is right. The person you love *is* still there – but not there.”

A caregiver wants to be the best that they can be, but they may have unrealistic expectations, i.e., wanting to spend all of their time with their loved one. Caregivers experience the tension between the notion that caregiving can never fix the underlying problem and the need always exists within caregivers. Consequently, caregivers feel a continuous paradox between what they are doing and what they are not doing.

Caring for a loved one with dementia is not a monolithic experience. Even though all caregivers experience some sense of disruption resulting from their loved one’s dementia diagnosis, the way that caregivers respond to their uncertain future following the disruption is unique to each caregiver. One method of communicating their uncertain future is through the language of paradox which can be broken down into three types of paradoxes. First, the paradox of time focuses on caregivers’ uncertainty in terms of how to grieve for a person who is physically the same but mentally different. Second, the paradox of relational understanding focuses on how caregivers are able to interact with others in light of the fact that their personal life is no longer constant. Third, the paradox of caregiving focuses on caregivers struggling to define what acceptable caregiving looks like to them in a world in which they are grappling with idealized notions of caregiving.

#### *Theme #4: Avoiding Distinction by Not Acknowledging Caregiving Role*

Dementia caregivers may avoid discussing caregiving at all with non-dementia caregivers because it is their distinguishing characteristic in a situation. Caregivers try to hide their involvement as a dementia caregiver from their children and friends. Eighteen caregivers try to avoid acknowledging their role as a dementia caregiver over the course of their caregiver

journey, and it is evenly split across women and men. These caregivers choose to leave out this detail when they are in social situations precisely because they think it will make them distinct from their friends and family.

It is important to remember that being a caregiver is not the only role that a caregiver inhabits. When a dementia caregiver is tending to a spouse with dementia, the caregiver may attempt to hide this role from the couple's children. For instance, Jim and U Hla Htay attempt to protect their children from the reality of caring for someone with dementia. These men feel that the disease is painful enough for them and their spouse that they do not want to pass the knowledge onto their children. Furthermore, Debbie notes that "And this [desperate need to protect them from experiencing the same feeling of despair that was overwhelming me when I hear the formal diagnosis of vascular dementia] marked my attitude, also, to the task of telling our adult children." Parents want to protect their children from the reality that their other parent have dementia, and as a result hide their caregiving role from their children.

In some cases, dementia caregivers try to hide their caregiving role from friends. Typically, they find the diagnosis to be shameful, and do not want to acknowledge it themselves, much less to the outside world. This sentiment is expressed through Lou-Ellen comments regarding how her mother started to care for her father when he had dementia:

She had decided she wanted to move, they moved to Florida. They moved into an apartment they probably couldn't afford at that time, but they stayed there for awhile and you know, they, he walked on the beach and they had everybody down at the pool and as he was getting less and less, well it was less and less apparent, I think to other people. My mom knew, but she would dress him up and they'd go out to dinner with people. And it was a long time before people started to really notice. She did a great job in a way of hiding it because she was embarrassed by it. Right. The senile old man stereotype is terrifying for her and also for him. And I think she was trying to protect him. We would go out to dinner with them and he would come out and she'd have them all dressed up in a little sports shirt and a tie and hair all nicely combed and she had done it all, you know, taking care of him. Over time what happened was it became impossible for her to manage on her own.



While many caregivers do not go through the lengths Lou-Ellen's mother do before she herself developed dementia, a majority of caregivers do experience some type of shame and pain that the person they loved is experiencing this illness.

Distinction can be viewed as the uniqueness of an individual's role. Dementia caregivers define the uniqueness of their role through two methods. First, dementia caregivers experience a range of paradoxes as a result of disruption. These paradoxes mainly fall into three camps: time, relational understanding, and caregiving. Second, dementia caregivers focused on hiding their distinction in order to conform. Dementia caregivers hide their caregiver status by not admitting to identifying as a dementia caregiver.

