

DISPARITIES IN KIDNEY DONATION AND TRANSPLANTION IN  
AFRICAN AMERICANS AND THE ROLE OF MISTRUST

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## ABSTRACT

Organ transplantation has the potential to improve and prolong the lives of many chronically ill people. However, organs are a scarce resource and a commodity to which not everyone has equal access. Equity issues are particularly evident amongst African Americans concerning kidney donation and transplantation. In this paper, I discuss the history of kidney transplantation and the disparities that exist in the African American community for both organ donation and transplantation. I explain how the organ allocation system has structural barriers that do not account for the social determinants of health. Then I explore the significant barrier of African Americans' mistrust of the health care system and its role in kidney donation and transplantation. I use the principles of urban bioethics to discuss possible solutions to mistrust including community engagement, diversifying the physician work force, and concepts that move beyond cultural competency to cultural humility and structural competency.

I would like to dedicate this paper to my husband for his unwavering support and to the entire Urban Bioethics Department for their commitment to creating more socially conscious physicians.

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## CHAPTER 1: NARRATIVE

As a physician, I am honored to take care of a diverse population of patients. They each tell the story of the American health care experience from their unique perspectives. Below I will tell a story that illustrates the experience of living with a chronic medical condition, end stage renal disease (ESRD), while hoping for organ transplantation. My relationship with this patient and many others like him is the genesis for this paper. His story is my motivation for understanding organ transplantation in the African American community and the intersection of race and health.

I passed by his room again today. I have passed by his room more times than I can recall over the last twelve months. He was my clinic patient throughout residency, but I saw him more inpatient than outpatient. This was a reflection of his poor disease state. It was hard not to blame society for creating the perfect storm of social barriers for him.

On that day I entered his room like I do every time I recognize his name among the many that line the doors of patient rooms in the hospital. I chat with his mother if she is by his bedside, or I ask him to call her so I can say hello. He is African American and the same age as me. As an African American millennial myself, we have many things in common. We like the same hip-hop music and television shows. But it is clear that we live in two very different worlds. He has diabetes, hypertension, and ESRD. He is one of the youngest patients I have taken care of on dialysis. However, dialysis has not been good to him. He has experienced most of the complications of dialysis including infections, dysfunctional dialysis access, and more infections. Over the last two years he has lost both of his legs and vision in his right eye.

His story is not too different from many who live in the inner-city of North Philadelphia. He grew up in a single-family household and never knew his father. His twin brother was engulfed by the violence that surrounded them and was incarcerated when they were both still teenagers. He did not finish high school. He has had his fair share of adverse childhood events. He lives in a food desert surrounded by poverty. It is understandable why his health is so poor, but it does not seem just. He expressed to me that day that he wanted to give up. He was tired of fighting. I encouraged him to continue the fight, but in reality, I have no idea what it means to be him.

He is currently working on getting listed for a kidney transplant, but I often feel like they considered him too late. With all his medical complexity and constant hospitalizations, I am not sure he will ever get the transplant. However, I do believe that if he had started the transplant process before he went on dialysis, when his kidneys first began to fail, his life would be different now.

He personifies the disparities in kidney transplantation of African Americans. Because of social factors, he has had poor access to health care which contributed to his development of diabetes and hypertension. As these diseases progressed, he developed kidney disease and then ESRD. As his health declined further, so did his access to care. He required rides to his doctors' appointments because of his bilateral leg amputations and logistically he missed many of them. He did not have access to fresh fruits and vegetables, so he often resorted to corner store snacks and empty calories. Every time he was hospitalized his medications were changed. His mother did the best she could with his medications, but often she was confused. She had more lists than she could handle, and often she did not know which medications to give him.

They both want him to be listed for kidney transplantation but each hospitalization seems like a set-back. He misses evaluations with transplantation doctors because he is in the hospital from another dialysis complication. He and his mother are as engaged as possible in his health, but I know they have been stripped of their agency by a health care system that does not account for the intricacies of social determinants of health. He represents a small piece of the story.

