Analyzing Racial and Socioeconomic Differences in the Treatment and Outcomes of Adults with Alzheimer's Disease

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On my honor as a University Student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments

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Abstract

Alzheimer's disease is a progressive disease that degrades cognitive functions including memory, processing, and behavior over time. It is characterized by changes in mood, memory loss, and a lack of ability to perform tasks such as eating and drinking, all of which worsens over time. Because it is a progressive disease, it is essential that patients are diagnosed with Alzheimer's disease as early as possible so they can begin taking medications and getting treatments that will slow the progression of the disease and lengthen their life, while also preserving their quality of life. However, a disparity exists in the medical field in which certain patient populations, specifically patients who are Black, are diagnosed later in the disease progression than white patients, thus decreasing the amount of time they have before their symptoms worsen. This paper will explore this disparity, the reasons behind it, and what the outcomes of this disparity are.

Introduction

Alzheimer's disease is a progressive disease that affects over 65 million Americans aged 65 and older, which is only expected to increase over time (*Alzheimer's Disease Facts and Figures*, n.d.). Although this disease affects much of the American population, it has the highest prevalence in African Americans, with a rate of 13.8%, followed by Hispanics at 12.2% and non-Hispanic whites at 10.3% (*CDC Newsroom*, 2016). However, despite having the highest prevalence among African Americans, Alzheimer's Disease is 35% less likely to be diagnosed in African Americans than in other races after their initial visits to physicians (*Data Shows Racial Disparities in Alzheimer's Disease Diagnosis between Black and White Research Study Participants*, n.d.). This fact follows a commonly observed trend in which Black Americans are not diagnosed with diseases or taken seriously until they are presenting with extreme and undeniable symptoms. This makes it more difficult for Black patients to receive adequate medical care that can properly address their needs and concerns, and as a whole, makes the medical system less accessible and useful for Black patients. Especially in the case of Alzheimer's disease, it is important that patients are diagnosed as quickly as possible, because while there is not a cure for the disease, there are medications that can be taken to slow the progression of it, and this will help patients retain their quality of life for as long as possible.

In this paper, I use Actor-Network Theory (ANT) to explain and analyze the healthcare system and why these disparities exist. As I discuss later in this paper, the healthcare system has historically failed minority patients, and this has created a legacy in which these patients do not receive adequate care. Understanding the actors involved in this network will allow for the disparities to be better understood and addressed. Furthermore, the use of ANT will also answer the research question of what disparities exist between racial and socioeconomic classes and how these disparities affect patient outcomes.

Research Methods

To gather information on this subject, I analyzed a variety of studies from different sources to provide a comprehensive overview of the actors involved in the topic and how they interact with the network, or the healthcare system. The main actors that are involved are patients, doctors, and caregivers of patients with Alzheimer’s disease. I searched for articles and studies that outlined the history of these actors and how they have interacted with one another in the past and present. I also utilized statistical data from the Centers for Disease control to establish the fact that a racial disparity does in fact exist. Additionally, this paper uses sources that describe how Black Americans have interacted with the healthcare system throughout history, which was used to further support the argument of the paper. Finally, I located research studies that outline biases in the diagnosis of Alzheimer’s disease, cultural factors that can influence diagnoses, and economic factors involved in patient care. All of this research was synthesized to create an argument that the healthcare system has historically failed poorer communities, as well as Black communities, and that this trend continues with the treatment and diagnosis of Alzheimer’s disease.

A History of Mistreatment

To put the issue of racial disparities into context, one only has to look at the way Black patients have been treated throughout history. In her book <u>Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present</u>, Harriet Washington outlines a dark history in which Black patients were used to test untried drugs, were given forced anatomical investigations, and a multitude of other abuses at the hands of doctors. Washington tells the stories of enslaved women being given non-consensual gynecological surgeries and exams without anesthetic by Dr. James Marion Sims, a man who later went on to receive praise as the “father of American gynecology” (Washington, 2006, pg 356). Since the 1800s, Black Americans have been subjected to abuse at the hands of doctors who received little to no blowback for their actions, and in some cases were celebrated for them. This understandably has led to a distrust of doctors and the healthcare system as a whole by Black Americans.