### **Inclusion and Distinction Creating Belonging for Dementia Caregivers (RQ#3)**

The previous research questions illuminate how distinction and inclusion are enacted as a part of belonging. Additionally, each of those concepts interacts with one other in important ways to understand belonging overall. Inclusion and distinction interact to help create a sense of belonging for dementia caregivers in different social situations. I define belonging in this research study as going beyond simple membership to mean a sense of fitting into a group based on facets of one's identity and enacted connections to the group. The interaction between the two subcomponents demonstrates that belonging is a two-way street and is multi-faceted. Belonging emerges in thirty-nine stories in some capacity. However, it is important to understand how they interact for a more complete picture of belonging.

#### *Theme #5: Belonging is a Two-Way Street*

One theme that emerges from the narratives is that a sense of belonging did not rest solely in the caregiver's hands. Rather, other individuals in a situation have equal if not more power than caregivers to enact belonging. Caregivers are constrained by the material reality of

their situation – there is only so much time in a day to get everything done for the care recipient and may not be able to leave their house for an extended period of time. However, other individuals may have more flexibility in terms of time and location in which to enact connections within a group.

Twenty-five caregivers enact belonging in terms of mutual action from other individuals. Debbie notes that “One of the seemingly inevitable results of the impact of dementia on the carer (particularly in the case of spouses) is the sense of isolation as one’s old social life becomes impossible. Friends sometimes try to keep in touch but often without success, as many people just ‘can’t handle it’ when confronted with the difficulties of communication with their old friend who has developed this daunting condition.” Consequently, a dementia caregiver may still try to enact social conditions with friends, but it may shift based on their new role as a caregiver. For instance, Rob discovers how he has to change his routine to avoid social isolation:

No, it's not the most exciting thing to do to sit in my living room and watch Golden Girls reruns over herbal tea. But if you want to spend time with me, then that's what you're going to have to do because I can't be readily available anymore. You know, you have to make those decisions and getting yourself to a point where you are aggressive and upfront and clear with everybody in your life. This is what I want. This is what I need. This is what I can do. This is what I can't do. Accept it or there's the door. So when I hate to reference a movie, but Steel Magnolias, I always think about this one scene where, where Shelby, when she had that long very cool eighties you know, high maintenance hair and she had just had the sun after, she wasn't supposed to because she was a brittle diabetic and she went to the hair salon to get a short haircut and all of a sudden ladies were shocked that she was getting a short haircut. And she said, I just feel the need to simplify things and that's what you have to do. You have to simplify things. Gotta be Shelby for a little while.

Friendships that develop prior to the loved one being diagnosed with dementia can endure, but the non-caregivers typically are willing to go with the flow in terms of the changes in caregiver’s life. Nancy notes that “I talked a lot to friends [as my partner was progressing through the stages of dementia]. One of the greatest tragedies was that Marilyn’s friends basically abandoned her.

They were not present. My friends were very present for me. Her friends I think were scared shitless and basically disappeared.” The contrast between the caregiver’s friends and the person living with dementia’s friends illustrates that maintaining previous ties is possible in the wake of a dementia diagnosis. A majority of caregivers note that they while they lost some friends, pre-existing relationships are strengthened with people that are willing to be flexible. In addition, caregivers are able to make new relationships with other caregivers because they are willing to be flexible.

*Theme #6: Belonging is Multi-Faceted*

Belonging is not a one size fits all. A caregiver does not suddenly cross a line and belong. It is constantly being negotiated, and a caregiver can belong one day and not the next. Belonging is a complex concept because it has many different but related parts. Specifically, belonging in terms of dementia caregivers depends on prior relational history, material circumstances, and caregiver identity. Thirty-six caregivers view belonging as a concept with many features.

Dementia caregivers have complex relationships with the people they are caring for throughout this phase in the person’s life. Lou-Ellen touches upon this notion when she discussed caring for her mother:

Caregiving for people with dementia is probably the hardest job on the planet. You're watching somebody you love disappear. It's very uncertain how they're going to behave. Unpredictable, and you're bringing to that relationship, that experience, all the baggage that comes from your previous relationship and requires you in a way to reinvent everything you know about the way you've communicated with this person before. And if you can do that, everything else gets easier. So I've often said the smartest thing what I try to tell people as the most important thing anyone ever told me was that if somebody who has dementia is talking to you and says the sky is green, then you say what a beautiful shade of green. And if they say it's the day and it's not you say it's not because it's because you don't, you put to putting yourself in the other person's world changes the way the experience is going to take place and absence of that anxiety and that tension changes the experience and makes it, takes it from being almost unmanageable to being barely manageable, which is better. Um, it's never going to be great and then it creates

some way for you to sort of negotiate and manage what you're going to be having to go through to just, you know, aptly put the long goodbye during this period.

