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CAREGIVERS OF PARENTS WITH ALZHEIMER'S DISEASE: QUALITY OF LIFE FOR CAREGIVERS: PERSPECTIVES & FAMILY DYNAMICS

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CAREGIVERS OF PARENTS WITH ALZHEIMER'S DISEASE: QUALITY OF LIFE FOR
CAREGIVERS: PERSPECTIVES & FAMILY DYNAMICS

THESIS

A thesis submitted in partial fulfillment of the
requirements for the degree of Master of Science in
Family Sciences in the College of Agriculture, Food
and Environment at the University of Kentucky

By

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ABSTRACT OF THESIS

Caregivers of Parents with Alzheimer's Disease: Quality of Life for Caregivers: Perspectives & Family Dynamics

This study furthers Alzheimer's family literature regarding the impact of caregiver attachment, readiness to provide care, and caregiver quality of life. A sample of 33 participants caring for a parent with Alzheimer's disease in the state of Kentucky was recruited to complete a questionnaire for the study. The questionnaire consisted of an online survey about participants' experiences and attachments growing up with their parents, their experiences becoming caregivers to their parents with Alzheimer's disease, and participants' current perspectives of their own quality of life. Positive perspectives in regards to quality of life among caregivers seem to be a predictor of both stronger readiness to care and stronger attachments. These findings inform therapists about the importance of recognizing a caregiver's presenting problems of burden and their significance to attachment and readiness to provide such care. This recognition may impact therapy to strengthen a caregiver's positive adaptation, thus it may also decrease burden.

KEYWORDS: Caregivers, General Functioning Attachment, Readiness, Quality of Life, Caregivers' Perspectives

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Chapter One: Introduction

Alzheimer's disease does more than take away an individual's cognition; it is a progressive and destructive disease that as a result also has deleterious effects on entire families (Werner, Mittelman, Goldstein, & Heinik, 2011). In the United States, approximately 5.8 million individuals live with Alzheimer's disease and this number is expected to rise to 14 million by the year 2050 (Alzheimer's Association, 2019). Memory loss is a key symptom of the disease, but eventually, people living with Alzheimer's disease will experience increased trouble with thinking and reasoning, decision-making, and performing familiar tasks. Changes in the brain will also affect mood, behavior and personality. They will become increasingly dependent on caregivers, who are most often family members. It is not uncommon for caregiving families to lose their sense of stability (Alzheimer's Association, 2019). Many family members can even experience grieving a loss similar to the death of a loved one (Sanders et al., 2008). Caring for someone with the disease may be emotional and overwhelming, especially as the disease progresses and more care and supervision is required.

Of the 16+ million Alzheimer's caregivers, over 50% are adult children who act as primary caregivers for their parents (Alzheimer's Association, 2019). More specifically, most support comes from middle age females (Ruiz-Adame Reina et al., 2017). Alzheimer's caregivers spend approximately 18.5 billion hours providing unpaid care (Alzheimer's Association, 2019).

On average, a person with Alzheimer's disease lives four to eight years after diagnosis but some people have lived as long as 20 years. The disease progresses slowly across three general stages- early (mild), middle (moderate), and late (severe) stage (Alzheimer's Association, 2019). The specific trajectory of the disease is unique to each person diagnosed

but stages health care professionals and caregivers know what to expect. In the early stage of the disease, a person with Alzheimer's may maintain high amounts of independence but forget trivial things, such as where they placed their car keys. Family members may start to notice increasing memory lapses, trouble with recalling words and names, and increasing challenges with planning and organizing. Aside from occasional reminders and minor support, family members, in general, will likely have minor demands as it relates to caregiving in the early stages. In the middle stage, symptoms are more pronounced and more likely to negatively affect independence. In the middle stage, a person with Alzheimer's has increasing trouble remembering and performing routine tasks. They are more likely to wander or feel confused about time and place. They may even forget their own personal history. Some individuals will struggle with bladder and bowel control, have trouble sleeping, and/or experience major personality and behavior changes, such as becoming suspicious, delusional or compulsive (Alzheimer's Association, 2019). The middle stage typically lasts the longest and will require increasing care and supervision. As a result, dementia caregivers are at increasing risk for burden and burnout (Hiyoshi-Taniguchi, Becker, & Kinoshita, 2018). In the late stage of Alzheimer's disease, symptoms are severe and full-time care is needed with personal care and activities of daily living. In the late stages, a person with Alzheimer's disease will have trouble communicating, walking, sitting and even swallowing. Unable to respond to their environment or even control their own movements, they become vulnerable to infections such as pneumonia (Alzheimer's Association, 2019).

As the disease progresses, family caregivers are the most vulnerable during the middle and late stage of the disease. They also experience the greatest instability to their lives during the middle and late stage as physical and emotional care demands increase, round-the-clock

care is required, high financial costs are paid, and basic communication with their loved one is challenged. The externalized symptoms of Alzheimer's disease-- aggression, anxiety, and depression, correlate with reported instability experienced by dementia caregivers (Huang et al., 2012).

With the number of Alzheimer's diagnoses on the rise (Alzheimer's Association, 2019), increasing numbers of family caregivers are needed to provide care (Cooper et al., 2008). Yet with few caregiver preparation programs or training, family members may be both unprepared for and unaware of the road ahead and the negative effect it may have on the family (Sepe-Monti et al., 2016). Therefore, it is imperative to further examine the correlation of a family member with Alzheimer's and the stability/health of the family system (Sanders et al., 2008).

This study aims to better understand a dementia caregiver's life quality as it relates to their attachment to their family member with Alzheimer's disease and their confidence in their readiness to provide dementia care. These same caregivers often have families of their own (Brodarick, 2015), making it even more emotionally, physically, and financially challenging to juggle dementia care demands with their partner, dependent children, and career.

For the purpose of this study, the following definitions are important to note. *The family members with Alzheimer's* are defined as adults who have been diagnosed with Alzheimer's disease by a doctor. For this study, the family member with Alzheimer's must have been diagnosed with the disease for at least six months ago and either live at home, a long-term care facility, or with a family caregiver. A *caregiver* is a family member who is not paid to look after his/her relative with Alzheimer's disease. A *caregiver's perspective* is the caregiver's personal belief directed towards a certain emotion, behavior, or situation as it

relates to caregiving. *Attachment* is defined as the bond that is built based upon an individual's trust in safety, security, and protection with another.

