Racial Disparities in Renal Transplantation

Racial Disparities in Selecting Patients for Renal Transplantation

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ACRONYM LIST

- CKD: Chronic Kidney Disease
- ESRD: End-stage renal disease
- OPTN: Organ Procurement and Transplantation Network
- SRTR: Scientific Registry of Transplant Recipients
- SES: Socioeconomic status
- CDC: The Centers for Disease Control and Prevention
- LDL: Low Density Lipoprotein
- HLA: Human Leukocyte Antigens
- MHC: Major Histocompatibility
- NKF: National Kidney Foundation
- UNOS: United Network of Organ Sharing
- AAKP: The American Association of Kidney Patient
- PCP: Primary Care Physician
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ABSTRACT

Chronic Kidney Disease (CKD) is the slow progressive loss of kidney function. CKD slowly gets worse over time and the loss of function usually takes months to years to occur. The final stage of CKD is called end-stage renal disease (ESRD). At this stage, the kidneys are no longer able to remove wastes and excess fluids from the body and therefore, the patient will need dialysis or a kidney transplant (Churak, 2005; Feldman, Klag, Chiapella, & Whelton, 1992).

Research has repeatedly revealed the existence of racial disparities in use of renal transplantation where Caucasian patients have an advantage over other groups. The disparities are evident in patient accessibility to kidney transplantation and in placement of patients on the renal transplantation waiting list. Despite high rates of CKD and ESRD in minority groups, these groups are less likely to access renal transplantation compared to Caucasian patients. The evidence gathered from a comprehensive literature review suggests that Caucasian patients in United States have greater access to renal transplantation, leading to the hypothesis that the disparity in selecting patients for renal transplantation is a consequence of racial discrimination. This racial disparity may be more circumstantial than intentional. However, this has not been fully researched and determined.

Reviewing data from the Organ Procurement and Transplantation Network (OPTN) and Scientific Registry of Transplant Recipients (SRTR) Annual Report for 2010, it becomes apparent that racial disparities continue to exist in renal transplantation (OPTN & SRTR, 2012). The report shows that most racial groups; including Caucasians, African Americans, and Hispanics have gained in absolute numbers of donations received.
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from deceased and living donors; only Asians have not increased in their number of organ donations received. Despite the increase in the total numbers of donations to all the patients, the rates of transplantation remained highest among Caucasians at 66%, while other ethnic and racial groups received less than 15% of needed transplantations. The reasons for the disparities are not obvious, because an increase in living donations is evident and a policy change in 2003 had expanded organ acceptance (OPTN & SRTR, 2012).

To minimize or eliminate the racial gap in renal transplantation rates, recommendations for leadership include changes designed to facilitate minority patients being placed on the transplantation waiting list early. It is recommended that standardized protocols be established to explain and offer the option of renal transplantation for appropriate candidates at the time of initiating permanent dialysis. A second recommendation is to improve the waiting list process by developing a regional network that increases the opportunity for those on the waiting list to receive an organ. A third recommendation is to establish guidelines for living donor kidney transplantation, especially for African American patients. This can be achieved by developing education programs for donors and patients to encourage the use of living donor organs. The fourth and final recommendation is to plan future research to explore the reasons behind the persistence of racial disparities in renal transplantation despite policy change and increases in living kidney donations. Possible actors to implement those changes will include physician and nephrologists’ associations, the American Association of Kidney Patients, the National Kidney Foundation and the United Network for Organ Sharing.
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INTRODUCTION

Health care disparities have been present in accessing health care leading to some racial groups being unable to receive care at the same level as other groups. Existence of racial disparities in the health sector has been explained partially by racism, socioeconomic status (SES), unfavorable geographical location, lack of organ donation by minority groups, differences in social networks, and differences in health beliefs culture (Churak, 2005). Minority groups are the most adversely affected, as evidenced by kidney transplantation, where Caucasians have greater access to kidney transplantation and have a greater likelihood to gain a place on the transplantation waiting list in the United States of America. This leads to the hypothesis that racial disparities exist in the selection of patients for renal transplantation.

Available literature revealed differences in racial prevalence of CKD; where African Americans are 4.0 times more likely to have kidney disease than Caucasians, followed by Hispanics at 2.8 times the rate of Caucasians (Churak, 2005). Similarly, the African American population has consistently suffered from a greater than 3.5 higher rate of ESRD than has the Caucasian population. The rates of hypertensive and diabetic ESRD are all substantially greater in African Americans than in Caucasians, and hypertension has accounted for a far greater proportion of ESRD in African American than any other diagnosis (Feldman et al., 1992).

There is a paucity of national data on the occurrence of ESRD in Hispanic Americans. However, data from Texas strongly suggest that the incidence rate of treated ESRD is much higher in Mexican Americans than in non-Hispanic Whites (Feldman et al., 1992). Native Americans experience ESRD at a rate intermediate between those of
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whites and blacks, but their rate of diabetic ESRD is higher than in either blacks or whites (Feldman et al., 1992).

Renal transplantation is one of the areas with identifiable racial disparities in access and delivery of health care. Patients from minority groups especially African Americans have a disadvantage compared to Caucasian patients (Epstein et al., 2000; Furth et al., 2000). The problem is further complicated by the fact that chronic kidney disease and end stage renal disease are disproportionately represented in different racial groups, with those with little access having greater representation such as African Americans, and Native Americans (Epstein et al., 2000; Gadegbeku, Freeman, & Agodoa, 2002; Isaacs et al., 2000; Kucirka, Grams, Balhara, Jaar, & Segev, 2012; Myaskovsky et al., 2012; Patzer, Perryman, et al., 2012; Schold et al., 2011).

