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## Perspectives of Caregivers on Early Onset Dementia: An investigation of the role of attachment and shifts in identity

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Perspectives of Caregivers on Early Onset Dementia:

An investigation of the role of attachment and shifts in identity

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Honors Thesis

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Abstract

Early onset dementia (EOD) alters the lives of person with dementia (PWD) and caregivers as it broadens from helping with the instrumental activities of daily living to full time assistance with essential activities of daily living. Research literature reports that pre-morbid attachment style continues to be emotionally and behaviorally expressed over the course of dementia; individual and shared narratives contribute to maintenance of personhood and identity; and that maintenance of self and other contributes to quality of life. The purpose of this study was to investigate changes in caregiver perceptions of themselves and their quality of life in the caregiving process as roles and responsibilities shifted across the dementia cycle. Ten open source, archived video, audio, and text materials submitted by partners of individuals living with EOD were used for this study. Bartholomew and Horowitz's four-category model of attachment and Hagstrom and Daniel's narrative analysis were used to code and cross code shifting patterns of attachment and identity across dementia stages. Results indicate caregiver strategies become more fluid and flexible to accommodate the inflexibility and unpredictability of the PWD. Securely attached caregivers have a grounded sense of self that moves from reliance to resilience as the scope of caregiving broadens, and they seek ways to maintain the identity of the PWD. Securely attached caregivers experience a higher quality of life and remain aware of the PWD's quality of life. These results suggest that quality of life for self and the PWD benefit from maintenance of self-identity and attribution of identity to the PWD. The findings have the potential to provide clinicians with a model for goal setting with caregivers and partners with EOD that can advance quality of life for persons – caregiver, patient, family – living with dementia.

### Perspectives of Caregivers on Early Onset Dementia:

#### An investigation of the role of attachment and shifts in identity

Dementia is an incurable, neurogenic, disease that impacts every aspect of an individual's life. Dementia is an umbrella term for neurodegenerative diseases that can affect cognitive functioning. These diseases are characterized by progressive changes in memory, disorganization of thinking and problem-solving, and language issues that affect a person's ability to perform everyday activities (What Is Dementia, 2020). The prevalence of dementia is growing with an estimated 5.8 million Americans living with Alzheimer's in 2019 (Alzheimer's Disease Facts, 2019). Dementia is listed as the 6<sup>th</sup> leading cause of death in the United States (Facts and Figures, 2020).

Symptoms and effects of dementia appear gradually and intensify until the end of life. According to the World Health Organization there are three different stages of dementia: Early Stage, Middle Stage, and Late Stage. In the early stages of dementia, individuals may be forgetful, lose track of the time, or suddenly not know where they are- even when places are familiar. These problems become more advanced in the middle stages of dementia. In the last stage, individuals reach a peak of challenges including, but not limited to, difficulty recognizing familiar people, difficulty with motor skills, and behavior changes such as aggression that at times resembles mental or emotional problems (Dementia, 2019).

#### **Early Onset Dementia (EOD)**

According to the Mayo Clinic Website, roughly 5-6% of individuals diagnosed with Alzheimer's disease are categorized as early onset dementia (Graff-Radford, 2020). The symptoms are consistent with those described above, but EOD is diagnosed when an individual is younger than age 65. Around 5-6 % of dementia cases are occurring in mid-life. These are pre-

retirement age individuals between the ages of 30-64 years. Brooks (2020) reported on data from insurance companies that indicated a 200% increase of early onset dementia with the largest increase now for those between 30-44 years of age.

The implications of EOD are tragic. While the lives of those who experience EOD change rapidly, those who walk closely with the patient through their trails, e.g. caregivers and partners, experience each hardship second hand. Those between the ages of 40 and 65, the most common age range for EOD, are often losing a meaningful life when they are experiencing great successes. Many of these individuals might be experiencing peak work achievements; have a wife, husband, or children to take care of; are tending to the needs of elderly parents; and are looking forward to a secure future in retirement. EOD leaves individuals without a sense of understanding of themselves, the daily events in which they find themselves, or their role with loved ones. This magnitude of loss of identity produces instability. When one experiences instability, they often cling to what is familiar. The person experiencing EOD may cling to expected time bound routines, those who provide care, and silently held expectations of others for everyday needs. Thus, the caregiver as well as the person with EOD are finding their way through evolving relationships bound by this disease.

### **Early Onset Dementia and Caregiving**

The lives of those who experience EOD change as they move through the three stages of dementia. This in turn changes the lives of caregivers and partners as the level of care and support for quality of life shifts as the dementia deepens. For example, upon diagnosis little may change in the daily lives of the EOD or caregivers but with progression of the disease process instrumental activities of daily living (IADL) such as driving, shopping, and managing a budget shifts to the caregiver. This assistance changes over the course of the second phase of dementia

as independent management of essential activities of daily living (ADL) such as eating, toileting, and dressing requires caregiver assistance. By the third stage, the PWD is totally reliant on the caregiver 24 hours a day to manage ADL (Guo & Sapa, 2020; Small, Gutman, Makela, & Hillhouse, 2003). As this dependency evolves within the relationship, the caregiver's life may be subsumed by the needs of the person with EOD leaving little time for themselves. At the same time the caregiver is emotionally challenged by the loss of the loved one they knew who no longer knows them. (Oliver & Bock, 1987). In the midst of this evolving scenario, the hope of the caregiver is to ease the suffering of the PWD and find ways to provide some quality of life for both the PWD and themselves. Remaining attached and maintaining a sense of self is critical to this process.

### **Early Onset Dementia, Attachment Theory, and Social Identity**

The Attachment Theory has been used to explain how children bond with their caregivers and provides a foundation for relationships later in life (Fraley, 2018). Research suggests that those who experience insecure attachment styles were directly related to how they perceived the quality of their marriage (Crowell, Treboux, & Waters, 2002). Browne and Shlosberg (2006) expanded the theory to relationship attachment later in life stating it was a protective resource and extended their research to dementia. They also found that pre-morbid attachment style continued to be expressed emotionally and behaviorally over the course of dementia.

Dementia not only robs the individual of their sense of self over time, but also robs relationships of the bonds of togetherness as the able-minded partner shifts into the role of caregiver. According to the Mayo Clinic website many effects of stress may include, but are not limited to, the following: anxiety, restlessness, lack of motivation or focus, sadness or depression, sleep problems, etc. (Mayo Clinic Staff, 2019). These symptoms would impede

upon the quality of life of the caregiver significantly. Additionally, research has revealed that caregivers who experience attachment anxiety have poorer mental health and those who have attachment insecurity have a more controlling caregiving approach (Karantzas, Romano & Lee, 2019). Hagstrom and Daniels (2004) provide a mapping for social identity using the narrative perspective questions of ‘who are you?’, ‘who am I?’, and ‘who are we?’. This series of positional questions when paired with attachment theory provides theoretical perspective that can inform quality of care goal setting for individuals with EOD and their caregivers.

