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## **Maslow's Hierarchy and Early-Onset Alzheimer's Disease: Systematic Review of Stages and Interventions**

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Maslow's Hierarchy and Early-Onset Alzheimer's Disease:

Systematic Review of Stages and Interventions

By

Bethany M.M. Doerr, B.S.W.

MSW Clinical Research Paper

Presented to the Faculty of the  
School of Social Work  
St. Catherine University and the University of St. Thomas  
St. Paul, Minnesota  
in Partial fulfillment of the Requirements for the Degree of

Master of Social Work

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The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present the findings of the study. This project is neither a Master's thesis nor a dissertation.

## Abstract

Early-onset Alzheimer's disease occurs at a fairly young age and causes a life altering shift after being diagnosed. Helping persons diagnosed live to their fullest potential at all stages of the disease is a relevant and meaningful goal for social work. The purpose of this systematic literature review was to synthesize the current research on how interventions, therapies, and practices address the different levels of Maslow's Hierarchy of Needs for individuals living with younger/early-onset Alzheimer's disease. A systematic literature review design was used and the level of publication was limited to peer-reviewed English language academic articles within the time frame of 1990-2013. The electronic databases searched included Social Work Abstracts, SocIndex, and PsychINFO. Gray literature was also searched for the most up-to-date information. The inclusion terms used for this research were "early onset" or "younger-onset," Alzheimer's disease, senile dementia, dementia, patient, and quality of life. The exclusion terms were also applied. The systematic literature review was organized around the conceptual framework of Maslow's Hierarchy of Needs which include the five levels of: physiological needs, safety, love and belonging, self-esteem, and self-actualization. The findings indicated that there is a lack of specific research regarding the needs of persons with younger/early-onset Alzheimer's disease. The hierarchy of needs that received the most attention in the literature was biological and physiological and love and belongingness need. The areas that received the least amount of attention were esteem needs, self-actualization need, and safety needs. Findings shown that when using Maslow's Hierarchy it is best to adjust it in order to fit the each individual's needs. For instance when using it for an individual with early-onset Alzheimer's disease it would fit their disease process better to address the needs in reverse order starting with the self-actualization need. Future research suggests there needs to be more research, services, and resources on person-centered care for those with early-onset Alzheimer's disease and given more recognition in order to better help this group of individuals.

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Maslow's Hierarchy and Early-Onset Alzheimer's Disease:  
Systematic Review of Stages and Interventions

In today's society it seems there are considerable stigmas and fears that relate to the terms "aging" and "elderly." These stigmas create anxiety for some, causing them to think about the changes we experience as we age. The effects of aging on the body are a natural part of life that cannot be avoided, and it is becoming more common for people to be diagnosed with dementia or Alzheimer's diseases as they age.

Younger/early-onset Alzheimer's disease (YOAD) is one disorder which, unlike the usual progression of aging, is experienced by those under the age of 65 (Robinson, Saisan, & Segal, 2014). Younger/early-onset Alzheimer's disease is not a widely known or researched disease, although Alzheimer's disease in general is. Its definition according to the National Institute on Aging (2012) is that "Alzheimer's disease is an irreversible, progressive brain disease that slowly destroys memory and thinking skills, and eventually even the ability to carry out the simplest tasks"(para. 1). This disease occurs most commonly later in life, usually after 65 years of age. Many young people who may be showing symptoms of YOAD may disregard the symptoms due to their age. Alzheimer's disease can only be diagnosed by an autopsy performed after death, but there are common signs and symptoms that lead to the probable diagnosis (National Institute on Aging 2012).

In popular literature today, there are many terms used to signify cognitive decline including: dementia, Mild Cognitive Impairment, Younger/early-onset Alzheimer's disease, early stage Alzheimer's disease, and late onset Alzheimer's disease. Each of these terms are very different from each other in relation to what they mean. The term dementia is used to define the loss of or decline in memory, thinking, and social abilities, enough so that it affects a person's

daily living (Mayo Clinic, 2014). Alzheimer's disease is the most common cause of progressive dementia (Mayo Clinic, 2014). The term Mild Cognitive Impairment is defined as discrepancies in memory that aren't severe enough to affect daily living (UCSF Memory and Aging Center, 2013). Mild Cognitive Impairment is mostly unnoticed by the individual experiencing it and may remain stable for many years with no progression in further memory decline (UCSF Memory and Aging Center, 2013). There are many forms of Alzheimer's disease and many differences in each. The differences between the diagnoses for Alzheimer's disease are: younger/early-onset Alzheimer's disease which occurs before age 65 and late onset Alzheimer's disease which is diagnosed after age 65 (Alzheimer's Association, 2014). The term early stage Alzheimer's disease can be used interchangeably between defining the symptoms that occur in the beginning of the disease either in younger/early-onset Alzheimer's diagnosis or late onset Alzheimer's diagnosis (Robinson, Saisan, & Segal, 2014). Although often used interchangeably, these terms are very distinct. This paper will focus on younger/early-onset Alzheimer's disease (YOAD), however acknowledges that sometimes literature uses different terms.

When younger/early-onset Alzheimer's disease is diagnosed symptoms can start to appear within individuals as young as 30, but the average age for YOAD to occur is between 40 and 50 years old (Alzheimer's Association, 2014). Someone experiencing YOAD may be able to trace the disease through their genetics, whereas late onset can occur in anyone and is a form of brain deterioration (Panegyres, & Huei-Yang Chen, 2013). In fact, many individuals who have symptoms of younger/early-onset Alzheimer's disease (YOAD) may not be correctly diagnosed with this disease due to their age. This is due to doctors not expecting the disease in younger people (Alzheimer's Association).

The Alzheimer's Association (2014) alarmingly states, "Every 67 seconds someone in the United States develops Alzheimer's" (para. 2, Quick Facts). According to Kuhn and Fulton (2004), it is estimated that five million Americans currently have Alzheimer's disease, but by 2040 those being affected by this disease is predicted to increase to 11 million. Within the five million Americans who are diagnosed with Alzheimer's disease, five percent are diagnosed with Younger-Onset, and currently approximately 200,000 people have early onset Alzheimer's disease (Alzheimer's Association, 2014). According to the Alzheimer's Association (2014), statistics show that two-thirds of Alzheimer's disease patients are women and it has been proven that women are at a higher risk of having Alzheimer's disease than men.

Although it has been shown that this diagnosis is affecting a growing number of people, we know little about persons with younger/early-onset Alzheimer's disease experience of the disease and how to address their needs as individuals. Symptoms and changes that are known for this disease are: memory problems, changes in smell, taste and vision, heightened sensitivity, personality changes, difficulty completing normal daily tasks, mood changes, and problems with word finding (National Institute on Aging, 2012). According to Panegyres and Huei-Yang Chen (2013), younger/early-onset Alzheimer's disease leads to cognitive decline more quickly than late onset, and therefore interventions need to be implemented as soon as the diagnosis is made.

There are also fairly typical stages of cognitive decline that can occur. According to Robinson, Saisan, and Segal, (2014), there are seven stages that individuals with this diagnosis can encounter as the disease progresses. During the first stage, there is barely any impairment seen and usually diagnosis is impossible. The second stage involves very mild decline such as memory loss and the symptoms include: confusion, loss of spontaneity, loss of initiative, mood/personality changes, poor judgment, and taking longer to perform routine chores. The third

stage is mild decline which includes impairments in language, motor ability, recognition of objects, and increasing memory loss and confusion. In the fourth stage (moderate decline), symptoms present themselves as having problems recognizing family members or close friends, repetitive statements and/or movements, restlessness (sun downing), problems organizing thoughts, illogical thinking, word omission, reading and writing difficulties, acting suspicious, irritable, fidgety, and teary or silly. In the fifth stage (moderately severe decline) symptoms are very similar to that of the sixth stage (severe decline), which are weight loss, even with a good diet, deterioration in self-care, difficulties in verbal communication, possibly putting everything in mouth or touching everything, loss of bladder and/or bowels, possible difficulty with seizures, swallowing, skin breakdown, and infections. Finally, the last stage includes very severe decline and this stage can be also known as the terminal stage, which presents symptoms of loss in ability to ambulate, loss of ability to sit, loss of ability to smile, loss of ability to hold up head, and loss of ability to swallow.

Once diagnosed with younger/early-onset Alzheimer's disease, these individuals have many new considerations that need to be addressed and will want to include those who will want to be involved, in order to make the stages of this disease more manageable. Changes include: changes in the family system, new roles of family members, new financial considerations, the need for a care team, and need for knowledge of the mental and physical impacts the disease will have (Alzheimer's Association, 2014).

### **Meeting the Needs of Persons with YOAD: Maslow's Hierarchy**

Maslow (1943) created a theory in 1943 called 'A Theory of Human Motivation,' and within this, Maslow created a hierarchy of what he found to be the necessary needs of humans. Maslow (1943) was interested in what drives individuals' daily actions and how their needs

cause certain reactions to happen. He wanted to understand what motivates people to act the way they do and why, relating to what he viewed as a person's normal everyday essential needs.

Maslow (1943) analyzed what patterns that humans move through and what motivations drives a person's reactions and needs. Maslow (1943) indicated five distinct needs and termed them, "physiological, safety, social, esteem, and self-actualization." The most important need is placed at the bottom and the least or last need that is usually met by an individual lies at the top.

