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The Importance of Early Detection for Alzheimer's Disease

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Abstract: *The number of Americans who are suffering from late diagnoses of Alzheimer's disease (AD) increases in the U.S. each year. Therefore, there is a need for more access toward early detection of this disease in order to ensure optimal quality of life and treatments for individuals. AD is one of the leading causes of deaths and, with the lack of funds for research, the number of AD diagnoses is expected to continue to increase. Medicare, Medicaid, and National Institute of Health services are providing funds for the current issues, however, it is not enough. There are many forms of poor access to services for individuals to seek early detection, but if that can change and financial assistance is provided, not only would many more individuals and their families benefit, but the states and nation would as well.*

Keywords: Alzheimer's Disease; dementia; healthcare policy

Alzheimer's disease is a terminal illness that affects an individual's cognition. Although the disease is a condition that is typically recognized in late adulthood, signs of memory loss can occur as early as in the third decade of life (Ahmed, Baker, & Butler, 2016). Currently, AD is the sixth leading cause of death in the United States and every 65 seconds someone develops the disease (Medletter Associates, 2015). With such a high prevalence of AD, our nation is greatly impacted, and changes need to be made. Care for AD is extremely expensive, and without an increase in funding for research, there may never be a cure.

National and State Healthcare Issue

Of all diseases affecting Americans, AD is the most expensive, totaling to roughly 277 billion dollars in 2018 (Alzheimer's Association, 2019). Among those billions of dollars, about 186 billion came from Medicare and Medicaid ("Alzheimer's Disease Facts and Figures," 2018). These state and nationally funded programs are spending the most amount of the American tax dollars on this disease, yet, even with society's contribution to the taxes, there is hardly any progress in AD research for a prevention or cure, as the money is predominately used for maintenance of care for those already diagnosed (Alzheimer's Association, 2019). If AD diagnoses could be made earlier, less of the Medicare and Medicaid dollars would be spent on treating this diagnosis. Indeed, if this were the case, the individuals would be receiving assistance sooner and, as a result, would be able to plan out their desired course of treatment throughout a longer span than an individual who is diagnosed later and needs serious and constant medical attention (Alzheimer's Association, 2019). Perhaps most importantly, this change could allocate a larger portion of the Medicare and Medicaid's assistance toward finding a prevention or cure. "Among all Americans alive today, if those who will get Alzheimer's disease were diagnosed when they had mild cognitive impairment, before dementia, it would collectively save \$7 trillion to \$7.9 trillion in health and long-term care costs" (Alzheimer's Disease Facts and Figures, 2018, p. 57).

In addition to this being a huge shift in research, this would also mean that another large portion of the money could be spent on imaging and neurological examinations which are greatly needed to diagnose individuals. Indeed, although these tests are costly, they are essential to officially determine if the individual truly has AD. In addition, if the individual has the access for these images and exams early, it will save them money overall. From a national healthcare perspective, there is also less of an expense for AD discovered while the individual is in the mild cognitive impairment stage, compared to diagnosing the disease while the individual has progressed to the dementia stage (Alzheimer's Association, 2019). This is due to the rapid spikes in costs directly before and after late diagnosis (Alzheimer's Association, 2019). Indeed, because individuals diagnosed with AD in the mild cognitive impairment stage have had time to plan their medical future and are aware of the cause of their illness, by the time they have reached the dementia stage, they have significantly less long-term care and medical costs. Furthermore, by the time of reaching dementia, these individuals have their mild cognitive impairments controlled and managed (Alzheimer's Association, 2019). Unfortunately, those diagnosed late also have unmanaged mild cognitive impairment, which likely resulted in many doctors' visits and unnecessary costs toward symptom control, and could have been managed by a neurological examination to pinpoint the illness and begin treatment (Alzheimer's Association, 2019). Then, all at once, the individual diagnosed late may need the medical imaging and many other tests in a short period of time, in addition to other long-term and constant care, which are large expenses (Alzheimer's Association, 2019).