This study aims to answer how the quality of life of the caregiver was affected, due to the diagnosis, in hopes that more information can lead to higher qualities of life for those experiencing the hardships of helping a loved one through early onset dementia.

### **Summary and Questions of the Study**

Dementia is a neurogenic disease with no cure. Early onset dementia is a subtype of dementia diagnosed when an individual is symptomatic at or below 65 years of age. Life changes occur for both the patient and caregiver throughout early, middle, and late stages of dementia. These are often associated with changes in the amount of assistance needed by the EOD to conduct instrumental activities of daily living that progresses to assistance with essential activities of daily living. Understanding caregiver attachment as it relates to an EOD diagnosis is critical in helping to enhance quality of life. This study aims to answer the following questions:

1. In what ways do caregiving strategies evolve in the coping process across stages of dementia?
2. In what ways does the changing scope of caregiving with deepening dementia impact caregiver self-identity?

3. In what ways does the changing scope of caregiving with deepening dementia impact the identity attributed to the PWD?
4. Does a secure versus insecure attachment style/status of the caregiver influence their quality of life as the burden of caregiving progresses?
5. Does a secure versus insecure attachment style/status of the caregiver influence their perception of quality of life for the partner with dementia?

### **Methodology**

This study consisted of two phases. The goal of the first phase of the study was to identify key elements associated with the progression of dementia that impacted caregiving and the challenge to caregivers in this process. This information was used in the second phase of the study to organize the reading of publicly available textual and digital stories for themes associated with attachment and social constructed identity across disease progression.

#### **Phase I**

##### **Materials**

A single book written for caregivers of individuals experiencing dementia that contained notations by an unknown reader was used for the first phase of the study.

##### **Procedures**

The book was read to identify shifts in caregiving over the progressive course of dementia. Descriptions of dementia behavior provided in vignettes throughout the book were used to determine stages of dementia and key points of caregiving in light of these behaviors. The second reading of the book focused on the handwritten margin notes and notations as personalization of the book contents. Each notation was then placed into a spreadsheet document.

## **Analysis**

Each chapter of the book was reviewed for the number of reader annotations that related to the book content. The changing scope of caregiving as the dementia deepened was captured by the interpretation, expansions, and personalization of the notations in contrast to the copyrighted text.

## **Phase II**

### **Materials**

The range of materials for the second phase of the study, identified in the feasibility and literature phases of the study, included ten open source archived video, audio, and text materials collected from partners of individuals living with EOD. The archived materials were located at major universities for use by researchers seeking to contribute to the understanding of dementia and possible treatments.

### **Procedures**

The procedure of the study began by selecting a corpus of material that provided caregiver insight at three points in the progression of dementia: the initial stage that usually occurs at or about the time of the diagnosis, the middle stage when individuals are struggling to maintain everyday life, and the late stage when the PWD are unable to care for themselves. Line-by-line transcripts of the video and audio material were transcribed and added to text materials.

Each entry of material was read, transcribed, coded for the patient experience, the caregiver experience, and the caregiver response. The caregiver experience and response collectively provided insight on what was happening and how the caregiver acknowledged the situation.

## **Analysis**

Key words were aligned with Bartholomew and Horowitz's (1991) four-category model of attachment to identify caregiver attachment, their attribution of this to the partner with EOD, and possible changes in both of these as the dementia deepens. Secure and insecure attachment was identified based on the patient's ability to continue to think first about their significant other and second about this process for themselves over the course of dementia. Narrative analysis (Hagstrom & Daniels, 2004) was used to identify themes related to the self-identity of the caregivers as well as their attributions of identity to the partner with EOD (see Appendix B). Both the attachment themes and identity themes were analyzed to capture the distinctions between caregivers who placed their identities with their dementing loved one and those who maintained their identity and worked to maintain their loved one's identity. This process of analysis and the subsequent coding for inter-rater agreement was used to answer the five questions of the study.

## **Results**

### **Phase I - Analysis of a Single Book on Dementia Caregiving with Anonymous Notes**

The book *Coping with Alzheimer's: A caregiver's Emotional Survival Guide* (Oliver & Bock, 1987), written to emphasize the journey of dementia caregiving, was read and analyzed to gain a deeper understanding of the caregiver experience. The book is comprised of thematic chapters that address key issues caregivers' experience as dementia progresses. A variety of caregiver stories and explanations are used throughout the book as examples of how to disarm difficult situations. This particular copy was a used book marked up by a caregiver who made reference to her and her husband's challenges. The notations illustrated her connection to the

material, experiential familiarity with the progression of the dementia, and her lived experiences and struggles. Her notations provided a personalized story within the book's story of dementia.

### **Content and Organization of the Book**

The book consists of an introduction for caregivers, 14 chapters divided into three parts that align with disease progressions, and an epilogue. This organization leads the reader through the initial shock with the diagnosis to understanding the deepening of dementia, to maintaining the loved one's integrity, to doing the best to maintain caregiver and patient comfort. The last was used as a guide for determining the health of a couple's relationship when confronting and making difficult decisions.

### **The Personalized Notation Story**

The notations of the reader of the book provided reflections about herself, her husband, and changes in both as daily life changed. The titles of the chapters capture the key challenges faced by caregivers. These began with acknowledging the feelings and emotions that the caregiver may experience when dementia is at different stages. There was underlining, check marks, and stars to indicate descriptions that the reader was relating with but little notation. The personal notations became more frequent in subsequent chapters with the most personalization occurring in chapters six, seven, ten, and thirteen. In these chapters, key issues evolved from shame in chapter six to self-pity in chapter seven, depression in chapter ten, and making do when dealing as dementia related behaviors increase late in the disease progression. There was in all a total of 142 lines of notation in the text.

The caregiver notations provide a window into her personal process as she engaged with the text. For example, notes in the chapter on depression included self-directed advice such as, "*Accept him as he is!*" and "*No 'should' as expectations*". Other margin notes in the chapters

listed above included advise to herself and her actions, for example “*Relax*”; “*Accept*”; and “*Change your expectation*”. These depict the process of caregiver self-awareness and hints for changing her behavior to ease the emotional caregiving toll. Toward the end of the book a final self-directed notation gives the reader’s message to herself: “*Alzheimer’s is a disease not a disgrace!*”

Phase I of this study resulted in a framework for mapping how caregiving and caring for oneself in the caregiving process emerges over the course of progressive dementia. This framework was used to design the second phase of the study.