The five needs over time were formatted within a pyramid. According to McLeod (2007) "This five stage model can be divided into basic (or deficiency) needs (e.g. physiological, safety, love, and esteem) and growth needs (self-actualization)" (Para. 4). When the basic needs are not met the need becomes a more pressing matter. Addressing a need of a person cannot occur without the fulfillment of the previous one (Maslow, 1943). Human beings are driven by many needs and wants. Maslow (1943) states that individuals are motivated and react as a result of their needs and what needs have been met so far. Maslow's hierarchy of needs is still used today in many ways such as a business model within corporations, within schools as an educational model, and within the social work profession or psychology profession. Although it is still used today many use the models a supplement or reference combine with a more holistic model (McLeod, 2007). According to McLeod (2007), there is lack in validity to the whole hierarchy of needs because when Maslow tested out the self-actualization level he developed characteristic qualities that he thought were shown by his sample of 18 white male subjects. Scientifically this causes some problems in the reduction of validity to the research, because there is a personal bias to the findings as a result of Maslow using what he considered as meeting the level of self-actualization and bias in the research sample of only using a sample of white well educated males (McLeod, 2007). Also, it has been found that not all of the levels have to be met in the

order they are presented to reach optimal feeling of self-actualization. The levels can be met out of order or not at all in order for someone to be satisfied with their life, but many still used this method as a good starting reference in different circumstances and professions. I have chosen to use Maslow's hierarchy of needs described below as a framework and structure for this research in order to assess to what degree the intervention, therapies, and needs of a person with YOAD are being addressed.

**Biological and physiological needs.** Maslow (1943) saw that a person's biological and physiological needs must be met in order for a person to live and maintain thriving. The list of needs in this category are air, food, drink, shelter, warmth, sex, and sleep (Maslow, 1943). The paper will discuss this first level of needs by relating it to someone with YOAD in ways to help the patient improve daily living by maintaining their physical, emotional, and social health (Alzheimer's Association, 2014). This section will provide evidence of interventions that would help with the essential needs of the disease process. These are needs such as having proper shelter, environmental needs such as air, warmth, sleep, schedules, and reminders to eat, drink, and complete daily tasks. Also, this focus will consider ways professionals working with YOAD encounter discussions about the disease process and the first essential steps that need to be taken in order to assist with planning for the future. This important step is included here as it often centers on the disease progression and how it affects all characteristics of life which include this very basic aspect.

**Safety needs.** Maslow's (1943) second and subsequent essential level of need that is seen as important to a person's well-being is their ability to feel safe. Some examples of Maslow's safety needs are protection from elements, security, order, law, stability, and freedom from fear (Maslow, 1943). This set of needs in relation to someone with YOAD would focus on the future

of the patient and their needs for possible financial stability as their disease progresses. Many people diagnosed with YOAD are still working and the loss of the ability to work can affect their family's source of income and financial situation. As the disease progresses further, experiences of being disoriented, wandering, and general confusion occur. How these are considered in interventions will be presented here. Addressing these needs will also help bring attention to possible services available that can be implemented to help plan for the future. These may ease the individual's mind on the stability of their home life and how they will be cared for in the future.

**Love and belongingness needs.** Maslow's (1943) need for love and belongingness is crucial in a person's life to be able to experience positive reinforcement and feel the need of being wanted by others. Loneliness is a symptom that can occur in any person's life, but when diagnosed with a disease such as YOAD, many can feel even more alone than usual. Some of the needs listed under love and belongingness that Maslow found crucial were friendship, intimacy and affection, as well as love from family and significant others (Maslow, 1943). Relating this to experiences of YOAD, this section of the research will consist of literature focusing on ways for the individual to live out their life as normal as possible.

To focus on quality of life over quantity with this diagnosis is crucial, especially as it is diagnosed at a younger age, because the person will lose more years due to the early progression of this disease. This section encompasses research on therapies to help with family relationships as the disease progresses and the struggles it brings. For instance, some individuals with this disease may still be raising children, employed, and active in the community when symptoms begin to occur. Therefore, the individual with YOAD would want to consider issues between partners as well as love and respect of one's children which relates to this areas of one's needs.

This allows for acceptance and understanding within the family system. Woods (1999) states that research emphasis is mainly on the caregiver's stresses and burdens rather than those of the care receiver. The lack of research on the person with the disease is interesting and likely makes it harder to justify the actual feelings and needs of the individual diagnosed with YOAD.

**Esteem needs.** Maslow's (1943) level of needs addressing a person's self-esteem can be very critical within an individual with YOAD. The motivation to fill the self-esteem need within a person is the ability for a person to acquire a sense of achievement, mastery, independence, status, dominance, prestige, self-respect, and respect from others (Maslow, 1943). These needs are what Maslow found to be significant in addressing the ability to have a positive self-esteem. A person diagnosed with YOAD can experience a wide array of everyday emotions. Allowing them the freedom of doing things independently provides them with the ability to experience fulfilling these needs. It is important to address these needs with individuals living with YOAD so they can achieve a quality of life without having the added stigma of the diagnosis. This section will incorporate the literature found in the areas where an individual who has YOAD struggles with having the feeling of self-fulfillment, self-esteem, purpose in life, and self-respect.

It is important for persons living with YOAD to have self-respect and respect from others. In other words, family members and providers will need to address the whole affected person, and not just see the diagnosis and provide treatment. Now that the disease is becoming more prevalent, a shift from the emphasis on dementia care to the person with dementia is needed (Woods, 1999). Woods (1999) also states "the person with dementia was not an object, not a vegetable, not an empty body, not a child, but an adult, who, given support, might exercise choices and respond to a respectful approach" (p. #35). Persons given this diagnosis may

figuratively disappear if all that is seen is the disease, which is why Maslow's esteem need will be addressed within this research.

**Self-actualization.** Maslow's (1943) last stage of hierarchy of needs is self-actualization. When all the other needs are able to be met, this is the last social need that a person should have in order to best meet life's expectations. This stage encompasses a person's ability to realize their own personal potential, self-fulfillment in life, seek personal growth, and peak experiences (Maslow, 1943). In order to identify this need within the research, the literature that will be analyzed pertains to seeking the individual's personal needs and potential with this type of disease, as well as what services, therapies, and/or practices would best help the patient seek self-fulfillment. Many helping professionals like social service providers are educated on advocating for the patient and are knowledgeable in ways to best assist those in these different situations and circumstances. Knowledgeable professionals can assist the patient in realizing the supports and positive aspects they still have in their lives while enduring this disease. Some physical symbols and reminders of positive aspects of life that professionals can help with may be drafting life reviews, creating cookbooks of life long family recipes, or comfort books while the patient is still in their early stage of cognitive ability.

### **Research Question**

How do interventions, therapies, and practices address the different levels of Maslow's hierarchy of needs for individuals living with younger/early-onset Alzheimer's disease?

While the literature regarding caregiving of persons with Alzheimer's disease is extensive and growing, the literature based on YOAD is very limited in regards to focusing on the person living with the disease. Other aspects of the disease like caregivers, medications, and medical advances have much more attention. Furthermore, in a quick review of the literature,

much less research can be found on younger/early-onset Alzheimer's disease (YOAD) compared to late onset Alzheimer's disease. Hence this research will attend to this gap, and in particular current interventions by professionals that can help practitioners understand the variety and general types of helping methods. This systematic review will specifically focus on the term younger/early-onset Alzheimer's disease (YOAD) although some of the literature found may use a different term to define this diagnosis. The purpose of this research is to synthesize the current findings on how researchers represent younger/early-onset Alzheimer's disease using the different levels of Maslow's hierarchy of needs.

### Research Conceptual Framework

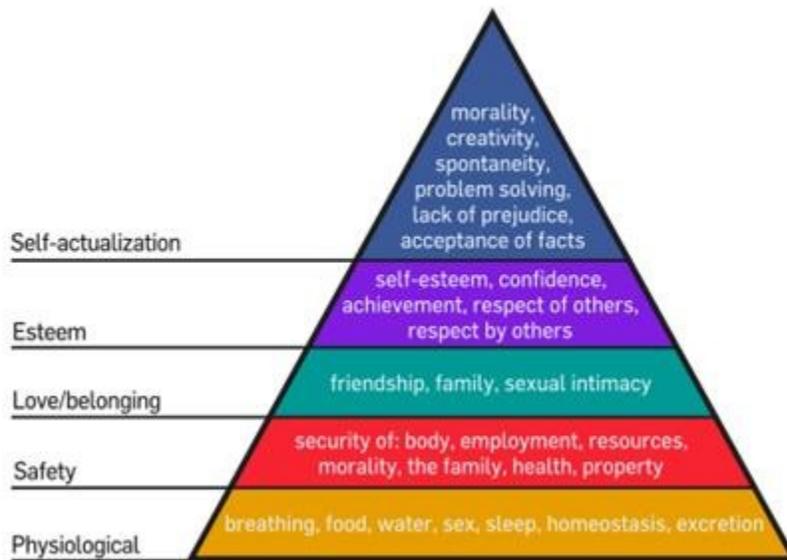


Figure I. Maslow's Hierarchy of Needs

Based on the research, the systematic literature review within Maslow's hierarchy of needs will start with the need that refers to advocating for the patient's biological and physiological needs. The physiological needs associate with environment needs which are air,

and proper shelter that can provide warmth and protection, schedules and notes for reminders to do daily tasks like eat, drink, and sleep, when to take medications, and to turn off appliances after using (Maslow, 1943). The next level would be safety needs which includes: protection from elements, services, security, law, proper insurances, stability in home life, and freedom to do things on their own as long as they can (Maslow, 1943). After that, the next level would be love and belongingness needs, which consists of still keeping the friends that one might have had before the diagnosis who could help with family relationships as the disease progresses and the struggles it brings with it (Maslow, 1943). The next level would then be how professionals can help the patient with esteem needs. Those involved can help the patient focus on the disease progression and possible therapies or counseling services for the patient. To advocate and help the patient realize the strengths and positives they still have in their lives as this disease takes its toll. To also have self-respect and respect from others in not just seeing the diagnosis and treating the illness, but to understand the person and treat the person's needs. The last level would be self-actualization, where the literature found addressed the patient's personal needs and potential with this disease, along with what services, therapies, and/or practices would help the patient seek self-fulfillment (Maslow, 1943). After describing how a person with YOAD can acquire these levels, the interventions that can assist with the process were discussed. Interventions found were placed with which levels they addressed best for assistance in obtaining the need. Select interventions might address many different levels, which will then be incorporated into what level or levels they can contribute to.

