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Loss and Attainment of Identity for Individuals Experiencing Early Onset Dementia

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Abstract

Qualitative research over the last decade suggests that connection with others and continued engagement in everyday life contribute to quality of life for those with EOD. This study aimed to map how personal and socially attributed identity shifted as everyday life changed over the dementia continuum. The goal was to determine if common narrative and life story themes marked key indicators of perceptions about and maintenance of self, others, and everyday life roles. The materials of the study were eleven open-source video, audio, and written documents submitted by individuals experiencing EOD and their family members for public use. The selected corpus of data was read for focused themes and subthemes related to disease description/symptomatology, behavior challenges, and situational needs. Participant stories in the first and second phases of the dementia continuum described how inclusion in everyday life activities, their roles within these activities, and interactions with others were keys to personhood preservation. Perceived loss of personhood was linked to exclusion and isolation by others from everyday life participation and sustained role activities. As the disease progressed, the responsibility of personhood preservation and identity attribution shifted from the person with EOD to those who assumed caregiving roles. Identified themes reflected how both preservation and loss of identity influenced the perceived quality of life.

Loss and Attainment of Identity for Individuals Experiencing Young Onset Dementia

Dementia is an incurable, neurogenic disease characterized by the general loss of cognitive functions that impedes everyday life. Dementia shatters lives as it disrupts memory, inhibits both receptive and expressive language, erodes problem-solving strategies, and creates trouble with daily tasks. Most importantly, it painstakingly robs what most makes people human: the connection to other people and the world around them (Cole, 2019). It strips individuals of their recollections of the past and their innate abilities to plan and predict future events, leaving them stuck in the only thing remaining, the present. As the severity of the symptoms increases, individuals eventually lose their self-perception, and others may no longer perceive them as the people they once were (Shadden, Hagstrom, & Koski, 2008). Since the person with dementia (PWD) cannot prevent the loss of self-awareness despite their efforts, how can caregivers, speech-language pathologists, and other medical professionals protect and preserve the sense of identity the PWD deserves?

Review of the Literature

Overview of Dementia

Dementia is a neurological condition characterized by progressive changes in memory, emotion, language, and mental functioning that separates the individual from social others and meaningful participation in everyday life (Damasio, 1993). As of 2010, it was estimated that 24.3 million people in the world were experiencing dementia, with 4.6 million new cases diagnosed each year. It was also estimated that the number diagnosed would double around every two decades, leading to a total of over 81 million by 2040 (Tripathi & Vibha, 2009). Therefore, dementia is not a small or insignificant problem across worldwide societies. It impacts mothers, fathers, grandparents, and even younger people, removing them from fulfilling lives to

seemingly mindless individuals dependent on others for the most straightforward goal-directed actions. Beginning with mild memory loss and disorganization, the disease progresses to total disability as defined by the ability to think, problem-solve, and remember from one moment to the next.

Dementia is often thought of as a disease process associated with aging and viewed as an aspect of growing older. Nuland (1994), when reviewing the history of dementia, summarized the work of Penel and Esquirol, published in the mid-1800s, that described behavioral symptoms and progression of the disease in individuals in their fifties. Reports and research through much of the 20th century referred to dementia as Alzheimer's Disease, in honor of Dr. Alzheimer's identification of senile plaques and fibrillary tangles that change the brain's cortical cells. According to the historical overview on the Alzheimer's Association website (2020), Dr. Alzheimer was struck with a variety of problems that included psychological changes and memory loss in one of his patients. His description of the symptoms' progression and lack of response to treatment led him to postmortem analysis of brain tissue. Alzheimer's patient analysis ultimately led to a reconceptualization of the combined psychological, behavioral, and neurological symptoms as descriptors of dementia that are hallmarks of today's understanding of the disease process.

Early Onset Dementia (EOD)

As individuals' lifespan in the United States and other industrialized cultures expanded to and beyond the seventh decade, the diagnosis of dementia emerged more frequently in the older populations. The same disease process but in individuals under the age of 65 began to appear in the research literature at the dawn of the 21st century, given the diagnostic label of early-onset dementia (EOD). The Alzheimer's Association funded and produced an extensive report on EOD

in 2006 that described it as a national challenge that ended with a call to action that would address the quality of life changes for those affected, including their families.