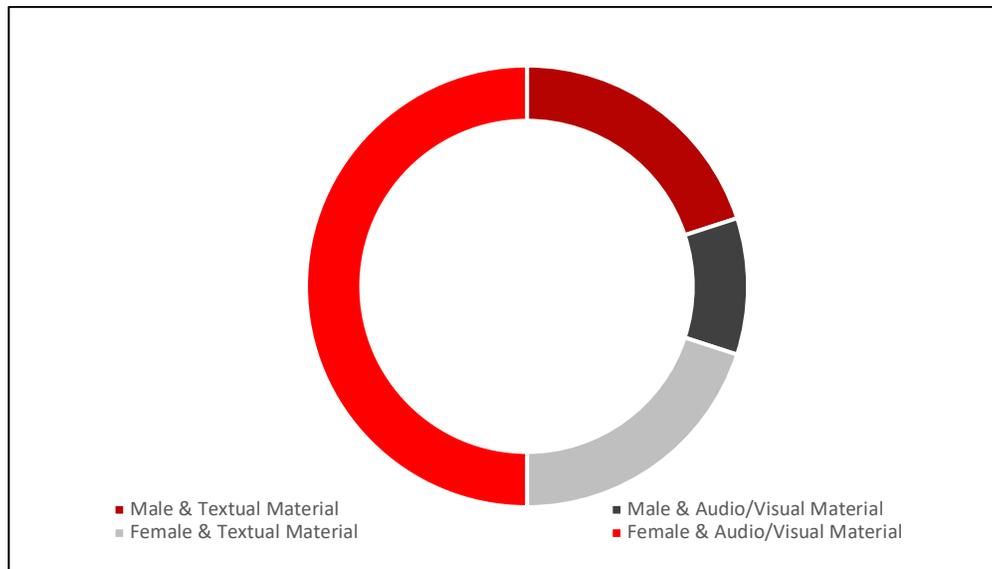
## **Phase II – Analysis of Publicly Available Written and Digital Stories**

### **Demographics**

The second phase of the study used data collected through publicly available online database resources. This included text and video material that described the caregiver experience with progressive stages and changes following the diagnosis of EOD. The data set included five text resources and five video resources. The age range of the individuals who had told their stories via text or video varied greatly from teenagers to 60-year-olds. Four of these were male caregivers and six female caregivers (see Figure 1). Four of the caregivers were from the United States and six from the United Kingdom. English was the language used in all the text, audio, and video material. Additionally, all but two of the collected stories came from full-time caregivers. The timeframe of the collected stories ranged from early diagnosis to care facility placement in the final states of the disease process.

**Figure 1.**

*Caregiver Gender & Material Type*



**Question One**

The first question of this study asked about the way caregiving strategies evolve in the coping process across stages of dementia. Data from both the phase I and phase II materials were used to answer this question. A coping pattern that moved from denial to sacrifice to mental reframing emerged from the data. These three elements in the same order were consistently expressed by caregivers as they talked about the need to be fluid and flexible in how they dealt with unpredictable shifts in behavior as the inability of the partner with EOD increased. Themes related to adjustment and reflection emerged from the data as caregivers talked about ways they gained emotional relief from the burden of caregiving. These themes were inconsistent, appearing and evolving as the scope of caregiving broadened in response to the deepening of the dementia. Table 1 summarizes the fluid and flexible themes that emerged from the data. Examples of the data points for these themes can be found in Appendix C.

**Table 1.**

*Themes and Subthemes that Characterize Caregiving Coping Strategies*

Fluid Themes	Flexible Themes
Denial	Adjustment
Sacrifice	Reflection
Mental Reframing	

The stories that led to the results for question one were consistent across and within the material of the study. Consistent with the literature on the progression of dementia, the stories affirmed a pattern of grief and denial when faced with the diagnosis, and increased awareness of the PWD having as many good days as bad days. As a result, caregivers expressed that they were not able to consistently determine who their loved one was because of the shifting symptoms. At this point the caregivers began the process of expecting the unexpected.

As their loved one’s dementia continued to deepen, caregivers begin to acknowledge that life was permanently changing and maintaining a state of balance was necessary. Therefore, expecting their loved one to do something that would have seemed impossible even a year ago, was no longer something to be alarmed by. As caregivers continued through this process, they began to recognize sacrifice. The sacrifice did not end with the caregiver themselves. Instead, caregivers recognized the sacrifices that the family unit was making as whole.

Finally, strategies evolved to accept the loss of the living loved one. Patterns differed in this last stage of dementia. Some caregivers remained committed to loving the person with deep dementia for who they once were in the relationship, while others mourned the loss of the partner

as they had been. The overall theme associated with the strategies of acceptance took the shape of caregivers continually thanking their loved one for all they have done in the journey of their lives.

### **Question Two**

The second question of the study asked about the changing scope of caregiving with deepening dementia and the impact of this on caregiver self-identity. Only two stories in the entire corpus provided longitudinal perspectives between deepening dementia and its impact on caregiver self-identity. One of these came from a video source and one written source. The rest of the corpus included multiple single incident stories where caregivers talked about their experiences in relationship in light of specific levels of care needed by the PWD. Both the longitudinal and incident stories were used to answer the second question of this study.

#### ***Longitudinal Theme: From reliance to resilience***

Reliant themes are characterized by stories where caregivers do not accept or acknowledge their loss and or sacrifice but instead are reliant on the PWD to validate who they are. This is shown most explicitly through extended stages of grief and denial. Themes of resilience are characterized by stories where caregivers are accepting and/or acknowledging of their loss and sacrifice. The pattern emerged where the caregiver's scope continued to broaden as dementia deepened and they in turn began to relax, accepting the things that could not be changed.

Both of the caregivers who provided longitudinal stories had patterns of resilience. In the first stages of dementia, they had a difficult time coping and understanding the EOD diagnosis. As the progression of the disease continued, the caregivers began to accept their current

circumstances and move forward with newfound strength. The following points obtained from two stories in the Phase II data sets are examples of their resilience themes.

He began to fade away gradually at first but with gathering speed until eventually the person I fell in love with over forty years ago is no longer beside me... There are positives to this new life in which we find ourselves. I've given up work, so we spend more time together... I have more time for friends, I remember birthdays, I notice more, take onboard other people's opinions, and feel that I'm in better company. (Jane's Story, n.d.)

As can be seen from this story Jane transitioned from understanding and expressing the loss she was experiencing, to maintaining her own identity by recognizing things that made a positive impact on her. Another example of this comes from the Ed's story:

No, the change in the year has been profound. Watching the person that you love so much who has been you know so much a part of your life... There is a lot more you know that I used to get from her that she would do for me. That's gone... I have made a commitment to this beautiful woman that I will live with her forever. So, whatever happens, um we're definitely doing it together. (White & Fitch, 2014).

While both examples are longitudinal, there are distinct differences in how and where they are expressed. In the Jane example, she was reflecting on her life alongside her husband. The challenges of the disease left her without a partner, and she found herself discovering positive moments or experiences that made her happy. Though Ed's story did not mention positive outcomes or coping strategies, he acknowledged the loss he was experiencing, the challenge of that loss, and who he would continue to be as his wife's dementia deepened.