Literature Review

Alzheimer's disease is the most common form of dementia. It gradually takes away a person's ability to have standard cognitive functioning (Hamill, 2012). On average, a person lives with Alzheimer's Disease four to eight years, but can live as long as twenty years after diagnosis (Alzheimer's Association, 2019). The Alzheimer's Association (2019) categorizes the progression of the disease into early, middle, and late stages. Caregiving demands increase with each stage. In the early stages, individuals diagnosed with Alzheimer's are still fairly independent. They may struggle to use the correct word, recall a new name, and perform new tasks. It is also not uncommon for someone in the early stages to lose valuable objects and have challenges with organization (Sperling et al., 2011; Stages of Alzheimer's, 2019). The middle stage, lasting approximately two to ten years, is the longest stage and requires increasing levels of care as the individual begins to show more noticeable signs of and struggles with the disease (Dassa & Amir, 2014). These symptoms include forgetting one's own personal history, changes in emotion/behavior patterns, confusion about location/date, and an increase chance of wandering (Sperling et al., 2011; Stages of Alzheimer's, 2019). Toward the end of this stage, it is not uncommon for individuals to need help with most activities of daily living, such as eating, walking, and using the bathroom (Alzheimer's Association, 2019). As symptoms become more pronounced, it is not uncommon for the family member with Alzheimer's to fall into a state of depression until the later stages when the sense of perception is lost (Orgeta et al., 2017). In the final stage of this disease, dementia symptoms are severe. Individuals lose the ability to respond to their environment, to carry on a

conversation and, eventually, to control movement. They may still say words or phrases, but communicating pain becomes difficult. As memory and cognitive skills worsen, significant personality changes may take place and individuals may need extensive nursing care (Sperling et al., 2011; Stages of Alzheimer, 2019).

Upon an Alzheimer's disease diagnosis, it is important for families to be realistic about the road ahead as the progressive and devastating nature of the disease will eventually require consistent and fulltime care (Liu et al., 2017). Because the disease negatively affects memory, it is significantly helpful for family members to be a part of caregiving because it might delay some of the negative effects (Norton et al., 2009). For example, research suggests that family members with Alzheimer's disease have increased memory function and positive emotions when interacting at familiar gatherings (Feinstein, Duff, & Tranel, 2010). One possible explanation could be that family members are more recognizable and trustworthy to those with this disease. This is important information for caregivers, because not only can meaningful social interactions delay disease progression, it can consequently, delay a higher demand of care.

Attachment

John Bowlby and Mary Ainsworth's attachment theory suggests that human beings require intimate human relationships throughout the life cycle. An individual's first attachment is with their parents in infancy (Bowlby, 1969). This attachment is established through infant survival based on parental ability to care. For example, a mother who nurses her child is more likely to form an emotional bond with her child, which will shape positive attachment (Bowlby, 1969). Ainsworth's (1978) demonstrates ways in which attachment quality is continuously changing depending on the personalities of the individuals through life. For

example, there are several attachment styles in the parent-child relationship: Secure, avoidant, ambivalent, and disorganized (Kerns, Brumariu, & Seibert, 2011). Avoidant attachment occurs when children learn to separate themselves from having many feelings towards others.

Ambivalent attachment occurs when children experience separation anxiety and are unable to be soothed when the parents return. Disorganized attachment occurs when children appear confused when needing to be soothed because they feel neglected by their parents. Lastly, secure attachment is when children feel safe even when their parents leave an environment for a certain period of time because they know they will return (Kerns, Brumariu, & Seibert, 2011). As a result of a secure attachment style, individuals are more likely to have a positive sense of security with their parents, self-soothe, seek out a social support, and sustain cognitive organizational functioning (Bernier, Beauchamp, Carlson, & Lalonde, 2015; Oldfield, Humphrey, & Hebron, 2016; Ensink, Normandin, & Plamondon, 2016). Research indicates that the attachment styles established in early childhood are likely to continue into adulthood (Duncan & Magnuson, 2011).

The ideal form of attachment--secure attachment, contributes to a family's stability to function as a healthy system. This is referred to as general functioning attachment (Boterhoven de Han et al., 2015). General functioning attachment is an important lens through which to study adult caregivers. For example, research demonstrates that the strength of attachment between a parent and adult child before a dementia diagnosis is a key factor in determining relationship strength later into the disease (Fauth et al., 2012). Evidence suggests that when the parent-adult child bond is secure before a dementia diagnosis, the attachment may be more resistant to the stressors associated with dementia caregiving (Fauth et al., 2012). As a result,

it is more likely that a dementia caregiver with a general functioning attachment style can maintain family functioning and stability within their personal lives.

In Alzheimer's disease, changes in personality and behavior are associated with disease progression. As a result, the caregiver's attachment to his/her parent may evolve. For example, imagine a middle age daughter, taking care of her 80-year-old mother with Alzheimer's disease. In the beginning, the two women shared Sunday afternoon mother-daughter time. But as the disease progressed, the daughter believed that her mother would not remember the event by the time they would get home. Furthermore, the daughter struggled to find the increasing time it took to take her mother out and she also felt financial strain. In this story, one may sense the daughter's sense of loss, sadness, or possibly even a sense of disconnection to her mother. In dementia caregiving, it is not uncommon for caregivers to feel increasingly emotionally disconnected from the family member with Alzheimer's, which can change the bond from a secure attachment into an anxious attachment style (Nelis, Clare, & Whitaker, 2014).

Fluctuating attachment styles is not an uncommon scenario amongst aging families and in particular dementia caregivers (Wang et al., 2019). Data from past studies provide evidence that caregivers' attachment styles are correlated to feelings of obligation to the loved one with Alzheimer's as a drive for caregiving (Lee et al., 2018). Most of the research involving caregiver attachment analyzes it through the lens of caregiver burden and obligation.

As Alzheimer's disease progresses, it is not uncommon for all family member's emotions and attachment styles to shift (Ebel, 2013). At the start of diagnosis, most family members do not know how to respond to this new trauma or how to support the family member with Alzheimer's (Del Carmen Perez-Funtes, Linares, Fernandez, & del Mar Molero

Jurado, 2017). Eventually, the family observes the errors in functioning and attempts to remind the family member with Alzheimer's how to perform these functions or performs the functions for him or her. This is when anger directed toward the family caregivers is most likely to arise (Wilks, Little, Gough, & Spurlock, 2011). Research states that these emotional backlashes are not meant to push the family caregivers away, but rather are an attempt for the person with Alzheimer's disease to maintain independence (Wilks, Little, Gough, & Spurlock, 2011). As the disease progresses, a caregiver may be appointed to have legal authority over the family member with Alzheimer's. This caregiver is most commonly a close member such as a spouse or adult child (Richardson, Lee, Berg-Weger, & Grossberg, 2013). This caregiver's close connection adds another significant burden to the caregiver through him or her having to adjust his or her attachment to the family member with Alzheimer's and maintain other relationships as well. When the family member with Alzheimer's loses the ability to safely live alone the caregiver might decide to enroll in adult daycare services, involve more family members, or send the family member with Alzheimer's to a care facility. Some families will make arrangements for the person with Alzheimer's disease to live with them (Sansoni, Anderson, Varona, & Varela, 2013).

