

**Opinion Article***Copyright © All rights are reserved by Donna Gibson McCrary & Carmelita Dotson*

The Challenges Associated with Alzheimer's and Caregiving

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People are living longer now with advances in technology that impact various methods of medical testing and medication, which has led to an increase in the prevalence of Alzheimer's Disease (AD), which is classified as a form of dementia [1]. This has led to a significant increase in families and patient's seeking resources to assist with caregiving responsibilities. Dr. Alois Alzheimer, a German neuropathologist identified this disease in 1906, which resulted in the disease being named, Alzheimer's [2]. It is defined as the loss of one's cognitive functions which includes memory, language, judgment, praxis and orientation [3]. Alzheimer's patients normally receive most of their care from informal caregivers, that are usually family members. Last year approximately 25% of the United States population were providing care for someone with AD or some form of dementia and that number is expected to increase as the population continues to grow and people live longer [1]. There are significant economic implications as well as significant caregiver stress and burden associated with this disease [4].

Introduction

Alzheimer's is one of those diseases that is frightening to the patient, family and the caregiver. Like many illnesses, the patient often recognizes there is something wrong; but they don't tell anyone or seek assistance from their medical care provider. People often feel some sort of shame or powerlessness when reporting they are experiencing symptoms associated with loss of control which can lead to loss of independence. This acknowledgement signifies the onset of a serious deficit in one's independence, control, and way of life. The initial symptoms are often few and far between which can mask itself as normal, everyday forgetfulness. Family members are usually not educated on the signs and symptoms of this disease therefore, their loved ones are not diagnosed in a timely manner, which results in not receiving a proper treatment regimen for management of the progression of Alzheimer's Disease (AD).

With people living longer, due to advances in technology and an emphasis on healthy eating, there is an increase in neurodegenerative diseases like Alzheimer's. It has become a modern epidemic as it is a worldwide health issue affecting 44 million people in 2015 [5] and is expected to increase to 131 million by 2050, with a \$818 billion cost to the economy. According to Chen MC & Lin H [4], the World Health Organization found worldwide there are approximately 50 million people living with dementia. Alzheimer's disease disrupts one's social and occupational functioning. It is the most common form of dementia, which is an irreversible neurodegenerative disorder. AD is incurable and it is a terminal disease, normally found in the elderly [6-8]. Most patients diagnosed with Alzheimer's disease reside at home with family (informal caregivers) providing over 70% of their care [9]. By the year 2050, it is expected that 16 million people will be diagnosed with the disease if a cure is not found [10]. African Americans are two to three times more likely than whites

to develop Alzheimer's, and the number of African Americans at risk will more than double in the next 30 years. The reason for this health disparity is not clear; however, African Americans are more prone to high blood pressure, high cholesterol, and diabetes than their white counterparts [11,12]. Alzheimer's has been linked to these diseases which are prevalent in the African American community. This disease is a serious challenge for society and the healthcare system [13]. Therefore, all people need to be aware of the signs, symptoms, characteristics, and prevention methods associated with this disease.

Characteristics of Alzheimer's Dementia

This disease takes a toll on the entire family with the patient eventually needing assistance with day-to-day care and as the disease progresses, 24 hour a day care. During the initial phase of the disease, the patient and caregivers can continue with their normal routine, as medication helps prolong the disease from progressing. Many people are not accurately diagnosed and go for prolonged periods of time without the medication needed to keep this ugly disease from ravaging their mind, body and character. The patient diagnosed with AD interacts daily with various systems in their environment however, individuals they encounter, often are not educated on the signs and symptoms associated with AD. This lack of knowledge and understanding can create chaos and confusion for all parties involved. The patient's behaviour is influenced by the systems with which they interact daily, and these systems have an impact on their behaviour directly or indirectly throughout the disease process. It is common for an AD patient to become frustrated, aggressive, or angry in response to day-to-day interactions. Family members, co-workers and friends may not understand or recognize this behaviour, which can result in ill feelings towards the care recipient. Therefore, it is imperative for family and/or caregivers to know how to respond to the care recipient in order to deescalate a situation.

