

Experiencing Dementia in the Workplace: Impacts of Younger Onset Dementia on Employment

Carmen Travis

Research Advisor: Barbara Kopp Miller, Ph.D.

Department of Rehabilitation Services

Occupational Therapy Doctorate Program

University of Toledo

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### **Abstract**

*Objective:* The purpose of this study was to examine the relationship between younger onset dementia and employment experiences that occurred as a result of related symptoms. This study will provide a source for occupational therapists, employers, and researchers to build upon when identifying modifications necessary to the workplace to encourage maintenance of employment by an individual with this diagnosis.

*Method:* The participants ( $N = 10$ ) for this interview study were individuals with younger onset dementia or their caregivers. Approximately 150 flyers were distributed via e-mail or in-person, through the Alzheimer's Association and a local Alzheimer's Care facility to recruit participants. Interested parties contacted the researcher for additional information.

*Results:* Overall, a person's co-workers were reported as being the first to notice declining abilities. In most cases, individuals with younger onset dementia voluntarily chose to discontinue employment upon receiving a diagnosis. Termination of work was found to bring on feelings of loss of dignity, loss of independence, and loss of purpose. In most cases, individuals did not begin participating in meaningful occupations outside of the home to compensate for the loss of purpose felt from losing a job.

*Conclusion:* Occupational therapists can play a pivotal role in providing awareness to both employers and their employees on the signs and symptoms of Alzheimer's disease and dementia. Additionally, employers can utilize occupational therapists to provide annual or biennial cognitive screenings for employees to detect cognitive impairment in the beginning stages and implement graded responsibilities when necessary. Future research is necessary to develop an understanding of employer's attitudes and opinions toward permitting an employee diagnosed with younger onset dementia to remain employed with modified job responsibilities.

## **Experiencing Dementia in the Workplace: Impacts of Younger Onset Dementia on Employment**

Alzheimer's disease was first diagnosed over 100 years ago; however, it was not until the past few decades that there has been an increasing amount of literature focusing on its symptoms, causes, and treatment. Furthermore, it was not until 2006 that the national office of the Alzheimer's Association publically acknowledged the growing population of individuals under the age of 65 who receive a diagnosis of younger onset dementia. Although Alzheimer's disease is a devastating diagnosis to receive at any age, when diagnosed with younger onset dementia a person experiences added emotional stress and unique challenges (Alzheimer's Association, 2011). The current study identifies and discusses specific experiences individuals with dementia encounter while in the workplace and, specifically, the impact symptoms of young onset dementia has on their experience in the workplace. Before the current study is introduced, a brief review will be provided regarding Alzheimer's disease, dementia, and younger onset dementia.

### **Alzheimer's disease and Dementia**

Dementia is characterized by a decline in level of functional abilities, loss of recent memories progressing to the loss of more remote memories, and other cognitive deficits including agnosia, aphasia, and apraxia, as well as the loss of executive functioning (Morrison, 2006). Different types of dementia are associated with different types of cell damage in particular regions of the brain (Alzheimer's Association, 2012b). By identifying the underlying cause of the disease, the course of dementia can be more accurately determined. In some cases, dementia can be treatable, stopped, or reversed (Mace & Rabins, 2011). However, 50-80% of reported cases of dementia are a result of Alzheimer's disease for which there is no prevention or cure (Alzheimer's Association, 2012a; Mace & Rabins, 2011).

According to a 2011 report by the Alzheimer's Association, vascular dementia is the second most leading cause of dementia (i.e., post-stroke dementia). Other common causes are Lewy body dementia, Parkinson's disease, and Frontotemporal dementia. Additionally, dementia may be caused by chronic alcoholism or drug abuse. Despite ruling out these other causes, the only way to truly obtain an accurate diagnose of dementia of the Alzheimer's type is after death through an autopsy of the brain to identify if plaques and tangles are present (American Psychiatric Association, 2000).

According to the American Psychiatric Association (2000) there are three primary criteria for diagnosing Alzheimer's disease; (1) the development of multiple cognitive deficits manifested by cognitive disturbances and one other impairment, (2) significant decline in social or occupational functional ability as a result of the cognitive deficit, and (3) a course of gradual onset and continual decline. In addition, other possible causes of dementia need to be eliminated in order for Alzheimer's disease to be diagnosed.

The signs and symptoms of Alzheimer's disease vary depending on the individual and the level of severity will fluctuate from person to person. The Alzheimer's Association provides 10 signs and symptoms that can be used as warning signs for Alzheimer's disease:

- Memory loss that disrupts daily living;
- New difficulties with developing and following a plan or working with numbers;
- Increased difficulty when completing a routine task such as driving to a familiar location;
- Confusion with time or planning, trouble understanding visual images and spatial relationships, and new problems with speaking or writing;
- Misplacing items;

- Inability to retrace one's own steps;
- Poor judgment;
- Changes in mood;
- Changes in personality; and
- Withdrawal from work or social activities.

Alzheimer's disease and dementia symptoms present uniquely in every individual and some can experience different symptoms to a variety of degrees (Alzheimer's Association, 2012c).

Because Alzheimer's disease most often initially impairs a person's memory, the first signs can be mistaken for the typical process of aging. However, Alzheimer's disease is progressive; most often described using a three stage approach. As it advances through the stages, virtually all of a person's performance skills will be affected (Fraker, 2012).

The early stage typically lasts from two to three years and is classically marked with significant impairment of short-term memory. Signs of aphasia and paraphasia begin to emerge and visospatial skills begin to decline as well (Bear, Connors, & Paradiso, 2001). Problems in areas of executive functioning such as planning, organizing, and sequencing will decrease a person's ability to complete instrumental occupations of daily living (Hales & Yudofsky, 2003). The middle stage of Alzheimer's disease lasts from two to ten years. During this time a person becomes unable to retain information longer than a few moments, will not recognize oneself or family (National Institute on Aging, 2003), and has increased aphasia (Frank, 2003; Zogla, 1999). Persons in this stage will be unable to orient themselves in familiar or unfamiliar environments (Zogla, 1999) and the classic Alzheimer's disease characteristic of wandering emerges. Depression and auditory hallucinations are not uncommon (Kovach, 1997). In the late stage of the disease, a person becomes fully dependent on others for basic occupations of daily

living such as toileting, eating, and dressing. This stage can last from eight to twelve years during which time a person is no longer able to retrieve or create new memories (Shenk, 2003) or participate in purposeful or goal directed occupations (Kovach, 1997).

### **Prevalence of Dementia Type**

In their 2014 Facts and Figures Report, the Alzheimer's Association reported that there were an estimated 411,000 new cases of Alzheimer's disease in the year 2000. That number increased by an estimated 10% in 2010, to an annual incidence of 454,000 diagnoses. They projected that by 2030 the annual incidence of Alzheimer's disease will increase by 50% to 615,000 new cases in adults 65 and older. If their projections are accurate, there will be 959,000 people diagnosed with Alzheimer's disease during the year 2050. Furthermore, by the year 2050, it is estimated that the number of individuals with a diagnosis of Alzheimer's disease will triple from the current 5.2 million individuals with a diagnosis to anywhere from 11 to 16 million individuals with a diagnosis of Alzheimer's disease. Every 69 seconds someone in the United States is currently developing Alzheimer's disease and by 2050, a person will develop Alzheimer's disease every 33 seconds. These calculations foretell the lifetime risk of developing the disease as being highly probable (Alzheimer's Association, 2014).

While neither Alzheimer's disease nor dementia is a normal symptom of aging, older age is the highest known risk factor in acquiring the disease (Alzheimer's Association, 2012a). Dementia is generally diagnosed in adults age 65 and over, however; the number of younger adults with dementia is on the rise and over the last 15 to 20 years there has been an increasing awareness of younger onset dementia where symptoms begin prior to the age of 65 (Sampson, Warren, & Rossor, 2004). One 2011 study reported that of those who receive a diagnosis, the rate is approximately 1 percent at age 65, 10 percent at age 75, 20 to 30 percent at age 80, and 30

to 50 percent at age 90 (Mace & Rabins, 2011). However, the 2014 Facts and Figures report published by the Alzheimer's Association states that approximately 4% of those diagnosed with Alzheimer's disease are under the age of 65 (Alzheimer's Association, 2014). Although rare, younger onset dementia can occur in individuals as young as 45 years old, all the way to when a person is still in his or her early 30's. Even more uncommon, but still possible, individuals can show signs of dementia in their mid-20s (Rinfrette, 2010).

It was not until recently that dementia became recognizable in the younger age groups (Yokota et al., 2005). In 2006, the Alzheimer's Association published their first report on younger onset dementia in which they estimated that there were between 220,000 and 640,000 individuals with this diagnosis (Alzheimer's Association, 2005). Although there are no comparable statistics, this report supports estimates that the prevalence of younger onset dementia is 6 to 10% of those diagnosed with Alzheimer's disease (Alzheimer's Association, 2003). More recently, the 2014 Facts and Figures Report compiled by the Alzheimer's Association estimated that of the 5.4 million people diagnosed with Alzheimer's Disease, 4% are less than 65 years old (Alzheimer's Association, 2014).

The causes of dementia in individuals under 65 years of age are more heterogeneous and the onset of dementia is more likely to be unrelated to Alzheimer's disease (Harvey, 1998). Despite this, Alzheimer's disease is still the leading cause of younger onset dementia (Williams, Dearden, & Cameron, 2001; Harvey, Skelton-Robinson, & Rossor, 2003; Yokota et al., 2005). Although individuals experiencing younger onset dementia display many of the same characteristics as do those diagnosed with dementia after 65 years, several studies have found that younger onset dementia can manifest in a different pattern in comparison to the older population. For example, non-cognitive and behavioral symptoms are more likely to be

exhibited by the younger population (Harvey, 1998; Keady & Nolan, 1997). While physical dysfunction is less problematic (Fossey & Baker, 1995), there is a higher rate of hallucinations and delusions (Ferran et al., 1996). In addition, a study in Ireland showed that 56% of persons with younger onset dementia suffer from depression, while 71% suffer from anxiety (Haase, 2005).

### **Younger Onset Dementia and Employment**

As mentioned before, it was not until 2006 that younger onset dementia was recognized publically by the national office of the Alzheimer's Association. Specialist service provision for younger people with dementia is horribly inadequate in most countries including the United States, Ireland, the UK and Australia (Alzheimer's Society, 2006, 2007; Haase, 2005; National Audit Office, 2007; Alzheimer's Association, 2006; Alzheimer's Australia, 2007). For the most part, policies for those with younger onset dementia are written into the framework for services for older people with dementia. While this lack of preparation has a negative effect for a person with younger onset dementia in the areas of familial roles and responsibilities and quality of life, it poses a unique problem in terms of dealing with dementia while still employed.

Unlike those diagnosed with dementia later in life, younger onset dementia is typically diagnosed when a person is still working and providing full or partial income for a household. Over the last decade, the amount of research on young people with dementia has increased with one of the central emerging themes being problems that arise from loss of employment and job related revenue (Alzheimer's Association, 2006). Younger onset dementia can strike as early as the fourth decade of life when a person is likely to be mid-career (Fossey & Baker, 1995). In a study conducted by Harris and Keady (2004), participants with younger onset dementia felt they

had been diagnosed in the peak of their careers and retirement had not been a consideration for their near future.