Around 5-6 % of all diagnosed dementia cases are younger onset dementia (Mayo Clinic, 2019). The incidence of EOD is reported to be approximately 5-6 per 100,000 people with ages from 30-49, which then triples with people in the 50-64 age group. In each subsequent 5-year interval following age 65, the rate of dementia increases two-fold (Garre-Olmo, et al., 2010). As of 2015, there were 200,00 cases of EOD diagnosed in the United States alone, with the anticipated diagnoses only to increase as time goes on (dementia.org, 2015). There is some evidence that EOD is more likely to be genetically based, as 10% of these patients report a parent or grandparent experiencing dementia (Alzheimer's Society, 2020). Suppose EOD is linked to a recognized genetic condition, such as the MAPT gene (Jiang, S., et al., 2018), and the individual is the first in the family history with dementia. In that case, it may have serious implications for brothers, sisters, and/or children of the person with EOD (Alzheimer's Society, 2020).

Early-onset dementia presents circumstances typically not faced by their regular onset dementia peers. Due to the disease's cognitive nature, catching it early on and identifying possible non-genetic factors is nearly impossible until the disease is debilitating. Individuals with early-onset dementia are commonly much healthier and do not have histories of heart diseases and circulation issues. Patients tend to be more physically fit, and if diagnosed, dementia may be the only health-related ailment an individual and family are facing. Taylor (2015) argued that some patients might sustain a high quality of life with few outwardly exhibited dementia-like symptoms if they have a robust vocabulary, learn continuously, and are extroverts used to conversing and sharing their life experiences. His lived experience and observations suggests that a proactive approach to living and adding quality of life may shape disease progression.

Everyday Life Impacts of Early Onset Dementia

Aside from the worry for patients and their family's future, ordinary life circumstances are entirely altered. EOD patients are more likely to be working a full-time job with some advancing in their careers. They may have a partner who is also working full time with similar career aspirations. They may have dependent children, whose education is being financed by the individual. They may even be caring for their own aging relatives. Lastly, their fiscal responsibilities may include mortgages, car payments, medical copays and deductible, etc. that complicate everyday life if one's income is lost, leading to serious financial concerns (Alzheimer's Society, 2020). These 50–60-year-olds who have seen themselves as successful individuals working hard to have a good life, begin to experience cognitive changes that may lead to loss of jobs or early retirement, as well as increased dependence on support systems to manage everyday life (Garre-Olmo et al., 2010). The working spouse/partner/family members may be faced with planning activities of daily living for those with EOD. Shared income, home management, and social activities are shifted to sole responsibilities. Perhaps more significantly, the loss of personhood is keenly felt because of life situations linked to everyday activities that have been purposeful and meaningful in mid-life.

The decimation of a person's expected life course upon a diagnosis of dementia can differ between EOD and retired individuals due to differences in what constitutes a meaningful life. This can be complicated by the manifestation of preceding stressors in different ways (Johannessen, et al., 2018). In this process, first individuals and then their families struggle to cope. They may conceal the diagnosis, refuse to acknowledge it, experience social retraction, and suffer existential anxiety. These are realistic though negative coping strategies some patients

may cycle through during the shock of diagnosis and may impact how they live their lives afterward.

Hagstrom (2008) describes three phases of dementia. First, the *beginning phase* (Phase I), which is accompanied by the shock of the diagnosis of a person experiencing dementia and their family with minimal communication complications. Next, the *middle phase* (Phase II) when the patient accepts the disease, is noticed and accepted by others, and the symptoms are unmistakable. And lastly, the *later phase* (Phase III) when patients pose a real danger to themselves and likely are moved to professional care. Individuals cannot communicate outwardly to the world surrounding them. Hagstrom (2008) used the story of an older woman with dementia to write about the three phases of dementia. The account begins as 'Flo' moves from her home to reside with her daughter while she can still manage life and ends in the final phase at which point in Flo's story was no longer hers to be told, instead it was told through others, some of long-standing and others newly met (Shadden, Hagstrom, & Koski 2008). This perspective on the progression is consistent with increased difficulty with instrumental activities of daily living (IADL) such as driving, shopping, and managing a budget, to loss of independent management of essential activities of daily living (ADL) such as eating, toileting, and dressing (Guo & Sapra, 2020; Small, Gutman, Makela, & Hillhouse, 2003).

In contrast to Flo, Richard Taylor, a clinical psychologist, was diagnosed at age 58. He was determined not to hide his struggles but openly shared them as a model for maintaining selfhood for as long as possible. During the introduction to his book, *Alzheimer's from the Inside Out*, Taylor (2007) suggests, "Writing about things can be immensely helpful when talking about them is no longer working" (p. xviii). This powerful, simple suggestion from Taylor brings forth an important concept for EOD patients, setting up their account of their stories for when they

will no longer be able to do so. These two accounts provide a contrast between early-onset dementia and late-onset dementia, as well as possible similarities in the struggle to maintain a sense of self.

