An Analysis of the Overrepresentation of African Americans in the Prescription of Hemodialysis Following a Diagnosis with End-Stage Renal 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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Introduction:

Imagine having a life consisting of three four-hour sessions in a dialysis clinic each week to have the entire blood supply in the body drained because the kidneys are failing. This is not only exhausting, painful, and time-consuming, but this process is a life-sentence, as the kidneys do not regenerate function once this state has been reached. The frequency of appointments per week is not conducive to a traditional job or to travel away from the clinic, resulting in a diagnosis of kidney failure becoming an untraversable obstacle to living out a normal and high-quality life. This treatment for kidney failure handcuffs patients to this way of life, and this is the sad reality for the 37 million patients who select this treatment modality following the diagnosed need for medical intervention (*Chronic Kidney Disease Basics*, n.d.). The average lifespan once dialysis is begun is only 5-10 years (*Dialysis*, n.d.).

Kidney diseases are nicknamed “the silent killer” and are the leading cause of death in the United States (*Chronic Kidney Disease Basics*, n.d.). Among other important roles, the kidneys’ primary purpose is to filter the blood, which is performed constantly throughout the day (Kamińska et al., 2020). There is no current medical treatment that can restore kidneys to their original function once they are damaged beyond the point of repair, and the crux of kidney failure, warranting its nickname, is that the decline of the kidneys is typically asymptomatic until they are already chronically injured, known as chronic kidney disease (CKD). Once CKD is diagnosed, medical intervention must be made to facilitate blood filtration since the kidneys are no longer able to adequately do this, and at this point the diagnosis is termed end-stage renal disease (ESRD)(*End-Stage Renal Disease*, n.d.).

Patients have one of three options once diagnosed with ESRD: hemodialysis, peritoneal dialysis, or a kidney transplant (Dialysis, n.d.). Transplants are by-far considered to be the best option for treatment, as full kidney function is restored. Peritoneal dialysis is considered to be the more comfortable and conducive to a higher quality of life modality for dialysis patients (Norris et. al., 2017). While it may be expected that in-clinic hemodialysis is the exception, it is actually the norm (Bello et al., 2022). In fact, 69% of all patients obtaining treatment for ESRD are receiving hemodialysis, and 89% of all dialysis patients are receiving hemodialysis (Bello et al., 2022). To make matters worse, kidney failure is riddled with racial disparities. African Americans represent only 13.1% of the United States population yet constitute 36% of patients receiving hemodialysis treatments (Umeukeje & Young, 2019). African Americans are also four times more likely to develop kidney failure than their white counterparts and are less likely to receive pre-dialysis care from a nephrologist (*Kidney Disease: the Basics*, n.d.).

In this paper, I argue that African American patients are disproportionately barred from receiving other treatment modalities due to the high cost of alternative modalities, lower medical literacy, and lower transplant access; I analyze these factors through the synthesis of a literature review and statistics gathered from research journals, followed by a discussion of the implications of these findings and a subsequent analysis through a sociotechnical framework.

Methods:

First, an overview of the literature regarding the requirements to receive each of the treatment modalities following an ESRD diagnosis, and these will be described with statistics specifically for African American patients. The cost of each of these modalities as well as the process for registration and payment will be described. Other factors such as historically-disadvantaged healthcare and greater risk for comorbidities will be described for the African American population, and this will have a special emphasis on medical literacy.

Data will be pulled from the literature review in conjunction with several research papers regarding each of the areas aforementioned, and statistics regarding the likelihood for African Americans to incur kidney damage and necessitate a treatment for kidney failure will be described. The history of dialysis and the various insurance coverage changes of the modalities will be described, and these factors will all be described and analyzed for the implications these findings have in the disproportionate representation of African Americans who receive hemodialysis. The conclusion will suggest ways to ameliorate the disparity through both local and government action, and the following analysis will hopefully inspire work to combat the racial disparities seen within this context and foster a more equitable healthcare system and overall nation and world.

Literature Review:

Extensive research has been conducted investigating the various factors that have led to African Americans incurring a diagnosis of ESRD at a much higher rate than their White counterparts. Factors encompassing systemic socioeconomic disadvantages such as access to healthcare and the susceptibility of kidney damage due to poor diet and higher incidence of obesity certainly play a role (Norris et al., 2017). The natural rationale for why African Americans are overrepresented in the population of patients receiving in-clinic hemodialysis is that they are diagnosed at a higher rate, which is true. In fact, the United States Renal Data Service’s most recent report shows an end-stage renal disease prevalence of 5,855 cases per million for African Americans, compared to 1,704 cases per million for white Americans (*Annual Data Report*, 2022).