## CHAPTER 2

### INTRODUCTION

Organ transplantation has the potential to improve and prolong the lives of many chronically ill people. However, organs are a scarce resource and are awarded through complex and often flawed allocation systems. As a result, organs are a commodity to which not everyone has equal access. Equity issues are particularly evident amongst African Americans concerning kidney transplantation. Although African Americans carry a higher burden of kidney disease they are transplanted less; this is evident by the patient story above. In terms of organ donation in the African American community, deceased donor kidney donation has remained stable but living donor organ donations continue to decline compared to Whites over the last decade (Hart et al.). Many explanations have been proposed for the disparities observed in kidney transplantation and kidney donation amongst African Americans. African American mistrust of the health care system and health care providers appears to be a significant barrier. In order to better understand the barrier of mistrust in kidney transplantation and donation in this population and possible solutions, one must use an urban bioethics framework.

First, I will describe the history of kidney replacement therapy in America including dialysis and organ transplantation. Second, I will identify the disparities in organ donation and transplantation in the African American community. Third, I will offer an argument for why African Americans' mistrust is a barrier for organ transplantation and donation. Finally, I will provide solutions by using the urban bioethics principles of agency, solidarity, and social justice.

Throughout the paper I will use the terms Black and African American interchangeably. For the purpose of this paper, Black and African American represent those persons with a heritage of slavery and the objectification, discrimination, and disenfranchisement that followed through systems such as Jim Crow. They also represent those people of color who may not have a direct lineage to slavery but suffer the same discrimination because of the color of their skin. This happens as result of the social construct of race. For example, Africans who immigrate to the United States may have no heritage of slavery but because of the color of their skin share many experiences of racism as those African Americans with slavery heritage.

## CHAPTER 3

### BACKGROUND

End stage renal disease is unique when compared to other end stage organ diseases because of the existence of dialysis, a renal replacement therapy. With dialysis, patients are able to prolong their lives by utilizing a non-organ modality. During the inception of dialysis in the late 1940s, ethical dilemmas - similar to those we see now in organ transplantation - occurred because it was a limited resource.

Dialysis became enmeshed in a complex set of social, economic, political and ethical issues: the allocation of scarce material and nonmaterial resources; the selection, “nonselection,” and “deselection” of patients for treatment... Many of these issues converged and acquired a significance beyond their strict medical importance. So-called “psychological and social suitability” and “social worth” criteria were among those being used to decide which persons would be accepted for dialysis. (Fox 741)

Dialysis was a privilege interconnected with one’s social status, and societal hierarchy was intertwined with beliefs, likely fueled by prejudices and discrimination about racial minorities and the poor. Thus, when layered with the social and racial climate of the era, dialysis allocation was multifaceted and unjust. In the face of this injustice, political and social mobilization led to the incorporation of dialysis into the Social Security Act in 1972. As a result, dialysis was no longer a luxury; the cost is now fully covered by the federal government.

Several years after the creation of dialysis the first successful kidney transplant occurred in 1954. Now, with medical advancement and technology, kidney transplantation improves the quality and duration of life. Medin et al. noted that “the five-year survival of living donor transplant recipients was 94% compared with 76% among recipients of cadaveric kidneys whereas the dialysis patients had only a 60% five-year

survival” (702). Transplantation provides a greater benefit for patients than dialysis. Not only does transplantation decrease mortality, but patients are freed from the social burden of dialysis. Dialysis involves three long treatment sessions per week. Many patients may not be able to find employment or even go on a family vacation. Although dialysis can be a life-saving modality, it is not without its complications and flaws. Thus, transplantation is the better option. However, transplantation is a limited resource. According to the unified network for organ donation and transplantation, the Organ Procurement and Transplantation Network (OPTN), in 2018 almost 21,000 people received a kidney transplant. Of those transplanted 45.8% were white, 26.3% were black and 18.5 % were Hispanic (“National Data”). Many people still eagerly wait for organ transplantation. The demand far exceeds the supply.