Based on available literature, minority groups not only suffer from disproportionate prevalence of kidney disease, but also from poor access to renal transplantation, an indication that racial discrimination might exist in renal transplantation (Churak, 2005). Therefore, this paper will investigate the issue of racial disparities in renal transplantation. The issue will be addressed using a comprehensive literature review, and data review from OPTN and SRTR. I will then discuss the findings and offer leadership recommendations to help approach this critical issue.

LITERATURE REVIEW

Definition of Health Disparities

The Centers for Disease Control and Prevention (CDC) defines health disparities as “preventable differences in the burden of disease, injury, violence, or opportunities to achieve optimal health that are experienced by socially disadvantaged populations”
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(CDC, 2011). Expanding on the definition of health disparities, the National Conference of State Legislature defines health disparities as “population-specific differences in the presence of disease, health outcomes, quality of health care and access to health care services that exist across racial and ethnic groups. Health disparities reflect the inequitable distribution of resources among different groups with minority groups in terms of race, ethnicity, gender, sexual orientation, disability, location, and education being disadvantaged (NCSL, 2011).

**Racial Disparities in CKD and ESRD**

Documentation of health disparities in medical conditions such as kidney transplantation reveals racial and ethnic differences (Churak, 2005). These disparities are also evident in conditions leading to renal transplantation such as chronic kidney disease and end stage renal diseases (Gadegbeku et al., 2002). The Healthy People 2010 report provides a critical overview of health indicators for kidney disease in the United States population, identifying the disproportionate disease burden of minority racial groups and their greater risk of chronic kidney disease (HealthyPeople, 2010). The report revealed that African Americans have a disproportionate overall risk for chronic kidney disease and they progress to end stage renal disease earlier compared to Caucasian patients with a comparative age of 55.8 years versus 62.2 years respectively.

The annual increase in end stage renal disease is higher among minorities compared to that of the Caucasians. Asians rank highest at 11%, followed by American Indians at 10%, and African Americans at 7%, while the increase in Caucasian patients is 6%. The American Indians according to the report, will continue to have new cases of end stage renal disease at accelerated rates compared to other racial groups, with two communities, Zuni Pueblo in New Mexico and Sacaton in Arizona, being
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disproportionately represented. Available data used in the report also indicates that Hispanics are at a greater risk of developing chronic kidney disease and end stage renal disease compared to other groups because of high rates of diabetes in the group (HealthyPeople, 2010).

The Healthy People report also discussed the rates of ESRD among population groups in the United States, although the statistics used are old as they are based on data from on late 1990s (1997-1999). Although African Americans represent approximately 12.6% of the United States population, they have an ESRD burden of 29.8%, while American Indians represent 0.9% of the United States population; they have a 1.7% burden for ESRD. When compared with Caucasians, it was found that African Americans are 4.5 times more likely to have ESRD while American Indians are 3.7 times as likely to develop ESRD. Similar comparisons with Asian Americans also revealed higher rates compared with Caucasians (HealthyPeople, 2010).

Causes of Racial Disparities in Renal Transplantation:

There is growing evidence that racial and ethnic disparities exist in renal transplantation. The minorities will constitute nearly half of the United States population by the year 2050. Therefore, racial differences in end-stage renal disease and kidney transplantation rates will likely be exaggerated and thus will have important implications on the quality and quantity of life and on the cost of healthcare for minorities in the future. Many factors were suggested as possible causes for this disparity. Those factors include (Churak, 2005).

1. Racism
2. Age
3. Socioeconomic Status (SES)
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4. Unfavorable geographical locations
5. Social Networks and health beliefs culture
6. Patients’ interest in transplantation
7. Living organ donation
8. Physician bias
9. Clinical appropriateness
10. Biologic factors

Racism

Three types of racism have been identified as possible causes of racial disparities in kidney disease in general and kidney transplantation in particular (Hood, 2001). The first type is interpersonal racism, which is defined as discrimination and prejudice to which persons are subjected based on their ethnicity or race (Hood, 2001). The second type is internalized racism, which is defined as the acceptance of stereotypes held by others (Hood, 2001). The third and last form is institutional racism, which is defined as formal and informal practices, policies, and/or procedures that cause differences in access to opportunities and resources due to a person’s race or ethnicity (Hood, 2001).

Wolfe et al. compared waitlisting and transplantation rates by gender, race, and diabetes and evaluated the physiologic factors related to renal transplantation (panel-reactive antibodies, blood type, HLA matchability) and related transplantation practices (early and multiple waitlisting) as potential explanatory factors to disparities in renal transplantation. The study revealed that differences in renal transplantation rates in different were not explained by referral practices and other factors used in their study (R. A. Wolfe et al., 2000).
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Garg et al. revealed that African Americans were less likely to be listed than Caucasians even after adjustment for differences in health status and socio-demographic characteristics (Garg, Diener-West, & Powe, 2001). The authors concluded that the race might have independent negative impact on renal transplantation rates.