Self-Identity and Narration

Individuals' self-identity must always be considered a quality of life goal during treatment and care providing of those with dementia. Hagstrom and Daniels (2004) define identity as "...the representation of oneself that emerges from participation in/with multiple groups across social context..." (p. 217). They contend that identity is socially bound, created, and altered by how people relate to the world surrounding them. When asking someone a seemingly simple question such as "what is your identity?" people may struggle to answer. Still, simple questions may elicit intriguing, complex answers that reflect their sense of identity. Questions such as "Who am I?", "Who are you?", "Who are we?" catalyzes answers that prompt personalized stories. The responses reflect how they fit into a larger social whole through reference markers such as painters, husbands, sons, athletes, consumers, producers, citizens, etc. From this powerful naming of roles, people personalize how those labels apply to themselves, how they influenced life around them, and how their lives influenced them.

Using narration as a key to maintaining self was the same process suggested by Taylor (2015). From the seemingly insignificant tales one might tell their loved one about their workday to delivering a best man speech, fragments of life are stitched together by storytelling. Narrating acts as a tool for understanding oneself and communicating with others (McAdams, Josselson, & Lieblich, 2006). A diagnosis of EOD adds a new chapter and ultimate rewriting of life narrative.

As patients come to terms with EOD, successful patients (referring to those who have kept it at bay for long periods) view their story as a quest narrative. They seek to tell and retell

the crisis they are facing to those surrounding them to create a conflict, in this case, their mind, to fight back against returning to the normal that they all once knew. For the patients of EOD and their families, it is a life-altering event. Patients seek solidarity with their loved ones and with other patients. Regardless of the amount of fight that each patient puts out against their opponent, their struggle eventually ends. They fight their illness by spreading awareness through videos, stories, poems, bike rides, dances, and various other personally relevant activities to tell their story and make sure they are remembered for the person they were/are.

Summary and Questions of the Study

Dementia is an incurable, neurogenic disease that can strike at any age. Dementia is increasing in individuals younger than the age of 65. This increase is particularly concerning because these individuals are in the prime of life, working, raising families, and contributing to society on numerous levels. While first identified in 1907, there is still no cure for this neurogenic disorder regardless of the age of onset. While medical science continues to seek treatment or at least something to slow the disease progress, the quality of life of these individuals and their families is a pressing and perhaps attainable therapeutic goal, but only if more is understood about the identity and narrative shifts personhood for individuals experiencing EOD. The purpose of this study was to build on prior qualitative research to map the ways that personal and socially attributed identity shift as quality-of-life changes with disease progression. The goal is to provide insight about the triangulation among progressive loss of personal identity, stages of dementia, and quality of life. The specific questions of the study were as follows:

1. Are there similarities of themes in the stories of individuals with EOD?
2. Do the themes change in similar ways across the three phases of dementia?

3. Do the themes reflect how sense-of-self is maintained or rejected through the progression of the disease?

Methodology

Materials

The materials of the study were eleven open-source video, audio, and text material submitted by individuals experiencing EOD and their family members for public use. They were found in books, internet blogs, websites, and posted YouTube videos.

Procedures and Analysis

Additions to the collection of materials were on-going until major and minor themes had solidified through narrative analysis (Hagstrom, 2004). The procedure for analyses began with line-by-line transcripts of the textual, video and audio materials. Thematic analysis of the corpus was segmented into the progression of dementia identified by descriptions of symptoms associated with the initial phase of diagnosis; the middle stage when individuals are struggling to maintain everyday life; and the late stage when they are unable to care for themselves. These sets were read for two sets of focused subthemes. The first of these were read for disease description, behavioral challenges, situational needs, and themes associated with personal identity and quality of life changes. The second reading identified themes that focus on attributed self-identity, attributed self-identity of the caregivers, and attributions of identity toward others, whether a person experiencing EOD or a partner/caregiver.

The cross-coded themes that emerged from the qualitative analysis described how personal identity was grounded in interactions and daily living across the three phases of dementia. These findings were compared and contrasted with earlier research on EOD as well as the literature on social identity in other clinical populations (Shadden, Hagstrom, & Koski, 2008)