## CHAPTER 4

### DISPARITIES AND BARRIERS TO TRANSPLANTATION

African Americans are disproportionately affected by ESRD and diseases that lead to chronic kidney disease such as hypertension and diabetes. Hypotheses for this disparity range from genetics predisposition to environmental factors. Regardless, they receive fewer kidney transplantations. Patzer found:

Although the incidence of ESRD is higher among blacks than whites, the proportion of ESRD patients whether transplanted or placed on the deceased donor waitlist within 1 year of ESRD registration during 2003 was 14.5 % for white patients versus 10.1 % black patients. (1333)

The limited number of African American patients on the waitlist also indicates that African American patients are often not even being considered for the treatment.

Similarly, Young and Gaston found that “Black patients are less likely than whites to be identified as candidates to receive transplants and, ultimately, to appear on waiting lists for transplants within the first year of Medicare eligibility; this discrepancy is not evident for other minority groups” (1545). African Americans organ transplantation is inconsistent with their burden of disease leading to a disparity. Many barriers have been proposed for this disparity including physicians, genetic differences, patient education and other social factors.

Nephrologists, physicians who are the specialist that treat kidney disease, decide who to refer for transplant evaluation. They are the gatekeepers to transplantation and as such represent themselves as a large obstacle for kidney transplantation in African Americans. In one study, Ayanian et al. found that “Nephrologists were less likely to recognize the survival benefits of transplantation over dialysis therapy for black patients

than for white patients, but they were similarly likely to believe transplant improves quality of life for black and white patients” (356). African Americans are not routinely considered by their physicians for transplantation and thus fewer of them are referred a transplant center for evaluation. However, even when African Americans are referred for evaluation, fewer of them are placed on the waitlist.

Minority patients experience low referral rates to kidney and liver transplant centers, fewer completed evaluations and fewer become candidates after screening than Caucasian patients. Referral rates for minorities are lower both for initial evaluation of transplantation and for placement on the transplant waitlist. (Higgins and Fishman 2557)

There is a contradiction between the opinions of physicians on the benefits of transplantation and their actions towards a select group of patients.

Nephrologists’ decision about whether or not to refer disenfranchises African Americans from access to a life changing and saving treatment. Whether or not the patient would ultimately qualify is irrelevant as they are stripped of the opportunity for consideration. Epstein et al. state:

Our results suggest that lower rates of renal transplantation among black patients in part reflect racial differences in clinical characteristics that make fewer blacks clinically appropriate candidates for transplantation. However, blacks also appeared to receive fewer transplants, regardless of the clinical indications, a pattern that results in the relative underuse of transplantation among blacks who are appropriate candidates for transplantation and relative overuse among whites who are inappropriate candidates. (1542)

For unclear reasons, perhaps implicit bias and miseducation of clinicians compounded with complex patient characteristics, African American patients are not being referred for kidney transplantation. There is a clear disparity and inequity in kidney transplantation of African Americans which is evident at each step of the transplant process, from referral

to a transplant center to waitlisting to transplantation. Unfortunately, this disparity is further propagated by physicians who ultimately decide a patient's fate for transplantation.

Biological differences have also been proposed as an explanation for disparities in renal transplantation. HLA matching, which is necessary to decrease rejection, is difficult in African American patients. Roberts et al. explain:

Because of racial or ethnic differences in the frequency of alleles at each locus, whites are more likely than those in other racial or ethnic groups to find a good match in the donor kidney pool. This biologic fact, when coupled with the current allocation policy, increases the transplantation rate among white candidates while it conversely reduces the access of candidates with less common HLA phenotypes, including those who are members of minority groups. (546)

The donor pool is overly saturated with non-minority profiles, which sheds light on the issue of diversity of donors which will be discussed later. Whether or not immunosuppressive therapy can overcome these biological differences is undetermined and research efforts to answer this question are complicated by a lack of diversity and inclusion of research participants (Higgins and Fisherman). In attempts to increase equity, the OPTN adjusted the allocation system to account for these HLA differences. However, disparities may still exist.