**Age**

Racial disparities in renal transplantation exist among both adults and children. Furth et al. conducted research to assess the potential causes of racial differences in pediatric kidney transplant waiting lists using a sample of children and adolescents with ESRD (Furth et al., 2000). The purpose of the research was to investigate the role of racial disparities - among other factors - responsible for increased time to transplantation in African American pediatric patients. The authors hypothesized that the increased time to transplantation in African American pediatric patients is attributed, not only to a shortage of suitable donor organs, but also to racial differences. This national longitudinal cohort study considered children less than 19 years old who were Medicare eligible. The outcome indicated that African American patients had less opportunity to be placed on the wait list at any given time, from initial dialysis to placement on the waiting list, when compared to Caucasian patients. When the researchers controlled for age, gender, socio-economic status, geographic region, ESRD cause, and year of incidence for renal failure, African Americans had 12% less opportunity for being placed on the waiting list compared to Caucasians. The researchers recommended additional research to determine factors causing the disparities in terms of physician bias when identifying patients qualifying for transplantation, preferences of parents, and differences in time of presentation of the patient to nephrologists (Furth et al., 2000).
Chesney and Wyatt investigated renal transplantation disparities in children where they compared patients with end stage renal disease in Israel with those of the United States of America (Chesney & Wyatt, 2003). The researchers hypothesized that the access for renal transplantation in Israel was equal for Jewish and Arab while it is different in the United States between Caucasians and other racial groups. In the case of the United States, the article indicated minimal disparities among the different racial groups of children aged 0-19 years in regard to deceased transplants for patients on dialysis. In relation to gender, the number of Caucasian males was 15 per 100, 17.5 for African Americans, 17.5 for Native Americans, and 25 for Asian males. The rates for the girls were 15 for Caucasian, 11 for African American, 16 for Native America, and 21 for Asian females. However, Caucasian children had greater opportunity for living-related transplants, at three times that of African American children. Furthermore, 70% of Caucasian children received a transplant within two years on dialysis compared to 44% of African American children. The difference is associated with higher living-related transplants among Caucasian patients compared to African American patients. The authors concluded that racial disparities in relation to deceased transplants might not be critical; however, an overview of entire transplantation population indicates critical disparities (Chesney & Wyatt, 2003).

Patzer et al., researchers at the Divisions of Transplantation Surgery at Emory University School of Medicine, based their research on data generated between 2000 and 2008 from the United States Renal Data Systems and followed to September 2009 (Patzer, Amaral, et al., 2012). The researchers examined the persistence of racial disparities and investigated the role of socio-economic status in the pediatric patients with ESRD in the United States. Their research revealed differences between Caucasians,
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African Americans, Hispanics, females, and poor neighborhood children below 21 years of age. Of the 8,452 patients included, 30.8% were African American, 27.6% white-Hispanic, 44.3% female, and 28.0% lived in poor neighborhoods. A total of 63.4% of the study population were placed on the waiting list, of whom 32.5% received a deceased donor transplant. Racial disparities persisted in transplant even after adjustment for socioeconomic status, where minorities were less likely to receive a transplant compared to whites, and this disparity was more pronounced among patients 18-20 years old (Patzer, Amaral, et al., 2012).

The Healthy People Report 2010 revealed discrepancy in renal transplantation through different age groups. The report indicated that the renal transplantation rates in the pediatric age were 19% for African American females compared to 26% for Caucasian females (HealthyPeople, 2010). The racial discrepancies were more evident in the group aged 20 to 44 years, where African American males have a rate of renal transplantation of 7 per 100 patient years compared to 17 for Caucasian males, and 7 for African American females compared to 15 for Caucasian females. In this age group, the male patients show greater disparities though overall differences are greater when considering combined numbers of African American male and female patients versus combined numbers of Caucasian male and female patients. The trend continues in 45 to 65 year olds, where for every four African American male patients receiving renal transplantation, eight Caucasian male patients receive the same, while for every two African American female patients, six Caucasian females receive renal transplantation (HealthyPeople, 2010).
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**Socioeconomic Status (SES)**

Socioeconomic status is a powerful factor contributing to the racial disparities in kidney transplantation. Churak defined SES as “the level of attained education, occupation and income” (Churak, 2005). Studies showed that patients listed for transplant were better educated, more often Caucasian, employed, and more likely to have health insurance (Isaacs et al., 2000; Kasiske, London, & Ellison, 1998). One study was done by Ozminkowski et al., revealed that high income patients were 1.5 times as likely as middle-income patients to be listed on the deceased waiting list (Ozminkowski, White, Hassol, & Murphy, 1997). In addition, the high-income patients were 2.5 times more likely to receive a kidney transplant than middle-income patients and five times more likely than low-income patients (Ozminkowski et al., 1997). Another means by which socioeconomic status contributes to renal disparities is via its effect on health education. Studies showed that minority and low-income populations receive less or no education about kidney transplantation as a treatment modality for ESRD as Caucasians and high-income populations (van Ryn & Fu, 2003).

Patzer et al., researchers at the Divisions of Transplantation Surgery at Emory University School of Medicine and GA Children's Hospital of Philadelphia, based their reseach on adult patients referred for renal transplant evaluation at a single transplant center in the Southeastern United States from 2005 to 2007 and followed through May 2010 and followed transplant receipients. (Patzer, Perryman, et al., 2012). The authors observed racial disparities in access to referral, transplantation evaluation, wait listing and organ receipt. Socioeconomic status (SES) explained almost one-third of the lower rate of transplant among African American versus Caucasian patients, but even after adjustment for demographic, clinical and SES factors, African Americans had a 59%
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lower rate of transplant than Caucasians. One limitation of the study was using a single transplant center with subsequent questions about generalization. The authors concluded that while SES explained some of the racial differences, African Americans had a significant lower rate of transplant than Caucasians even after accounting for demographic and SES factors (Patzer, Perryman, et al., 2012).