Table 1. References

Database	Total # of articles	# of articles used	Years 1990-2014
SocIndex	9	3	1990-2011
PsychINFO	72	9	1990-2014
Social Work abstracts	108 scholarly peer reviewed journals	8	1990-2014
Gray Literature <b>Alzheimer's Association</b>	542	18	2000-2014
Gray Literature <b>PubMed.gov</b>	500	3	2011-2014
Gray Literature <b>USA.gov, Senior Citizens' Resources</b>	1,000	4	2008-2013

Note: This table refers to the references, how many were found within each database, how many references were actually used and the years they were published.

### Methods

This paper encompassed literature from an international body of research on younger-onset Alzheimer's disease (YOAD). The level of publication allowed is limited to peer-reviewed academic articles and limited to English speaking articles of research. Although some earlier research exists, only the literature published within the time frame of 1990-2013 was reviewed. The electronic databases that were used to locate sources for this literature are Social Work Abstracts, SocIndex, and PsychINFO. Gray literature was also included for example; research institute, government doc. and edu. websites to widen the search of research. Specifically these include Alzheimer's Association, PubMed.gov, and USA.gov, Senior Citizens' Resources. Following set guidelines of systematic search for articles, search terms were selectively chosen to find relevant results material on a particular topic. My search terms were narrowed down to

“early onset” or “younger-onset,” Alzheimer’s disease, senile dementia, dementia, patient, and quality of life, in order to optimize sensitivity to finding the most relevant literature on this topic and eliminate irrelevant literature.

For this research study there were articles that included search terms which were considered irrelevant, although often paired with my relevant search terms. These were categorized as exclusion terms. In this type of research information on caregivers seems to be very common among current research on Alzheimer’s disease. This research is not trying to understand or expand on the experience of the caregiver, such as stresses or burdens, or what the caregiver’s interpretations are about the disease. Due to the lack of research that focuses just on the patient diagnosed with younger/early-onset Alzheimer’s, disease some of my literature findings do have information within them about caregivers in relation to the individuals who are diagnosed with younger/early-onset Alzheimer’s disease, but that part of the article is not considered. Also, literature on medical background, new medically technological findings, nutrition, medicine/pharmaceutical medications, genetics, amyloid precursor protein, gene mutations, Late Onset Alzheimer’s Disease, and later onset dementia is excluded. The systematic literature review will follow the conceptual framework of Maslow’s hierarchy of needs where the literature will be articulated and consolidated into the five sections of the pyramid of needs (Maslow, 1943). Maslow’s hierarchy of needs will frame this paper in regards to advocating and focusing on the patients’ needs and will start at the bottom of the triangle and work up each corresponding level.

### **Systematic Literature Review**

The purpose of this literature review was to synthesize the current research on how interventions, therapies, and practices address the different levels of Maslow’s hierarchy of needs

for individuals living with younger/early-onset Alzheimer's disease. Before the interventions are discussed, it may be interesting to note how the problem of younger/early-onset Alzheimer's disease was discussed. Of the 45 articles that met the inclusion criteria, most of the literature acknowledged the lack of adequate resources for those with YOAD.

Furthermore, with regard to the problem of YOAD, research also showed that those who are diagnosed with younger/early onset Alzheimer's disease have very distinctive and complex changes in their life course. These changes include difficulties receiving an adequate diagnosis, biological and physiological changes within self, safety needs such as financial and work issues, love and belongingness needs such as relationship changes amongst family and friends, self-esteem issues such as dependency on others, and lastly social isolation/self-actualization needs such as, lack of meaning for life as demonstrated in the literature review. These changes were intertwined throughout all of the research literature.

### **Biological and Physiological Needs**

After pairing the literature on the interventions, the degree to which each level of Maslow's hierarchy was present, YOAD interventions became apparent. The most elemental level, the Physical and Biological needs level, was the most prevalent need addressed within the literature. The biological and physiological needs of Maslow's hierarchy encompassed research that related to the physical aspects of the quality of life of a person living with younger/early onset Alzheimer's disease. These aspects include adequate and stable home life to adjust to their change in behaviors and cognitive abilities. The literature found that what best addressed this need was first to receive a proper diagnosis among those who are younger and experiencing symptoms of Alzheimer's disease.

**Receiving proper diagnosis.** Biologically and physically, bodies are changing all the time as we age, and many different factors can play a role in how we feel or how healthy we are. Having symptoms such as memory loss or disorientation can be very unsettling and bring about other emotions. Diagnosing YOAD is challenging because younger people in general frequently experience several burdens in their daily life that can result in behavioral, cognitive and psychiatric symptoms that can delay the proper diagnosis (Comer, 2007; Chemali et al., 2012). Research shows that there is a higher percentage of people with moderate to severe dementia who are unrecognized and properly diagnosed by primary care physicians as having cognitive impairment (Galluzzi, et al., 2010). Symptoms in younger persons such as sudden significant cognitive loss, difficulty concentrating, and lack of energy or initiative can also be symptoms of depression, which could result in a delay of receiving an accurate diagnosis. (Harris, 2008; Chemali et al., 2012). The changes that occur biologically and physiologically as a result of the Alzheimer's disease can make receiving a proper diagnosis difficult due to the age of the individual and how some of the signs of this disease, such as difficulty concentrating, lack of energy, and memory difficulties can also be symptoms of other mental illnesses or simply overwork, which is often associated with midlife (Harris, 2008; Chemali et al., 2012). Adams and McClendon (2006) found that persons often are not aware of their cognitive decline because the symptoms can be masked and not recognized as unusual long before they become more severe, even to the point where the individual notices their daily life being impacted or others start to notice changes within the individual that weren't noticeable in the past. Also those suspecting symptoms of YOAD may even deny or hide the symptoms from medical professionals and family members as a way of normalizing their symptoms and may not decide

to pursue help or pursue the cause of the symptoms due to their own denial (Adams & McClendon, 2006).

Research also by Adams and McClendon (2006) found that persons who are newly diagnosed with YOAD are likely to experience this diagnosis as a traumatic loss. When diagnosed with younger/early onset Alzheimer's disease, it is often perceived at first as being unfair, a progressing death sentence, or stripping a person of their competencies and life (Tindall & Manthorpe, 1997; Lichtenberg, 2012; Benerjee, 2007). Although these feelings and emotions of shock and distress may be experienced most strongly with the individual who has recently been diagnosed with younger/early onset Alzheimer's disease, it may bring relief to the family due to actually knowing what is happening to their loved one (Chemali et al., 2012).

Early onset Alzheimer's disease comes unexpectedly. The type of illness and the symptoms that occur as a result of the disease are rare at a younger age and unanticipated; the normal life path is disrupted due to the onset of this disease, with events occurring out of sequence and unplanned (Yokokawa, 2012). As we age our bodies do start to require some increased dependency on others for help, but an increase to considerable dependency earlier than expected can cause disruptive effects to the life course. Being diagnosed with a dementing illness at a young age is considered 'off time' which results in a shift in normalcy, additional stress, depression and anticipatory grief (Yokokawa, 2012; Harris, 2008; Dadić-Hero et al., 2011).

While being diagnosed with early signs of dementia or Alzheimer's disease is life-altering, it is important to know of it, because this allows for the affected person to take part in planning for the future when they will eventually be unable to think for themselves or take care of themselves (Adams & McClendon, 2006; Galluzzi et al., 2010; Chemali et al., 2012; Bakker

et al., 2010). Research also supports that knowing the diagnosis and becoming informed about the disease has helped patients and families overcome their initial feelings of anger or fear to be replaced with understanding. This knowledge helps promote valuable moments that support the patient's ability to feel safer and more comfortable than when initially diagnosed (Wainer, 201, Bakker et al., 2010).

**Changes in behaviors.** As younger/early onset Alzheimer's disease progresses, the person starts to experience biological and physiological changes. These changes often take a psychological toll and many psychiatric symptoms that begin to occur as the disease takes course typically result in a reaction of depression, apathy, anxiety, and angry outbursts or refusal to cooperate (Adams & McClendon, 2006; Bakker et al., 2010). Personality changes occur due to the disease. However the interventions that address these changes are likely found in safety and belonging and love levels. Therefore, it is critical to really see the psychological changes here that are the result of the biological changes. Research by Smith (2008), states that agitated behaviors such as aggression, pacing, and irritability are common and can greatly impact the quality of life for those suffering from diseases such as dementia and Alzheimer's disease. These changes in behaviors are still not understood and there needs to be further research, but there is definitely a relationship between cognitive impairment and behavioral problems within these types of diseases (Smith, 2008). An example of changes of behavior from a case report of research by Bakker et al., (2010) was of a 50 year old diagnosed with YOAD who started to forget appointments more often, experienced difficulties in managing finances, lost his job as a salesman, started to show less initiative, experienced more and more difficulties with household tasks, and began drinking excessively due to the decline in abilities and functionality. Similarly, research states that the loss of memory, attention, communication, insight, judgment, and

behavior due to a disease such as dementia and Alzheimer's makes it difficult to precisely measure the ability of impairment to a person's ability to obtain a quality of life. This is a result of the different circumstances of each individual's experience with having the disease (Banerjee, 2007; Bakker et. al., 2010).