Several factors account for differences in transplantation rates between races after listing. These include: HLA differences as a barrier to organ allocation; the Organ Procurement Organization or donation service area of waitlisting; and patient insurance type. However, even with correction of these characteristics, there is an 18% lower transplantation rate for African Americans compared to non-Hispanic whites. (Higgins and Fisherman 2557)

Although biology may play a role in transplantation, social factors seem to contribute more. The measure taken by the OPTN attempted to level the playing field but it does

little to account for the non-biological barriers that prevent African Americans from even being placed on the waitlist. Improved donor matching is obsolete without addressing the other barriers.

The first step for kidney transplantation is patient education and knowledge of an alternative to hemodialysis. However, lack of education about transplantation has been cited as a barrier that contributes to fewer African Americans being transplanted. A study by Jones et al. shows:

The 2 most commonly cited reasons by African Americans and Hispanics for not having a transplant evaluation were that they did not understand the benefits of transplantation or transplant process, both of which are modifiable with education. Studies have found that once African American and Hispanic patients' transplant knowledge improved there was an increase in their willingness to pursue transplantation. (5)

African Americans are ill-informed about their medical options, which deprives them of their decision-making capacity. Advising patients about their health care options occurs in the doctor-patient encounter. The foundation of this encounter is shared decision-making, but this is difficult without effective communication. Ayanian and Clearly et al. found that "blacks may be more likely than whites to encounter problems communicating with their physicians and may have less trust in the healthcare system" (1667). This communication barrier is not inconceivable considering possible cultural differences in communication styles and that the majority of health care workers are white. Without appropriate communication and knowledge patients do not have the capacity to make informed decisions about their health.

Even if patients are able to access transplant centers, they face difficulty in meeting all the prerequisites to get placed on the transplant list. These prerequisites

include appointments with multiple physicians, laboratory draws and radiologic testing.

When assessing patient barriers to transplantation Watchman et al. found:

The most common was the time-consuming pre-transplantation evaluation process, which previous research indicates may be a greater barrier for African Americans, who have lower rates of pretransplantation evaluation completion than whites. Importantly, the tone with which many participants discussed the transplantation evaluation and allocation process suggested underlying mistrust in the equity of the process...Tests and appointments were often perceived as hoops to jump through, described by some as if they were intentional barriers to transplantation. (244)

In most cases these patients are on dialysis, which already limits their free time. This also does not take into account employment and family obligations patients may have, such as taking care of loved ones and children. Social factors intersect to make obtaining health challenging for minority patients. Kasieke et al. explain:

Education, language, economics, and subtle cultural barrier may also combine with financial hardship to make it more difficult for minority patients to pursue aggressively and ultimately undergo transplantation. Many health care workers may not be aware of or adequately trained to deal with socioeconomic factors that may make it difficult for minority patients to undergo transplantation. (304)

The health care system makes false assumptions about the ‘standard’ patient’s health literacy, language, income, and social support network that leads to disparities. Until these social determinants of health are addressed qualified transplant candidates will unnecessarily remain on dialysis or continue to be wrongly deemed unfit for transplantation.

## CHAPTER 5

### ORGAN ALLOCATION

In the previous section I described the disparities in evaluation for transplantation. Now I will describe how the kidney allocation system further perpetuates these disparities. There are several qualifiers that decide a patient's eligibility and placement on the waiting list. The kidney allocation system greatly factors waiting-time into transplantation. This is based on the principle of 'first come, first served'. Thus, if African Americans are not referred or evaluated early before placement on dialysis, they lose critical time they could have accrued on the waiting list. "First-come, first-served allows morally irrelevant qualities--such as wealth, power, and connections-- to decide who receives scarce interventions, and is therefore practically flawed" (Persad 424). The patients who benefit from this principle are those who already experience privilege. This process ignores all the complex social issues that limit access to general health care and transplant care which is explained above. It instead leads to widened disparities when some privileged patients are listed at multiple transplant center locations. "Prospective transplant recipients, seeking to improve their chances for transplants, often undergo evaluation at various transplant centers across the nation. Each center has its own protocols and criteria for evaluation on who they will accept and where they are placed on their transplant wait list (Moore 5). Meanwhile, many African Americans struggle to even be listed at one site.