The effect of SES factors on access to the waiting list of renal transplantation was confirmed by Hall et al., who revealed that adjustment of health insurance coverage and zip code poverty accounted for 18% of the reduced rate of transplant among African Americans and 14% of the reduced transplant rate among Hispanics. Once on the waiting list, however, health insurance and zip code poverty accounted for little of the racial disparities, indicating that SES influences the earlier step of access to the waiting list, but may not play a significant role after placement in the waiting list (Hall et al., 2011).

Unfavorable geographical locations

Unfavorable geographical location is identified as a factor affecting access to kidney transplantation and, hence, adding to the racial disparities in kidney transplant (Held, Pauly, Bovbjerg, Newmann, & Salvatierra, 1988). The patients who live in poor neighborhoods have normally few or substandard medical services (Bach, Pham, Schrag, Tate, & Hargraves, 2004). Limited transportation is identified as a barrier to transplantation for American Indians and Alaskan natives since many of them reside in rural settings (Ayanian et al., 2004). Other ethnic groups who reside in urban settings may have problems with transportation and as a result they develop advanced co-morbidities, which would negatively impact their transplant candidacy (Ayanian et al., 2004).
Social Networks and Health Beliefs Culture

Social networks play a role in the disparities of kidney transplantation. Sets of relationships between members of a social group make up a social network (Arthur, 2002). A diverse network may provide greater access to information and resources and ease a patient’s transition and adjustment to new circumstances (Arthur, 2002). The social network theory suggests that people in higher socioeconomic groups are more likely to have a heterogeneous social network, whereas lower socioeconomic groups are more likely to have a homogeneous social network (Arthur, 2002). According to the social network theory the Caucasian patients with ESRD have greater social resources acquired through a multitude of weak tie networks (Arthur, 2002). On the other hand, African Americans tend to rely more than Caucasians on strong ties with their family, immediate community and church (Arthur, 2002). These strong community ties may weaken the African American resources for renal transplantation and will make it less likely for them to know people who have donated an organ or signed an organ donation card (Arthur, 2002). Furthermore, it was shown that people with strong religious beliefs like African Americans are less likely to pursue or be listed for transplant (Holley, McCauley, Doherty, Stackiewicz, & Johnson, 1996).

Patients’ interest in Transplantation

The personal interest in transplantation is associated with multiple factors that include inadequate transplant education, distrust of the healthcare system, depression, uncertainty, fatalism, feelings of helplessness and the observation of other patients’ transplant failures (W. A. Wolfe & Toomey, 2004). The failure of other patients’ transplants has a strong negative impact on some minority patients’ decisions, especially African Americans, to pursue a kidney transplant (W. A. Wolfe & Toomey, 2004).
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**Living Organ Donation**

Minority opposition to organ donation is well documented in the literature and is attributed to multiple factors. Lack of information about the need for transplants, distrust of the medical profession, a belief that donating organs will not benefit other minorities and perceived religious beliefs all play a part in the low organ donation rates in minorities (Held et al., 1988). African Americans consider spirituality and religion important components in their lives, and some religious beliefs require that the body of the deceased be kept intact (Satcher, 1999). Some minorities fear that their life will become less valuable if they are organ donors or that they would receive inadequate care during the donation period (Satcher, 1999). Some researchers recommended encouraging living donations as means to reduce the racial disparities in renal transplantation (Waterman, Rodrigue, Purnell, Ladin, & Boulware, 2010).

**Physician bias**

Some studies revealed that African Americans live longer than other minority populations on dialysis (Young & Gaston, 2000). On the other hand the survival of the transplanted kidney in African Americans is worse in comparison to Caucasians (Gaston, Ayres, Dooley, & Diethelm, 1993; Young & Gaston, 2000). Some may inappropriately interpret these factors and conclude that kidney transplantation is not as appropriate in African American as in Caucasians (Georgi et al., 1996; Held et al., 1988). The option of transplantation may, therefore, not be offered and, hence, reluctance from some of the health care providers to recommend transplant upfront or for the patient to accept upfront (Young & Gaston, 2000). While older African American patients may do better in dialysis, it was found that younger African American patients do worse on dialysis compared to Caucasian patients (Callender, Maddox, & Miles, 2006). The misconception
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occurs because data showing positive indications of dialysis fails to consider the numbers of African Americans that stay on dialysis. 10% of African American patients on dialysis receive transplantation and 90% remain on dialysis, compared to 20% transplantation and 80% dialysis for Caucasian patients. This means the healthy African American patients are staying on dialysis, whereas healthy Caucasian patients are being transplanted, thus the misconception (Callender et al., 2006).

On the other hand, Gao et al., conducted research on racial differences in chronic kidney disease and showed no evidence of physician bias when using a uniform health care system (Gao et al., 2008). The researchers used a clinical database of more than 13,000 beneficiaries of the Department of Defense where race independently correlated with provider compliance with selected Kidney Disease Outcomes Quality measures. Their findings showed that in a uniform health system, the provider compliance with selected CKD targets was not significantly lower for African American beneficiaries than for Caucasians with the exception of low density lipoprotein (LDL) cholesterol monitoring. Patients classified as other race were generally less likely to achieve targets than Caucasians. The researchers concluded from this finding that uniform health care could be useful in reducing racial disparities in health care (Gao et al., 2008).