The emergence of cognitive dysfunction is often noticed first in the employment setting where higher expectation of abilities and capacities are expected from an employer (Hunt, 2011). The standard of expected quality of work is often affected by the person's inability to find the correct words for client and social interactions such as meeting and conversations with co-workers. Furthermore, decreased ability to juggle more than one on-the-job task at a time, impaired planning and organizing, and difficulty expressing complex ideas make diminishing mental capacities evident (Harris & Keady, 2004). These changes in a person's job performance are rarely understood, thereby resulting in inadequate or no accommodations to the person's work load (Rose, Fang, Palmer, Richeson, & Burgener, 2010).

Impairments in these areas can have an enormous impact on employment status which directly relates to a person's financial stability. In a survey conducted by the Alzheimer's Association, it was found that two-thirds of participants diagnosed with dementia either voluntarily retired or were fired from his or her job (Alzheimer's Association, 2006). Likewise, Sperlinger and Furst (1994) found that 74% of participants in their study retired early due to symptoms of younger onset dementia.

In 2006, The Alzheimer's Association reported that 22% of individuals age 54-64 years old with a cognitive impairment were still working and received an average annual income of \$17,840 while 62% had an annual income below \$11,000. In contrast, 65% of individuals without a cognitive impairment in this age range had an annual income of \$42,852. One participant in the Harris and Keady (2004) study, who was in his 50's explained the impacts symptoms of dementia had on his job performance: "I have been forced to take early retirement

and for a person who has worked since he was seven years old. . . dependency on your wife is difficult to accept” (Harris & Keady, 2004, p. 118). Another participant explained: “Having to take a 40 percent reduction in income has had a severe impact on our household.” (Harris & Keady, 2004, p. 118).

### **Impact on Family Roles**

Loss of the ability to participate in household financial responsibilities can have a negative impact on how one may interpret his or her role within the family. A woman diagnosed with younger onset dementia in her 40’s stated:

My life changed in my marriage, too. Now my husband is the sole breadwinner, payer of bills, and driver of our children. This [change] was reflected in our marriage of shared responsibility, shared friendship, and shared partnership in every way. . . It is hard to know that my husband’s life will be put on hold for years” (Harris & Keady, 2004, p. 117).

Not only do younger people with dementia have a higher level of financial responsibility, they are often fulfilling multiple roles within the family structure as well. Because dementia is associated with older age, when problems arise in the area of grocery shopping, meal preparation, home management, and parental obligations, dementia is not typically considered and tensions can occur between family members (Fraker, 2012). As cognitive abilities decline, individuals are forced to assume a dependent role. Younger people with dementia will no longer be able to parent their children or maintain a leadership role within the family (Hunt, 2011).

### **Impact on quality of life and self-hood**

A study by Harris and Keady (2004) revealed that younger people with dementia are more acutely aware of the changes the disease is causing not only to their family but to

themselves as well. Roles and responsibilities are a reflection of one's self-identity and the inability to participate in these can impact a person's quality of life in a negative way.

Johannessen and Moller (2011) discovered that participants in their study felt there was a stigma associated with dementia and that it was more negative when associated with a diagnosis at a younger age. Participants perceived themselves to be fighting for dignity due to their embarrassment of receiving a diagnosis at such a young age, and had fears of becoming a burden to society. Although the capacity to perform tasks requiring cognitive abilities diminish and it becomes difficult to fulfill usual social roles, an individual's core concept of who he or she is, remains (Harris & Durkin, 2002; Kitwood, 1997).

An individual's self-image is negatively impacted by the feeling of inadequacy when not being able to remember the next step in a task, or when unable to follow along with or participate in a conversation (Johannessen & Moller 2011). These capabilities are on direct display when at work where an employer has high expectations of performance (Hunt, 2011). When a decline in mental ability initially occurs, it may, for a short period of time, be concealable in areas such as personal appointments, meal preparation, and household responsibilities. However, the impacts of such a decline on a person's job performance are typically more difficult to conceal from an employer who has a higher expectation of functioning. A person's identity is largely defined by his/her career and when competence is questioned in this area, it can impact all other aspects of an individual's life.

### **Role of Occupational Therapy with Alzheimer's disease**

Occupational therapy is a health care profession founded on the performance of meaningful occupations for the promotion of wellbeing and the prevention of debilitating effects of inactivity. According to the Canadian Model of Occupational Therapy, people are active by

nature and their occupations are determined by their perceived roles in the culture they live (Law, Cooper, Strong, Steward, Rigby, & Letts, 1997). Well-being is maintained by achieving a balance between occupations in self-care, productivity, and leisure (Baldwin, Chaplin, Murray, & Kindell, 2003). Occupational therapy can be beneficial to a person from time symptoms of dementia emerge and a balance of occupations can no longer be maintained, until late stages in the illness. When working with clients with dementia, a therapist's focus is to enhance the remaining abilities in order to help them maintain the highest possible quality of life (American Occupational Therapy Association (AOTA), 1994).

An occupational therapy functional assessment is central to the achievement of success for this population. Initial assessments are preferably done in the client's home or natural work environment. Along with interview and observation, the assessment will aid in determining the present level of functioning in areas such as work, home management, driving skills, safety, self-care, mobility, communication skills, and leisure skills. By assessing a person's ability to initiate, maintain, and complete a task, areas of deficit can be defined and the most relevant interventions can be determined (Baldwin et al., 2003). In addition, an occupational therapy assessment can determine the reality of continued independent living based on performance abilities and the level of supported services needed (AOTA, 1994). Standardized assessments are also used to measure the person's cognitive ability to perform and the quality of a person's occupational performance (Schaber, 2010).

In addition to an assessment, occupational therapy has several roles with this population. Through implementing the use of specialized tools such as the use of adaptive equipment, addition of visual cues, or use of reality reorienting prompts, client performance can be improved (Padilla, 2004; AOTA, 1994). An occupational therapist will promote safety by identifying

environmental hazards such as removal of clutter and modifying electrical appliances (Warner, 2000; AOTA 1994). Through task modification, a client's occupational performance can be improved. This involves changing materials used, providing the appropriate amount of verbal and visual cues, sequencing steps, and decreasing distractibility (AOTA, 2008). Finally, a large part of the role of an occupational therapist when working with a client with Alzheimer's disease is teaching caregivers communication techniques to optimize client performance and decrease aversive behaviors (AOTA, 1994). The client's need for physical, verbal, or visual prompts can be identified for different occupations (Padilla, 2011) and caregivers are taught to use calm and supportive tones when providing instruction that matches the client's level of cognitive functioning. Through utilizing occupational therapy interventions in these four areas the American Occupational Therapy Association hopes to meet three basic goals for this population: (1) to maintain, restore, or improve functional capacity; (2) to promote participation in activities that optimize physical and mental health; and (3) to ease care giving activities (AOTA, 1994).

### **Role of Occupational Therapy with Younger Onset Dementia**

Occupational therapists must be conscious of the differences between the services a client with younger onset dementia will need as opposed to services for an older client. Although acquiring dementia at a young age does not eliminate the debilitating physical and cognitive effects a client experiences from the progression of the disease, there are additional components to consider. Younger people experiencing lapses in memory and difficulty performing their daily occupations are often said to be "too young" to have dementia. Due to the perception of Alzheimer's disease being a disease of old age, it is commonly misdiagnosed as depression, burnout, and menopausal changes (Harris & Keady, 2004; Haase, 2005). Characteristics of this population for further consideration are the greater physical strength and increased physical

activity in younger people with dementia, the lack of appropriate support groups and age-related services, and the desire to participate in meaningful occupations and continue employment (Beattie, Draker-White, Gilliard, & Means, 2004).

Occupational therapists can play a role in the diagnosis of younger onset dementia through the functional assessment process to evaluate performance of occupations and instrumental occupations of daily living. An occupational therapist can work with his or her clients to identify what they personally believe to be preventing them from achieving a healthy balance that includes leisure activities (Baldwin et al., 2003). It is especially important for younger people with dementia to maintain a high quality self-image; therefore, the aim of occupational therapy for this population should involve enhancing self-esteem and confidence through age appropriate activities (Chaplin, 2003). Ideal interventions for this population should be culturally valued, person-centered, achievable, age-appropriate, and productive and/or active. For individuals with younger onset dementia, a major part of the occupational therapy intervention is the maximization of productivity. Quite possibly, the largest aspect of productivity in this population, in comparison individuals with late onset dementia, is employment. When occupational therapists get involved with an individual with younger onset dementia early enough in the disease process, they can be of great value to the individual's ability to maintain his or her job for as long as possible (Chaplin, 2003).

### **Role of Occupational Therapy with Employment**

The symptoms of younger onset dementia are often first experienced at person's place of employment. Sperlinger and Furst (1994) found that 73% of individuals in their study were forced to take early retirement. Unfortunately, many employers and even employees themselves, lack the knowledge to recognize or respond to the signs of dementia. As the number of

individuals who receive this diagnosis increases, experts are urging companies to train their supervisors to raise awareness for this disorder and remove the stigma that surrounds it (Saint-Cyr, 2011). A change in job performance resulting in a decrease from baseline ability is never normal. Although there are many different possible causes, if an employer or employee notices a significant decline in performance it is important that the cause is determined (Alzheimer's & Dementia Alliance of Wisconsin, 2009a).

Once a diagnosis is made, and an occupational therapist completes an assessment, the therapist can work with the employer and employee to make environmental modifications and adaptations that will enable an employee to retain employment for as long as possible. The Alzheimer's & Dementia Alliance of Wisconsin (2009b) provide several examples of signs of younger onset dementia, and natural ways in which an occupational therapist can help in the workplace. Employees may become frustrated in their job; in this case, tasks can be matched to the remaining skills. Employees may begin to have difficulty recalling information. This can be addressed with the use of memory aids. If an employee begins to struggle learning new things, written instructions can provide additional assistance. If an employee becomes distracted easily and shows signs of having a hard time paying attention, noisy and extraneous activity can be eliminated as much as possible. In addition, workspace clutter can be reduced. Often times, an employee who has difficulty starting or maintaining a task is considered lazy or unmotivated. In this situation, additional encouragement or verbal and visual cues may be helpful. Finally, employees with a diagnosis of younger onset dementia may have difficulty structuring their time appropriately and may show signs of struggling with judgment and reasoning. In these situations, added assistance in the form of a written schedule or maintenance of a structured routine may increase the person's performance (Alzheimer's & Dementia Alliance of Wisconsin, 2009b).

Maintaining a job for as long as possible is obviously beneficial to the employee; however, it has benefits for the employer as well. Although some responsibilities may need to be delegated, a person with younger onset dementia can retain skills acquired from many years of on the job experience. Early stages of dementia effects more recent memories but typically does not affect the ability to reason and make decisions. This allows a person with younger onset dementia to remain an asset on the job (Alzheimer's & Dementia Alliance of Wisconsin, 2009b).

Although research in the area of early onset dementia has increased in the past few years, it is still limited and largely focuses on obtaining a diagnosis and identifying the genetic differences between early and late onset dementia. While dealing with loss of employment has been identified as a key issue within this population, there is a void in the literature when it comes to studies focusing solely on the interaction of the disease with person's employment responsibilities. The current study focused on individuals with younger onset dementia and how the disease impacted their ability to perform their duties in workplace. This study sought to 1) explore the specific impairments of the disease and their relationship to employment, 2) provide insight to experiences that occurred in the workplace as a result of symptoms related to this condition, and 3) investigate companies and employers responses to disclosure and emergence of impairments and efforts, or lack of efforts, made to support continued employment.