The transplantation system conceals itself behind the idea of medical democracy which varies from the reality of African American patients. Medical democracy says "all potential transplant patients are equally deserving of replacement organs. Further all

citizens are entitled to equal access to these unusual commodities” (Sharp 142).

Therefore, the foundation of allocation systems must be fair, and physician encounters with potential transplant candidates must be uniform. But disparities are evidence that this is untrue. Sharp explains:

The medicalized social worth assigned both to organ donors and living recipients is far from uniform, where the myth of medical democratization squelches debates about medical justice. Although the language of equal opportunity is pervasive, the ideals of democratization may nevertheless operate as a potent form of silencing with variable results. Whereas such rhetoric is designed to combat racist sentiments, ironically it also obstructs open discussions of race and culture. (149)

It is hard to have conversations about inequality within a system that prides itself on being equitable. However, in the face of mounting disparities in kidney transplantation, the kidney allocation system has proven itself to be unjust. The distribution of organs is far more complicated than the principles on which the allocation is placed, in specific ‘first come, first served’. There are structural inequalities within the American health care and organ transplantation system. Patients with a myriad of social barriers are ill-equipped to navigate the system and many providers lack the empathy or awareness of these social factors to fix the system.

## CHAPTER 6

### DISPARITIES AND BARRIER TO ORGAN DONATION

As previously described, there are disparities and barriers to organ transplantation in African Americans. Likewise, organ donation poses obstacles for African Americans. The total percentage of African American donors in 2018, both cadaver and living, was 12.5%, which is equal to the proportion of African Americans living in the United States (“National Data”). But African Americans carry a higher burden of kidney disease than other ethnicities. According to Hart et al., “White donors continued to donate most living donor kidneys (70%); proportions of black living donors declined from 13.4% in 2005 to 9.6% in 2016” (4). Living donor kidney transplantation (LDKT) is especially important because it has been shown to increase survival over cadaveric donation by shortening or eliminating the waitlist time and even allowing patients to receive transplants even before dialysis (Lunsford et al.). At first glance this seems like a possible solution to the disparities in kidney transplantation but barriers exist. “Barriers to living donation in African Americans are not well known, but studies have reported on the barriers to cadaveric donation. Distrust of the medical system, less access to care, lack of education, religious myths and racism have all been suggested as possible barriers” (Lunsford et al. 325).

One of the largest barriers to organ donation is knowledge which is linked to health literacy. This includes lack of awareness of living donor transplantation options for patients. Purnell et al. state:

A large proportion of the reduced rate of LDKT among all racial-ethnic minority groups was attributed to differences in predialysis care measures. Suboptimal predialysis care may contribute to poor provider-patient and

providers-family communication regarding full range of treatment options. Limited communication during this critical phase prior to ESKD onset appears to associate with less knowledge about the benefits of LDKT. (1559)

Patients are unaware of their options involving their health. Nevertheless, little has been done to overcome the barriers to both living and cadaveric organ donation in the African American community. Siminoff and Sturm state:

Current national and state-wide organ procurement policies have failed to increase the rate of African American donors to a level on par with White Americans--African Americans agree to donate at about half the rate which White Americans agree to donate--let alone to a level sufficient to meet the actual demand for organs. (61)

Public health policies and multidimensional community-based interventions are needed to help end the disparities in organ donation and transplantation.

However, even when opportunities present themselves for African American patients to be cadaveric donors, they are not adequately utilized. Hartwig found that, "Staff are less likely to request organ donation from African Americans, and the failure to request is due to failure to identify them as potential donors" (1334). Similar to organ transplantation there is a component of health care provider bias that inhibits organ donation. Hartwig states, "Avoidance behavior is created by lack of understanding of another culture's beliefs and family structure and can lead to reciprocal alienation between African American families and white health care workers" (1334). This further reinforces the need for culturally competent health care providers and the importance of the doctor-patient relationship.

## CHAPTER 7

### MISTRUST

African American mistrust has been cited by many scholars as a possible factor in the multitude of health care disparities experienced by African Americans. As stated above, distrust of the health care system has also been identified as a barrier in the realm of organ transplantation. But to understand mistrust in organ transplantation, we must first understand the role of African American mistrust in general within the American health care system.

