EXPLORING THE EXPERIENCES AND PERCEPTIONS OF PERSONS DIAGNOSED WITH EARLY ONSET DEMENTIA AND THEIR PRIMARY CAREGIVERS

by Kathryn M. Beanblossom

This study explores how early onset dementia (EOD); i.e., dementia before the age of 65, affects an individual’s life and the life of their primary caregiver, how participants’ view the current services they receive from their local Alzheimer’s Association, and what additional services would benefit those affected by EOD. Participants were recruited from two Alzheimer’s Association chapters in the Midwest, where all participants attended a support group. Interviews were conducted with 7 persons with dementia and 6 of their primary caregivers. Using a case study approach, three central elements dominated the participants’ stories. First, the initial support received from doctors when diagnosed has a large impact on families. Second, families are generally happy with the support group they attend, whether it is specific to EOD or not; however, some participants did identify limitations to their support group. Finally, a greater amount of meaningful activities for persons with EOD are desired.
EXPLORING THE EXPERIENCES AND PERCEPTIONS OF PERSONS DIAGNOSED WITH EARLY ONSET DEMENTIA AND THEIR PRIMARY CAREGIVERS

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Dedication

I dedicate this thesis to my late great-grandmother, Cecile Beanblossom and my late and dear friend, Ann Hohl. It was my Grandma Cecile’s energy and passion for life that inspired me at a young age to work with older adults. And it was Ann who opened my eyes to the world of dementia and showed me that even the ugliest of diseases can never fully hide the true beauty of a person. You both were in my mind and heart throughout the entirety of this program.
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Introduction

Dementia is a term used to describe a decline in mental ability that interferes with daily life. It is not a specific disease, but it used to describe a wide range of symptoms (Alzheimer’s Association, 2013c). According to the Diagnostic and Statistical Manual of Mental Disorders 4th editions: DSM-IV (1994) clinical features of dementia may include short-term memory loss, deficiency in abstract thinking, loss of calculating ability, loss of good judgment, changes in personality, and hallucinations and delusions. The course of dementia may be either static or progressive, depending on the cause of the dementia. The etiology of dementia may vary, with causes including Lewy Body disease, frontotemporal dementia, alcoholic dementia, and Alzheimer’s disease. Alzheimer’s disease is the most common form of dementia, with the greatest risk factor for Alzheimer’s disease being age. Most individuals with the disease are 65 or older, and an individual’s likelihood of developing the disease doubles approximately every five years after the age of 65 (Alzheimer’s Association, 2013c). However, for an increasing number of adults, this is not the case. Early onset dementia (EOD) is characterized as dementia with an onset before the age of 65 (Alzheimer’s Association, 2013d), and the disease has clinical and psychosocial impacts on an individual that are unique compared to those that accompany dementia in later life. EOD has a more varied diagnosis (Mendez, 2006), along with a quicker progression, more severe impairments, more extensive brain damage, and a shorter life expectancy than dementia in later life (Tindall & Manthorpe, 1997). Additionally, with a diagnosis before the age of 65, many individuals are still working, raising families, and have an active role in society (Alzheimer’s Association, 2013d; Bakker, de Vugt, Vernooij-Dassen, van Vliet, Verhey, & Koopmans, 2010).

Services for individuals diagnosed with EOD and their caregivers are often not developed specifically for EOD, but for people with dementia in later life. Therefore, the notion of specialized services (e.g., services for individuals with dementia younger than age 65) versus non-specialized services (e.g., services for individuals with dementia of all ages) is one that is currently debated throughout research (Bakker et al., 2010; Beattie, Draker-White, Gilliard, & Means, 2002; Harris, 2004; Kinney, Kart, & Reddecliff, 2011; Reed, Cantley, Clarke, & Stanley, 2002). A primary service for those with dementia and their caregivers is support groups. Support groups serve as the most popular program model for individuals in the early stages of dementia, with clinicians attesting to their therapeutic benefits, including discussion forums and problem
solving (Snyder, Jenkins, & Joosten, 2007). Furthermore, support groups have been found to have a significant positive effect on the psychological well-being, depression, burden, and social outcomes for caregivers of persons with dementia (Chien, Chu, Guo, Liao, Chang, Chen & Chou, 2011).

Although the early diagnosis of EOD in one’s life and the losses that come as a result cause distinct challenges, there is currently a lack of literature that draws upon the experiences of those diagnosed with early onset dementia. As Harris and Keady (2004) point out, a great deal of information on EOD is gathered from healthcare providers, and little literature is based on the experiences and perspectives of those diagnosed with EOD. By gaining the perspectives of those diagnosed, service providers can better be informed on the type of services truly desired by this population. Furthermore, due to the notion that persons with EOD do not live independently, but interdependently (Elder, 1996), the unique implications of dementia before the age of 65 impacts those who help care for them on a day-to-day basis as well, and their perspectives must also be valued.

The purpose of this study was to use the life course and life span development perspectives to contextualize an exploration of how EOD affects an individual’s life and the life of their primary caregiver; how participants (i.e., the persons with EOD) and co-participants (i.e. the primary caregivers) view the current services they receive from their local Alzheimer’s Association chapter; and what additional services would benefit men and women with EOD and their primary caregiver. The autonomous perspectives of persons with EOD and their primary caregiver are explored, as well as their social and environmental opportunities and/or constraints (e.g., services). Qualitative interviews were conducted with 7 people diagnosed with EOD and 6 of their primary caregivers, recruited from two Alzheimer’s Association chapters in the Midwest. Participants and co-participants completed interviews about how EOD impacts their life. All participants and co-participants were participants of Alzheimer’s Associations support groups. Furthermore, four of the participants and their co-participants attended a monthly support group for individuals of all ages who were in the early stages of dementia. Three attended a support group specifically for people with early onset dementia (people younger than age 65). The findings from this study are presented using a multiple case study approach.
Background

Theoretical Framework: Life Course/Life Span Development

Two common (and related) perspectives that are often used to conceptualize research on various aspects of aging are the life course and life span development perspectives. Both the life course and life span development perspectives recognize that development and aging are a life-long process that is multidimensional, multidirectional, and involves gains and losses (Elder, 1996; Baltes, 1987). Both perspectives also argue that an individual’s life unfolds in a set of trajectories (Elder, 1996; Settersten, 2003), which is defined by George (1993) as “long-term patterns of stability and change” (p. 358). These trajectories consist of events, turning points, and transitions (i.e., changes in status; George, 1993).

Despite these similarities, life course and life span are two distinct perspectives consisting of distinct themes that will be utilized throughout this research. Elder (1996) identifies four paradigmatic themes of the life course perspective. First, human lives unfold in a specific historical time and geographic location. Depending on the year and geographic location in which an individual is born, he/she will be exposed to different historical surroundings that subsequently influence them (Elder, 1996). Second, development occurs in the context of both human agency and social constraint (i.e., although individuals make their own choices, they are guided by the environment in which they live). Third, the timing of initiation and departure from social roles and events matters. Elder (1996) refers social timing to the “incidence, duration, and sequence of roles, and to relevant expectations and beliefs based on age” (p. 6). Whether an individual follows the normative social timing of events or not makes a difference. Finally, Elder (1996) maintains that lives are linked. Individuals live their life interdependently, embedded in social relationships. Elder (1996) identifies this concept to be the central principle of the life course perspective.

Hoyer (2006) identifies four themes associated with a life span development approach to aging. First, aging is a life-long process. Therefore, one’s past and future influences an individual at any point in time. Second, aging is multi-directional and multi-dimensional. Within different characteristics, the amount and direction of change varies between individuals (Hoyer, 2006). Third, the life span development perspective states that development consists of losses and gains, but there is plasticity (i.e., potential for change within an individual) and resiliency (i.e., adapting to and recovering from stressful life events) throughout an individual’s life span (Baltes, 1987).
Finally, Hoyer (2006) identifies aging as a product of biological and environmental influences. Combinations of the biological and environmental influences may be beneficial or it may be damaging to an individual.

The major difference between these paradigmatic themes of the life course and life span development perspective is the overall focus. The life course perspective focuses more on the larger societal system at work. The life course perspective looks at individuals over the entire course of their life and the impact societal events have had on them. On the contrary, the life span development perspective is focused on the individual changes (biologically, psychologically, and socially) that occur throughout one’s life. The life span development perspective looks at behaviors of individuals at certain points in time throughout their life. Using the life course and life span development perspectives, the individual similarities and differences of participants and co-participants, as well as how society has impacted them, are explored throughout this research. For example, the life course perspective suggests that development occurs in the context of human agency and social constraints; whereas the life span development perspective maintains that an individual is influenced by biological and environmental factors. Therefore, while it is important to study the autonomous perspectives of persons with EOD and their caregiver, one must also take into account social and environmental opportunities and constraints. In this study, the researcher taps one of the social and environmental factors for this population, the services offered in their local community.

**Distinguishing Early Onset Dementia**

In terms of defining dementia, Alzheimer’s disease, early onset and early stage, the lines are often blurred and many times the terms are used interchangeably. Morhardt and Weintraub (2007) define dementia as a “clinical syndrome that is characterized by the insidious onset and gradual progression of cognitive and/or behavioral symptoms that constitute a departure from the individual’s customary way of thinking and/or behaving” (p. 17). Alzheimer’s disease is the most common form of dementia, affecting nearly 5.4 million Americans (Alzheimer’s Association, 2013b). There is no single test that determines if an individual has Alzheimer’s, but physicians often incorporate medical history, mental status testing, a physical and neurological exam, and tests to rule out other diseases in order to determine a diagnosis (Alzheimer’s Association, 2013b). Early onset and early stage are often used interchangeably in the literature, by professionals, and in social service organizations. Nonetheless, technically the terms have
different meanings and it is important to understand the differences. The focus of this research is early onset dementia, which refers to dementia in which symptoms occur before the age of 65. In contrast, early stage refers to the stage or severity of dementia, regardless of the person’s age (Morhardt & Weintraub, 2007). Of the 5.4 million Americans currently diagnosed with Alzheimer’s disease, nearly 4% or approximately 200,000 Americans have a diagnosis of early onset, also referred to as younger onset.

Clinical Manifestations

Early onset dementia has a more varied diagnosis than dementia in later life, with diagnoses including Alzheimer’s disease, frontotemporal dementia, vascular dementia, traumatic head injury, and alcohol-related dementia (Mendez, 2006). In addition, the progression of early onset dementia often includes a quicker progression, with more severe impairments, more extensive brain damage, and a shorter life expectancy than dementia in later life (Tindall & Manthorpe, 1997).

In addition to memory impairment, symptoms of EOD often include impairment in visuospatial function and praxis, language, and executive skills (e.g., orientation to time and place). Koedam, Lauffer, van der Flier, Scheltens, and Pijnenburg (2010) found that these non-memory symptoms, particularly apraxia (i.e., having trouble saying what you want correctly and consistently) and visuospatial dysfunction (i.e., difficulty in understanding visual representations and their spatial relationships), are often more prevalent in EOD than late onset dementia. Behavioral symptoms such as delusions and hallucinations are also common among individuals with EOD (Reed et al., 2002). It has even been suggested that these non-cognitive and behavioral symptoms are more prevalent in younger rather than older adults diagnosed with dementia (Reed et al., 2002).

Psychosocial Implications

With a diagnosis before the age of 65, many individuals are still working, raising families, and have an active role in society (Alzheimer’s Association, 2013d; Bakker et al., 2010). Harris and Keady (2009) describe challenges for those diagnosed with early onset dementia as “difficulties of getting a timely and proper diagnosis, issues of selfhood and self esteem, changing relationships within entire family structure, awareness of changes in self, workforce and retirement/financial issues, intense feelings of social isolation and being marginalized, off-time dependency, and boredom and lack of meaningful occupation” (p. 437).
Although some of these challenges, as well as the departure from social roles, can arguably be faced by those diagnosed with dementia in later life as well, it is the timing of these events that causes the unique distress on individuals and families affected by EOD. In congruence to the life course perspective, by departing from social roles at a young age individuals are not adhering to normative social timing, resulting in unique implications (Elder, 1996).