**Interventions.** The interventions that were found in the literature to best address the biological and physiological needs are Cognitive Behavioral Therapy also known as CBT and family systems model. CBT can assist a person who may presenting symptoms of depression or hopelessness, which often is found within the beginning stages of being diagnosed with YOAD (Werheid et al., 2009; Adams and McClendon, 2006). CBT needs to be adjusted and adapted to the needs and capabilities of the individual because not one form of the disease is the same in every person (Werheid et al., 2009; Adams and McClendon, 2006). When first being diagnosed with YOAD, preplanning of the future and adjusting life to the progression and needs of the disease needs to occur (Yokokawa, 2012). CBT can assist with challenges in a person's sudden change in environment and helps address issues with daily living needs (Adams & McClendon, 2006). CBT has also been shown to help the individual who has YOAD with their overall mood and problematic behaviors (Werheid et al., 2009; Adams and McClendon, 2006).

The other intervention I found within the literature that contributes to this level of need is the family systems model. Using the family systems model, professionals can develop an understanding of different family dynamics and how those interactions and dynamics can influence their reactions when dealing with chronic illness as well as the impact the illness has on the family unit as a whole (Roach et al., 2014). As a professional seeking out and becoming familiar with family dynamics, the storylines and narratives that occurred before the diagnosis can help support interventions after the diagnosis is made to best fit that family and their way of

living (Roach et al., 2014). According to Roach et al., (2014) categorizing family dynamics into different types of storylines is the easiest way of establishing and describing a family dyad who are experiencing YOAD within their family system. These storylines can allow for professionals to look at the dynamics within the family relationship and how the diagnosis affected the families' ability to function before and after the diagnosis to analyze how impactful the disease was on the family system (Roach et al., 2014). This intervention will further help professionals with integrating family-centered care to those families who may be in havoc of losing their working family units due to an onset of a chronic disease such as YOAD (Roach et al., 2014).

### **Safety Needs**

After pairing the literature on the interventions, the degree to which each level of Maslow's hierarchy was present in YOAD interventions became apparent. The safety needs of Maslow's hierarchy was found to be the least commonly addressed within the literature. It encompassed research results that related to services that helped a person's ability to stabilize their life in relation to financial responsibilities. Freedom from fear of what may happen to their family given that they will be unable to help them as much as they anticipated before being diagnosed with YOAD. Research literature shows that there are many losses that occur when being diagnosed with Alzheimer's disease early on. The ability to feel stability, order, and security while enduring this disease ends up becoming compromised.

**Loss of work income, early retirement.** Research shows that when diagnosed early on with a cognitive disease there are strong feelings of loss, fear, and abandonment in both the individual who is diagnosed and in the loved ones of those caring for the individual (Harris & Keady, 2008). Harris and Keady (2008) having these feelings can cause patients to start isolating themselves and to feel alone in the community with limited access to external help and support.

Robertson et al., (2013) states that individuals who have been diagnosed with YOAD are usually still employed and working within the community as well as being either the only provider of income for their family or a major stakeholder in the amount of income for the family.

Being diagnosed with dementia is usually unexpected for individuals and their families who are unprepared for changes in the responsibilities of the household, workplace, and within the community (Harris & Keady, 2008). Similarly those diagnosed with YOAD in their 40s and 50s were not planning for their retirement and consider themselves at the prime of their careers and not the other way around (Harris, 2008). Many recognize that something is wrong because of symptoms that start occurring at work such as coworkers noticing differences within the individual, difficulty completing normal tasks, unusual angry outbursts at co-workers and becoming lost driving to work (Harris, 2008).

**Lack of medical financial help from government.** Research shows that those diagnosed at a younger age often lose their income, and due to their age don't qualify or meet requirements for insurance benefits that may be available to those who are elderly and diagnosed with dementia or Alzheimer's, ultimately making the individual and/or family have to large out of pocket costs (Bakker et al. 2011; Chemali et al., 2012). Similarly, Chemali et al., (2012) states that services in home still remain difficult to access especially for those who don't have the financial means to pay privately for these resources. In current research there is a clear depiction concerning financial means for those who are diagnosed earlier in life with Alzheimer's disease (Cummings & Cockerham, 1997). Thus, there is a deficiency in affordable services required by individuals with this diagnoses and it reflects upon society's misunderstanding of which health care services should be provided and to whom they are most desired (Cummings & Cockerham, 1997). Lack of coverage and enormous amount of out of pocket spending for younger

individuals who may be suffering from dementia or Alzheimer's disease end up causing a lot of worry, burden, and/or stress on not only the family, but the individual who has to observe their family's struggle due to their diagnosis (Delavande, et al., 2013). Delavande, et al., (2013) also stated that the high amount of out of pocket spending can often cause a family to declare bankruptcy, which can ultimately make it difficult to even be able to afford everyday needs such as food, clothing, and electricity.

**Impact on family.** Furthermore, having YOAD ultimately makes a person have to stop working, which then shifts the responsibility of income to the family who is caring for the person diagnosed. This can be a huge burden to overcome depending on the families' financial situation and/or lifestyles (Chemali et al., 2012). Individuals with younger/early onset Alzheimer's disease (YOAD) are more likely to be in their prime of their career and have children who are still in school (Phelps, 2013). The severity of problems that can occur as a result of loss of cognition, such as behavioral problems, wandering, and forgetfulness with an individual at home during the day puts a great amount of stress on those caring for this individual and often results in institutionalization (Bakker et al., 2013). Because services provided for this type of disease are geared toward individuals who are in their later life when diagnosed; there is a lack of resources directed towards helping those who are diagnosed early on (Armari et al., 2012). As a result of Alzheimer's disease, younger family members are faced with enormous challenges that most people their age never plan to encounter and their needs are different from those family members of individuals who are much older with the disease (Phelps, 2013; Chemali et al., 2012).

**Interventions.** The intervention that best addresses this need is social theory. According to Cox and Pardasani (2013), professionals using a social theory approach when working with those who have recently been diagnosed with Alzheimer's disease and are still active within the

community and workplace can help with the new adjustment in lifestyle. These theories specifically help social workers be able to advocate for an individual with YOAD to best adapt to their environment at the beginning stages of the disease when they are still able to work and still be fully involved in the community (Cox & Pardasani (2013). Social workers can use this approach to focus on the person-in-environment in assisting the individual to understand and adjust to the changes and help advocate for possible accommodations that may be needed within the workplace (Cox & Pardasani, 2013). Cox and Pardasani (2013) also state that social workers can do work on a macro level by changing organizational responses and policies to promote and make them more open to YOAD individuals and caregivers within the work place. The other intervention that can be of assistance when providing support with Maslow's level of obtaining safety needs is the family systems model. This model would help with understanding the family dyad and provide the professional with information of what the support system is like along with resources needed to be of assistance to best support or help the family (Roach et al., 2014).

### **Love and Belongingness Needs**

After pairing the literature on the interventions, the degree to which each level of Maslow's hierarchy was present in YOAD interventions became apparent. The love and belongingness needs of Maslow's hierarchy was the second most common need within the literature found. This need is very important for the quality of life of an individual with YOAD. Within the literature, there were many interventions found that addressed being able to support this need within the hierarchy such as CBT, music therapy, dance, community intervention, family systems theory, and group work. This need encompassed research results that relate to the ability to feel affection, love, intimacy, and friendship. The research found focused on the relationships between the individuals diagnosed and their work groups, friends, partners, and

family systems. Research also focused on how a person's social networks changed and were reassessed after the diagnosis occurred. Research that focused on the individual and their personal experience with relationships was lacking; it mostly encompassed the experiences of others such as caregivers, children, friends, bosses, and coworkers.

**The impact on relationships.** Relationships take a toll when signs of dementia and Alzheimer's start occurring in someone who is fairly young and normally shouldn't be experiencing cognitive decline (Robertson et al., 2013). When the cognitive abilities of an individual start to decline, their responsibilities and personhood take a toll; as a result relationships change within the household, workplace, and community (Robertson et al., 2013). Research states that being a spouse and intimate partner becomes challenging as the dementing illness progresses (Harris, 2008). In this scenario, many lose a parenting partner, feelings may change toward the person who has the illness, and balancing taking care of the person while trying to salvage an intimate and loving relationship as it once was is difficult (Phelps, 2013; Harris, 2008; Harris & Keady, 2008; Kuppuswamy, et al., 2007). Research by Harris (2008) found that those who have YOAD often struggle to still have feelings of being attractive to their spouse or appealing in any way. Similarly spouses may feel very uncomfortable when it comes to being intimate with their partner who has a dementing illness, when that spouse may or may not be able to truly consent to their wants or needs (Kuppuswamy, et al., 2007).