Caregivers are grappling with the notion of the person they knew before the diagnosis and the person they are currently caring for in the present. Ellen speaks about how Alzheimer's is at Stage 17 right now because of the amount of changes she has witnessed in comparison to the woman she knew before Alzheimer's disease.

They, the, um, personality starts to change a lot. And my mother actually was basically a very kind of judgmental person, very superficial when I'm trying to say, and the Alzheimer's, you know, as someone said to me once, meet your new mother, her personality has changed so that I, it's like I forgive her for every horrible thing she ever did in the past. And there were many, many things. Okay. Now she just gets my unconditional love and understanding and um, because nobody, I don't think unless you are around somebody with Alzheimer's, I don't think anyone understands what Alzheimer's does to a person. If someone told me this is what Alzheimer's is, this is how people behave when they have it. I would think they were either Drama Queens or um, fabricating something. I mean it's unbelievable. I have seen when I say my mother is going through, there is no such thing as stage 17 of Alzheimer's but it's the changes she's gone through that I've witnessed are mind blowing and staggering.

The multi-faceted nature of belonging is most present between the relationship between the caregiver and the person living with dementia. That relationship is typically major relationship in a caregiver's life, and it impacts the way a caregiver interacts in different social settings.

Belonging is created when inclusion and distinction are enacted by a dementia caregiver. In terms of dementia caregivers, belonging is enacted in two ways. First, it is a two-way street, meaning that it is as much the caregiver's responsibility as it is other individuals' in the specific social situation to help create a sense of belonging. Second, belonging has many different aspects that can be affected by the caregiver's background.

## **Chapter 4: Insights and Conclusions**

The results discussed in the previous chapter explain how dementia caregivers construct a sense of belonging through communication. In this chapter, the implications of the three research questions are discussed, as well as the theoretical and practical implications of the findings.

### **Sense of Disruption**

A dementia diagnosis can be jarring for both the individual living with the illness and their caregiver. Both parties have to come to accept that the dementia patient's identity will change over the course of the illness. Additionally, previously held routines and plans for the future have to be altered in order to make sense of this new reality. Together, all of these changes put create a starkly different life for a caregiver than their life pre-dementia diagnosis.

The caregiver narratives illustrate that dementia caregivers experience occupational disruption over the course of their caregiving journey. One type of change that occurs in a caregiver's life is occupational engagement. Occupational engagement is a broad category to include all types of activity such as work. Beyond work it includes "initial or subsequent participation in activities that form part of the individual's identity" (Creek, 2003). However, activities can be disrupted when an individual is not able to participate in their occupations (Whiteford, 2004). When a loved one is diagnosed with dementia, the caregiver must adjust how they interact with their loved one. For instance, when an adult child starts to care for a parent diagnosed with dementia, they can no longer seek advice from their parent. Rather the parent starts to ask the child for advice on matters as the illness progresses in the parent. This implication is consistent with findings from Miller et al (2008) conclusion about family caregiving. The change in occupation for the adult child changes interacts both with the parent and the outside world.

Occupational disruption is not a black or white concept. Occupational disruption can allow for caregivers to engage in new activities (Hasselkus & Murray, 2007). This study helps to support the notion of occupational disruption within the context of dementia caregiving by demonstrating the positive aspects of disruption on interpersonal relationships. For example, some family members are able to become closer. While their routines prior to dementia caregiving are disrupted, families are able to come together and craft new routines around caregiving. Additionally, it can help to mend distraught family relations. For example, some caregivers find that the role of being a caregiver is a monumental task and seek help from other family members. Over the course of caring for the loved with dementia, caregivers who are part of the same family engage in new routines that require cooperation and coordination, allowing them opportunity to work out grievances in order to effectively coordinate the caree's care. As a result of the occupational disruption, caregivers have to figure out new ways of fulfilling the roles in their lives which allow for potential new connections with family members.