Just as persons with EOD must depart from social roles, caregivers must adjust to new social roles, often at a younger-than-expected age. Therefore, not only are persons with EOD not adhering to normative social timing, their caregivers aren’t as well. This also supports Elder’s (1996) notion that lives are linked and not lived independently, but interdependently. Furthermore, previous literature has found that the experience of caregivers of those diagnosed with EOD may be more difficult and burdensome due to the clinical and behavioral features of the disease (e.g., apraxia, visuospatial dysfunction, delusions, and hallucinations), as well as the young age of the caregivers (Arai, Matsumoto, Ikeda, & Arai, 2007). Thus, the experiences and perspectives of primary caregivers are just as critical to study as the individual with EOD.

**Services for Individuals with Early Onset Dementia and Their Families**

The Alzheimer’s Association chapters in the Midwest, from where the participants were recruited, serve families affected by dementia through support, education, and resources (Alzheimer’s Association, 2013a). In terms of support, chapters offer a 24/7 helpline, care consultations, and support groups. Chapters provide publications, programs, training, and alliances with other local organizations to educate the public on dementia. Finally, in terms of resources, Alzheimer’s Association chapters help families get connected with MedicAlert and Safe Return, with local resources and referrals, with online resources, and with current clinical trials (Alzheimer’s Association, 2013a).

The importance of gaining insight into appropriate services for individuals with EOD and their primary caregiver cannot be overlooked. As Reed et al. (2002) point out, it is well accepted in society that dementia is an “old person’s disease.” As a result of this assumption, services for those with dementia and their families are geared toward older adults. Therefore, individuals with early onset and their families are often forced to utilize the services designed for those over the age of 65. Bakker et al. (2010) believe this to be problematic, as the providers of services designed for older adults struggle to recognize the specific needs of younger adults, such as
issues concerning work, childrearing, financial difficulties, and inability of the person with EOD to fulfill previous roles.

As previously discussed, the clinical manifestations of EOD and the psychosocial implications of the disease may look very different than that of dementia in later life. The fit between a person with early onset, their family, and the services available to them prove to be a great obstacle and concern for all those affected by EOD. Therefore, Bakker et al. (2010) advocated for specialized services for EOD that monitor changes in individuals with EOD and their caregiver’s needs and addresses issues in continuity of care. Similarly, in their literature review, Beattie et al. (2002) found that 78.3% of the reviewed articles recommended specialized services for those with EOD. This study noted, however, that these recommendations were predominately made by advocacy groups or in practice settings, rather than being empirical research. On the contrary, Reed et al. (2002) support the notion of services that cater to individualized needs, disregarding the age of the clients. This debate of specialized versus non-specialized services is in need of further research and is addressed in this current study.

Beyond the debate of specialized versus non-specialized services, there are only a few studies that explore what specific services would benefit those with EOD and/or their primary caregiver. Beattie et al. (2002) found that previous literature supports flexible, age-appropriate, and dedicated services. Based on interviews that focused on the experiences of younger people with dementia, Harris (2004) recommended services that provide peer socialization and more workshops that focus on the challenges of those diagnosed with early onset dementia. This broad (and sometimes vague) range of services that researchers have previously found beneficial to persons with EOD and their primary caregiver will be explored further with the participants and co-participants in this study.

As previously discussed, the Alzheimer’s Association helps families affected by dementia through support, education, and resources. Participants and co-participants in the current study all participated in support groups. Studies exploring the effect support groups have on individuals in the early stages of dementia have recently emerged as an area of interest in the literature. Snyder et al. (2007) note that support groups serve as the most popular program model for individuals in the early stages of dementia, with clinicians attesting to their therapeutic benefits, including discussion forums and problem solving. Logsdon, Pike, McCurry, Hunter, Maher, Snyder and Teri (2010) found that men and women in a time-limited support group in the
early stages of memory loss had significant differences in quality of life, depression, and family communication compared to those who did not participate in the support group. Support groups for caregivers have long been researched and found to reduce anxiety, depression, a sense of burden (Greene & Monahan, 1989), stress, and improve quality of life (Zanetti, Metitieri, Bianchetti, & Trabucchi, 1998). More recently, Chien et al. (2011) found that support groups have a significant positive effect on the psychological well-being, depression, burden, and social outcomes for caregivers of persons with dementia. When Snyder et al. (2007) evaluated the effectiveness of support groups for individuals in the early stages of dementia based on participant feedback, participants reported on the educational value of the group, socialization, and their ability to better cope with symptoms and accept the diagnosis. With the debate on specialized versus non-specialized services in the forefront of literature, it is important to recognize that this research has been conducted on individuals in the early stages of dementia, not specifically with early onset. The researcher could not identify any studies to date that address the benefits and limitations of support groups for individuals with EOD and their caregivers.

It is also important to note that previous literature indicates various coping styles of individuals living with dementia, such as individuals taking a practical approach and gathering information about their disease (Clare, 2002). Mason, Clare, and Pistrang (2005) alluded to the fact that some individuals’ coping style may not be based on talking at all. Therefore, it is not advantageous to assume that all individuals benefit from support groups.

*Giving Individuals with Early Onset Dementia and Their Caregiver a Voice*

Although the diagnosis of EOD in one’s life and the changes that come as a result cause distinct challenges, there is currently a lack of literature that draws upon the experiences of those diagnosed with EOD. As Harris and Keady (2004) point out, a great deal of information on EOD is gathered from healthcare providers, and little literature is based on the experiences and perspectives of those diagnosed with EOD. An emerging area of research has found that individuals in the early stages of dementia are able to accurately and consistently respond to fact-based questions and consistently to state-dependent items (Clark, Tucke, & Whitlatch, 2008), are able to express their desires about the care they currently receive and would like to receive in the future (Whitlach & Feinberg, 2005), and are able to consistently express their desires about basic preferences (Whitlach, Feinberg, & Tucke, 2005). Research conducted by Menne, Kinney, and
Morhardt (2002) and Kinney et al. (2011) with individuals in the early stages of dementia documents the ability of diagnosed individuals to articulate their experiences, and they recommend research that explores the experiences of those living with dementia. Furthermore, Downs (1997) confirms that individuals in all stages of dementia retain a sense of self and research exploring their perspectives is needed. Therefore, even though much of the current literature lacks the voices of persons diagnosed with early onset dementia, there is supporting literature that documents the voice of these persons are accurate, consistent, and should be heard.

Furthermore, when recognizing the voices and perspectives of individuals diagnosed with EOD, one must also recognize the voices and perspectives of their caregivers. As previously discussed, EOD can have unique clinical manifestations and psychosocial implications for those diagnosed. Due to the linkage of lives (Elder, 1996) and the notion that persons with EOD do not live independently, but interdependently, the unique implications of dementia before the age of 65 impacts those who help care for them on a day-to-day basis as well. Caregivers are forced to adapt to new social roles, and since those diagnosed with EOD are younger than age 65, many times their caregivers are as well. Therefore, persons with EOD are not only adapting to new roles and losses at a time in their life that contradicts normative social timing, but their caregivers are as well. Multiple perspectives (of persons with EOD and their caregiver) on the individual impact of the disease and larger societal impacts are gathered to better understand the experiences and perspectives of all affected by early onset.

**Purpose**

The clinical and psychosocial impacts that affect those diagnosed with EOD and their families are unique compared to those diagnosed with dementia in later life. Consistent with the life span development and life course approaches, the diagnosis of EOD disrupts the typical timeline of one’s life and the life of their primary caregiver, and this phenomena merits further exploration. Despite this need, the voices of those diagnosed with EOD and their primary caregiver are often overlooked, particularly regarding perceptions of services. To address this limitation, the perspectives of those diagnosed with EOD and their primary caregiver were documented. Specifically, three fundamental research questions were addressed: 1) How does a diagnosis of early onset dementia disrupt one’s life, as well as the life of their primary caregiver? 2) How do participants and co-participants’ view the current services they receive from their
local Alzheimer’s Association chapter? 3) What additional services would make life better for those diagnosed with early onset dementia and their primary caregiver?

Methods

A multiple case study design was utilized. Interviews were conducted with 7 participants (i.e., persons with EOD) and 6 co-participants (i.e., primary caregivers). The purposes of the interviews were to: 1) describe how a diagnosis of early onset dementia disrupts one’s life, as well as the life of their primary caregiver; 2) learn about participants and co-participants’ views of the services provided by their local Alzheimer’s Association; and 3) explore what additional services would make life better for those diagnosed with early onset dementia and their primary caregiver. Yin (2003) states a case study approach should be used when the researcher is focusing on answering a “how” or “why” question, the researcher cannot control the behavior of those involved in the study, and the focus of the study is on a phenomenon that cannot be easily separated from its context. The current study explores how EOD disrupts ones’ life and affects the services they receive and would like to receive. The study explores the phenomena of EOD within multiple contexts; including the person with dementia, the primary caregiver and the services they receive from their local Alzheimer’s Association. By utilizing a multiple case study design, the researcher explored EOD within its various contexts and through multiple lenses (Baxter & Jack, 2008) by gaining the perspectives of various participants.

Recruitment

Prior to data collection the researcher received approval for the study from Miami University’s Institutional Review Board (IRB). The study was partially funded by Miami University’s Scripps Gerontology Center and Miami University’s Graduate School. Recruitment of participants began in summer of 2012. Participants were recruited based on purposive sampling (i.e., sampling based on a specific characteristic) and convenience sampling. Participants were recruited through two local Alzheimer’s Association chapters in the Midwest. To protect the identity of the informants the chapters will be referred to as Chapter A and Chapter B. These two chapters were chosen due to their willingness to work with the researcher.

Chapter A offers a support group for individuals in the early stages of dementia and their primary caregiver. Individuals are not necessarily diagnosed before the age of 65. The support group for primary caregivers meets twice a month and although the persons with dementia meet
twice a month. Their first meeting consists of a support group, whereas their second meeting consists of some sort of structured activity. Chapter B offers a support group specific for individuals with EOD and their primary caregivers. This is offered in two different locations; each location offers the group once a month.

Although the same recruitment materials were used for Chapter A and Chapter B (see Appendix A), the recruitment process varied slightly based on each chapter’s preferences. Specifically, in Chapter A staff members distributed the recruitment material (see Appendix A) and a stamped envelope addressed to the researcher to individuals and/or their primary caregiver that staff deem appropriate for the research. Interested individuals put their name and contact information in the space provided on the informational sheet and mailed it directly to the researcher.

Recruitment through Chapter B took place before the chapter’s two monthly support groups for individuals with early onset dementia and their primary caregivers. The researcher attended the start of both meetings and explained the study and criteria to those diagnosed with dementia and their primary caregiver. The researcher gave all those attending the meeting the recruitment material (see Appendix A). The researcher asked the potential participants to please fill in their contact information if they were interested in the study and would like to be contacted with more information. The researcher collected forms that were completed at that time. The researcher also provided stamped envelopes addressed to the researcher to potential participants who preferred to fill out the form at a later date. The researcher contacted all potential participants from Chapter A and Chapter B at a later date to explain the research in more depth and answer any questions the potential participants had. Across the two support groups, the researcher contacted 10 potential participants and their primary caregivers. One participant and co-participant were no longer interested and two were deemed ineligible based on the study’s criteria (i.e. the co-participant did not have legal authority to consent on behalf of the participant). Therefore, the researcher enrolled and interviewed 7 participants and 6 co-participants.