Clinical appropriateness

Some researchers suggested that racial disparities in renal transplantation stem from differences in clinical characteristics that affect appropriateness as well as from underuse of transplantation among African Americans and overuse among Caucasians. Epstein et al, researchers at the Departments of Medicine and Health Care Policy at Harvard University School of Medicine, developed criteria for determining the appropriateness of renal transplantation for patients with end-stage renal disease (Epstein
et al., 2000). The authors based their criteria for appropriateness on the presence or absence of factors constituting absolute or relative contraindications to kidney transplantation. They rated transplantation candidates based on “appropriateness” as follows: appropriate (no contraindications), inappropriate (one or more absolute contraindications or three or more relative contraindications), or equivocal (one or two relative contraindications). The researchers based their research on data from five states and the District of Columbia and included patients who had started dialysis in 1996 or 1997. The study revealed that African American patients were less likely than Caucasian patients to be rated as appropriate candidates for transplantation and were more likely to have had incomplete evaluations. Among patients considered to be appropriate candidates for transplantation, African Americans were less likely than Caucasians to be referred for evaluation, to be placed on a waiting list or to undergo transplantation. Under patients classified as inappropriate, Caucasians had a better opportunity for being referred for evaluation, placed on the waiting list and undergo transplantation compared to African American patients in the same category. Based on the evidence, the researchers concluded that racial disparities in renal transplantation exist with differences in clinical characteristics affecting appropriateness and underuse of transplantation among African American patients and overuse among Caucasian patients (Epstein et al., 2000).

**Biologic Factors**

Biologic factors such as Human Leukocyte Antigen (HLA), ABO blood type and Major histocompatibility (MHC) put minorities pursing a kidney transplant at a significant disadvantage (Churak, 2005). HLA matching is a known factor that contributes to racial and ethnic disparities in kidney transplantation (W. A. Wolfe & Toomey, 2004). HLA matching is the primary determinant of kidney allocation.
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Significant racial differences in antigen expression exist with African Americans having less defined HLA antigenic specificities than do Caucasians. Hence the distribution of HLA antigens differs among races (W. A. Wolfe & Toomey, 2004). The closer the HLA antigen match, the more likely the kidney will not be allocated to a minority because the majority of donated kidneys are from Caucasians (W. A. Wolfe & Toomey, 2004).

There is known racial differences in the distribution of ABO blood types with African Americans having higher prevalence of blood type O than Caucasians. Given the necessity for blood type compatibility, patients with blood type O have a lower rate of kidney transplantation than patients with other blood types (Koyama & Cecka, 1991; R. A. Wolfe et al., 2000).

Minority transplant candidates are also more likely than their Caucasians counterparts to have significant anti-major histocompatibility (MHC) reactivity, which prohibits transplantation from some donors (Koyama & Cecka, 1991).

Recommendations to improve Racial Disparities in Renal Transplantation

Evidence of racial disparity led some researchers to examine and investigate ways to reduce disparities for chronic kidney disease, end stage renal disease, and renal transplantation. Some of those solutions include implementation of uniform access to health care (Norris & Nissenson, 2008) and encouraging living-related donor transplantation (Chesney & Wyatt, 2003). Patzer et al., recommends examining the factors responsible for increasing the racial gap in access to renal transplantation especially between Caucasian and African American patients (Patzer, Amaral, et al., 2012).

Waterman, et al. supported the recommendation of encouraging living donor kidney transplantation as a way of addressing kidney transplant disparities among racial
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groups (Waterman et al., 2010). The authors suggested that increasing awareness of living donors may encourage acceptance and donation of kidney thus enabling minority groups disadvantaged in cadaveric kidney transplantation to attain kidneys. Many factors may play a role in enhancing living donor transplantation, including the personal values of the patient, extended social networks, the health care system, and community perception. There is need to educate patients, donors, and providers on efficient use of living donor kidney transplantation, and addressing financial and surgical barriers affecting this form of transplantation. Suggested ways to improve living donations and use are development of transplant education tailored to accept cultural differences, putting in place practice guidelines for clarifying eligibility for transplant, partnerships between community kidney providers and transplant centers, and conducting community outreach and media campaigns (Waterman et al., 2010).

Navaneethan and Singh addressed the issue of racial disparity in renal transplantation from a different prospective. The main objective of their study was to generate better evidence-based understanding of the barriers that impede access to renal transplantation among African Americans in the United States (Navaneethan & Singh, 2006). They identified two categories of barriers that include patient and health care related barriers. The patient-related barriers included personal and cultural beliefs about transplantation, lower socioeconomic status and levels of education. The healthcare-related barriers included physician perception about survival of African Americans post-transplantation, inadequate transplant work-up despite being referred, and HLA (human leukocyte antigens) mismatching status. The authors recommended establishment of an approach focusing on these barriers to reduce disparities in renal transplantation in the United States (Navaneethan & Singh, 2006).
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A positive movement in reducing racial disparity was accomplished in 2003 with the reversal of renal allocation policy that gave African American patients greater opportunity to access a new organ from a cadaveric donor that was previously unavailable (Hall et al., 2011). The donor-recipient pairs with matching HLA have less risk of subsequent transplant failure. As such, priority points historically have been given to candidates with matching HLA subtypes to the proposed donor. However, at the same time, HLA subtype matching was thought to amplify racial disparity in rates of deceased donor kidney transplant because of different distributions of HLA subtypes and donation rates in different racial groups. Prior to the reversal, Caucasian patients had a higher likelihood of attaining a living kidney transplant compared to African Americans. The role of HLA became less important in matching with the advancement in immunosuppressive medications that led to fewer organ rejections. The advancement in immunosuppressive medications and the decreasing role the HLA in the matching process helped in changing the policy. Before the reversal, African Americans were 37% less likely to get a cadaveric transplantation, but this has improved to 23% since the policy change. However, despite the improvements brought by policy change in narrowing the gap to access, disparities continue to exist as an attribute of patient and health provider related factors, such as patient’s reluctance to accept organ offers from certain people (Hall et al., 2011).