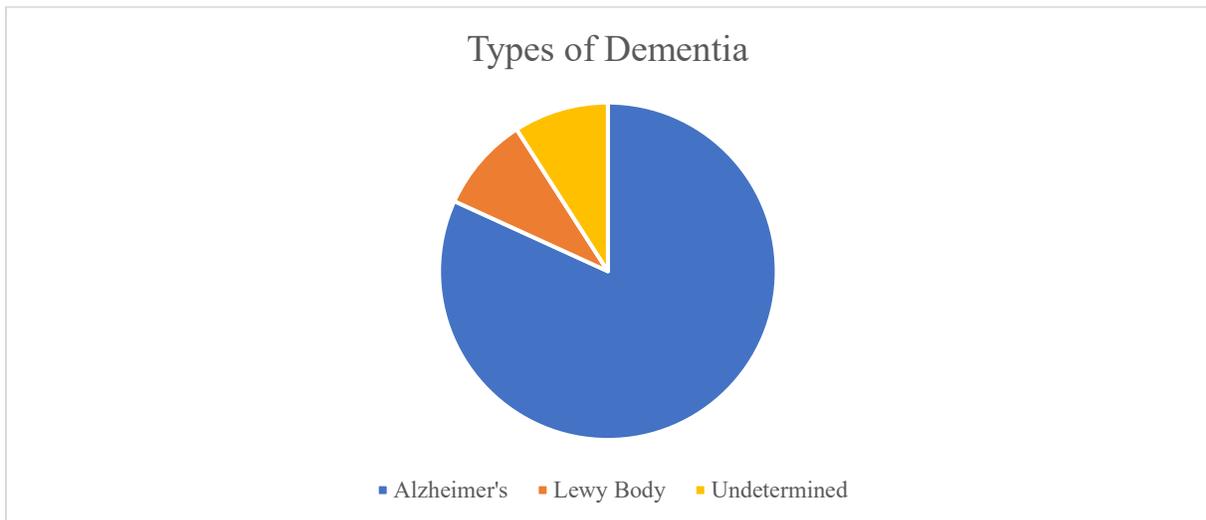
Results

Demographics

The materials of the study were open-source video, audio, and text material submitted by individuals experiencing EOD and their family members for public use. While only the publicly available stories were used as data, these stories were told by individuals. Therefore, the writing convention of using the word 'participant/s' are used to describe the story tellers. Participants were individuals below the age of 65 who had been diagnosed with some form of dementia such as Alzheimer's, frontal-temporal, vascular, and Lewy Body. This distribution of kinds of dementia are displayed in Figure 1.

Figure 1

Types of Dementia Reported by Participants

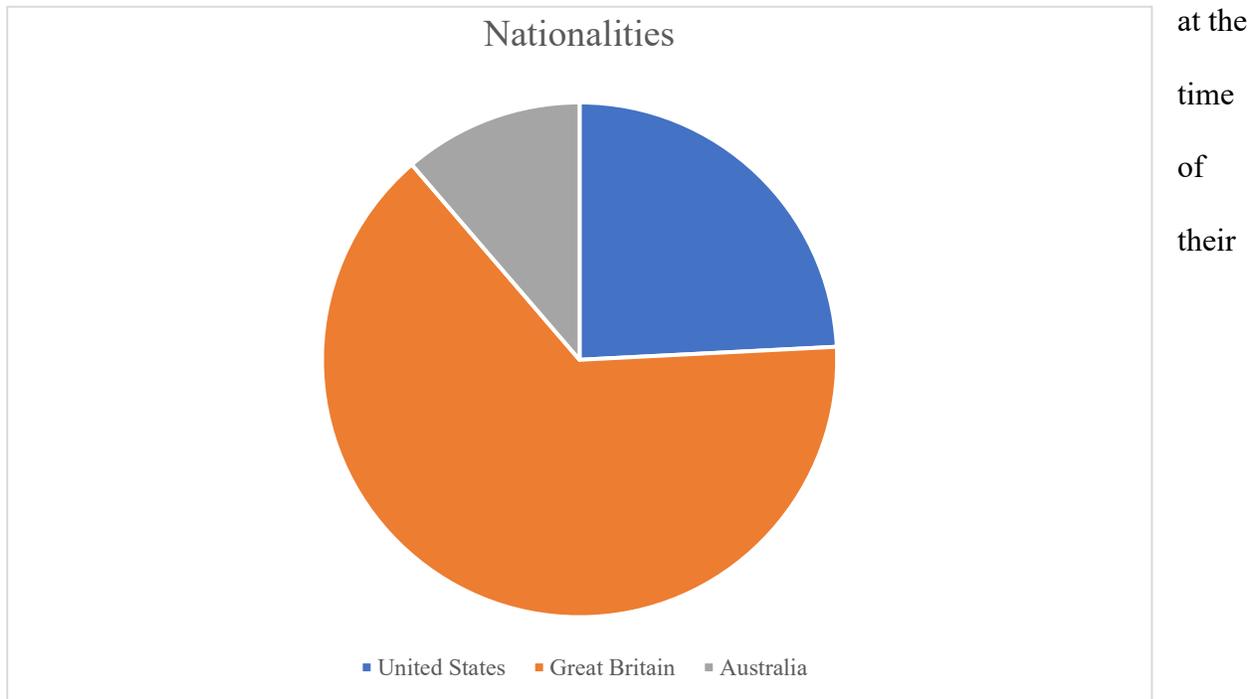


Three participants were from the United States, six from the United Kingdom, and one participant from Australia. Figure 2 illustrates the nationalities of the participants.