***Brief Source Material across EOD Progression: Reliance and resilience***

The themes that emerged from the two longitudinal sources were used as a base line to determine if they occurred in the shorter texts and video material. A key mid-stage element in the longitudinal stories was worry about the safety of the EOD partner. This theme emerged in 20% of the entire corpus (i.e., both longitudinal stories). Caregivers acknowledged not only their fate, but the PWD's fate in the brief segments that described the deepening of dementia. These stories consistently reflected caregiver choices that characterized learning how to be resilient. When telling these stories, they positioned themselves at a point where they would not just feel as though they are surviving but they feel that they are enjoying certain aspects of life. Five examples representing the three stages of dementia are included in Appendix D.

**Question Three**

The third question of this study focused on how the changing scope of caregiving as dementia deepened impacted the identity attributed to the person with dementia. All ten stories in the Phase II audio/visual and textual stories were used to answer this question. The analysis revealed that attribution of identity for the PWD was different for securely versus insecurely attached caregivers.

Caregivers that appeared securely attached throughout the deepening of dementia, worked to maintain the identity of the PWD. Sixty percent of the corpus material acknowledged the PWD as a loving wife, mother, or husband. For example, Karen said about her husband Jack:

I think all of this comes from our 34 years of marriage; I love my husband. He's my soulmate. I did not have a lot of patience at the beginning, and I have a lot of patience now. It's a gift Jack has given me (VHA Home HealthCare, 2017).

One of the stories included the concept of a desire to continue finding hobbies that the PWD would enjoy as their dementia continued to deepen.

If only we could find ways to bring her back. We wanted more than anything to see her face light up, and those moments when she looked happy or excited, however brief, became precious (James's Story, n.d.).

Another story was so aware of the possibility of an evolving identity of the PWD that there was curiosity for how they were continuing to experience their own disease.

"What must it be like? Um how much does Pam know about what's happened, what's happening, and what's will happen to her? Every time I see her, I hope I hug her. Every time I see her, I tell her I love her. I tell her how magnificent her smile is. I tell her what a great life we've had together, and I thank her for what she's done for me. And she was an incredibly attentive, loving mother." (White & Fitch, 2014).

These examples illustrate the impact of caregiving related to secure attachment.

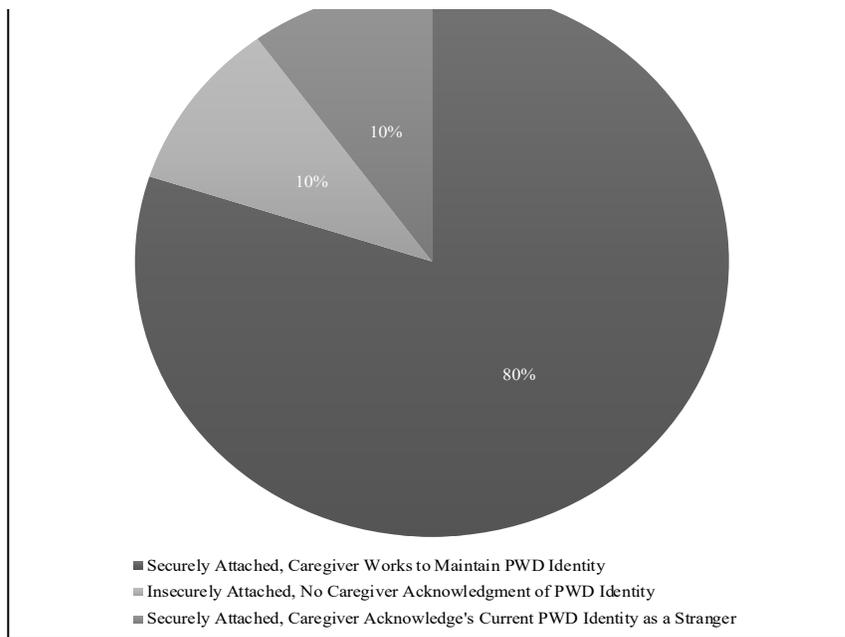
The pattern for insecure attachment in caregiving was distinctly different. In 20% of the insecure attached caregivers, there was distance of the once known identity of the PWD and the current identity of the PWD. An example of this is shown in Denise's story:

Living with Randy now is pretty much like living with a stranger. The Randy that I knew and loved, that Randy is not there anymore. So, it's kind of like I am taking care of this stranger that I don't even know anymore. They lose they lose the ability to show emotion so they really can't connect with people any longer. There is no there is no display of affection, there is no empathy for people (Kansas City Star, 2013).

Denise acknowledged her husband as two identities, the person she once knew and a stranger. Even more notable, she did not acknowledge Randy as her husband in the current tense; instead, Denise just referred to him as Randy. Of this 20% of insecurely attached caregivers, 10% acknowledged the PWD as a stranger and 10% did not acknowledge the PWD at their current state (see Figure 2).

**Figure 2.**

*Caregiver Attachment Styles and Perception of PWD Identity*



As can be seen, attribution of personhood for the individual with dementia is impacted by the attachment status of the caregivers. For caregivers who appear to be securely attached they aim to maintain the identity of the PWD in the home and in everyday contexts. Caregivers who were not identified as securely attached, isolated themselves from the PWD as the disease deepened.

#### **Question Four**

Question four of the study asks if the caregiver attachment style/status influences their quality of life as the burden of caregiving progresses. For the purposes of this study, an insecure attachment style is defined as the caregiver being able to acknowledge the disease but being afraid of accepting the ways it will alter the lives of both the caregiver and their family.

Insecurely attached caregivers in this study did not acknowledge the disease in the ways they described the PWD experiences. Instead, the insecurely attached caregiver saw the challenges of life from their perspective. Securely attached caregivers were unafraid of accepting the disease and the ways it might alter the lives of both the caregiver and their family. Securely attached caregivers made the needs of the person with dementia a top priority and wanted to steadfastly provide a sense of security for the PWD. Phase II audio/visual and textual stories were used to answer this question. Life changes over the course of living with dementia for the caregiver in tandem with the progression of disease for the PWD. Therefore, it is only in the context of the story with all the complex elements woven together that show the contrast of secure versus insecure caregiver attachment. Eighty percent of the corpus material suggested that secure attachment positively influences the quality of life for the caregiver. Twenty percent of the material suggested insecure attachment negatively influences the quality of life for the caregiver.

Examples of these attachment styles are presented as follows:

#### ***Insecure Attachment Negatively Affecting Quality of Life***

The caregiver saw the disease as primarily affecting them versus the PWD:

It [EOD] takes away the person, they are out of it so to speak. They don't realize what effect it has on to the people who are caring for them. I think the careers

suffer the most. It is both a physical and mental stain on the caregiver's and those close to the person with dementia (Carol & Ken's Story, n.d.).