Basic Data about Renal Transplant from OPTN and SRTR

The literature review revealed the existence of racial disparities in the use of renal transplantation where Caucasian patients have an advantage over other groups. Findings from OPTN and SRTR Annual Data Report from 2010 confirm these disparities (OPTN & SRTR, 2012). The report presented data on renal transplantation waiting lists,
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donations from deceased donors, and donations from living donors for the period 1998-
2009 (OPTN & SRTR, 2012). The report also highlights the demographic attributes of all
patients and contains statistics regarding patients who underwent transplantation while on
the waiting list and those removed from the list because of death.

Figure 1: Adult patients waiting for a kidney transplant

**Waiting List:** According to the OPTN & SRTR Annual Data Report, there has been a
small but steady increase in the number of new patients added to the waiting list for a
deceased donor kidney (Figure 1). In 2003, a major OPTN policy change allowed
patients on the list to accrue waiting time while inactive. Before 2003, an unknown
number of patients on the list had been listed as active so they could accrue waiting time,
even though they would not have accepted a kidney offer. After 2003, without this
incentive to list inactive patients as active, the number of patients listed as inactive grew
incrementally. Nevertheless, the growth in the total number of patients on the waiting list
has been almost linear, suggesting that the growth in inactive listings since 2003 is indeed
an artifact of the OPTN policy change (figure 1) (OPTN & SRTR, 2012).
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Figure 2: Waiting time for a kidney transplant

During the period 1998–2009, the increase in the number of patients on the deceased donor waiting list without a corresponding increase in the number of organs donated led to a relative decline in the transplant rates. This decline has particularly affected minorities, who tend to wait longer. Waiting times differ by region and group, but tend to be longer for minority groups than for Caucasians (figure 2).

This increase in patient numbers led to changes in the age, gender, and racial profile of the deceased donor kidney transplant waiting list. The representation of different ethnic groups in this patient population has changed: the number of Hispanics and Asians has increased, the number of Caucasians has decreased and the number of African Americans remained relatively stable in the period 1998–2009 (figure 3).
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Figure 3: Distribution of adult patients waiting for a kidney transplant
Number of unique patients on wait list counted on the Dec. 31 of each year

As of December 31, 2009, patients over the age of 45 constituted 73.7% of the entire waiting list. Caucasians have the highest racial representation on the waiting list at 38.1%, followed by African Americans at 34.9% Hispanics at 18.0% (figure 4A and 4B)

Figure 4 A: Characteristics of adult patients wait-listed for a kidney transplant on 12/31/2009
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Deceased Donations: Donation by the deceased is one of the primary ways of providing a kidney to a recipient (OPTN & SRTR, 2012). Kidney donation from cadavers has increased in the last decade. Caucasians, African Americans, and Hispanics have similar rates of donation, while Asians donate at lower rates. It is saddening to find that kidneys from deceased donors have a very high discard rate, with the discard rate from older donors is approaching 60% (Figure 5).

Figure 4 B: Characteristics of adult patients wait-listed for a kidney transplant on 12/31/2009

Figure 5: Kidney donations from deceased donors per million populations
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**Living Donations:** Another method of providing kidneys for transplantation is through living donation, which is higher among Caucasians and lowest among Asians. The rate of living donations increased every year from 1998 to 2004, declined from 2005 to 2008 and increased 7.0% in 2009 compared to 2008 (Figure 6) (OPTN & SRTR, 2012). Substantial geographic variation remains in the rates of living kidney donation with the highest rates seen in north central US lowest in the southeast.

![Figure 6: Kidney donations from living donors](image)

Overall, adult kidney transplantation increased by approximately 34% from 1998–2006, with living donor transplants showing the highest increase (51%) and deceased donor transplants also increasing by 26%. The overall increase in transplantation from 2008–2009 was not enough to meet the needs of patients on the waiting list, as indicated by a 3.2% decline in the number of patients on the waiting list in 2009 (Figure 7) (OPTN & SRTR, 2012).
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Figure 7: Total adult kidney transplants (includes kidney-pancreas)

DISCUSSION

The selection of recipients for donated kidneys has traditionally favored Caucasian patients, particularly prior to the 2003 policy change that reduced the importance of HLA in kidney recipient determination (Hall et al., 2011). Compatibility of donated organs also seems to be higher with Caucasian patients, evidenced by the fact that they are more likely than African American patients to receive donated kidneys on the basis of HLA matching (Chesney & Wyatt, 2003; Furth et al., 2000; Navaneethan & Singh, 2006). Caucasian patients also have a higher likelihood of being eligible for renal transplantation based on clinical appropriateness than other groups, and they have greater opportunities for complete evaluations and referrals (Epstein et al., 2000). Both clinical appropriateness and HLA criteria inadvertently favor Caucasian patients, thereby providing them more opportunities to receive donated kidneys compared to other racial groups. Caucasian patients have greater opportunities for renal transplantation and use those opportunities more. However, the disparities in selection seem to be more circumstantial as opposed to being planned.
Furthermore, Caucasian patients are more likely to be placed on the renal transplantation waiting list than are African Americans (Furth et al., 2000). Therefore, Caucasian patients have a better opportunity to receive a kidney transplant by virtue of being on the transplant waiting list for cadaveric kidneys.