Research also states that being diagnosed at a younger age with a dementing illness plays a huge factor in roles and involvement within a family system, such as being a spouse or intimate partner, parent to children, and sister or brother (Harris, 2008). An individual who has been diagnosed with YOAD and has fairly young children has to deal with the feelings of denying their children two competent parents who can help them through school and life. Furthermore,

these patients may also feel the guilt of their children having to eventually help take care of them (Phelps, 2013). According to research by Harris and Keady (2008), it is important for young people who are suffering from a dementing illness such as Alzheimer's or dementia to maintain their identities and self-hood for as long as possible in a positive way in order to sustain their ability to maintain roles within society and their family structure.

Furthermore, according to Harris and Keady (2008), in general it is found that experiences with having a disease such as dementia or Alzheimer's usually impacts and significantly takes a toll on the patient's circle of social networks. We as a society, have expectations for different roles and positions within society, and when a person can no longer fulfill that role, stress and conflict may ultimately occur (Harris & Keady, 2008; Phelps, 2013; Harris, 2008). Due to YOAD, a person may endure feelings of worthlessness or being useless because of the symptoms of the disease. They have to ultimately quit their job which is often associated with one's self-identity, sense of worth and one's status within society which isolates them from all of their friends and coworkers (Harris & Keady, 2008; Robertson, 2013). Many individuals described this change as feeling as though they had 'lost everything that defined them, and the disease took the one thing that gave them the most freedom and self-worth' (Harris and Keady, 2008 p. 439). Research states that many family and friends stop visiting or even socializing with the individual who has been diagnosed with dementia or Alzheimer's disease because of the uncertainty of how to act around someone who is having cognitive changes and of how to deal with the changes of who that person once was to who they are becoming (Robertson, 2013; Harris, 2008). Likewise, many people who are fairly young and suffering from a disease such as Alzheimer's feel socially isolated like they don't belong in everyday society anymore and have almost become outcasts (Harris, 2008).

**Interventions.** The interventions that can be used to help with the need for love and belongingness are music therapy, dance therapy, art therapy, group work, family systems, and community programs (Ortega et al., 2011; Tay et al., 2014; Roach et al., 2014; UniJunn-Krebs, 2004; Mather, 2006; Roberston et al., 2013). Music therapy, dance therapy, and art therapy can help with a person's quality of life in areas of social interaction, which results in positive psychological well-being (Tay et al., 2014). Dance therapy in particular has been shown to reduce anxiety and improve physical abilities (Tay et al., 2014). These non-clinical interventions allow for YOAD individuals to feel like they can have something in common with others and gain the sense of belongingness when participating in these therapies (Tay et al., 2014). Group work is very similar in promoting acceptance, belongingness, and common issues amongst those who are suffering from YOAD or those who are caring for someone with YOAD (UniJunn-Krebs, 2004). Groups can also give a sense of security and safety to a person and allow for the ability to feel they can expose their difficulties and faults because others are experiencing similar things (UniJunn-Krebs, 2004). Group work provides benefits of positive social interaction, such as feelings of self-worth and that they are not going through it alone-(UniJunn-Krebs, 2004).

Family systems model would also help in the area of love and belongingness because it provides a sense of meaning to the relationships within the family and gives appreciation to the roles within the family unit (Roach et al., 2014). The family systems model helps show caregivers and YOAD individuals the support they have amongst each other, and the appreciation and love of each other (Roach et al., 2014). Other interventions that provide a sense of love and belongingness are community programs. These programs allow for individuals with YOAD the ability to engage in meaningful activities within the community and promote socialization, which is crucial in this diagnosis because often times those with YOAD isolate

themselves and become disconnected from people (Robertson et al., 2013). Programs created for YOAD also highlight the importance of social status and self-worth, which are both important aspects of feeling like one belongs (Roberston et al., 2013). Roberston et al., (2013) also states the programs are supportive of developing new friendships and provide new interest within life.

### **Esteem Needs**

After pairing the literature on the interventions, the degree to which the esteem needs of Maslow's hierarchy was present in YOAD interventions became apparent. The esteem needs of Maslow's hierarchy was the third most commonly addressed need found within the literature. This need encompassed the ability to feel achievement, mastery, independence, status, dominance, prestige, self-respect, purpose, and respect from others. The research found addressed individuals' ability to feel self-respect, issues in regards to self-esteem, the feeling of purposelessness in life after diagnosis of YOAD and being burdensome on others. In this section, there will also be literature on the stigma around being diagnosed with Alzheimer's disease early on and how that affects the patient and their family.

**Self-esteem, self-worth, respect, independence, stigma.** Many suffering from YOAD eventually lose all of who they were and are as a person; first this disease strips them of their independence, then identity, and eventually life (Comer, 2007). "The destruction of brain tissues entails a destruction of abilities and qualities essential to people's identity...Losing one's ability to sustain a coherent self-narrative may be considered one of life's most dreadful losses" (Comer, 2007, p. 59). Harris and Keady (2008) state most individuals who are diagnosed with YOAD encounter a major change in their own identity and who they are as an individual, parent, spouse, child, or sibling. When an individual is first noticing symptoms of YOAD they ultimately have to come to the conclusion that they have to give up most of their out-of-home

independent activities such as work or meaningful engagement with friends; this results in belittling a person's social status, self-esteem, and self-worth (Robertson et al., 2013). A person's natural ability to do certain tasks becomes very difficult as the disease progresses; it is very hard for family members or care-takers to fully understand what the person feels, needs, and wants due to being unable to express themselves the way they may want to (Yokokawa, 2012).

Yokokawa (2012), found that the activity of going to the bathroom and being able to toilet themselves was a key element that related to self-esteem. Once this activity of daily living became a challenge and a person with YOAD needed assistance to successfully complete this activity, that person's self-esteem seemed to plummet. Similarly, being diagnosed with a dementing illness so early in life, with some days being unable to do a task that was taught as a child, can be very humiliating and degrading, creating strong feelings of daily self-doubt and worthlessness (Harris & Keady, 2008; Yokokawa, 2012). One of the first abilities an individual who has been diagnosed with younger/early onset Alzheimer's disease loses is the ability to drive and have an active driver's license. The decision of not driving anymore has been described as one of the hardest choices to make emotionally because it is the first step to loss of independence (Gauthier & Leuzy, 2012). Harris and Keady (2008) found in their research that participants within their research expressed that losing their abilities to understand, think, complete daily tasks or remember how to do things significantly affected the way they saw and felt about themselves.

Healy (2008) supports that labels and stereotypes of illnesses, such as cognitively impairing illnesses, lessens a person's self-respect and autonomy. They can cause people to have assumptions and preconceived notions about an individual before even meeting the person. Research is finding that although there is no cure for Alzheimer's and dementia, and it is a

disease that affects the ability to comprehend and understand what may be going on, it doesn't mean that there isn't still a person who needs to feel worthy of living and making choices for themselves. The patient's quality of life should never be determined by their cognitive abilities to understand (Edmund, 2008). All Alzheimer's disease patients have areas that can be considered strengths, where they can still feel self-fulfillment, and they have the ability to counterbalance or compensate for their losses in certain areas of functioning (Edmund, 2008). Stigma is a huge element that corresponds with the disease of younger/early onset Alzheimer's disease and younger families' emotional and psychosocial feelings are greatly affected by the onset of this disease (Chemali, 2012). When helping and caring for these individuals who have been diagnosed with YOAD it is important to still give 'respect' and 'dignity' to these individuals. Even if they are unable to cognitively comprehend everything they still need to feel self-worthy and in control in some way or another (Silverstein et al., 2010). Furthermore research by Leuzy and Gauthier (2012) found that individuals with YOAD should be able to and have the right to receive diagnostic information; this way it provides autonomy for the individual and allows the individual to obtain and have an active role in their care.

**Interventions.** The interventions that best address the person's ability to gain self-esteem are CBT, grief facilitation, and some group work. CBT is known for the ability to want to change or make change within life's circumstances and situations, but needs to be adapted to the needs and capabilities of each patient (Werheid et al., 2009). CBT can help with self-esteem by increasing areas of control, self-efficacy, and motivation for life while enduring YOAD (Helcer et al., 2012). The other intervention that can assist with self-esteem is grief facilitation. Grief facilitation should be done during the earliest stage of Alzheimer's or dementia (Adams & McClendon, 2006). Professionals should assist with grief facilitation right as a person is

diagnosed with YOAD because accepting this diagnosis brings a lot of pain and feelings of loss (Adams & McClendon, 2006). Depression and isolation have been shown to be symptoms that occur as a result of this diagnosis due to the increased amount of anticipated losses that they will encounter sooner than later in life (Adams & McClendon, 2006). Adams and McClendon (2006) also state that grief facilitation will help with self-esteem by allowing for the individual with YOAD to express their repeated feelings of loss and resentment toward the disease and they don't become depressed as a result of not being able express these feelings.

### **Self-Actualization Needs**

The fourth most prevalent level of needs found within the literature that pertained to Maslow's hierarchy of needs and the quality of life of individuals with YOAD was self-actualization. Due to the limited information in this section, I decided to reframe this need and relate the information that was found on the interventions, therapies, and practices of professionals in order to address the quality of life for those with YOAD. Maslow's self-actualization need encompasses a person's ability to feel self-fulfillment, realize personal potential, personal growth, and accepting life's experiences. The literature found that relates to this need encompassed therapies, interventions, and practices that professionals can use to help individuals come to terms with their current or new diagnosis of YOAD. There were many different therapies, interventions, practices, and community programs found within the research that have been shown to increase self-fulfillment among those who have YOAD and are of great assistance to their families as well. This section will also address the research found on how professionals can best help those with this diagnosis gain a sense of self-esteem, purpose, and meaning.