Sample Selection

To be eligible to participate in the study, a potential participant must have received a diagnosis from a physician of some form of dementia before the age of 65. The initial inclusion criteria were that the participant (e.g., the person with dementia) must be able to identify one individual (i.e., the primary caregiver or the co-participant) who is most responsible for assisting
her/him on a day-to-day basis. It was also required that the co-participant live with the participant and have legal authority to consent on behalf of the participant (i.e., have Power of Attorney). However, a participant who lived independently, could not identify a primary caregiver, and had no other individual with legal authority of her wished to participate in the study. After modifying the IRB protocol, this individual was enrolled in the study. Participants were recruited with no regard to gender, race, or ethnicity.

Face-to-face, semi-structured interviews were conducted with 7 participants (i.e., persons with EOD) and 6 co-participants (i.e., primary caregivers) and were analyzed using a multiple case study design. Due to the scale of the project, 7 participants and 6 co-participants is an adequate sample size to gain comprehensive data. For example, Menne et al. (2002) conducted interviews with 6 individuals in the early stages of dementia to explore the day-to-day experiences of living with a dementia. In evaluating a program for individuals with EOD, Kinney et al. (2011) conducted interviews with 6 men with EOD, as well as a focus group with 6 caregivers. Additionally, Bakker et al. (2010) used a single case study design to explore the experiences of a caregiver and the needs of a person with EOD and their caregiver. Furthermore, Mason (2010) states the guiding principle for determining sample size should be saturation (i.e., when data collection does not shed any new light on the phenomenon under exploration). Sample size and saturation may be determined by the scope of the study, nature of the topic, quality of the data, and the study design (Mason, 2010). By considering these factors, the researcher reached saturation by interviewing 7 participants and 6 co-participants.

Of the 7 participants (5 men and 2 women), ages ranged from 56 to 67. Participants were diagnosed at ages ranging from approximately 38 to 62. Participants’ diagnosis varied, including early onset Alzheimer’s disease, frontotemporal dementia, vascular dementia with Alzheimer’s, non-specified dementia, and mild cognitive impairment with dementia. Two participants were working part-time at the time of the interview, four were retired, and one was receiving disability. Four participants were receiving services from Chapter A and three from Chapter B. All participants identified themselves as Caucasian.

Of the 6 co-participants (1 man and 5 women), ages ranged from 52 to 66. Two co-participants worked full-time, three were retired, and one did not work. All co-participants were spouses living with the participant. Three co-participants were receiving services from Chapter A and three from Chapter B. All identified themselves as Caucasian. Table 1. presents a detailed
description of each dyad’s (i.e., the participant and co-participant) demographic characteristics. Participants and co-participants are identified by a pseudonym.

Table 1.
Demographic Characteristics of Participants and Co-participants

<table>
<thead>
<tr>
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<th>Participant</th>
<th>Co-participant</th>
</tr>
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<tbody>
<tr>
<td><strong>Pseudonym</strong></td>
<td>Mr. Pat Jones</td>
<td>Mrs. Mary Jones</td>
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<td>63</td>
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<td>Spouse</td>
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<th></th>
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<th>Co-participant</th>
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<tbody>
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<td><strong>Pseudonym</strong></td>
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<td>Mr. George Wolf</td>
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The Interviews

Separate face-to-face interviews were conducted with the participant and their corresponding co-participant (if applicable) at the location of their choice. Five interviews were conducted at the participants’/co-participants’ home, one was conducted at the participant’s/co-participant’s local Alzheimer’s Association, and one was conducted at the participant’s local library. All co-participants (e.g., primary caregivers) were legally authorized representatives (i.e., Power of Attorneys) to the participant. Written assent was obtained from each participant and written consent was obtained from each co-participant for themselves and the participants to be interviewed (see Appendix B). This took place immediately prior to the interview with both parties present. In the case where the participant lived independently, did not identify a primary caregiver, and had not given legal authority to a representative, the participant assented to her participation without the consent of another. The researcher deemed the participant competent to do so, given the approval of Miami University’s IRB. In obtaining consent and assent, the researcher explained that the participant and/or co-participant could withdrawal from the study at any time without any penalty. Participants and co-participants consented to the recording of the interviews with an audio recorder that would later be transcribed and used for data analysis. It was explained that all names would be kept confidential and be destroyed once an identifying marker had been established.

The person with EOD was interviewed first and the co-participant was interviewed afterwards. This was to prevent the researcher from being biased by how the co-participants answered questions and if necessary, the researcher could ask follow-up questions of the co-participants based on the interviews with the persons with EOD. In one instance, however, the person with EOD was not home at the time of the interview and per the co-participant’s request, she was interviewed first. Prior to beginning the actual interview, the participant and co-participant were asked to provide basic demographic information. Demographic questions for the person diagnosed with EOD consisted of gender, age, race/ethnicity, when they received a diagnosis of EOD, and occupation. Demographic questions for the co-participant included gender, age, race/ethnicity, relation to person with EOD, and occupation. If the participant was unsure of an answer to one of these questions, it was later asked to the co-participant.

Open-ended, semi-structured interviews were then conducted in order to explore specific experiences of individuals with EOD and the co-participant while integrating follow-up
questions and discussions as appropriate. Interviews lasted anywhere from 40 to 80 minutes. Interviews with the participants and co-participants were exploratory in nature; however, an interview guide was used to prompt the researcher (see appendix C). The questions asked of the participant and co-participant was similar in nature.

Data Analysis

A fundamental strength of this study is the in-depth look into the experiences and lives of individuals diagnosed with EOD and their primary caregivers. The researcher began analyzing the data by reading through each interview. Due to the commonalities between the individual diagnosed and their primary caregiver (where applicable), the researcher chose to consider each dyad as the unit of analysis. Each unit of analysis was organized by developing what Yin (1994) refers to as a case description, or a descriptive framework. The researcher took notes on each participant and co-participants’ interviews, highlighting topics that were repeated across the units of analyses. From these observations, the researcher decided to structure each unit of analysis into three segments: the diagnosis, the support group, and gaps in services. These segments were chosen based on the three overarching research questions and relevant and repeated topics that participants and co-participants addressed during interviews.

Modes of analysis were adopted from Yin (1994), including pattern-matching and analyzing embedded units. Pattern-matching is considered one of the most desirable analytic strategies by Yin (1994) in which empirically based patterns are compared to those observed in the unit of analyses. For example, Beattie et al. (2002) and Bakker et al. (2010) advocate for specialized services that cater particularly to those diagnosed with dementia before the age of 65. The researcher looked to see if the patterns in each unit of analysis match the empirically based pattern of Beattie et al. (2002) and Bakker et al. (2010). If the results are as predicted, the researcher can draw a conclusion supporting Beattie et al. (2002) and Bakker et al. (2010). However, if even one variable does not behave as predicted (i.e., a unit of analysis does not desire specialized services), the initial proposition would have to be questioned (Yin, 1994).

Analyzing embedded units is most apparent in multiple case studies. According to Yin (1994), analyzing embedded units is considered a lesser mode of analysis that must be used in combination with a more dominant mode of analysis (in this case, pattern-matching). In congruence with Yin’s (1994) approach, each unit of analysis was analyzed individually first, looking for patterns (i.e., trends). Patterns were then compared across all participants and co-
participants, along with empirically based patterns. Conclusions that were drawn from multiple cases became the conclusions for the overall study (Yin, 1994).

Results

This chapter is organized in seven sections. Each section begins with a brief description of the participant and co-participant (when applicable). A case study follows, organized by the diagnosis, the support group, and gaps in services.

Mr. Pat Jones & Mrs. Mary Jones

Mr. Pat Jones (age 67) and Mrs. Mary Jones (age 63) are a European American couple who have been married for 45 years. They reside in a suburb of a working class community. The couple has a son who lives approximately 1 ½ hours away from their home and a daughter who lives approximately 30 minutes away. The researcher met with the couple once at their house. Each person was interviewed separately. Mr. Jones was interviewed first, and the interview lasted approximately 50 minutes; Mrs. Jones’ interview was approximately 1 hour. Both Mr. and Mrs. Jones are retired, and the couple stated they spend most of their days enjoying their retirement with one another. The couple shared their perspectives, outlooks, and experiences of living with early onset dementia. In doing so, the following central elements of their story emerged:

The Diagnosis

Mr. Jones was diagnosed with dementia 5 years ago at the age of 62. However, a couple years before the official diagnosis, Mrs. Jones felt there was something wrong with her husband and had spoken to his doctor about her feeling.

She said: And for a couple years I’d say, “You know there’s something funky with [Pat] but I don’t know what it is.” And I couldn’t... there was no... nothing I could really put my finger on other than he refused to drive.

Mrs. Jones continued to speak to the doctor about her husband, urging further examinations and tests. It was not until Mr. Jones personally spoke to his doctor that he ordered blood work, an MRI, and other tests. After these all came back negative, the doctor recommended that Mr. Jones see a psychiatrist for depression. Although the couple did not believe this was the problem, Mr. Jones complied. His psychiatrist asked Mr. Jones to complete the clock test. In the clock test, an
individual is required to draw a clock by hand, insert the numbers, and point the hands to the
time indicated by the examiner. He was also asked to draw two intersecting pentagrams, another
test often administered by physicians when evaluating a patient for memory problems. It was
after these tests that Mr. and Mrs. Jones received a diagnosis:

Mrs. Jones explained: [Pat] is across the desk and I’m sitting over here and he asks [Pat] to
draw the face of a clock and the intersecting pentagram – and neither of which [Pat] could
do…. But anyway, that’s all he did. I mean we weren’t in there maybe ten minutes if we were in
there that long. And as soon as [Pat] did that he [the doctor] took his paperwork back like this
and he looked at this and looked over at me and totally ignored [Pat] and he looked over at me
and said, “Get his power of attorney.” And I said, “What?” He said, “Go get his power of
attorney today – immediately.” And I said, “I have his medical power of attorney. We have
each…” “No. I mean his power of attorney.” I said, “Why?” And he said, “Well, he has
Alzheimer’s and it won’t be long.”

After receiving this news, the Jones’ had very little follow-up conversation with the doctor and
were sent home. According to Mrs. Jones, they were given little information, guidance, or
comfort and, therefore, were confused as to what they should do next. Mrs. Jones described this
ambiguous time as “horrendous.” It was up to the couple to take the next step in figuring out how
to manage early onset dementia.

The Support Group

After receiving their diagnosis, Mr. and Mrs. Jones were “devastated.” As they both
individually tried to grasp their emotions, Mrs. Jones expressed her need to seek out additional
support.

She explained: I also said to [Pat] ... I said, “Okay, because we are one another’s
support system and because I’ve already talked to [daughter] and she’s kind of falling apart on
me because she too needs her explosion, gather up time...” I said, “I need to find somebody to
talk to about this.”

Mrs. Jones went online, found her local Alzheimer’s Association, and attended a support group
for the first few times without Mr. Jones. The support group is an early stage support group for
caregivers and, therefore, men and women of all ages who are caring for someone in the early
stages of dementia attend. The support group takes place twice a month and Mrs. Jones attends
on a regular basis. Mrs. Jones initially went to the support group seeking definitive, black and
white answers. She wanted facts and details about the disease process and how the disease would specifically affect her husband. She soon found that she would not find these answers at the support group. She learned that these definitive, factual answers do not exist, due to the unpredictability of the disease.

Even though the support group did not result in the outcome Mrs. Jones sought, she said it was the relationships she has made that keeps her returning every month. She has friendships at the support group that she considers valuable. She feels that she can help these people by attending the support group and at times when she has felt down, she has been able to call on a few of them for support as well.