Another type of change in a caregiver's life is understanding how the pieces of their life fit together in the wake of their loved one's dementia diagnosis. Biological disruption refers to sense of disconnect between an individual and their life course (Bury, 1982). Dementia caregivers are unsure of how to make sense of their life story after their loved one is diagnosed with dementia. In the narratives, biological disruption affects caregivers who are the spouse of diagnosed individual harder than the adult children of the diagnosed individual. Spouses often plan to spend their entire lives with their partners, and a dementia diagnosis throws those plans into jeopardy. Oftentimes, adult children are not spending every day with their parents prior to the dementia diagnosis so their life course is less connected to the identity of the person living with dementia.

Disruption relates to belonging on a theoretical level because it demonstrates that belonging in a social situation is not as simple as flipping a switch. Belonging is an ongoing process, and the process of belonging does not stop because a caregiver's life was disrupted by a loved one's dementia diagnosis. Belonging provides a useful theoretical lens to see the disruption present in dementia caregivers' lives. While other research finds disruption, belonging places it in the context to see how dementia caregivers connect with others. Belonging is a useful lens for understanding the changes in relationships.

Disruption relates to belonging on a practical level because it helps to highlight the sense of loss that caregivers experience when their loved one is diagnosed with dementia. Caregivers are distraught after their loved one's diagnosis because their world is upended and they are not sure what to expect next in their dementia caregiver journey. Health care providers can help caregivers navigate this uncertain part of their lives. If health care providers start to speak about disruption as a natural part of dementia caregiving, it can help caregivers open up about their experiences and normalize disruption within the caregiving journey. One way providers can begin to implement discussions about disruption is to implement a questionnaire that allows caregivers to reflexively think about their relationship before and after the dementia diagnosis through the lens of belonging. Relationships are severed but by looking through belonging, but it show how it changes. By framing dementia caregiver as a journey marked with a pervasive sense of disruption, it helps caregivers know what to expect and they will be less fearful during their caregiving journey.

### **Becoming an Insider**

The first question focuses on the communicative indicators of inclusion for dementia caregivers. Inclusion can be conceptualized as "being a part of something else (such as a

particular set or group)” (Haugh, 2005 p. 47). Within the notion of inclusion, the opposite is exclusion, which is built into the definition of inclusion.

Caregivers are attempting to be mindful about how they navigate their relationship with their loved one with dementia. The narratives highlight that caregivers do not simply view their relationship as a powerful person exercising power on a helpless person. Rather, they are mindful of a delicate balance that must be achieved because individuals living with dementia are people who have lived a full life with their ability to exert their own preferences. The illness does not change the past, and caregivers are using their past relationships to inform how they care for their loved one. Learning to walk the tightrope between autonomy and benevolence is what partially marks dementia caregivers from other types of caregivers, thereby including a set of caregivers while excluding other types of caregivers. This balance requires the caregiver to acquire a new skill set such as putting themselves in their loved one’s shoes. Dementia caregiving is characterized as a complicated relationship that highlights a tension between power and control (Dunham & Cannon, 2008). Specifically, the caregiver feels a sense of powerlessness when exercising power, and the caree both resists and as well as encourages care. For example, caregivers can feel uncomfortable helping to perform activities of daily living such as helping the caree get dressed. The caree needs this help but still wants to exert a certain amount of autonomy over their life. In this case, caregivers may try to walk this tightrope by allowing the caree to dress themselves but being close by in case they need help getting dressed. While they may not actively wrestle with these tensions, these tensions are evident in the narratives based on the fact that caregivers are attempting to not infantilize their loved ones.

By avoiding treating dementia patients as children, caregivers help to preserve the person’s place in world (Kitwood, 1997). Indirectly, it also helps caregivers maintain a sense of



belonging because it allows the caregiver to enact parts of their role pre-dementia diagnosis. The change from outsider to insider connects to inclusion because it demonstrates how someone can go from being an individual to being part of something larger than them self. On a practical level, this understanding from outsider to insider in terms of dementia caregivers can be used to better advise caregivers at the start of their caregiving journey. By enlightening individuals to the changes they may experience as they become dementia caregivers, it helps to make the process less frightening and stigmatized.