## **Method**

### **Participants**

The targeted population for this study included a total of ten participants. Potential participants included males and females who were experiencing symptoms of young onset dementia while part of a workforce. Participants could be employed in any position when the symptoms began or the diagnosis occurred. Inclusion criteria included having received or

having a probable diagnosis of younger onset dementia or a diagnosis of progressive memory loss disorder prior to the age of 65. This criterion was recommended by the Executive Director of the local chapter of the Alzheimer's Association. Additional inclusion criteria was the retention of the ability to recall and communicate past experiences as well as to read and write, be self-sufficient, and be functioning independently at the time of the interview.

Caregivers to individuals with younger onset dementia were also included as potential participants for this study. This included both current caregivers as well as past caregivers. Inclusion criteria included being the primary caregiver, either spouse, child, or family member, to an individual who had a diagnosis of, or a probable diagnosis of, younger onset dementia or progressive memory loss disorder prior to the age of 65.

A list of potential participants was obtained from the Alzheimer's Association database as well as through a local skilled nursing facility specializing in the care of individuals with various types of dementia. Recruitment for both individuals with a diagnosis of younger onset dementia, as well as caregivers of the individuals with dementia, was done via mail or email, through distribution of a flyer containing a brief description of the study. Please refer to Appendix A for an example of the flyer sent to potential participants with younger onset dementia and Appendix B for an example of a flyer for both current and past caregivers. Interested parties were asked to respond via telephone or email, and were then provided with more detail about the study. If the participant was agreeable to participate, a time and location to complete the interview was scheduled.

## Measures

**Participant Questionnaire.** There were three different participant questionnaires, one for individuals diagnosed with younger onset dementia (see Appendix C), one for current

caregivers (see Appendix D), and one for past caregivers (see Appendix E). All questionnaires were similar and contained general demographic questions as well as brief questions regarding employment, job type, and responsibilities. Participants were asked about their age, race, education background, and marital status. If participants were currently employed, they were asked questions regarding their position and responsibilities, the company they are employed with including the length of time they have been there. Participants were further asked to note whether or not they were employed with the same company they were at the time of their diagnosis and presentation of symptoms. If participants were no longer employed, they were asked the same basic questions as employed participants regarding their employment prior to their discontinuation of work. Both working and non-working participants were asked the percentage their income contributes/contributed to their total household income. Both the Current Caregiver Questionnaire and Past Caregiver Questionnaire presented similar questions created to obtain the same information as the questionnaire for individuals with younger onset dementia. The difference between the questionnaires was the verbiage used to address the participant.

**Interview Guide.** An interview guide was created to ensure the discussion remains focused during the allotted time. Information was collected through unstructured interviews between the researcher and participant. Like the Participant Questionnaires, although entitled differently, all reflect the same questions in which the verbiage has been changed to reflect the sensitivities that may arise when addressing a current versus past caregiver. Please refer to Appendices F, G, and H to see the Interview Guide for Individuals with Younger Onset Dementia, Current Caregivers, and Past Caregivers, respectively. The researcher completed interviews compiled of open-ended and fixed-response questions during meetings with each

participant. Probe questions were used at various points throughout the interview to add clarification for certain responses. Interviews were completed on an individual basis on The University of Toledo's main campus, at the Alzheimer's Association, or during a meeting with the participant in his or her own home. The questions were designed to evoke a detailed response that will reflect the progression of the effects the disease has on participant's employment status. Questions also aimed to identify measures, if any, taken by the employer to prevent unemployment of the individual diagnosed with younger onset dementia.

### **Procedure**

Potential participants were presented with a flyer asking them to respond by email or phone if interested in participating in the study. Potential participants were screened for qualification of meeting the necessary inclusion criteria. This was done via self-report as well as through family or caregiver report. Once participants had been determined, the researcher discussed with them where they are most comfortable to carry out the interview; either in the participant's residence, at The University of Toledo, or at the Alzheimer's Association of Northwest Ohio. The researcher ensured that the interview setting was accessible and private. Willing participants completed a form of consent after being determined eligible.

The student researcher functioned as the interviewer and collected all data for this study. Assistance could be obtained from advisers who contain expertise in the area of interviews. Prior to the initiation of the interview, informed consent was obtained from each participant. The family member or caregiver was allowed to be present during the interview, however; he or she was asked to refrain from answering or interjecting during the participants answering of the questions. The researcher explained that she may ask for clarification occasionally.

The interview began with introductions and an explanation from the student regarding the current study and the reasons for it. A description of occupational therapy and the roles an occupational therapist can play in assistance in employment retention within this population was given to the participant and caregiver or family member. The caregiver/family member was provided with a list of the questions to make notations on throughout the interview. At the end of the interview, there was time allotted for the caregiver or family member to add any additional thoughts. The participant was then asked if he or she has any additional comments or information that may be relevant to the study.

Participants were ensured that all responses are confidential and will remain anonymous. All interviews were recorded on a tape recorder so they may be referred to in the future. Upon completion of all interviews, recorded interviews were transcribed and responses were analyzed.

## **Results**

### **Characteristics of Participants**

There were a total of 10 ( $N = 10$ ) participants in this study. Participants were identified by the Alzheimer's Association or through a local skilled nursing facility. Those who participated were either individuals who were diagnosed with younger onset dementia ( $n = 3$ ) or caregivers of individuals diagnosed with younger onset dementia ( $n = 7$ ). All caregivers, whether current or past, were considered the "primary" caregiver to the individual with dementia.

Those participants with a diagnosis of younger onset dementia ( $n = 3$ ) were between 64 and 69 years old ( $SD = 2.6$ ) at the time of the interview and had received their diagnosis between three and seven years prior. The mean age of this group of participants was 66 years old. All participants in this category identified themselves as being Caucasian, two were female and one

was male. All were diagnosed prior to the age of 64 and all were currently married. Education ranged from a high school diploma with training in a specific trade ( $n = 1$ ), to a Master's Degree ( $n = 2$ ). One of the participants was currently employed part-time and two participants were no longer working and had accepted the status of retirement. A caregiver was in close proximity during the completion of each interview and verified information provided on the questionnaire as accurate.

The participant who was employed at the time of the interview identified his place of employment as a local hardware store. On the Participant Questionnaire, he reported having been employed at the hardware store for approximately seven years, having been diagnosed with younger onset dementia four years ago, and currently works on average 12 hours a week. On question twelve, he identified his title as "Master Electrician," and reported this being his place of employment and position at the time of his diagnosis.

The other two participants with a diagnosis of younger onset dementia had discontinued working under the status of "retired." Both participants were employed full-time by local school systems; one as a teacher and coach and one as a school librarian and media clerk. On question 17 of the questionnaire, both participants reported having worked at their respective schools for 25 years. On question 19, "About what percentage did your income contribute to your total household income?" one participant responded 25% and one responded 55%.

Of those participants who completed the interview as a caregiver to an individual with younger onset dementia ( $n=7$ ), two were past caregivers of a spouse who was deceased, three were the spouse of an individual with a diagnosis, one was the sister, and one was the daughter. The current ages of the individuals being cared for ranged from 64 to 70 years old. Caregivers in this group reported their loved one experiencing an onset of symptoms anywhere from their

“early 50’s” to 64 years of age, with the mean being 58.3 years of age and the standard deviation being 3.7 years. Information to find the mean and standard deviation for this group was used from six of the seven participants as one participant could not provide an exact age for the onset of diagnosis of symptoms or a diagnosis. Information on the questionnaire was gathered on the individual with younger onset dementia. All were reported as being Caucasian, two were male and five were female. Education ranged from a high school diploma to a Ph.D. At the time of the interview, all participants reported that their loved one was no longer employed however, former positions included: professor teaching online classes at a university, personal secretary at a county courthouse, bookkeeper, projects estimator, teachers, and customer service representatives with length of time at the place of employment ranging from eight years to over 20 years. Prior to receiving a diagnosis, the overall contribution to the household income by individuals with dementia ranged from 50% to 100%. For those who remained working following their onset of symptoms, one was laid off, one was fired, and others opted to discontinue employment. Those who were in teaching positions remained in their position until the end of the school year and those in customer service positions were permitted to continue working.

### **Data Analysis**

The data analysis for this study followed a series of stages to analyze and interpret information collected. Data analysis began by reading the transcripts in their entirety and analyzing participant’s responses independently. The researchers then identified themes based on the participant’s responses and the interview guide. The goal of early analysis stages for the interview was to use raw data to form a series of descriptive statements representative of information gleaned from the interviews. Researchers employed an iterative strategy of

analyzing interview data independently, and then collaboratively, followed by further independent exploration. The use of this strategy allowed researchers to develop coding schemes and apply them to the collected data. This continuum is similar to the ones used by Enser (2006) as well as Boyzatis (1998), wherein a data-driven, inductive approach to thematic analysis was utilized. Examination of the descriptive data collected from the interview and analysis of the questionnaire served to guide the organization and refinement of the questionnaire for future research.

With intent to increase the reliability and validity of the study findings, the researchers employed an iterative strategy of analyzing data independently, and then collaboratively, followed by further independent exploration. The use of this strategy allowed researchers to develop coding schemes and apply them to the collected data. The following stages were employed by the researchers:

- 1) Interview transcripts were read independently by each researcher. The initial reading acquainted the researchers with the overall data generated. Next, the researchers reviewed major issues and effects Alzheimer's disease had on employment as discussed in each interview. Following the identification of issues and effects, each researcher formulated thoughts on prominent themes and patterns that emerged in this analysis portion.

- 2) Researchers then met to discuss the themes and patterns, to negotiate category development, and to develop a coding scheme for the major themes. Use of the interview guide provided a starting point for coding. The researchers worked independently to code half of the transcripts.

- 3) The primary researcher independently coded the remaining interview data based upon the coding schemes developed collaboratively with the other researcher. During this process the

researcher refined the coding, identify themes that were unclear, infrequently utilized, as well as those that seemed to be over-used. Data that did not fit into identified themes was categorized as miscellaneous.

4) The researchers met to discuss and review the results of the primary researcher's independent coding that utilized the preliminary coding scheme. The researchers made revisions, if necessary, and further defined categories to appropriately fit the data.

5) The final coding results from each researcher was reviewed and compared collaboratively. In order to resolve discrepancies in the coding of specific remarks, the researchers then examined the notes for consensus (i.e., agreement of two researchers).

6) The primary researcher independently reviewed the results for each category, returning to the research team for clarification, questions, and feedback during the preparation of the research manuscript.

In the current study, themes were categorized into two groups. Themes for the first group, Individuals with Younger Onset Dementia, were identified during analysis of the participant interviews. Themes for the second group, Caregivers, were categorized by question. Quotations serve to illustrate the firsthand accounts that match within a particular theme. Certain information has been omitted to maintain participant and organizational privacy, it has been replaced with bracketed [text] information. An ellipsis (. . .) has been added to indicate where non-essential words or passages have been omitted from the original quotation.

### **Individuals with Dementia**

Quotations from Individuals with Dementia ( $n = 3$ ) were limited due to the difficulty participants in this group seemed to experience when putting their thoughts into words. Basic information was easily conveyed in the interviews. Unfortunately, there was a general inability

to put thoughts together in detail. Information gathered from these participants fell into five different themes; 1) self-awareness of problems, 2) denial, 3) pride, 4) coping techniques, and 5) compensation. Quotations serving to provide insight to each of these themes are provided below.

**Self-awareness of problems.** When asked about first noticing initial symptoms, participants expressed a general feeling of skill depreciation.