After Mrs. Jones attended her support group a couple times, Mr. Jones decided to attend one on a regular basis as well. During Mrs. Jones’ support group for caregivers in the early stages of dementia, a separate support group for those in the early stages of the disease takes place. This, too, consists of men and women of all ages, as long as they are in early stages of dementia. He explained that he soon felt that talking about his diagnosis in a safe circle of friends was emotionally helpful.

Mr. Jones describes his support group: *It’s just the… It’s like they’re all friends. Everybody’s a friend. Everybody can say what they want to say and they know that they’re not going to go out and tell other people. We keep our stuff in our group to us. We don’t take it out and tell it to other people. And sometimes people… They feel better to talk – talk about what’s going on. And they want to know how everybody is doing. … But it’s fun to just sit there and talk with the other people. They can tell what their problems are. I tell them what my problems are. And it’s good… and to talk… Just to talk sometimes makes it better.*

Mr. Jones feels that talking about his diagnosis in a safe circle of friends is emotionally helpful.

Since the support groups for both Mr. and Mrs. Jones are early stage support groups, rather than support groups specifically for those diagnosed with early onset dementia, both groups consist of men and women of all ages. Mr. and Mrs. Jones stated that most of the people attending the support group were older; however, this did not bother either of them. Neither saw any problems with the variety or ages in their support group and even said they liked the diversity.

**Gaps in Services**
Mr. Jones feels he receives the support he needs from his wife, a long-time close friend, and the Alzheimer’s Association. Mrs. Jones feels she has everything she needs to assist her husband right now; however, she does identify the fact that another person to be with her husband at times may be helpful. Mrs. Jones feels as if she needs to stay close to her husband and does not always go places or participate in social activities if it means she is distant from him or gone for a long period of time. She states: *I think right now I wish he had more outside activity maybe that he didn’t need me.*

**Mr. George Wolf & Mrs. Betty Wolf**

Mr. George Wolf (age 59) and Mrs. Betty Wolf (age 62) are a European American couple married in 2001. Mr. Wolf has two children; one son and one daughter, and Mrs. Wolf has one daughter, all of whom live a distance from the couple. Mrs. Wolf was diagnosed with early onset Alzheimer’s disease two years ago. She currently works part-time teaching a class at a fitness center. She also volunteers for her church and the local Arthritis Foundation. Wolf described her faith as strong and her church a major support system for her. Mr. Wolf serves as the vice president of a financial institution. The interview took place at the couple’s local Alzheimer’s Association. Mrs. Wolf was interviewed first, separate from her spouse; the interview lasted approximately 40 minutes. The interview with Mr. Wolf lasted approximately 60 minutes.

**The Diagnosis**

When Mrs. Wolf first started noticing memory problems she confronted her family physician. As Mrs. Wolf described, “He very diligently followed up on everything and didn’t just say, “Well, it’s just part of aging.”” She then went through multiple tests, including blood work, CAT scan, MRI, and a PET scan. Afterwards her neurologist diagnosed Mrs. Wolf with early onset Alzheimer’s disease. Although Mrs. Wolf stated that in a way she was prepared for the diagnosis, she was still shocked to hear the words “Alzheimer’s disease.” Mr. Wolf had a similar reaction.

He explains: *So I was in a bit of... a state of shock to come to this realization that we had this diagnosis and that this was going to be a major part of the rest of our lives together. I guess it didn’t occur to me that this was going to be part of the package that would be our life.*
Mrs. and Mr. Wolf were both shocked to learn that Alzheimer’s disease would be a major part of their lives.

Mr. Wolf explained that when the neurologist diagnosed his wife with early onset Alzheimer’s the neurologist looked at the charts with him and his wife, he explained the pictures, and then explained why he came to the conclusion he did. Although neither Mr. nor Mrs. Wolf had many questions, the neurologist answered what questions they did have and made recommendations of places where they could learn more about the disease and what services were out there to help them. It was the neurologist who directed the couple to the Alzheimer’s Association. Mr. Wolf explained that receiving this diagnosis early in the progression of his wife’s disease was important in order to make long-term decisions. For example, he was able to get long-term care insurance from his employer, something he claims he would have never done if they hadn’t received this diagnosis.

The Support Group

Mrs. Wolf attends an early onset support group that is specific for those diagnosed with dementia before the age of 65. Although Mrs. Wolf thinks it is helpful to attend the support group and listen to others, she finds that those who attend the support group are often in later stages of dementia than she is.

Mrs. Wolf discusses the support group she attends: *And the same way with the support group we go to… there is… Most of them in there are more advanced than I am and I dread going a lot of times because I guess I see myself then and it’s kind of boring because you keep hearing the same things over and over… I guess I don’t really know the word to describe it best but when I told my husband once that I kind of dread going he is the one that said, “Well, maybe it’s because it’s a reflection of what might be,” and I think that’s a very fair analysis of it so… But I like all the people in there very much.*

Mrs. Wolf states that she often dreads going to the support group because she views individuals in the later stages of dementia and knows that is her future.

While Mrs. Wolf is at her support group, Mr. Wolf attends a support group for caregivers of individuals with early onset dementia. In some ways, Mr. Wolf feels the support group has been extremely helpful. He believes it has been beneficial in assuring him that they are not alone. He has learned a great deal about how other individuals cope with problems at different stages of
the disease, letting him know what’s on the horizon. Finally, Mr. Wolf feels the support group has been beneficial in reminding him that his problems could always be worse.

Mr. Wolf explains that going to the support group is not something he likes to do, but is something he thinks he needs to do.

He explains: \textit{It’s a reminder of where we are in our life and what we... and the burdens that we’re destined to carry and it’d be nice if we could let this cup pass from us but it isn’t going to happen so we know that we have it we have to move through, but those are all just reminders.}

Going to the support group reminds Mr. Wolf of the disease that affects their life and how it will affect their life in the future.

Gaps in Services

When asked what helps Mrs. Wolf day-to-day, she explained: \textit{My husband, my immediate family, my church, still being able to do things and see a positive outcome of it, still being able to work – teach classes.} As she progresses in the disease, Mrs. Wolf is aware that she will need more supervision and assistance with things such as taking a bath, getting dressed, putting on her makeup, and taking her pills. Mrs. Wolf also explains that staying engaged and active will remain important to her. She identified coloring as an activity that could keep her engaged in later stages of the disease.

\textbf{Mr. Tom Lowenstein and Mrs. Marie Lowenstein}

Mr. Tom Lowenstein (age 66) and Mrs. Marie Lowenstein (age 66) are a European American couple. They have three daughters and multiple grandchildren. Their youngest daughter moved a mile from the couple’s home 6 to 7 years ago. Recently, she quit her job in order to help care for her father and her grandmother. Her grandmother (Mrs. Lowenstein’s mother) has Alzheimer’s disease and lives within a couple of miles. Mrs. Lowenstein is the primary caregiver for both her husband and her mother. Mr. Lowenstein was diagnosed with mild cognitive impairment (MCI) with probable dementia in 2007 at the age of 61. He has been retired for approximately 10 years. For many years he worked at an advertising agency, then at an industrial agency, and for the last few years before he retired, he taught part-time as a substitute teacher and an adjunct professor of marketing and advertising at a local community college. Mrs. Lowenstein retired 4 years ago as a gerontological nurse at a health department.
Mrs. Lowenstein describes her husband as a very intellectual man, graduating magna cum laude from college; scoring higher on the Miller analogy test than any professor of his had ever seen; and loving nature, music, and the arts. Mr. Lowenstein describes himself as vociferous, egotistical, family oriented, and a very loving man. As Mrs. Lowenstein expressed, her husband is a “big guy” and she worries as she ages she will have difficulty helping him if his physical health declines. Therefore, Mr. Lowenstein is doing neuro-physical therapy two times a week to build his strength and endurance. The interview took place at the couple’s home of more than 30 years. The couple lives in a suburb of a metropolitan city. Mr. Lowenstein was interviewed first; the interview lasted approximately 50 minutes. Mrs. Lowenstein’s interview lasted approximately 70 minutes. Both interviews were conducted in isolation from the participant’s spouse.

The Diagnosis

Mr. Lowenstein thought there was something wrong with his mind long before he received a diagnosis. He was diagnosed at the age of 61; however, his wife stated that it was in his mid 50s that there was a big change in his level of functioning. Mr. Lowenstein believed he had a problem with his mind for 20 to 25 years before a diagnosis, at the approximate age of 40. Mrs. Lowenstein believes that her husband and she were in denial and, therefore, did not seek out a physician sooner. She explained that her husband is a brilliant man and it was because of his intelligence and humor that he was able to hide his symptoms for years. According to Mrs. Lowenstein, it was when her husband mismanaged their finances that they went looking for answers. The couple owned several rental apartments and he had lost checks from their renters. He also incorrectly filed their taxes, in response to which the IRS emptied all of the couple’s bank accounts, and according to Mrs. Lowenstein, left one penny to their name. The couple was forced to get assistance from a Certified Public Accountant to redo their taxes and explain to the government that Mr. Lowenstein had some form of dementia when he filed them. It was after this incident that the couple realized they needed to seek additional help.

The couple first went to their family doctor, who sent them to the hospital’s neuropsychiatric unit for testing. Mr. Lowenstein went through two days of testing, including an MRI. According to the couple, the physician who finally diagnosed Mr. Lowenstein with MCI with probable dementia was extremely dismissive and not empathetic to the couple’s feelings.
Mrs. Lowenstein describes receiving a diagnosis for her husband’s dementia: Well, it wasn’t… It was devastating. It wasn’t a big surprise but it was still devastating. It’s like this is the end our life, even though I know it’s a progressive, degenerative thing. I was very sad. And [my husband] being [my husband] was… He was concerned and he asked the neurosurgeon that did some tests to rule out hydrocephaly – he asked him, “Why did I…? How did this happen? Why do I have this disease? What causes that?” And this neurosurgeon, who is very famous and well thought of, his response to [my husband’s] question about “What’s caused this?” was “What do you care for? The outcome is the same.” And that’s all he said. And I said, “He cares because he would like to understand what’s going on.” But this doctor really… As soon as it wasn’t a neurological problem that he could fix, he was very dismissive. That was horrible – that part was.

Mr. Lowenstein expressed similar dissatisfaction when getting diagnosed, stating that he was “really pissed off.”

He explains: He... All he said was that “You have...” I don’t know whether he said something akin to Alzheimer’s or what but he said... Well, he said very, very little. There was no condolence. There was no value. There was no anything... It was an event, though, that I thought should have been couched in a little more doctor... physician-patient dialogue and he just rolled it out and said, “There it is,” and he didn’t want to talk and that’s... Having somebody tell you... Having somebody give you a diagnosis that you brain isn’t worth crap is... That’s a hardship – a hardship. And he was very, very laissez-faire about it – very...

Mr. and Mrs. Lowenstein feels receiving a dementia diagnosis is difficult and there should have been more dialogue with greater empathy from his physician during this time.

The Support Group

Mr. Lowenstein has been going to his local Alzheimer’s Association twice a month for five to six years. His first monthly trip is for a support group meeting for individuals in the early stages of dementia. This includes men and women of all ages. The second trip is for a structured activity meeting for the same individuals in the early stages of dementia. Examples of this meeting include a form of crafts, discussion of one specific subject, or a guest speaker. Although Mr. Lowenstein used to enjoy these two meetings every month, he expressed his exasperation lately with new members of the group.
Mr. Lowenstein explains: The people are not as open. They're not as out... They're not as direct in their comments as they used to be. I just feel like we’re kind of stifled. I liked it when it was just everybody was mixing and it was good. And some of those people are still there and I love them but most of the people just kind of sit around and they don’t say much. They don’t do much. They just... they’re there. So it’s just kind of like what you might expect a group of sick people to be but our early onset group was... We were very dynamic.

