Health Disparities in Kidney Transplantation: An Equity Analysis

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ABSTRACT
The growing incidence of end stage renal disease along with advances of the past 40 years that have improved the success rate of kidney transplantation have created an unprecedented demand for kidney transplant. Yet, certain racial and ethnic groups and women consistently have longer waiting times and lower rates of transplantation which makes a review of the kidney procurement and transplantation system in view of its equity imperative. Reasons given for these disparities have varied from cultural attitudes and beliefs on the part of patients and health care providers, socioeconomic status, rates of organ donation, and geographic location. The equity conceptual framework has proven itself to be a useful guide in identifying the symptoms of disparities in the procurement and organ allocation system but further studies are needed to identify the etiology of these disparities and target effective interventions and policies.

Key Words: equity, kidney transplantation, health disparities

INTRODUCTION
It has been predicted that by 2015 the annual incidence of end-stage renal disease (ESRD) will be 136,166 patients, the prevalence will be 712,290, and 107,760 deaths per year will occur among this population (Gilbertson et al, 2005). As a result of the rapid rise in ESRD, the demands for dialysis and transplantation have also dramatically increased. This has led to concerns about the availability and equitable allocation of kidneys for transplantation. With improvement in the area of immunosuppressive drug therapy and surgery, the success rate of kidney transplantation has greatly improved making it the primary choice of care for ESRD because it offers a longer life expectancy than dialysis (Organ Procurement and Transplantation Network [OPTN], 2005). Kidney transplantation is associated with an increase in quality of life and a decrease in healthcare cost (Gonzalez-Perez, Luke, Stearns & Wordsworth, 2005). However, access to transplantation is limited for the economically disadvantaged and certain racial/ethnic populations.
Inequalities in kidney transplantation rates have been documented for ethnic populations, women, and low-income groups (Garg, Diener-West, & Powe, 2001a; Garg, Diener-West, & Powe, 2001b; Soucie, Neylan, & McClellan, 1992). ESRD is five times more likely to occur in African Americans, four times in American Indians / Alaska Natives and three times as likely in Hispanics (American Society of Nephrology [ASN], 2004; US Department of Health & Human Services [USDHHS], 2002; United States Renal Disease System [USRDS], 2005). The increase in waiting times is another concern because graft outcomes worsen with the duration of ESRD (Norman, 2005). Racial and ethnic groups and women consistently have longer waiting times for a kidney transplant (Kronkosky Charitable Foundation, 2008).

Reasons given for these disparities have ranged from difficulty in finding human leukocyte antigens matches, cultural attitudes and beliefs on the part of patients and healthcare providers, socioeconomic status, rates of organ donations to geographic location (USDHHS, 2002). Access to kidney transplantation is also limited because of the shortage of donor organs, variation in selection criteria, medical compatibility, co-morbidity, geographical factors, and socioeconomic barriers (Healthy People 2010, 2000; Stolzmann et al, 2007). Since fewer than 35% of the patients waiting can be transplanted each year, the distribution and allocation of the limited number of available kidneys are a constant source of debate. Because of the improvements in kidney transplantation survival and the increasing need for organs, a review of the kidney procurement and transplantation system in view of its equity and health disparities is imperative.

Equity Conceptual Framework and Criteria

The equity conceptual framework as outlined by Aday, Begley, Lairson, and Balkrishnan (2004) in Evaluating the Healthcare System, is a useful tool in assessing national and community access and health disparities. This conceptual framework is grounded in the paradigms of:

- Distributive justice – freedom of choice and cost effectiveness of healthcare services,
- Social justice – similar treatment, common good, and need across populations, and
- Deliberative justice – participation of affected parties in decision-making.

With this theoretical base, equity is concerned with maximizing the fairness in the distribution of healthcare and minimizing the disparities across groups. Through the examination of and accounting for difference, the framework seeks to measure health disparities.

Designing a health system that is optimized by policy requires a critical review and analysis of that system’s equity. As Aday et al. (2004; p.3) phrased it, “the ultimate test of the equity of health policy is the extent to which disparities or inequalities in health persist among subgroups of the population.” The process of defining the problem requires specific criteria and measurements. The definition of the problem and solutions must be guided by underlying concerns about social conditions. This type of analysis entails delineating the scope, severity, causes, and importance of the problem.