A component of the aging process for many, includes mild cognitive impairment, which makes diagnosing AD problematic. A confirmed diagnosis is only possible once dementia has progressed to a point where the distinction between mild cognitive impairment and Alzheimer's is indisputable [6]. Initially, when AD was first introduced the only way to confirm the disease was by conducting an autopsy. The autopsy revealed the signs of AD in the brain tissue, a collection of plaque between the brain cells along with tau protein located just inside of the brain cells [10]. The area of the brain where plaques and tangles first take place is known as the hippocampus. This is of significance since this is the area of the brain associated with cognition. This results in difficulties with verbal memory, attention span, and orientation to one's environment, anxiety, restlessness, and mood swings [14].

No event marks the onset of this disease, but it can be defined as the first time the individual needs assistance completing one activity of daily living [15]. Having incidents of memory loss are the most common symptom of mild cognitive impairment which has been characterized as the pre-clinical phase of the disease. This type of memory loss inadvertently makes diagnosing the onset of

AD difficult and it helps mask the disease from those close to the individual [3]. Individuals often have trouble concentrating, and repetitive questioning. They are unaware of repeatedly asking the same questions [16]. There is a distinction between developing the disease early in life, known as either early onset or familial AD. This happens in multiple generations of the same family younger than age 65, and it often develops as young as age 30 or 40. A person diagnosed with early onset declines at a much faster rate and the disease is more severe for this population [14].

There are forms of memory that take place during the later stages of AD. There is episodic, semantic and procedural memory. Episodic memory impairment is more noticeable, and it involves not being able to remember specific events, like birthdays or certain holidays [3]; semantic memory is related to knowing words, objects and social customs. Patients may forget the names of simple objects like utensils; and procedural memory loss involves not remembering how to perform certain tasks. In late-stage AD, individuals may forget how to swallow food or drink water [16]. There are other types of dementia, such as alcohol related dementia, cardiovascular dementia, and infection related dementia, also there are some medical conditions that have similar symptoms as AD, like hypothyroidism, depression, and vitamin B12 deficiency [17].

Advantages of Early Diagnosis

An advantage of early diagnosis results in the patient being placed on a treatment regimen that can possibly slow the progression of the disease [12]. There is no cure for the disease at this time however, early diagnosis has benefits such as, finding out what is wrong; this helps all parties involved to be more patient, understanding and it enables the caregiver to act more appropriately on behalf of the care recipient. Early diagnosis provides access to appropriate medication, an opportunity for the patient to be actively involved in plans for their future and seek out formal services in the community that will benefit the patient and caregiver [18]. Some people want to be involved in their care plan for the future, like deciding who will be responsible for making decisions for them when they are unable to, where they will reside, whether they want to be resuscitated or not and funeral and burial arrangements.

The patient and family members experience a sense of relief with knowledge surrounding the diagnosis, cause, and prognosis associated with the illness [18]. As the disease progresses it affects long term memory. The individual may experience difficulty recognizing their loved ones, family members, neighbours, and close friends. This can be traumatic for both the family member and the individual diagnosed with AD [16]. Patients may start to speak and forget or cannot remember what he/she wanted to say. It is similar to the phrase, "it's on the tip of my tongue" often used when one cannot remember a person's name. They may spend several hours trying to remember a name or a thought, until it comes to them. The AD patient is unable to search their memory for this information, which can be so frustrating for the patient. This can result in the patient withdrawing from social situations and normal conversations with family and friends. This new normal for the

patient and family is filled with a number of emotions they are not prepared for.