African American mistrust is the result of a fractured relationship with the American health care system. From their introduction to medicine African Americans have been objectified and their bodies used as ‘a mere means’ to an end. This was made possible by the fact that African Americans were not seen as human but as property based on the social construct of race. For decades they carried the burden of medical experimentation without the benefits of its advances. Health care and medical science have even been used to prove inferiority and better delineate racial hierarchy. Health care, like society, was carefully segregated. As a result, I argue that the experience of race is engrained in the health care experience for many African Americans. “Slaves served both as instructional material for teaching medical students and as a source of entertainment at medical conventions” (Randall 196). This is displayed by early gynecological experiments performed on female slaves and exhibits like that of Sarah Baartman, an African woman whose body was put on display because of its juxtaposition to the White body as spectacle across Europe. The role of objectification on the medical gaze plays a role in trust of the health care system.

There are the well-publicized stories of the Tuskegee Syphilis Trial and Henrietta Lacks. These stories legitimize issues of mistrust and resonate through the community's consciousness. "The Tuskegee study served to reinforce the belief in the African American Community that the distrust of the medical system was not merely an historical issue" (Randall 198). It took decades to uncover the injustice of Tuskegee. There are likely other untold stories of inequity within the American health care system.

African Americans' beliefs that their lives are devalued by white society also influence their relationships with medical profession. They perceive at times correctly, that they are treated differently in the healthcare system solely because of their race, and such perceptions fuel mistrust of the medical profession. (Gamble 1776)

Systemic oppression and racism experienced by African Americans infiltrates all aspects of their lives, including health care. These constant assaults no doubt lead to mistrust. Smedley, Stith and Nelson state, "Discrimination in healthcare settings, as evidence by providers' overt behavior...or subtle, subjective mistreatment...can affect patients' feelings about their clinical relationships and thereby dampen their interest in vigorous diagnostic and therapeutic measures" (131-132). When patients do not trust their providers, they question their intentions and the validity of their treatment recommendations. This lack of care as a result of mistrust can inadvertently lead to worse health and thus disparities.

Experience of racism and discrimination, both actual and perceived, from health care providers who have a duty to treat all people negatively affects future health care interactions.

African Americans have experienced something that others have not: the unique combination of racism, slavery and segregation...Distrust of the health care system by African Americans runs from the feelings of ill

gains for participation in clinical trials to being used only as guinea pigs. (Kennedy, Mathis and Woods 57)

Understanding this narrative is essential to understanding the unique world-view of African Americans. Randall states while quoting Harris Leonard, “For African Americans, the combination of slavery, segregation, and racism have given us a different set of ‘intervening background assumptions about such essential bioethical concepts as personhood, bodily integrity, the moral community, fulfilling lives and utility’” (192). When general bioethical principles have a history of not applying to you, you have a hard time trusting the system.

Health care institutions and physicians have power, for example the power to offer or refuse treatment. These power dynamics affect the doctor-patient relationship and when power is used inappropriately it can lead to fractured trust. “Trust in turn is identified as a fundamental element of the physician-patient interaction” (Kennedy, Mathis and Woods 58). Trust is the backbone of any therapeutic relationship.

Trust is a multidimensional construct that includes perceptions of the health care provider’s technical ability, interpersonal skills, and the extent to which the patient perceives that his or her welfare is placed above other considerations. Trust is an important determinant of adherence to treatment and screening recommendations and the length and quality of relationships with health care providers. (Halbert et al. 896)

The patient experience and sick role are unique. These positions often require you to give up power, but if you do not trust the person within the relationship, this can be detrimental to the pursuit of health or wellbeing.