Impacts on Delivery of Healthcare

Access to early detection of AD allows individuals to have options for various forms of testing. Most recently, research has shown that the use of biomarkers in relation to cerebral spinal fluid has been found to show the earliest indications of the development of mild cognitive impairment (Buracchio & Kaye, 2009). Unfortunately, these tests and procedures are extremely

costly. Indeed, this can become a financial burden to the individual and the family, if even affordable. Currently, Medicare covers tests such as blood studies, urinalysis, electrocardiograms, chest X-rays, computerized tomography (CT) scans, electroencephalography (EEG), and magnetic resonance imaging (MRI) to assist in the diagnostic process. Positron emission tomography (PET) scans have been shown to be one of the better tools to assist in diagnosis, as they examine the deposits of amyloid protein plaque in the brain, which can occur years before any clinical signs of AD (Marcus, Mena, & Subramaniam, 2014). Furthermore, these scans can even show differentiation to target the specific type of dementia, including AD (Marcus, Mena, & Subramaniam, 2014). However, when used for diagnosing AD, they are very rarely covered by Medicare (Alzheimer's Association, 2019). Without the financial assistance of Medicare, individuals likely suffer a lack of access to this very important test. Indeed, PET scans play an integral role in the diagnostic process, and should be covered by Medicare, especially for individuals with AD. With the prevalence of the disease increasing, it is vital to locate and share information about early detection. If caught early, many cases could begin receiving treatments and develop a plan of action before the disease takes the majority of the person's cognition (Marcus, Mena, & Subramaniam, 2014).

Population Impacted

Many individuals, families, and workers are affected by Alzheimer's disease. Indeed, as of 2018, 5.5 million Americans over the age of 65 have a diagnosis of AD, and, with the baby boomer generation aging, this statistic is expected to dramatically increase for the next several decades ("Alzheimer's Disease Facts and Figures," 2018). This illness is not a small matter. It affects millions of individuals in this country and will continue to develop and impact more if significant changes are not made.

When considering AD and the population that it affects, it is common to focus on the individual, however, the family and caregivers also play roles into the individual's access for care. Family, close friends, and other unpaid workers make up 83 percent of aid for the late adulthood population. Nearly half of all care giving are for individuals suffering from AD or dementia (Alzheimer's Association, 2019). These caregivers are working with the AD population in what means may be available. This can result in family members assuming that role of primary care giver, but they may lack in healthcare knowledge which ultimately affects the individual's care (Taylor, Bouldin, & McGuire, 2018). The caregivers may not know of the available resources, may know the person cannot financially afford testing, or may struggle accepting the harsh reality that a person they love has mild cognitive impairments and could benefit from early detection (Bynum, 2014). Another consideration is the cost to the individual. Even if their care is coming primarily from unpaid family members, the financial burden on the individual including the costs for comorbidities add to an estimated \$28,500 per individual per year (Fishman, 2013). Those costs greatly impact the individual for the access of care that they can afford. In addition, if the individual has a family, these yearly financial obligations to manage the individual's care could greatly impact the way the whole family

functions. It could limit the family's ability to engage in valued occupations due to financial means.

Thesis statement

More Americans are suffering from late diagnoses of Alzheimer's disease in the U.S. each year. Therefore, there is a need for more access toward early detection of this disease in order to ensure optimal quality of life and financially affordable care.

Relationship

Connection to Course Content

When evaluating why individuals may not be tested for AD when exhibiting signs of mild cognitive impairment, it is important to consider the availability of care. According to Shi and Singh (2019), there are dimensions of access that can affect an individual's ability to receive care: availability, accessibility, and accommodation. In regards to availability, the family plays a critical role. Indeed, if the family does not recognize the need for early AD testing, the individual suffers without ever gaining the opportunity to be seen by a doctor for early diagnostic services. Additionally, another condition may be due to the negative stigmas associated with AD. The family of those individuals may have a resistant mindset regarding seeking help and, therefore, may be hesitant to employ a neurological examination. Lastly, another availability consideration is financial piece. With current funds, the cost for AD services and examinations may be outside of the financial scope. Lastly, AD individuals may experience a lack of access to care because they simply are not receiving enough assistance to be able to be seen by a doctor.

Another dimension is described as accessibility (Shi & Singh, 2019). Accessibility becomes a concern when individuals do not have access to a transportation in order to travel to a location where there is a knowledgeable AD provider. This issue can occur if the individuals do not have their own vehicle or do not have the ability to drive themselves the distance to the healthcare provider. For example, individuals in late adulthood are often limited to driving short distances that are 15 minutes or less, however, it is not uncommon to find that the closest medical provider is 45 minutes away. Individuals in such a predicament are restricted to care that could take place in their home or reliance on another person to drive them to an appointment. In this dimension of care, the transportation limitations are what is keeping the individual from quality care (Shi & Singh, 2019).