Racial disparities in renal transplantation outlined in the OPTN & SRTR Annual Data Report 2010 are smaller than expected from the literature review (OPTN & SRTR, 2012). However, Caucasians continue to have greater opportunities to receive donated kidneys because of their high numbers in the waiting list as compared to the other groups, a disparity that was identified in the literature review (Epstein et al., 2000; Furth et al., 2000). While the literature review indicated racial disparities in donations, particularly between African Americans and Caucasians (Waterman et al., 2010), the OPTN & SRTR report shows similarities in kidney donation rates between whites, African Americans, and Hispanics, with Asians showing lower rates of both deceased donation and living donation (OPTN & SRTR, 2012). Nevertheless, similarities in kidney donation rates did not translate into actual transplantations: differences persisted in transplantation rates, with whites having the highest rate for both deceased donation and living donation at 66.0% (OPTN & SRTR, 2012). The OPTN & SRTR showed that the transplantation rates for Hispanics, African Americans, and Asians are 14.6%, 14.0%, and 4.5%, respectively (OPTN & SRTR, 2012). These values confirm previous findings (Navaneethan & Singh, 2006; Patzer et al., 2012) on the existence of racial disparities in transplantation (Navaneethan & Singh, 2006; Patzer, Amaral, et al., 2012).

The high number of the Caucasians in the waiting list will give partial explanation to the racial disparities observed from the OPTN & SRTR report. Nevertheless, the report does not critically analyze the reasons why racial disparities exist. Further research is
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needed to identify factors that continue to exacerbate racial disparities in renal transplantation, particularly considering positive developments such as an increase in living donor transplants and expanded criteria donor, which allowed more deceased donors to be available the minorities.

**LEADERSHIP RECOMMENDATIONS**

The literature review and data analysis from the OPTN & SRTR annual report indicates that Caucasian patients have a greater opportunity than other groups to be selected for renal transplantation. The 2003 policy change was a step in the right direction that increased opportunities for African American patients to receive kidney transplants. However, disparities continue to exist, and this gap needs to be addressed (Hall et al., 2011). Many solutions that address the racial disparities in kidney transplantation were identified in the literature review. Those solutions include:

1. Increase the numbers of kidney transplantations from living donors (Chesney & Wyatt, 2003; Waterman et al., 2010).
2. Better understanding the personal and health factors that increase disparities in transplantation to better address them (Patzer, Amaral, et al., 2012)
3. Improve the performance of primary care providers with respect to early identification of chronic kidney disease (Muthyala, Sahmoun, Tendulkar, & Danielson, 2011), and
4. Provision of uniform access to kidney transplantation (Gao et al., 2008).

These recommendations emphasize the roles of leaders in reducing disparities by improving the organization of the waiting list, encouraging living kidney donations through providers, and providing donor and patient education.
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Placing patients on the waiting list at an early stage is critical to hastening the transplant process and overcoming potential racial disparities in transplantation. Although 35.6% of the persons on the kidney transplant waiting list are African-American, African-American persons account for only 21.9% of those who receive kidneys (Siminoff & Arnold, 1999). Furthermore, African American patients get on the waiting list almost 2 years later than Caucasian patients (Epstein et al., 2000). Epstein et al. attributed this disparity to multiple reasons that include a lack of information given to black patients, failure to make convincing arguments on the need for renal transplantation early in the course of kidney disease, personal biases, and stereotypes (Epstein et al., 2000). Although they should begin earlier, discussions on transplantation for black patients primarily occur after they enter stage-four chronic kidney disease or while they are on dialysis.

The United Network for Organ Sharing encourages physicians to begin discussing transplantation with patients at the onset of permanent dialysis with the goal of enrolling patients in the transplant waiting list at that time, irrespective of whether the doctor has indicated a need (Callender et al., 2006). Callender et al. recommended adopting the example of Europe where patients are placed on the kidney transplant waiting list as soon as they are permanently on dialysis (Callender et al., 2006). Stakeholders like the National Kidney Foundation (NKF), and the United Network for Organ Sharing (UNOS) can play an important leadership role by creating guidelines and policies suggesting that physicians and nephrologists discuss the option of transplantation with potential candidates at an early stage. Adoption of these recommendations would help to eliminate the racial disparities in waiting list enrollment and waiting time, thereby giving both African American and Caucasians patients a fair opportunity to receive renal transplants.
Another role for leaders with respect to the waiting list is the establishment of networks that can facilitate organ transport to compatible patients in order to increase the chances of a transplant being provided to a patient on the waiting list. Organizations such as the United Network for Organ Sharing (UNOS), the American Association of Kidney Patients (AAKP), and the National Kidney Foundation (NKF), together with associations established by nephrologists and physicians, can be instrumental in the creation of regional organ transport networks. The regional transport networks would bring states together and facilitate agreements under which available organs without matching patients in the local areas of the donors could be given to other patients in the regional networks. These arrangements would increase transplantation opportunities for all people on the waiting list, whether African Americans or Caucasians.

Another role for leaders in eliminating racial disparities in renal transplantation is to encourage living donations in appropriate settings. Some researchers have suggested this as a possible mechanism to reduce racial disparities in renal transplantation (Waterman et al., 2010). UNOS, AAKP, NKF, and physicians’ associations will play an important role in encouraging living donations, particularly by developing practice guidelines to ensure effective and adequate recruitment of potential donors. The guidelines will also need to suggest education for potential donors and patients in the event that patients are to be able to recruit donors and receive donated organs. The education materials could include topics such as eligibility requirements for donations, cultural perceptions of patients, communities, and donors, and the fears of donors. Waterman et al. mention the importance of culturally tailored education and community outreach in making living donor transplantation an effective mechanism of reducing racial disparities in renal transplantation (Waterman et al., 2010). Stakeholders in renal
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transplantation need to identify factors affecting rates of living kidney donations and establish mechanisms that increase rates of living kidney donations by addressing those factors.