One participant stated:

*“I couldn’t figure it out. I just couldn’t figure it out. . . . I just got really upset. . . . I can’t do a lot of things.”*

**Denial.** The most common theme that came up throughout the interviews was denial. This theme arose in the participant’s answers to various questions. They voiced the experience of denial from the onset of symptoms to the day they disclosed their diagnosis to their supervisor. One participant discussed how denial can affect a spouse who may notice symptoms first but desires to shield her significant other from the realization. He said:

*“I can do anything. But my skills were dropping off. My wife noticed it before me and didn’t want to tell me.”*

When asked about when he disclosed his diagnosis to his supervisor, the same participant again reported experiencing denial until he was no longer able to conceal his declining skills. He stated:

*“Probably later. Cuz I didn’t think it was a problem for a long time, but then it got there. Not being able to do things that were easy before.”*

One participant reported not only never disclosing her diagnosis to her employer, but never discussing it with anyone. When discussing dealing with the symptoms while employed, she stated that only one other individual was aware of her diagnosis. She shared the difficulties

of non-disclosure and the heavy reliance on her husband to share her secret both during and after her employment. She stated:

*“Those few people knew I had it . . . I don’t tell people I have it. It’s hard, it’s hard because I can’t read, I can’t write, I can’t do things. He does most of everything.”*

**Pride.** One participant talked extensively about his past work history of owning his own company to currently being one of the highest educated and most experienced individuals at his current place of employment [Local hardware store 1]. Throughout the interview, he discussed his love for the field he was in and the value of a hard-worker who is knowledgeable in what they do. When asked if, with the experience of symptoms of dementia, he thought he was still capable of performing all work tasks adequately, he said he believed he was. He followed up stating:

*“Oh before I go that way I’d say I’m quitting.”*

He placed a large emphasis on providing a high quality of work for a company he said valued his experience and knowledge and worked with him through his diagnosis.

**Coping techniques.** Participants identified different ways of coping with their diagnosis. One woman, as seen in the quotation earlier, seemed to place a heavy reliance on her husband and avoids allowing outsiders to know her situation. Another participant reported that when faced with difficulty or a challenging situation, she uses humor to cover her inability to answer a question or carry out a task. She stated:

*“I’m the kind of person, that if I possibly can, I’m gonna laugh about it. I’m gonna try to do my best, then I’m gonna laugh like hell. Then cry.”*

Both the husband and sister of this participant were present for the interview and confirmed this to be her largest method of coping with difficult situations since she was diagnosed with younger onset dementia.

Another participant discussed his faith and reliance on his knowledge that all things are in God's hands as a way that both he and his wife dealt with not only difficult situations but with carrying on day to day. He also stressed the importance of not looking too far ahead or stressing about future possibilities. He stated:

*“Having a disease, it's just a part of life. You have God as your companion and master. He's easy. You go one day at a time. You can't go two days at a time.”*

**Compensation.** Of the three participants with dementia, two were no longer working and one remained employed. Both women who had obtained retirement upon discontinuation of work were employed by local school systems. Both women reported putting in for retirement soon after and remaining in their position for the short period of time for remainder of the school year. Both women also reported that they did not implement any compensatory strategies outside of the use of notes to themselves to serve as reminders, and the use of a co-worker or family member to assist with work that was able to be completed at home.

The other participant reported that although he was slower to complete tasks, he still maintained the skill set necessary to complete his job duties [Local hardware store 1]. His responsibilities included overseeing several isles and answering customer questions regarding electrical work. He reported that sometimes, if he forgets the customer's question, he will ask the customer to repeat him or herself. When asked if he implements any compensatory strategies while at work, he reported that he does. He stated:

*“Yea, cuz every day I look at it. I continually walk the aisles for people. And as I walk the aisle I check for stock. House stock, misplaced stock. . .”*

The repetition of walking those aisles he was in charge of and being aware of appropriate stock served as a useful compensatory strategy. In addition, he reported that when coming across misplaced stock he put it in its correct location which aided in his knowledge of the rest of the store.

### **Caregivers**

Caregivers were the second group of participants. Their quotations were themed by question. This includes quotations from three past caregivers (PC), and four current caregivers (CC). Both past and current caregivers were asked the same questions regarding their spouse or loved one. Transcripts were reviewed and those quotations that the researchers felt most appropriately fell under the following themes:

1. What were the first symptoms that made you aware something was wrong?
2. When did your loved one tell you he/she was developing problems?
3. What were the first symptoms he/she noticed in the workplace that made him/her aware something was wrong?
4. How long were the symptoms experienced before going to the doctor?
5. After a diagnosis was received were you able to reflect back and identify signs that had been overlooked?
6. After receiving a diagnosis, what was your loved ones first area of concern?
7. What was your (caregiver) first area of concern?
8. Did you discuss how to handle the situation at work together?
9. How long after a diagnosis did your loved one wait before telling his or her supervisor?

10. How was the diagnosis disclosed?
11. Did the diagnosis provide any closure?
12. What was his or her supervisors initial reaction to the disclosure of a diagnosis?
13. In terms of work performance, what was the biggest change that was seen?
14. What was your biggest area of concern regarding the continuation of work with this condition?
15. How has this impacted other areas of his or her life?
16. Did he or she initiate any compensatory strategies either prior to or after receiving a diagnosis?
17. What, if any, modifications were made to his or her position or workplace?
18. What assistance do you think would have been helpful in retaining the position or job for a longer period of time?
19. Additional input from caregivers?

Quotations from participants that best highlight each question are included below.

**What were the first symptoms that made you aware something was wrong?.**

Symptoms of younger onset dementia first became noticeable to each participant in a different way. Some noticed deficits at home, while others received a call from a co-worker. Some caregivers identified the first noticeable symptoms as a concern their loved one shared with them regarding problems that were occurring at work, making their job more difficult. One caregiver recalled when his wife first spoke with him about the troubles she was having at work. It was during their conversation about her struggles that he realized there was a problem. When thinking of her first symptoms, he recounted:

*“Memory Lapse. She was having difficulty remembering the kid’s names . . . She*

*was having difficulty reading with the grade book to follow left to right or to follow across a sentence.”*

Another shared that his loved one was noticing problems at both work and at home. He stated:

*“Well she just told me that she was making lots of notes for what she had to do. Notes for what she had to do at home, and notes for what was going on at school.”*

One caregiver reported that forgetfulness was the first thing she noticed different about her mother. When discussing the extreme forgetfulness she noticed in her mother, she shared the following story:

*“Um, like after church, the ladies would go to like Sirloin Stockade to eat. And she would go to Pizza Hut. And she would sit there like ‘Um, where is everybody at?’ Like she didn’t remember it was Sirloin . . . And they had just talked about it, like literally as they were walking to their cars . . . but she wouldn’t remember. She would get really angry.”*

Sometimes, the declining abilities were work related, and although they were noticed in the workplace first, the decline was never brought up. One participant stated:

*“He was missing things on the blueprints and not bidding the jobs properly. However, nobody had really said anything to him.”*

She shared that her husband was ultimately laid off due to the company downsizing and his inadequate job performance was never brought up until years later.

Another past caregiver reported subtleties in the way her husband was behaving at home. She reported that her husband had a significant history of illness to which she initially attempted to attribute initial forgetfulness at home to. However, once problems at work arose she was forced to acknowledge this was related to something different. She stated:

*“But in the beginning neither one of you want to actually say, ‘I think there is something wrong.’ It is almost easier to, for example, with him; to believe that he was getting over worked so he was getting grouchy . . . He seemed to be doing things more slowly. Um, he wasn’t thinking things through like he used to. Very subtle . . . Then things started to show up in his work. And it was taking [Professor] longer and longer to do things. That was something I noticed . . . It just started getting to the point that when he was working it was very obvious that he was struggling.”*

She described the first time it became clear her husband’s difficulties stemmed from more than being overworked and past health history:

*“Yes, he was putting in more hours because he could do a lot of work at home. And so he’d be on the computer 14-16 hours a day sometimes. It had to do with his work. It was December and final grades had to go in. You know exams and final grades. And he couldn’t get, he couldn’t figure out the exams. He couldn’t figure out the grading system. And he worked and he worked and he worked and he stayed up all night long. They had to be in the next day, and he was just frantic about it. It wasn’t like, ‘I can’t figure it out.’ It was, ‘I have to do this, I have to get it done, I can’t figure it out, I don’t know!’ So he was really upset. And then the next day when he thought he had it figured out, it took him 3 to 4 trips to [University] and back just to get the grades submitted. And finally he got home and he was exhausted of course. And it just wasn’t [professor]. There was that slight shift in his personality. And it just wasn’t him.”*

She went on to discuss his concern for maintaining a certain standard for his job performance. In her quotation, we can see another instance where although a co-worker notices a change in job

performance, it is not brought to the attention of the individual experiencing symptoms of younger onset dementia. She stated:

*“He had to be very careful that students didn’t suffer because of what was happening with [Professor]. And that’s where his work place was wonderful. Because as he was starting to make small mistakes, which I didn’t even know about at first because it was at work; but as he was starting to make these small mistakes, other faculty would notice. So what we did, was, with [Professor] permission, was I called a very good friend of his that worked with him and told him our concerns. And he said, ‘well yea, I’ve been seeing that at work too.’ But he said, ‘I will help him any time he has a question, and I will watch. I will watch to see how things are going.’ And he did, and [Professor] felt comfortable talking to him. And as more and more problems developed, mainly: taking a long time to do his work, forgetting to do his work, confusing his students with each other, this friend of his started looking in on his coursework online and kind of shadowing him.”*

Experiences revealed in the above quotations range from one extreme to the other. While all reflected that memory lapse in the workplace is a key element to the initial onset of younger onset dementia, it is also apparent that co-workers and employers can play a valuable role in noticing symptoms made obvious in a person’s job performance.

**When did your loved one tell you he/she was developing problems?.** As was just mentioned, peers in the workplace and employers can play an important role when it comes to bringing the onset of symptoms to the attention of a fellow employee or their family. Denial was seen as a theme with the Participants with Dementia, and it was consistently seen throughout the

quotations provided by the caregivers. The daughter of one individual shared that her mother never acknowledged her diagnosis. She stated:

*“No, she never did. She always denied it and said there was nothing wrong.”*

The spouse of an individual stated that her husband also never came to her and shared that he was experiencing problems. She reported:

*“He was really touchy about that for a long time. He wasn’t mean, but he was in denial about any problems or having any problems for a long time. And always had an excuse. But there were some things that he couldn’t deny.”*

Another caregiver discussed that while his spouse did not come to him and verbalize symptoms of dementia were occurring; he could put it together through the symptoms she was displaying at home. He stated:

*“I did notice different changes, like her driving. She couldn’t go to the family doctor without me making a map and even then she’d get lost.”*

The information reflected in these quotations show how important it is to be aware of your loved ones typical behavior patterns and capabilities at home as they are unlikely to share developing deficits they are experiencing in the workplace.