In regards to accommodation, scheduling is often the primary issue. Indeed, when an individual has concerns regarding their mental functioning, the individual's primary care physician sends a referral to a specialist, however, the specialized practitioner may not have a work schedule that aligns the individual's needs (Shi & Singh, 2019). Additionally, a second conflict may be the individual's work schedule. If the individual is still working, they may need a very early appointment before work, yet the specialist may not come in the office until noon. This would delay the individual's ability to be seen by the specialist until there is a match of the two schedules, if ever seen at all. Indeed, this may restrict the individual from being seen for long periods of time, which would delay the individual on a very time sensitive matter (Shi

& Singh, 2019). If the individual is not seen due to time conflicts, they could be progressing through early stages of AD without even knowing it. By the time it is discovered by the specialist, the individual may be in a later stage than they would have if an appointment could have been made fitting their schedule.

Application to Occupational Science

Access for early detection of AD can be limited due to various types of occupational injustices. Someone that experiences occupational deprivation could struggle going to the doctor because they may notice a change in their behaviors and feel like the memory loss is out of their control (Hasselkus, 2011). The individual could feel like a piece of their personal identity is being taken away by this disease, and seclude themselves from anything that used to be enjoyable (Kielhofner, 2008). In addition, this may lead to avoid engaging in occupations in which another person might refer them to a doctor due to the drastic changes in ability to occupationally perform. What level the individual could previously perform at may be substantially different than their current abilities, which may be noticeable enough to warrant attention.

On the other hand, individuals may feel their memory lapses are temporary, so they refrain from participating in their occupations during these particular times of the day and also may feel that their memory lapses are not severe enough to see a practitioner about the potential condition (Hasselkus, 2011). According to Black (2018), symptoms of anxiety may emerge when discussing a potential diagnosis of AD to an individual. Indeed, this may cause worry and questioning, and lead the individual to solitary engagements to avoid any additional anxiety. Furthermore, there could be a transition to a denial period in which the individual does not believe or truly see the reality of their health status (Hasselkus, 2011). This form of injustice, called disruption, restricts individual's access to their healthcare needs because they limit their own ability and view to see the issue themselves (Hasselkus, 2011).

Another area to consider is access to medical professionals who have a valued sense of client-centered care. In this case, the provider is aware and knowledgeable of the client's concerns and behaviors, and provides services that are focused on ensuring the best support for that client's life (Hasselkus, 2011). By practicing client-centered care, the practitioner can promote ideas regarding ways to implement the client's interests within the realms of ability due to AD. For example, to encourage a single, male client who enjoys cooking with his friends, a provider may recommend that he begin going to restaurants with his friends instead. Indeed, this would still allow the client to participate in a social activity with his friends, but without risking injuring himself in the kitchen while cooking. This example is also especially helpful for client-centered care, not only because it allows the client to engage in their interests, but because it is also medically beneficial. Engaging in social activities is especially important for individuals with AD to promote cognitive functioning and, typically, women participate in this more than men (Mielke, 2018). By providing quality care, the practitioner is able to understand clients in a more holistic manner and truly make a bigger difference.

Relevance

Current Healthcare Policies

When viewing current healthcare policies, it is important to examine the funding and logistics of the available programs and services. "In 2011, Congress passed the National Alzheimer's Project which mandated a National Plan to Address Alzheimer's Disease in 2012, that set a target date of 2025 to develop methods of prevention and effective treatment" (Black, 2018). The National Institute of Health (NIH) redirected 40 million dollars in the budget to AD research in the year 2013 and has continued to be a financial support (Black, 2018). Since then, access to healthcare has become more affordable and available.

Drug rebates is an apt example of the increase in access. Before funding increases, Medicare had a cap on prescriptions and if a patient hit that cap, they would have to pay the rest of the amount out of pocket. By 2020, this will be phased out as Medicare will cover the full expense (Jiang, Hughes, & Wang, 2018). Another policy that has been enacted is the use of annual wellness visits, which are also funded by Medicare. Although these have already been in place, they now include cognitive impairment screens to assess for symptoms of AD or dementia, as well as talk with the family, caretakers, friends about any possible concerns. With this legislature in place, there has been an improved delivery on preventative care (Jiang, Hughes, & Wang, 2018).