Becoming a Caregiver

Family members are usually the primary caregiver for individuals diagnosed with Alzheimer's. [19]. The role of the caregiver is critical for the patient, whether the care is provided at home during the early stages of the disease or if he/she is admitted into a skilled nursing facility [20]. The number of family caregivers is expected to grow with people living longer across the nation [19], which is due to the increase in the number of individuals being diagnosed with the disease, as well as the increase in the cost of medical care for those with dementia [21]. Medical care can be less expensive when the AD patient is cared for in the home by a family member. Family caregivers are usually employed outside of the home in addition to having obligations to their immediate family members. Additional responsibilities can cause added stress and strain on the entire family [22]. The time and emotional demands associated with caregiving leave the caregiver with very little time for their other responsibilities in regard to their significant other and/or their children [19]. Obligations to work can negatively impact caregivers with increased work responsibilities, a reduction in hours worked, being late, and absenteeism. These factors can all lead to conflict on the job, as well as termination [23].

Caregivers can spend anywhere from 69 to 117 hours weekly providing care for their loved ones [9]. Without assistance from another family member or outside care provider, the caregiver will find it difficult to work outside of the home. It is such a blessing when family members come together to provide support and care for their loved ones. It really helps when there are several people rotating to care for the patient. However, in most cases, the caregiving is left up to one person, as the other family members fail to make a sacrifice to care for their loved one. It really helps when there are several people in the family assisting with care especially when the patient needs 24-hour care performing their activities for daily living (ADLs), like taking care of their personal hygiene, selecting their clothes, putting their clothing on and trying to button those, oh so little buttons. Things most people take for granted. It is often a challenge for the patient to go from sitting to standing, and from standing to walking. This is physically taxing, as the caregiver provides assistance with this task for an individual that at some point may not be able to help themselves with mobility.

Family members need to know that this type of caregiving comes with much responsibility and a significant amount of your time. It can be draining mentally, physically and emotionally, especially without assistance and respite care. It compares to having to care for a baby that is the size of an adult, except a healthy baby continues to become more independent, instead of dependent, as time goes on. Once a family member takes on the responsibilities of caregiving, a shift in power dynamics within the family may change. A family member that previously had no power to make decisions may now have the power to make decisions about medical care, finances, and long-term planning [19]. It can be challenging when a child, taking care of their parent, becomes the person in control; telling the patient what to do, when to eat, dress, shower, take meds

and even managing their finances. This can be extremely difficult for the patient, having your child tell you what to do is not easy. This change in role reversal must be handled with care and respect. It is extremely important to involve the patient as much as possible in all aspects of their life. A family member that had no power to make decisions prior to the care recipient's diagnosis, may now have the power to make all decisions surrounding their loved one. A family member that once held a position of power may now be in a position where their opinion has no merit [19].

Caregivers of persons diagnosed with AD usually provide the most tedious and difficult kind of care, such as assistance with all activities of daily living [14]. It is hard for the caregiver to make all the necessary adjustments to their loved one's memory impairment, physical aggression, catastrophic reactions and episodes of enuresis and encopresis. The patient experiencing loss of control of their bladder and bowel (enuresis and encopresis) can happen in places other than the bathroom, even with an adult diaper. Confusion can cause the patient to take the diaper off and release their bowels anywhere [24].

Caregivers are often so busy caring for their loved one, they take on this role at the expense of their own health. The responsibilities associated with the role of caregiver are so consuming the caregivers tend to neglect their own health, which can result in additional stressors on the family [21]. This stress puts them at increased risk for developing health problems, as well as emotional problems. They often suffer from distress, depression, anxiety, and physical health complications [20]. Caregivers can experience feelings associated with frustration, exhaustion, and heartbreak but they can also experience feelings of pride, joy and a closer bond with their loved one [14]. This disease doesn't just take away one's memory but their independence, pride, character, future, dreams, emotions, personality and history.