Three of the main causes of kidney damage and the subsequent need for a treatment modality of ESRD are obesity, diabetes, and hypertension, and these have all been found to have a higher prevalence in African American populations than their White counterpart, with 76.3% vs. 68.5% for obesity, 18% vs. 9.6% for diabetes, and 43.3% vs. 29.1% for hypertension (Laster et al., 2018).

Socioeconomic status and race and ethnicity have already been established to be intertwined, with African Americans being historically marginalized by society and more likely to be of a lower socioeconomic status than non-black counterparts. Besides access to healthcare when symptomatic, factors consistent with a lower socioeconomic status, such as a poor diet, lower access to exercise, and chronic stress are also factors that increase the susceptibility to develop diseases that can progress to ESRD, such as lupus nephritis or diabetes mellitus (Thornton et al., 2016).

It has also been established in previous literature that African Americans have historically had lower access to healthcare and poorer quality even when received, as Gillespie et al. found that at baseline, African Americans were still less likely than Whites to have received any pre-ESRD care (31% vs. 38%). African American patients were also less likely to have seen a nephrologist more than 12 months prior to initiating dialysis (24% vs. 30%) (Gillespie et. al., 2017). Despite a similar prevalence of the early stages of CKD, African Americans are 3–4 times more likely than their non-Hispanic White counterparts to progress to ESRD and require RRT (Norris et. al., 2017).

Lower access to medical care results in a later diagnosis of kidney damage, which leads to a greater likelihood that the patient has progressed chronic kidney disease (CKD) and is more likely to require dialysis (Chronic Kidney Disease Basics, n.d.). In 2017, non-Hispanic blacks were 3.2 times more likely to be diagnosed with ESRD compared to non-Hispanic whites (Diabetes and African Americans, 2021), which demonstrates the higher incidence of African American patients receiving a diagnosis necessitating kidney health intervention. A study by Nee et al. also found that African Americans are more likely to have diseases that progress silently and cause damage to the kidneys, such as lupus nephritis.

The three different treatment modalities following a diagnosis with ESRD are: hemodialysis, peritoneal dialysis, and kidney transplant. Hemodialysis uses a dialyzer, which is a filtering machine, to accomplish blood filtration. A vascular access site is made in the patient, which is typically the arm, and the blood is then filtered through the machine and back into the body. Hemodialysis can be conducted either in a dialysis clinic or at home. If the patient receives dialysis in a clinic, the sessions are three times a week for approximately four hours (*Dialysis*, n.d.), and this treatment modality typically leaves the patient feeling tired, lethargic, and achy within 24 hours of treatment as the waste inside the blood begins to accumulate again.

STS Framework Analysis:

Upon detailing what each modality entails, understanding why a patient may choose a particular treatment modality requires social context, which can be described through the framework of Bruno Latour's Actor Network Theory (ANT). The premise of Bruno Latour's Actor Network Theory is that any given technology in society has a complex network of both human and non-human actors that has led to the observed social relationships with technology that are seen (Latour, 1992). The analysis of African American patients receiving in-clinic hemodialysis at a disproportionate rate can be explained through this theory, as actors that find their origin in 1619 to factors such as doctor-patient interactions exist and contribute to the disturbing disparity observed. While on paper and through an engineering mindset of the treatment modalities that have been developed to treat kidney failure it seems as though everyone should select a transplant, this is not the case, and this is because of the various actors at play that inhibit this from happening. The disadvantages that African American patients face are seen in non-human actors such as socioeconomic disadvantages such as lack of access to healthcare, lower access to regular exercise and a healthy diet, and lower education. All of these components play an important and informative role in the modality African American patients select once given a diagnosis of ESRD. Other important non-human actors are the insurance policies in place in the United States as well as how the registration processes work for each of these programs.

Human actors include patient-doctor interactions, such as the presence or absence of a conversation in which the doctor fully describes the various treatment modalities. The relationship between African American patients and doctors is also impacted by distrust, and this is shaped by a history unethical experiments and trials carried out on these patients. The distrust certainly influences the medical decisions these patients make. Other human actors include the healthcare policymakers and healthcare providers who foster the treatments currently seen in place today. The human actors are also composed of the patients themselves, in which they play a role in selecting their treatment modality that is largely, if not entirely, informed by the actors described above. Although the various technologies exist to provide different forms of treatment, the complex relationships between the various actors described displays the reality observed in that the treatments are not equal in their accessibility for African American patients.