### **Martyrdom**

The results of this study help to illustrate a dark side of being a dementia caregiver. A caregiver who falls into a martyr category is someone who “believes that he or she is the only person who knows best how to care for the loved one” (FitzPatrick, 2016). Once an individual commits to being a dementia caregiver, it is easy for that one role to consume the caregiver’s life. Consequently, they start to feel excluded by other social groups that they used to interact with and they throw themselves into their caregiving duties even more. Eventually, caregivers feel they can only connect with other caregivers who are also martyr caregivers.

Martyrdom is a dark side of dementia caregiving because it illustrates that in a desire to belong to at least one group, caregivers are giving up other roles that make up their identity. Being a dementia caregiver is not a negative activity in itself. The positive aspect of being a caregiver is supporting a person in their time need. Dementia caregiving becomes negative when it starts to impact a caregiver’s quality of life. This negative aspect highlights a tension that emerges when caregiving is enacted. Dementia caregivers may think that they are the only individuals who can care for their loved one. This belief is connected to a sense of loss from other groups because a dementia caregiver’s new role separates them from others.

The practical implications of this finding are that by understanding this facet of caregiving, it is possible to warn early stage caregivers about this potential pitfall. By simultaneously recognizing a caregiver's connection to the caree as well as the loss of connection to others and how those are related to each other, it can help caregivers understand how they belong. Consequently, caregivers may be more cognizant to give themselves up towards the cause of caregiving to the point of reducing their quality of life.

While martyrdom recognizes loss, inclusion is present in other ways. Despite disruption, caregivers are able to enact inclusion in a variety of ways. The narratives reveal that inclusion is more difficult to achieve than meets the eye. Caregivers can enact inclusion through support groups, family members, and friends. Inclusion allows researchers to distill some of the complexities within belonging and allows them to look at relationships from a collective level.

### **Paradoxes**

The second research question focuses on the communicative indicators of distinction for dementia caregivers. Distinction is defined as knowledge of a group, meaning that how an individual stands out in a group gives an individual a feeling of belonging (Anthony et al., 2020). The opposite of distinction that is inherent within the definition is conformity, blending into a group. Paradoxes are one way in which caregivers were distinct in social settings. A paradox can be thought of as convergence of opposite types of behavior that appear to be mutually exclusive (MacQuarrie, 2005).

Paradoxes relate to the concept of distinction because it helps to show that distinction is a paradox. Distinction is about meaningfulness because it connects an individual to similar people but it also disconnects an individual at the same time. By framing distinction in terms of a paradox, it allows people to step back from either or thinking because these tensions exist in

tandem. On practical level, if health professionals are aware of these paradoxes, they are more aware of the importance of directing caregivers to appropriate information sources to navigate dementia caregiving, thereby reducing some of the naiveté about dementia caregiving.

In regards to the time paradox, caregivers are living in flux and in a sense walking on eggshells. They are trying to hold their world together in light of their caregiving responsibilities. This sentiment is echoed in African American dementia caregivers experiences because tension emerged between “hanging on” to their loved one but also recognizing that at some point they would have to let them go (Lindauer et al., 2016).

The relational understanding paradox can partially be explained by biological disruption. Biological disruption refers to sense of disconnect between an individual and their life course (Bury, 1982). As caregivers’ worlds are disrupted, their understanding of how they fit into the world in relation to their loved one is hard to place. On one hand, their loved one is physically the same, but personality-wise is a different person.

Finally, paradoxes connect to literature on caregiving. Dementia caregivers find there is no ideal mold for being the perfect caregiver. Consequently, caregivers are drawing on whatever resources they have available. However, since caregivers are not always are of the specialized resources available to them, the resources they do draw upon emphasize a nonexistent idealized notion of what a caregiver should be. This paradox is echoed in other dementia caregiver research. Boots et al (2015) finds that in early-stage dementia caregivers an early-stage needs paradox existed. Late-stage caregivers realize that they would have benefited from more tailored resources and guidance when they were dealing with the early stages of dementia. However, early-stage dementia caregivers are not aware of the resources they may need because they have not experienced caring for a person with dementia. In some way, the results about early-stage

dementia caregivers help to explain the paradox of caregiving. Caregivers are being judgmental to themselves because they are naïve about the realities of caregiving.