**What were the first symptoms he/she noticed in the workplace that made him/her aware something was wrong?** A commonality in responses to this question was the individuals with dementia ability to hide their developing deficits from loved ones. Again, it is noted that the individual with dementia did not share his or her symptoms with the caregivers, and so the respondents did not have specific details to answer the question. However, some caregivers did notice the ability of their loved one to hide signs of memory loss from them. One participant said:

*“He was very good at, not covering up, but . . . He would make his own make his own modifications and accommodations.”* Another stated:

*“She was very good at covering up. And she was in very big denial. She was in denial until I moved her to [SNF].”*

**How long were the symptoms experienced before going to the doctor?.** Specific dates were not identified by the caregivers in regards to the length of time between the onset of symptoms and the decision to go to the doctor. More easily identified was the amount of time between a diagnosis and the discontinuation of work. Past and present caregivers of individuals working in the education system were able to easily identify when first going to the doctor based on when it coincided with events on the academic calendar. For example, one reported it was the period of time from the beginning of the school year until final grades were due for the semester. Others reported that a specific doctor’s appointment was not made to address the symptoms; it was simply brought up at annual check-up. One caregiver shared her feelings on awaiting a diagnosis from the doctor. She stated:

*“At that point you pray for cancer because it gives you a fighting chance.”*

The daughter of another woman reported that she had a feeling it was younger onset dementia; however, her mother was in such denial she would not consider it. She reflected on the final incident before making her mother a doctor’s appointment. She shared:

*“. . . She started wrecking her car. Simple little things . . . she lived in the same town for 28 years. She was getting lost in town, she couldn’t find her way. I was having people call me and going ‘Oh my god, your mom is going bat shit crazy.’ ”*

**After a diagnosis was received, were you able to reflect back and identify signs that were overlooked?.** When responding to this question, many caregivers reported having noticed

the signs and symptoms but not attributing it to dementia due to their loved ones age.

Additionally, respondents discussed a period of denial following a diagnosis. In some cases, this was experienced by both the caregiver and the individual diagnosed. After receiving a diagnosis, one caregiver shared both her and her husband's initial response as well as the acknowledgment of the diagnosis. She stated:

*“That was really hard to admit, for both of us . . . I don't know if you ever really accept it because it continues to get worse. Um . . . He didn't acknowledge knowing right then. But I think that when we talked to the Department Chair person that he admitted to himself then that there was a problem.”*

Another participant described the denial her husband experienced:

*“Um. . . He did not reflect back. He, I would say was probably worse than I was. ‘It will go away. It will go away.’ And um . . . It didn't go away. But, he was afraid.”*

**After receiving a diagnosis, what was your loved ones first area of concern?.** When discussing the initial reaction to a diagnosis of Younger Onset Dementia, responses varied.

In reference to the loss of a job, one caregiver stated:

*“She wasn't concerned about work, she was ready to retire.”*

Others shared that the inability to continue work was in the forefront of their loved ones mind.

One caregiver stated:

*“I'm gonna say it was work related. That she would be able to continue teaching.”*

Another shared:

*“Well she didn't want to quit working but she knew she had to . . . Well, we were gonna be without the money. She made good money. I knew we were in trouble and so did she.”*

The loss of time with family was also a concern; one wife shared her husband's feelings:

*"Him not being around for the grand kids. And he loved life. He loved life. He loved people. He was a good guy."*

Another respondent shared their loved one had a general fear of the diagnosis:

*"Um, well, she, she was deathly afraid. She told me upfront 'I don't have Alzheimer's.' And that went on for 2 years . . ."*

Another participant shared her mother's initial reaction to her diagnosis:

*"Having to leave her home and not be independent anymore. She went into a state of depression. She did a lot of crying. Very angry. Turned pretty aggressive."*

**What was your (caregiver) first area of concern?** Caregivers commonly expressed feelings of loss of experiences that would be missed as well as fear of what was to come. One caregiver provided a detailed description of the different emotions she experienced following her husband's diagnosis. She stated:

*"My first area was deep fear. Really deep fear. Because I knew from my work and other things the road that we were going to go down. It just changed my life completely. I had to take over, I had to. There is so much you have to get organized, if you can, before a person is able to give informed consent for anything. So the business part becomes hard to deal with. It's difficult. But the emotional part is hard too. At first you think, its years down the road, nothing is going to happen real bad. But it wasn't years down the road. It was interesting because it's like, you know when you love somebody and you live with them and they change so much it's almost like you meet a new person and you begin to love that person. And that's how it was. But it was all very scary. And it was scary financially too. . . The other thing that was a reaction of both of*

*ours was just a really deep sadness of what we would never have. We talked about that at the time because he was able to. We would never have time to travel; we would never have time to enjoy grandchildren. We would never grow old together.”*

The perspective of a daughter caring for her mother was different. She expressed the desire to keep her mother safe. She stated:

*“Her safety with the wandering. She was compromising her food. You know she would keep the yogurt in the cabinet instead of the fridge and then still eating it. She got to where she wasn’t showering because she wouldn’t know how to use the faucets. Even to turn them on. She broke a lot of stuff and she . . . because she got angry because she didn’t know how to work it, so she would break it.”*

**Did you discuss how to handle the situation at work together?** Some individuals opted out of disclosing their diagnosis to their supervisor at work. The caregivers of these individuals reported their loved one ending employment voluntarily or “being ready” to no longer work. Others seemingly thought quitting work was their only option. One husband reported:

*“Yea we talked. Her first thought was ‘Should I quit?’ I said no.”*

Another caregiver stated she discussed with her husband how he wanted to handle the situation at work. She explained:

*“Yea we discussed that together. It went well because we could talk about anything. And at that point I know he wasn’t thinking like he used to. And he trusted me. And so we talked about everything we could, including work, while I was certain he still knew what he was talking about in terms of what he wanted.”*

Another caregiver shared her frustration over how her husband's situation was handled at work. Because he had already been laid off, she was asked if she and her husband discussed talking with his previous supervisor following his diagnosis. She responded:

*“All I heard was he got downsized. Cuz he was making so many mistakes. Missing meetings and screwing things up. You know, just not remembering things.”*

**How long after receiving a diagnosis did your loved one wait before telling his or her supervisor?.** This question was aimed to determine how important participants felt it was to inform their employer of their diagnosis. Again, similar to knowing the length of time between onset of symptoms and going to the doctor, here, participants either knew if they disclosed or if they did not. One caregiver simply stated:

*“She never did.”*

Another caregiver described the difference in experiences her mother, who held two jobs, encountered. At her secondary job, [Hardware store 2], where she was a cashier, her employer was tolerant and understanding. She reported his response as being:

*“At [Hardware store 2], yea. They, I mean, they suspected too. And they just kind of said, you know, you have a job as long as you want.”*

However, the description she gave of her experience at her primary place of employment, as personal secretary to a non-local County Appraiser, was not the same. She reported that her mother never disclosed her diagnosis to her boss, nor to the other secretaries she worked with in the office. She gave an account of her mother's experience while working with the symptoms of dementia. She reported:

*“. . . He was correcting her. He was trying to make her do her job and calling her on it when she wasn't doing it. And then, you know, you had all the other ladies that tried to*

*cover for her . . . And he thought she was out to get him . . . He's like 'You are crazy! Why are you doing this to me? Why are you making me look bad? What is the deal here?' Because he, in fact, he ended up losing his job as well . . . He wasn't compassionate at all . . . And he apologized as well. He said, 'It wasn't that I don't like your mother. . . It just didn't work out. And she compromised my job.' ”*

When asked how the other secretaries in the office responded to the situation between the boss and her mother, the caregiver stated that her co-workers defended her. She reported:

*“They took more to my mom's side, because they felt bad for her. But then it got to the point that the whole office was so in uproar, and it was just a hostile environment to work in, that they were just like '[Daughter] you have to get your mom out of here because, you know, we just can't do this anymore.' ”*

Another caregiver reflected on the situation and stated he was unsure as to whether or not his wife ever disclosed the information to anyone other than her partner at work. When discussing the plan they came up with for the situation he reported that she was to take retirement while he worked a few more years. Reflecting back on it, he stated:

*“Just it wasn't planned. Never in our wildest dreams did we think that that would happen, that in 20 years she was going to retire.”*

**How was the diagnosis disclosed?.** Each caregiver whose loved one opted to disclose their diagnosis to their employer discussed doing so with their loved one. One participant reported completing the disclosure as a team. She stated:

*“He and I both did. We went in together. And I think this is quite significant, he couldn't come up with the words to explain everything he wanted to explain. And it was*

*necessary this person know the whole story. So we did a lot of things together at that point in time so that I could speak for him.”*

Another described his wife’s decision to disclose her diagnosis to ensure her job was being performed adequately. He stated:

*“She told the principal that she could no longer function as she should as a teacher. The principal asked her to finish out the school year.”*

Interestingly, this individual who self-reported to her employer, months after her diagnosis, that her quality of work was declining, is also one who was in such great denial of her diagnosis, that it went on for two years.

**Did the diagnosis provide any closure?.** This question was included to determine whether or not those diagnosed with younger onset dementia were able to put an end to confusion regarding their declining skills. Responses and opinions toward the term “closure” varied.

One caregiver explained:

*“. . . It really put this whole household at peace so to speak. Because everything made sense. You know, how can I be annoyed with an individual . . . We had even started marriage counseling because I said ‘I cannot do this.’ ”*

She then described the change in her approach to her husband, and stated:

*“Yes. And then I became a mother hen. I was very watchful. . . I wasn’t going to let anyone talk behind his back. . . .”*

Another spouse disagreed with the term “closure”. She explained:

*“Well to get that kind of diagnosis it’s not closure because you are grieving. You are grieving a life that could be, you’re grieving things you didn’t do, things you don’t know.*

*I don't think it's comforting to get an Alzheimer's diagnosis. It would have been easier for him to pass away from something physical he was dealing with because mentally and emotionally you deal with those things a little easier. And the stigma that comes with having a cognitive impairment of any kind. And there is still a stigma that comes with having Alzheimer's disease and that is really unfortunate."*

Another participant explained how her mother's behavior changed after she was diagnosed and although she portrayed happiness with early retirement, she was feeling a sense of loss she tried to conceal from others. She reported:

*"She kind of turned a corner. She said, 'I'm going to take early retirement, and it's gonna be ok, and I'm going to enjoy life.' And she kind of played that, you know, that card that it was a good thing, and it's what she wanted. And that's what she portrayed to people. And then she would walk in her house and sit down and bawl. Because her life was over as she put it . . . She lost her identity when she was no longer working."*

**Who was the first person to notice there was a problem?.** Many of the caregivers reported that a co-worker of their loved one was the first to notice there were some differences in the individual. As previously stated, these observations were not always passed along to the spouse or family of the individual experiencing a decline. One caregiver reported that she believed she was the first to notice symptoms, however; when talking with her husband's close friend at work, it was discovered he had been having difficulties longer than expected. She explained:

*"He noticed that [professor] was staying a long time at work or that [professor] would come in and ask the same question several times."*

Another caregiver stated several times throughout the interview that she had a suspicion for years that her mother was having memory problems. She explained her concerns:

*“I always thought that something was wrong. That there was something off with her. Because I was always around her. And there were times off and on that I had moved back home and she babysat my daughters. There was something just off. After the fact the ladies were like ‘Yea, ya know, we were covering for your mom, and we didn’t want to say anything, but. . .’ “*

Seen here again is an example of co-workers having the first insights to a possible problem and protecting the individual experiencing the deficits.