With African American distrust in the general health care system as described above, it comes as no surprise that African Americans’ mistrust affects organ transplantation. “The inequalities experienced by African Americans in their overall

dealings with the health care system might negatively affect African Americans' willingness to donate organs" (Siminoff et al. 1000). Transplantation medicine is unique in that it deals particularly with bodily integrity and embodiment ethics. When there is a distinct history of objectification and consumerism of your body it is hard to entrust it. There is no guarantee that when you are the most vulnerable your body parts will not be seen as a commodity for someone else. "Blacks had more negative attitudes than whites toward how the healthcare system deals with organ donation and transplantation in general. They are less likely to believe that they will be treated fairly" (Siminoff, Lawrence, Arnold 150). Similarly, "African Americans express greater concerns about the trustworthiness of the health care system, both in general and in terms of the donation system specifically" (Siminoff et al. 999). Unfortunately, this mistrust can further perpetuate disparities in kidney transplantation.

## CHAPTER 8

### SOLUTIONS

One of the solutions to African Americans' mistrust of the health care system is best accomplished using an urban bioethics framework. Urban bioethics is one of very few disciplines that accounts for the intersectionality of social factors such as race, sexuality, gender and social economic class in health care. This is accomplished by using the urban bioethics principles of agency, solidarity, and social justice.

Agency is the capacity for patients to take make decisions and advocate for themselves. This differs from the general bioethics principle of autonomy because it takes into account that not everyone is given the equal opportunity to make a decision for themselves as a result of social factors such as race because of issues of racism and discrimination. This is particularly important because as I previously argued, race is engrained in the African American experience of health care. Solidarity is mutual support or unity with the understanding that we do not live in isolation of each other but in symbiotic relationships, whether we realize it or not. Social justice focuses on the concept of equity rather than equality. Social justice recognizes that not everyone starts from the same position, and because of social factors some members are allotted privilege. In this context African Americans are disadvantaged because of systemic racism and discrimination that affects every aspect of American society including health care.

For African Americans in particular, experiences of racism and discrimination have led to issues of mistrust as described in the previous section. This mistrust is grounded in centuries worth of objectification and unethical behavior. Unfortunately, this mistrust perpetuates morbidity and mortality in the African American community. The

burden to resolve this mistrust cannot fall solely on African Americans. King explains while quoting Howard McGary:

One could argue that individual and collective mistrust of the health care system by African Americans, to the extent that it results in inadequate diagnosis and treatment, is their own responsibility. This is to ignore however, that ‘what will count as reasonable will depend upon people’s past experiences, the likelihood and extent of the possible harm, and the resources that are available to cope with any bad eventualities’. (79)

The solution to African Americans’ mistrust of health care is a social justice rooted in solidarity. Decades of injustice from a society and culture that devalued difference has built a mountain of distrust; thus, collective effort is the only thing that can tear it down. Thus, America has an obligation to undo its wrongs.

African Americans have a broken relationship with health care that has been built on discrimination, mistreatment, and disparities. The only way to fix this relationship is by health care engaging with African Americans in a different way inside and outside the walls of the hospitals. The doctor-patient encounter can be restricting with its location and time constraints. Community engagement allows for a permissive environment. Thus, it is important for health care providers to step out of their ‘ivory tower’ and into the communities they serve. Community engagement is essential to dismantling power structures within health care and building solidarity.

The National Minority Organ Tissue Transplant Education Program (MOTTEP) is a community-based program that focuses on community engagement to increase awareness about organ donation and transplantation amongst minorities. The program is unique because it specifically targets obstacles found in a community survey which are similar to those listed previously including lack of awareness, religious myths, distrust of

the medical community, fear of premature death, and racism (Callender et al.). The program has “ethnically similar persons educated and empower the community with personal testimonies and culturally sensitive messages which encourage the community to sign donor cards, have family discussions and leave organs/tissues behind after death” (Callender et al. 1482). The program has led to improvement in minority donations. Because of the programs success it has now incorporated disease prevention in order to decrease the number of African Americans who get ESRD.

More culturally sensitive programs like MOTTEP that specifically target barriers in the African American community are needed. It is also essential that they incorporate health care providers, in particular transplant teams including the nurses and surgeons, within local communities to build relationships and trust. These programs can also become more successful by incorporating existing community organizations that have a legacy of trust within the communities like the NAACP, Black fraternal organizations, and places of worship. These techniques can also be used to target patients with ESRD not on transplantation lists, to increase awareness, education, and agency.