He feels the dynamics in his current group suppress their feelings more than individuals who have previously been a part of the group.

Mr. Lowenstein explains that many of the individuals who made up past support groups were older adults and they have since stopped coming or are deceased. Although some individuals in the group are younger than Mr. Lowenstein, the majority are older. This, however, does not negatively affect him and he explains, “I like it. I like it to be... I like to have as many people as would benefit from being a part of our organization to be active. Yeah, I like it.”

Mrs. Lowenstein is a co-facilitator of a support group that meets twice a month for caregivers of individuals in the early stages of dementia. She expressed mixed feelings about being a co-facilitator of the support group. She feels pressure, but it is also rewarding for her to help others. She has also learned a great deal from others’ opinions about the best approach to problems and from educational opportunities the Alzheimer’s Association provides. Although the members of Mrs. Lowenstein’s support group range in ages, she states that she also likes the variety in age.

In addition to the support groups the Lowenstein’s attend, Mr. Lowenstein volunteers at the Association, helping with things like writing notes and stuffing letters. Mrs. Lowenstein enjoys going to the educational lectures provided by the Association, and the couple participates in most of the outings and activities the Association puts on, including the annual Walk to End Alzheimer’s.

Mrs. Lowenstein describes her attitude toward the Association and the staff there: We try to support them because we just love the people that are there. I mean they’re just fabulous. They are very supportive and they’re very loving and very dependable. They’re good resources and good people that love what they’re doing so it makes a big difference.
Mrs. Lowenstein appreciates the staff at their local Alzheimer’s Association and tries to support them in return for the support they show her and her husband.

**Gaps in Services**

Mr. Lowenstein enjoys being involved with the Alzheimer’s Association and although he is not sure what opportunities there may be, he states he would like to be more actively engaged with them. Mrs. Lowenstein expressed the fact that her husband’s overall interest has decreased since his dementia has progressed. She feels as if it is difficult for her to keep him stimulated and engaged, due to lack of time and ideas. Her local Alzheimer’s Association has spoken to her about a center where people with dementia and their caregivers can come and choose various activities to do together. Mrs. Lowenstein is excited about the possibilities of a center such as this.

She explains: *Just the idea that [staff at Alzheimer’s Association] has about the community center or place where… Because it is hard day after day… I mean it’s important to keep people out and among the real world and if there were a place kind of like community centers – the senior centers – or even if they had a place for memory loss people at the senior centers – a place for them to go. That would be wonderful if people had transportation, if their partner or their caregiver could take them to keep them involved with the rest of the world that would be just great because there aren’t many activities and that’s the part that makes life less interesting if you’re always stuck at home with the same people, even if the people you’re with are great. It’s pretty crappy.*

In general, Mrs. Lowenstein would like her husband to stay engaged in activities and socialize with others.

**Mr. Don Marker and Mrs. Rosie Marker**

Mr. Don Marker (age 58) and Mrs. Rosie Marker (age 54) are a European American couple who have been married approximately 33 years. Mr. Marker joined the army in 1973 and once he left the army, he was a truck driver for fifteen years. He was forced to give up his driver’s license and leave his job after the doctor discovered brain aneurysms in March 2010. He is currently on disability, while Mrs. Marker does not work either as she also suffers from health issues herself. The couple has two daughters; one daughter lives in a different state and the other lives close by and assists her parents at times by taking Mr. Marker places, going on walks with
him, or picking up dinner for the couple. The interview took place at the couple’s home. Both participants were interviewed in private, with each interview lasting approximately 50 minutes.

The Diagnosis

Mrs. Marker and their daughters started noticing changes in Mr. Maker’s personality in 2008. He no longer liked being in crowds of people, his attention span had shortened, and he lost his patience, often having outbursts at his daughters. For approximately a year, his physician just kept an eye on him. It was after the changes in his personality become more apparent that more intensive tests were run. Three brain aneurysms were found and surgery was conducted to remove them. Afterwards, Mr. Marker was diagnosed with vascular dementia. In the past year after different personality changes occurred (e.g., inappropriately pulling down his pants in public), his physician diagnosed him with Early Onset Alzheimer’s disease.

The Markers believe that overall, physicians have worked well with them. Mrs. Marker explained that physicians first sat down with her and her husband to explain everything. Now, she works with her husband’s physicians, including a psychologist, a neurosurgeon, and a dermatologist, to provide the best care possible to her husband.

Mrs. Marker states: *I’m more or less the doctor’s eyes and ears and if something isn’t right I’ll write it down and I know which doctor to contact for what. So I’m helping them but they’re helping us. We’re kind of working together. We’re a team.*

Likewise, Mr. Marker states he is happy with the care he has received from his physicians.

Mr. Marker explains how his physicians show concern for him: *Oh, by trying to put me on the right regimen for medication and some of them have gotten on the phone and called me to see how I’m doing... But they just treat each other... They treat us as human being and not as a number or “Here’s another bill coming in,” I guess. They sat and they take the time with you and they answer every question they can to the best of their ability.*

Mr. and Mrs. Marker are happy with their physician. Mrs. Marker explains that she works as a team with her husband’s group of doctors and Mr. Marker states his doctors show concern for him by checking to see how is doing, treating him as a person, and taking time to talk to him and answer his questions.

The Support Group

Mr. Marker attends a monthly support group for men and women in the early stages of dementia through his local Alzheimer’s Association. In the past he has also attended a second
monthly meeting in which those in the early stages of the disease, often the same individuals who attend the support group, do some form of activity. His wife stated that lately he has not wanted to go to this second meeting, although she is not sure why. She hypothesizes that it may be because this meeting has less structure than the support group.

Mr. Marker considers the people at his monthly support group meeting a support system. He feels he learns from the people in the support group by listening to their stories and experiences. At the same time, he believes the people in the group learn from him as well, as he shares his experiences. Additionally, Mr. Marker state the support group can be enlightening as the individuals in the group try to “take a negative situation and turn around and make it positive.” The members of the group often go around and state what they are thankful for, and it puts into perspective things in life that many times they take for granted. Finally, Mr. Marker describes his support group as a “family,” giving each other support and friendship.

Mr. Marker describes his monthly support group at the Alzheimer’s Association: It’s one family and we all make the best of it right there. We don’t get down on each other or... We learn to just live, laugh, and love you know? And it’s the support... I have a hard time with words – the right word – but... camaraderie type deal. You’ll learn in life as you go along and I’ve learned with my army experience and driving a truck that you just can’t do something yourself a lot of time. It takes teamwork to complete the job. By that it just means I’m not the only one out there. Mr. Marker explains that part of the reason he appreciates the support group is the support and companionship he receives from other members. It reminds him that he is not alone.

Mr. Marker explains that the men and women who attend the support group are of all ages, with most of them older than he is. There are individuals with all different backgrounds and careers. However, Mr. Marker does not mind this diversity.

Mr. Marker explains: No, the more mixture the better because it’s... With a mixture of everybody and different experiences you actually get to know them and you learn a little bit more than you do with someone that has a similar problems, a similar past life and a similar day schedules that you have. So you don’t really learn anything from that. Mr. Marker states he learned more from the mixture of different people attending his support group.

Mrs. Marker attends a support group for caregivers of men and women in the early stages of dementia twice a month. Mrs. Marker states that a benefit of attending her support group is
what the members of the group learn from each other. She gives and receives suggestions on how to do things in regards to caring for her husband’s dementia, such as how to monitor his medication and legal paperwork. Along with these lessons, however, Mrs. Marker states, “I think mainly what I learned was I’m not alone.”

Mrs. Marker is the youngest in the support group, with most individuals at least eight to ten years older than she is. Due to this, Mrs. Marker feels she learns a lot of life lessons, not just lessons on dementia. At the same time, being the youngest in the support group makes Mrs. Marker feel cheated. She feels her husband should still be working and they could be saving for retirement. Despite this feeling, Mrs. Marker does think she receives the support she needs from the others in the group and describes this support by stating, “I guess it’d be like having an older sister or something.”

Gaps in Services

Mr. Marker plays games and brain teasers that exercise his mind on his computer a couple hours a day, stating he doesn’t want his mind to be “like a vegetable.” Although Mrs. Marker agrees that this is good for his mind, she thinks he needs more socialization and outside activity. She states it would be especially beneficial if someone could come and provide this socialization and outside activity for him, by taking him on a walk, for example.

Mr. Tom Hunt and Mrs. Sherry Love

Mr. Tom Hunt (age 60) and Mrs. Sherry Love (age 52) are a European American couple who have been married for 4 years. Mr. Hunt was in the military, serving in Vietnam and Desert Storm. He retired from his career in the federal government in May 2009. Later that year at the age of 57, he was diagnosed with frontotemporal dementia (FTD), a form of dementia in which the frontal and temporal lobes of the brain shrink, affecting the areas associated with planning and judgment, emotions, speaking and understanding speech, and certain types of movement (Alzheimer’s Association, 2013). Currently, Mr. Hunt works part-time at a local restaurant, doing various tasks including checking the dining room area, checking the beverages, and at times making bread. Mrs. Love works full-time as a real estate agent. She has two older sons who do not live with the couple and a 15 year old son who she adopted at three and a half months old. This son resides with her and Mr. Hunt and has a language disability. Mrs. Love and her son states this enables him to be more empathetic to the symptoms of Mr. Hunt’s disease.
Part of the week Mr. Hunt takes his step-son and a friend of his to school in the morning. The interviews took place at the couple’s home, a suburb just outside their local town. Although it was expected that Mr. Hunt would be interviewed first, when arriving at their home, Mr. Hunt was not home from picking up Mrs. Love’s son. Mrs. Love explained that he would not be home for 30 to 45 minutes and asked if her interview could take place first. After approximately 35 minutes into her interview, Mr. Hunt arrived home with her son. Mr. Hunt went in the other room while the interview was; however, Mrs. Love asked her son if he would like to stay. He did and occasionally he also spoke of the experiences of living with Mr. Hunt’s FTD. The interview lasted another 35 minutes, totaling approximately 70 minutes. Afterwards, Mrs. Love and her son went in the other room and Mr. Hunt was interviewed in private for approximately 60 minutes.

The Diagnosis

Although Mr. Hunt retired in May 2009 and received a diagnosis later that year, he feels his symptoms were present 3 to 5 years before he decided to retire. Thinking back, he believes his symptoms were part of the reason he retired, even though he had not received an official diagnosis at the time. Mrs. Love also felt that there were signs that Mr. Hunt was not himself, such as getting confused when she asked him to do something or having trouble prioritizing his activities. Mrs. Love got him into counseling and from there they saw a couple of neurologists until a diagnosis was made. Each counselor or doctor who they saw referred them to another medical professional when they realized Mr. Hunt’s symptoms were beyond their expertise. The couple considered themselves lucky that physicians recognized when they could not help Mr. Hunt and referred them on.

Mrs. Love explained: And got him into counseling and it just sort of went from there and we were lucky. Every doctor just fell into place and then that’s when they had tested him and diagnosed him with frontotemporal dementia.

Mr. Hunt agrees that they were fortunate to see physicians who listened to their concerns and took the appropriate steps to give him a diagnosis within a year of first going to a physician.

Mr. Hunt discusses receiving a diagnosis: I believe – and [my wife] believes the same thing – that we just happen to have got lucky to get in with the right doctors because we’ve known people that are in our support group that it took them a long time. I mean two and three
Mr. and Mrs. Hunt feel fortunate that they received a diagnosis within a year of seeking a physician due to Mr. Hunt’s symptoms. According to the couple, each physician they saw ran appropriate tests and referred him on when they did not know how they could help him.