**What was his/her supervisors initial reaction to the disclosure of the diagnosis?.** As we have seen in previous questions, some employers of the participants in this study were supportive of their employee disclosed his or her diagnosis. While one stated the employee could remain working as long as she wanted, another requested that she stay on for the remainder of the school year prior to taking retirement. Unfortunately, examples of a lack of understanding have also been seen with the employee being laid off and another being fired. The first quotation here shows how a situation of younger onset dementia can be confusing when it comes to determining the status employees with the diagnosis should take when leaving work. One participant shared:

*“Well they would have preferred her to just go on retirement, which I don’t know if she could have gotten at that time. Which I don’t know if it would have been disability retirement, but it wasn’t, it was work disability, which was actually more money which probably cost them more money.”*

Another participant shared her and her spouse's positive experience, adding she thought it was helpful to go in with a plan. She stated:

*“. . . He was very helpful. I do think that because we had decided that [Professor] would retire at the end of that semester that he was relieved.”*

Another participant shared both a positive and a negative experience had by her mother. She reported:

*“They [Employers at hardware store 2] were sad. Sad that it happened to her, you know. She's, you know, always been very independent . . . He [Employer at County Appraisers office] probably popped a bottle of champagne, like ‘Whooo hoooo! I'm not crazy!’ I mean deep down he suspected, I think everybody did. Because when you're around somebody who has it, you just kind of know.”*

**In terms of work performance, what was the biggest change that was seen?.** When discussing specific areas of difficulty responses varied based on the individual's job. For those required to use computers at their jobs, this presented as an area of difficulty. For those teachers required learning new student's names each semester or when switching classes, this was an area that was difficult. In all positions, tasks requiring the computation and use of numbers repeatedly came up as being one of the first areas the individual with dementia struggled with. This ranged from entering and calculating final grades, determining correct change, completing payroll, organizing books by call number, and calculating bids for architectural jobs. One participant reported:

*“I would say the cash register because she couldn't count money. And that was a big red flag at [Hardware store 2] . . . It just took her forever to do a simple task. It took her forever to write out a message for her boss. She would just obsess that, forever . . .*

*Forgetting appointments . . . And she went to where, Post-its, oh my god, Post-its were her friend. You would walk into the house and they were everywhere. And she would write a note, for a note, for that note. You know, as a reminder so she wouldn't forget."*

Another caregiver stated the classic symptom of forgetfulness as being the biggest change seen in her husband's day to day performance at work. She replied:

*"But after that he would make mistakes that other people would have to correct. Or forgetting to do things. He had a hard time figuring out some of the online things."*

While some participants pointed out what was reported to them by their loved one, or their loved one's co-workers, another participant made a noteworthy point. She stated:

*"That's just it; he may have not even known he was struggling. He may not have even realized he was making mistakes."*

**What was your biggest area of concern regarding the continuation of work with this condition?** Caregivers had a variety of concerns with their loved one working while experiencing symptoms of dementia. One caregiver echoed her sister's main concern for herself, which was the ability to remember her students. She stated:

*"Not remembering who the kids were. Like their names. I remember that as being the primary."*

She explained that in her last year teaching, her sister noticed she was unable to remember her student's names. She felt that the students would be able to take advantage of this and she would be unaware it was happening. She expressed that she did not want her sister's situation to be taken advantage of. Another participant had a similar concern. She stated:

*“Um, I guess I just didn’t like people talking about her. And saying she was stupid, or you know . . . kind of like that because she couldn’t do her job. And after that it was just safety. That’s always been my concern for her, just that she is safe.”*

Another participant stated that his main concern was her ability to carry out her duties.

He stated:

*“I don’t believe she could do the job, I . . . the other concern was financially, with the bills and everything . . . that was my reason for saying you’re not quitting.”*

Although this participant reported feeling his spouse no longer had the capabilities to complete her job, he was more concerned about their financial state if she were to quit immediately following her diagnosis. Instead, she remained employed until the end of the semester while they researched their options to discover the one best for them.

**How has this impacted other areas of their life?.** The major impacts identified by participants were feelings of stigmatization and solitude. Two reported feeling cut off from friends and unable to share their condition with anyone outside immediate family. Others reported that when they or their loved one shared the information, people no longer knew how to talk to them. One participant explained:

*“Well we talk about who we tell because people treat you different after they know. Most people . . . You just don’t see the people anymore. I don’t know if it’s they don’t know how to react. I guess that’s it . . . You have to be careful of who you tell because everybody just bails on you. Seems to be the way it is.”*

He went on to explain how it has further affected their active lifestyle:

*“We don’t do any hiking off by ourselves like we used to do. You’re always thinking about “what if” and I know you’re supposed to think possibilities not limitation, but you*

*do when it's in a place where she would never figure out how to get out of there or what to do."*

Another participant described the stress that occurs when one individual in the family unit is no longer able to contribute financially. She reported that it impacted more than just herself and her husband but her children as well and that effects are long lasting with monetary struggles continuing beyond the individual's passing away. She explained:

*"It upset the whole household. It upset the whole monetary structure of the household. It's devastating financially. It's devastating. I'm still coming out of it . . . You know, you plan the rest of your life. Not 59 and a widow. To a disease you have no control over."*

Another participant described how the loss of his career impacted his personal identity. She also provided an example where not only does the individual with dementia lose their job, but his spouse is required to quit her job as well in order to provide continued care for her loved one. She stated:

*"His work was his purpose. He loved it. For years and years and years. And shortly after that I had to stop working because he wasn't safe to be alone. He could dress himself and things like that. When he was out people wouldn't know there was much wrong but he couldn't be alone so I had to stop working. That was a big impact on me because I loved my work. But he was depressed for a long time. Because he had lost pretty much everything."*

This situation provides an excellent example of how not only does the individual with dementia lose his or her "purpose" in life, but caregivers are often required to go through drastic role changes as well. In this case, this spouse transitioned from being part of a financial team to

becoming the sole bread winner. While grieving that her husband obtained a diagnosis of younger onset dementia, she also began grieving the loss of her job with which she placed great value in addition to taking on the role of sole caregiver to her partner.

Another participant also describes how she was financially affected by her mother's loss of employment. She explained that in addition to becoming the primary caregiver, she took on the role of ensuring her mother's bills were paid on time and in full. She stated:

*"Both. If she didn't have enough, or whatever, I would contribute or pay them."*

These examples show us how drastically the lives of the entire family of an individual diagnosed with younger onset dementia can change within a very short period of time.

**Did he or she initiate any compensatory strategies, either prior to, or after receiving a diagnosis?.** Those participants that stated their loved one self-implemented a compensatory strategy reported the use of visual aids. The most common visual aide used was Post-it notes. In addition to these, charts, and diagrams or maps were also identified as being used. One participant reported that his wife used multiple visual aids:

*". . . Using Post-It notes and reminders. . . She would use her seating chart."*

One participant identified "talking around the question" as a way her husband reportedly compensated for his inability to answer questions asked of him at work or during interviews following the loss of his job. And although not related to compensatory strategies used at work, one participant described the maps of various grocery stores her husband would use to find his way around the aisles while shopping.

Alluding to the next question asked in the interview, one participant stated that the work place [Hardware store 2], made a modification to her mother's position by decreasing her responsibilities. She stated:

*“At that point [Hardware store 2] took her off the register. And she was relieved about that. Whatever she did she did. They just let her be a face.”*

**What, if any, modifications were made to his position or workspace?.** Most responses to this question reflected that no modifications were made to the workspace by the place of employment that would allow for longer employment retention, or to grade responsibilities to the employees changing capabilities. We have, however; seen from responses to previous questions, that one employer allowed his employee to carry out more simplified duties and be a “face” for customers to see when entering the store. One other participant identified a modification provided by an employer in the form of a co-worker being available for support to the individual with dementia. She stated:

*“The only modification that was made was his friend who was on the faculty. He could go to him with questions and things like that.”*

She went on to describe the grief her husband experienced over the loss of skills that once came easily to him and gave reasoning to why his workplace was so supportive. She explained:

*“. . . He cried when he found out he couldn't write. He sat down to write something and he had no clue. And he was a very dignified man and I think that people appreciated that he was trying so hard so there was that underlying support of just keeping an eye on him. And at the very end of the semester I would drive him back and forth [to the University].”*

**What assistance do you think would have been helpful in retaining the position or job for a longer period of time?.** During the interviews, only one participant responded that, given assistance, her husband could have continued to carry out his duties, in a modified form. She stated:

*“Yes. Yea, I think they could have. Maybe even just, you know, just getting the companies foot in the door to at least bid the project and then then have someone else do the bid work.”*

She explained that her husband worked for a construction company and would bid projects for acoustical work. She reported that his ability to work with numbers declined long before his ability to act as a salesman.

Others participating in the study did not echo her belief in their loved ones remaining capabilities or in the willingness of their employers to provide such assistance. One participant reasoned that it would not be financially beneficial to the company to provide his wife with such supports. He explained:

*“I don’t think they would have allowed it. Because of the money she was making with the Master’s degree. No. I don’t think they would . . . that was even thought of.”*

He went on to explain that his wife prided herself on the education she provided to her students. He stated:

*“I don’t think she would have been up to her standards doing it like that.”*

One participant became seemingly agitated by the question and demonstrated a complete lack of empathy to his wife’s diagnosis. He bluntly stated:

*“Well, if she wouldn’t have lost her mind she’d have kept her job.”*

**Additional input from caregivers.** Each interview concluded with the researcher asking the participant if there was any additional information they wished to provide or anything they think would be important for this study. Two of the seven participants in the Caregiver category provided an additional statement. One participant wanted to stress the amount of denial her

mother experienced and the length of time her state of denial lasted. In her statement, she recalled her mother being in denial until she was placed in a skilled nursing facility. She stated:

*“She just was really angry. She didn’t think she had a problem. She didn’t think she had a problem up until the point that we moved her here. She just didn’t see it.”*

Another participant wanted to stress the importance of continuing to treat individuals with dementia as they once were, with dignity and respect. Recalling from her own experience with her husband, she placed an emphasis on how directly a person’s job, or career, is tied to their identity. She stated:

*“I just think that in general people with dementia, a big part of the population think that you wake up one morning and you have dementia. And it’s not like that. It’s a progression from just an inkling that something is wrong and going through . . . and I think that employers and places of employment would adjust somewhat for the individual. If it means taking their job down a step, but with dignity. If it means bringing someone in that would help them compensate, it would help. I think it would help. Because when you lose your job and it has been such a big part of your life. A whole lot of life is gone. And it makes you think less of yourself. It makes you think that you are sick. When you are treated like you are sick you act like you are sick. And dignity is a very big factor. And even if you have to leave your job, it should be done in a dignified way. And not just kicked out the door. I think that is really important.”*

### **Discussion**

Dealing with loss of employment has been identified as a key issue within the younger onset dementia population. However, there is a void in the literature when it comes to studies focusing solely on the interaction of the disease with a person’s employment responsibilities.

The current study explored the specific impairments acquired by younger onset dementia and their relationship to employment by seeking to gain insight of the experiences that occurred in the workplace as a result of this condition. It further investigated the employer's and the company's response to both the emergence of impairments and the employee's disclosure of a diagnosis of younger onset dementia.

When talking with the individuals diagnosed with younger onset dementia, self-awareness of problems, denial, pride, coping techniques, and compensation, were the common themes extracted from the interviews. All participants reported general skill depreciation and increase in task difficulty as being their first insight to a possible problem. However, despite these problems, deficits were not met with an immediate response of obtaining a medical opinion due to the high level of denial all participants experienced. All three participants in this group reported experiencing denial in different ways. One reported that both he and his wife dealt with denial. And while she may have been the first to notice his symptoms, she was unwilling to admit the realization to herself or to him. He reported that even after receiving a diagnosis, he denied there was any real problem for quite some time. By the time a diagnosis was received, two participants felt they were no longer able to carry out their responsibilities. The theme of pride emerged when discussing continuation of work following receipt of a diagnosis. All participants voiced that they did not want the quality of work they provided to suffer due to the symptoms of the disease. Following a diagnosis, two participants felt compensatory strategies, in addition to the Post-it notes they were already using, would not increase their quality of work and independently discontinued work. The third participant implemented daily visual reminders, stating that he will familiarize himself with his work area several times during his shift.