Physician bias plays a significant role in the care and access of patients to organ transplantation as well as new medications and novel health care treatments. If the physician is the gate keeper his or her own implicit and explicit bias affects the care of the patient and further reinforces the paternalism of the doctor-patient relationship. This in turn contributes to disparities. Siminoff and Sturm argue that:

Instituting changes in the training of individuals who approach families for organ donation in order to dispel the myths about African Americans and organ donation may lead to better good faith efforts on the part of those making the request and more sensitive approaches to the request process.  
(70)

In order to eliminate bias, physicians must be trained in cultural competency and communicating with culturally diverse populations.

Experience with health care providers who communicate well (eg: use direct and empathetic communication) may improve patient trust among both populations. Thus, interventions that focus on improving physician behaviors, such as communication skills and partnership building, may improve trust among African Americans and whites. (Halbert 900)

Communication by providers is integral to patient health. It cultivates agency amongst black patients and has the potential to decrease disparities.

A critical component of communicating with diverse populations is cultural competency. In 2000, the licensing board for medical education started requiring medical students to be culturally competent upon completion of their medical education. Although most medical schools offer cultural competency education, there is no standardized curriculum or clear understanding of what cultural competency means. As a result, many physicians leave medical school understanding pathophysiology but not the complexity of human interactions or the role their gaze and subjectivity play on the patient encounter. Perhaps this is made worse by the fact that most medical school faculty and students are not culturally diverse. “Racial and ethnic diversity of health professions faculty and students helps to ensure that all students will develop the cultural competencies necessary for treating patients in an increasingly diverse nation” (Smedley, Stith and Nelson 123). One important and sometimes forgotten component of cultural competency is increasing the diversity of health care providers and educators.

Part of the complexity of cultural competency is that one’s culture is not stagnant but a continuously evolving experienced based on how groups of people interact with

each other. This is why cultural competency education must not only occur once but ought to continue throughout one's medical career in the form of standardized education for medical residents and continuing medical education for attending physicians. Jernigan et al. offer two other education concepts that include cultural humility and structural competency that more align with longitudinal education:

Cultural humility posits that one can never be fully competent in another person's culture. Instead one must undertake a lifelong commitment involving self-evaluation, self-critiquing, and redressing power imbalances... Structural competency, which addresses institutional biases and emphasizes the importance of examining the structural determinants of physician-patient interactions, such as the health care delivery system, location clinics... hours of clinic operation, urban and rural infrastructure. (163)

These concepts provide a holistic view of how to take care of the complete patient including the complex social structures that influence their health and thus the understanding of social justice and equity. It incorporates the social determinants of health that are essential to patient care.

Furthermore, institutions such as transplant centers and allocation organizations must also take an active role in acknowledging concepts of cultural humility and structural competency. Now that disparities involving African Americans have been defined, there must be a conscious and continual effort to eliminate barriers to care. This could include educational seminars about the importance of early referral to nephrologist and transplant centers and early integration of social workers or navigators who can actively work with patients to address issues of transportation and health literacy. There must also be democratic deliberation with communities about organ transplantation and allocation and ways to improve the system and build trust. It is also essential to

acknowledge concepts of embodiment and ensure that not only 'healthy' people are engaged in decision making involving transplantation of the 'sick'.

## CONCLUSION

The organ transplantation system operates under the assumption that America is an idealistic society where everyone has equal and just access to health care. It also falsely presents itself as a medically democratic system. However, when examined in a social context it is obvious that disparities impede the access of those with social 'disease' such as poverty and non-majority race to a scarce and limited resource. Fixing disparities in transplantation will require that allocation be dedicated to concepts of social justice. Social justice is particularly important because transplant medicine is communal. Improving organ transplantation incidence, will also require intensive community engagement initiatives directed at African Americans that are collaborative rather than passive. Finally, it will require some reflection on the part physicians who have knowingly and unknowingly contributed to this health crisis through implicit and explicit biases. The fact is that transplantation is not functioning at its potential. Instead, the allocation structure serves as another reflection of the dysfunctional American health care system. But the system can be fixed with conscious and continued efforts rooted in the concepts of urban bioethics.

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