**LOGIC MODEL:**

I developed a logic model to assist in identifying, documenting, and evaluating the contributing factors to the racial disparity in kidney transplantation. The model will help in implementing the leadership recommendations discussed above to reduce and eliminate the racial disparities observed in kidney transplantation. The model will identify the underlying problem, determine the goal and objectives, and will specify the inputs, expected outcomes and output measures (Figure 8).

**The problem:** Research in the last few years revealed the existence of racial disparities in renal transplantation where Caucasian patients have an advantage over other racial groups.

**Goals:** The primary goal is to reduce or eliminate racial disparities in renal transplantation. The secondary goal is to increase the number of living donations especially from minorities.

**Objectives:** Will include reduction of racial disparities by:

- Increase the living donations in minorities by 30-40% in two years
- Increase the percentage of minorities in the waiting list by 30-40% in two years
- Formation of regional organ transport networks to provide uniform access to kidney transplantation by December 2014.

**Inputs:**

The inputs will include the resources that will be used to implement the recommendations. Those resources include human resources, fiscal resource and other
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inputs required to support the program like national transplant organization, knowledge base for the program and involvement of different collaborators. The above-mentioned resources needed to conduct the recommendations should be articulated during the early stages of the program development to insure that a program is realistically implemented and capable of meeting its stated goals. The inputs will include:

General nephrologists: Their roles include early referral of patients with chronic kidney disease and end stage renal disease for evaluation of kidney transplantation.

Transplant nephrologists: Their roles include early placement of eligible patients in the waiting list regardless of their race.

Dialysis centers clinics: Their roles include early education and referral of patients with end stage renal disease to be evaluated for renal transplantation.

UNOS, AAKP, NKF and Other physician associations: Their role is creation of guidelines and policies suggesting that physicians and nephrologists discuss the option of transplantation with potential candidates at an early stage. Those organizations can also help in creation of regional organ transport networks, which can bring states together and facilitate agreements under which available organs without matching patients in the local areas of the donors could be given to other patients in the regional networks.

Volunteers and community representatives: Their role is to help in tailored education and community outreach.

Activities:

The Activities needed to achieve the objectives will be divided into assessment, plan, implementation and evaluation as described below.

1. Assess
   - The status of living donation
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- The dialysis center resources
- The resources of primary care physicians

2. Plan

- Formulate educational programs about the renal transplantation according to the available resources.

3. Implement programs

- Education of patients with chronic kidney disease about the importance of early referral for transplantation evaluation.
- Education of the patients with end stage renal disease during dialysis sessions about renal transplantation and offer early placement in the waiting list if no contraindication.
- Education of primary care physicians about the importance of early referral of patients with chronic kidney disease for evaluation or renal transplantation.
- Establishment of networks that can facilitate organ transport to compatible patients
- Tailored education and community outreach

4. Evaluate

- The program evaluation will be done through assessment of the output measures, which will be mentioned later.

Outcomes:

The outcomes can be divided into short-term, intermediate and long-term outcome.

Short-term outcome:

- Increased referral of CKD patient from primary care physicians
- Increased educational sessions of CKD patients
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- Increased educational sessions in the dialysis units
- Increased educational sessions in the community
- Establishment of networks that can facilitate organ transport to compatible patients
- Tailored education and community outreach

Intermediate outcome

- Improve the performance of primary care providers in early identification of CKD
- More patients (esp. minorities) with CKD evaluated for transplant
- More patients (esp. minorities) with ESRD evaluated for transplant
- More patients (esp. minorities) placed in the waiting list in early stage
- Increase community awareness of living donations

Long-term outcome

- Reduce racial disparity in kidney transplantation
- More living donations in minorities
- Providing uniform access to kidney transplantation

Output measures: to evaluate the outcomes will include:

- Annual review of rates of living kidney donation
- Annual feedback from stakeholders
- Monthly Internal dialysis center monitoring systems
- Assess feedback from patients every three months
- Annual analysis of cost effective analysis

CONCLUSION

Health disparities exist due to differences in socioeconomic status, geographic location, resource distribution, and race. There are identifiable racial disparities in access
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to and delivery of renal transplants: patients from minority groups have a disadvantage compared to Caucasian patients. Caucasian patients have a higher likelihood of qualifying for renal transplantation compared to African American patients, and Caucasian patients have greater opportunities for being placed on the renal transplantation waiting list. Caucasian patients have greater chances of being compatible with donated organs than African American patients because many cadaveric donors are Caucasians. On the other hand, Caucasian patients also have greater chances of securing living donors than African American patients.

Many courses of action, particularly at the level of leadership, need to be taken in order to overcome racial disparities in renal transplantation. Recommended courses of action include changes in how patients are placed on the transplantation waiting list, with early placement being advised for all patients, and the introduction of networking to accommodate people on the waiting list. Possible actors include UNOS, NKF, AAKP, and physicians’ or nephrologists’ associations. Another recommendation is to improve donor and patient education regarding living donor kidney transplantation, particularly among African American patients. In order to achieve this, it is important to establish guidelines for healthcare providers regarding the appropriate use of living donor kidney transplantation.

Racial disparities in renal transplantation enumerated in the OPTN & SRTR Annual Data Report 2010 seem smaller than expected from the literature review, and the report fails to provide a clear explanation of the etiology of those disparities. The reasons for the disparities are not obvious, because an increase in living donations is evident and a policy change in 2003 had expanded organ acceptance. Future research could also
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consider factors contributing to low donation rates and transplantation rates among Asians compared to other minority groups such as African Americans and Hispanics.

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