Analysis:

From the literature review, it has been established that African Americans undoubtedly incur more kidney damage and are more likely to receive the ESRD diagnosis, but the obfuscated component of this fact is why African Americans may choose hemodialysis as opposed to other modalities, or in many cases, if this is really a choice. The seemingly-simple choice of three options is much more convoluted and unattainable than it seems on the surface. The disparities among treatments are evident from the study conducted in 2016 that found in a study of 160,000 patients who required ESRD treatment that when compared to Whites, African Americans were 60% less likely to receive home hemodialysis and 47% less likely to receive peritoneal dialysis (Mehrotta et al., 2016). Each of the three treatment modalities once given the diagnosis can be analyzed within the context of an African American patient in the U.S. healthcare system.

Home hemodialysis is considered to be more favorable, but it is less popular despite studies finding that it results in a longer life expectancy than in-clinic hemodialysis (Vinson et al., 2019). Home dialysis is considered to be preferable and conducive to a higher quality of life because it can be done daily in 1-2 hour sessions, which allows the patient to feel better due to having the blood filtered each day and can be scheduled when it is convenient for the patient. The practicality of home dialysis is also an advantage, as patients do not have to leave their home nor spend extra time and money traveling to a dialysis clinic. It was discovered that zip codes with a higher proportion of African Americans had fewer facilities that provided in-home dialysis therapeutics (Prakash et al., 2014).

Peritoneal dialysis is dialysis that occurs through the peritoneal membrane using dialysate bags to exchange the fluids. Peritoneal dialysis requires a medically-adept caretaker, which can be the patient or someone else to exchange the dialysate bags every 12 hours (*Dialysis*, n.d.). The at-home treatment also requires a sterile environment with high precision for treatments, and this is not attainable for many patients who are already socioeconomically-disadvantaged.

Kidney transplants are also riddled with inequities, as transplants are significantly more difficult for African American patients to receive than their White counterparts (Boulware et al., 2021). African American patients have an average of 76.5 days longer waiting period for a kidney transplant than a White patient with the same condition (Harding, 2017). Transplant medications are also no longer funded by the government starting three years after the kidney transplant, which often leads to compatibility issues and can result in the ultimate failure of the organ (*Medicare Pays For A Kidney Transplant, But Not The Drugs To Keep It Viable*, 2016).

In addition to the discrepancies between modality accessibility described above, another primary driving factor for modality decisions is the cost. In order to receive Medicare, the patient must have worked or be a dependent of an American citizen who has worked for at least 10 years (*Insurance and costs for dialysis*, n.d.), which may restrict some patients' access to hemodialysis treatments. Medicare Part B covers the training and most supplies for home hemodialysis, but the deductible must be paid to receive full benefits under Medicare. Also, the same support received in in-clinic dialysis centers is not available for home hemodialysis sessions, but Medicare Part B covers the cost of providing medical assistance in the event of an emergency (*Dialysis Supplies & Services Coverage*, n.d.); however, regular dialysis aids are not covered by insurance. Medicaid and Medigap are available for low income patients, but this process is complex to navigate through and can only be obtained in specific conditions at particular times, such as the fact that Medigap policies cannot be purchased or changed after the patient's designated enrollment period (*When can I buy Medigap?*, n.d.).

Another factor that has been studied is the lack of medical literacy for African American patients, which would result in more medical decisions being made in which the patient was not fully-informed. Patients may qualify for other treatments but not be aware of their opportunities. Patients in the Chronic Renal Insufficiency Cohort Study determined that 28% of African Americans in the study had limited health literacy compared to just 5% of White study participants. Health literacy has been linked to increased hospitalizations and visits to the emergency room within CKD patients, both of which are expensive, and lower health literacy in CKD patients has been linked to a higher mortality rate (Laster, 2018).

The disturbing statistics regarding cost and affordability of the various treatment modalities display how limited and complicated the choice actually is for African Americans after they receive a diagnosis with ESRD. If the patients are less likely to be medically literate, then it would be unsurprising to find that they are less able to seek out the proper insurance programs needed and are less likely to be successful in finding the programs that are in existence to help patients in these disadvantaged positions. Furthermore, the same patients with decreased education about the system and their options are less likely to successfully register on the transplant list or to have the knowledge to administer dialysis care for themselves.