### ***Secure Attachment Positively affecting quality of life***

Caregivers focused on making the most of their current situation.

He was proud of me and encouraging in everything I ever wanted to do. This was excellent for my self-esteem, but without his open admiration, I've had to learn to love myself. To appreciate my own strengths and work on my weaknesses (Jane's story, n.d.).

### ***Quality of Life Contrast between Securely and Insecurely Attached Caregivers***

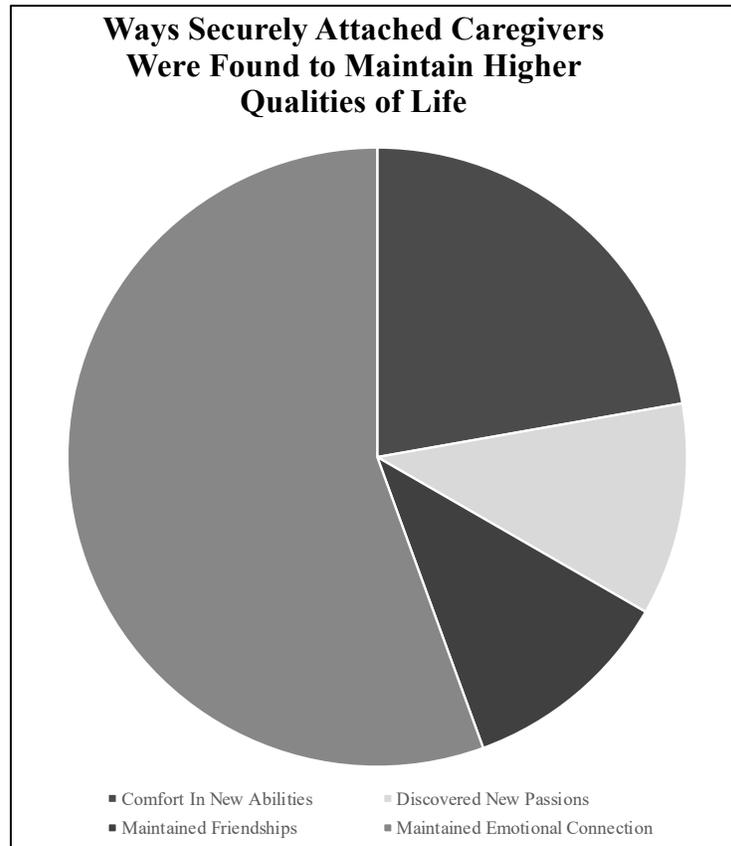
As shown in Ken and Carol's story, Ken expressed the toll that caregiving has taken on him mentally and emotionally. With the lack of context, it is important to note that Ken also expressed in his story that life around him was crumbling with additional challenges beyond his wife's EOD diagnosis and progression. The challenges presented before Ken were hard for him to navigate and see beyond. However, Jane's story expressed that even amid the heartbreak and loss of her husband, she was still able to grow and appreciate her newfound strengths. Jane was acknowledging of her circumstances and able to see beyond them- thus, enhancing her quality of life. Ken was unable to grasp a comfortable and positive life beyond Carol- negatively impacting his quality of life.

Overall, the analysis for this question illustrates the ways that securely attached caregivers have a different experience as their partners go through the stages of dementia.

Figure three captures these differences.

**Figure 3.**

*Commonalities of Coping Mechanisms for Securely attached caregivers.*



### **Question Five**

Question five of the study asks if secure versus insecure attachment style/status of the caregiver influences their attribution of quality of life experienced by the PWD. Phase I and Phase II audio/visual and textual stories were used to answer this question.

Information of Phase I of the study that used book material and reflection on this suggested that the PWD loses the ability to make sense of and control their environment.

However, the caregiver's ability to do both remains. The unnamed caregivers' annotations and marking of text intertwined with the book material provides an example of this:

Instead of saying, 'he shouldn't make ridiculous accusations against me' tell yourself 'why shouldn't he make ridiculous accusations? It would be better if he didn't, but he is not able to make rational distinctions. However, I can!' (Oliver & Bock, 1987).

As can be seen, a maintained awareness and attentiveness to the PWD's experience and diverting challenging situations allowed the caregiver to attribute an enhanced quality of life for herself as well as the person with dementia.

Phase II audio/visual and textual stories also suggested that a secure attachment style provided more awareness of the PWD's experience, therefore, caregiver's focused on the PWD's quality of life. Fifty percent of the corpus material detailed questioning of the PWD's experience or emphasizing strategies that the caregiver was hopeful to enhance the PWD's quality of life. Evidence of this includes wanting to create new hobbies for the PWD to enjoy, enhancing the PWD's feelings of security through reassurance, reminding the PWD who they are and how loved they are, etc. This dialogue between Dawn and her husband John illustrates this point:

John: God doesn't want us to make mistakes I don't think. I could be wrong- and yet we do.

Dawn: Yep, I mess up. Forgive us our trespasses as we forgive those who trespass against us.

John: And lead us not into temptation but deliver us from evil. Well, I got a gift from God.

Dawn: And you're my gift from God (mmlern.org, 2018).

Dawn's words revealed how she used scripture to aid to her husband. The speaking turns between them refocused his insecurity into a positive understanding from which he would find comforting. As a securely attached adult, Dawn desired for John to feel comfortable mentally and emotionally as his dementia continued to deepen.

Twenty percent of the corpus material was identified as the caregiver having insecure attachment. The following story suggested that the caregiver did not acknowledge the PWD's perspective in the dementing process. It is noteworthy that this reflection, on the part of the caregiver, occurred after the caregiver was no longer taking primary care of his wife at the time of the blog posting.

You tend to just sit there trying to switch off from thinking about Carol and re-focus your mind on the million and one jobs you could be doing, sometimes you can other times you just have a glass of wine and say to yourself, 'I will do it tomorrow,' and of course when tomorrow comes you don't do it-it's so bloody hard at times (Carol & Ken's Story, n.d.).

While caregivers change over the course of living and caring for PWDs, these results revealed that the attribution about the PWD's quality of life differed between those caregivers who were securely attached versus those that are not.

### **Inter-Rater Agreement**

Inter-rater agreement was used to determine validity of coding for both attachment and identity. Coding directions and questions (see Appendix D) and definitions of terms (see Appendix A) were provided to the cross coder for further clarification. The cross coder was asked to code 13.15% of all Phase II materials (i.e., one section of coded material per story). There were only two points of disagreement, one based on a foundation of a lack of context and

the other due to a different interpretation of the abstracted text. This resulted in 99.3% agreement for the entire Phase II corpus material.