Another extremely prominent example of Black Americans being mistreated by the medical system is seen in the Tuskegee Syphilis Study, in which 600 Black men with syphilis were studied and told that they were going to be treated for syphilis between the years 1932 and 1972. Most of these men were poor and illiterate sharecroppers that did not have access to medical care, so they were eager to get what seemed like free treatment that would cure them of a serious condition. However, due to a lack of experience with human studies and how the system worked, they did not know that they were being taken advantage of. Penicillin had become the standard treatment for syphilis, but the participants in the study were never given any and were instead left untreated and uninformed. Because of this, dozens of the participants in the study died or passed the disease on to families or others (*About the USPHS Syphilis Study | Tuskegee University*, n.d.). This is just one of many examples of studies being done without informed consent and that take advantage of uninformed communities. When the details of the study were released to the public, there was an increase in the distrust of doctors and healthcare by the Black community, as it became obvious that they were not valued and were being taken advantage of.

Furthermore, when communities that are not experienced with the medical system and how studies should work are taken advantage of, they are often not able to advocate for themselves in the studies. It is possible that they are not aware of the injustices that occur, such as with informed consent or them being lied to, or if they are aware, they often do not have the means or the methods to take legal action or protect their rights. This made it easy in the past for these communities to be exploited, and as the studies, such as the Tuskegee Syphilis Study were exposed, distrust within these communities rose.

This distrust carries over into modern medicine as well. A study done on medical students at the University of Virginia in 2016 found that even if the students did not demonstrate racial biases, they were still more likely to underestimate the pain that Black patients would feel as opposed to white patients (Hoffman et al., 2016). This has led to Black patients being under prescribed pain medications, not having their symptoms taken seriously, and not being able to get proper and accurate diagnoses from their doctors due to how their symptoms and pain is perceived. This is a very dangerous situation, and the results of it can be seen in mortality rates for Black women versus white women. Black women face mortality rates from pregnancy that are three times higher than those of white women, and this has been attributed to their care providers not believing their complaints, refusing them tests, and not administering proper pain medication (Hill et al., 2022). When patients are not taken seriously or have their symptoms ignored, they will likely expose these experiences to their friends, family, or to the public afterwards, and over the years, many of these stories have come out.

This was exemplified when Serena Williams, a well-known tennis player, gave birth. Williams experienced difficulty breathing, and when she reported this to her doctors, she was told that her pain medication had left her confused. However, she was able to ask for and receive a CT scan, which showed several blood clots in her lungs, a condition that can be fatal (Salam, 2011) . Because Williams is wealthy, famous, and knew to advocate for herself, she was able to receive life-saving treatment, but this is not the case for many Black women, and Williams was quick to share her experience as a Black woman giving birth. She spoke about how her symptoms were written off as her being confused, and had she not received a CT scan, she would likely have had severe complications. Experiences like this increase distrust in the medical system, as they publicize how often Black patients are mistreated or have their symptoms ignored. Overall, the historical mistreatment of Black patients by the medical field has cultivated a distrust and lack of care for Black patients, which has disastrous effects.

Diagnosing Alzheimer's Disease

The first step in treating Alzheimer's disease is diagnosing it correctly. The main cognitive assessment that is used to do this is the Mini-Mental Status Examination (MMSE) (*Screening Tests Used for Alzheimer's and Other Dementias*, n.d.). This test has algorithms in place that are meant to remove biases and create an even field to accurately cognitive impairment in different patient populations, ranging from race to socioeconomic status. However, a study found that the algorithms that are meant to provide accurate assessments on cognitive impairments were more likely to assign cognitive impairment to people who live in historically lower class neighborhoods, even if they did not demonstrate signs of cognitive impairment (Espino et al., 2001). This means that the algorithms that exist to "even the field" and reduce biases in the MMSE are not entirely accurate and can therefore result in different and unnecessary treatments for people from poorer neighborhoods.