From a cost perspective, the same socioeconomically-disadvantaged patients who are less likely to have adequate healthcare to receive an earlier diagnosis are unlikely to have the means to pay for a home healthcare worker or the supplies of home hemodialysis or peritoneal dialysis. The already observed racial disparities are likely to be accentuated by the current treatment options for African American patients following a diagnosis of ESRD because not only do they have a lower lifespan and quality of life, but they also now have to attend in-clinic visits three times a week during working hours and will, therefore, be less likely to be able to work and to overcome poverty. The patients will also physically feel worse and will likely not be able to provide as well or have the time, resources, and energy to contribute to society and earn money that they would if they were receiving a different treatment modality. The “haves” of society, who are often White patients, are far more likely than their African Americans, who through 400 years of systemic racism are often the “have nots” in this case to live longer and have better overall health outcomes following an ESRD diagnosis. The result is that African American patients get the short end of the stick and are stuck with 5-10 years on dialysis before they pass away, which is perhaps not the same ending they would face if the system were not this way.

Conclusion:

While there are considered to be three treatment modalities for ESRD, for many patients and for African Americans in particular, there is often realistically only one, and this is the least desirable of the options and is the least conducive to a long and high quality of life for the patients. The elucidation of the disproportionate number of African American patients receiving hemodialysis may have two effects. There can be efforts to ameliorate the described contributing factors to why African Americans incur kidney damage in the first place that would be considered a preventative approach with the hope that ESRD would be decreased and no modality of treatment would even be needed. Some of these efforts include increased testing and accessibility for kidney damage diagnoses, opportunities for better diet and healthy lifestyle practices, improved education to enhance medical literacy, and increased medical access in general to foster earlier diagnoses of diseases such as lupus nephritis and diabetes that lead to kidney damage.

Efforts to accomplish increased testing could be groups traveling to lower-income areas and conducting drives for free testing. Government mandates could also be created that facilitate employee access to the free testing of kidney diseases and allot time off for this occasion. Another important component of enhancing earlier diagnosis of diseases is through increased education, which could be accomplished through state education legislation that requires renal health to be incorporated in the school curriculum. Finally, legislation such as food stamps and free and reduced lunch programs could be mandated to be healthier so that people using the program are not limited to unhealthy options that are likely to result in obesity and increase the likelihood of incurring kidney damage. Further research focused in public health can also be conducted to determine the optimal ways to reduce socioeconomically-disadvantaged patients' risk of developing diseases and other medical complications that cause kidney damage.

The other methods of action that can be taken is focused on the modality opportunities themselves given that an ESRD diagnosis has already been established. The change that would result in immediate improvement is to decrease the cost of alternative modalities to make this more equitable and realistic opportunity for African American patients. New policies could be created in the federal government to increase access to home hemodialysis and peritoneal dialysis through increased Medicare, Medicaid, and Medigap coverage of these expenses. For example, the expenses of hiring a home healthcare aid, regular training for home and peritoneal dialysis, supplies, and medications could be covered by insurance. The cost of obtaining a diagnosis in the first place could also be reduced through free kidney testing and outreach programs to increase testing that could be subsidized by the government; this would result in earlier discoveries of kidney damage and would decrease the likelihood of the progression to CKD and ESRD and necessitate any treatment modality.

Efforts could also be made in the medical field and schools to increase general knowledge around kidney health. Doctors should be mandated to fully describe each treatment modality to patients and help facilitate patients receiving the best treatment that they qualify for to minimize the number of patients who receive hemodialysis as their treatment modality solely due to inadequate medical literacy. The process of registering for the transplant list as well as obtaining insurance coverage of each modality should also be made easier to minimize patients not receiving the best care due to confusion and an inability to navigate the process. Finally, the federal government could mandate that dialysis clinics are located at a designated mileage away from patients in order to ensure that patients who are historically disadvantaged or who may live far away do not have to travel too far to receive the dialysis treatments.

Any actions taken to minimize the suffering that patients, who are disproportionately African American, endure are greatly-needed advancements that will contribute to the creation of a freer and more equitable society, and these changes will lead to more patients having a better chance to live their lives how they hope to and to provide a better tomorrow with improved healthcare for future generations to come.

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