### **Discussion**

Early onset dementia alters the lives of PWD and caregivers as it broadens from helping with the instrumental activities of daily living to full time assistance with essential activities of daily living. Past research found that pre-morbid attachment style continues to be emotionally and behaviorally expressed over the course of dementia; individual and shared narratives contribute to maintenance of personhood and identity; and that maintenance of self and other contributes to quality of life. The purpose of this study was to investigate changes in caregiver perceptions of themselves and their quality of life in the caregiving process as roles and responsibilities shifted across the dementia cycle.

This study found that while caregiving strategies varied across case stories a consistent theme emerged that caregivers needed to be fluid and flexible due to unpredictable shifts in behavior and the inability of the partner with EOD to be flexible. Longitudinal studies provided insight on the caregiver self-identity as the scope of caregiving expanded with deepening dementia. Caregivers often found themselves in a state of reluctance in the beginning stages of a dementia diagnosis but experienced a shift of resilience throughout the dementia progression. Additional findings suggest that caregivers who appeared securely attached throughout the deepening of dementia, worked to maintain the identity of the PWD. A key finding was that 60% of the audiovisual and textual corpus material in late stage dementia spoke about the PWD as a loving wife, mother, husband, or friend suggesting that even as the dementia deepened the identity given to the PWD from the caregiver was consistent over time. Further, the data suggested that 90% of stories show a correlation of secure attachment and higher quality of life

for the caregiver. Finally, caregivers securely attached to the PWD were more attentive to the PWD's needs. As a result, the caregivers perceived the PWD with a higher quality of life.

This study focused specifically on two subsets of attachment styles for the caregiver-secure and insecure attachment. This research found that attachment style can affect quality of life with insecurely attached caregivers having a lower quality of life and securely attached caregivers with a higher quality of life. Research previously conducted by Browne and Sholsberg (2006) suggested that pre-morbid attachment styles continued to be expressed emotionally and behaviorally over the course of dementia for the PWD. According to Browne and Sholsberg, this pre-morbid attachment style, though not explicitly defined, did positively correlate to those who had been previously securely attached in adult relationships prior to their dementia diagnosis. As a result of attachment being fluid for the PWD from secure to pre-morbid throughout the dementia progression, it is still unclear if the PWD's attachment works independently from the caregiver's attachment as the disease progresses or if a secure caregiver adopts a new subset of attachment to match the pre-morbid attachment style of the PWD. Stated differently, there is still uncertainty if the caregiver can experience secure attachment, thus maintaining a higher quality of life, while adopting or matching a pre-morbid attachment style to stay in consistency with their spouse, partner, person with dementia.

Socially situated self-other identity is naturally self-reevaluated over time, particularly in the transitional phases of life. The Hagstrom and Daniels (2004) model using narrative perspective questions of 'who are you?', 'who am I?', and 'who are we?' reveal that fluidity is expected across various contexts of life. There is an expectation that caregivers would experience a shift in identity as the abrupt changes of an EOD diagnosis alters life as they knew it. However, this re-evaluation appears to be more frequent for caregivers of PWD in a shorter time frame

than most as a result of the caregiver experience changing significantly across the three phases of dementia. These shifts in identity were most notable as caregivers moved from themes of reliance to resilience. This research did not provide enough information on what occurs in the caregiver's experience in order for them to make that shift to resilience. More research may clarify how or when that shift naturally occurs and at what stage is it unlikely for caregivers to not adopt a resilience mindset.

The stress that a PWD endures as the disease progresses is displayed partially in the unpredictability of their emotions and behaviors. As caregivers begin to expect the unexpected, they are forced to adopt an entirely new outlook of their daily life. This research found that a higher quality of life is expected in securely attached relationships. However, it is imperative to note that it is not secure attachment alone that affects quality of life. Attachment is just one portion of the caregiver experience. As understood in reviewing current literature, the stress that caregivers endure is found far beyond digesting the diagnosis. According to previous research, caregivers can become distressed as a result of the broadening of providing care. As the PWD moves through the three stages of dementia the caregiver is forced to quickly learn how and when to provide care for both the IADL, in the first and second stages, and ADL, at the end of the second stage and throughout the third stage (Guo & Sapra, 2020; Small, Gutman, Makela, & Hillhouse, 2003). The unfamiliarity of taking care of a previously capable spouse, sibling, parent, etc. can be surprising and particularly challenging for caregivers. As individuals often experience stress, they tend to cling to what is familiar. If clinicians can help ease the tensions of such unfamiliarity and stress, then there is potential for caregiver and PWD quality of life to increase rather than decrease. Therefore, even if the caregiver and PWD experience insecure attachment, there are alternative ways to continue to enhance quality of life.

**Limitations of the study**

This study was composed of publicly available audiovisual and textual materials. Though these materials had to meet certain criteria to be reviewed, selective ways that caregivers expressed their experience could not be explored. For example, some audiovisual materials used in the coding process were caregivers expressing their story following winning an award. As a result of this platform, the caregiver may have not expressed the challenges of caregiving to the extent that they were experienced. In addition, all textual materials except for the Phase I were found on a UK Dementia databank. These stories were presented in the form of a blog with a lack of uniformity in what each caregiver experience was like across the stages of dementia. Materials with more information on caregiver experience across all stages of dementia would provide more insight on changes in caregiver attachment and identity. Additionally, there were few materials publicly available from the United States. Ideally, this study would have been conducted in person using an interview technique to guide caregivers throughout recounting their experience. Research on this topic would benefit from inclusion of material from caregivers of various age groups and ethnicities. This would have provided an even broader and greater corpus of materials.

**Future Directions**

The caregiver perspective of an EOD diagnosis as it relates to attachment and identity is relatively new to research. As a result, there are numerous ways to better understand the caregiver experience to enhance PWD and caregiver quality of life. It is noteworthy that most of the caregivers in this study gave examples that evidenced secure attachment. There is the possibility that even securely attached caregivers may have times over the progress of the disease

when they are not evidencing secure attachment behavior. This is an interesting question for future research.

Research should be conducted on caregivers of various age ranges and with different relationship types. For example, understanding ways caregivers shift in identity in attachment with a parent versus a spouse versus a sibling. Goal setting would look different for each age group. Additionally, further research should be done on caregivers and attachment for those that have been married long time versus those that are in the early years of marriage. Lastly, more research on changes in caregiver attachment style could include research that would track shifts when the caregiver is no longer providing the primary care, for example when additional help is used in the home or the PWD is placed in a care facility. Clinicians having access to this information would provide them with knowledge on when to recommend additional levels of care and how to introduce those levels of care as dementia deepens to enhance caregiver quality of life.

## **Conclusion**

This study aimed to answer how the quality of life of the caregiver was affected, due to the dementia diagnosis, in hopes that more information can lead to higher qualities of life for those experiencing the hardships of helping a loved one through early onset dementia. Valuable information evolved from the analysis of publicly available sources that revealed consistencies between caregivers as they sought to maintain quality of life for the PWD. The results of this study have the potential to provide clinicians with a model for goal setting with caregivers and partners with EOD that can advance quality of life for persons – caregiver, patient, family – living with dementia.