Equity is related to the characteristics of the delivery system, population, the use of services, and satisfaction with those services (Aday et al, 2004). The framework requires an examination of both procedural and substantive equity. In evaluating procedural equity, the focus should be placed on the type and extent of the affected group’s participation in the formation and implementation of policies and programs. The distribution of providers, facilities and payment sources as well as the availability and type of organizations and financing of these services must be explored. The population at risk (predisposing, enabling and need factors), environmental conditions (physical, social, and economic), economic (cost-effectiveness in terms of utilization and satisfaction), and health risks factors (environmental and behavioral) are essential to this type of appraisal. The substantive equity assessment should focus on the health needs of the community and patients. Specific attention should be given to clinical indicators and population rates. All of these areas can be evaluated at the
system, institutional and community level (Aday et al, 2004). To evaluate the usefulness of the framework, it was used to appraise the procedural and substantive equity of the kidney procurement and transplantation system.

**PROCEDURAL EQUITY**

**Deliberative Justice**

*Health Policy - Participation:*

To address the nation’s critical organ donation shortage and improve the matching and placement process, the United States Congress passed the National Organ Transplant Act of 1984 (P.L. 98-507). This act established the Organ Procurement and Transplantation Network [OPTN] to maintain a national registry for organ matching. The act called for a unified network to be operated by a private, non-profit organization under federal contract. The OPTN is responsible for all policies and bylaws that govern the procedural aspects of policy development, allocation of donated organs, and the collection of transplant data nationwide. All policies and bylaws of the OPTN must be forwarded for review and approval by the Secretary of the U.S. Department of Health and Human Services before becoming binding under the authority of federal regulation (OPTN, 2006). The public is included in the process of developing consensus based policies and procedures through solicitation of feedback by means of the “public comment”. Policy proposals approved by the Board of Directors are widely distributed for public comment prior to final policy implementation. The distribution list includes: transplant professionals, health policy analysts, patients, government officials, transplant community, and interested individuals from the general public. Individuals and families directly affected by organ donation and transplantation have two avenues of participation - via the “public comment” process or “transplant community” input. Members of the general public with a particular interest in donation and/or transplantation can also become members of the OPTN (OPTN, 2006).

**Distributive Justice**

*Delivery System – Freedom of Choice:*

**Availability:** Currently there are 58 organ procurement organizations [OPO] across the United States that provides organ procurement services to 252 transplant centers. To facilitate kidney transplantation the US is divided into 11 geographic regions. These regions play a role in organ allocation. With the exception of perfectly matched donor kidneys, organs are offered to sick patients within the area in which they were donated before being offered to other parts of the country. This helps to reduce organ preservation time, improve organ quality and survival outcomes, reduce the costs incurred by the transplant patient, and increase access to transplantation. Each OPO must develop and implement a plan to address a diverse population related to organ donation (OPTN, 2009).

The state of Texas has 26 transplant centers. Four Regions of the state have no transplant centers; three Regions have one center; and the other Regions range from 5 to 2 centers (Texas Department of Health Kidney Health Care [KHC], 2005). The number of centers correlates with KHC recipient demographics that show more than half (62%) of the recipients live in the larger urban areas where as, the rural and predominate Hispanic regions such as the Lower Rio Grande Valley for 3,141 recipients, have one transplant center (KHC, 2005).

**Organization:** The selection of a candidate for kidney transplantation has considerable variability across transplant centers. Practicing nephrologists must complete an evaluation, refer the patient to a transplant center, and prepare the candidate for successful early transplantation. The transplant center will run a number of tests and consider the patient’s mental and physical heath, as well as his or her social support system. If the center determines that the patient is a transplant candidate, they will add the patient’s medical profile to the national patient waiting list for organ transplant...
(Transplant Living, 2009). Candidates on the waiting list require periodic reviews while ascending the wait-list and thorough repeat evaluations. The nephrologist is an indispensable component in the evaluation of candidates for kidney transplantation, from referral to the transplant center to eventual transplantation (Sandling, 2005).