The Support Group

For the past two years, Mr. Hunt has attended a monthly support group for individuals with early onset dementia once a month at his local Alzheimer’s Association. Although all the men and women in his support group were diagnosed younger than age 65 with a type of dementia, he is the only one who has a diagnosis of FTD. The benefits of the support group for Mr. Hunt are communication and socialization, things that often he has difficulty with due to FTD. He explains that the support group helps “open” him up and stimulates his mind as the group discusses how their month has been, any problems individuals are facing, or other subjects “just to communicate.”

Even though Mr. Hunt is the only person attending the support group with FTD, this does not bother him. He states the members of the group help each other, no matter what their diagnosis. Because the support group is for individuals with early onset, the members of the group are approximately the same age as Mr. Hunt. He explains that he does not have a problem with this, but would also not have a problem if the members of the group varied in ages.

Mr. Hunt clarifies: I believe with the various types of dementias it throws us into a common arena and it doesn’t make any difference how old they are or how young they are. If they’ve been diagnosed then we’ve got that camaraderie to where we can still... I can... Yeah, the age probably would help to see where they’re at and maybe the older ones can help the younger ones and vice versa.

To Mr. Hunt, a diagnosis of dementia places individuals of all different ages into a similar situation, in which they can all learn from each other.

For two years Mrs. Love has also been involved with support groups through their local Alzheimer’s Association. Like her husband, once a month she attends an early onset support group designated for caregivers of men and women diagnosed with a form of dementia before the age of 65. Mrs. Love also attends a FTD support group once a month, for men and women of all ages who are caregivers to someone with FTD. The greatest benefit of these support groups to
Mrs. Love is the friendships she has established. She has met other members in her groups who she will meet for lunch, talk with on the phone, or go out with throughout the month. Additionally, the support group and the Alzheimer’s Association in general has been Mrs. Love’s main source for education. They have helped prepare her for the future, including advising her on legal matters and looking for long-term options for Mr. Hunt as the disease progresses.

To Mrs. Love, the FTD support group is important due to the unique symptoms the disease can cause. She feels she receives answers that are specific to FTD in this support group. According to Mrs. Love, the FTD support group that her local Alzheimer’s Association chapter offers is the only one in the area and, therefore, caregivers from different cities and counties travel to attend.

Since the FTD support group is not specific to early onset, the members include some older adults as well. Although she does not mind the older adults who attend the FTD support group and has even gotten close to an older woman, the younger members of her early onset group are especially helpful to her in regards to her son who lives at home. Mrs. Love explains that with the early onset group, other caregivers also have children at home and it is helpful to talk about this unique circumstance with others who are experiencing similar situations.

**Gaps in Services**

Mrs. Love believes her local Alzheimer’s Association has provided her with the education, guidance and support she has needed, while also preparing her for the future with her husband. For Mr. Hunt, communication and socialization with people who are going through similar situations is very important to him. This is where the support group is especially beneficial to him and, as he states, it “helps with the isolation.” Therefore, neither Mr. Hunt nor Mrs. Love could identify any additional services or activities that would help them day-to-day.

**Mr. Jack White and Mrs. Sandy White**

Mr. Jack White (age 56) and Mrs. Sandy White (age 53) are a European American couple who have been married for 12 years. Mr. White has one daughter, one son, and grandchildren who live close by. According to the couple, they do not see Mr. White’s children often. Mrs. White also has a son, a daughter and an 18 year-old granddaughter. The couple recently moved in with her daughter, son-in-law, and granddaughter due to financial reasons. Mr. White
previously worked with computers, but has since retired. Mrs. White retired 1 ½ years ago from a career working for the state. Mr. White currently attends an adult day center two days a week. Often over the weekend the couple likes to go camping, and Mr. White works on his rock collection. Mr. and Mrs. White used to ride Harley motorcycles together, traveling the country. They were forced to give this up as Mr. White’s dementia progressed. According to Mrs. White, she cares for almost all of her husband’s activities of daily living (ADLs) and instrumental activities of daily living (IADLs), including shaving, getting dressed, and is starting to assist him with toileting. The interview took place at Mrs. White’s daughter and son-in-law’s home. Mr. White was interviewed first, lasting approximately 50 minutes; Mrs. White’s interview lasted approximately 60 minutes.

The Diagnosis

According to Mrs. White, the couple first realized Mr. White was having problems when he was working as a manager from home in 2008. Frustrated when he could not do this job to the best of his ability, he took a job as a customer engineer technician instead. At the same time, the couple owned a bar and grill. Mrs. White stated that this ran her husband down and he, therefore, quit his job as a technician to focus on the bar and grill. Within a year, Mr. White shut the bar and grill down with plans to obtain another job. According to Mrs. White, though, her husband could not fill out an application on the computer. It was then the couple sought professional help from a physician. The couple went to see a neurologist, but was not given a diagnosis, even though they both knew something was not right. After time had passed and more testing was done, such as a MRI and blood work, Mr. White was diagnosed with early onset Alzheimer’s disease at the age of 53.

Mrs. White stated: They really – the medical field – procrastinated it and I don’t know if it would have helped him if he would have been on Aricept quicker or possibly [husband] would have still been getting his benefits properly? Maybe we wouldn’t have lost so much?

Mrs. White explained that receiving a diagnosis for her husband was drug out by his physicians and in this time, the couple struggled financially, due to Mr. White not working and not receiving benefits. She wonders how things could have been different if they would have received the diagnosis sooner. According to Mrs. White, the neurologist that diagnosed her husband gave her the book The 36 Hour Day by Nancy L. Mace and Peter V. Rabins. She did not
know what to do once they received a diagnosis, so sought out the Alzheimer’s Association. According to Mrs. White, she felt relief after she did, receiving a lot of answers to her questions.

**The Support Group**

Mr. White attends an early onset support group once a month at his local Alzheimer’s Association. He states that he likes the group and likes that everyone in the group can talk about their problems.

Mr. White states: *That’s nice because it’s between us like you know, we can talk to each other and I know that group is really good.*

Mr. White explains that the men and women in the support group are around the same age as him, but it wouldn’t matter to him if someone was younger or older.

He explained: *We all have the same problems.*

At the time of Mr. White’s support group, Mrs. White attends a monthly support group for caregivers of men and women with early onset dementia. To her, the support group is about sharing, giving and receiving suggestions, and getting answers to your questions. She has found relief in the support group and the answers the participants provide. Another few times a month, she gets together with members of the support group outside the Alzheimer’s Association for lunch and socialization. She explains that it is in these meetings that they can talk more explicitly about the struggles they are having. Additionally, Mrs. White has been involved with the Alzheimer’s Association by participating in the Walk to End Alzheimer’s, advocating at City Hall, and participating in shows and videos to raise awareness of dementia.

Being an early onset support group, Mrs. White states the members are all around the same age. She likes this and believes it makes a difference. Having participated in support groups where there are caregivers of all ages, she believes the older women of the group do not share as openly as the younger members of her current support group.

Mrs. White explains her experience with an older support group: *I think it matters when it comes to the support group. I did a support group with all women and they were all older... Well, first of all older folks hold back a little more. They are more discreet on their descriptions. They don’t say everything.*

Mrs. White also felt she did not have much in common with the older caregivers. She believed they were going through different situations and had different questions they needed answers to.
She explains: *I guess it was I needed to be where what was happening with mine. I think the group’s good like that, personally. I didn’t have anything in common with those ladies either because they were so much older and their husbands were... most of them. One was pretty quiet and didn’t say much unless you said something to him. Another one was pretty active and he wanted to go around like taking off the cabinet doors, taking a walk outside the yard. He was at the wandering stage and she’d have to coax him in – “Come on. We’re going to go do something” – to help redirect. And then of course doing the cabinets – she had to hide all the tools – that kind of thing so... But that’s not what we had going on. I was like, “Oh, okay. How am I going to retire and how am I going to care for him? Am I ever going to work again? Am I ever going to be able to travel? Who is going to help me?”*

Mrs. White appreciates the fact that the support group she attends is geared specifically for those under the age of 65. Having attended a support group for caregivers of all ages, she feels the older members of those support groups do not share as openly as younger members. She also struggled to connect to the older members, due to having less in common with them.

**Gaps in Services**

Mrs. White explains that more time by herself would make a large, positive impact on her. She likes to do things in the evenings, such as go to concerts, to the theatre, or go dancing. However, she can no longer do those things with Mr. White. Even though she lives with her daughter and son-in-law, Mrs. White states her husband likes to solely depend on her. As a result, she greatly misses a social aspect that is important to her. In order to have this extra help with her husband, it is very expensive and she cannot afford it very often. Therefore, many times she does without.

**Ms. Samantha Stevens**

Ms. Samantha Stevens (age 58) is a European American who believes she may also have Native American heritage, although she cannot be positive since she was adopted at a young age. Ms. Stevens lives independently with her cat. Ms. Stevens has been married twice before to the same man. Her ex-husband lives in the city next to her. They check on each other by phone several times throughout the day and usually see each other on a daily basis. Ms. Stevens has a 28 year old daughter who also lives nearby. Ms. Stevens retired for medical reasons in 1996 from working in the Air Force, after her cognitive difficulties started affecting her work. Throughout
the year she volunteers periodically at a local Catholic school, with the city’s marching band, and with various activities through her local Alzheimer’s Association, including making ornaments for their annual Christmas Gala. Ms. Stevens was interviewed for approximately 80 minutes at her local library.

The Diagnosis

In 1992 at the age of 38 Ms. Stevens realized she was getting lost in familiar surroundings, transposing or repeating words in handwritten notes, and having trouble with numbers. She made great effort to tell her physicians about her difficulties, but felt as if everyone dismissed it because of her age. She stated this was “frustrating” and “horrifying.” Later that year, a physician diagnosed her with post-concussive syndrome at the age of 38. Ms. Stevens explained that her symptoms continued and she consistently followed up with her physician. Since the mid ’90s Ms. Stevens and her physician suspected that exposure to neurotoxic chemicals in her previous work, along with several head injuries, was causing a neurological disorder. In 2000 her physician confirmed their hypotheses and diagnosed her with Toxic Encephalopathy. Since she had retired and gotten away from these toxic chemicals, though, physicians predicted that her cognitive functioning would plateau. On the contrary, the cognitive abilities of Ms. Stevens continued to decline. Therefore, in 2005 her physician diagnosed her with early onset dementia of the Alzheimer’s type.

After receiving this diagnosis, Ms. Stevens left the physician’s office with very little knowledge of Alzheimer’s disease. She went to her local library and checked out books and DVDs on the disease.

Ms. Stevens explains her experience of seeking out information on Alzheimer’s disease on her own: But yeah, I didn’t know a lot about Alzheimer’s when I got the diagnosis. I had never been around it... I came over here to the library and I checked out like 14 books and the only two DVDs they had and the books were all directed to caregivers. Nothing was directed to me and they all basically said, “Don’t feel too bad about that person with dementia there because they’re not going to really understand or know what’s happening and it’s not really a problem for them. You poor soul that has to deal with them” and it was all “poor caregivers” and it was like, “Screw you people. Excuse me?” I’m raising my hand in here. I do know what’s going on here. I do know that what they’ve just said to me. I am really interested in what this means for me and how I function with this diagnosis and how fast things are going to happen
and what’s going to happen to me and I’m very aware and I think this is a crock of shit that none of you people think that I need to be in on the joke at all.

Ms. Stevens found that all books and DVDs on dementia at her local library were directed towards caregivers and explained that the person with dementia would not comprehend the progression of their disease. Therefore, Ms. Stevens was forced to figure out how to live with the disease herself and developed systems and plans, such as her “what to do when I get lost” plan. Ms. Stevens found that she is able to follow written directions. Therefore, her plan consists of writing down directions beforehand or asking someone at a local convenient store to write them down if she gets lost. On her own Ms. Stevens conducted more research and soon found her local Alzheimer’s Association and contacted them for additional answers and support.