Unfortunately, the NIH's contribution to AD is scarce in relation to its need. In comparison to funding for other leading diseases in the U.S., AD funding is significantly less. Indeed, the NIH provides over 6 billion dollars yearly for cancer, which is 150 times the amount spent on AD. For yearly funding for heart disease, over 4 billion dollars is spent, or 100 times the funding given to AD. Lastly, the NIH assistance in HIV/AIDS support is over 75 times the amount of AD, adding to the 3 billion dollars yearly (Black, 2018). Although funding for AD is increasing, much more support is needed to make true strides in research for such a prevalent disease.

Implications of Early Detection

There are many steps that need to be taken for improvement of access toward early detection of AD. First and foremost, additional funding is crucial for any major progress. According to Black (2018), with the limited federal financial support, the U.S. is far from finding a cure or even the prevention of AD. An avenue that could be taken to increase the funding could be advocating for the NIH to reallocate more funds for AD research. When evaluating the leading causes of death, HIV/AIDS is ranked below AD, yet receives seventy-five times the funding (Black, 2018). If some funds could be reallocated from HIV/AIDS to make a more proportional distribution relating to ranking of leading causes of death, there could be major improvements and advancements in the AD field.

When considering the individual, going to the doctor and having services recommended to be tested for AD in the early stages of cognitive decline can result in faster medication prescriptions, faster access to a medical specialist concerning care, and faster plan of action for the family (Alzheimer's Association, 2019). Early detection gives the individual and their family more time to process the hard truth of the terminal

illness, but typically provides a longer life span for that individual during such a crucial time. While the individual is in the early stage of memory loss, they are still mostly themselves and can make decisions regarding their future.

Education for the individuals and their families is another area that should be considered. In some cases, when individuals who seem to be “too young” for an AD diagnosis, they may be dismissed and not taken seriously regarding the various signs or symptoms they are experiencing. It can appear as depression or stress induced, thus negating to press the individual’s concern (Ahmed, Baker, & Butler, 2016). Ultimately, it may even result in false reassurance to the individual by examining only the status of age (Ahmed, Baker, & Butler, 2016). If there was an increase in knowledge about the disease and how early an individual can display symptoms, it may help influence the individual to take the necessary steps to get tested early, rather than wait. In addition, continuing to stay educated and up to date about the current AD research could help the practitioner to stay alert and aware of young individuals who they might not otherwise have expected to have AD (Black, 2019).

Consequences on Healthcare Service Deliveries

Early detection for AD may lead to a rise in the 16.1 million Americans that are providing unpaid care for these individuals (Alzheimer’s Association, 2019). Although this may be true, the bigger fact to consider is that early detection and diagnosis of this disease saves both families and the U.S. government large sums of money. Even just a portion of the collective money saved could then be turned right back toward the unpaid caregivers for this population, reimbursement for neurological exams for early testing of AD, and research to find a cure or prevention of this terminal illness.

Early detection of AD provides many benefits. The major benefit is through use of exams and testing, which allows the practitioner to be certain that the individual does in fact suffer from this illness, and that the symptoms are not caused by something else. In addition, it provides time for the individuals to manage the care of their mild cognitive impairments before they progress to a later stage and develop dementia. Another benefit is that by detecting the disease early, the family can prepare and decide how they will spend their money for the journey toward the individual needing constant care and medical attention. When viewing the situation through an emotional lens, early detection also provides time for the individual and family to understand the lifestyle modifications and fluctuations, changes in the individual’s perception of their quality of life, as well as pushing past the associated stigmas and understanding the reality.

Conclusion

More Americans are suffering from late diagnoses of Alzheimer’s disease in the U.S. each year; therefore, there is a need for more access toward early detection of this disease to ensure optimal quality of life and treatments for individuals to financially afford care. AD can develop in the beginning of middle adulthood, but with various reasonings for a lack of

access to care, they may go untreated for many years. The individuals may not be able to afford the cost of testing, may avoid testing due to labels and stigma, or may not even recognize the extent of their cognitive impairment. More governmental assistance needs to be placed into action for research and advancements in AD, because without it, AD may continue to climb the ladder of leading causes of death and affect more and more individuals without ever having a cure.

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