Despite survival and improved quality of life with transplantation, according to Owen (2003) most eligible ESRD recipients in the US had not been placed on a transplant waiting list 6 months after beginning dialysis. The registration for kidney transplantation for dialysis patients under the age of 70 still falls below the Year 2010 Healthy People objective – “25% of dialysis patients will be placed on the kidney transplant waiting list.” In 2006, the breakdown of registration was: American Indian or Alaska Native – 11.6%, Black/African Americans – 12.3%, Hispanics – 15.3%, White – 17.7%, Male – 17.2%, and Female – 14.5% (CDC, 2009). Patients referred late for a transplant evaluation cannot undergo pre-emptive kidney transplantation (Owen, 2003). The late timing of referral to a nephrologist and placement on the a waiting list have been contributed to physician bias and their belief that transplant would not improve survival for ethnic patients (Ayanian et al, 2004; Owen, 2003; Stolzmann et al, 2007). The National Kidney Foundation (NKF) has initiated a campaign to raise awareness among physicians for early referrals to nephrologists; this in turn may lead to early referral for transplantation (NKF, 2006).

The allocation of a cadaveric donor kidney is based on the allocation policies established by the OPTN Board of Directors (OPTN, 2006). It dictates that kidneys should be allocated to patients with the greatest need for a transplant or who would benefit most. According to Norman (2005) the data has shown that the system discriminates against African Americans, who represent about 35% of the kidney waiting list. The data also show that African Americans have the lowest graft survival of all the races. Geographic area plays a part in the distribution of kidneys. Because of the cross-matching requirement, potential damaging effects of long cold ischemia times, and the expense of transporting kidneys, cadaveric kidneys are distributed to the local list first, then to a regional list, and finally, if no suitable recipients is found, to the national list (OPTN, 2009). There is a payback requirement which dictates that an organ procurement organization that receives a shared kidney must pay back a kidney through the Organ Center (Norman, 2005). The allocation of kidneys is either based on a point system or waiting list.

Financing: Kidney transplants are the least expensive of all organ transplants with a cost between $25,000 and $30,000. Medicare covers all reasonable expenses with the exception of the Part A and the Part B 20% co-insurance for kidney transplant. Medicare also covers immunosuppressive medications for three years after kidney transplant. Congress has extended this coverage for the life of the transplanted kidney if the patient is eligible for Medicare due to age, or receives Social Security Disability Income (ESRD Network, 2006). In Texas to assist with the gaps in Medicare coverage, the KHC program provides financial assistance for hospitalization, medications, and transportation costs incurred with transplantation. In 2004, KHC covered 10% of the total client services expenditures for living donor with an average per recipient of $1,924 and 23% for cadaveric donor transplant with a per recipient of $1,988 (KHC, 2005). All costs related to the donation of organ transplants are paid for by the donor program.

Realized Access-Cost-effectiveness

Utilization: Survival rates have steadily improved with kidney transplant. Patients who receive kidney transplants have a longer life expectancy than dialysis patients. One year patient survival rates were highest for kidney recipients, ranging from about 97% (living donor) to 90% (cadaveric donor); corresponding survival for liver, intestine, and heart recipients was approximately 84% to 82% for liver, about 82% for lung, and lowest for the small number of heart-lung recipients with around 75% surviving at one-year. Five years survival rates from living donor were 80% and 68% with cadav-
eric donor (USDHHS, 2007). The percentage of transplanted organs that are still functional (graft survival) at one year (89% cadaveric & 95% living donor) and five years (66.7% cadaveric & 80.2% living donor) are lower than other organ survival rates because kidney patients may survive a graft failure by receiving a second transplant or with alternative therapy such as dialysis (OPTN, 2005).

All patients who are transplanted do not have the same waiting list times. Waiting time is defined as a function of the amount of time it takes to provide transplants for a percentage of the total number of new registrants (OPTN, 2009). For example, in 2006, it took 368 days to provide kidney transplants to 25% of those waiting with 7,873 of the 31,495 registered receiving a transplant within one year of registration. In Texas, 28,291 of the 98,263 people on the waiting list received a transplant (OPTN, 2007). The median waiting list times are dependent on the ABO blood group (the four principals blood types: A, B, AB, & O), race, level of sensitization, and geography (Norman, 2005). The risk of late referral is greatest for African Americans and Native Americans. Most transplant recipients have not been placed on a transplant waiting list 6 months after beginning dialysis (Healthy People 2010, 2000; Owen, 2003; Stolzmann et al, 2007). Time spent waiting for a cadaveric transplant varies by transplant centers with the median time on the waiting list being 39 months. The median waiting time is much shorter for children and adolescents. They are similar for men and women but somewhat less for whites than people of color (USRDS, 2005). The time waiting is also much shorter with a living donor (ESRD Network, 2006). Another reason for such long waiting period is the shortage of organs available for transplantation. In 2006, the kidney organs recovered were 6,434 living donor and 10,212 deceased donor (USDHHS, 2007).