### **Avoiding Distinction**

Caregivers who avoid the dementia caregiver aspect of their identity want to avoid being distinct because they felt that it prevents them from being included in other social groups. In terms of caregivers' friends, caregivers avoid sharing their caregiving trials because they perceived their struggles as a burden to others. The Alzheimer's Association (2017) notes that half of all caregivers do not feel as though they could talk to anyone in work or social settings about their caregiving experiences. However, by avoiding conversations about caregiving among non-caregivers, dementia caregivers are worsening their own social isolation and crafting an unhealthy solution to dealing with the paradoxes listed in the study's findings. The lack of acknowledgement of one's caregiving duties relates to belonging because it demonstrates how individuals are willing to hide parts of their identity to fit into a social group. On a practical level, this finding helps to show that more work needs to be accomplished to destigmatize dementia and dementia caregiving.

### **Interaction between Inclusion and Distinction**

The third research question focuses on how communicative indicators of inclusion and distinction interact to create a sense of belonging for dementia caregivers. Belonging goes beyond simple membership to mean a sense of fitting into a group based on facets of one's identity and enacted connections to the group. The interaction between these two subcomponents helps to show that belonging is multi-faceted, meaning that belonging is affected by a variety of factors. The narratives highlight that for many caregivers, their experience of caring for someone with dementia are impacted by their inherited cultural narratives about

dementia. If the caregiver has a neutral narrative about dementia prior to the diagnosis (one based on the science and facts), then they are able to navigate the challenges of being a caregiver better including enacting belonging. If caregivers hold onto dementia narratives steeped in fear and stigma, then they have a tougher time creating a sense of belonging.

This study helps illuminate the usefulness of a belonging framework to understanding complex relationships. Prior research on belonging has applied this framework to groups such as illness support groups and volunteers (Iverson, 2013; Anthony et al., 2020). Dementia caregivers have complex relationships with others because their world is constantly changing, and they have to figure out to relate to individuals within this new reality. As a result, inclusion and distinction do not neatly line up to create a sense of belonging. For instance, inclusion can be present in a caregiver's relationship with a non-caregiver but not distinction. On the other hand, both subcomponents can be present but a caregiver does not feel a sense of belonging in a social situation. These subcomponents cannot be plugged in like variables in an equation to create belonging for caregivers. This research helps to expand the number of scenarios that can result when inclusion and distinction interact as well as increase researchers' understanding regarding the complexity of these subcomponents.

Finally, this study implies that belonging is a messy concept. Belonging is not a simple concept and neither are its subcomponents. Distinction is a subcomponent that contains many paradoxes and is a paradox itself. By applying the belonging framework to dementia caregivers, it allows researchers to see the complexity of belonging and its subcomponents. On a practical level, this finding demonstrates that belonging in this population and other populations should not be simplified.

## **Conclusion**

This study helped to achieve three outcomes for understanding belonging for dementia caregivers. First, it illuminates an expressed need for belonging and how to navigate it. Second, it goes beyond the general sense of social support towards a relational understanding. Third, it helps caregivers reflect on this need for belonging and help people close to them understand their need for belonging. Exploring the application of belonging to dementia caregiving extends health communication literature and has practical applications.

### **Theoretical Implications**

This study helps to provide a richer account of belonging in communication studies. One implication of this research is it highlights that belonging is not static but rather a dynamic, constantly negotiated concept. Additionally, the notion of identity comes up in terms of how caregivers belonged in different social situations, and it sets the stage for further understanding the relationship between belonging and identity when caregivers are aiding someone with a chronic illness.