Figure 2

Nationalities of Participants

All stories were written or spoken in English by individuals who were in the workforce



respective dementia diagnoses. Their careers were in commercial real-estate, psychology, the arts, education, academics, and government level positions. In total, nine of the stories were from individuals who identified as male and two who identified as female. The criteria for selected publicly available storied material (YouTube, websites, published books) included individuals who had self-identified with early onset dementia and provided information in a narrative, story-telling style. The sample included stories told/written by the individual with EOD in the earlier stages of the disease while the story telling became intertwined with those of the caregivers as the dementia processed. Examples from four individuals abstracted from the corpus are used as data point examples across the questions of the study.

Question One

The first question of this study asked if similarities of themes were present in the stories of individuals with EOD. Data from all eleven stories were used to answer this question. The first reading was for disease description, behavioral challenges, situational needs, and themes associated with personal identity and quality of life changes. The second reading identified themes that focused on attributed self-identity, self-identity attributed to the caregivers, and attributions of identity toward others whether a person experiencing EOD or a partner/caregiver.

Two major themes emerged in the stories of individuals with early onset dementia. First, the feeling of being lost (i.e., isolated, confused, miscommunicated with, excluded, depressed), and the effort expended for preservation of personhood not only for themselves but also for other individuals with early onset dementia. Second, the participants identified how inclusion in everyday life activities, their roles, and interactions were keys to personhood preservation. Among the participants of the study, subthemes were also identified. These subthemes, which contributed to major overarching themes of either loss of personhood or preservation of personhood, were prevalent across stories and within the stories of individuals. The definitions of the major and minor themes are available in Appendix B and reported in Table 1 below.

Table 1

Major and Minor Themes in Personal & Socially Attributed Identity

Major themes	Minor Themes
Personhood Preservation	Advocacy
	Legacy-Building
	Community
Loss of Personhood	Exclusion
	Isolation
	Withdrawal

Question Two

The second question of this study asked if themes changed in similar ways across the three phases of dementia. It was not possible to determine the specific phases of dementia experienced by individuals or how these shifted since the stories were not longitudinal for single individuals. It was possible to identify stages within single stories. Therefore, this question was answered by using individual snapshots and within story reflections/contrasts between the time of the story telling and how the dementia was described. Descriptions provided by individuals experiencing dementia tended to match the criteria for late stage I and much of stage II dementia. Co-constructed stories that included both the PWD and a partner/caregiver matched the criteria of mid-to-late-Stage II dementia. No individuals directly providing information by the time the PWD was in Stage III.

Loss of personhood through exclusion. One participant, Tommy (Dunne, n.d.) shared this when describing feeling of being excluded. He related this within a story about golfing with his wife. His wife's friends came up to them and the friends ask her how he was even though he was standing right there. In the story Tommy related about this experience he said:

It was at this point I realized that when you get dementia you gain a superpower; you have the ability to become invisible.

This same kind of experience occurred a little later in the progression dementia while interacting with a caregiver. He summarized this in his reflection by saying:

We can follow a conversation, but no one gives us a chance to answer and people always ask us closed questions, you know - are you alright?

Tommy was speaking as a person who was reflecting his sense of identity as a member of the EOD community at large. This was expressed by other participants in this study who also felt

excluded when caregivers or care teams did not acknowledge that they were also still present in the planning process for care. Tommy talked about exclusion this way:

It is important to plan for when the individual will no longer be capable of making healthy decisions regarding their health plan, assets, responsibilities, but the importance of acknowledging the individual as someone who is still present must not be understated.

Tommy continued to advocate his belief writing:

People are in for a big surprise when they realize that we still have our intelligence, we can still think, the only difference is, we just need a bit of time to get the words out. The words are in there, so please have patience with us. There is so much to tell.

Personhood perseverance through legacy building and advocacy. In identifying themes of preservation of personhood, participants wanted opportunities to express themselves. They wanted opportunities to share tips with others currently with dementia or those in the future with dementia and chances to simply speak their minds. Participant Taylor (Taylor, 2007) eloquently stated:

When I started to write these essays, it was not my intent to address them to care givers. I wrote to clarify for myself what was going on with and in me. Then, I showed them to a few other people who shared my diagnosis of early onset, early-stage Alzheimer's disease. I saw their eyes brighten and sometimes fill with tears as they read of some of their own issues in my writings. It was then that I decided to share my writings with others. I wanted others to know they are not alone with an Alzheimer's changing mind. There are others with them on the Alzheimer's

road less traveled who are uneasy about the present and the future, and unable to figure things out as they have in the past.