A systematic review explored how general function attachment styles impact both parent-child attachment and mental health (Nelis, Clare, & Whitaker, 2014). For example, an adult child caregiver's degree of attachment to his or her parent is correlated to their feelings of psychological distress. Distress can be a sign of burden. Dementia caregivers' burden can be related to providing proper care, financial implications, job strain, physical exhaustion, and mental exhaustion (Pinquart & Sörensen, 2011). Current research supports that adult children caregivers who experience anxious or avoidant attachment styles are more likely to experience

poor mental health (Monin, Feeney, & Schulz, 2018). Empirical evidence also suggests that strong parent-child attachments within families lead to positive outcomes, even in times of distress (Wray-Lake, et.al, 2012). Dementia caregivers have the demand of performing complex tasks around 20 hours per week (Shi, Chan, Ferretti, & McCallion, 2018). Strong attachments can foster much-needed resiliency for family caregivers throughout the stages of Alzheimer's. However, even if these caregivers have secure attachments to their parent with Alzheimer's it has been reported as a strenuous duty (Richardson, Lee, Berg-Weger, & Grossberg, 2013).

Family Systems Theory

General functioning attachment is especially important in Alzheimer's families as the disease does not only affect the person who has been diagnosed or the primary caregiver; it impacts an entire family. Bowen's family systems theory reinforces this process. Family systems theory conceptualizes families as an emotional unit and uses systemic thinking to explain interactions within the family unit (The Bowen Center for the Study of the Family, 2019). This theory explains how the effects of events can be felt as a chain reaction through the family unit. Past research provided empirical evidence to suggest that treatment with Alzheimer's families should emphasize the family as a whole versus just the family member living with the disease (Bonder, 1987). However, there is still value in determining the emotional process of the family system when providing care for a family member with Alzheimer's disease. Caregivers can experience a spectrum of emotions throughout the process of caring, and these emotions may have a negative impact on family members.

For example, when family members first learn that a loved one has been diagnosed with Alzheimer's it is not uncommon for a grief cycle to be triggered, which can continue

throughout the disease trajectory/caregiving journey (Large & Slinger, 2015). Families and caregivers make personal sacrifices to adhere to the increasing needs of their loved one. Research demonstrates that such sacrifice is often encouraged by a sense of duty or obligation (Epps, 2014). Also, as the demand for care increases, individual caregivers are more susceptible to spending less time in their communities and more time providing care, which can lead to a higher sense of burden (Scott et al., 2018). Continuous dementia care puts a caregiver's physical health at risk (Richardson, Lee, Berg-Weger, & Grossberg, 2013). Dementia caregivers are more likely than their non-caregiving counterparts to develop depression, higher levels of anxiety, and lower overall well-being (Scott et al., 2018). As a result, the family system as a whole now has to divide attention between the family member with Alzheimer's and the caregiver who now has health risks of his or her own. Taking care of a loved one with Alzheimer's not only takes a family system's time and energy, but there is also a significant financial cost. These extra demands contribute to caregivers' sense of burden. Research suggests that caregivers using the assistance of long-term care facilities report lower levels of burden compared to caregivers who use care for family members with Alzheimer's disease at home (Verbeek et al., 2010). Perhaps these caregivers report lower levels of burden due to extra care support and safety.

Throughout the stages of Alzheimer's it is common for each member of the family to experience a sense of grief (Sanders, Ott, Kelber, & Noonan, 2008). Grief is processed through five different stages: denial, anger, bargaining, depression, and acceptance (Halasyamani & Tolman, 2018). An example for Alzheimer's families can be when they receive the news that their family member has been diagnosed with Alzheimer's disease. They might reject the diagnosis because "it could never happen to them." The news can manifest to anger and be

expressed to others not involved or at fault. There may be attempts to bargain with their higher power to stop this event in exchange for something. Then follows the loss felt fully in the present, the caregiver experiences the pain and loses motivation for daily routines that leads to depression. This process concludes with fully accepting the event and the family will adjust themselves to life following the event. However, dementia families can process through grief multiple times throughout the stages caring for their family member with the disease (Sanders, Ott, Kelber, & Noonan, 2008).

Caregiver Readiness

Caregiver readiness is defined as the family member's sense of ability and knowledge to care for his or her family member with Alzheimer's. Whether or not one or more family member(s) is ready to care for the family member with Alzheimer's may impact the family system as a whole. There is a lack of psychoeducation resources to help current dementia caregivers; this can have an impact on the caregiver's sense of preparedness (Martin-Carrasco et al., 2009). Thus it has an impact on the readiness of the entire family system. The area of caregiver readiness is incorporated to increase the preparedness of providing physical care and managing the stressors associated with caregiving. A caregiver's readiness also has associations to social factors (Dias et al., 2015). Dias' et al. (2015) systematic review determined that dementia caregivers have stronger resilience when they have close attachments to their family unit, including the member with Alzheimer's. There is a known correlation between secure attachment style and high strength of resilience (Karreman & Vingerhoets, 2012). Research demonstrates that having an intervention program for caregivers lowers their level of morbidity (Cristancho-Lacroix, Wrobel, Cantegreil-Kallen, Dub, Rouquette, & Rigaud, 2015).

The readiness of a caregiver to look after his or her family member with Alzheimer's is a key factor in determining the strength of the caregiver's health (Richardson et al., 2013). Over time, caregiver readiness programs have improved their intervention techniques with positive outcomes for the caregiver and the whole family. Certain programs may include strategies focusing on areas such as family system support, support within one's spirituality, and internal coping strategies. Internal coping strategies involve techniques for problem solving, reframing the problem(s), and learning to accept the challenges of caregiving (Pratt, Schmall, Wright, & Cleland, 1985). However, research has not yet determined how these positive outcomes are affecting other areas of the caregiver's life.

Potential protective factors that could prevent loss of health are the caregivers' readiness to give care, the caregivers' resiliency, and the view of their quality of life (Richardson et al., 2013). Programs engaging the family unit are showing positive results for caregiver readiness. Perhaps this is effective through the caregiver's secure attachment with his/her family. However, there is currently no research looking at a correlation between these factors and the effect in the caregiver's quality of life.

Caregiver's Perspective

Dementia caregivers' perspectives can range positively and negatively on the spectrum. Caring for someone with Alzheimer's is often viewed as a burden (Peacock et al., 2010). However, some caregivers can view this experience as a way to give back or to become closer with the family member with Alzheimer's (Peacock et al., 2010). Therefore, the perspectives that each individual caregiver has may be important for how the family system as a whole views the experience of caring for a family member with Alzheimer's. This perspective may be formed based on the caregivers' attachments to their families and their readiness to provide

appropriate care. For example, a family system with secure attachments may hold a positive perspective on caregiving, thus creating high resilience (Karreman & Vingerhoets, 2012). This caregiver's resilience may also be correlated to their readiness to provide care.

Studies involving the caregivers' thoughts are directed towards the family members with Alzheimer's future. This appeared to be correlated to high levels of anxiety and concern (Yikilkan, Aypak, & Gorpelioglu, 2014). Research has abundant data on the negative perspectives of caregiver health; there is opportunity for more collection related to caregivers' positive perspectives and if they affect the caregiver's quality of life. Past studies analyzing caregivers' positive perspectives determined dementia caregivers believe the experience has brought them improved caregiving skills, patience, a sense of purpose, a positive sentiment override, and gratification (Cheng et al., 2015). The current study has initiated the progress of future research relating to this topic to determine if an attachment and strong readiness may correlate to positive perspectives.