**Self-fulfillment.** It is unsettling for many to hear that they have been diagnosed with YOAD, but having a whole multidisciplinary team focused just on your care can result in being better informed of the delivery of care services and community agencies (Vickrey, 2008). Valgardsdottir et al., (2013) state that lack of knowledge or insight can affect newly diagnosed Alzheimer's disease individuals' ability to realize their changes in mental state and quality of life overall, which is why addressing life orientation and different coping abilities can be crucial when being diagnosed with Alzheimer's disease early on. It is key for professionals who deal with dementing illnesses to promote a continuation of care with YOAD patients, and by doing this they should focus on a person's well-being and normalcy of one's life previous to being diagnosed (Edvardson et al., 2009). Edvardson et al., (2009) states that in order to focus on a person's well-being and continuation of daily life being as normal as possible, there needs to be five main focus areas when helping someone diagnosed with Alzheimer's disease. These are 'knowing the person,' 'welcoming family,' providing meaningful activities,' 'being in a personalized environment,' and 'experiencing flexibility and continuity.' Similarly, Adams and McClendon (2006) state that ways to help those who have been diagnosed with early onset Alzheimer's disease are to become involved with support groups, cognitive behavioral therapies (CBT), and existential therapies. Receiving treatment as soon as an individual finds out they have Alzheimer's or dementia can allow for the individual to have more involvement in their care, more ability to be involved in treatments, the ability to still make their own choices and still have some control over their life (Adams & McClendon, 2006). Lastly, autonomy is a big issue with those suffering from YOAD, as is the balance of safety risk versus the individual's right to self-determination and autonomy (Healy, 2008). Luckily social workers assist with promoting autonomy amongst those who are suffering from YOAD as well as outweighing their self-

determination and patient rights versus the safety risks involved (Healy, 2008). It is important to promote ones autonomy and the ability to speak for oneself early on because it can provide strong feelings of self-fulfillment knowing that sooner than later these abilities will no longer exist for them (Healy, 2008).

**Therapies, theories, and interventions.** Research has shown that many individuals who are diagnosed with Alzheimer's disease ultimately lose the feeling of control over their lives that they had before the onset of the disease (Choi & Fiszdon, 2012; Helcer et al., 2012). Therapies can help individuals regain that sense of control, self-worth, and intrinsic motivation for treatment both psychologically and neurologically (Choi & Fiszdon, 2012; Helcer et al., 2012). According to research by Adams and McClendon (2006) a person who has been recently diagnosed with early onset dementia or Alzheimer's disease and the amount of grief occurring within the person needs to be assessed by using grief facilitation therapy which can help the individual become accepting of the diagnosis, and work through the anticipated losses that come with the disease. Adams and McClendon (2006) also found that more interpersonal therapeutic work in the early stages of the disease process can be very helpful, for example using reminiscence therapy. An example of this work could be to create positive physical symbols of a person's life like constructing a life review or life history where the individual can reflect on their life (Adams & McClendon, 2006). Another therapy that has been shown to help those who have early Alzheimer's disease, especially who may have shown signs and symptoms of depression or hopelessness, is cognitive behavioral therapy (CBT), but it needs to be adjusted and adapted to the needs and capabilities of the individual (Werheid et al., 2009; Adams & McClendon, 2006). CBT helps with challenges in a person's sudden change in environment, helps address issues with daily living needs, and helps to address or evaluate self-worth or beliefs

of oneself (Adams & McClendon, 2006). CBT has been shown to help the individual who has YOAD's overall mood and problematic behaviors (Werheid et al., 2009; Adams & McClendon, 2006). Other therapies that are shown by research to be beneficial to the quality of life of individuals with Alzheimer's disease are existential theory and multi-professional rehabilitation programs like physical therapy, occupational therapy, art therapy, music therapy, and dance, all of which help a person with finding meaning within their life, cognitive stability, and help promote better social and psychological well-being (Adams & McClendon, 2006; Ortega et al., 2011; Tay et al., 2014).

Recent research addressed some theories and models used by social work professionals that have been shown to help YOAD individuals. According to Cox and Pardasani (2013), while working with those who have recently been diagnosed with Alzheimer's disease who are still active within the community and workplace, the best model to use in order to address the change in life style is an ecological approach as well as critical social theory. These two theories allow social workers to focus on the person in their environment and best advocate for those with YOAD by providing counseling, support, resources, accommodations, and key information to employees still working with a newly diagnosed individual (Cox & Pardasani, 2013). Research by Roach et al., (2014) found that using the family systems model helped provide an understanding of the different family dynamics, how it influenced their interactions when dealing with chronic illness and the impact the illness has on the family unit as a whole. Similar research by Edvardsson et al., (2009) states that involving family in the person's care, wants, and needs was important when focusing on person centered care of the individual because they are essentially part of the process by helping and caring for the individual. Understanding and knowing the different family dynamics, storylines, and narratives before the diagnosis can help

support interventions after the diagnosis to best help the individual's quality of life, because each person, relationship, and family is different (Roach et al., 2013).

Community programs and group work with those suffering from Alzheimer's disease and dementia has shown to help prevent decline into personal isolation and fulfill the need for feelings of self-worth and usefulness (UniJunn-Krebs, 2004; Mather, 2006; Roberston et al., 2013). Group work has the ability to offer people with a dementing illness the feeling of being able to relate to others and a sense of togetherness, all within a safe, nonjudgmental, and encouraging space (UniJunn-Krebs, 2008). Similar to groups are community programs directed toward those who are diagnosed with a cognitive disease which helps reconnect those with younger onset dementia with the community and gives them a sense of purpose in life to help increase their self-esteem and satisfaction (Robertson et al., 2013; Mather, 2006).

Furthermore Robertson et al., (2013) and Mather (2006) found that community programs such as work based programs or social programs encourage and help those who have younger onset dementia to be able to relate and feel a sense of belongingness with others, gain new friendships, provide participants with advice and education through professional counseling and support, provide the ability to contribute to the community while giving a sense of self-achievement, and help increase awareness of early onset dementia and Alzheimer's disease. McLaughlin et al., (2010) created an instrument for professionals that would be useful to help measure the degree of independence for those who are suffering from Alzheimer's disease. This scale allows one to analyze an individual's dependence on others and help provide the individual diagnosed, family, and professionals with an idea of what services might be needed or created early on in the disease process and what services will be needed or created in the future. Professionals play a crucial role in the lives of those with YOAD because interventions,

knowledge of resources, and services help provide these individuals with a quality of life as much as possible while encountering this dramatic life change (Howe, 2008).

### **Findings**

Through this literature review, we can further understand the quality of life of someone with younger/early onset Alzheimer's disease, as well as provide possible interventions, therapies, services, and resources to best assist in providing a better quality of life while enduring this disease. The ecological framework of Maslow's hierarchy used within this paper served as a useful mechanism in providing clarity and meaning on various topics and themes in the research and to contribute to my understanding of the importance of quality of life of a person who may suffer from this disease.

The researcher found that the biological and physiological needs of Maslow's hierarchy in relation to having a quality of life among those suffering or diagnosed with YOAD focused mainly on proper diagnosis and changes in behavior. There are repercussions to these topics in regards to their effects on a person's ability to sustain a quality of life with this disease. Knowing the proper diagnosis is crucial for planning for the future and gaining the necessary resources to help assist with retaining a sense of quality within life as the disease progresses. Findings found that once the diagnosis has been given and is known, not only helps the individual start to cope and plan for what is to come in the future, but also helps the family gain a sense of understanding of how to prepare for what this diagnosis will bring. Knowing this diagnosis, allows for further knowledge of the possible changes within the person biologically, psychologically, and physiologically that may take place and alter a person's life (Smith, 2008). Changes in behaviors as a result of having this disease can significantly alter not only a person's everyday life and

place added stress and burden on the individual diagnosed, but on the family as well. Knowing the diagnosis can only help prepare for these possible changes.

The level of safety needs within the research on Maslow's hierarchy focused on the importance of financial resources, stability within the family system, and the feeling of security by the individual with YOAD. It is clear that there needs to be more adequate and feasible financial resources specifically for those diagnosed with YOAD (Cummings & Cockerham, 1997). YOAD occurs unexpectedly and early enough that it usually doesn't only affect the person who is diagnosed, but others such as spouse, children, and parents. The effects it may have on a family or individual financially can affect the ability to sustain a quality of life without the constant feeling of not being able to provide for the family or provide a sense of security (Chemali et al., 2012). Financial resources and services in general are needed for those who may be suffering from YOAD to help provide a piece of mind and sense of security as they encounter the effects of this disease. Furthermore, there was more focus on financial issues within the research in regards to safety needs than other physical or behavioral needs that could have been listed under safety. Some of these could be wandering, the ability to still do errands around the home, cooking, driving, and other daily tasks that could be an issue in regards to the safety of the individual with YOAD.