Each participant of the study exhibited a similar desire, whether explicitly stated or not, to share their personal story as a contribution to the battle against the disease.

Joint construction of personhood stories. The vignettes that follow illustrate the intersection of personhood and progression of dementia. It became evident in the coding of these stories that the preservation of personhood as the disease progressed shifted from the individual with early onset dementia to the caregivers. In the instance of 'Christopher' and 'Veronica' (BBC News, 2015), it was evident that he was gravitating towards the middle stage of illness from his description of how Veronica began to assist him with communication. It appeared that this was consented. In other case where individuals were earlier in the disease process during the brief snapshot that they provided, they often felt alienated from situations when caregivers prematurely did not provide them ample opportunity to share.

Question Three

The third question of the study looked at how sense-of-self was maintained or rejected as the disease progressed. Data from all eleven stories were used to answer this question. The first reading was for disease description, behavioral challenges, situational needs, and themes associated with personal identity and quality of life changes. The second reading identified themes that focused on attributed self-identity, self-identity attributed to the caregivers, and attributions of identity toward others whether a person experiencing EOD or a partner/caregiver.

Data collected for this study shows how sense of self is both maintained and rejected through the progression of the disease. The very essence of dementia is that it steals away personhood as it disrupts memory, inhibits both receptive and expressive language, erodes

problem-solving strategies, and creates problems with daily tasks. Most importantly, it causes those afflicted with it to gradually lose self-perception, and others, including family, may no longer perceive them as the people they once were. The feeling of being lost, or losing one's personhood was seen through the isolation, exclusion, depression, etc. that arose after diagnosis.

Many of the individuals felt the same loss of personhood in the initial phases of the disease. They described a sensation of isolation when waiting for diagnosis, a limbo of sorts (even purgatory) when waiting to "see what was wrong" or waiting to find the etiology of their symptoms (Taylor, 2007). One participant, Alex (*Alex's Story*, n.d.) reported:

Whilst undergoing tests and waiting for an answer to my problems I started losing self-confidence and felt scared as I didn't understand why my concentration and memory was slipping.

Being a person with early onset dementia is also seen as an addition to identity, but it is not as simple as that. This clarity is enlightening as it finally ends the question of "what is wrong, why am I not performing the same way, what is happening," and so forth. Christine (Bryden, n.d.), a participant who had been involved in academics stated this after her official diagnosis:

I was so relieved to be no longer working, as it had become such a struggle over the last few years, with blinding migraines every week. It was these terrible migraines – beginning on Monday and only easing the following Sunday - that had made me seek medical help. It took five years before the doctor finally referred me for a brain scan.

The individual must grapple with the all too real diagnosis mental, emotional, social, and financial ramifications of the diagnosis. Participant, Alex (*Alex's Story*, n.d.), described the impact of diagnosis on his professional life and emotional wellbeing:

Losing my job had a big impact on me, even though my employer treated me well and allowed me to retire with a full pension, which I am very grateful for as I know others are not so fortunate. It also led to my downward spiral into dark thoughts of suicide.

Almost all participants featured in this study described at least some instance where they considered suicide, fell into depression, or felt existential dread.

Aside from the person with dementia, the responses other people can influence perceived personhood. This can include a range of individuals such as caregivers, employers, friends, family, and even strangers. The identity they attributed to the individual is equally as important as the identity attributed by the PWD to themselves. In the instance of the caregiver Karen talking about her husband, Jack (VHA Home HealthCare, 2017), she shares her attribution of progressive loss of his identity as they had once known it:

He can't do anything for himself. Jack can't get out of his bed, he can't take the covers off if he's hot, he can't feed himself, he can't talk. And the walking is down to a shuffle....
I want Jack to look nice. I want Jack to smell nice. I want the dignity and respect that he deserves. I want him to have his clothes on every day and not be in pajamas.

As evident by the inability to perform ADLs present in this example, Jack was in the late phase of dementia where all identity is being attributed to him through his wife. She also seeks to give others the opportunity to attribute personhood to Jack by maintaining his appearance through things such as clothing and his hygiene.

When given the proper opportunity to share their experience, the individuals are able to express themselves to the best of their abilities and their wants and needs. Alex (*Alex's Story*, n.d.), who had a passion for music wrote:

I aim to continue playing with the band but it is getting harder so have already found my own replacement as the band want to continue. I will keep writing for them.

Several other participants felt that continuing passion, such as painting, writing, walking, and other valued activities, helped them maintain themselves. It also allowed them to advocate for their own identity, and through sharing their positive experiences, advocate for other individuals with early onset dementia to pursue a higher quality of life rather than rejecting life while living with their diagnosis.