Cultural Factors of Alzheimer's Disease

Along with how the disease is diagnosed, there are a variety of cultural factors that can affect how and when patients seek help for symptoms of Alzheimer's disease. One of the more significant cultural factors is education and knowledge of what Alzheimer's disease actually is and what its symptoms are. A study found that African Americans were significantly more likely to view symptoms of Alzheimer's disease as a normal part of aging, meaning that they were less likely to consider them symptoms and seek medical advice (Chin et al., 2011). This means that the patients were less likely to be concerned with memory loss and motor function loss until they became extreme enough for the patients to seek help, thus giving the disease more time to progress untreated and closing the important window in which medications can be administered to significantly slow the progression of the disease. Without proper education on what natural aging symptoms include, patients cannot be expected to seek help for things they do not view as symptoms, so it is important that education on Alzheimer's is more widespread.

Another important cultural factor is the trust in the medical system, as discussed earlier. As this paper has previously established, there are a variety of reasons throughout history of why Black people do not trust the medical system and their doctors. When patients do not trust their doctors, they are less likely to honestly report their symptoms or concerns, and this makes it more difficult for the doctors to administer proper care.

Furthermore, a cultural factor that has been thought to contribute to higher rates of Alzheimer's disease in poorer communities is the fact that many lower class neighborhoods are food deserts, meaning they exist in places where it is difficult or impossible to buy high quality food, as well as fresh fruits and vegetables. This contributes to lower nutrition, which in turn has been thought to cause higher blood pressure, cholesterol, and diabetes, all of which have been associated with Alzheimer's disease (Chin et al., 2011). Additionally, in these communities, people typically experience higher levels of stress due to economic hardships, higher crime rates, and more violence, and higher levels of stress have also been shown to age the brain and contribute to Alzheimer's disease (Chin et al., 2011). However, because Alzheimer's not fully understood, none of these factors can be used to pinpoint a reason why the rates of Alzheimer's are highest among African Americans.

Economic Factors of Alzheimer's Disease

Economics play a very important role in peoples' ability and willingness to seek medical help (Tóth et al., 2018). Patients from poorer communities are likely less able to afford to seek help, or to take time off work for doctor's visits. Furthermore, if the patients are unable to care for themselves or take themselves to appointments, this responsibility typically falls on a family member, and it is likely that they are too busy to take patients to and from doctor's appointments, especially in the case of Alzheimer's disease which requires frequent visits and check-ups. Additionally, depending on a patient's insurance, they may not be able to afford the many MRIs, PET scans, and medications that they will need as a result of this disease.

Care is also very expensive for Alzheimer's patients, as many require intensive care and physical therapy, which the average family member serving as a caregiver cannot provide. In 2022, the median cost for an assisted living facility was $4,635 per month, while the median cost of a semi-private room in a nursing home was $97,747 per year. Even home care, which is more accessible, had a median cost of $1,113 per week (*Planning for Care Costs*, n.d.). This is much more than many families can afford, and this makes care less accessible to them. Less accessible care means that family members are often tasked with performing difficult tasks that they may not be qualified for or willing to do, and this leaves the patients at a large disadvantage.

All of these factors play into people from poorer communities being less able to seek medical help, and instead ignoring their symptoms and letting them progress and worsen. Economic factors play a very significant role in how patients seek and receive treatment, and in the case of patients who need caregivers, more actors are at play, meaning everything is more difficult to coordinate.

Analysis: Actor Network Theory

Using Actor Network Theory (ANT), one can better understand the roles that the actors play with one another, as well as how the network is affected. In this case, the actors involved are the patients, doctors, caregivers, and communities. The network is the healthcare system, and the fact that most of the actors have a negative view of the network means that they are less likely to make use of the network. An important set of actors in this topic is the communities and caregivers of patients with Alzheimer’s disease, as it is possible that communities perpetuate stigmas against mental health, aging, and seeking help, which can all prevent a person from looking for and finding assistance with their concerns. People who come from communities where it is seen as weak to admit problems with memory are less likely to report symptoms, and therefore their disease will progress without treatment for a greater period of time. Furthermore, some caregivers may not be willing to take symptoms seriously and may overlook memory and behavioral changes and see them as normal signs of aging, as discussed earlier, thus letting the disease progress undiagnosed and untreated. Another important actor interaction is the interactions between doctors and their patients, as when doctors ignore or disregard their patients’ complaints and symptoms, the patients are less likely to return and seek help in the future.