Purpose

Current research shows there is empirical evidence to support the claim that caregivers' perspectives and attachments will be negatively affected by taking care of the family member with Alzheimer's (Ude, 2016). Also, there is empirical evidence that a caregiver's readiness to provide care to the family member with Alzheimer's may have an impact on his or her perspectives and attachments. This study is unique to previous research due to the analysis of determining if a correlation exists between a caregiver's attachment and their readiness to be a caregiver. The researcher of the current study has examined the kind of role attachment and caregiver readiness has on a caregiver's perspective towards caregiver life quality.

Research Questions

Most current research on Alzheimer's family dynamics describe stress or depression levels of the family system, but do not address the relationship between the adult caregiver and the family member with Alzheimer's. Furthermore, the research does not show how this situation can foster a positive environment for the family system. Questions will be asked to the caregivers that will attempt to fill in these research gaps. The primary research question is associated with the impact of caregiving for a family member with Alzheimer's disease on family dynamics. Specifically, how do caregivers' and their families set boundaries, create a sense of closeness, and determine the strength of these relationships pre and post diagnosis of the disease? Furthermore, how does a caregiver's sense of readiness and their perceptions of the family member with Alzheimer's affect the caregiver's quality of life? The present investigation assessed the correlation between caregivers' life quality, attachments to family, and their readiness to provide care to their family member with Alzheimer's disease.

H1: caregivers with positive perspectives will be more prepared to care for their family member with Alzheimer's disease and have stronger attachments than caregivers with negative perspectives.

H2: there is a correlation between perspectives of life quality and readiness.

H3: there is a correlation between perspectives of life quality and attachment.

Chapter Two: Methods

Sampling

A sample of adult-children caregivers completed an online survey through Qualtrics. Participants were recruited with connections through the University of Kentucky Sanders-Brown Center on Aging, the Greater Kentucky and Southern Indiana Chapter of the

Alzheimer's Association in Lexington, Dementia Care Specialist, Marie Smart, LSW, and through IRB approved flyers posted in public areas across Lexington, Kentucky.

Participants were made aware that by participating in the study, there would be a drawing of one \$50 check for every 100 people who complete the survey. Therefore, caregivers were made aware that they have a 1 in 100 chance of winning \$50. The reason for using lottery incentives was due to the finding that lottery incentives are successful at increasing participant response rates on surveys (Laguilles, Williams, & Sanders, 2011). To randomize the selection of the \$50 check recipients, each caregiver was assigned a number and then Microsoft Excel was used to generate random numbers, which corresponded to the winning participant.

Participants

The first section of the survey contained demographic based questions, such as age of caregiver, age of the family member with Alzheimer's, biological sex of the caregiver, biological sex of the family member with Alzheimer's, household's estimated annual income before tax, race, number of years caregiving, and the family member with Alzheimer's current place of residence (See Appendix B). These questions were asked to ensure that participants taking this survey were qualified to be a part of this study. Also it was used as additional evidence related to participants' answers to further survey questions.

Inclusion criteria required participants to: (a) an adult child caregiver for a parent with Alzheimer's disease for at least six months; and (b) at least 18 years or older. Thirty-three participants completed the survey, thirty-five total that consented. Caregivers' identified as white females (88.2%). This includes both the caregivers (ages 26-72 years old) and the family members with Alzheimer's disease (ages 53-95 years old). Of the participants, 63.6%

identified as the primary caregiver. Parents with Alzheimer's either lived at home alone (12.1%), at home (30.3%), an assisted living facility (27.2%), or living with them (30.3%). Caregiver socioeconomic statuses (SES) ranged from making under \$25,000 (9.4%), \$25,000-\$34,999 (12.5%), \$35,000-\$49,999 (6.3%), \$50,000-\$74,999 (28.1%), \$75,000-\$100,000 (15.6%), and over \$100,000 (28.1%) per year. Caregivers either had at least one child living at home (36.4%) or did not have any children living at home (63.6%) while they cared for their family member with Alzheimer's. Caregivers' reported their family members with Alzheimer's were living in an array of environments: at home with someone (30.3%), at home alone (12.1%), at a caregiver's home (30.3%), or an assisted living facility (27.3%).

Procedure

Research procedures followed a protocol that was approved by the University of Kentucky's Institutional Review Board. The survey was given online using Qualtrics. The survey began with an informed consent page (see Appendix A). Participants were asked to complete all parts of the survey, but were informed that they could stop the survey anytime they desired, as the survey was voluntary.

Measures

Caregiver's Perspectives. Participants completed the 28-item Caregiver Quality of Life Index-Cancer (CQOLC), which was originally given to participants providing care for family members with different forms of cancer (Duan et al., 2015). However, the questions addressed important subjects related to Alzheimer's caregivers too. In this study, the participants that took this survey were the caregivers of family members with Alzheimer's disease and the questions were revised to address Alzheimer's rather than cancer. This measurement is in place to answer what the caregiver's current perspectives are in relation to

tasks and their relationships (see Appendix D: CQOLC). The CQOLC responses are scored from 0 (not at all) to 4 (very much). Three subscales were used with empirical evidence to support them: Burden, disruptiveness, and positive adaptation. An example of an item that will be included is, “It bothers me that my priorities have changed” Lafaye (2013) and his colleagues reported Cronbach’s alpha coefficients 0.89, 0.83, and 0.73, with a total score of 0.90 for the CQOLC.

Attachment. Attachments were measured through use of the McMaster Family Assessment Device (FAD; Georgiades, Boyle, Jenkins, Sanford, & Lipman, 2008) (see Appendix C). The FAD is a questionnaire designed to assess whole family functioning. In this study, the FAD was used to understand caregiver attachments to family members growing up in their childhood. These items are on a 4-point Likert scale and contain 31 statements. For this study, the researcher used the subscales general functioning, communication, roles, and problem solving. Examples of the items include, “We made sure members met their family responsibilities” and “Making decisions is a problem for our family.” This survey’s internal consistency has a reported Cronbach’s alpha coefficient of 0.85 (Georgiades, Boyle, Jenkins, Sanford, & Lipman, 2008). The purpose of using this questionnaire was to receive a retrospective viewpoint of caregiver’s attachment patterns from their family-of-origin that may present themselves currently while caregiving and the caregiver’s life quality.

Readiness. The Preparedness for Caregiving Scale (PCS) assessed the caregivers’ readiness to take care of the family member with Alzheimer’s disease (Henriksson, Andershed, Benzein, & Arestedt, 2012) (see Appendix E). Hudson and Hayman-White’s (2006) account that the PCS has a moderate to high internal consistency with Cronbach’s alpha coefficients ranging from 0.86 to 0.92. This survey contains 8 items on a 5-point Likert scale with

preparedness ranging from “not at all prepared (0)” to “very well prepared (4).” Examples of the questions included, “How well prepared do you think you are to take care of your family member’s physical needs?” and “Overall, how well prepared do you think you are to care for your family member?”