The most noteworthy pattern than emerged from the data used to answer the third question of the study was that participants in the study were all driven to share their experiences for fellow patients, caregivers, and family alike. The overarching theme was that working to maintain a sense of self for yourself has personal value, value for your core support group/family, and for all those who may read or hear your journey with dementia. Past sharing their stories on in the public venue, many of them continued to detail strategies they used to cope with dementia through continued YouTube videos, blogposts, Twitter accounts, and other outlets until they were no longer able to do so even with assistance from others.

Discussion

Qualitative research over the last decade suggests that connection with others and continued engagement in everyday life contribute to quality of life for those with EOD. Marks of engagement are inherent in the narratives told by individuals experiencing EOD and those told by family members and caregivers that are the fabric of social connection (McAdams, Josselson, & Lieblich, 2006). This study aimed to map how personal and socially attributed identity shifted as everyday life changed over the dementia continuum. The goal was to determine if common

narrative and life story themes marked key indicators of perceptions and maintenance of self, others, and everyday life roles.

Participant stories in the first and second phases of the dementia continuum described how inclusion in everyday life activities, their roles, and interactions were keys to personhood preservation. They also expressed their negative feelings when excluded by others from everyday life participation and roles. Individuals with EOD and their partners jointly constructed late phase two stories while caregivers solely provided the phase three stories. As the disease progressed, the responsibility of personhood preservation and identity attribution shifted exclusively to others around the person with EOD. Identified themes reflected how both preservation and loss of identity influenced the perceived quality of life. This aligns with Nuland's (1994) depiction of dementia from diagnosis to death. The goal of his book was to share not only a medical description of the dying process but also the personal and interpersonal aspects of care and letting go. In the chapter on dementia, he prioritizes the shifting roles and personal toll on the patient and family as the mind and body are gradually lost in the daily living and often slow process of dying.

Marks of engagement are inherent in the narratives told by individuals experiencing EOD and those told by family members and caregivers that are the fabric of social connection (McAdams, Josselson, & Lieblich, 2006). The resulting coded themes from individuals with early onset dementia selected for the corpus of data for this study were consistent with what was present in the literature. Individuals with EOD undergo a myriad of unique struggles due to their age and life circumstances at the time of diagnosis. Many of the participants detailed the struggle of losing their careers, worrying for their family, and the possible "burden" they may present to their loved ones. Facing these challenges, participants of the study described the process of

social retraction and alienation from the people that they were before their diagnosis. Through the process of sharing their stories, either through video or writing, individuals with EOD were able to create a lasting record of themselves. This act of personhood preservation allowed them to do several things: maintain/document their identity despite the progression of the illness, advocate for others with early onset dementia, and most importantly, to fight with all their being to remain the people they were before.

The findings of this study are consistent with the outcomes found by Johannessen and colleagues (2018) that identified connection with others and continued engagement in everyday life as things that contribute to quality of life for those with EOD. The narratives analyzed for this study identified stressors such as finances, the struggle of leaving their professional life, and personhood concerns as they began to grapple with life even in the early stages of living with EOD. While the eventual loss of self-perception is inevitable, the quality of interactions with caregivers, family, friends, and care team members is a vital variable that may be controlled and maintained throughout the dementia continuum. Improving the quality of meaningful interactions between the person with dementia and others (caregivers, family, friends, care team members, etc.) through inclusive, engaging conversation in everyday life and role involvement contributed to a perceived higher quality of life. If they are still perceived as the person they once rather than just a person with a neurodegenerative disease, who may be coddled and not shown attention due to their health status, personhood will be better preserved rather than needlessly lost due to lack of acknowledgement.

The conclusions of this study also agree with other literature concerning the importance of preserving identity throughout the dementing process (Shadden, Hagstrom & Koski, 2008). As noted in much of the dementia literature, individuals with early-onset dementia exhibit a

strong sense of personhood throughout the disease continuum that must be recognized, understood, and respected. In efforts of honoring personhood through personalized care, family members, health professionals, and other members of the community will be able to create a space of caring that recognizes that individuals with early-onset dementia exist beyond their disease (Sakamoto, Moore, & Johnson, 2017). Individuals with EOD do have a voice that reflects their perceptions of personhood means to them and this should be listened to and considered throughout the treatment process. Speech-language pathologists (SLP) are especially suited to facilitate communication that empowers those with EOD and their family members to preserve personhood.

Limitations:

It was challenging to find data that was coming from the individuals who were diagnosed with early onset dementia. Much of the publicly available content (YouTube videos, blogs, books, etc.) are from the perspective of caregivers, family, and friends for those intended audiences. These are important audiences of course, but not much is offered in the realm for the individuals with EOD themselves. When data is available from the individual with EOD, it is often in the context of providing endorsements for specific healthcare facilities, treatment services, or doctors, so information provided is perhaps biased towards positivity.