Additionally, the findings help to move belonging beyond social support to understanding how relationships impact belonging. Dementia caregivers clearly benefit from feeling a sense of belonging. These findings help to show that caregivers are not powerless when constructing a sense of belonging. Caregivers enact their relationships, and they can enact relationships that allow them to be fully supported throughout their caregiving journey. Belonging is a useful framework for analyzing situations that arise within dementia care research.

Finally, the study helps to provide new avenues of research within the subcomponents of belonging. Individuals enact belonging in a social situation based on their specific set of circumstances. As a result, different paradoxes may result depending on the situation and circumstances. These paradoxes may be the difference between individuals being able to

construct a sense of belonging or not. Consequently, it highlights the need to look for paradoxes within belonging and to start to look for paradoxes of belonging in difficult situations.

### **Practical Applications**

The practical applications of this study are salient with the rise of dementia. More and more, dementia caregivers are not trained professionals but rather the loved ones of the individual diagnosed with dementia. To prevent this group of caregivers from becoming invisible patients, it is important to pay attention to them while they are on their caregiving journey.

The findings in the study can help clinicians better understand the struggles that dementia caregivers are experiencing and allow them to have the background to check in with them. Specifically, this dialogue between a clinician and a caregiver can start once the caregiver's loved one is diagnosed with dementia. Receiving a dementia diagnosis not only impacts the individual living with dementia but also those who care for the diagnosed individual. Clinicians need to make this reality clear to a potential caregiver and help a potential caregiver start to sort out their emotions regarding their new reality of being a dementia caregiver. This recommendation does not simply involve giving a caregiver a pamphlet on caregiving but by starting an ongoing conversation as the disease progresses in their loved one.

These findings can also be used better target caregivers during health promotion campaigns designed to improve their health or connect them to resources. Health care organizations need to understand that dementia caregivers are not a monolithic entity. A dementia caregiver does not fit a specific mold because dementia impacts the person with the diagnosis in unique ways. Consequently, when attempting to communicate with this population, organizations need to segment out this population and target messaging to each segment. For instance, adult children who become caregivers react differently to their caregiving responsibilities than spouses who become dementia caregivers. By sending out blanket

messaging that does not take into account differences in belonging, health care organizations risk further alienating this population.

The concepts of belonging can be a useful tool to help caregivers understanding how caregiving is impacting their lives in broader and more complex manner. Caregivers can start to reflexively interrogate their relationships to understand how they are changing as a result of their caregiving responsibilities. This type of reflexivity allows caregivers to take ownership of their caregiving journey rather than being simply being a passenger.

### **Limitations and Future Research**

The major limitation of this study boils down to the usage of published caregiver narratives. While this method allows for greater variety in caregivers' demographics and makes the most sense given the constraints on caregivers' time, it does create some limitations for this study. Consequently, since the narratives are a form of secondary data, I was not able to specifically ask the caregivers who shared their stories about belonging in different social situations since becoming a caregiver.

This study is able to shed light on belonging as a concept in communication studies and how this concept applies to dementia caregivers. In terms of future research into belonging, researchers could look at how this concept applies to other communities. Belonging or lack of belonging can impact different communities differently, so it is helpful to understand the degree of impact based on the type of community. In terms of dementia research, researchers can explore how caregivers differed in terms of belonging at different stages of caring for their loved one (i.e., early stage dementia vs. advanced stage dementia) to see if there are differences in terms of caregivers' belonging. Additionally, researchers can explore how belonging differs based on race and ethnicity for dementia caregivers. Minorities are at greater risk for dementia and many have different conceptualizations of dementia based on their specific culture which



may impact how caregivers understand themselves in relation to their loved one diagnosed with dementia.

Overall, a belonging framework helps dementia caregivers understand how their lives have changed post-dementia diagnosis. Dementia is a disease shrouded in stigma. Caregivers understand that their lives will change as a result of their loved one's diagnosis but they are unsure about the specific ways in which they will change. Belonging allows a way for caregivers to understand the specific ways their relationships with others will change. Dementia may be a foreign illness but caregivers have experienced a sense of belonging in their lives pre-dementia diagnosis. Belonging allows caregivers a tool in understand dementia's impacts on their lives and the ability to deconstruct some of the stigma surrounding the illness.

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