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## Appendix A

### Key Terms of the Study

**Early Onset Dementia (EOD)**: Any form of dementia that is clinically diagnosed prior to the patient turning 65 years old.

**Secure Attachment**: Defined as when a caregiver is unafraid of accepting the disease and the ways it will alter the lives of both the caregiver and their family. Securely attached caregivers are shown to put the needs of the person with dementia as a top priority and wanting to always provide a sense of security for the PWD.

**Insecure Attachment**: Defined as when a caregiver can acknowledge the disease but is afraid of accepting the ways it will alter the lives of both the caregiver and their family. Insecurely attached caregivers cannot acknowledge the disease in the way the PWD experiences it. Instead, an insecurely attached caregiver only sees the challenges of life from their perspective.

**Self-Identity**: The ways the caregiver attributes who they are, who the person with EOD is to them, and who they are collectively as a couple.

**Reliance**: The caregiver is unaccepting of acknowledging loss and sacrifice. Instead, they are reliant on the PWD to validate who they are. This is shown most explicitly through extensive stages of grief and denial.

**Resilience**: The caregiver is accepting of acknowledging loss and sacrifice. As the caregiver's scope continues to broaden as dementia deepens, the caregiver begins to relax in accepting the things that cannot be changed. This often is shown through the caregiver picking up new hobbies, creating time for friends, becoming more independent, making lists of things to do.

**Fluid Themes**: Themes that are shown consistently in a pattern across materials. These themes can emerge at different times for each story but will consistently be in each story.

**Flexible Themes**: Themes that when put into practice by the caregiver provide relief for the caregiver emotionally. These themes are inconsistent and may appear and evolve as the scope of caregiving broadens and the dementia deepens.

**Denial**: A coping strategy defined as caregivers being unwilling or unable to accept that a loved one is presenting with early onset dementia symptoms or has been diagnosed with early onset dementia. Denial can take the form of justifying symptoms as a normal progression of aging or a moment of distraction/confusion.

**Sacrifice**: A coping strategy defined as the loss of an expectation for how the caregiver should be perceived by the PWD, plans that the caregiver and PWD made regarding their future, and the manner in which the PWD should behave.

**Mental Reframing:** The process by which the caregiver actively changes the way they perceive a challenging circumstance. Mental reframing can look like the caregiver focusing on new skills they learned rather than being frustrated that their spouse, mother, sibling cannot help them. Another way a caregiver can reframe is by removing themselves from an upsetting situation and assess their options prior to responding to the situation.

**Adjustment:** The everyday adaptations made to accommodate caregiving for the PWD. Examples of adjustment are changing the pace or routine, preparing for ways to cope with side effects of caring for a PWD, or altering plans to prevent the PWD from being overly anxious or agitated.

**Reflection:** The process of the caregiver remembering coping strategies that worked, who the PWD was to them prior to the diagnosis, what they learned from caregiving, how caregiving most impacted them, or how they will continue to provide care for the PWD.

**Appendix B**

Possible Combinations of Attachment and Identity of the Caregiver

Simple One-Perspective Use

Securely Attached    Insecurely Attached    Reluctant    Resilient

Elaborated Two- Perspective Use

Securely Attached/ Reluctant

Insecurely Attached/ Reluctant

Securely Attached/ Resilient

Insecurely Attached/ Resilient

## Appendix C

### Examples of Fluid and Flexible Themes and Subthemes

#### *Fluid Themes.*

- Denial
  - Caregivers would often justify EOD symptoms across a variety of contexts. One story explicitly stated, “Her increasingly disorganized behavior and moments of sadness were something we learnt to live with- blaming hormones, tiredness, or simple forgetfulness. Stop it, Mum! I’d say, getting really irritated. I feel terrible when I remember because I know now that it wasn’t her fault” (James’s story, n.d.).
  - During times of denial, caregivers would question the EOD diagnosis. An example from the coded material is best pictured when Vicky took her husband Jeff to a doctor for further clarification on why he was presenting with various symptoms. In reflection of the doctor’s visit Vicky stated, “I didn’t believe the diagnosis. I, I thought that they had, there was just something wrong. There was just stress and so on” (VHA Home HealthCare, 2014).
- Sacrifice
  - Caregivers often must sacrifice the expectation of how they once pictured life. Those providing care to the PWD move from familiarity and comfort to uncertainty. “He can’t change. He acts compulsively out of the demands of his failing brain. Only you can change, by changing your expectation of him.” (Oliver & Bock, 1987).

- Caregivers sacrifice more than future plans with the PWD. Caregivers must sacrifice the concept of ‘normalcy.’ For example, in one story the wife admitted in her blog post, “The man who made me laugh every day from the minute I woke to the minute I went to bed has been replaced by a man who is frequently grumpy, often cross, and seemingly at odds with the world” (Jane’s Story, n.d.). If she continued the expectation that her husband’s mental and emotional state does not alter through the dementing process, Jane would have experienced difficulty coping through the continually progressing stages.
- Mental reframing
  - During the process of mental reframing, caregivers begin to accept who they can be in this new season of life. “She is not the same person I once knew. She has lost the flexibility to have options. But I haven’t. I can choose not to upset myself unduly about what she does- even though I hate the position I’m in, and I still think it’s unfair” (Oliver & Bock, 1987).
  - In Jane’s Story, Jane expressed how she can perceive life in a different way. Even though her life is immensely difficult, she can still see positives things come out of a terrible circumstance. In her blog post, Jane states, “There are positives to this new life in which we find ourselves. I’ve given up work, so we spend more time together. I have discovered the joys of gardening. I have time to walk the dog.... So definitely not all bad” (Jane’s Story, n.d.).
  - Jeff and Kim Borgoff’s family is forced to using the mental reframing coping mechanism following his diagnosis of EOD. Jeff and Kim are “preparing for the worst and praying for the best” (TODAY, 2017). In this circumstance mental

reframing takes the form of expectancy of life to look different than it has in the past.

### *Flexible themes*

- Adjustment
  - Caregivers must adjust from how they once experienced life alongside the PWD. These adjustments can be mental and emotional alterations. For example, Ed always wanted to keep life moving in a fast pace. Ed expresses in a video, “My nickname is ‘Fast Eddie’ and it’s because I tend to get things done in a hurry...Just getting her out of the house and into the car to go shopping is a big deal. And her walk is now a shuffle not a walk so it’s just slow slow, slow” (White & Fitch, 2014).
  - Another example of adjustment is acknowledging and preparing for change in the future. Karen expressed her focus in adjusting to a new reality when she stated, “When the house is quiet, and the house will be quiet someday- and they know I’m trying to accept that” (VHA Home HealthCare, 2017). Karen’s anticipation of adjustment puts her in a position of not being surprised by these changes. Instead, this position allowed her freedom to cope with the evolving caregiving experience.
- Reflection
  - When talking about an experience, people finish the story in reflection of what helped or mattered most during that time- for caregivers sharing their stories this is no different. Dawn reflected on the experience of caregiving for her husband by

stating, “We laughed. I mean that’s how we got through the disease. We had fun. We really did” (mmlearn.org, 2018).