It was also difficult to find materials from participants who were in the later phases of dementia or their family members, which would have contributed more data for the first question of the study. These individuals have been part of various research studies, but not involved in narrative data collections possibly because their receptive and expressive language is progressively inhibited. Stories from caregivers and family members were also rare as cared for the person with EOD becomes more time consuming in the later phases.

The participants of this studies were largely diagnosed with Alzheimer's disease as the etiology for their dementia. While this is representative of a majority of both early-onset dementia and regular-onset dementia, there may be differences in self-identity and personhood preservation dependent on the etiology of the dementia diagnosis. This is because of possible variations in the progression (gradual, rapid, stair-step due to ischemic events) associated with different diseases.

Each participant's story, while rich with data points that resulted in the coded themes of personhood preservation and loss of personhood, were only snapshots of where they were mentally, emotionally, and physically at the time that they were documented (written, audio, visual). While these snapshots are illuminating of what they were experiencing, as the disease progresses, so does their experience and opinions of it and themselves. This study does not provide, nor does it claim to, longitudinal data on individuals with EOD that may be relevant to caregivers, family, and healthcare professionals providing support to those with EOD.

Future Directions:

This study could be continued in a longitudinal, interview format to track specific participants as they progress through the dementia disease process to provide more insight to the long-term fight for identity in relations to quality of life in individuals with early-onset dementia. There could be a partnership with a long-term care facility or memory care unit to continue the study of identity in those with EOD.

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Appendix A

Institutional Review Board Exemption



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.

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

Appendix B

Definition of Terms

Personhood preservation: An overarching term that encapsulates experiences, actions, ideas, roles, that promote the sense of self for individuals with EOD and their sense of connection to others and the world. This can be exhibited through advocacy, legacy activities, and community seeking among other things.

Loss of Personhood: Actions and interactions that lead to isolate and exclude the individual from others around them. Also, actions that contributed to withdraw from others. Loss of personhood may be from the effects of disease but also from interactions with caregivers, family, healthcare professionals, etc.

Advocacy: The act of the individual with EOD acting on behalf of themselves as someone with dementia. It also encapsulates sharing information (whether it be their story, tips, coping strategies) so that other in the future with dementia and their caregivers.

Legacy: Actions of the individual that contribute to their personal legacy as an individual person but also for their remaining family and caregiver's future.

Community: Actions and ideas that contribute to the individual with EOD finding solidarity with others currently afflicted with EOD or to connect to their community.

Exclusion: Actions by others without that lead to the exclusion physically or non-acknowledgment of those with dementia. This can be seen in life roles, participation/exclusion.

Isolation: A theme that contributes to the loss of personhood. Individuals with EOD experience Isolation when excluded from everyday life role, which is out of their control (i.e., power dynamics may not be in their favor).

Withdrawal: Withdrawal contributes to the loss of personhood in individuals with EOD. It may be conscious or subconscious response due to diagnosis and the diseases effects on cognition that some. Withdrawal may result from isolating experiences and exclusion behaviors unwittingly exhibited by caregivers, family, friends, and other people without dementia.

Appendix C

Cross-Coding Instructions

1: Read transcript for disease description (info analysis), behavioral challenges (patient categories—what were they experiencing literally), situational needs (patient needs/caregiver needs), and themes associated to personal identity (possible themes).

2: Reread transcript for attributed self-identity (noted in patient categories, themes), attributed self-identity of caregivers (on the person with dementia or themselves if applicable, seen in patient categories/caregiver behavior).

-Look at excerpts with these themes in mind:

-What is the person saying literally?

-How does affect them as a person (does is contribute to identity or “take away” identity)

-Why did they say what they say? Consider the context?

3: Apply coded theme (could be multiple, even from opposing overarching themes).

*Personhood preservation / Loss of Personhood is not the “coded” theme but the general effect produced by subthemes.

Appendix D

Links to Digital Materials of the Study

- Alex's Story: [Alex's story | YoungDementia UK](#)
- Christine's Story: [Christine's story | YoungDementia UK](#)
- Into the Fog: [Into the Fog: Living with Early-Onset Alzheimer's | WebMD - YouTube](#)
- Martin's Story: [Martin's story | YoungDementia UK](#)
- Month in the life documentary: [Dementia: A month in the life \(FULL documentary\) - BBC News - YouTube](#)
- Ronnie's Story: [Ronnie's story | YoungDementia UK](#)
- Tommy's Story: [Tommy's story | YoungDementia UK](#)