**Satisfaction:** Kidney transplantation studies have shown that patients notice improvements in their global quality of life, especially physical function. The data suggest that after transplantation patients recover a portion of the capacities that they had before the chronic kidney failure, because the transplant allows a less restrictive diet and way of life, better use of time, and improved mobility. Except for the medications and routine consultations, patients have the opportunity to redirect their interests and activities. They have a better chance to apply for jobs, because they do not need to undergo dialysis (Lazzaretti, Carvalho, Mulinari, & Rasia, 2004).

**Distributive and Social Justice**

**Population-at risk: Similar treatment**

The shortage of donors has created inequalities in access to kidney transplantation. Patients in California and the Southwest have a longer waiting time for a transplant than patient in the North Central states. People of color tend to wait longer than whites and women wait longer than men. Donation rates for deceased donors have changed little and remain lower for women and African Americans but living donation rates have increased. More women are living donors than men. The rate of living donor is similar between Hispanics and whites but remains low for African Americans (USRDS, 2005, KHC, 2005). Of the 27,961 kidney transplant performed in the United States in 2008, 20% were among Blacks, 13% among Hispanics and 1% among American Indians/Alaska Natives. Women made up only 37% of those transplanted while 63% were males (OPTN, 2009).

Because of the lack of available donors in this country, 7,191 kidney patients died in 2006 while waiting for life-saving organ transplants (NKF, 2006, USDHHS, 2007). Of the transplants performed in 2008, 16,517 were kidney alone. In Texas, the number of people on the waiting list as of May 2009 was 4,375 male, 3,351 female, 1,880 white, 1,898 black, and 3,687 Hispanic. Of the 1,276 transplants performed in 2008, 35% were among whites, 22% blacks, and 34% Hispanics. In terms of donor type, 33% were from living donors and 67% cadaver donors (OPTN, 2009). Hispanic recipients received transplants from 170 living donors and 325 cadaveric donors while white recipients received transplants from 196 living donors and 256 cadaveric donors. Yet, African Americans recipients only received transplants from 44 living donors and 231 cadaveric donors (OPTN, 2009).
Social Justice

Environment – Common good:

Recognition of and care for chronic kidney disease (CKD) will influence the survival of ESRD patients and thereby reduce their need for transplantation. Hypertension control can reduce the rate of progression of CKD to ESRD as well as reduces the risk of cardiovascular complications. Anemia management in CKD has been found to be of benefit. Timing of the initiation of renal replacement therapy is another critical component to reducing the need for transplantation. And the management of rehabilitation, vocational and preventive health services is deficient in the care of the CKD patients (Owen, 2003). Improving the healthcare delivery for CKD patients may decrease the number of ESRD patients and thereby lessen the need for transplantation.

Health Risk - Need:

Diabetes and hypertension have been found to be the most common cause of kidney failure in both Texas and the US. Diabetes as a primary diagnosis accounted for 38% of the cases in 1994 and increased to 52% of new cases in 2008. Of the Texans with kidney failure due to diabetes 68.7% were among Hispanics. African Americans were disproportionately affected by hypertension (40%) as the primary cause. The percentage of women with a primary diagnosis of diabetes was higher than that of males, but males with a primary diagnosis of hypertension continued to outnumber females (KHC, 2004).

SUBSTANTIVE EQUITY

Health - Need:

Survival probability for kidney transplant recipients has increased largely due to improvement in surgical techniques, greater specificity of immunosuppressive therapies and better long-term medical management. Overall, patients have an expected 15 years remaining life with transplantation (USRDS, 2005). The mortality rate is highest among the first four months after transplantation. Thereafter the death rate due to cardiovascular disease, followed by infections and malignancies are relatively constant throughout the post transplant period. However, donor factors are associated not only with graft survival but also higher mortality. Use of an Expanded Criteria Donor Kidney (ECD), a low or unmatched kidney, is associated with higher mortality rate. Transplanting kidneys with hepatitis C are associated with an increased risk of a graft failure and death from infection. In 2004, more than half of the transplant centers reported to United Network for Organ Sharing [NOS] that their centers provided follow-up care after transplantation (USRDS, 2005).