When analyzing the non-human actors of the treatment and diagnosis of patients with Alzheimer’s disease, it is important to consider the hospitals, insurance companies, education systems, and resources available to the different communities. One major contributing factor is geographic location. Poorer areas tend to have fewer physicians (Horev et al., 2004) and less access to hospitals, thus making access to care more difficult. Furthermore, people from poorer areas, or people for whom English is a second language might have more trouble with handling insurances and getting their costs covered, and as a result, they may be unwilling to seek medical treatment. This ties into the education systems, which tend to be worse in poorer and non-white areas (Porter, 2015). Without sufficient educations, people may be unaware of how to operate in an already complicated medical system, or they may not identify certain symptoms as symptoms, and instead view them as a normal part of aging, as discussed earlier. These non-human factors create a system that increases the gap between socioeconomic classes and races when it comes to access to medical care.

Discussion

Overall, the continued mistreatment of minority communities increases distrust of the medical system and makes it less likely that patients will seek help. This essentially creates a positive feedback loop, in which patients do not seek help, their symptoms worsen, this increases distrust in the medical system, and as a result they become even less likely to seek help. Furthermore, studies have found that when communities have higher prevalence of debilitating diseases (such as Alzheimer’s disease), there is an effect on society as a whole (Wong, 2020). This is seen by the fact that Alzheimer’s patients often need caregivers, and because many people cannot afford home nurses or to go to care facilities, family members must stay home to care for the patient. This makes it more difficult for the caregiver to work, go to school, or do tasks to prepare for their future. As a result, more strain is placed on the caregivers, and it becomes more difficult for them to get the education that they need for higher paying jobs, or the time for them to work longer hours or more difficult jobs. This can contribute to communities being remaining poorer, as people within the communities are less able to break the cycle due to their other commitments, essentially creating another positive feedback loop that just increases disparities. It is important that doctors and other medical practitioners are properly trained to give equal treatment to their patients so as to minimize these disparities. Although there is a deep history of mistreatment of Black patients, and this history has contributed to an intense distrust of the medical system, which contributes to these disparities, it is possible to begin to repair the relationships by properly educating doctors and providing equal access to treatment and diagnoses for patients.

Limitations and Potential Solutions

A major limitation of this paper is the fact that Alzheimer's disease is a relatively new disease that is not fully understood. This means that causes, treatments, and diagnosis methods are not perfected or fully known, therefore making it more difficult to pinpoint cultural and medical differences in communities. While it may be that poorer communities' lack of access to fresh and healthy foods is a contributing factor to the development of Alzheimer's disease, this cannot be proven because the exact causes of the disease are not fully understood. The same can be said for higher stress rates contributing to the disease, which has been thought to cause hypertension, or high blood pressure, which contributes to the disease, but this too is not certain.

Potential solutions for this disparity may include increasing education in less informed communities to make sure people are aware of symptoms, what is normal and abnormal aging, and how to seek help if people have concerns. Additionally, doctors and medical students need better training so they are better able to understand their patients' concerns and empathize with them. This could be done with a class that outlines historical mistreatment of minority communities, as well as training on how to fairly take everybody seriously and value their opinions. Finally, a more technological improvement that could be made is refinement of the algorithms that are used to diagnose patients to accurately remove biases and get the most reliable results possible.

Conclusion

To conclude, this paper used Actor Network Theory to analyze and understand the different factors that contribute to a disparity in the diagnosis and treatment of Alzheimer's disease. One of the more notable factors is the historic mistrust of doctors from minority communities due to historic mistreatment of them from white communities. Another notable factor is a lack of education and information on the normal signs of aging, which is something that could be taught through community outreach. These disparities have significant effects on communities and society as a whole, so it is important that something is done to properly balance concerns and to rebuild trust in communities.

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