Chapter Three: Results

The data collected highlighted the dementia caregiver trials as well as their success stories. While specific demographics and stories varied, the overall theme was the same: the caregivers’ family attachment styles and readiness to care shaped their perspectives.

The first hypothesis of the study was that there would be a positive correlation between readiness to provide care and strength of the caregiver’s attachment. The second hypothesis was that there would be a correlation between perspectives of life quality and readiness. The third hypothesis was that there would be a correlation between perspectives of life quality and attachment. All data was analyzed using SPSS and put into a Pearson Correlation table (see Table 1).

Table 1.
Correlations between CQOLC, PCS, and FAD

	CQOLC Burden	CQOLC Disruptiveness	CQOLC Pos. Adaptation	CQOLC Total	PCS Total	FAD Prob. Solving	FAD Communication	FAD Roles	FAD General Functioning
CQOLC Burden	—								
CQOLC Disruptiveness	.618**	—							
CQOLC Pos. Adaptation	-.732**	-.609**	—						
CQOLC Total	.880**	.845**	-.628**	—					
PCS Total	-.343*	-.144	.533**	-.335	—				
FAD Prob. Solving	.024	.048	-.011	.013	-.092	—			
FAD Communication	-.193	.056	-.025	-.239	.179	.698*	—		
FAD Role	-.186	-.002	-.058	-.236	-.217	.574*	.576*	—	
FAD General Functioning	-.116	.121	-.004	-.121	.366*	.621*	.709*	.491**	—

** . Correlation is significant at the 0.01 level (1-tailed).

* . Correlation is significant at the 0.05 level (1-tailed).

The first hypothesis was measured using a bivariate Pearson Correlation test.

Readiness to provide care was represented by the PCS total. The test searched for correlations between the PCS total and the four subscales of the FAD. The four subscales representing the FAD were roles, general functioning, problem solving, and communication.

There was not a significant correlation between PCS total and FAD roles, $r = -.243$, $p = .242$, $n = 25$. Second, there was not a significant correlation between PCS total and FAD problem solving, $r = -.111$, $p = .607$, $n = 24$. Also, there was not a significant correlation between PCS total and FAD communication, $r = .173$, $p = .409$, $n = 25$. However, there was a significant correlation between PCS total and FAD general functioning, $r = .413$, $p = .036$, $n =$

26. This shows that as caregivers' perceptions of readiness increased, their attachment with general functioning also increased.

The second hypothesis was measured using a bivariate Pearson Correlation test. Perceptions of life were represented by CQOLC within three subscales. The CQOLC subscales used were burden, disruptiveness, and positive adaptation. Readiness was represented by PCS total. The test searched for correlations between the three subscales of CQOLC and PCS total.

There was not a significant correlation between CQOLC disruptiveness and PCS total, $r = -.140$, $p = .505$, $n = 25$. Although, there was a significant correlation between CQOLC positive adaptation and PCS total, $r = .534$, $p = .006$, $n = 25$. This can be seen as a positive correlation in which caregivers adapted more optimistically in addition to having a stronger sense of readiness. There was a slightly significant correlation between CQOLC burden and PCS total, $r = -.340$, $p = .096$, $n = 25$. This negative correlation can be interpreted as when caregivers' perceived burden increased, then their sense of readiness to provide care decreased. In other words, when a sense of readiness increased then caregivers' burden decreased.

The third hypothesis was measured using a bivariate Pearson Correlation test. Perspectives of life were represented by CQOLC within three subscales. The CQOLC subscales used were burden, disruptiveness, and positive adaptation. The FAD subscales represented attachment. The four subscales used from the FAD were roles, general functioning, problem solving, and communication. In all subscale combinations there were not any significant correlations between FAD subscales and CQOLC subscales, $p > .17$.

Table 2.
Results of Demographics Information

Question	A	B	C	D	E	F	G	H
1	Youngest: age 26			Average: age 54				Oldest: age 72
2	5.71%	94.29%						
3	12.12%	87.88%						
4	Youngest: age 53			Average: age 80				Oldest: age 95
5	9.38%	12.5%	6.25%	28.13%	15.63%	28.13%		
6	0%	0%	3.03%	96.97%	0%	0%	0%	0%
7	12.12%	30.30%	27.27%	30.30%				
8	63.64%	36.36%						
9	36.36%	63.64%						
10	0%	39.39%	24.24%	21.21%	9.09%	6.06%		
11	12.5%	34.38%	21.88%	12.5%	6.25%	12.5%		
12	3.23%	38.71%	12.9%	16.13%	12.9%	16.13%		

Table 3.
Results of FAD

Questions	Strongly Agree	Agree	Disagree	Strongly Disagree
1	23.33%	53.33%	23.33%	0%
2	3.33%	50%	30%	16.67%
3	10.34%	44.83%	34.48%	10.34%
4	13.79%	51.72%	24.14%	10.34%
5	0%	64.29%	28.57%	7.14%
6	13.79%	58.62%	24.14%	3.45%
7	6.9%	27.59%	62.07%	3.45%
8	7.14%	53.57%	32.14%	7.14%
9	3.45%	62.07%	31.03%	3.45%
10	3.57%	32.14%	60.71%	3.57%
11	7.14%	57.14%	32.14%	3.57%
12	0%	28.57%	67.86%	3.57%
13	3.45%	82.76%	13.79%	0%
14	10.34%	17.24%	65.52%	6.9%
15	6.9%	20.69%	48.28%	24.14%
16	3.45%	20.69%	68.97%	6.9%
17	13.79%	51.72%	27.59%	6.9%
18	6.9%	20.69%	72.41%	0%
19	6.9%	17.24%	75.86%	0%
20	0%	20.69%	58.62%	20.69%
21	37.93%	51.72%	6.9%	3.45%
22	3.57%	17.86%	67.86%	10.71%
23	17.86%	57.14%	17.86%	7.14%
24	7.14%	28.57%	46.43%	17.86%
25	17.86%	53.57%	25%	3.57%
26	7.14%	21.43%	46.43%	25%
27	17.86%	53.57%	25%	3.57%
28	3.57%	10.71%	64.29%	21.43%
29	10.71%	64.29%	25%	0%
30	7.14%	17.86%	42.86%	32.14%
31	21.43%	53.57%	17.86%	7.14%