CONCLUSION

Kidney transplantation is the preferred modality for the treatment of ESRD. Yet, attention to risk factors for CKD and ESRD and intervention to slow the progressions are urgently needed especially among racial and ethnic groups and women. There are potential ways to address the problem of health disparities and inequity created by the kidney transplant system. A combination of programs and policies should be activated to increase the number of donors. An active communication program between nephrologists, patients and families, and transplant centers are necessary to achieve successful transplantation. Nephrologists should be familiar with the combination donor and recipients factors that are likely to yield detrimental results, which candidates are more suitable for ECD kidney transplant, and which patients are unsuitable for a cadaveric donor kidney because of a multitude of secondary diseases such as peripheral vascular and cardiac diseases. Another is to create a public communication programs about the importance of organ donation whether cadaveric or living, geared toward ethnically diverse communities.
### Table: Assessing the Equity of Kidney Transplantation

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<th>Dimensions</th>
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<td><strong>Deliberative Justice</strong></td>
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<td>Health policy</td>
<td>Participation</td>
<td>Ensure that affected groups participate in formulating and implementing policies and programs.</td>
<td><strong>Population:</strong> Organ Transplant Act of 1984 created the Organ Procurement and Transplantation Network (OPTN) that solicit public input on policies via “public comments” or “transplant community.” Anyone can become a member of OPTN. Clinical: A physician (nephrologist) must complete an evaluation and refer the patient to a transplant center. Research show that physician bias may influence when a patient is referred as well as the patient preference for a transplant. Ethnic individuals are often referred late for a transplant evaluation and not fully informed of their ESRD treatment options.</td>
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<td><strong>Distributive Justice</strong></td>
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| Delivery System | Freedom of Choice | Maximize the availability and minimize the constraints on patient’s choice of providers and services. | **Availability:** U.S. has 58 organ procurement organizations & 261 transplant centers. TX has 23 transplant centers with 1 recently opening in a Hispanic dominate area. Organization: Allocation of organ is based on a point system or waiting list. Cadaveric donor is allocated to patients with greatest need for transplant or who would benefit the most. Ethnic individuals often receive a lower score for a deceased donor transplant based on the UNOS/OPTN kidney allocation point system. The registration for kidney transplantation for dialysis patients under the age of 70 still falls below the Year 2010 Healthy People objectives. Registration in 2006 (Objective-25% of dialysis patients will be placed on the kidney transplant waiting list):  
  - American Indian or Alaska Native – 11.6%  
  - Black/African Americans – 12.3%  
  - Hispanics – 15.3%  
  - White – 17.7%  
  - Male – 17.2%  
  - Female – 14.5%  
(CDC, 2009) |
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<td>Realized Access&lt;br/&gt;Utilization&lt;br/&gt;Satisfaction</td>
<td>Cost-effectiveness</td>
<td>Enhance access to prevention and treatment benefits and services that are most likely to be cost-effective.</td>
<td><strong>Financing:</strong> Kidney organ transplant costs between $25,000 and $30,000. Medicare covers 80% of reasonable expenses except the 20% co-insurance and immunosuppressive medications for 3 years and for life if the individual is eligible for Medicare. In Texas, the Kidney Health Care program covers 10% of services expenditures for a living donor and 20% for a cadaveric donor transplant.</td>
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<td>Utilization: Average survival rates for adults (USDHHS, 2007)</td>
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<td>Kidney-deceased donor</td>
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<td>Kidney-Living donor</td>
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Satisfaction: Kidney transplantation studies have shown that patients notice improvement in their global quality of life, especially physical function. Except for the medications and routine consultations, patients have the opportunity to redirect their interests and activities.

| Distributive and Social Justice | | | |
|Population at risk<br/>Predisposing<br/>Enabling<br/>Need | Similar treatment | Minimize disparities in access to benefits and services across subgroups, particularly among those most at risk. | **Predisposing:** Waiting list time in 2006 (Health People Objective- 30% will receive a kidney transplant within 3 years of the date of renal failure): American Indian or Alaska Native – 8.6% Black/African Americans – 9.4% Hispanics – 14.5% White – 23.1% Male – 19.4% Female – 15.8% (CDC, 2009) The number of people on the waiting list as of May 2009 was: Male – 4,375 Female - 3,351 Whites – 1,880 Blacks – 1,898 Hispanics – 3,687 (OPTN, 2009) |