- Another example of reflection is acknowledging what the PWD means to the caregiver and how they made it through those difficult times. James stated, “Looking back, I realize I was very lucky to have a mum who gave everything for her children, which is why I probably felt compelled to give everything back” (James’s Story, n.d.). James remembering his mom’s love for her children aids him in the coping process by allowing him to be grateful for how he could contribute to this season.
- Another way to reflect is to remember what strategies helped in navigating the unknown. Vicky shared what helped most during difficult seasons, “Trying to keep the sense of humor and a positive outlook that is the best way to make it through this. If you continually dwell on the negative, then it’ll just bring yourself down as well” (VHA Home HealthCare, 2014). This form of reflection can help the caregiver cope by remembering that they have and will continue to navigate the unknown, make the adjustments, learn from challenging circumstances, and ultimately find new strength to move forward.

**Appendix D**

Examples of Reliance and Resilience Themes

<b>Caregiver Story</b>	<b>Description of PWD Functioning</b>	<b>Story of Caregiver Experience</b>	<b>Analysis of Caregiver Self-Identity</b>
Tiana's Story	Tiana's mother is still meeting with an empowerment group to continue to have a level of independence. She also has friends come over to help while Tiana is at school. It appears she needs help with instrumental activities of daily living and is in the first stage of dementia.	"The day will come when I wake up one morning and my mum won't recognise me. I know that she will be afraid, and I certainly don't look forward to that, but for now we are enjoying the time we have together and taking each day as it comes" (Tiana's Story, n.d.).	Tiana shows resiliency. She is accepting that at some point in life there will continue to be more loss and greater sacrifice. She is thinking about her mom in not wanting her mom to be afraid of this time. Tiana is wanting to make the most of the time she has left with her mom. As a teenager, Tiana shows immense strength.
James' Story	James' mother was unable to do activities that she once enjoyed. Based on contextual evidence and the loss of instrumental activities of daily living, James' mother was in stage one or two.	"We needed to find a new way to keep her busy and give a sense of purpose. If only we could find ways to bring her back. We wanted more than anything to see her face light up, and those moments when she looked happy or excited, however brief, became precious" (James's Story, n.d.).	James shows resiliency in this context. He accepts loss as it pertains in this situation- the loss of his mother's social calendar. James moves beyond just accepting the loss by desiring to enhance the quality of life for his mom. He does this by creating new opportunities for her to find a sense of purpose.
Carol & Ken's Story	Carol is placed in a care facility at the time Ken tells the story. Carol appears to need help with	"Pick's disease and all forms of dementia are the cruelest disease on the planet. It takes away the person, they are out of it so to speak. They	Ken appears to be reliant in this context. Ken is unwilling to accept loss and sacrifice. He understands that he is

	<p>instrumental activities of daily living and potentially some help with activities of daily living- suggesting she is in stage two or three.</p>	<p>don't realise what effect it has on to the people who are caring for them. I think the careers suffer the most. It is both a physical and mental strain on the careers and those close to the person with dementia" (Carol &amp; Ken's Story, n.d.).</p>	<p>experiencing loss, but he has not been able to move past the grief and hurt of loss. He believes this disease is hardest on the caregiver, but he never mentions the experience for Carol or how she perceives life. He appears to need Carol to validate him and their relationship instead of having the effect that she is having on him as a husband-and-wife team.</p>
<p>Karen &amp; Jack's Story</p>	<p>Jack is unable to perform the essential activities of daily living. At this point in the story, Karen is dressing Jack and primarily ensuring that he continues to have proper hygiene. Therefore, Jack is likely in the third stage.</p>	<p>"I want Jack to look nice. I want him to smell nice. I want him to have the dignity and respect that he deserves. I want him to wear his clothes every day and not be in his pajamas" (VHA Home HealthCare, 2017).</p>	<p>Karen shows resiliency in this context. She accepts what Jack cannot do and thinks about his desires along the way. Karen wants Jack to receive the "dignity and respect he deserves." Therefore, she is willing to sacrifice time and energy to ensure that.</p>
<p>Vicky &amp; Jeff's Story</p>	<p>Vicky is having to take care of all the essential activities of daily living. Based on various pieces of contextual evidence, Jeff is in the third stage of dementia.</p>	<p>"Trying to keep the sense of humor and a positive outlook that is the best way to make it through this. If you continually dwell on the negative, then it'll just bring yourself down as well" (VHA Home HealthCare, 2014).</p>	<p>Vicky shows resiliency in this context. She had to make the difficult decision to place her husband in a care facility. Despite this enormous difficulty, she acknowledges that a positive outlook is the only way to make it through the challenges.</p>

## Appendix E

### Coding Directions/Questions

Directions: Answer the following (A) and (B) questions for each of the segments. Only one response can be marked in for each question. Mark each answer choice (yes and no) after looking for descriptive features within the sentence. If you cannot decide between answer choices for a question, do not mark a response.

#### I. Caregiver Identity

- A. Does the caregiver respond with a sense of stability when acknowledging his/her current circumstances? (Yes No)
- B. Does the caregiver seem unable or unwilling to see life beyond the scope of the pain they are currently experiencing with the PWD? (Yes No)

#### II. Caregiver Attachment

- A. Does the caregiver explicitly want to put the patient's needs as a first priority?  
(Yes No)  
Work to maintain the identity of the patient? (Yes No)
- B. Does the Caregiver get swept away in the challenges of life that they lose sight of who the PWD is to them? (Yes No)
- C. Does the text specify close communication/ interaction with the PWD?  
(Yes No)

## Appendix F

### IRB Grant Exemption Notice



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**To:** Fran W Hagstrom  
GRAD 303

**From:** Douglas J Adams, Chair  
IRB Expedited Review

**Date:** 07/23/2020

**Action:** **Exemption Granted**

**Action Date:** 07/23/2020

**Protocol #:** 2007271812

**Study Title:** The Shaping of Identity when Living with Dementia

The above-referenced protocol has been determined to be exempt.

If you wish to make any modifications in the approved protocol that may affect the level of risk to your participants, you must seek approval prior to implementing those changes. All modifications must provide sufficient detail to assess the impact of the change.

If you have any questions or need any assistance from the IRB, please contact the IRB Coordinator at 109 MLKG Building, 5-2208, or [irb@uark.edu](mailto:irb@uark.edu).

cc: Benjamin Joseph Wright, Key Personnel  
Claire Elizabeth Wood, Key Personnel  
Annabelle Christine Linker, Key Personnel