Despite this group's difficulty in conveying their thoughts throughout the interview process, these themes arose time and time again. In addition to the four themes previously discussed, the use of Coping Techniques was frequently brought up and therefore identified as the fifth theme. All participants had a personal way of coping with living with the diagnosis, each of which was reflected by his or her personality. While one participant used humor to laugh off all difficult situations, another turned to her husband to be her source of strength and support. Another participant turned to his faith in God and lived by the belief that his life was in God's hands and could only be lived one day at a time.

For this study, the caregiver responses were themed by question and have been previously listed in the Results section. This resulted in a total of 19 themes. Much of the past research reports that symptoms of younger onset dementia are often first experienced and noticed in the workplace where diminished capacities are made evident through the failure of an employee to meet expectations of his or her employer (Sperlinger & Furst, 1994; Harris & Keady, 2004; Hunt, 2011). When asked about initial symptoms, the Caregiver group reported experiences that reflected these findings. While not all participants reported the workplace being where symptoms were first made evident, they did all report their loved one experiencing a general decline in abilities that presented most commonly as difficulty with numbers, inability to use office equipment, forgetfulness, and inability to complete tasks in a reasonable amount of time. However, as with the other group, despite awareness of deficits, the decline in job performance brought to the attention of the individual experiencing deficits. This may be due to the absence of awareness of younger onset dementia and lack of understanding of the disease as was found in the research of Rose et al. (2010). As one participant of this study stated, when it

comes to Alzheimer's disease, many people in society think a person just wakes up and is unable to function. There is a lack of understanding of the progression of the disease.

It was found that the individual experiencing symptoms of dementia did not typically disclose an awareness of deficits to their loved ones. Rather, as found with the previous group, the employed individual went through long periods of denial and either never disclosed experiencing a decline in symptoms or waited until the family member became aware and forced the acquisition of medical advice. The caregivers were not able to report an exact length of time from the onset of symptoms to the receipt of diagnosis; however, they were able to report the specific incident that made the possibility of dementia clear to them. Once a diagnosis was received, this group reported that responses of the individual with younger onset dementia ranged from continual denial to fear of the future.

When discussing the initial reaction to a diagnosis of Younger Onset Dementia, some caregivers reported that employment and sadness over the loss of a career was his or her loved ones first area of concern. And while one reported that his wife was ready to retire and not concerned about losing her job, the loss of independence from no longer being able to work was something employees experienced. Others reported that work was not at the forefront of their loved ones mind and the loss of time with family was the biggest concern. From a caregiver perspective, fear of the progression of the disease, sadness of the loss of time, and safety of the loved one were the most common concerns that were reported.

There were a few questions that pertained to the disclosing of a diagnosis to the employer. The experience of employees varied, some caregivers reported their loved one never disclosing their diagnosis and discontinuing employment voluntarily. Interestingly, two individuals working in retail-type positions were given the option of remaining employed "as a

face,” with one participant remaining employed, part-time, at the time of the interview. Another participant reportedly obtained a retail position following voluntary termination of employment as a bookkeeper, and remained employed without disclosing a diagnosis until she no longer wanting to continue to work. In this study, those employees who chose to disclose their diagnosis to their employer were met with tolerance and accommodation to fulfil their responsibilities. It is important to note that those individuals in this study who disclosed their diagnosis simultaneously presented their plan for cessation of work in the near future. All participants who, while employed, obtained a diagnosis following their decline in capabilities subsequently opted to terminate employment voluntarily with or without disclosure to their employer.

One participant reported that her mother’s employer took her off of the cash register and allowed her to “be a face” in the hardware store for as long as she wanted to continue employment. Another reported that her husband’s employer allowed a fellow employee to provide assistance throughout the remainder of the semester at which time it was planned he would take retirement. Other than these two instances, employers did not offer modifications or compensatory strategies to their employees with presented with a disclosure of a diagnosis. Post-it notes to serve as reminders and assistance provided by spouses when work was brought home were the most common self- implemented compensatory strategies.

In the current study, all participants reported feeling concerns over financial stability after the discontinuation of employment which was compared to loss of “purpose,” forfeiture of “independence,” and the stripping of “dignity.” This echoes findings of Johannessen and Moller (2011) whose participants reported feeling stigmatized and fighting for dignity following loss of employment. In one instance, a caregiver admitted, that prior to receipt of a diagnosis, her

husband's inability to obtain employment was the cause of marital problems. This was similar to findings of a study done by Fraker (2012), which revealed that when dementia is not considered, deficits leading to the inability to carry-out roles can create tension between family members.

### **Implications for Occupational Therapy**

In general, individuals in the work place, most commonly those working closest to the individual experiencing symptoms of dementia, were later found to be aware of the decline of capabilities. In the situations where employers reacted with an attitude of intolerance toward their employee's development of deficits, a disclosure of the diagnosis had not been provided. As stated in the research of Saint-Cyr (2011), many employers and employees lack the knowledge and awareness to recognize the signs of dementia, therefore; decline in work performance is often viewed as burnout or decreased effort. Results of the current study implicate that, at the very least, occupational therapists can provide education to both employers and their employees regarding the signs and symptoms of dementia. This education could benefit not only those who may develop younger onset dementia, but those individuals who are a part of the ever growing aging workforce as well.

Companies may benefit from working with occupational therapists to provide annual or biennial screenings of their employees. If upon evaluation cognitive decline is discovered the occupational therapist can work with the client to provide insight on his or her options for disclosure. Additionally, the occupational therapist can work with the employer in order to grade job responsibilities to the employee's abilities. This will allow for employees to leave their position "with dignity" and avoid unnecessary feelings of stigmatization. Furthermore this allows for the involvement of occupational therapy, early in the diagnosis, to provide resources and referrals as needed to both the individual with dementia and his or her family. Finally,

occupational therapists can assist the individual with seeking alternatives to employment such as options for volunteering and development of meaningful hobbies.

### **Limitations**

According to Lysack, Luborsky, and Dillaway (2006), the limitations to interviews include: 1) the provision of irrelevant information by the respondent, 2) responses influenced by social desirability bias, and 3) the respondent, at times, having an unclear understanding of the research question. In addition to these limitations, the authors discuss that when completing interviews, trust and rapport between interviewer and respondent are essential in order for the respondent to feel comfortable sharing information on topics that can be very personal. Furthermore, it is mentioned that experience and skill yields the best results when completing interviews, especially with vulnerable populations, such as those with cognitive disabilities.

The largest limitation to this study was the small sample size specific to one location. The study originally sought to recruit participants with a diagnosis of younger onset dementia. However, it proved to be difficult not only to identify individuals with this diagnosis, but to identify those individuals with younger onset dementia who maintained the ability to recall and communicate past events. Of those three participants who were diagnosed with the disease, they did not complete a standardized test to determine eligibility to participate. Due to the difficulty with initial recruitment efforts, the researcher opened recruitment up to the primary caregiver of the individual with younger onset dementia. However, in some cases, the primary caregiver was not necessarily the individual with the most information on this situation. In all cases, the caregiver account is subjective and despite sometimes constant communication between the caregiver and individual with dementia, information pertaining to the questions in the interview may be unknown.

**Future Research**

Research pertaining to those with younger onset dementia and employment is limited. Future research on this topic can expand the geographical region from which it recruits in order to obtain a larger pool of participants. To do this, interviews could be completed with the use of technology, such as Skype.

It would be beneficial for future research, in the form of focus groups or interviews, to focus on different occupational fields in order to compare employer's responses and employees' experiences. Future research can also be completed in the form of focus groups with employers to determine their level of awareness of the disease as well as their willingness to and feelings on allowing the continuation of employment with graded responsibilities. Additionally, interviews or focus groups could be held with individuals who are employed in various occupational fields in order to gain insight to their feelings and expectations on the treatment of a co-worker who possibly develops younger onset dementia, or on the continuation of his or her own employment should they ever receive such a diagnosis.

**Conclusion**

This study examined the experiences of individuals diagnosed with younger onset dementia while in the workplace. It specifically focused on how the emergence of deficits impacted job performance and the response of the individual's employer. The results indicate that co-workers are commonly first to notice deficits; however, this is generally not passed on to the family or even brought to the attention of the co-worker. Employers were overall tolerant of their employee when a diagnosis was disclosed and a plan for employment cessation was presented. In situations where the employer was not tolerant, neither the employee nor the employer was aware deficits were related to Alzheimer's disease; however, the employer did not

seek evaluation prior to the termination of employment. Loss of employment was compared to the loss of independence, dignity, and purpose. Occupational therapists can work with employers to provide awareness about the diagnosis, including signs and symptoms that may present in the workplace, provide screenings, and to work with the employee and employer to grade responsibilities to an employee's with dementia capabilities. Further research is needed to explore employer's awareness and understanding of Alzheimer's disease along with their attitudes and opinions on allowing an individual with dementia to remain employed with the assistance of an occupational therapist to grade work related responsibilities.

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# Research opportunity for individuals with young onset dementia.

## The purpose of the research:

Interviews will be conducted to identify the relationship between young onset dementia and employment. The interviews will help identify how occupational therapists can work with individuals experiencing symptoms of young onset dementia, and their related impairments, while remaining active members of the workforce.

If you are interested in participating in this study:

Please contact:  
Carmen Travis at  
419.329.0301

Or

[Carmen.Travis@rockets.utoledo.edu](mailto:Carmen.Travis@rockets.utoledo.edu)

## You may **qualify** to participate if:

- ❖ You were diagnosed with, or received a Probable Diagnosis of Dementia at or prior to the age of 65;
- ❖ You were diagnosed with Progressive Memory Loss Disorder;
- ❖ Were employed at the time of the onset of symptoms and diagnosis;
- ❖ Have the ability to read, write, and clearly communicate past and current experiences;
- ❖ Are self-sufficient and function independently.

# Experiencing Dementia in the Workplace

Research is being conducted by an Occupational Therapy Doctorate Student to identify the relationship between dementia and employment. The information gathered through interviews with past and current caregivers will help identify how occupational therapists can work with individuals experiencing symptoms of dementia to maintain their employment for as long as possible.

You may qualify to participate if you have been in the past or currently are the caregiver of an individual who:

- ❖ Experienced symptoms and received a diagnosis prior to the age of 65;
- ❖ Received a diagnosis of dementia or a probable diagnosis of dementia while employed;
- ❖ Received a diagnosis of progressive memory loss disorder while employed.