Support Services

There are available services to assist individuals and families with various aspects of caregiving, emotional and educational support provided by healthcare providers and the community. These services include information and referral, educational programs, counselling, and respite or adult day care. These services are instrumental to the health and welfare of not only the caregiver but to the care recipient. Many of these services not only support but improve the caregiver's opportunities to make the necessary adjustments in order to better care for their loved one [7]. If information is not provided by your medical care provider, be sure to research support services in your local area. Contacting your local Alzheimer's Association should provide you with additional information that will help you on this journey as well.

Risk Factors

Some major causes of AD involve being insulin resistant, oxidative stress, which is having an imbalance of free radicals and antioxidants. This results in amyloid protein accumulation. Increased levels of cholesterol are a risk factor, causing dysfunction with amyloid protein's ability to process and increase production of the protein and the development of plaques. Having high plasma

homocysteine (Hcy) levels, low folic and B12 levels in the blood stream are risk factors of AD. Seventy-seven cross sectional studies that were conducted on over 34,000 subjects and thirty-three studies on 12,000 subjects found a relationship between dementia and Hcy and/or B12 [3].

Another study investigated the effects of taking B vitamins versus a placebo with subjects diagnosed with mild cognitive impairment. Shrinkage of the brain was measured with an MRI scan along with cognitive functioning. A Hcy of more than 9.5 is directly related to accelerated brain shrinkage, as well as a decline in cognition. The subjects that received folic acid, vitamins B12, and B6 had a reduction in the rate of brain shrinkage [3]. According to Shan Y [6], there is little research on whether AD can be prevented, however, Holford P [3], identified a cross sectional study of 4750 elderly residents revealed taking vitamin E and C are related to a reduction in AD. Lowering the risk of AD is associated with taking vitamin E and multivitamins with vitamin C.

There is no definitive cure for AD. Current medications for treatment of AD only slow the progression of the disease or work to improve the symptoms temporarily [3]. The stage of the disease determines which drug the physician will prescribe. Donepezil, also known as Aricept, slows the decline of memory loss by approximately 5% during the early to moderate stages of AD [14]. There are three cholinesterase inhibitors; Donepezil is one of three cholinesterase, and it works to limit the loss of acetylcholine in the brain. The other two cholinesterase inhibitors are rivastigmine (Exelon), and galantamine (Razadyne) they are used to treat mild to moderate stages of AD [6]. These drugs help to slow down the decline in one's cognitive ability, ADLs, and everyday behavior. Memantine, also sold as Namenda, is also used to treat AD in the moderate to severe stages, and it works to decrease the levels of neurotransmitter glutamate, that harms neurons at a high rate. Currently there are no drugs on the market that reverse the destruction of brain tissue by plaques and tangles associated with this disease [14]. Scientists believe AD starts approximately 10-20 years before the first sign of cognitive impairment is detected. This is one reason it takes years for a diagnosis to be confirmed. If you are over the age of 50, consider being tested for cognitive functioning and be aware of the risk factors associated with AD. The main risk factor is age, however, with early onset, age is not a factor. Developing cardiovascular disease, including high blood pressure, atherosclerosis, diabetes, obesity and individuals that have experienced some form of trauma to the head are all risk factors for AD [16].

Conclusion

There are ways to protect against this disease. Physical activity is inexpensive and accessible for prevention and management of this disease. Participating in some form of physical activity on a regular basis will reduce the risk of developing the disease. For individuals diagnosed with AD, exercising has been found to improve some physical and mental symptoms associated with the disease. A population-based analysis of seven modifiable risk factors found the U.S., United Kingdom and Europe with the largest proportion of AD was due to physical inactivity [25]. In the

United States fast food is a way of life for many and with so many outside obligations, individuals find it difficult to make time to eat healthy and to exercise. The World Health Organization recommends people between the ages of 18 to 64 spend at least 2.5 hours a week of moderate to intense aerobic activity. This will help to achieve cardiorespiratory and muscular fitness, bone health, and reduce stress that can lead to depression.

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Conflict of interest

None of the authors have a conflict of interest.

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