Within the research that there were more interventions that addressed the need to feel love and belongingness than any of the other needs within the literature. It was found within the love and belongingness level of Maslow's hierarchy, that those who suffer from YOAD are dramatically burdened by their disease within this area. Having any type of illness will affect a person's relationships and the ability to keep up relationships, but losing self-identity makes keeping up with relationships even harder (Robertson et al., 2013). Those in the community and

those who do have a relationship with someone who has YOAD need to become more educated and knowledgeable about this disease because many individuals are afraid of diseases like Alzheimer's and the unknown that accompanies it. An overarching issue that was addressed amongst the research was how this impacted the quality of life and the individual's feeling like they have no self-identity or self-worth and that they are enduring this disease alone (Harris & Keady, 2008). Many YOAD patients may start to isolate themselves and as a result their quality of life diminishes greatly. One of life's greatest needs is to be able to feel loved and needed by others; thus this level of love and belongingness needs of the hierarchy should be further recognized and addressed by those helping or supporting someone with YOAD.

Significant amounts of research documented the importance of addressing an individual who is diagnosed with YOAD and how this diagnosis affects their ability to feel self-fulfillment and worth, in regards to their self-esteem. It seemed as though the ability to achieve a positive self-esteem helped a person achieve other needs when trying to attest to having a quality of life within those who are diagnosed with YOAD. If a person has a low self-esteem and lacks the feeling of respect, dignity, and self-worth then that person is probably not living a very positive quality of life (Robertson et al., 2013). This disease ultimately strips a person of their independence and the ability to know who they are or what their purpose is in life (Comer, 2007). Research shows that there are many stigmas and stereotypes that surround this type of disease, which ultimately affects the person who is diagnosed with the disease in a negative way (Chemali, 2012). It is important to support the research that addressed giving a person with this disease a sense of meaning by providing them with tasks, jobs, and finding the individuals strengths in abilities they still have to help compensate for the loss of other abilities (Edmund,

2008). This will help provide the person with a sense of self-worth as well as help satisfy the need for the feeling of independence.

My synthesis of the literature in the self-actualization level of Maslow's hierarchy contributes to ways in which professionals can help support and address a person's ability to achieve a better quality of life when diagnosed with YOAD. Furthering research, new therapies, and interventions by professionals who see the need to recognize and address this disease in order to best help those who have it, will allow the patient the ability to obtain self-fulfillment. There are some current therapies that can help and support those with YOAD, but there is still a long way to go in order to really help these individuals obtain the level of self-actualization that is desired. These individuals live at a time in their life where they are at a crossroads between their diagnosis and the resources and services available to them. In order to really allow for these individuals to seek a quality of life, we need to direct our practices, services, and resources to more person centered care (Edvardsson et al., 2009). It may be more likely for those in earlier stages of the disease to reach or obtain the level of self-actualization when diagnosed as a result of the disease progression and symptoms. During the earlier stages of the disease, the individual still has the cognitive ability to be active and involved in therapies and programs. Whereas, when the disease progresses into later stages many lose the ability to carry on conversations or are unable to fully participate in activities.

### **Discussion**

A total of 45 articles were used that related to the topic and met the terms of the inclusion criteria, it was concluded that research is currently lacking and there needs to be more research done in terms of specifically addressing the person with younger/early-onset Alzheimer's disease. Especially since there continues to be an increase in the percentage of those being

diagnosed with YOAD and the increasing aging population due to the baby boomer generation. The focus of research seems to be more directed towards caregivers and how to help them. Addressing the families' perception and experience with encountering the disease as caregivers rather than research addressing person-centered experiences of those who are diagnosed with the disease, is important. In addition, the researcher only found a couple of studies out of all the studies done that were specifically on the person with YOAD and didn't incorporate caregivers or family in the article as well. After taking these factors into account, it is evident that research on persons with younger/early-onset Alzheimer's disease continue to be lacking as an area of focus for research.

It was even harder to find articles specifically on younger/early onset Alzheimer's disease that didn't include or address late onset Alzheimer's disease or other forms of dementia. Most of the articles found mainly addressed Alzheimer's disease in a more generalized term rather than specifically stating their focus was on younger/early-onset Alzheimer's disease or later onset Alzheimer's disease. The researcher was in agreement with the researchers who have noticed and recommended that we address the age and service needs of those who are diagnosed with Alzheimer's earlier versus later in life because of the different lifestyles and stages of life they are in. Furthermore focusing specifically on YOAD individuals is essential because it can better help determine what services and resources are needed depending on the age of onset of the disease and overall life circumstances of those diagnosed.

In health care and society there are projected principles and the distribution of justice which have indicated maximizing benefits for as many individuals as possible, trying to provide services where they are needed (Cummings & Cockerham, 1997). Although researchers have identified some ways to best help those have a quality of life after diagnosis of younger/early

onset Alzheimer's disease, research has also found that there is a lack of services and activities within communities that are created and directed specifically for those with early onset Alzheimer's disease. Unfortunately, most services and community programs are directed toward those who are older and have late onset Alzheimer's disease (Silverstein et al., 2010; Cummings & Cockerham, 1997; Bakker, 2010; Gibson et al., 2014). There also seemed to be a lack of literature on safety concerns that fit into the safety level of needs that really addressed behavioral and physical means of safety with YOAD. This is a serious issue that should be researched. Many of these individuals are still driving and working within the community when the onset of symptoms begin. This disease affects behavior and cognition which can have some serious safety concerns. There needs to be more research done regarding informing professionals and those diagnosed of all the factors of safety that vary when diagnosed with Alzheimer's early on versus later in life.

The majority of services and resources directed toward those who are elderly are hard to adapt to those who are diagnosed with early onset dementia. Society ends up having major concerns that the needs and resources for those who are younger are lacking and these individuals are not properly being taken care of (Bakker et al., 2010). Further research by Silverstein et al., (2010) found that creating more programs and services directed toward early onset Alzheimer's disease would better support and provide positive 'cognitive stimulation' for this age group and allow for maintaining self-esteem, which further supports obtaining a quality of life. Ultimately, services for those with early onset Alzheimer's disease have not yet been formulated specifically for this type of disease or are recognized by service providers and society as a whole. In order to be of assistance to this group of individuals, all services need to be directed toward person-centered care that looks at a person in a holistic way in order to promote

a sense of self-actualization. Gibson et al., (2014) addressed key concerns, such as ‘addressing needs of social and emotional support, assistance with financial planning, employment, and providing benefits,’ in which services need to be adjusted and given further attention in order to best accommodate those who are younger suffering from this particular disease.

In regards to the framework of Maslow’s hierarchy of needs, if using it as a tool when working with YOAD individuals, it needs to be adjusted. Maslow doesn’t focus on the bigger picture when he created the levels of needs. He focuses on the concrete needs of an individual which makes it hard to adjust the levels to everyone depending on their environment and lifestyle. When framing it to work with those who have YOAD, a professional should really address meeting the level of needs in reverse order as a result of this disease’s progression, beginning with self-actualization, which can really only be met with someone who has full cognitive and physical abilities to participate. As the disease progresses, it becomes harder to help an individual meet the levels of needs. Similarly, interventions and therapies should be implemented right away with those who have this disease because it is harder for the individual to participate as they lose their cognitive abilities.

The research found and used for this synthesis had many different types of research designs and ways of obtaining data. It seems the most effective design to use in order to obtain accurate data and information was a qualitative research design where the researchers spoke directly with the individuals with the diagnosis to get their perception on the needs and feelings while encountering this type of disease.

The research that was reviewed involved studies conducted with mainly white/Caucasian participants. More research is needed on other races or nationalities in regards to percentages,

service needs, quality of life, interventions, and resources for those who are diagnosed with YOAD.

### **Limitations**

In this research study, studies in which the researchers focused on data regarding quality of life of individuals suffering from younger/early onset Alzheimer's disease or early onset dementia as a result of the terms being used interchangeably were included. Research conducted from perspectives of others, such as caregivers and family, will allow for further insight into this issue. Although this research focused primarily on quality of life of individuals diagnosed with YOAD, it is important to note that YOAD does not only affect the quality of life of the individual, but also affects others close to the individual, such as family, children, parents, friends, and caregivers. There was a lack of research regarding interventions that were specifically directed toward YOAD, which made finding literature on this topic more challenging. My research is limited to work published in English, and within the dates of 1990-2014. There may be important insights on this topic from research published earlier than 1990 and by other individuals in a relationship with or involved with the care of those who are diagnosed with younger/early onset Alzheimer's disease.

### **Conclusion**

This research focused on exploring the Younger/early onset Alzheimer's disease and how interventions, therapies, and practices can address Maslow's hierarchy of needs in addressing the quality of life of the person with the disease. It is evident that YOAD is becoming more widely researched and studied. It has been proven that younger/early onset Alzheimer's disease has increased and there is a higher percentage of people being diagnosed with this disease earlier in life (Harris & Keady, 2008). As a result, there is a difference in diagnosis and it is harder for a

younger individual to be diagnosed with this disease due to the common misconception of at what age this disease usually appears (Galluzzi, et al., 2010). It is also hard to distinguish an accurate diagnosis for an individual, have when terms used for cognitive diagnosis seemed to be used in a more generalized way as well as used interchangeably within research between the terms Alzheimer's disease and severe dementia. If we want to address the needs of YOAD individuals, we need to first become more familiar with the disease and diagnose those who show signs of the disease earlier on, in order to allow for them to plan for what the future will bring now that they have this disease. Maslow's hierarchy of needs model can help address and provide a reference for those who want to assure that an individual with this type of disease is living an acceptable quality of life.