The Support Group

Ms. Stevens attends a support group for men and women in the early stages of dementia once a month at her local Alzheimer’s Association and participates in a structured activity with the same group once a month. The first time she attended the support group, Ms. Stevens did not think she would fit in because she was too high functioning. After attending she believed she was in the middle in terms of functioning, whereas she thought half the people attending were higher functioning than her and half were lower functioning. To Ms. Stevens there is a splintering in the support group between the older and younger members.

Ms. Stevens explains: The older ones had chances that we will never have – ever. They got to work their career and many of them got to retire, even before they developed dementia. They got to work that full job and get the full pension with the full retirement benefits. They got their house paid off, their mortgage paid off, their children grown. Their children are all functional and on jobs of their own. They’re not just still in college or something. They are at a much more secure point in life than we are.

Ms. Stevens feels the older members of the support group have gotten opportunities and experiences that the younger members have not, due to a diagnosis early in their life. Additionally, she does not think the Alzheimer’s Association provides men and women with the educational resources to help those who are diagnosed at a young age and are facing these unique issues.

Gaps in Services
Ms. Stevens believes there needs to be more information for those diagnosed with dementia at a young age. She believes there needs to be more factual information available so men and women can understand how things will progress and make plans.

Additionally, Ms. Stevens believes that those with early onset still have a great deal to offer others, even if they can’t work anymore.

Ms. Stevens explains: *There is a wealth in here where we could... Maybe we’re not ready to be on the job anymore but we could be hell of an asset in a really volunteer start realm where people need something and “Okay maybe I’m not going to remember your name next time when I come in and maybe you’re going to have to tell me again what I’m doing here but once you stick me over there and say ‘put these boxes over here’ I can do that really well.” And I could be an asset. So I think finding uses for us is really good or letting us find uses.*

Ms. Stevens believes that those diagnosed with early onset still have a lot to offer society and need to stay active and stay involved. If not, she states, “You lose everything.”

**Conclusion and Discussion**

Coping with the clinical manifestations (e.g., a more varied diagnosis and a quicker progression) and psychosocial implications (e.g., departing from social roles at home and in the workplace) before the age of 65 can have unique consequences for those affected by early onset dementia. Consistent with the life course perspective, the timing of transitions, trajectories, and turning points in one’s life matters (Elder, 1996). The diagnosis of dementia before the age of 65 is “off time” to the typical timeline of one’s life, resulting in an individual departing from social roles long before they ever anticipated. The life course perspective also maintains that lives are linked (Elder, 1996) and, therefore, the departure of persons with EOD from social roles also affects their primary caregiver. The primary caregiver is often forced to depart from social roles and adapt to new roles, also “off time” to the typical timeline of an individual’s life.

The life span development perspective maintains that an individual’s life span constitutes losses, gains, and plasticity, with an influence from biological and environmental processes (Baltes, 1987). Consistent with the life span development perspective, EOD represents a “tipping point” in which plasticity is diminished; the balance between gains and losses, which with normal aging gradually shifts from gains to losses, is greatly accelerated; and the biological consequences of the disease may or may not be supported by the environment. Services provided
by organizations, such as the Alzheimer’s Association, attempt to help families affected by dementia cope with the disease by providing a positive environmental influence. Many of these services, though, are not age specific and are designed for individuals of all ages living with dementia and their families.

Support groups in general have been found to reduce depression and improve the quality of life for persons with dementia and caregivers (Chien et al., 2011; Logsdon et al., 2010), few studies have explored what specific services would benefit individuals diagnosed with EOD and their caregivers. The studies that have addressed these specific services offer general guidelines such as age-appropriate, flexible to the changing patterns of dementia and flexible in terms of their opening hours in order to accommodate to a caregiver’s work day (Beattie et al., 2002). Harris (2004) recommended services that provide peer socialization and frequent workshops that focus on the challenges of those diagnosed with early onset dementia.

In this study, the face-to-face structured interviews with participants and, where available, the co-participant, resulted in three main findings: 1) participants and co-participants sought compassionate consultation and guidance from their healthcare provider when receiving a diagnosis of EOD; 2) participants and co-participants are generally happy with the support group they attend, whether it is specific to EOD or not; however, some participants did identify limitations to their support group; and 3) both participants and co-participants desire opportunities for persons with EOD to engage in meaningful activities. Because there was a high degree of overlap between participants’ and co-participants’ experiences and perceptions, the researcher chose to consider the dyad as the unit of analysis (except for the “solo” participant). The subsequent sections summarize the findings that derive from the multiple case studies, while discussing implications these finding may have. The sections are organized by the diagnosis, support groups, and gaps in services.

The Diagnosis

Although the topic of receiving a diagnosis of EOD was a recurring theme throughout the interviews, the experience of receiving this diagnosis varied across the dyads. One dyad struggled financially because the participant, who was the primary income earner for the family, was not able to work or receive benefits during the diagnosis process. The co-participant often wondered if they would be in the financial hardship they were experiencing at the time of the interviews had they received a diagnosis more quickly. Another woman started experiencing symptoms at the age of 38 and felt
extremely frustrated when healthcare professionals and even her family would not listen to the struggles she expressed. This supports Harris and Keady’s (2009) explanation that receiving a timely and proper diagnosis of EOD is a unique challenge for families. Another dyad felt fortunate they were able to receive a diagnosis within a year of seeking a physician about the participant’s symptoms.

More common than the story of receiving a proper and timely diagnosis, however, was the dyads’ reflection on their relationship with their physician when receiving a diagnosis. Participants and co-participants repeatedly expressed their degree of satisfaction with the rapport they had with their doctor. Those who were satisfied explained that their doctors took time to explain the diagnosis to them, answer any questions they had, and treat the person diagnosed as a “human being and not as a number.” Unfortunately, not all of the participants and co-participants had this experience. Other couples described their experience getting a diagnosis from the physician as “horrendous,” “horrible,” and evoking a negative emotional response (e.g., “really pissed off”). The latter group of participants and co-participants unanimously stated their physicians were very direct and dismissive when giving the diagnosis of dementia. A diagnosis was given without further information on what to do or where to go, and without much empathy or compassion.

This dissatisfaction families felt when receiving a diagnosis of EOD from their physician might be exacerbated by being “off time” in one’s anticipated life trajectory (Elder, 1996). The non-normative timing of a diagnosis such as this has unique impacts on families that dyads felt should be acknowledged and discussed when given a diagnosis. This supports Kuhn’s (2007) recommendation that families who have received a diagnosis of dementia need basic medical information and strategies for coping with their changing roles. He recommends this be done through face-to-face consultation, reading materials, and a referral to their local Alzheimer’s Association chapter. Based on interviews with participants and co-participants, it is also recommended that physicians dedicate time to explain the diagnosis and disease to families and answer any questions they may have. This supports Connell, Boise, Stuckey, Holmes, and Hudson’s (2004) findings that caregivers desire a diagnosis be disclosed in a gentle and compassionate manner. Caregivers stated that physicians often did not provide adequate information and referrals after receiving a diagnosis, and physicians expressed the discomfort they often felt when disclosing a diagnosis (Connell et al., 2004). Therefore, it is recommended that organizations such as the Alzheimer’s Association and other service providers include a physician outreach component to their work, providing their local physicians with appropriate information and resources to help them better work with families affected by dementias in general and EOD in particular.
The Support Group

All seven participants and six co-participants attended a support group sponsored by their local Alzheimer’s Association at least once a month. Of those participants and co-participants who commented on their length of involvement with a support group, durations ranged from approximately a year to more than five years. Based on participant feedback, Snyder et al. (2007) evaluated the effectiveness of supports groups for individuals in the early stages of dementia and found that participants reported on the socialization, educational value of the group, and their ability to better cope with symptoms and accept the diagnosis. In general, participants and co-participants were satisfied with the support group they attended, whether it was specifically for individuals with early onset or was target to those in the early stages of dementia. Consistent with Snyder’s et al. (2007) findings, dyads commented on the three interrelated benefits they obtained from participation in support group(s). Participants and co-participants commented on friendships they have made in the support group, referring to them as “family” and reminding them that they are “not alone.” They derived pleasure from that fact that they are able to share with their support group members and trust them to keep their information and feelings confidential. They expressed that often times just sharing and having someone to talk to helps them cope.

Dyads also identified an educational component to the support groups, expressing that group members helped them learn better ways to cope and live with the disease by listening to the advice and experiences of other group members. In addition, dyads spoke to the reciprocal value of education, and they expressed their satisfaction in knowing their own experiences have helped others. However, despite identifying benefits to participating in her support group (which she had attended for over five years), one participant expressed the need for more factual information regarding EOD, such as a timeline of what symptoms she could expect and when they would occur. It is worth noting that this participant did not identify a co-participant.

Reed et al. (2002) points out that dementia is often thought of as an “older person’s disease,” and services for those diagnosed and their families are, therefore, often geared toward older adults. Previous literature has advocated for specialized services for EOD (Bakker et al., 2010; Beattie, et al, 2002), due to the unique clinical manifestations (e.g., a more varied diagnosis and a quicker progression of the disease) and unique psychosocial impacts (e.g., individuals still working and raising families) that stem from EOD. On the contrary, Reed et al. (2002) argues that services should cater to individualized needs, irrespective of age. Other previous literature has not taken a stand on specialized versus non-specialized services, recommending that more research be conducted to explore this issue (Harris, 2004). This debate
was explored in this study, specifically examining participants’ and co-participants’ perspectives of whether the age of other members in their support group was relevant. Dyads were recruited from two Alzheimer’s Association chapters, one of which provided a support group for individuals in the early stages of dementia and their primary caregiver regardless of age (Chapter A) and the other which provided a support group specifically for those diagnosed with dementia before the age of 65 and their primary caregiver (Chapter B). The researcher found that almost all participants and co-participants stated they did not or would not mind if men and women of all ages attended their support group. Participants and co-participants from both Chapter A and Chapter B stated they like diversity, they could learn from older individuals in the group, and that “they all have the same problems.”

However, there were several participants who did not agree with the majority opinion about age irrelevance in support group composition. Further, individual dyads did not always agree about this. One participant from Chapter A (who did not identify a primary caregiver) feels there is a splintering in her support group between the older and younger members, due to the fact that the older members have gotten opportunities and experiences that the younger members have not, such as retiring before they developed dementia, paying off their mortgage, and raising their children to self-sufficiency. This is consistent with the life course perspective’s notion that the timing of transitions along life trajectories matter, and that being “off time” from normative social timing has unique consequences (Elder, 1996).

Another co-participant who attended a support group through Chapter B also said the ages of the men and women in her support group matter. Even though she attends a support group that is specifically for caregivers of individuals diagnosed before the age of 65, she had previously attended a support group that included caregivers of all ages. She left this support group because she believed older members did not share as openly as younger members and she struggled to build a connection with the group, due to having less in common with the members. Her husband, on the other hand, explained that having men and women in his support group of all ages would not matter to him. The participant currently attends an adult day center with individuals of all ages and is satisfied with the age diversity there. Another participant stated she often dreads going to her support group because she sees men and women in more advanced stages of dementia, and she knows that is her future. It is interesting; however, that this particular participant attends a support group through Chapter B, where all individuals participating in the support group are younger than age 65. In contrast, her husband discussed the friendships he has made in the support group, as he found other individuals with similar interests. Therefore, even though the life course perspective speaks to the principle of linked lives, this does not necessarily imply perfect
congruence. Additionally, the life course perspective maintains that individuals construct their own personal agency, making individual choices within social opportunities and constraints (Elder, 1996).