Table 4.
Results of CQOLC

Questions	Not at all	A little bit	Somewhat	Quite a bit	Very much
1	17.24%	24.14%	41.38%	13.79%	3.45%
2	21.43%	21.43%	17.86%	21.43%	17.86%
3	10.71%	21.43%	17.86%	28.57%	21.43%
4	10.71%	32.14%	7.14%	25%	25%
5	21.43%	32.14%	14.29%	14.29%	17.86%
6	26.67%	36.67%	20%	10%	6.67%
7	40.74%	11.11%	37.04%	11.11%	0%
8	50%	21.43%	14.29%	14.29%	0%
9	0%	14.29%	25%	28.57%	32.14%
10	7.14%	39.29%	32.14%	7.14%	14.29%
11	14.29%	28.57%	25%	10.71%	21.43%
12	3.57%	25%	21.43%	25%	25%
13	20%	23.33%	33.33%	16.67%	6.67%
14	7.14%	28.57%	21.43%	14.29%	28.57%
15	7.14%	28.57%	21.43%	14.29%	28.57%
16	25.93%	22.22%	18.52%	14.81%	18.52%
17	25%	10.71%	10.71%	35.71%	17.86%
18	7.14%	14.29%	35.71%	35.71%	7.14%
19	17.86%	7.14%	14.29%	42.86%	17.86%
20	50%	17.86%	14.29%	14.29%	3.57%
21	10.71%	39.29%	28.57%	7.14%	14.29%
22	14.81%	18.52%	40.74%	18.52%	7.41%
23	14.29%	57.14%	17.86%	3.57%	7.14%
24	57.14%	10.71%	14.29%	14.29%	3.57%
25	0%	0%	14.29%	25%	60.71%
26	25%	25%	17.86%	10.71%	21.43%
27	33.33%	22.22%	25.93%	14.81%	3.7%
28	10.71%	25%	7.14%	28.57%	28.57%

Table 5.
Results of PCS

Questions	Not at all prepared	Not too well prepared	Somewhat well prepared	Pretty well prepared	Very well prepared
1	0%	17.86%	42.86%	21.43%	17.86%
2	0%	35.71%	17.86%	32.14%	14.29%
3	0%	22.22%	33.33%	33.33%	11.11%
4	10.71%	25%	46.43%	17.86%	0%
5	7.14%	28.57%	39.29%	21.43%	3.57%
6	7.14%	25%	14.29%	39.29%	14.29%
7	7.14%	17.86%	28.57%	35.71%	10.71%
8	0%	14.29%	46.43%	21.43%	17.86%

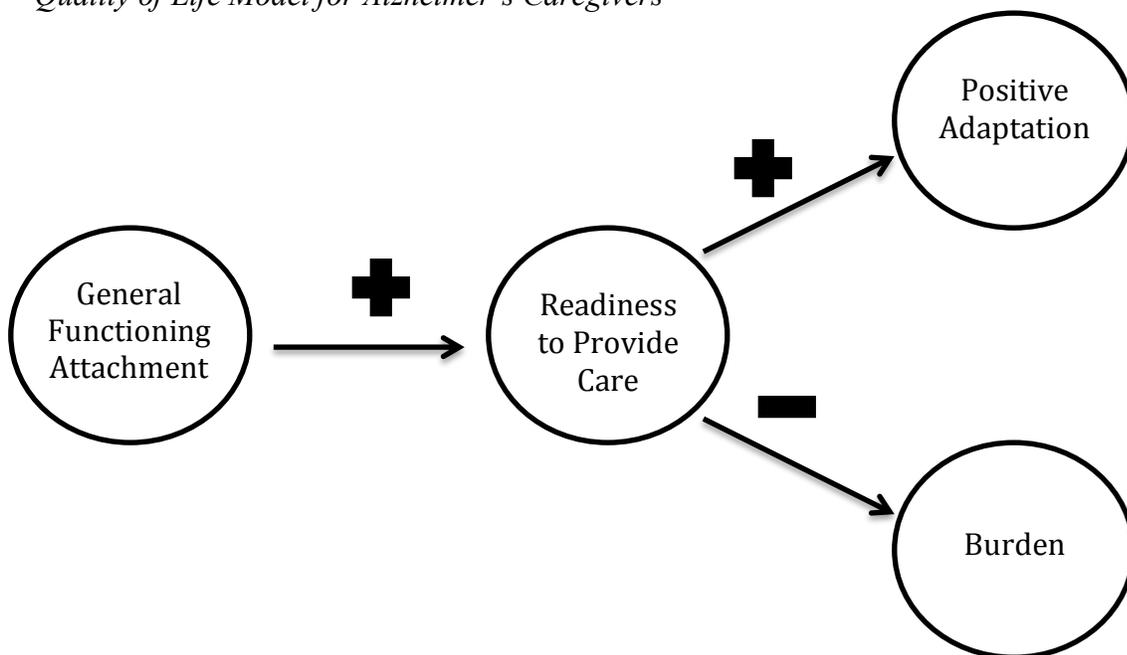
Chapter Four: Discussion

The results support two out of the three original hypotheses. This includes support that caregivers with positive perspectives will be more prepared to care for their family member with Alzheimer's disease and have stronger attachments than caregivers with negative perspectives. It also includes support for a significant correlation between perspectives of life and readiness. However, the third hypothesis is not supported because there is no significant correlation between perspectives of life quality and attachment.

The first hypothesis of the study stated that there would be a positive correlation between readiness to provide care and strength of the caregiver's attachment. The analysis supports this hypothesis. A Pearson Correlation test compared the data between a caregiver's perspective on readiness to provide care and their attachments in regards to general functioning within the family system. The bivariate correlation suggests that there was a statistically significant positive correlation between attachment subscale general functioning and readiness, but there was not a connection between readiness and attachment subscales involving roles, communication, or problem solving. Yet, perhaps attachment specific to

general functioning is the significant foundation. As previously stated, attachment is defined as a bond that is built based upon an individual's trust in safety, security, and protection. Previous studies have reported a correlation between general functioning and secure attachments (Boterhoven de Han et al., 2015). It is feasible that attachment bonds built on physical actions or general function is a parallel comparison to the actions performed as a caregiver. It can then be implied that the attachment history of the caregiver has an impact on a caregiver's sense of readiness to provide care for his or her family member with Alzheimer's disease (see Figure 1).

Figure 1
Quality of Life Model for Alzheimer's Caregivers



The second hypothesis of the study stated there would be a correlation between perceptions of life quality and readiness. The analysis strongly supports this hypothesis. The data have a significant positive correlation between positive adaptation and preparedness to give care. As the data suggests, it can be understood that when these caregivers believe

themselves to be prepared, they also maintain a positive outlook on life events (see Figure 1). Additionally, the data suggest a slight significance between readiness to provide care and burden. The bivariate indicated a negative correlation between the two variables. The analysis shows that for this study, when caregivers did not believe themselves to be prepared that their sense of burden would worsen (see Figure 1).

The third hypothesis of the study stated that there would be a correlation between perspectives of life and attachment. This hypothesis is not supported. This result contradicts previous research that attachment affects an individual throughout the life cycle (Doyle & Cicchetti, 2017). Perhaps the participants were not given appropriate language in the directions of the CQOLC, where the FAD was clear.

The researcher developed a theoretical model to help explain the correlation results of this study. When caregivers are nurtured in a secure family system, they report strong general functioning attachment characteristics. This attachment has a positive correlation to a caregiver's readiness to provide care to their family member with Alzheimer's disease. Similarly, the data show a positive correlation between readiness and caregivers' positive adaptation. Consequently, these caregivers have positive life quality. However, other data report having a slightly significant negative correlation between readiness and burden. These caregivers would have more negative quality of life as caregivers (see Figure 1).