Any attempts that are made to spread awareness and knowledge about this younger/early onset Alzheimer's disease will help improve the lives of what seems to be an invisible group of individuals (Harris & Keady, 2008). Professionals can be a huge asset to those suffering from this disease by providing and developing more interventions, therapies, and services specifically adapted to younger individuals with Alzheimer's disease. Spreading awareness of this disease and how early it can occur will allow for normalizing the disease and help reduce the stigmas behind it. The current need for further research, more resources, and additional services geared towards those with YOAD needs to be highly recognized and addressed among this group of individuals not only at a personal or professional level, but as a society as a whole in order to best meet the needs of this group of individuals.

Database	Process of Searching
SocINDEX Peer Reviewed Academic Journals 1990-2011	First search: Alzheimer's disease OR dementia Second/new search: "Early Onset" OR "Younger Onset" Search History: Select both searches S1 & S2 AND the terms together and hit search
<b>Title &amp; Author</b>	
<p>'We can't keep going on like this': identifying family storylines in young onset dementia. By: Roach, Pamela, Keady, John, Bee, Penny, Williams, Sion</p> <p>Changes in Life-Quality, a Possible Symptom of Dementia Development. By: Dadič-Hero, Elizabeta; Grahovac, Tanja; Kovač, Marina.</p> <p>Selfhood in younger onset dementia: Transitions and testimonies. By: Harris, Phyllis Braudy; Keady, John.</p>	
Social Work Abstracts	Search: Alzheimer's disease OR dementia AND "younger onset" AND "early onset" Year:1990-2014 Scholarly peer reviewed journals 108
<p>Alzheimer's in the workplace: A challenge for social work. By: Cox, C.B.; Pardasani, M..</p> <p>Misdiagnosis of Alzheimer's disease: Case studies in capacity assessment. By: Lichtenberg, P.A..</p> <p>Early-stage cognitive impairment: a social work practice and research agenda. By: Adams, K.B.; McClendon, M.J.</p> <p>Sexuality and intimacy between individuals with Alzheimer's disease and their partners: caregivers describe their experiences. By: Kuppuswamy, M.; Davies, H.D.; Spira, A.P.; Zeiss, A.M.; Tinklenberg, J.R...</p> <p>The perspective of younger people with dementia: still an overlooked population. By: Harris, P.B..</p> <p>Group work with seniors who have Alzheimer's or dementia in a social adult day program. By: Junn-Krebs, U..</p> <p>Community-dwelling cognitively impaired frail elders: an analysis of social workers' decisions concerning support for autonomy. By: Healy, T.C..</p> <p>Ethical dilemmas in discharge planning for patients with Alzheimer's disease. By: Cummings, S.M.; Cockerham, C.</p>	
PsychINFO 1990-2014	First search: Term finder: Alzheimer's Disease

Peer reviewed	<p>Check related terms Dementia and Senile Dementia OR together                  Classification Code check all 3300's                  Second Search: Term finder: "early onset" "younger onset" OR together then search Third step: Go to Recent searches Check both searches together with AND then hit search</p>
<p>Side by side: A workplace engagement program for people with younger onset dementia. By: Robertson, Jacinta; Evans, David; Horsnell, Tim</p> <p>The use of formal and informal care in early onset dementia: Results from the NeedYD study.</p> <p>Usefulness of video for observing lifestyle impairments in dementia patients. By: <a href="#">Yokokawa, Kiyoshi</a></p> <p>Ethical issues in Alzheimer's disease: An overview. By: Leuzy, Antoine; Gauthier, Serge</p> <p>Needs in early onset dementia: A Qualitative Case from the NeedYD study. By: Bakker, Christian; de Vugt, Marjolein E.; Vernooij-Dassen, Myrra; van Vliet, Deliane; Verhey, Frans R. J.; Koopmans, Raymond T. C. M.</p> <p>Promoting a continuation of self and normality: Person-centred care as described by people with dementia, their family members and aged care staff. By: Edvardsson, David; Fetherstonhaugh, Deirdre; Nay, Rhonda</p> <p>Adult day health care for participants with Alzheimer's disease. By: Silverstein, Nina M.; Wong, Cathy M.; Brueck, Kristen E.</p> <p>Memory Lane Café: Follow-up support for people with early stage dementia and their families and carers. By: Mather, Lynn</p> <p>Early onset dementia: A case of ill-timing? By: Tindall, Linda; Manthorpe, Jill</p>	
<b>Database</b>	<b>Process of searching</b>
Gray Literature & PubMed.gov	<p><a href="http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2695741/">http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2695741/</a></p> <p>U.S. national Library of Medicine USA.gov</p> <p><a href="http://www.jaoa.osteopathic.org/content/110/9_suppl_8/S37.long">http://www.jaoa.osteopathic.org/content/110/9_suppl_8/S37.long</a></p> <p>The Journal of the American Osteopathic Association</p> <p><a href="http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3265995/">http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3265995/</a></p> <p>National institute on aging  <a href="http://aoa.gov/AoA_Programs/HPW/Alz_Grants/docs/Slides20Aug2013YoungerOnsetDementia.pdf">http://aoa.gov/AoA_Programs/HPW/Alz_Grants/docs/Slides20Aug2013YoungerOnsetDementia.pdf</a></p> <p>"early onset Alzheimer's disease"</p> <p><a href="http://www.ncbi.nlm.nih.gov/pubmed/23220922">http://www.ncbi.nlm.nih.gov/pubmed/23220922</a></p> <p>PubMed.gov</p>
<p>Improving the Quality of Life in Patients with Alzheimer's Disease By: Edmund Howe, MD, JD</p>	

Modern Care for Patients With Alzheimer Disease: Rationale for Early Intervention By: Katherine E. Galluzzi, DO; Denah M. Appelt, PhD; Brian J. Balin, PhD

Diagnosing early onset dementia and then what? A frustrating system of aftercare resources By: Chemali I, Schamber, Tarbi, Acar, Avila-Urizar

Younger onset dementia By: Creighton Phelps, PhD

The needs of patients with early onset dementia. By: Armari E1, Jarmolowicz A, Panegyres PK.

Early onset Alzheimer's disease - diagnosis, therapy and management By: Fortschr Neurol Psychiatr.

Exploring the service and support needs of families with early-onset By: [Gibson AK](#), [Anderson KA](#), Acocks S

Database	Process of searching
Alzheimer's Association Research Journals (Advanced Search)	You searched for "early onset" in All Content OR "younger onset" in All Content AND patient in All Content AND quality of life in All Content

Early-onset dementia: Needs of patients and carers in the early diagnostic stage By: Theresa Green, Eric Smith, David Hogan, Dawn Pearson, Pamela Roach

A cross-national examination of the association between behavioral, psychological, cognitive and functional symptoms on quality of life of people with Alzheimer's disease By: Amy Duhig, Sube Banerjee, Steven Hass, James Jackson, Ryan Pollard

Improving the quality of life and cognition in persons with dementia through creative dance movements By: Sze Yan Tay, Christopher Gabriel, Simon Kang Seng Ting, Shahul Hameed

Neuropsychiatric Symptoms and Quality of Life in Patients with very mild and mild Alzheimer's disease By: Anne Koivisto, Kristiina Hongisto (former Karttunen), Hilikka Soininen, Pertti Karppi, Asta Hiltunen, Tarja Välimäki

Subjective experiences following a diagnosis of Alzheimer's disease By: Arndis Valgardsdottir, Daniel Olason, Kristin Hannesdottir, Erla Gretarsdottir, Jón Snaedal

Commentary on "Health economics and the value of therapy in Alzheimer's disease." Patient-reported outcomes in clinical trials for Alzheimer's disease By: Rebecca E. Ready

The effects of a multiprofessional cognitive and functional rehabilitation program for patients with mild Alzheimer's disease By: Luciane Ortega, Mônica Yassuda, Paula Nunes, Ivan Aprahamian, Franklin Santos, Glenda Santos, Paula Brum, Sheila Borges, and others

Impact of physical activity and cognition on activities of daily living in home-dwelling patients with mild to moderate Alzheimer's disease By: Kristine Hoffmann, Kristian Steen Frederiksen, Nanna Aue Sobol, Nina Beyer, Asmus Vogel, Birgitte Bo Andersen, Annette Lolk, Hanne Gottrup, and others

Cognitive-behavioral psychotherapy for early Alzheimer's disease By: Katja Werheid, Angelika Thoene-Otto, Barbara Cramer, Lutz Frölich, Hermann-Josef Gertz, Carolin Knorr, Alexander Kurz

Be heard here first: A strategic voice for Alzheimer's advocacy By: Meryl Comer

Dependence as a unifying construct in defining Alzheimer's disease severity By: Trent McLaughlin, Howard

Feldman, Howard Fillit, Mary Sano, Frederick Schmitt, Paul Aisen, Christopher Leibman, Lisa Mucha, and others

Self-efficacy for cognitive remediation in Alzheimer's disease By: Jimmy Choi, Joanna Fiszdon

Dementia and out-of-pocket spending on health care services By: Adeline Delavande, Michael D. Hurd, Paco Martorell, Kenneth M. Langa

Promoting Alzheimer's disease AD information and awareness By: Wainer Silva

S2-05-02: A randomized trial of a coordinated care management intervention to improve quality and outcomes of dementia care By: Barbara Vickrey

P2-262: Prayer as an intervention for agitated dementia residents By: Lena G. Smith

Note: The databases listed above are Social Work Abstracts, SocIndex, PsychINFO, Educational Full Text, and Dissertations and theses along with some Gray literature. The search terms are currently Alzheimer's disease, senile dementia, dementia, "early onset," "younger onset," patient, and quality of life.

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