If you are interested in participating in this study  
Please Contact:

Carmen Travis at 419.329.0301 or [Carmen.Travis@rockets.utoledo.edu](mailto:Carmen.Travis@rockets.utoledo.edu)

Appendix C

Participant Questionnaire for Individuals with Younger Onset Dementia

**Participant #:** \_\_\_\_\_

1. Age: \_\_\_\_\_

2. Gender (*Please circle*):      Male              Female

3. Race (*Please circle*):

|                |                 |                  |
|----------------|-----------------|------------------|
| Hispanic       | Caucasian       | African American |
| Asian American | American Indian | Other: _____     |

4. Highest Level of Education:

|                              |                         |                   |
|------------------------------|-------------------------|-------------------|
| Under 12 <sup>th</sup> grade | High School Diploma/GED | Bachelor's Degree |
| Masters Degree               | Doctoral Degree         | Other: _____      |

5. Marital Status (*Please circle*):

|         |              |          |
|---------|--------------|----------|
| Married | Separated    | Divorced |
| Single  | Other: _____ |          |

6. Age of onset of symptoms: \_\_\_\_\_

7. How long have you had a diagnosis of dementia? \_\_\_\_\_

8. Are you currently employed?      Yes              No

*If yes, please answer questions 9-14. If no, please continue to question 15.*

9. How many hours a week do you work? \_\_\_\_\_

10. At which company are you employed?

\_\_\_\_\_

11. How long have you been at your current place of employment? \_\_\_\_\_

\_\_\_\_\_

12. Please name your position and describe your responsibilities \_\_\_\_\_

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13. About what percentage does your income contribute to your total household income? \_\_\_\_\_

14. Is this the same company you were employed with at the time of your diagnosis?

Yes      No

15. Under what circumstances did you discontinue employment?

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16. What status, if any, did you obtain upon your discontinuation of employment (i.e. retirement, disability, ect.)? \_\_\_\_\_

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17. How long had you been employed with your company? \_\_\_\_\_

18. What was your position and responsibilities prior to discontinuation of employment?

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19. About what percentage did your income contribute to your total household income? \_\_\_\_\_

Appendix D

Participant Questionnaire for Current Caregivers

**Participant #:** \_\_\_\_\_

Please answer the following questions as they pertain to yourself:

1. Age: \_\_\_\_\_

2. Gender (*Please circle*):      Male          Female

3. Race (*Please circle*):

Hispanic

Caucasian

African American

Asian American

American Indian

Other: \_\_\_\_\_

4. Highest Level of Education:

Under 12<sup>th</sup> grade

High School Diploma/GED

Bachelor's Degree

Masters Degree

Doctoral Degree

Other: \_\_\_\_\_

5. Marital Status (*Please circle*):

Married

Separated

Divorced

Single

Widowed

Other: \_\_\_\_\_

6. What is your relationship to the individual you have or are currently providing care to?

\_\_\_\_\_

\_\_\_\_\_

Please answer the following questions as they pertain to the individual you have or are currently caring for:

6. Age: \_\_\_\_\_

7. Gender: \_\_\_\_\_

8. Race: \_\_\_\_\_

9. Age of onset of symptoms: \_\_\_\_\_



21. How long had they been employed with that company? \_\_\_\_\_

22. What was the position and responsibilities prior to discontinuation of employment?

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Appendix E

Participant Questionnaire for Past Caregivers

**Participant #:** \_\_\_\_\_

Please answer the following questions as they pertain to yourself:

1. Age: \_\_\_\_\_

2. Gender (*Please circle*):      Male          Female

3. Race (*Please circle*):

Hispanic

Caucasian

African American

Asian American

American Indian

Other: \_\_\_\_\_

4. Highest Level of Education:

Under 12<sup>th</sup> grade

High School Diploma/GED

Bachelor's Degree

Masters Degree

Doctoral Degree

Other: \_\_\_\_\_

5. Marital Status (*Please circle*):

Married

Separated

Divorced

Single

Widowed

Other: \_\_\_\_\_

6. What is your relationship to the individual you have or are currently providing care to?

Please answer the following questions as they pertain to the individual you cared for:

7. Age: \_\_\_\_\_

8. Gender: \_\_\_\_\_

9. Race: \_\_\_\_\_

10. Age of onset of symptoms: \_\_\_\_\_

11. When was a diagnosis of dementia received? \_\_\_\_\_

12. Highest Level of Education: \_\_\_\_\_

13. How many hours a week was your loved one working when a diagnosis was received?
14. Where were they employed?
15. How long had they worked there?
16. Please name the position and describe their responsibilities.
17. About what percentage did their income contribute to your total household income?
18. Under what circumstances was employment discontinued?
19. What status, if any, was obtained upon discontinuation of employment (i.e. retirement, disability, ect.)?
20. How long had they been employed with that company?
21. Did your loved one maintain the same position from the time of diagnosis until discontinuation of work? *(If no, please skip to question 22).*
22. Did his or her responsibilities remain the same? If no, please describe the differences. *(Please skip to the question 24).*

23. Did your loved one seek alternative work after losing the job where he or she was diagnosed?

24. Please describe his or her responsibilities in their new position.

25. What was the position and responsibilities immediately prior to discontinuation of employment?

## Appendix E

## Interview Guide for Individual with Younger Onset Dementia

1. Introduction and thanks for participation.
  - a. Why the study is being done.
  - b. Description of occupational therapy.
2. Questions regarding initial symptoms:
  - a. What were the first symptoms that made you aware something was wrong?
  - b. How long did you experience symptoms before going to the doctor?
3. Receiving a diagnosis:
  - a. After you received a diagnosis, did you look back and identify other signs/symptoms that you may have overlooked?
  - b. After receiving a diagnosis, what was your first area of concern?
  - c. How long after receiving your diagnosis did you wait before telling your supervisor?
  - d. How did you disclose your diagnosis?
  - e. If you received a diagnosis after discontinuation of work, did the diagnosis provide any closure?
4. Working with young onset dementia:
  - a. Who was the first to notice there was a problem?
  - b. How long did you remain at work after you started noticing problems before seeking help?
  - c. How long did you remain at work after receiving a diagnosis?
  - d. What was your supervisor's initial reaction to the disclosure of your diagnosis?
  - e. In terms of your work performance, what is the biggest change you have seen?
  - f. What was the first work task you began struggling with?
  - g. Are you still employed with the same company/position as when you first noticed symptoms/received a diagnosis?
  - h. Do you think you still perform your work tasks adequately?
  - i. What is your biggest area of concern regarding working with this condition?
5. Compensation and Accommodations in the workplace:
  - a. Did you initiate any compensations yourself, either prior to, or after receiving your diagnosis?
  - b. What, if any, modifications were made to your position or to your workspace?
    - i. Were these readily provided for you or did you seek them out?
  - c. Did you receive any services to assist you in keeping your position or job?
6. Retaining Employment:
  - a. What assistance do you think would have been helpful in retaining your position or job for a longer period of time?
  - b. Did your employer seek outside assistance to determine your competency to

remain in your position?

7. Volunteering
  - a. Were you volunteering prior to your diagnosis?
  - b. Have you begun to volunteer since your diagnosis?
  - c. Did you begin to volunteer due to loss of employment?
  - d. Does volunteering offer the same level of fulfillment as employment?
8. Any input from caregiver/family member?
9. Anything that may be of importance?
10. Thanks for participation and time.

## Appendix G

## Interview Guide for Current Caregivers

1. Introduction and thanks for participation.
  - a. Why the study is being done.
  - b. Description of occupational therapy.
2. Questions regarding initial symptoms:
  - a. What were the first symptoms that made you and your spouse aware something was wrong?
  - b. When did your loved one tell you he/she was developing problems?
  - c. What were the first symptoms he/she noticed in the workplace that made him/her aware something was wrong?
  - d. How long were symptoms experienced before going to the doctor?
3. Receiving a diagnosis:
  - a. After a diagnosis was received, were you able to reflect back and identify signs that were overlooked?
  - b. After receiving a diagnosis, what were your loved ones first area of concern?
  - c. What was your (caregiver) first area of concern?
  - d. Did you discuss how to handle the situation at work together?
  - e. How long after receiving your diagnosis did your loved one wait before telling his/her supervisor?
  - f. How was the diagnosis disclosed?
  - g. If the diagnosis was received after discontinuation of work, did the diagnosis provide any closure?
4. Working with younger onset dementia:
  - a. Who was the first to notice there was a problem?
  - b. After noticing problems at work, how long did he/she wait prior to seeking help?
  - c. How long did he/she remain at work after receiving a diagnosis?
  - d. What was his/her supervisor's initial reaction to the disclosure of the diagnosis?
  - e. In terms of work performance, what is the biggest change that was seen?
  - f. What was the first work task that began being problematic?
  - g. Did he/she remain employed with the same company/position as when symptoms were first noticed or diagnosis was received?
  - h. What is your biggest area of concern regarding working with this condition?
  - i. Has this impacted other areas of his/her life?
5. Compensation and Accommodations in the workplace:

- a. Did he/she initiate any compensation themselves, either prior to, or after receiving a diagnosis?
  - b. What, if any, modifications were made to his/her position or to their workspace?
    - i. Were these readily provided for them or did he/she seek them out?
6. Retaining Employment:
- a. What assistance do you think would have been helpful in retaining the position or job for a longer period of time?
  - b. Did his/her employer seek outside assistance to determine competency to remain in the position?
7. Volunteering
- a. Was he/she volunteering prior to receiving a diagnosis?
  - b. Had they begun to volunteer since receiving a diagnosis?
  - c. Did they begin to volunteer due to loss of employment?
  - d. Did volunteering offer the same level of fulfillment as employment?
8. Any additional input from caregiver/family member?
9. Anything that may be of importance?
10. Thanks for participation and time.

## Appendix H

## Interview Guide for Past Caregivers

1. Introduction and thanks for participation.
  - a. Why the study is being done.
  - b. Description of occupational therapy.
  
2. Questions regarding initial symptoms:
  - a. What were the first symptoms that made you aware something was wrong?
  - b. When did your loved one tell you he/she was developing problems?
  - c. What were the first symptoms noticed in the workplace that made him/her aware something was wrong?
  - d. How long were symptoms experienced before going to the doctor?
  
3. Receiving a diagnosis:
  - a. After a diagnosis was received, were you able to reflect back and identify signs that were overlooked?
  - b. After receiving a diagnosis, what were your loved ones first area of concern?
  - c. What was your (caregiver) first area of concern?
  - d. Did you discuss how to handle the situation at work together?
  - e. How long after receiving your diagnosis did your loved one wait before telling his/her supervisor?
  - f. How was the diagnosis disclosed?
  - g. If the diagnosis was received after discontinuation of work, did the diagnosis provide any closure?
  
4. Working with younger onset dementia:
  - a. Who was the first to notice there was a problem?
  - b. After noticing problems at work, how long did he/she wait prior to seeking help?
  - c. How long did he/she remain at work after receiving a diagnosis?
  - d. What was his/her supervisor's initial reaction to the disclosure of the diagnosis?
  - e. In terms of work performance, what is the biggest change that was seen?
  - f. What was the first work task that began being problematic?
  - g. Did he/she remain employed with the same company/position as when symptoms were first noticed or diagnosis was received, or did he/she obtain employment elsewhere?
  - h. What was his or her biggest area of concern regarding working with this condition?
  - i. Did this impact other areas of your life?

5. Compensation and Accommodations in the workplace:
  - a. Did he/she initiate any compensation themselves, either prior to, or after receiving a diagnosis?
  - b. What, if any, modifications were made to his/her position or to their workspace?
    - i. Were these readily provided for them or did he/she seek them out?
  - c. Were any services provided to assist him/her in keeping their current position or job?
6. Retaining Employment:
  - a. What assistance do you think would have been helpful in retaining the position or job for a longer period of time?
  - b. Did his/her employer seek outside assistance to determine competency to remain in the position?
7. Volunteering
  - a. Was he/she volunteering prior to receiving a diagnosis?
  - b. Had they begun to volunteer after receiving a diagnosis?
  - c. Did they begin to volunteer due to loss of employment?
  - d. Did volunteering offer the same level of fulfillment as employment?
8. Any additional input from caregiver/family member?
9. Anything that may be of importance?
10. Thanks for participation and time.