Clinical Implications

Prior studies that focused research on the dementia caregivers analyzed their levels of duty, obligation, and sense of burden (Lee et al., 2018; Epps, 2014). This current study's results demonstrated that caregivers with strong past experiences with attachments in regards to general functioning may have a greater sense of readiness to provide care, and either

forecast positive adaptations of difficult events or a sense of burden. This is an important finding to the field of family sciences and the environment of family therapy.

These findings suggest that when a dementia caregiver reports a sense of burden, it can be correlated to how prepared they are to provide care. Clinical implications may consider this research useful for a potential model of providing beneficial therapy for dementia families. A therapy model that addresses attachments and family roles would work in parallel with dementia caregivers and their families in a therapeutic setting. Family Systems theory would assume families that maintain a good emotional connection experience low anxiety (Nichols, 2013).

Imagine a couple entering therapy with the presenting problem of communication issues between partners. After an intake session, the therapist learns that both the husband and wife feel distressed, overburdened, and disconnected to each other but for different reasons. The husband reports overburden taking care of their three young children, keeping the house clean, and finishing his projects at work on time. While the wife reports feeling overburden as a caregiver to her mother with Alzheimer's disease without any help from her brother and her husband being too exhausted from other duties to help her. A therapist can provide greater relief to this couple by using this study's model to understand where this Alzheimer's family may be coming from, rather than hypothesizing this is a couple's-only problem.

Family systems theory interventions would be supported by the data of the current study when using the techniques of relationship experiments and coaching. Family science researchers defined relationship experiments as therapists' attempt to help the client in achieving a greater understanding of their roles within the family dynamics (Rootes, Jankowsji, & Sandage, 2010). While coaching, is defined as the therapists' attempt to help the

client understand their emotional process and how it plays a role in the family system (Barnett et al., 2017). Using the earlier case example, the therapist can spend sessions discussing the emotional process of burden both partners feel and the role it currently plays in their relationships. This better understanding between partners may grow connection between the couple and use it to foster positive change within the entire family system, not only the couple relationship.

As the population with Alzheimer's disease is predicted to triple in size by 2050 clinicians will likely see increasing numbers of dementia families more frequently in a therapy setting (Alzheimer's Association, 2019). With more predicted and frequent therapy sessions, there are more opportunities to focus on the caregivers' readiness to provide care. This readiness appears to be a vital contributor to whether the caregivers experience burden or positive adaptation.

Limitations

Although the present study offers important findings to the field of family science, research has its limitations. The data collected by the researcher is limited due to the low number of participants involved. This narrow number of participants limits diversity of caregivers in demographics such as sex and race of the family members with Alzheimer's and the caregivers. The majority of the sample was white and female, consequently, limiting the generalizability of the results found in this study. Furthermore, participants of the current study contacted the researcher to discuss potential areas of the questionnaire that were omitted this suggest that the study may have excluded some factors that could have been explored. Finally, the present study focused on current and retrospective caregiver views. This restricts researchers from analyzing how attachment, readiness, and quality of life change over time, as

the family member with Alzheimer's continues to progress through the later stages of the disease and caregiver burden increases.

Recommendations for Future Research

Data for this study was collected from thirty-three participants from the state of Kentucky. Future research on this topic should be conducted using a larger sample size from multiple states. A larger sample size would increase diversity among participants. As a consequence, the results would strengthen its applicability to the general population of Alzheimer's caregivers.

This study used a lottery for a \$50 check as an incentive to recruit participants. Another recommendation would be to use incentives of greater interest to Alzheimer's caregivers. These caregivers typically have high-demanding days. An incentive that is of greater personal value might increase participation.

An additional recommendation would be to collect data further exploring the caregiver's experience. Reflecting on data collection from gatekeepers in the community, there appeared to be a gap of resources or knowledge between urban and rural living caregivers. Also, how many other caretakers involved might impact the participant's experience. Future research would benefit asking participants questions about their geographical location, available resources, and caregiving support.

Conclusion

The present study provides a link to the current research of caregiver burden by its exploration of how attachment and readiness of a caregiver have positive effects on life quality. Evidence supports a correlation between general function attachment and preparedness to provide care. Furthermore, there is a significant connection between preparedness to provide

care and positive adaptation, with an additional correlation to burden. While these findings did not lead to a specific reason for caregiver quality of life, it reveals the importance of positive adaptations to maintain a satisfactory quality of life. These findings may now be implemented in clinical setting for mental health professionals that help the caregivers, their family members with Alzheimer's, and possibly the family systems. Alzheimer's is a problem that is felt systemically and not only through those diagnosed. This study is a call for the field of mental health to implement empirically proven theories and treatment plans specifically for Alzheimer's families. The findings of this study are the developmental steps towards this goal.

Appendix A

Informed Consent

You are being invited to take part in a research study about adult children caregiving for parents with Alzheimer's disease. You are being invited to this study because you are 18 years or older taking care of your parent with Alzheimer's disease. Your response is highly valued and will continue to contribute to research that may greatly improve the understanding of the effects of attachments and the readiness to care give on caregiver's of Alzheimer's perspectives. There is no limit on the length of time we will store your data and information. Researchers may contact you for future studies unless you decide to withdraw from the study.

Although you will not get immediate personal benefit from taking part in this research study, your responses may help us understand more about our needs as current and future professionals when working with families of Alzheimer's disease.

We hope to receive completed questionnaires from about 60 people, so your answers are important to us. You have a choice about whether or not to complete the questionnaire, but if you do participate, you are free to skip any questions or discontinue at any time.

The questionnaire will take about 10 to 20 minutes to complete. The questions within this survey are of a personal nature. Although we have tried to minimize this, some questions may make you feel upset or uncomfortable, and you may choose to not answer them. If some questions do upset you or make you uncomfortable, we can provide you resources for people who may be able to help you with these feelings at the end of the survey.

Your response to the survey is confidential, which means no names or e-mail addresses will appear or be used on research documents, or be used in presentations or publications. The research team will not know that any information you provided came from you.

Please be aware, while we make every effort to safeguard your data if it is received from the online survey/data gathering company, given the nature of online surveys, as with anything involving the Internet, we can never guarantee the confidentiality of the data while still on the survey/data gathering company's servers, or while en route to either them or us. It is also possible the raw data collected for research purposes may be used for marketing or reporting purposes by the survey/data gathering company after the research is concluded, depending on the company's Terms of Service and Privacy policies.

If you have any questions about this study, please contact me at matthewgcornu@uky.edu or my academic advisors Ronald Werner-Wilson, Ph.D. at Ronald.werner-wilson@uky.edu or Amy Kostelic, Ph.D. at amy.hosier@uky.edu. If you have complaints, suggestions, or questions about your rights as a research volunteer, contact the staff in the University of Kentucky Office of Research Integrity at 859-257-9428. Thank you in advance for your assistance with this important research study.