Although more research is needed regarding the implications of age integrated versus age segregated support groups, it is recommended that support groups and the organizations that provide them should investigate participants’ individual needs, by survey and/or informal discussion, and attempt to address it. This may seem like a daunting task, but if most participants are satisfied with their support group, as were participants in this research, few accommodations will be needed. For example, the dissatisfaction of the participant from Chapter A who is looking for more factual information from the support group should be followed up by a staff member and/or support group leader. Although the chapter does not offer a support group specifically for EOD, they can provide the participant with educational material that directly affects her. This may adhere to what she was looking for and as a result, be more satisfied in a support group with older members.

**Gaps in Services**

Although participants and co-participants often did not identify a particular service that they would benefit from (e.g., an age specific adult day center), they did identify certain wishes that can be satisfied with the appropriate service. For example, co-participants often expressed their desire to have some sort of outside activity for participants; something to keep them engaged and encourage their socialization with others. Similarly, participants many times expressed the desire to stay engaged in a meaningful activity and socialize with people in similar situations as themselves. This supports Harris’s (2004) conclusion that more services with peer socialization is needed.

This desire to stay engaged is consistent with the life span development perspective and the notion that an individual’s social and environmental opportunities and constraints have a direct influence on them (Hoyer, 2006). Although both support groups provided participants and co-participants an opportunity to learn how to cope with the disease, meet people in similar situations, and receive education, the lack of opportunities for persons with EOD to stay engaged in meaningful activities is a social constraint. We hear from listening to participants and co-participants that this constraint does in fact influence them. For example, one participant expressed, “If you don’t keep working and doing and stay active and stay involved you lose everything.” Consistent with the life course perspective (Elder, 1996), this might be particularly important for people with EOD, who oftentimes lose multiple social roles in a relative short period of time because of the disease. As such, the opportunity to participate in age-appropriate activities with others in similar situations could help to compensate for these earlier
losses. An additional benefit identified by Kinney et al. (2011) is that such activities also promote additional, nondisease-related interactions with their primary caregivers.

Dyads also alluded to the fact that more volunteering opportunities would help individuals with EOD stay engaged and active in society. This is consistent with Kinney et al.’s (2011) interviews with participants of a weekly, supervised volunteer program for men with EOD at the local zoo. The researchers found that the volunteer program provided a positive experience for individuals with EOD. Even without a formal program such as this, however, persons with EOD can volunteer at local organizations and service providers, like their local Alzheimer’s Association, or throughout their community with a greater push from service providers and families. Helping persons with EOD stay engaged and active may be as simple as presenting them the opportunity to do so. For example, an organized volunteer day at a local organization may encourage persons with EOD to come and help, while also socializing with others who chose to participate. Or, caregivers and persons with EOD can collaborate with others in their support group to volunteer at a local organization together. Although organized services that will engage persons with EOD and promote socialization are ideal, smaller efforts can also be made to fulfill this desire identified by participants and co-participants.

Limitations and Directions for Future Research

This study is not without limitations. The researcher obtained perspectives and opinions of seven persons diagnosed with EOD and, for six of them, their primary caregivers, from two Alzheimer’s Association chapters in the Midwest. As such, these participants and co-participants are already connected with and receiving at least one service from their local Alzheimer’s Association (i.e., participating in a support group). Interviews with persons with EOD and their primary caregiver who are not connected to an Alzheimer’s Association chapter and/or are not attending a support group may yield very different results and is recommended, as their preference for services may be very different from this sample. For example, are families not connected to their local Alzheimer’s Associations because they are seeking different services than the ones provided? Or, are there other reasons families are not taking advantage of services provided by their local Alzheimer’s Association, such as geographic location, lack of awareness and/or personal preference? Consistent with the life course perspective, what are the social and environmental constraints that keep these individuals from engaging in services provided by the Alzheimer’s Association, what role does personal agency play in this process, and how can we turn these constraints into opportunities for this unreached population?
Although kinship tie between the individual with EOD and their primary caregiver was not a criteria for participation, all primary caregivers were spouses to the person with EOD. Clearly, the marital relationship plays a role in the participants’ and co-participants’ experiences and perceptions of any major event, including EOD. And, during several interviews, the marital relationship was alluded to. For example, one couple prided themselves on being married 45 years and explained that they “just kind of enjoy being together.” Another couple stated a challenge of coping with the disease is the fact that they have only been married four years. Despite these occasional comments, the marital relationship was not further elaborated on. Although it would have been interesting to explore the role of the marital relationship in the process of negotiating the demands of EOD, the focus of this research was on the experience of EOD and the role of services in managing the disease. Therefore, the dynamics of marital relationships is beyond the scope of this study, but should be explored in future research.

In addition to the marital relationship, other aspects could have been further explored in order to help gain insight into participants’ and co-participants’ experiences and perceptions. As the life span development perspective focuses on the individual changes (biological, psychological, and social) that occur throughout one’s life (Hoyer, 2006), the individual similarities and differences of participants and co-participants (e.g., the stage of disease of the person with EOD and social support outside of their local Alzheimer’s Association) would be advantageous to explore more in depth. Consistent with the life course perspective, it would also be beneficial to further explore societal impacts on participants and co-participants (e.g., work history and financial stability of dyads). By further exploring individual and societal impacts on persons with EOD and their primary caregiver, a broader and more complete picture of this population may be discovered.

Despite the study’s limitations, findings from this study indicate that persons diagnosed with EOD and their primary caregivers seek empathy, understanding and communication from healthcare providers when receiving a diagnosis. Although most participants and co-participants were satisfied with the support group they attend at their local Alzheimer’s Association, benefiting from the education value, friendships, and emotional support, it is important for leaders and staff members to recognize those who do not and help cater to their individual needs. Finally, service providers should create more opportunities for persons with EOD to stay active and engaged, such as volunteer programs. Participants and co-participants in this study have been generous in expressing their experiences of living with the disease and adapting to the unique implications that come as a result of it. It is now up to us to listen to
their voices and cater our perceptions, services, and research in a way that improves the lives of all those affected by early onset dementia.
References
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Appendix A.

**Join us in a new research project on services of individuals diagnosed with early onset dementia and their family members**

Kathryn Beanblossom, a graduate student studying gerontology at Miami University in Oxford, Ohio is conducting a research project on early onset dementia to fulfill the requirements of her master’s thesis.

In-depth interviews will be conducted with the individual diagnosed with early onset dementia and the individual who most assists them on a day-to-day basis. You are eligible to participate in this research if…

- You have been diagnosed with early onset dementia or currently live with a loved one who has been diagnosed with early onset dementia.
- The individual who has been identified as most assisting the person with early onset dementia on a day-to-day basis and the individual with a diagnosis of early onset dementia currently reside in the same household.
- The individual diagnosed with early onset dementia is of age 65 years or younger, and her/his relative has the legal authority to consent on behalf of the participant (i.e., has Power of Attorney).
- The individual diagnosed with early onset dementia and the person assisting on a day-to-day basis is willing to discuss the disease, how it affects them, and services available and desired for them and their family.

Participation in the project is entirely voluntary and will not affect any services that you might receive or be interested in receiving from the Alzheimer’s Association. Interviews are anticipated to last approximately 60 minutes and will take place in the setting of the participants’ choice.

If you would like more information in participating in this research project, please fill out the information on the next page and return it to a staff member at your local Alzheimer’s Association. They will return the completed document to me and I will contact you shortly after receiving it. You may contact Kathryn at any time if you have questions or concerns at:

Kathryn Beanblossom, beanblkm@muohio.edu or (937) 417-1855
YES! PLEASE CONTACT ME TO TELL ME MORE ABOUT THE RESEARCH ON SERVICES FOR INDIVIDUALS DIAGNOSED WITH EARLY ONSET DEMENTIA AND THEIR FAMILY MEMBERS

Name of Participant (individual diagnosed with early onset dementia)

__________________________________

Phone Number _________________

Date _________________

Name of Co-Participant (co-resident person most responsible for assisting participant)

____________________________________________

Phone Number _________________

Date _________________

PLEASE PLACE THIS SHEET IN THE PROVIDED ENVELOPE, SEAL IT, AND MAIL IT AT YOUR CONVENIENCE.
Appendix B.

Consent Form for Participants (Individuals with Early Onset Dementia) and Co-participants (Primary Caregivers)

I understand that I am participating in a project designed to study the need for and use of services of those diagnosed with early onset dementia and their primary caregiver, as well as their perceptions and experiences of the disease. This project is being conducted to serve as the principle investigator’s master’s thesis in relation with the Sociology and Gerontology Department at Miami University.

My participation is completely voluntary. I understand that before being selected to participate in this study, the researcher will ask us questions that determine if we are appropriate for the study based on the qualifications the researcher deems necessary.

I understand that if we are deemed eligible by the researcher, we will participate in interviews. I also understand that the interviews with individuals with early onset dementia and the interviews with caregivers will be held separately, and the individual not being interviewed will be not be in the room while the interview takes place. Each interview will last approximately 60 minutes. In addition to this interview, I give the researcher permission to revisit if additional information or clarification is needed.

I understand that potential benefits of participation include the opportunity to reflect on my own experiences with early onset dementia and to express potential services and programs that my family and I would benefit from in regards to coping with this disease. Potential benefits to society are a better understanding of the experiences of coping with early onset dementia, as well as knowledge, which has the potential to lead to implementation, of services and programs that may be useful to those diagnosed with early onset dementia and their families.

I understand that the interviews will be audio-taped so that my comments can be transcribed later for purposes of data analysis. All information collected about me and my family is confidential. There are no financial costs associated with participation in this project.

I understand that if, at any point during the interviews, I do not wish to continue for any reason I may end my participation in the study. I am giving my consent to participate freely, and with full understanding.

I understand that I may contact Miami’s Office for the Advancement of Research and Scholarship, (513) 529-3600, if I have any questions about my rights as a participant in this study. I will contact either the primary investigator, Kathryn Beanblossom (937-417-1855) or her faculty advisor, Dr. Jennifer Kinney (513-529-2915 (office); 513-255-6947 (cell)), if I have any questions about this study.
Participant Assent

I agree to participate in the research study titled, “Early onset dementia: An exploration of the need for and use of services,” which includes interviews with myself and my family member who assists me on a daily basis. I further agree that my family member and I will participate in these interviews in solitude, without the other one presence. The interviews will be audio-taped and the researcher has permission to request a revisit if additional information or clarification is needed after the initial interview.

Participant Name: ________________________________

Participant Signature ______________________________

Date: ______________________________

Co-participant Consent

I give consent for my family member with dementia and me to participate in the study “Early onset dementia: An exploration of the need for and use of services,” which includes interviews with myself and my family member with early onset dementia. I further agree that my family member and I will participate in these interviews in solitude, without the other one presence. The interviews will be audio-taped and the researcher has permission to request a revisit if additional information or clarification is needed after the initial interview.

Co-participant Name: ________________________________

Co-participant Signature ______________________________

Date: ______________________________
Consent for Use of Quotes from Interviews

I give my consent to use quotations (without identification and/or attribution) from the interview audiotapes for use in professional presentations and publications.

Name: ___________________________________________________

Date: _____________________________________________________
Appendix C.

Guided Interview Questions

*Interview questions for the person diagnosed with early onset dementia (i.e., participant)*

- What is a typical day like for you?
- What do you do during the day?
- Has this changed from what you used to do during the day?
- Does anyone help you complete tasks throughout the day that you used to complete on your own?
- Are there things you would like to do if someone was available to help you?

*Interview questions for the caregiver (i.e., co-participant)*

- What is a typical day like for you in relation to your loved one with dementia?
- What do you feel your loved one with dementia could use help with?
- Are there things you would like to do for your loved one that you are not able to do?
- What resources would help you best take care of your loved one?
- What would need to be in place in order for your relative to do things that he/she would like to do?