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<td><em>Enabling</em>: The shortage of donors has created inequalities in access to kidney transplantation. In 2006, the kidney organs recovered were 6,434 living donor and 10,212 deceased donor (USDHHS, 2007). Need: In 2006, it took 368 days to provide kidney transplants to 25% of those waiting with 7,873 of the 31,495 registered received a transplant within one year of registration. In Texas, 28,291 out of the 98,263 people on the waiting list received a transplant in 2006 (OPTN, 2007)</td>
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<td><strong>Social Justice</strong></td>
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<td><em>Environment</em>: Research documents that recognition of and care for chronic kidney disease (CKD) will reduce the need for transplant. Need improvement of the control and management of hypertension, obesity and diabetes among ethnic population and anemia mgmt.</td>
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<td>Environment</td>
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<td><em>Health risks</em>: Diabetes, obesity and hypertension have been found to be higher risk factors for end-stage-renal-disease. Lack of exercise, high fat diets, and increase stress are also factors that can lead to ESRD and need for kidney transplant. In Texas, 52% of all new cases of ESRD were due to diabetes (ESRD Network, 2008).</td>
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<td>• Physical</td>
<td>Common</td>
<td>Emphasize primary prevention (disease prevention and health promotion), and related…</td>
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<td><strong>Substantive Equity</strong></td>
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<td>Health</td>
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<td><em>Patients</em>: Expected 15 years remaining life with a transplant. Follow-up care is provided in 50% of the transplant centers.</td>
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<td>• Patients</td>
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Policy changes are needed to reduce the number of persons on the waiting list. Waiting time points should be issued when a patient begins dialysis. This would eliminate the number of patients being placed on the waiting list early (primarily whites) just to accumulate waiting points. Transplant recipients could be told that they will not be placed on the cadaveric donor waiting list until all options for a living donor have been explored and exhausted. This type of policy might stimulate more family members and friends to volunteer a kidney. The criteria for distribution of a cadaveric donor should be looked at again especially the geographical requirements. Because of this, some ESRD patients have put themselves on waiting list in more than one area. Consolidating smaller waiting list into larger regional lists may alleviate transplant access inequities and improve matching of donor organs to transplant recipients. All people, wherever their condition or background must be able to be assessed by whatever transplant services are available.

The rules and policies that guide organ allocation should be clear and understandable by all people concerned. Transparency of the organ procurement and allocation system is imperative to avoid any kind of arbitrariness. It should be clear from the beginning of who has the responsibility within the system for the final decisions in organ allocation. Such visibility is a precondition for just allocation of health care. On a personal level, to avoid systemic bias against certain groups of patients based on personal or societal rather than medical factors requires a realization that personal values and expectancies influence the process of organ allocation. Keeping this in mind will help preserve the readiness to reflect on one's own judgments.

New legislative and regulatory initiatives are need to eliminate fiscal and administrative barriers to appropriate care of CKD and ESRD patients. Clinical practice guidelines and performance measures are needed to articulate best clinical practices for CKD as well as ways to monitor them is highly needed. The ultimate intent is to improve ESRD outcomes by focusing on CKD processes of care. Policies and practices geared toward reducing the inequalities in organ allocation are being supplemented by those developed to address obesity, diabetes and hypertension among ethnic and racial groups on a national level. In terms of achieving substantive equity it can be realize by reducing the morbidity, mortality, incidence, and health cost associated with CKD as well as disparities between the ethnic groups.

Clearly there are a number of factors that limits access to kidney transplantations but racial/ethnic disparities should not be one of them. The growing incidence of ESRD has created an unprecedented demand for kidney transplant. It will be increasingly important to allocate kidneys equitable. The equity conceptual framework has proved useful in identifying the symptoms of disparities but more analytic research is needed to discover the underlying etiology or origins of these disparities and target effective interventions and policies. Health services research and programs should focus on improving the health of patients and communities as the ultimate goal of health policy.

REFERENCES


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