Sincerely,

Matthew Cornu
Department of Family Sciences, University of Kentucky
Email: matthewgcornu@uky.edu

Appendix B

Demographic Information

1. What is your age? _____
2. What is your biological sex?
 - a. Male
 - b. Female
 - c. Intersex
3. What is your parent's biological sex (with Alzheimer's)?
 - a. Male
 - b. Female
 - c. Intersex
4. What is your parent's current age (with Alzheimer's)? _____
5. What was your total household income before tax in the past 12 months?
 - a. Less than \$25,000
 - b. \$25,000 to \$34,999
 - c. \$35,000 to \$49,999
 - d. \$50,000 to \$74,999
 - e. \$75,000 to \$100,000
 - f. More than \$100,000
6. Which of the following best describes your racial or ethnic identity? (Select all that apply)
 - a. American Indian or Native Alaskan
 - b. Asian or Asian American
 - c. Black or African American
 - d. Caucasian (non-Hispanic)
 - e. Latino or Hispanic
 - f. Middle Eastern or Arab American
 - g. Native Hawaiian or other Pacific Islander
 - h. None of the above
7. Where is your parent with Alzheimer's current residence?
 - a. At home alone
 - b. At home
 - c. Assisted living facility
 - d. Living with you
8. Are you the primary caregiver of your parent with Alzheimer's?
 - a. Yes
 - b. No

9. Are you caring for both your parent with Alzheimer's and children at home?
- Yes
 - No
10. How many years have you been taking care of your parent with Alzheimer's?
- Less than a year
 - 1 year to 3 years
 - 3 years to 5 years
 - 5 years to 7 years
 - 7 years to 9 years
 - 10 years or more
11. How many hours in a day do you spend caretaking for your parent with Alzheimer's?
- Less than 1 hour
 - 1 hour to 2 hours
 - 3 hours to 5 hours
 - 5 hours to 8 hours
 - 8 hours to 10 hours
 - More than 10 hours
12. How long has your parent been diagnosis with Alzheimer's?
- 6 months
 - 1 year to 3 years
 - 3 years to 5 years
 - 5 years to 7 years
 - 7 years to 9 years
 - 10 years or more

Appendix C

McMaster Family Assessment Device (FAD) Subscales: General Functioning, Communication, Roles, & Problem Solving

Please answer the following in the form of reflecting on the interactions and attachments of your family when you were growing up as a child in the home (i.e. parents and siblings).

Response categories:

Strongly agree-----Agree-----Disagree-----Strongly disagree

1. We usually acted on our decisions regarding problems.
2. After our family tried to solve a problem, we usually discussed if it worked or not.
3. We resolved most emotional upsets that came up.
4. We confronted problems involving feelings.
5. We tried to think of different ways to solve problems.
6. When someone was upset the others knew why.
7. You couldn't tell how a person was feeling from what they were saying.
8. People came right out and said things instead of hinting at them.
9. We were frank with each other.
10. We didn't talk to each other when we were angry.
11. When we didn't like what someone had done, we would tell them.
12. When you asked someone to do something, you would have to check that they did it.
13. We made sure members met their family responsibilities.
14. Family tasks didn't get spread around enough.
15. We had trouble meeting our bills.
16. There was little time to explore personal interests.
17. We discussed who was to do household jobs.
18. If people were asked to do something, they need reminding.
19. We were generally dissatisfied with the family duties assigned to us.
20. Planning family activities is difficult because we misunderstand each other.
21. In time of crisis we can turn to each other for support.
22. We cannot talk to each other about sadness we feel.
23. Individuals are accepted for what they are.
24. We avoid discussing our fears and concerns.
25. We can express feelings to each other.
26. There are lots of bad feelings in the family.
27. We feel accepted for what we are.
28. Making decisions is a problem for our family.
29. We are able to make decisions about how to solve problems.
30. We don't get along well together.
31. We confide in each other.

Appendix D

CAREGIVER QUALITY OF LIFE- CANCER-Revised

Below is a list of statements that other people caring for loved ones with an illness have said are important. By circling one number per line, please indicate how true each statement has been for you.

0 = Not at all **1** = A little bit **2** = Somewhat **3** = Quite a bit **4** = Very much

1.) It bothers me that my daily routine is altered.	0	1	2	3	4
2.) My sleep is less restful.	0	1	2	3	4
3.) My daily life is imposed upon.	0	1	2	3	4
4.) It is a challenge to maintain my outside interests.	0	1	2	3	4
5.) I am under a financial strain.	0	1	2	3	4
7.) My economic future is uncertain.	0	1	2	3	4
8.) I have more of a positive outlook on life since my loved one's illness.	0	1	2	3	4
9.) My level of stress and worries is high.	0	1	2	3	4
10.) It bothers me, limiting my focus to day-to-day.	0	1	2	3	4
11.) I feel sad.	0	1	2	3	4
12.) I feel under increased mental strain.	0	1	2	3	4
13.) I get support from my friends and neighbors.	0	1	2	3	4
14.) I feel guilty.	0	1	2	3	4
15.) I feel frustrated.	0	1	2	3	4
16.) I feel nervous.	0	1	2	3	4
17.) I worry about the impact my loved one's illness has had on my children or other family members.	0	1	2	3	4
18.) I have developed a closer relationship with my loved one.	0	1	2	3	4

19.) I feel adequately informed about my loved one's illness.	0	1	2	3	4
20.) It bothers me that I need to be available to chauffeur my loved one to appointments.	0	1	2	3	4
21.) The responsibility I have for my loved one's care is overwhelming.	0	1	2	3	4
22.) Family communication has increased.	0	1	2	3	4
23.) It bothers me that my priorities have changed.	0	1	2	3	4
24.) The need to protect my loved one bothers me.	0	1	2	3	4
25.) It upsets me to see my loved one deteriorate.	0	1	2	3	4
26.) I am discouraged about the future.	0	1	2	3	4
27.) I am satisfied with the support I get from my family.	0	1	2	3	4
28.) It bothers me that other family members have not shown interest in taking care of my loved one.	0	1	2	3	4

Appendix E

The Preparedness for Caregiving Scale

We know that people may feel well prepared for some aspects of giving care to another person, and not as well prepared for other aspects. We would like to know how well prepared you think you are to do each of the following, even if you are not doing that type of care now.

0-----1-----2-----3-----4
Not at Not too Somewhat Pretty Very
all well well well well
prepared prepared prepared prepared prepared

- 1.) How well prepared do you think you are to take care of your family member's physical needs? _____
- 2.) How well prepared do you think you are to take care of his or her emotional needs? _____
- 3.) How well prepared do you think you are to find out about and set up services for him or her? _____
- 4.) How well prepared do you think you are for the stress of caregiving? _____
- 5.) How well prepared do you think you are to make caregiving activities pleasant for both you and your family member? _____
- 6.) How well prepared do you think you are to respond to and handle emergencies that involve him or her? _____
- 7.) How well prepared do you think you are to get the help and information you need from the health care system? _____
- 8.) Overall, how well prepared do you think you are to care for your family member? _____

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